AHCCCS
Arizona Health Care Cost Containment System

Parents as Paid Caregivers Waiver Amendment Public Comments

August 2023

LETTERS

RAISING VOICES
COALITION

Paid Parent Caregiver Proposal Adjustment Request

July 2023

Dear AHCCCS and 1115 Waiver Team,

As a parent of a child who receives DDD and ALTCS services I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility, and it has been extremely beneficial to our family and my child. I would like to share my personal experiences and feedback based on my review of the current proposal for a permanent Paid Parent Caregiver program.

Under the current proposal, the request of an ongoing program option which allows parents of disabled minors in Arizona to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies is not being met. Please consider updating the proposal based on the following questions, suggested solutions, and personal experiences.

Should Habilitation be included in the Paid Parent Caregiver Program?
We have heard the concerns about member isolation and lack of community involvement if parents continue as Paid Parent Caregivers facilitating their child's Habilitation services. Respectfully the parent caregiver community proposes the following solutions:

1. Examine available research and personal feedback statements from members and their families to evaluate the true potential impacts of social isolation and community involvement when parents of disabled children provide Habilitation services. The parent caregiver community's collective experience is that members who have parents facilitating their Attendant Care and Habilitation services have experienced greater member social engagement and community involvement over the last three years. Parent caregivers now have an increased ability to take their children to sporting team practices, community events, movie theaters, all ability parks, church activities and libraries. This is because parent providers can perform the appropriately trained and qualified supports in the correct time and location that is applicable to each member.
2. Implement precise guidelines to facilitate generalization for all Habilitation providers regardless of the DCW's familial status. Habilitation services are designed to have goals where data is collected to evaluate if those goals need to be changed, have been met, or need to be addressed differently. For a goal to be considered met, a member should be demonstrating that they are able to successfully meet that goal outside of the timeframe with a provider in one setting. This is referred to as generalization. The effective implementation of generalization with the pediatric IDD population would lessen, if not eliminate, any complications with adult transitional services. Under this model a program that includes parents as paid Habilitation providers would actually assist and improve in the success of adult transition. There are times when disabled children work successfully with different types of providers in clinics or schools, but the parents are not carrying the work over at home. This can happen for a variety of reasons. Having parents as Habilitation providers would help ensure the child's goals are congruent and carried over in the home and community setting. This will give the member a better chance of independence as they transition through different life stages. With generalization policies in place, Habilitation services being performed by parent providers will actually help facilitate successful transition into adulthood.
3. We know from provider agency data that "the top 3 issues regarding recruiting and retaining career non-family caregivers are schedules of the client members, interest in the position and finding qualified applicants." Most members have Habilitation

goals and ADLs that are most appropriately delivered throughout the natural routine of their day. A parent provider is uniquely available in the morning, after school or in the evenings when each member is motivated and focused on the pertinent task. If a non-family provider is available their schedules typically allow them to work in longer time chunks that are not always the most ideal for the member and creates artificial goal or ADL practice. Continuity of care and greater member outcomes can be associated with consistently provided Habilitation care by parent providers who have the greatest ability to be flexible and available for their member children.

Should parent providers be limited to 40 hours a week of paid care per child?
We have heard the concerns of AHCCCS regarding the potential for a difficult adult transition to non-family supports once parent caregivers are no longer able or willing to help facilitate the disabled member's care. The parent caregiver community would like to propose the following collaborative solution to create a win-win scenario:

1. Create a program provision that outlines an extraordinary circumstances clause and the application process that allows parents to provide over 40 hours of paid care per week of authorized and evaluated services per member. These extraordinary circumstances could include, but are not limited to:
    a. The lack of a non-parent DCW being available in the last 3 months to fill the member's assessed hours that exceed 40 hours per week. Ongoing DCW searches should continue to be made by the member's agency to fill the assessed hours beyond 40 hours per week of Attendant Care and Habilitation.
    b. The expressed desire made by a member for a parent caregiver to facilitate their assessed DCW hours so that their Article 9 rights are honored.
    c. The profound disabilities and/or significant behaviors of a member where a non-family provider is not equipped to provide DCW support. This determination can be made through a stakeholder team approach, including but not limited to the member's, DDD Support Coordinator, DDD Nurse, DDD Supervisors, Behavioral Plan Experts, Parents / Guardians, Psychologist, or Medical Doctor.
2. Form equality between all Family Provider Programs by allowing all Direct Care Workers, regardless of familial relationship or member age, to provide up to 16 hours of paid care per day. This will allow for employee equality across the lifespan of the member and limit the potential anti-family provider rhetoric currently present within state policies and DDD Support Coordination culture. All evaluations of hours should be based on member needs regardless of who is providing the services to create uniform implementation of all applicable HCBS services by the DCWs available to fulfill those hours.
3. The Family Support Program currently in this proposal addresses caregiver burnout. It is one of the available solutions to facilitate further community support within the disability and caregiver community that will provide greater access to non-profits facilitating counseling services, support groups and meet up activities.
4. Reevaluate Respite reimbursement rates to also address caregiver burnout. If Respite services are not available to the member or their family, parent burnout will continue to be an issue regardless of parents having the option of providing Attendant Care or Habilitation hours. With a comprehensive Paid Parent Caregiver Program in place non-family DCW providers will have greater flexibility to provide Respite services to these same families.

How should current evaluation protocols, training and practices be updated to facilitate equality for all members when accessing member needs?
AHCCCS has stated their intention to amend applicable policy, further suggested action on this topic includes:

1. Forming a committee of community and department stakeholders to amend and critique current DDD and AHCCCS policies and need assessment forms so that the most effective and efficient implementation of this permanent option is utilized moving forward.
2. Provide appropriately determined training and program implementation to DDD and ALTCS Support Coordinators so that Attendant Care and Habilitation hours are equitably evaluated based on the member's needs and to remove organizational bias of familial providers across the member's lifespan. Specifically investigate and determine appropriate DDD staffing needs and training for the members served in rural areas and those from minority backgrounds.
3. Create the option for private sector Support Coordination. Other states have this option within their Medicaid services, and this could be an additional feature in our DDD portfolio to allow for the member's needs to be best evaluated.

In conclusion, Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. By not allowing parents of minors to provide Habilitation and Attendant Care services or work over 40 hours a week most of the minor disabled community in Arizona will be underserved. A comprehensive Paid Parent Caregiver program validates the irreplaceable work that parents provide in their homes and communities.

Click here to connect with the Arizona parent led grassroot initiative leaders: www.raisingvoicescoalition.com

Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves all DDD and ALTCS members in Arizona.

Thank you!

CMS perspective on the above noted requested program adjustments and paying Legally Responsible Individuals:

June 28, 2023 - Email Correspondence between CMS and Raising Voices Coalition:
https://drive.google.com/file/d/10CPccmIY7gEr5vq9C6vIaKmncSQOV7kc/view?usp=share_link

May 23, 2023 - Transcription of National Meeting between CMS Leaders and Parent Advocates:
https://docs.google.com/document/d/1h02v6Yk7frWGADcqKgm1zmd0uquMNfW3Jcd0zjHCxOk/mobilebasic?fbclid=IwAR2QLqbwJMQQRz0nj-XqhYzlFlkQbUV5wnyAyv98hivRVYpCjaYHhLBCzYg

Studies and data that support the changes being requested:

Data results from a 2023 Arizona survey of parents who have children with disabilities:
https://docs.google.com/document/d/16PZOk99caDUitg0XmQKqEv2mxXOBeaRywSD_zmjAnYw/edit?usp=sharing

A report on the current caregiver crisis by the National Association of Homecare and Hospice:
https://www.hcaoa.org/uploads/1/3/3/0/133041104/workforce_report_and_call_to_action_final_03272023.pdf

Higher satisfaction of paid supports for adults and minors with disabilities when care is received from paid family providers:
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1089106/

A comparison of healthcare utilization when children receive paid care by a family member vs non-family provider:
.https://www.jpeds.com/article/S0022-3476(23)00106-3/fulltext

Youth with Autism Spectrum Disorder have less ED visits and patient outcomes when patient providers are involved:
https://www.reliasmedia.com/articles/148366-autism-spectrum-disorder-in-the-emergency-department
https://www.psychiatrist.com/jcp/mental/child/youth-with-autism-in-the-emergency-department/

An evaluation of parent provider involvement in generalization of children with autism:
https://www.sciencedirect.com/.../abs/pii/S0891422205000958

Impacts of the caregiving relationship: https://academic.oup.com/gerontologist/article/56/6/1102/2952858

State Approaches to Reimbursing Family Caregivers of Children and Youth with Special Health Care Needs
through Medicaid - NASHP
https://drive.google.com/file/d/1TSt-Rj95DTn711EV8UTq7YqF0yoo0j8u/view?usp=sharing

Effectiveness and Evaluation of Paid Parent Providers of Disabled Minors as a Permanent Option for Families in Arizona

Raising Voices Coalition / Arizona Developmental Disabilities Planning Council

Brandi Coon and Lauryn Van Rooy

Abstract

This survey seeks to understand the statistical data and experiences of parent caregivers who participated in a temporary flexibility which allowed parents of minors with disabilities in Arizona to be paid caregivers beginning in 2020. The data presented in this summary was collected through an online survey.

Demographic information collected showed a majority of the participants live in Maricopa County and identify as white females. The key results of this study showed a decrease in abuse and neglect rates, increase in Direct Care Worker longevity, greater housing and financial stability for families with disabled children, and a dramatic decrease in stress levels of parent caregivers.

Background

In 2020 the State of Arizona issued a temporary flexibility allowing parents of minor children receiving Department of Developmental Disability (DDD) and Arizona Long Term Care System (ALTCS) services to certified and trained Direct Care Workers (DCW) for their own children. Prior to 2020 the State of Arizona had programs which allowed parents of adult DDD and ALTCS members to be their child's DCW and a second program which permitted spouses of adults with disabilities to be paid providers.

In 2021 the Arizona Health Care Cost Containment System (AHCCCS) submitted their Americans Rescue Plan Act (ARPA) proposal to the Centers for Medicare and Medicaid Services (CMS) which included funds to expand and support the direct care workforce and extended Paid Parent Providers of minors beyond the Covid-19 flexibility. This plan and associated funding was approved in 2022. The current end date of the Covid-19 Flexibilities associated with Paid Parent Providers of minors is November 30, 2023 and the end date of the ARPA program is slated as September 30, 2024.

A statewide and national call to action has been initiated by stakeholders and caregivers of those with disabilities to allow a permanent option in state plans which permits paid family caregivers. CMS has issued multiple notices to state Medicaid directors explaining waiver navigation and offering suggestions to create permanent program options for paid family caregivers across the country. This survey and its resulting data consider the impacts of the temporary Paid Parent Provider program has had on Arizona families of minor children with disabilities from their first hand perspectives.

Objective

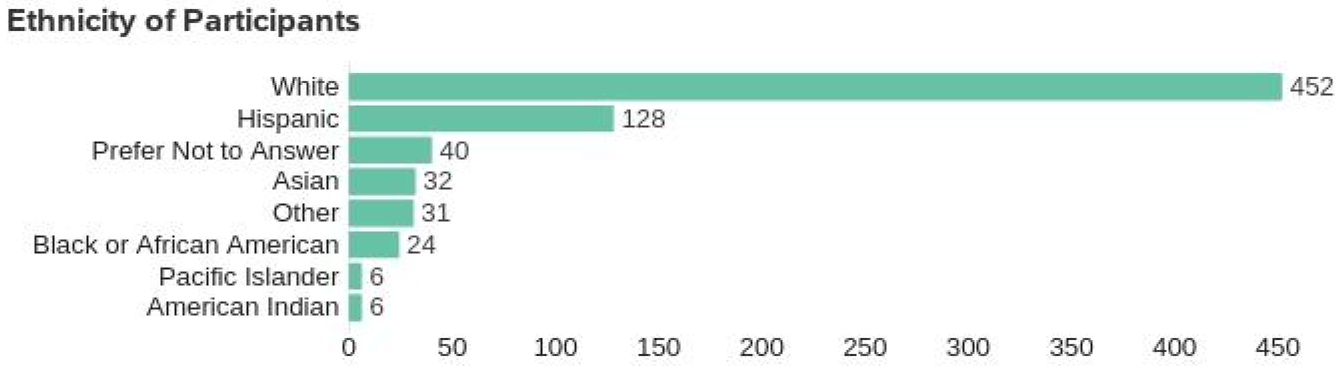
The objective was to examine the anecdotal experience and program effectiveness of Paid Parent Providers of minor disabled children in Arizona. The survey was conducted virtually in early 2023, translated into 6 different languages and advertised to parents of disabled children through outreach efforts on social media platforms and disability organization contacts in the State of Arizona.

Results and Discussion

Demographic Information

One thousand parents of minors with disabilities that participate in the DDD and/or ALTCS program chose to take part in this survey. Ninety-two percent of the participants were female and 93% of survey participants were between the ages of 26 and 55. The ethnicity of the participants identified as follows: 63% White, 18% Hispanic and 19% other minority races. Six participants are members of an Arizona tribe. Seventy two percent of participants live in Maricopa County, 11% live in Pinal County, 10% live in Pima County and 7% live in other Arizona counties. Twenty-nine percent of survey takers are single and 71% are married.

The demographic information collected highlighted an absence of participation for those who live in rural areas of Arizona along with those from minority cultures. There are two hypotheses for the lack of participation from these populations, the first includes a lack of social or organizational connection with family caregiving resources available within the state. And the second is perceived systematic bias from DDD Support Coordinators interacting with these families due to gatekeeping state offered services to members and their families based on their personal viewpoints.



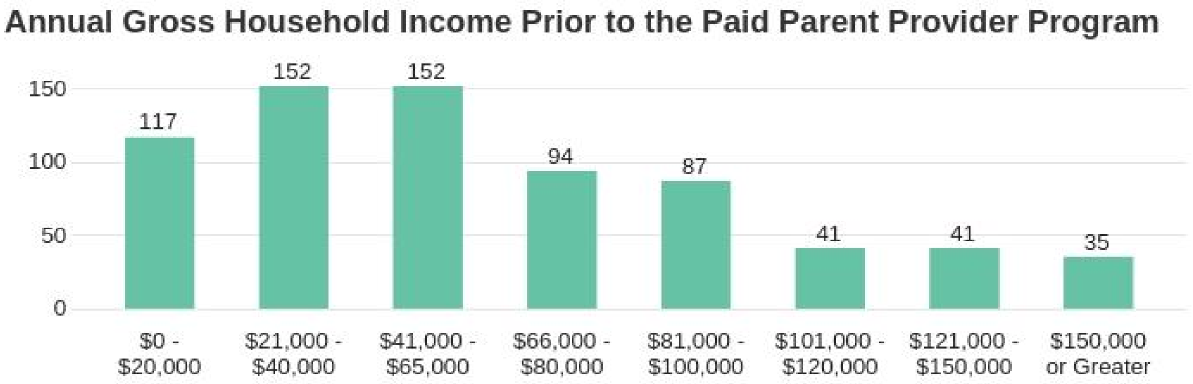
Eighty-five percent of caregivers have some level of post secondary education. Seventy-five percent of participants have one child that receives DDD and/or ALTCS services in their home, 25% have more than one child in their home receiving DDD and/or ALTCS services.

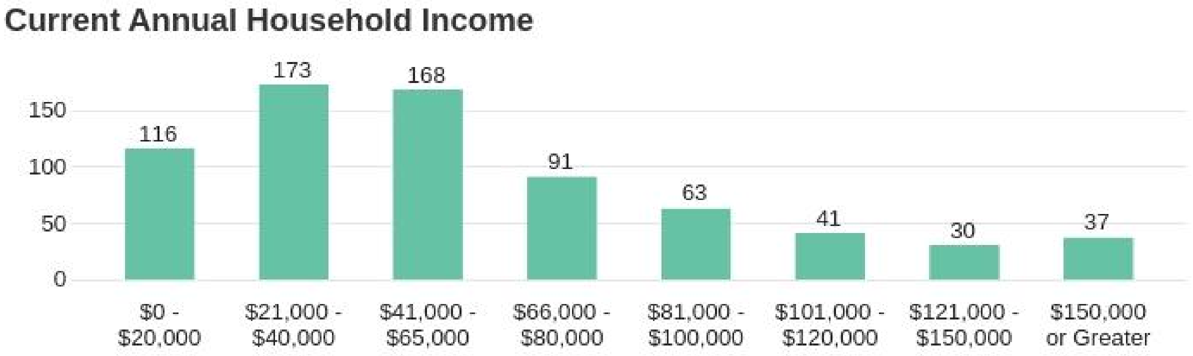
Family and Member Impact

On a scale of 1 to 100 with 100 being the highest possible level of stress a person can experience, the survey asked parent caregivers to rate their stress levels in the areas of Finance, Physical Health, Mental Health, Medical Management, Relationship, Employment, Time Management and Household Management. The reported mean stress level prior to the Parent Provider Program was 78. With the Paid Parent Provider program in place, parents evaluated their stress levels in the same categories at 32.

> **“The Paid Parent Program addresses the social disparities and systematic barriers for families and children who have developmental disabilities and those who are medically fragile. In rural and poverty ridden communities access to quality services is not accessible.**
> **Due to the salary for a Provider there is a high turnover, unethical issues or even more trauma sustained. Parent Provider incorporates families strengths, culture and resiliency.”**
>
> **Anonymous Parent Provider**

On average, household incomes remained about the same when comparing gross income before and after implementation of this program. An assumption about the temporary Paid Parent Provider program is that families who have children with disabilities are moving up in significant economic status due to their employment as paid providers. The data collected in this survey disproves this theory. When evaluating annual gross income of families who have minors with disabilities, it was identified that only 5% of households increased their income from at or below $65,000 before beginning this program, to above $65,000 per year after the utilization of this program.


Annual Gross Household Income Prior to the Paid Parent Provider Program


Current Annual Household Income

<u>Housing and Financial Stability</u>

A critical aspect of family stability is housing and financial consistency. Allowing the Paid Parent Provider program to expire would significantly impact the ability of families with disabled minors to meet the daily financial needs of their households.

Fifty percent of households that participated in this survey reported a moderate to high risk of losing their housing prior to 2020. With the temporary program in place, only 9% stated they are at a medium to high risk of losing their housing. If the program were to end, 61% of participants indicated a medium to high risk of losing their housing. Thirty-two percent of households with minor DDD and/or ALTCS members identified themselves as the sole financial provider of their household.

Sixty-eight percent of parent providers stated they were unable to work prior to starting the temporary Paid Parent Provider program. Eighty-two percent of parents of DDD and/or ALTCS minor members shared that if this program were to end their financial stability would be compromised to the extent that they could not pay all of their monthly bills and household expenses.

If this program expires, these parent caregivers would not have the flexibility to move back into the typical workforce due to the care requirements of their disabled children. This is because there is a lack of non-family direct care providers to backfill the loss of Paid Parent Providers. Eighty-five percent of Paid Parent Providers have achieved some level of secondary education and 93% are between the ages of 26 and 55. The expiration of this program would require parent providers to go from being compensated for state authorized, allocated and approved hours to working for free in the same capacity because of a regulatory rule in the state plan.

Social Service Impact / Impact on Services and Resources

A direct result of the temporary Paid Parent Provider flexibility ending will be an increase in the utilization of social services. Some of these could include, but are not limited to, Housing Vouchers, SNAP, WIC, Social Security and AHCCCS programs for the family as a whole. The individual members enrolled in DDD and/or ALTCS will have increased costs in a variety of areas of their care that will have a significant impact on the Long Term Care budget overall.

According to our survey, 24% of parents of minor DDD and/or ALTCS members stated that if this program were to end their household would be in a state of financial hardship that would require them to consider permanent placement outside their home for their minor disabled child. This could include prolonged hospitalizations, group homes or voluntary DCS placement.

Abuse and Neglect Prevention

Grievances and abuse have decreased since the implementation of this program in 2020. Families reported that in the last 5 years, 18% have reported a DDD and/or AHCCCS grievance against a non-family provider. This is in contrast with 2% of grievances with DDD and/or AHCCCS being made against a parent in the last 5 years. Eighty percent of members see at least 2 to 4 mandatory reporters on a weekly basis in their home or clinic for Home and Community Based Services (HCBS). This does not include the mandatory reporters children with disabilities interact with in school or medical settings.

Parents of children with disabilities rated their satisfaction level regarding the care their disabled children received from a non-family provider and a Paid Parent Provider. The scale was 1 to 5 with 5 being the highest level of satisfaction they could receive. Parent Providers were rated at 4.5 and non-family providers were rated 2.4. Ninety-nine percent of parents of minor DDD and/or ALTCS members believe that Paid Parent Providers have been beneficial for their families.

Provider Agencies

A second survey collected data from provider agency owners or founders. Out of 20 agencies surveyed, 18 were located in Maricopa county, 1 in Pinal County and 1 in Pima County. Fifty percent of agency employees are Paid Parent Providers. Seventy-two percent of the members the provider agencies serve are disabled minors and 28% are disabled adults.

According to the provider agency survey, in the last 5 years an average of 12 abuse or neglect grievances per agency have been filed by agencies with DDD and/or AHCCCS regarding a non-parent provider. In the last 5 years 0 grievances on average, have been filed with DDD and/or AHCCCS regarding abuse or neglect by parent providers of disabled minors.

“The Parent Provider Program has given the members we support the ability to receive consistent, quality care. APS/DCS incidents have reduced, which means our members are neglected and abused less. My fear is if this program stops, there are NOT enough qualified caregivers to fill the hours needed for our members.”

Anonymous Agency Owner

Eighty-one percent of parent providers employed by a provider agency have a two year employment average, 64% of non-parent DCW providers have a 1 year or less of employment length average. It is important to consider that the temporary Paid Parent Provider program for minors has only been in place since 2020, with most parents not beginning their employment until 2021 due to a lack of knowledge of the option. The hypothesis is that employment of parent providers will continue to show employment longevity as the program is allowed to continue permanently in Arizona.

In the years 2018-2020 provider agencies had the following assigned hours go unused each week in the following categories due to a lack of providers:

- Attendant Care - 279 Hours
- Habilitation - 258 Hours
- Respite - 371 Hours

In the years 2021-2022 provider agencies had the following assigned hours go unused each week in the following categories due to a lack of providers:

- Attendant Care - 200 Hours
- Habilitation - 116 Hours
- Respite - 446 Hours

These numbers do not reflect the additional unutilized hours in the DDD call report system. An increase of Attendant Care and Habilitation utilization is directly correlated to the option of Paid Parent Providers. Respite hours cannot be billed by parent providers due to the nature of the service hour which is intended to give family caregivers a break.

Provider agencies state that the top 3 issues regarding recruiting and retaining career non-family caregivers are schedules of the client members, interest in the position and finding qualified applicants.

Funding

Sources for funding this survey included donations from parents of individuals with disabilities and provider agencies in Arizona. Publication and marketing of the survey was done through grassroot efforts and partnerships with stakeholder disability organizations across the state of Arizona.

Conclusion

Home and Community Based Services are necessary for those who qualify for DDD and ALTCS. There is a major disconnect happening between the services that these individuals qualify for and the services they receive due to lack of consistent, qualified and available Direct Care Workers. This study provides evidence that it is feasible for Paid Parent Providers to perform their child’s Attendant Care and Habilitation hours with a lower employee turnover than non-family caregivers beyond the Covid-19 Flexibilities and ARPA extension.

Change to create a permanent Paid Parent Provider option in Arizona can be completed in one of two ways. The first, AHCCCS can amend their 1115 waiver to remove the wording that restricts parents of minor DDD and/or ALTCS members from becoming authorized providers. The second is through legislative action that would permit Paid Parent Providers in Arizona.

The benefits to members and their families far outweigh the tradition of historic DCW programs. Changing circumstances require us to do better with the funds we manage, situations we face and members we serve. Parent caregivers have been the backbone of the Developmental Disability community for decades. Comprehensive Paid Parent Provider programs validate the irreplaceable work they provide on a daily basis in their homes and communities.

Supplemental Research

Foster C., Kwon S., Blakley C., Carter K., Sobotka S. A., Goodman D. M., Agrawal R., Brittan M., (2023) Paying Family Medical Caregivers for Children's Home Healthcare in Colorado: A Working Medicaid Model, *The Journal of Pediatrics,* 2013 February.https://www.jpeds.com/article/S0022-3476(23)00106-3/fulltext

Lytle S., Hunt A., Moratschek S., Hall-Mennes M., Sajatovic M., (2018), Youth With Autism Spectrum Disorder in the Emergency Department, Journal of Clinical Psychology, 2018 May/June, 79. https://pubmed.ncbi.nlm.nih.gov/29742331/

Penning M. J., Wu Z., (2015), Caregiver Stress and Mental Health: Impact of Caregiving Relationship and Gender, *The Gerontologist, Volume 56, Issue 6*, 1 December 2016, 1102–1113. https://academic.oup.com/gerontologist/article/56/6/1102/2952858

RAISING VOICES

COALITION

Ask: A Permanent Parent Provider program that allows parents of disabled minor children to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies.

History: In 2020 the State of Arizona allowed, on a temporary flexibility during the pandemic, parents of minor children enrolled Department of Developmental Disability (DDD) and Arizona Long Term Care System (ALTCS) to be certified and trained Direct Care Workers (DCW) for their own children. Prior to 2020 the State of Arizona had established programs which permitted parents of adult DDD and ALTCS members to be their child's DCW and a second program which permitted spouses of adults with disabilities to be paid providers.

In 2021 AHCCCS submitted their Americans Rescue Plan Act (ARPA) proposal to the Centers for Medicare and Medicaid Services (CMS) which included funds to expand and support the direct care workforce and extended authorization for Paid Parent Providers of minors beyond the expiration of the flexibility available during the pandemic. This plan and associated funding was approved in 2022. The current end date of the authorization pursuant to Covid-19 flexibilities for the Paid Parent Providers of minors is November 30, 2023 and the end date of the ARPA funding and associated Paid Parent Provider program is currently September 30, 2024.

A statewide and national call to action has been initiated by stakeholders and caregivers of those with disabilities to allow a permanent option in state plans which permits paid family caregivers. CMS has issued multiple notices to state Medicaid directors explaining the waiver navigation process and support for the creation of permanent program options for paid family caregivers across the country.

This goal can be reached 1 of 2 ways:

1. Amend the Arizona 1115 Demonstration Waiver to allow parents of minor DDD and ALTCS members to be paid providers with the same requirements and limitations of other DCW providers.

2. State Legislation that authorizes parents of any DDD and ALTCS member to provide Attendant Care and Habilitation services for their minor children with the same requirements and limitations of other DCW providers. The legislation would require AHCCCS to issue an amendment to the Arizona 1115 Demonstration Waiver to support this permanent program adjustment.

Why this is needed: Home and Community Based Services are necessary for those in Arizona who qualify for DDD and ALTCS. There is a major disconnect happening between the services that these individuals qualify for and the services they receive due to the lack of consistent, qualified and available Direct Care Workers.

The social, cultural and systematic benefits that members will receive from this permanent program are significant and superior to the current DCW program. Changing circumstances require us as a nation to do better with the funds we manage, situations we face and members we serve. Parent caregivers have been the backbone of the Developmental Disability community for decades. Comprehensive Paid Parent Provider programs validate the irreplaceable work they provide on a daily basis in their homes and communities.

June 27, 2023 Update: AHCCCS has published a proposal for a permanent *Paid Parent Caregiver Program* which will allow parents of minor DDD and ALTCS children to perform 40 hours a week of Attendant Care. This proposal does not represent the current flexibility in place for these families in Arizona. A new service for the DDD and ALTCS population is also proposed titled, "Family Support." This will give peer to peer support to family caregivers. While AHCCCS initiation of a permanent option is a step in the right direction, parents are currently able to provide both Habiliation and Attendant Care services for their minor child without an hour restriction depending on that child's authorized hour allocation. Public comment is requested by AHCCCS regarding this proposal until August 21, 2023. We urge stakeholders to share their feedback with AHCCCS regarding these program limitations in the hopes of changing these program restrictions prior to the submission of the 1115 Waiver Amendment to CMS.

Contact Information:

Brandi Coon
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Lauryn Van Rooy
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Supporting Documentation:

2023 Arizona Data Report - Paid Parent Providers
https://docs.google.com/document/d/16PZOk99caDUitg0XmQKqEv2mxXOBeaRywSD_zmjAnYw/edit?usp=sharing

CMS PowerPoint - Leveraging Family Caregivers for Personal Care Services
https://www.medicaid.gov/medicaid/home-community-based-services/downloads/leveraging-family-care.pdf

NASHP - State Approaches to Reimbursing Family Caregivers of Children and Youth with Special Health Care Needs through Medicaid
https://drive.google.com/file/d/1TSt-Rj95DTn711EV8UTq7YqF0yoo0j8u/view?usp=sharing

Disability Organizations that Support this Initiative:

UCP United Cerebral Palsy
of Southern Arizona

Care 4 the Caregivers

AZA United
ARIZONA AUTISM UNITED

ryan house
open doors, open hearts

Arizona Developmental Disabilities Planning Council

Kindness
evolves

Autism Society
of Greater Phoenix

ADVOCACY31NINE

AAPPD
ARIZONA ASSOCIATION OF PROVIDERS FOR PEOPLE WITH DISABILITIES

Arizona State Legislature
House & Senate Democrats
1700 West Washington Street
Phoenix, Arizona 85007

AHCCCS
c/o Division of Community Advocacy and Intergovernmental Relations
801 E. Jefferson Street, MD 4200
Phoenix, AZ 85034

Dear AHCCCS and 1115 Waiver Team,

We write in support of the AHCCCS 1115 Demonstration Waiver Amendment Request regarding parents as paid providers for their minor children. Provider agencies have struggled over the years and the public health emergency has intensified challenges. The provisional parent-provider program was a beneficial short-term solution, but we are deeply concerned about the challenges that will be imposed on Arizona's families by the currently written proposal

One of the changes that will impact our constituents and their loved ones significantly is the removal of habilitation as a qualified service for parent providers of minor children. This change puts families at risk in an already challenging workforce shortage where about 80% of our habilitation workforce across HCBS providers collectively comprises family caregivers, including parents, siblings, grandparents, and other extended family members. The workforce shortage will exponentially increase when agencies must transition habilitation services for minor children. This will create a very major adjustment, both internally and externally. To survive the losses, agencies will be forced to eliminate value-based services, stop community engagement activities, consider budget and administrative reductions, or focus on adult services or alternative HCBS services such as residential or day programs.

According to a survey conducted by the Raising Voices Coalition, the rates of abuse and neglect of children with disabilities have significantly decreased thanks to the paid parent program. Caregivers have noticed a positive transformation in mental health as well.

Parent providers are caring for their minor children 24/7 and whether paid or unpaid, these parents will always face an increased risk for burnout and compassion fatigue. Having the 40-hour limit on parent-provided services for minor children is an additional safeguard for parent providers that we support. The alignment of the weekly hourly limit ensures that agencies are continued to be held accountable for realistic and attainable recruiting standards to meet the service overages. Further, the family services that will be included in the 1115 waiver amendment will support not only members and their families but assist agencies in the attainability of sustaining a workforce that can uniquely meet the member's and family's needs. Eliminating habilitation to prevent burnout or fatigue is unrealistic. We urge careful consideration of these implications to safeguard the well-being of disabled individuals and the stability of the HCBS community.

Sincerely,

[redacted]

Representative Jennifer Longdon
Arizona State Representative, LD 5

[redacted]

Representative Oscar De Los Santos
Arizona State Representative, LD 11

[redacted]

Representative Melody Hernandez
Arizona State Representative, LD 8

[redacted]

Representative Cesar Aguilar
Arizona State Representative, LD 26

[redacted]

Senator Flavio Bravo
[redacted] D 26

Arizona State Senator, LD 22

[redacted]

Senator Rosanna Gabaldon
Arizona State Senator, LD 21

[redacted]

Representative Lupe Contreras
Arizona State Representative, LD 22

[redacted]

Representative Nancy Gutierrez
Arizona State Representative, LD 18

[redacted]

Senator Lela Alston
Arizona State Senator, LD 5

[redacted]

Representative Lorena Austin
Arizona State Representative, LD 9

[redacted]

Representative Patricia Contreras
Arizona State Representative, LD 12

[redacted]

[redacted]

Senator Sally Ann Gonzales
Arizona State Senator, LD 20

[redacted]

Senator Christine Marsh
Arizona State Senator, LD 4

[redacted]

Representative Jennifer Pawlik
Arizona State Representative, LD 13

[redacted]

Representative Marcelino Quinonez
Arizona State Representative, LD 11

[redacted]

Representative Mariana Sandoval
Arizona State Representative, 23

[redacted]

Representative Keith Seaman
Arizona State Representative, LD 16

[redacted]

Representative Leezah Elsa Sun
Arizona State Representative, LD 22

[redacted]

Representative Myron Tsosie
Arizona State Representative, LD 6

[redacted]

Senator Catherine Miranda
Arizona State Senator, LD 11

[redacted]

Representative Mae Peshlakai
Arizona State Representative, LD 6

[redacted]

Representative Athena Salman
Arizona State Representative, LD 8

[redacted]

Representative Judy Schwiebert
Arizona State Representative, LD 2

[redacted]

Representative Stephanie Stahl Hamilton
Arizona State Representative, LD 21

[redacted]

Representative Stacey Travers
Arizona State Representative, LD 12

DEPARTMENT OF ECONOMIC SECURITY
Your Partner For A Stronger Arizona

Katie Hobbs
Governor

Angie Rodgers
Director

AHCCCS
[redacted]

ATTN: Division of Community Advocacy and Intergovernmental Relations

To whom It may concern:

The Arizona Health Care Cost Containment System (AHCCCS) is requesting an amendment to the State's current Demonstration project to allow for the permanent extension of payments to parents who serve as paid caregivers for minor children, previously allowed through a temporary COVID Appendix K flexibility. This letter serves as a public comment from the Department of Economic Security, Division of Developmental Disabilities (The Division) regarding the AHCCCS draft waiver amendment proposal.

Parents as Paid Providers of Their Minor Children-Provisions

- **Provision 1**: Under this proposal, parents who do provide these services must meet all direct care worker requirements as established by AHCCCS policy, including being employed/contracted by an AHCCCS Registered Direct Care Service Agency, passing specific direct care worker competency tests, and demonstrating compliance with Electronic Visit Verification (EVV) per the 21 st Century Cures Act (Cures Act).

Comment: The Division agrees with this provision.

- **Provision 2:**The services and number of authorized hours will be assessed and determined through the Person-Centered Service Planning (PCSP) process including a determination of what services/hours will be provided by informal (uncompensated) supports. The provision of informal support must be voluntary on the part of the caregiver.

Comment: The Division agrees with this provision but seeks guidance on how to make this determination. Is it simply asking the HDM? A responsible person? The Division recommends language to indicate the voluntary provision of informal support based on "extraordinary need" related specifically to the person's qualifying disability.

- **Provision 3**:In accordance with AHCCCS Medical Policy Manual (AMPM) Section 1620, case managers will review with a member/family members/Health Care Decision Makers (and other members of the service planning team) various service delivery models and utilize a decision tree to make an informed decision regarding the model that will best meet the member's needs, including decisions about the individuals who will serve as caregivers such as DCWs recruited by the agency and/or member/family, non-parental family members, **and/or parents as a last resort when other options have been exhausted and when the parent is willing and able to provide the paid care.**

Comment: The Division seeks guidance on this provision. The HDM/ responsible person determines who provides the service. What will be acceptable reasons to exclude other caregiver types, and how is "last resort" determined?

- **Provision 4:** Consistent with AHCCCS' ALTCS guiding principles, the person-centered planning process should maximize member direction and support the member to make an informed decision and lead/participate in the process to the fullest extent possible. Case managers will document any selection of a member-directed service model option in the PCSP, including the option for parents of minor children to provide paid care.

Comment: There is currently no requirement to document the specific DSP in the PCSP. Choosing a family member or parent for adults is not considered a "member-directed service model." The rationale for identifying this choice of DSP as "member directed" when the legally responsible person is also the person identifying the chosen DSP and is delivering the services appears misaligned with the intent of member direction.

- **Provision 5**:Parents who provide these services must also maintain quarterly in-person case management visits as well as agency supervisory visits as further detailed in AMPM 1240-A.

Comment: The Division agrees with this provision as this aligns with all DSPs. The Division recommends developing a way to track these visits for all DSPs. AHCCCS should consider a way to track this using EVV.

- **Provision 6:** Parents would be limited to 40 hours of paid care, per child, in a given week, where paid care by a parent caregiver cannot exceed more than 16 hours in a single day.

Comment: The Division agrees with this provision but recommends rewarding the requirement to read "16 hours in a 24-hour period" to ensure that the duration is calculated from the time the DSP actually starts work. The Division's data shows that 92.3% of Parents providers for minors provide care to their children (inclusive of habilitation as currently permitted) for 40 hours or less. The Division requests support in developing a shared card in DOMO to track parents across agencies and identify 40-hour weekly and 16 hours daily limits. Coding will be required to identify parent providers. The Division requests AHCCCS lead coding changes so encounters are not affected.

- **Provision 7:**If two children are receiving direct care services (attendant care, personal care, or homemaker services), the parent(s) may provide up to a combined 80 hours of paid care per week (40 hours for each child).

[redacted]

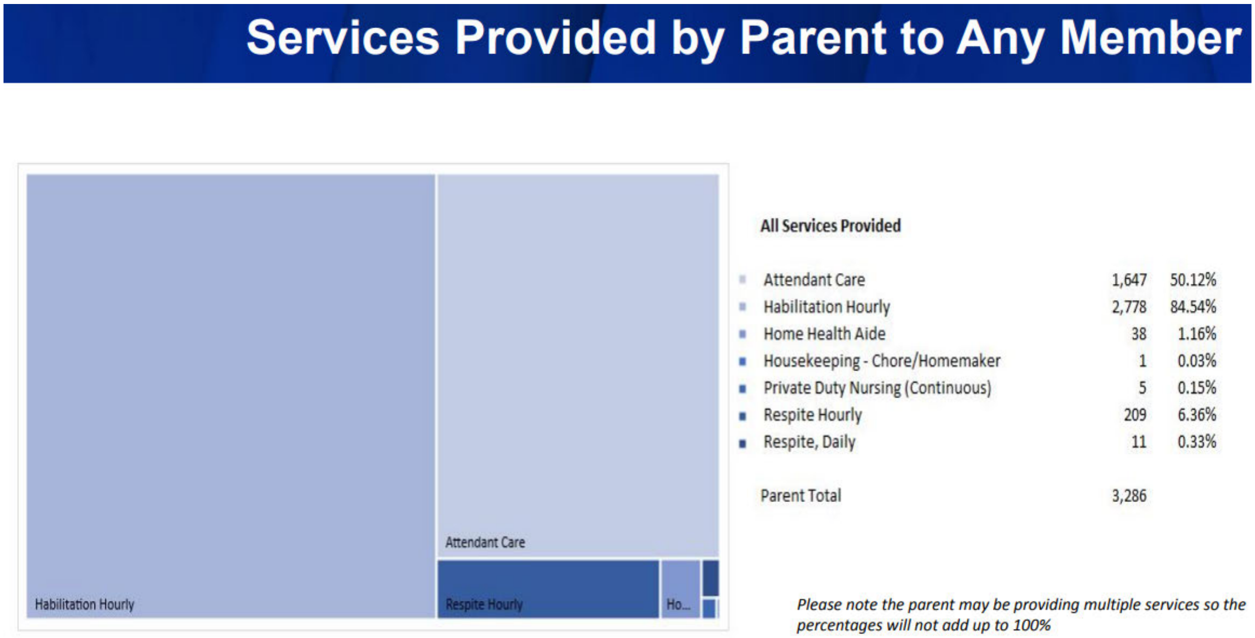
Comment: The Division agrees with this provision but requests support in developing a shared card in DOMO to track parents across agencies and identifying 40-hour weekly limits and 16 hours daily limits. Coding will be required to identify parent providers. The Division requests AHCCCS leads coding changes so encounters are not affected.

- **Provision 8:**The exact number of hours (up to 40 per child) approved for payment will be determined through the person-centered planning process and must meet medical necessity requirements.

Comment: The Division agrees with this provision.

Additional Considerations

Although not expressly outlined in Appendix K Waiver Language, Habilitation, and Support were permitted to be provided by parents during the public health emergency, provided that Provisions #1, 2, and 5 above were met. In order to support members and families with the least disruption to the workforce, the Division supports including Habilitation in the waiver amendment or state plan amendment as appropriate. As shown in the table below- 84.54% of parents providing HCBS to minor children are providing Habilitation, Support.



Services Provided by Parent to Any Member

All Services Provided

Attendant Care	1,647	50.12%
Habilitation Hourly	2,778	84.54%
Home Health Aide	38	1.16%
Housekeeping - Chore/Homemaker	1	0.03%
Private Duty Nursing (Continuous)	5	0.15%
Respite Hourly	209	6.36%
Respite, Daily	11	0.33%
Parent Total	3,286	

Please note the parent may be providing multiple services so the percentages will not add up to 100%

Extend Family Support/Home Care Maintenance

[redacted]

The Agency is also proposing to establish a home care training family support (family support) service as part of the HCBS benefit package detailed in “Attachment L” of the State’s approved STC document (Project Number 11-W-00275/9).

- **Provision 1:** AHCCCS seeks authority to provide family support to primary caregivers (providing compensated and uncompensated care) of children and adults enrolled in the Arizona Long Term Care System (ALTCS)program. The service will be provided by family members who have lived experience supporting a family member enrolled in the ALTCS program and demonstrate the competencies required to provide the service. Family support may involve activities such as assisting the family in learning skills related to adjustment to the member’s disability or aging process or significant life events or transitions, enhancing and improving the health and wellbeing of the member and family unit, navigating the healthcare system, self-advocacy, development of natural supports and community support systems, participating in the PCSP development, and implementation of individual and family goals and long-term life planning.

Comment: The Division supports the concept of Family Support in this provision. However, we are concerned that the current network doesn't have the capacity or expertise to support families caring for individuals with ID/ DD. Families in the DDD Network are referred to Raising Special Kids to receive Parent-to-Parent Connection under our current contract. The Division requests clarification if this provision would require it to be provided by the existing network of Family-Run Organizations (FROs) with new credentialing requirements established for the ALTCS population or if the ALTCS program contractors will be required to develop a network specific to the ALTCS population. **The Division requests a meeting with AHCCCS to discuss the intent of this provision.**

- **Provision 2:** Family support would be limited to ALTCS members residing at home who will not supplant case management services. Primary family caregivers, including families created through birth, foster care, adoption, marriage, or a self-created family unit, are eligible for the service. The case manager will authorize the service with limits on the amount, frequency, and/or duration specified in PCSP and based on assessed needs.

Comment: The Division supports the concept of Family Support in this provision. However, we are concerned that the current network doesn't have the capacity or expertise to support families caring for individuals with ID/ DD. Families in the DDD Network are referred to Raising Special Kids to receive Parent-to-Parent Connection under our current contract. The Division requests clarification if this provision would require it to be provided by the existing network of Family-Run Organizations (FROs) with new credentialing requirements established for the ALTCS population or if the ALTCS program contractors will be required to develop a network specific to the ALTCS population.

[redacted]

- **Provision 3:** The PCSP will include a specific assessment of the family members' physical and mental well-being and outline targeted goals for both the family member and the member specific to the family support service. Family support may be provided individually or in a group setting.

Comment: The Division requests guidance on what tools or resources would be developed to complete the assessment outlined in Provision 3.

- **Provision 4:** More than one provider agency may bill for family support provided to a member simultaneously if indicated by the member's assessed needs as identified through their PCSP.

Comment: This Provision is unclear as Family Support is provided to the family, not directly to the member. Is the intent to change the scope of Family Support to be provided directly to the member? The Division requests guidance on what circumstances billing outlined in Provision 4 might be appropriate.

We appreciate the opportunity to provide comments. For questions, please feel free to contact me at [redacted]

Respectfully,
[redacted]

Nicolette Fidel
Chief Operating Officer, DES DDD

C. Zane Garcia Ramadan, Assistant Director/CEO, DES DDD
Leag Gibbs, OIFA Administrator, DES DDD
Sherri Wince, Chief Strategy Officer, DES DDD
Cindy Treadwell, Deputy Assistant Director, Support Coordination, DES DDD

August 18, 2023

AHCCCS
c/o Division of Community Advocacy and Intergovernmental Relations
801 E. Jefferson Street, MD 4200
Phoenix, AZ 85034
waiverpublicinput@azahcccs.gov

To Whom It May Concern:

Thank you for accepting public comment regarding the issue of allowing for the permanent extension of payments to parents who serve as paid caregivers for minor children, previously allowed through a temporary COVID Appendix K flexibility. On behalf of Circle of Life Home Care and Soaring Eagles Home Care, we applaud this effort.

The Covid-19 pandemic has amplified the already existing aging and disability services workforce shortage crisis. Many people who worked in the caring professions have left the workforce for various reasons. This lack of access to consistent staff support has placed people with disabilities at risk, jeopardizing their health and safety or forcing them to move to more costly congregate care settings. Many parents have ended up bearing the brunt of this caregiver shortage, often jeopardizing their ability to maintain employment outside of the home. The extension of this flexibility would improve the lives of many children and their families.

However, we urge AHCCCS to reconsider its 40 hours per week cap. The cap of 40 hours per week in two-parent households is inconsistent and impractical. As you know, individuals with more acute needs require more than 40 hours per week of care. When outside staff are unavailable and/or unreliable, there should be no reason a child goes without care when both parents are willing and available to provide up to 40 hours each to their child. Please lift the 40 hour per week cap or allow exceptions when outside care is unavailable.

Thank you for accepting our support of the extension and for considering our request to lift the cap. We sincerely thank you for your ongoing support of Arizona’s most vulnerable families.

Sincerely,

Stephanie Roberts
Policy Leaders
TEAM Public Choices
Circle of Life & Soaring Eagles Home Care

Arizona Chapter

INCORPORATED IN ARIZONA

American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN®

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August 14, 2023

AHCCCS
c/o Division of Community Advocacy and Intergovernmental Relations
801 E. Jefferson Street, MD 4200
Phoenix, AZ 85034

Re: Arizona Section 1115 Waiver Amendment Request: Parents as Paid Caregivers

To Whom it May Concern:

The Arizona Chapter of the American Academy of Pediatrics (AzAAP), representing over 1100 Arizona pediatricians, hereby submits its public comment on the Arizona Section 1115 Waiver Amendment Request to make permanent the current temporary program allowing parents to serve as paid caregivers for their minor children. AzAAP fully supports the creation of a permanent program to allow parents to be paid for the extraordinary care they provide for children with disabilities or chronic illnesses. AzAAP also supports the proposal to allow family support/home care maintenance for primary family caregivers to facilitate a supportive home environment. We thank AHCCCS for initiating this waiver request for the benefit of Arizona children and families served by the ALTCS program.

Parents play a vital role in providing high-quality care to children with disabilities and medical complexities. This is even more the case when Arizona is experiencing a critical shortage of direct care and home health workers. The extraordinary time and effort required of parent caregivers often impacts their ability to work outside the home, as well as their overall health and the stability of the family. Allowing parents to be compensated for their role as providers of essential care will have significant benefits for children and families. AzAAP supports public policies and practices that value the caregiving roles of families and address the unique needs of children with disabilities and medical complexities.

AzAAP encourages AHCCCS to consider the concerns brought forth by the family advocates, including their objection to the exclusion of habilitation as a paid service by parents and limitation of payment to parent caregivers to 40 hours per week per child. AHCCCS's waiver request should be designed to ensure that all children have access to high-quality direct care services, whether from a family member or non-family member. AHCCCS should ensure that its program design best promotes high-quality care, community involvement, successful transition to adulthood, and overall family wellness. At a minimum, AHCCCS's proposal should contain a provision to accommodate for services or hours in extraordinary circumstances, such as when a non-parent direct care worker is not available or not properly qualified to meet the child's needs.

In sum, AzAAP supports the extension of the temporary program allowing parents to be paid caregivers for their minor children and to provide access to family support services. AzAAP encourages AHCCCS to consider the information brought forward by the impacted families and to amend its waiver request as necessary to best support the children and families served in ALTCS.

Sincerely,

[redacted]

Mary Ellen Rimsza, MD, FAAP
AzAAP Advocacy Committee Chair
AzAAP Medical Director, Child Fatality Review

Autism Society
of Greater Phoenix

The Board of Autism Society of Greater Phoenix believes AHCCCS should request that CMS make permanent the temporary Paid Provider Program. AHCCCS should amend the Arizona 1115 Demonstration Waiver to allow parents of minor DDD and ALTCS members to be paid providers with the same requirements and limitations of other DCW providers. The State Legislation should authorize parents of any DDD and ALTCS member to provide Attendant Care and Habilitation services for their minor children with the same requirements and limitations of other DCW providers.

The current Parent Provider program allows parents of disabled minor children to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies. This program is crucial to families because of the lack of qualified providers available to serve those with DDD and ALTCS. Home and Community Based Services are necessary for those in Arizona who qualify for DDD and ALTCS and these children deserve caring, consistent, qualified direct care workers.

The social, cultural and systematic benefits that members will receive from this permanent program are significant and superior to the current DCW program. Changing circumstances require us as a nation to do better with the funds we manage, situations we face and members we serve. Parent caregivers have been the backbone of the Developmental Disability community for decades. Comprehensive Paid Parent Provider programs validate the irreplaceable work they provide on a daily basis in their homes and communities.

Our Board believes this change must happen to meet the needs of families who qualify for DDD and ALTCS. It is imperative that we acknowledge the struggle to find an adequate number of qualified compassionate caregivers for those with special needs. As the baby boomers age, the elderly and those with disabled children will compete for the same small group of providers. This shortage has created a growing gap between the demand for quality care and the available supply of caregivers. It is evident that the existing workforce cannot meet the increased demands. The most vulnerable of our population deserve the services that they qualify for and that those services be provided by qualified, consistent direct care workers. The scarcity of caregiver workers can have long-term negative effects on the development and well-being of children, especially those with special needs. We need an innovative solution, and we believe the Paid Parent Provider Program is that solution.

Community
Legal Services
1952 70 YEARS 2022
Law Offices
Maricopa County Central Office
Health and Economic Stability Unit

August 18, 2023

Director Carmen Heredia
AHCCCS
[redacted]

VIA EMAIL: [redacted]

RE: Public Comment – Arizona Section 1115 Waiver Amendment Request: Parents as Paid Caregivers

Dear Director Heredia:

For over seven decades, Community Legal Services ("CLS") has provided low-income Arizonans free legal advice, advocacy and assistance on a variety of civil matters. One area of our practice focuses on assisting individuals and families on matters related to public benefits, such as access to health services through AHCCCS and its various programs. Many of our clients receive vital services through the ALTCS program.

The COVID-19 pandemic required the implementation of numerous Medicaid flexibilities to ensure the continuity of care for our country's most vulnerable populations. In many ways, those flexibilities served as pilot programs, providing the opportunity to "test drive" new initiatives. CLS applauds AHCCCS for having the insight .to recognize the value of retaining some pandemic-based flexibilities, particularly allowing parents to be certified as Direct Care Workers, paid to provide Attendant Care Services to their minor children. This initiative has contributed immeasurably to overcoming the historical deficiency of provider services.

While AHCCCS is seeking authority to make the parent-caregiver role a permanent option, they have elected to allow an end to the pandemic-era flexibility that allows parents to be paid to provide habilitation services to their minor children. CLS is aware of the controversy surrounding this decision, it is not our intent to choose sides, but instead to propose a compromise: Allowing the parent habilitation provider flexibility to be retained as an exception, a failsafe measure, to be used in instances in which clinical habilitation providers cannot fulfill the need.

Children who need these services are considered “at risk” for developing permanent limitations that could otherwise be minimized through the use of habilitative therapies. When provided consistently, these therapies not only prevent the worsening of developmental delays, but can also improve a child’s functional abilities and increase independence.

Because of the potential impact these therapies can have on a child’s quality of life, children should never be deprived of them due to the lack of providers, especially when there is a viable alternative. Creating an exception that supports licensing parents so that they may have the tools to step in when no other habilitation provider is available would be a yet another significant step toward addressing provider shortages, which are particularly prevalent in rural communities.

On behalf of CLS and our clients, thank you for not only acknowledging the issue of provider shortages, but taking positive steps toward creating viable solutions. We also appreciate the opportunity to submit this comment which we hope you will consider as you finalize the proposed waiver amendment.

Respectfully Submitted,

Dina R. Norwood
Dina R. Norwood
Managing Attorney
Health & Economic Stability Unit

AAPPD
ARIZONA ASSOCIATION OF
PROVIDERS
FOR PEOPLE WITH
DISABILITIES

Submitted via Electronic Mail

August 21, 2023

To Whom It May Concern:

We are pleased to see a proposal to assist families of children with special needs in Arizona and make permanent the current Home and Community Based COVID-19 flexibility that allows for parents to be paid caregivers for their minor children and sets up a home care training family support service.

The Arizona Association for Providers of Persons with Disabilities (AAPPD) represents over 115 providers contracted with the State of Arizona to deliver services to individuals with intellectual, and developmental disabilities (IDD). Since 1985, AAPPD has provided advocacy, counsel, and other services to its member organizations that share a common dedication to the needs of individuals with disabilities and their families, and we recognize that making this temporary flexibility permanent will be an important and positive change for many individuals receiving services in Arizona as well as their families.

Over the past several years, and prior to the COVID-19 public health emergency, AAPPD has advocated for additional permanent funding for reimbursement rate increases to help providers with cost increases that have not been covered and, most importantly, to provide service providers the ability to raise the hourly wages of direct care workers (DCW).

Simply put, the Arizona healthcare system does not have enough direct care workers and, for IDD providers, paying at or near minimum wage is not helping service providers to attract more individuals to this work - Arizona will have approximately 154,700 job openings for DCWs by 2026.

Over the past decade, the direct care workforce shortage has worsened – exacerbated by the COVID-19 pandemic. We are grateful for the measures put in place by the Division of Developmental Disabilities (DDD) and AHCCCS during the public health emergency, as the additional temporary and temporary ARPA funds enabled service providers to initiate hazard pay rates, provide stipends/bonuses, increase compensation temporarily, and have partially covered the additional costs related to COVID-19 and post-public health emergency inflation.

However, even with the measures made possible by additional funding, attracting DCWs remains challenging given the current job market and economy.

The IDD system in Arizona also continues to see too high a number of daily unassigned authorizations that range across services, meaning an individual is assessed for a service but a service provider has not accepted the authorization to provide the service and this individual is waiting.

The job market, economy, and hiring challenges providers are currently experiencing are unlikely to change between now and November. AAPPD's members have reported that the proposed change to eliminate parents from providing the Habilitation service puts creates an untenable position for some agencies. One of our smaller agencies reported that they will need to hire 45-50 providers before November, which is not feasible given current job market trends. Our provider members report and discuss hiring best practices frequently with most already engaging with community colleges, participating in job fairs, and maintain constant communication with any helpful entities. Unfortunately, this approach has not yielded sufficient results as demonstrated by the current struggle to get qualified applicants.

Of course, for the agency referenced above, 40-45 members within the agency will be facing gaps in habilitation service starting in November if this service is not included in the proposal. In addition, for agencies utilizing parents as paid caregivers for the Habilitation service, which we can verify nearly all of our members who provide that service do, hiring and training a significant number of providers create financial strain.

A parent caregiver match is the easiest match a provider agency can make; however, it can also be very challenging in terms of compliance with necessary trainings and other state mandated requirements. Professional DCWs are held to specific standards of conduct, ethics, and accountability. These standards may not apply or be as easily enforceable when parents assume the role of paid caregivers. AAPPD supports the fast and thoughtful creation of any policies or procedures by DDD that would be necessary to manage this permanent change, as external oversight and quality assurance mechanisms are more challenging to implement when parents are the primary caregivers. We also believe that special care must be provided to policy surrounding incident reporting and instances of alleged abuse and neglect, as this type of caregiving set up current brings more questions than answers in situations where abuse or neglect is reported.

For example, an AAPPD member recently had a parent caregiver who had accusation of abuse. A neighbor reported the caregiver to DCS for physical abuse and drunken behavior. Apparently, this was not the first time he was reported. Our member agency found out about the report after DDD sent a fact-finding report because the parent caregiver was suspended as a provider. The fact-finding report was sent 17 days after the incident. Our member agency has suspended the parent caregiver as an employee, but the parent was also given a no contact order, which our member agency cannot enforce. Our agency could not furnish information on the fact finding report and immediately reached out to express their concern and ask questions related to this scenario – especially with this program on the way to becoming permanent. What responsibility does the agency have in these situations? How can agencies ensure that parents aren't drinking etc. while providing care and billing for it? How does a provider fill out an incident report in this case? These are all difficult questions to address, but they must be addressed quickly when this flexibility is made permanent.

Additionally, our members have posed the following questions related to the proposal:

- How are we addressing caregiver burnout and family dynamics?
  Our understanding of the purpose of the ATC services to provide additional support and relief to primary caregivers. Also, juggling the roles of a parent and a paid caregiver could strain the parent-child relationship and blur boundaries. For siblings, if one parent is paid to provide care, it could create resentment or jealousy among other siblings who may perceive unequal treatment. Sibling relationships could be strained if the parent's attention and energy are disproportionately directed towards the child with IDD.

- Paying parents to be DCWs might inadvertently reinforce a sense of financial dependence and limit the individual's ability to develop a more independent lifestyle.
  This approach could potentially hinder their self-esteem and hinder their progress towards achieving greater self-sufficiency. How will we ensure that the members are getting community socialization if they are with parents for 40 hours per week? A diverse team of caregivers with different cultures, backgrounds, and lifestyles can expose individuals with IDD to different experiences, perspectives, and teaching methods, enhancing their growth and development. Will special protections be put in place during the planning team meetings to ensure the care being provided is quality care?

- If an agency has a DCW available but parents refuse to have the outside DCW work, will there be a protocol for reporting that they declined to accept an outside DCW position?
  With data and reporting advancing, we want to make sure that this important point is considered.

- If family members have a full 40 hours of ATC how will the time necessary to complete the DCW required fundamentals training be addressed?
  Are agencies going to be required to provide a fill in DCW to allow time for the parent to complete training? Are agencies still going to be responsible for the cost of the DCW course for parent providers?

- Are agencies going to be responsible for providing a fill in for the gap of service if a family member is sick and cannot work with their child?

- How are we addressing long term sustainability?
  Due to the pandemic this was a valuable short-term solution, but it might not be sustainable in the long run. As children with IDD grow older, their needs may become more complex, requiring a higher level of professional care that parents may not be equipped to provide. This approach may not adequately prepare individuals with IDD for a future where their parents may no longer be available to provide care due to age, health, or other factors. We believe this challenge can be overcome, however, the decisions made now will certainly impact the sustainability of this caregiving option long term.

The current underfunding of the IDD system in Arizona, the DCW workforce crisis, the importance of access to timely services and consistency in caregiving, and the economic benefits to families with children with special needs, make the effort to permanently allow parents of minor children to become paid caregivers an easy one for AAPPD to support – the individuals who will not have access to service if this flexibility goes away in 2024 is simply too great at this time for us not to support this amendment proposal. However, this proposal should consider the inclusion of Habilitation as this does seem to be where the bulk of our AAPPD members are employing parent caregivers, and AHCCCS should move quickly with DDD to create and implement policy changes surrounding the final approved amendment.

We appreciate your consideration of these comments and look forward to working with AHCCCS to provide feedback on and implement the final proposal, please feel free to reach out to me at [redacted] or [redacted] with any questions.

Sincerely,

Rachelle Giles
Staff
[redacted]

ACDL™
ARIZONA CENTER for DISABILITY LAW

August 21, 2023

Via Email Only to: [redacted]
AHCCCS
[redacted]

RE: Comments Supporting Section 1115 Demonstration Waiver Amendment Request – Parents as Paid Caregivers

To the Division of Community Advocacy and Intergovernmental Relations:

The Arizona Center for Disability Law ("ACDL") is a non-profit law firm that assists Arizonans with disabilities to promote and protect their legal rights to independence, justice, and equality. ACDL is the designated protection and advocacy agency for people with disabilities in Arizona. Each year, ACDL develops annual focus areas to guide its advocacy work. ACDL's current focus areas include increasing access for people with disabilities who are Medicaid beneficiaries to medical services, programs, and facilities.

ACDL writes in support of the AHCCCS 1115 Demonstration Waiver ("Waiver") Amendment Request regarding parents as paid caregivers for their minor children, to continue allowing this option for families supporting children with disabilities. Ultimately, however, ACDL seeks a long-term solution to address the direct care worker ("DCW") crisis and the overall inadequacy of AHCCCS' provider network in Arizona.

The Waiver has been extraordinarily beneficial in the short term. During the height of the COVID-19 pandemic, it was critical that AHCCCS mitigate the risks to its medically fragile members by reducing exposure to outside DCWs. Permitting parents to be compensated for work as DCWs allowed minor members to receive extraordinary care in a safer setting, particularly as children were the last to get vaccinated.

While the pandemic continues, outcomes have improved significantly, and infection rates are continuing to decrease. Vaccines and access to personal protective equipment have made the provision of healthcare by outside DCWs safer for many. ACDL receives positive feedback from parents who are caregivers to minor children. These parents, who are paid to provide both attendant care and habilitation care, are able to ensure that their children do not go without the extraordinary care they are entitled to.

While ACDL supports the effort to make permanent AHCCCS's payment of parents for the provision of care to minor-children for attendant care, it is critical to recognize this as what it is – a band aid for a much larger crisis.

Providers in our community often report that they were only funded at approximately 70% *before* the minimum wage voter initiative was passed in 2016. Since that time, the rising minimum wage in Arizona has tightened competition for workers among home and community-based services ("HCBS") agencies, and with other workforce sectors. Direct care work is demanding, and the employees are underpaid. The jobs have also become more dangerous since the start of the pandemic. And it has become easier to receive comparable pay in jobs that do not come with a health risk, do not require physical labor, and do not risk compassion fatigue. This reality results in high turnover rates among DCWs, reducing the size of the provider network and placing additional strain on families of minor children with disabilities to make up the shortfall in coverage.

In 2020, the median hourly wage for a DCW in Arizona was $12.65 per hour.[1] Today, ZipRecruiter identified the average pay for a cashier at McDonald's as $13.73 per hour.[2] An AHCCCS study provides that Arizona will need to fill 190,000 DCW jobs by 2030.[3] The crisis is here, and it cannot be solved without a systemic overhaul of the programs that fund DCWs in Arizona.

The Waiver Amendment Request is imperfect. Three problems stand out. Primarily, the Waiver Amendment Request will no longer include habilitation hours for parent-caregivers of minor children. Those hours, not insignificant in total, will need to be provided instead by the direct care workforce – which is not currently sufficiently staffed to cover these additional hours. AHCCCS gives no explanation for this change, which will surely leave minor children in Arizona without the habilitation services they require and are entitled to receive.

Second, ACDL receives reports from paid parent-caregivers whose minor children's approved attendant care and habilitation hours are reduced, often without explanation or justification based on the child's needs. These children appear to be victims of a systemic misconceived reliance on parent-caregivers continuing to provide the required attendant and habilitation care whether they are paid or not. If AHCCCS intends to continue to use parents to help mitigate its DCW shortage, it should treat them as it would any other DCW – and, more importantly, it should not punish their minor children by reducing approved service hours because their parents are providing the required care. This problem should be addressed systemically.

Finally, it is critical that AHCCCS understand that, while some families prefer to provide care to their minor children under the Waiver, many do not, or are unable to do so. It must

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[1] https://www.azahcccs.gov/shared/Downloads/News/2021/ArizonaPaidCaregiverSurveyReport.pdf at p. 39.

[2] https://www.ziprecruiter.com/Salaries/Mcdonalds-Cashier-Salary--in-Arizona

[3] https://www.azahcccs.gov/shared/Downloads/News/2021/ArizonaPaidCaregiverSurveyReport.pdf

remain a family’s choice as to whether the parent or parents will be the paid caregiver for minor children with disabilities. For many, the risks during the pandemic were simply too great for some families to risk permitting outside DCWs into their homes. As a result, many parents left the workforce to begin to provide care for their children. As some risks from the pandemic have been mitigated, many parents need to return to full-time or part-time employment out of the home – often, to more gainful employment. Due to the DCW shortage, however, these parents have been unable to find reliable in-home care for their children. Accordingly, they have been forced to remain underemployed to provide attendant and habilitation services for their children, which has caused a financial strain on many families. This is compounded by the fact that it is also extraordinarily difficult to find consistent respite care for parents. AHCCCS’ inadequate network of providers and the DCW shortage is causing burnout among parent-caregivers, and children with disabilities and their families are suffering as a result. There must be a network of DCWs that is adequate to address the need for services, and does not rely on parent-caregivers to fill gaps in coverage when it would not be their choice to do so.

CONCLUSION

While ACDL supports the Waiver Amendment Request in principle, the most critical problem remains the DCW crisis and AHCCCS’ inadequate network of providers. Ultimately, the problem will need to be resolved legislatively. ACDL looks forward to serving as a resource to AHCCCS as the community works together to ensure that its direct care programs are appropriately funded in the future.

Sincerely,

/s Meaghan K. Kramer

Meaghan K. Kramer
Managing Attorney, Healthcare

[redacted]

[redacted] [redacted]

August 21, 2023

Comments submitted via e-mail to waiverpublicinput@azahcccs.gov

AHCCCS
c/o Division of Community Advocacy and Intergovernmental Relations
801 E. Jefferson Street, MD 4200
Phoenix, AZ 85034

RE: Comments on Arizona Health Care Cost Containment System Waiver Proposal Regarding Paid Parent Caregivers

Dear AHCCCS Representative:

The William E. Morris Institute for Justice ("MIJ") is a non-profit organization dedicated to protecting the most basic civil and human rights of low-income Arizonans and other Arizonans in historically marginalized communities. MIJ prioritizes advocacy on systemic issues in several substantive legal practice areas involving public benefits and safety net programs, including Medicaid and healthcare access. MIJ takes great interest in how Medicaid waivers operate in Arizona and across the United States because Arizona's entire Medicaid program, the Arizona Health Care Cost Containment System ("AHCCCS"), operates under a waiver.

MIJ appreciates the opportunity to submit comments regarding AHCCCS's Waiver Proposal ("Proposal") to make permanent certain flexibilities AHCCCS has utilized, starting during the federally declared Coronavirus Disease 2019 ("COVID-19") Public Health Emergency ("PHE"), to allow parents of minor children with disabilities to receive payments to provide critical services AHCCCS generally provides and supports through the Arizona Long Term Care System ("ALTCS").

Section 1115 of the Social Security Act grants the Centers for Medicare and Medicaid Services ("CMS") limited authority to "waive" a state's compliance with certain federal laws in order to experiment and test novel policies to advance Medicaid's purpose of furnishing medical assistance to people with limited incomes. With the Proposal, AHCCCS requests an amendment to the State's current Demonstration project, "Arizona Medicaid Section 1115 Demonstration" under Section 1115 of the Social Security Act (Project Number 11-W-00275/9).

MIJ generally supports the Proposal and the paid parent caregiver flexibilities AHCCCS seeks to preserve permanently. However, MIJ offers the comments in this letter to highlight necessary actions AHCCCS must take to ensure that, if approved and implemented, the Proposal functionally delivers on AHCCCS's publicly stated goals in making permanent the paid parent caregiver flexibilities that have been in effect and working in Arizona over the last two years. MIJ's comments on the Proposal are primarily focused on [1] supporting paid parent caregivers, their children, and their families through robust AHCCCS actions to maximize utilization of the caregiver payment income exclusion set forth in federal law to provide healthcare through Medicaid to eligible paid parent caregivers, and [2] removing rigid requirements capping hours of AHCCCS-approved services paid parent caregivers can provide.

AHCCCS's Goals in the Waiver Proposal

AHCCCS notes in the Proposal that, in response to the PHE declared due to the COVID-19 pandemic, AHCCCS submitted and received approval for an Appendix K waiver amendment to allow for certain flexibilities to their Medicaid program, including the authorization of payments to parents who serve as paid caregivers for minor children. AHCCCS stated that its goal for seeking a Section 1115 waiver to continue a version of the Appendix K waiver flexibilities is "to better address the direct care worker (DCW) shortage by permanently extending payments to parents who serve as paid caregivers for minor children while also further developing the Arizona Long Term Care System (ALTCS) to include extended family supports to preserve a supportive home environment and mitigate access to care challenges."[1]

MIJ supports AHCCCS's commitment to take meaningful actions both [1] to help AHCCCS navigate challenges posed by the ongoing critical labor shortage affecting the availability of direct care workers to provide necessary Home and Community Based Services to Arizonans with disabilities, and [2] to mitigate ongoing access to care challenges experienced by ALTCS-covered Arizonans. AHCCCS states in its proposal, "Outside of extending [Parents as Paid Caregivers], AHCCCS prioritized use of the

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[1] *Arizona Section 1115 Waiver Amendment Request: Parents as Paid Caregivers* (AHCCCS), July 16, 2023, Page 2, available at https://www.azahcccs.gov/Resources/Downloads/Federal/ParentsAsPaidCaregivers-AZ1115WaiverAmendmentDraft.pdf

[American Rescue Plan] funding to develop a multi-pronged approach to address recruitment and retention of [direct care workers] to bolster the workforce to assume the provision of care after the conclusion of the flexibility."[2] In the Proposal, AHCCCS does not discuss or provide any data indicating the measured outcomes and performance of its multi-pronged approach.

We note that AHCCCS has affirmative obligations and duties to ensure vulnerable Arizonans with disabilities, including children with disabilities, receive critical Medicaid services in their homes, whenever appropriate. AHCCCS must provide an adequate network for Home and Community Based Services. And AHCCCS must design and align its administration and direction of ALTCS services in furtherance of the agency's obligations to Arizonans with disabilities, including the State of Arizona's duties under *Olmstead v. L.C.*, 527 U.S. 581 (1999), the landmark disability rights decision from the Supreme Court of the United States, mandating de-institutionalization and community integration for Americans with disabilities.

COVID-19 Remains a Threat to Arizonans' Health and Safety

Undoubtedly, in recent years, AHCCCS's actions to ensure that parents of minor children could provide services as paid in-home caregivers protected the health and safety of some vulnerable families and children during the ongoing COVID-19 pandemic and the now-lifted federal COVID-19 PHE.[3] Providing services through paid parent caregivers also helped Arizona fulfill its mandatory *Olmstead* duties and to advance disability rights with an expanded roster of care workers to meet community needs during an unprecedented period of economic and public health uncertainty arising out of the COVID-19 pandemic. AHCCCS's flexible response in securing an Appendix K waiver to pay parents for in-home services to minor children was helpful to families concerned with protecting the health and safety of their home through various measures, including limiting visitors from the outside to mitigate the risk of transmission and spread of COVID-19, especially to vulnerable children with disabilities.

While public perceptions and sentiments regarding COVID-19 have changed in 2023, the COVID-19 pandemic and disease continues to cause harm in Arizona.[4] For this

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[2] *Id.* at 4.

[3] The United States Department of Health and Human Services ended the federal COVID-19 Public Health Emergency, effective May 11, 2023.

[4] Data from the Arizona Department of Health Services indicate that, in the week preceding August 16, 2023, there were 2,325 reported cases of COVID-19 in Arizona and 13 COVID-19 deaths. *See* data available at https://www.azdhs.gov/covid19/data/index.php.

reason alone, it makes sense for AHCCCS to continue its previous actions to safeguard the health and well-being of children with disabilities in need of in-home Medicaid services.

However, for AHCCCS to fully realize its stated goals in the Proposal, AHCCCS must recognize critical accompanying steps the agency must take to maximize support and flexibility for parents who serve as caregivers, as well as the family members to whom they provide critical services. While MIJ supports the Proposal, we strongly believe it needs more safeguards to ensure healthcare access for paid parent caregivers to ensure its effectiveness. Specifically, AHCCCS must ensure that it does all it can to ensure that eligible paid parent caregivers have their own access to critical healthcare services, while designing service plans to ensure that Arizona children with disabilities have all the necessary resources available to best meet their needs in their homes. For over a year, MIJ and other advocates have regularly communicated with AHCCCS concerning the failures and insufficiencies of its implementation of the paid parent caregiver income exclusion applicable during Medicaid eligibility determination and renewal processes for parent caregivers.

Ensuring Healthcare Accessibility for Eligible Paid Parent Caregivers

The payments parents serving as in-home caregivers receive for AHCCCS-approved services must be excluded from income calculations in AHCCCS eligibility determinations. The caregiver payment income exclusion is a creature of federal law by virtue of IRS Notice 2014-7,[5] which became effective along with the implementation of the Modified Adjusted Gross Income ("MAGI") methodology for determining Medicaid eligibility in January 2014. Under IRS Notice 2014-7, payments received by family members for Home and Community Based Services are excluded from MAGI. The intended effect of the income exclusion is that some paid parent caregivers will have a measure of economic security from receiving AHCCCS-approved payments for services as non-taxable income, while maintaining their own eligibility for Medicaid coverage, since the payments are not counted as income in Medicaid eligibility determination processes.

The benefit of Medicaid eligibility has been realized by many paid parent caregivers in Arizona, allowing them access to healthcare as AHCCCS members while they provide critical Medicaid-covered services to their children with disabilities, who rely on AHCCCS-provided care and services to live in their homes. Yet AHCCCS has been slow to implement effective measures to maximize Medicaid coverage for paid

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[5] https://www.irs.gov/irb/2014-04_IRB#NOT-2014-7

parent caregivers. Simply put, AHCCCS has not ensured that paid parent caregivers consistently have their Medicaid eligibility assessed accurately in application and renewal processes.

As an initial matter, AHCCCS only implemented a policy clarifying the exclusion of so-called "difficulty of care" payments from income calculations in Medicaid eligibility determinations for the first time on September 1, 2022. Although AHCCCS's Appendix K flexibilities were effective in March of 2020, it took over two years for AHCCCS to attempt to implement a Medicaid eligibility policy that complies with IRS Notice 2014-7. Over the last year-plus, advocates have seen numerous cases involving caregiver payments improperly counted as income in Medicaid eligibility determinations for caregiver parents. AHCCCS's handling of eligibility determinations in paid parent caregivers' Medicaid cases has been inconsistent and, at times, led to Medicaid coverage interruptions.

There appear to be both technological and human systems that have not been designed and/or trained to track this special population of Medicaid beneficiaries and the caregiver payments they receive, which should be categorically excluded from income calculations in Medicaid eligibility applications and renewals. Problems with AHCCCS's tracking of paid parent caregiver members have been evident during the ongoing Medicaid continuous coverage unwinding, during which paid parent caregivers have received notices indicating that they are not eligible for Medicaid coverage because of caregiver payments, or that they need to verify income that AHCCCS knows – or should know – is attributable caregiver payments to provide Medicaid services to their children in their homes.

One root cause of some of the problems the paid parent caregiver community has experienced is AHCCCS's incomplete and ineffective implementation of the policy change the agency put in place almost a year ago. The initial policy solution for paid parent caregivers' Medicaid eligibility was implemented through what AHCCCS calls a "News Flash," an electronic internal AHCCCS communication to staff. AHCCCS issued New Flash #2022-031M regarding implementation of IRS Notice 2014-7 in administering Medicaid eligibility determination processes. Since this initial implementation of eligibility policy, paid parent caregivers have continued to run into problems ensuring ongoing access to Medicaid coverage, with AHCCCS eligibility staff regularly seeming to be unaware of the special status of caregiver payments in MAGI calculations and AHCCCS's own federally required policy excluding such payments from income.

To support paid parent caregivers, AHCCCS must train its staff to exclude difficulty of care payments from Medicaid applicants' and members' income in eligibility determinations, pursuant to IRS Notice 2014-7 and any associated policies AHCCCS has implemented to give effect to the caregiver payment income exclusion required by federal law. AHCCCS must continue to communicate with its staff about the caregiver payment income exclusion. AHCCCS must develop and provide trainings specific to the issue, as well as training components within materials related to the programs and services paid parent caregivers deliver to their children through their work. In short, AHCCCS's eligibility teams and other key staff must know the details about the caregiver payment income exclusion and how the income exclusion benefits parents and families in need of in-home care and services. To extend the current system, without improvements and changes, will continue to short-change families.

Relatedly, AHCCCS must undertake a comprehensive and effective communication plan, targeting paid parent caregivers, to inform them about the paid parent caregiver program and the exclusion of caregiver payments from income in Medicaid eligibility determinations for caregiver parents. AHCCCS is, of course, in possession of data identifying paid parent caregivers and can easily determine if they are enrolled in Medicaid. For any who are not, AHCCCS should provide information about the potential benefit of Medicaid to their health and well-being. Additionally, AHCCCS is in possession of key data about Arizona children receiving ALTCS, including their identities and addresses, to address outreach materials to their families about the paid parent caregiver option for critical services and the associated caregiver payment income exclusion.

Communication about AHCCCS's policy on the exclusion of caregiver payments in Medicaid eligibility determinations should be a part of the onboarding and training plans for paid parent caregivers, who can learn about the potential benefits for which they may not know they are eligible. AHCCCS should also take all available steps not just to educate paid parent caregivers about their potential Medicaid eligibility, but to ask questions to screen them proactively for potential need and eligibility for Medicaid coverage.

Finally, AHCCCS should additionally engage in a public communications campaign about the paid parent caregiver program and the exclusion of caregiver payments from income in Medicaid eligibility determinations. AHCCCS should broadly celebrate the income exclusion policy the agency implemented last year as a step toward more comprehensive care systems for Arizonans with disabilities and the State's meaningful actions toward ensuring vulnerable Arizonans can live in community settings, rather than institutions and group homes, with healthy parent caregivers.

AHCCCS should use the caregiver payment income exclusion as a resource and tool to recruit more in-home caregivers. As noted by AHCCCS, the agency is experiencing problems delivering care and services due to a critical labor shortage. In short, there are not enough direct care workers. Paid parent caregivers can be part of the solution to this problem, but AHCCCS should recognize that caregivers cannot give care to their children if they are ill and cannot get proper medical care for themselves. Broader public messaging and encouragement to Arizonans both [1] to become caregivers and [2] to realize the potential pathway to healthcare arising out of the caregiver payment income exclusion could be an incredible benefit to everyone involved, from the State of Arizona, to parents looking for care solutions, to Arizonans with disabilities presently experiencing access to care problems.

Ensuring Flexibility in Weekly Hours for Paid Parent Caregiver Services

In the Proposal, AHCCCS articulated the workforce challenges that serve as reasons it seeks the paid parent caregiver waiver:

> Addressing workforce shortages needs to focus simultaneously on filling the current gaps as well as preparing for future membership growth to mitigate compounded shortages in the future. In recognition of these challenges, the Agency proposed numerous interventions and investments described above aimed at attracting and retaining the DCW workforce through its Section 9817 ARPA Spending Plan, including payments to parents of minor children. However, over the course of implementing the aforementioned initiatives, based on stakeholder feedback and available data it became apparent to the State that the [Parents as Paid Caregivers] program continues to be a critical lifeline for the complex children and families that AHCCCS serves. The anticipated workforce needs and projected increase in our ALTCS population, combined with the anticipated number of [direct care workers] entering the workforce, creates a scenario where augmenting the DCW workforce in Arizona through his [sic] [Parents as Paid Caregivers] program ***is essential to ensuring members are able to receive the care they need*** [emphasis added].[6]

While observing how essential paid parent caregivers are, given current and anticipated workforce realities and care network needs, AHCCCS included a cap and limit on the number of hours for which paid parent caregivers may be approved for

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[6] *Arizona Section 1115 Waiver Amendment Request: Parents as Paid Caregivers* (AHCCCS), July 16, 2023, Page 4, available at https://www.azahcccs.gov/Resources/Downloads/Federal/ParentsAsPaidCaregivers-AZ1115WaiverAmendmentDraft.pdf

payment to provide critical services to their children with disabilities in a given week. Specifically, AHCCCS stated the following:

> Parents who provide these services must also maintain quarterly in-person case management visits as well as agency supervisory visits as further detailed in AMPM 1240-A. Parents would be limited to 40 hours of paid care, per child, in a given week where paid care by a parent caregiver cannot exceed more than 16 hours in a single day. If two children are receiving direct care services (attendant care, personal care or homemaker services), the parent(s) may provide up to a combined 80 hours of paid care per week (40 hours for each child). The exact number of hours (up to 40 per child) approved for payment will be determined through the person-centered planning process and must meet medical necessity requirements. Although these hourly limitations are in place, members can still receive more than 40 hours of authorized paid care in a given week through the use of an alternate caregiver.[7]

In sum, AHCCCS proposes a rigid cap on approved service hours for paid parent caregivers. The plain language of the Proposal includes no flexibility regarding the weekly hours cap AHCCCS proposes to mandate.

The rigidity of the Proposal on capping approved weekly hours for paid parent caregiver services may run counter to AHCCCS's broader goals in advancing the Proposal. If AHCCCS is committed to a "person-centered planning process" that is meaningful and dynamic, then AHCCCS should preserve more flexibility in approving weekly hours for paid parent caregivers than the language of the Proposal allows.

It is entirely possible, if not probable, that there may be cases where a person-centered planning process regarding an Arizona child with a disability will determine that the child has a need for 45 or 50 hours of in-home services a paid parent caregiver could provide in a way that works well for the family and meets the child's disability-related care needs most effectively and safely. In such a case, under the proposal, a family may endure hardship and inconvenience trying to coordinate with AHCCCS service providers out of the home for 5-10 hours of direct care services, facing all of the logistical and labor market challenges and obstacles Arizonans receiving ALTCS services experience on a daily basis at present. In some cases, families may be forced to provide certain critical services out of necessity, without compensation, rather than experience harms arising out of critical services gaps.

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[7] *Id.* at 5.

AHCCCS should reconsider the rigid weekly hours caps included in its Proposal. Paid parent caregivers may be the best source of care available to meet AHCCCS's goals and, more importantly, the needs of Arizona children with disabilities receiving critical services in their homes. Restricting approved weekly service hours may run counter to the fundamental reasons AHCCCS has established the Proposal is necessary and important.

Conclusion

MIJ has advocated extensively with AHCCCS over the last year and two months regarding the agency's policies, practices, and systems affecting Medicaid eligibility determinations for paid parent caregivers. MIJ specifically advocated for the policy change AHCCCS implemented almost a year ago and continues to voice concerns about systemic problems causing unnecessary healthcare coverage interruptions and other harms to paid parent caregivers.

MIJ believes that the Proposal presents an opportunity for AHCCCS to advance healthcare goals for Arizona children with disabilities and their in-home care networks. Ensuring that paid parent caregivers have healthcare should be a paramount concern for AHCCCS. Making the paid parent caregiver flexibilities permanent presents an opportunity for AHCCCS to address current problems with its Medicaid eligibility determination procedures for paid parent caregivers. AHCCCS can demonstrate its commitment to the Proposal, and the affected families and children, by bolstering all current actions to maximize Medicaid coverage for the paid parent caregiver population.

Thank you for your consideration of our comments on this critical issue affecting the people of Arizona. Please contact me at dpschaffer@mijaz.org if you have any questions or if MIJ can provide any additional information to supplement our request.

Sincerely,

/s/ *Drew P. Schaffer*

Drew P. Schaffer, Director
[redacted]

Raising Special Kids

July 17, 2023

AHCCCS
[redacted]

RE: Public Comment – Arizona Section 1115 Waiver Amendment Request: Parents as Paid Caregivers

Director Carmen Heredia,

Thank you for the opportunity to provide comment on the AHCCCS *Arizona Section 1115 Waiver Amendment Request: Parents as Paid Caregivers* proposal dated June 16, 2023.

As a statewide provider of family support for parents and family members raising an infant, toddler, child, youth, or young adult with disabilities Raising Special Kids (RSK) appreciates Arizona's Medicaid program for its support of family caregivers.

In our role as a statewide advocate for Arizona families of children with disabilities, we support the efforts by AHCCCS to seek a well-balanced approach as we transition from the Public Health Emergency toward more standard practices. If the waiver amendment is approved by CMS, we hope to see:

- Pressure on families relieved by compensating parents for caregiving services, with appropriate safeguards that meet the definition of extraordinary care and prevent institutionalization.
- The inclusion of Family Support as a covered service to assist families of children receiving HCBS.
- Continued attention to and monitoring of managed care organizations and provider agencies to recruit, train, and maintain a professional workforce of sufficient capacity to provide Home and Community Based Services.

RSK reviewed the proposed Arizona section 1115 waiver request, consulted and engaged with stakeholders, and considered diverse viewpoints regarding the waiver request. RSK generally supports the proposed waiver request in its entirety and believes it finds the appropriate balance between the CMS standards for "extraordinary" care to prevent institutionalization while also meeting the needs of parents caring for children with high support needs. The waiver request correctly addresses policy issues related to ensuring individuals receiving HCBS have full access to the benefits of community living and that family caregivers meet the necessary qualifications and other criteria for providers of care.

Details on specific support for the request, the need for further information, and our concerns for possible unintended consequences are as follows:

1. Role of Family

Families play a critical role in the health, education, and development of children with disabilities and RSK supports allowing 40 hours maximum per week of paid caregiving services. This establishes a needed balance to preserve and support the role of the family in Arizona's Medicaid system. RSK expresses its reservations concerning provisions that would allow families (as they have under PHE flexibilities) to become paid providers of *habilitative services* for their child. This service expansion would change their roles to become *both caregiver and primary paid service provider.* The effects of this could increase caregiver burnout, and lead to greater social isolation of both the child and family. Achieving optimal outcomes for children requires parents and professionals to consult and collaborate on the provision of care and support needed within home and community-based settings.

2. Network Capacity

As a family-serving organization, RSK acknowledges the persistent need for and ongoing shortage of Arizona's direct care workforce and HCBS service providers. RSK supports the restraint used in this request to stop short of making all PHE flexibilities permanent policy. We support AHCCCS in its thoughtful approach to maintain needed investment and preserve incentives for recruiting and training a viable and professional workforce. We believe a shift to a system where families were incentivized to provide habilitative HCBS could lead to complacency among Arizona's provider network about the necessity to develop and maintain sufficient capacity which may ultimately degrade Arizona's system of care for supporting individuals with disabilities and their families. The unintended consequences may lead to provider agencies heavily recruiting parents and family members, leading to an even greater shortage of trained and qualified direct care workers.

3. Extended Family Support

Years of data show that Family and Peer Support services have a high social impact, resulting in improved outcomes for children, youth, and young adults with disabilities and their families by increasing resiliency and decreasing the need for crisis services. As the PHE flexibility benefits end, the need for peer-based parent support will increase. AHCCCS has appropriately reflected in the waiver request the need for and importance of this uniquely effective form of family support. Parents who have lived experience in supporting a family member receiving HCBS will increasingly be a necessary and important connection and link for families to sources of information, training, and support. We have questions surrounding how this will be defined and implemented among families of individuals receiving HCBS. We encourage AHCCCS to work with stakeholders and community-based organizations like Raising Special Kids to ensure peer support services will be provided and maintained at a high level of quality and offered in ways that meet the diverse needs of families.

Summary

Arizona families struggled prior to the pandemic to secure adequate caregiver and habilitative services for their child(ren), primarily due to an insufficient network and provider shortages. During the pandemic, those struggles increased dramatically and the flexibility of allowing families to become paid caregivers for their minor children was a much-needed solution. As Arizona transitions out of the PHE, families continue to face significant challenges as they strive to fill the gaps. RSK offers its strong support for the waiver request and, as this important work continues, is committed to supporting AHCCCS in its efforts to improve and sustain our system of care for Arizona's most vulnerable populations.

Raising
Special
Kids

About Raising Special Kids

Raising Special Kids (RSK) is an Arizona nonprofit organization founded in 1979 with a mission of strengthening families and systems of care to improve the lives of children with disabilities. RSK is Arizona's federally designated Family-to-Family Health Information Center funded by the US Department of Health and Human Services Health Resources and Services Administration (HHS/HRSA), and a founding member of Parent-to-Parent USA providing evidence-based peer-to-peer support to Arizona's parents and family members raising children with the full range of disabilities. As the Arizona chapter of Family Voices, RSK promotes partnerships with families to improve healthcare services and policies for children. In addition to serving and supporting individual families, RSK exists to assist providers, state and federal agencies, legislators, and other stakeholders to better understand and serve children and youth with disabilities and special health care needs.

Christopher Tiffany
Executive Director

July 19, 2023

Arizona Health Care Cost Containment System (AHCCCS)

Subject: Request to Extend Coverage and Allow Parents to Remain Primary Caregivers for Children with Special Needs

To whom it may concern: (Public Input forum)

I hope this letter finds you well. I am writing to advocate on behalf of my minor child, [redacted] who has autism. As her parent and caregiver, I strongly believe that she needs a voice and someone who understands her unique needs and challenges. I am requesting your support and consideration in extending coverage and allowing parents to remain as primary caregivers for children with special needs.

[redacted] is a wonderful and resilient individual with great potential, but she faces significant difficulties in communication due to her autism. As a result, expressing her needs, emotions, and preferences can be incredibly challenging for her. As her parent, I have spent countless hours understanding her communication methods, establishing trust, and ensuring her well-being.

Being her primary caregiver, I have developed a deep understanding of [redacted] likes, dislikes, triggers, and strategies to help her thrive. This intimate knowledge of her personality and unique abilities allows me to provide the best possible care and support for her overall development.

As parents of children with special needs, we invest not only our time and energy but also our hearts into their care. We are relentless in our pursuit of the best resources, therapies, and educational opportunities for our children. Our commitment to their well-being is unwavering, and we tirelessly advocate for their rights to ensure they are given every opportunity to lead fulfilling lives.

While I appreciate the efforts of caregivers and professionals who work with children like [redacted], it is essential to recognize that parents play an irreplaceable role in the lives of their children with special needs. Our love, dedication, and understanding are vital components of their growth and progress.

Therefore, I urge you to extend the coverage and support for parents like me, allowing us to remain as primary caregivers for our children with special needs. Recognizing and valuing the importance of parents in this capacity will enhance the overall well-being and development of these children.

I kindly request an opportunity to discuss this matter further with you and explore ways to enhance support for families like ours. Together, we can create a more inclusive and empathetic environment for children with special needs.

Thank you for your time and consideration. I look forward to your positive response and the opportunity to make a meaningful difference in the lives of children with autism.

Sincerely,

David DelGrosso [redacted]

[redacted]

[redacted]

CALLS

Contact Information

Contact Person	Griselle Purviance
Complainant Phone	[redacted]
Complainant Address	[redacted]
Complainant's Email	[redacted]

Member Information

Member's Name	[redacted]
Member's AHCCCS ID or ASSIST ID	[redacted]
Member's Date of Birth	[redacted]

Reason for the Call

Brief Summary of the Call

As a parent of a child with DDD and AHCCCS. I am very disappointed that AHCCCS wants to cut these services for the members. I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which would go into place in November 2023, my child and many more like them will lose access to their Habilitation services or more than 40 hours a week of care by parent providers of minor members. The reason my child will not have access to their appropriately evaluated services is due to the DCW shortage. My agency has specifically stated that they will not be able to recruit, hire and train enough providers to fill the gaps in service these new rules will create.

---------- Forwarded message ---------
From: Mariela Padilla Martin <mpadillamartin@azdes.gov>
Date: Tuesday, August 8, 2023 at 7:18:16 PM UTC-4
Subject: Parent Paid Provider Program
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Contact Information

Contact Person
Jeremiah Purviance

Complainant Phone
[redacted]

Complainant Address
[redacted]

Complainant's Email
[redacted]

Member Information

Member's Name
[redacted]

Member's AHCCCS ID or ASSIST ID
[redacted]

Member's Date of Birth
[redacted]

Reason for the Call

Brief Summary of the Call

Jeremiah is calling the CSC stating he would like to file a grievance to DDD about the Parent Paid Provider program through AHCCCS. He wants to file a grievance against DDD and AHCCCS about the proposal happening in November, he states his children and many others will be affected. They will lose their AHCCCS Habilitation services 40 hours a week. He states that the child will not have services. He states there is never anyone to fill the gaps and services once these new proposals happen in November. He states there is a direct care worker shortage and once this proposal takes place his child will not have services. He says his son will not get the services that he has been evaluated to have, he states this should be permanent and not end in November. He states DDD is submitting this new proposal without HAB to AHCCCS which is affecting many parent-paid providers.

Agency: Arizona Care Providers

From: Judith Wilson [redacted]
Date: Wednesday, July 26, 2023 at 12:50:46 PM UTC-4
Subject: Member Grievance RS # [redacted]
To: Waiver Public Input - AHCCCS <waiverpublicinput@azahcccs.gov>
Cc: sommer.mutter[redacted] [redacted]

Contact Information

Sommer Muttet	**Contact Person**
[redacted]	**Complainant Phone**
[redacted]	**Complainant Address**
[redacted]	**Complainant's Email**

Member Information

[redacted]	**Member's Name**
[redacted]	**Member's AHCCCS ID or ASSIST ID**
[redacted]	**Member's Date of Birth**

Reason for the Call

Brief Summary of the Call

I am the mother of a child who receives DDD and ALTCS services. I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which would go into place in November 2023, my son and many more like him will lose access to their Habilitation services or more than 40 hours a week of care by parent providers of minor members. The reason my son will not have access to their appropriately evaluated services is due to the DCW shortage. My agency has specifically stated that they will not be able to recruit, hire and train enough providers to fill the gaps in service these new rules will create.

It is my belief that this new proposal is intentional in discriminating against and specifically targets parent providers. Should my son lose Habilitation services due to this new proposal he will without a doubt suffer, have setbacks and will regress on learned skills and working towards new godesals.

---------- Forwarded message ---------
From: Judith Wilson [redacted]
Date: Wednesday, July 26, 2023 at 12:36:54 PM UTC-4
Subject: Member Grievance RS # [redacted]
To: Waiver Public Input - AHCCCS <waiverpublicinput@azahcccs.gov>
Cc: Jennifer.Harley [redacted]

Contact Information

Contact Person

Jennifer Harley

Complainant Phone

[redacted]

Complainant Address

[redacted]

Complainant's Email

[redacted]

Member Information

Member's Name

[redacted]

Member's AHCCCS ID or ASSIST ID

[redacted]

Member's Date of Birth

[redacted]

Reason for the Call

Brief Summary of the Call

Hello, I am a parent of a child who receives DDD and ALTCS services. I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which would go into place in November 2023, my child will lose access to their Habilitation services. The reason my child will not have access to their appropriately evaluated services is due to the DCW shortage. My agency has specifically stated that they will not be able to recruit, hire and train enough providers to fill the gaps in service these new rules will create.

---------- Forwarded message ---------
From: Judith Wilson [redacted]
Date: Wednesday, July 26, 2023 at 12:20:11 PM UTC-4
Subject: Member Grievance RS #[redacted]
To: Waiver Public Input - AHCCCS <waiverpublicinput@azahcccs.gov>
Cc: Nicole G[redacted]

Hi Nicole, I forgot to let you know that I am sending you a copy of the Grievance that was sent to AHCCCS.

Contact Information

Contact Person

Nicole Guysi

Complainant Phone

[redacted]

Complainant Address

[redacted]

Complainant's Email

[redacted]

Member Information

Member's Name

[redacted]

Member's AHCCCS ID or ASSIST ID

[redacted]

Member's Date of Birth

[redacted]

Reason for the Call

Brief Summary of the Call

I am a parent of a child who receives DDD and ALTCS services and I am filing a grievance against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. This proposal, which would go into place in November 2023, means children will lose access to their Habilitation services or more than 40 hours a week of care by parent providers of minor members. The DCW shortage means that children whose parents are currently providing these services will not have a provider. We have two agencies that we split hours between but yet still no provider despite their recruiting efforts.

EMAILS

From: Hughes Joseph <s[redacted]>
Date: Thursday, August 10, 2023 at 10:08:19 PM UTC-4
Subject: Public comment respectfully submitted
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

We would like to thank you for the opportunity to address the public comments on parents as paid providers. Taking each talking point, we will address our observations and recommendations. **Address the shortage of Direct Care Workers and caregivers by allowing payments to parents who* are *paid caregivers for their children.* The shortage of providers has been a concern for members/parents as far back as we can remember. Since Arizona is somewhat unique with its waiver to consider the member's income and not the family, parents have flocked to Arizona as an oasis for excellent programs and from the constrictions and restrictions of other states with similar Medicaid-funded programs. This influx, long ago created a quagmire in the mandate for supports and providers to satisfy the demand. Historically it has been a struggle for the DDD to find agencies to meet the ever-growing need for providers. Once parents were allowed to become paid providers for adults, the number of unsupported members decreased significantly and has maintained the gap in the decade-plus since its inception. As an agency, we have seen the pendulum swing from many "qualified" providers to very few "qualified" providers for the underserved member population, specifically within the school-age groups. The onset of the Covid pandemic proved to be particularly difficult. When the offer to train and pay parents as Attendant Care and Habilitation providers for the under-supported school-age groups, we saw a significant decrease in members who were not served. **Increase member satisfaction and promote positive health and well-being outcomes for these children.* It is a fact that parents, in general, are nurturing and intend to teach and advance their children with love while learning independence. We have found that, by in large, parents know what their children need to help them move toward self-sufficiency. With the training and guidance that we as an agency have provided the parents, we have seen examples of growth in the children, parents, and guardians. For whatever reason, members are learning, in fact, thriving. With the trained eye and direction of the trainers, parents have picked up the pace and become a powerhouse. These roles have typically been provided by someone hired by an agency who is a stranger to the family/member and whom they must trust to do the job because they have specific training. With parents as paid providers, they feel safe and assured that their child is getting the best care and training possible. While it does not always work out for all parents to be in the role of the trained provider, there are a great deal of parents to whom this works out perfectly. We have found that some parents don't want to take on that role. We respect and understand that. In most cases, we can support them with some work from our amazing H.R. and hiring staff. **Extend an additional support service to restore, enhance, and maintain family functioning to preserve effective care for the member in the home and community and ensure that members receive high-quality care while increasing timely accessibility to care providers.* Many parents who chose to do the Attendant Care and Habilitation for their children have expressed great relief in the scheduling of support staff and the intrusion into their private lives for services. Parents seamlessly transition their children into teaching or supporting them when scheduling conflicts are reduced due to an outside direct support provider. Having parents as paid direct support providers also allows our agency to have a more natural relationship with them. We have seen an increase in parental input and more opportunities for us to assist, teach and support them. Because this offers opportunities to be more intimate with parenting, teaching, and personal issues, the collaboration in the members' success has been greatly beneficial. We understand that Attendant Care is the service that the DDD is addressing with the AHCCCS to help fill the support gap; we would like to take this opportunity to ask for consideration to include Habilitation. Finding qualified DSPs has become increasingly tricky post-COVID. Fast food establishments and other entry-level jobs offering higher pay with fewer liability concerns make hiring, training, and retaining qualified candidates harder. As an agency, we are selective about who we hire to work with this vulnerable population, which reduces an already depleted workforce. Parents can fill the gap, and in most cases, for reasons already stated, are a perfect solution until the hiring playing field levels out. We humbly recommend that parents and guardians of minors be able to continue to be paid providers for Attendant Care and Habilitation. Thank you for considering this matter.

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Smiles for Special Needs, LLC.
2424 E. Southern Ave.
Mesa, Arizona 85204
Phone: 480 361-1972
Fax: 480 525-1540
Email: smilesfors...@gmail.com
Website: smilesforspecialneeds.com

From: Jessi [redacted]
Date: Thursday, August 10, 2023 at 9:55:58 PM UTC-4
Subject: Caregiver Shortage
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To Whom It May Concern:

I thank you for your time and consideration on this critical issue. I recently attended the forum on August 2nd. Though I believe we made progress on some ideas I think we failed to provide in-depth detail on short term goals, timelines, and encompassing everyone's concerns.

According to the data caveat you provided on the 2nd, it stated that currently, there was no identifier to indicate if the person delivering the service, is a parent. Then on your next slide it indicated that 3,469 parents provide services to minor out of 16,880. I would like to know which is it? Both slides contradicted each other. I believe that there are more members who benefit from parents providing services. If these services weren't provided by a parent, it would impact our community as a whole. My reasoning for this is, because I provide services, I have made it available for other non-parent caregivers to take care of other members (minors or adults). It should also be stated that if the proposal stays as written our members will have a significant decrease in services that are there to support them and assist with growth of independence. I would also like to know that if these numbers are true, where is the state going to get 3,469 providers at one time?

The optimal way to increase our caregiver shortage is to allow parents of minor children continue to provide services that include habilitation and no cap on hours. We are the lifeline for our children, and it would be beneficial to everyone involved if we could collaborate and conquer the challenges our children face.

I would also like to see full transparency in resources. I spent many years searching for resources to get my oldest son diagnosed and services provided. Even to this day I find it challenging and disheartening to wait almost a year for a doctor's appointment at PCH just to find out they can't provide the services we are needing. I feel that this is wasted time and energy and we are still on step one but with more aspirated urgency then before.

A more detailed orientated training with up-to-date policies for support coordinators would be beneficial. I have had a few incidents where I was told one thing only to find out that it isn't true, and/or the policy has changed. First a support coordinator should be trained on better explanations of the programs and services offered. A support coordinator should be very detailed in your meetings as to the process that is going to take place and be able to answer questions accordingly. Our support coordinator acted like I was a professional at the process and never took the time to fully explain all the steps or answer my questions. When I asked questions, I was told this is how it is done, and you will learn that as time goes on. I felt rushed and unequipped in our decision making. The update to training should include what the requirements for attendant care are for each age. In the beginning of Covid though we were never assessed, we were provided 20 hours of attendant care due to supervision. This last year it was decreased to 10 hours a week, again with no assessment. When I inquired why they were decreased I was informed that my children only qualify for supervision and as a parent it is my responsibility to take care of their daily needs. I just recently was informed that my children could qualify for more attendant care hours under extra ordinary care. As my children (11 and 12) still need assistance with hygiene routines, using the restroom, and other daily activities. These are huge discrepancies that should be addressed as they are seen as discrimination to our members and families. Support coordinators should be trained fully on your system and the process of figuring out the number of hours a member should receive for the year, adding more hours, adjusting goals, etc. This has been an ongoing issue since I have started as a provider. During a 90-day meeting it was explained that my child would receive respite care and she broke down the hours to 12 hours a week for us. I diligently only billed 12 hours a week only to run out before October 1st. When I looked it up in the system it stated I was only given 400 hours for the year. When I contacted the agency about it, they informed me that I needed to discuss this with my support coordinator and ask for more hours. My support coordinator, as always, said I needed to have my agency reach out to her. Due to this it took a while for her to approve more respite hours for my son. I have also been able to catch mistakes on their habilitation goals not being updated in the system and the proper paperwork not being sent to our agency. I was explained from our agency that at the bottom of each goal it states who is to provide this service goal. If it doesn't state, the caregiver they cannot legally add it as a goal. I was again told to reach out to my support coordinator to get this resolved only to be told by my support coordinator she cannot talk to me about this matter and the agency needs to reach out to address this issue. Due to this my son's habilitation goals weren't worked immediately. Since I have two son's and one support coordinator, she tends to do everything at once for both children. Though this saves time it also causes conflict when she mixes them up or tries to adjust hours and goals before they are due. One example of this took months to discover and several more months to get resolved. My youngest son was up for his annual review while my other son still had months to go. During the meeting she stated she was going to update the hours and goals for both children but since my oldest wasn't due, yet it would be easier to update at a later time. As weeks went by, I noticed both children's services were not updated. When I reached out to my support coordinator, she stated that this would take effect for my youngest in November which would be in about a week and wouldn't take effect for my oldest until January. As January came my son's hours and habilitation goals weren't updated, I became concerned. I contacted my support coordinator and was told she couldn't discuss this with me, and I needed the agency to contact her. As time went on, I contacted her again and was told that she never stated the services were going to start in January and they should have started in November. Then I was given the run around about who's mistake it was. As I continued to let both the agency and support coordinator know, I really didn't care who made the mistake but that it was fixed immediately. At this point, I had to contact the supervisor of our coordinator because this issue wasn't getting resolved. After contacting the supervisor, I was informed by my support coordinator that the mistake was made by Wellsky as they were a new company, with new EVV rules. Wellsky was the only one who could fix it. I again reiterated that I didn't care who was to blame, I just wanted it fixed immediately. I expressed my frustration that she was making it seem as though it was just about the money. I explained to her that my son was still going to be provided for and receive showers and such with or without the money. I also explained that a non-family provider wouldn't wait several months for a paycheck as they have bills to pay. After waiting over a week, I again called my support supervisor and was told she could no longer talk to me about this issue. It wasn't until I persisted and let her know that I would personally contact Wellsky that this was somehow resolved. By this time, it was February. I can say I was back paid from November to February, but this issue shouldn't have taken this long to resolve. No other person is going to continue to provide a service for that long without payment. I have also had issues with correct OT and SLP hours being issued and when I call about it my support coordinator seems annoyed and refuses to discuss this with me. She insists that these issues need to be taken up with the agencies, but the agencies are the ones telling me to call her. All in all, I don't feel supported and have now requested my agency to be present at all 90-day reviews so there is no miscommunication.

To better support your providers, more hands-on training needs to be done. When I started as a caregiver in 2005, I wasn't given the proper tools to be efficient at my job. The only requirements were that I passed a background check, received my fingerprints card, CPR/First aid certifications and passed the article 9. I was then given the address to the members home and told to take care of them. I wasn't even sure how to fill out the paperwork for goals. For five years I never saw a supervisor unless I went to the office to renew something. When our first caregiver came to our home, I was surprised that things hadn't changed. She was very nice but was very lost on how to address my children's needs. At times she would be in tears because she was overwhelmed or thought my she had done something to upset my son. I had to constantly explain in the beginning that it takes time for him to trust people and communicate with them. She hadn't done anything to provoke this. When his habilitation goals changed, she was never sure how to address them. This caused my child and her to be frustrated and feel overwhelmed. After spending over a year together she decided to move on, and we were given another caregiver. Our new caregiver had no prior experience and was only given two days of training. Due to her leaving my oldest unattended we had to let her go. Caregivers should have two weeks of training with a new member to become familiar with the member, their routines, strengths and weaknesses, and how to properly address their needs. Every time a new habilitation goal is presented an agencies supervisor should hold a meeting to discuss in detail what this goal should look like when teaching it and then should come to the house for a couple days to make sure it is being properly addressed. I understand this is a huge undertaking, but it would benefit our members. If the agency isn't available to do this, then AHCCCS should create a new department to properly continue hands on training to caregivers each time a new goal is introduced.

Speaking of new departments and such, it would be nice to promote within the system. Most of us have only seen one side of the program but we are well acquainted with the rules and obligations a DDD worker must take on. To curve all caregiver's burnout, it would be nice to give options to promote to support coordinators. This would also help support the support coordinator shortage we are experiencing. During the monthly emails you send out you could announce that you are hiring. You could also have agencies announce this option to caregivers. This is also a way to address other issues quickly as it doesn't need to be put into law.

As an old caregiver myself I believe one huge way to obtain and keep caregivers is to offer a decent wage, raises, bonuses, and other incentives. When I worked as a caregiver in 2005 my gross income was just over $14,000 for the year. After five years in the field with only a few cents raises I needed to leave to find a better job. A couple year later I was missing providing services, so I called Arion to inquire about coming back. I was informed that even with all my experience I would only be hired at $10 to $12 an hour depending on what service I was providing. I was making over $20 an hour as a server and couldn't afford to take that kind of pay cut. Currently, minimum wage is $13.85 an hour which we all know isn't a livable wage. Due to this when I managed restaurants, I paid dishwashers starting pay at $16 an hour. They were also able to gain three raises within a year. When you compare the effort, stress and knowledge it takes to wash dishes, to the effort, stress and knowledge it takes to be a qualified caregiver, the pay rate should convey this. If it doesn't then most people are going to prefer washing dishes at a higher rate than taking care of our members. Giving a dollar raise each year would also help retain quality caregivers. As for bonuses this should be off of a merit system. Members should be sent surveys to rate the quality of care they are receiving. If a caregiver always shows up on time for their shift, doesn't continuously call out, doesn't have any write ups or issues, and follows all the agencies/state policies, in a certain amount of time then bonuses should be given. Health insurance should be affordable and be an option for all providers. Student loans forgiveness is a nice incentive as well but unless you are going to offer more than a restaurant most recently graduated students are going to find a job in their field choice and pick up a server job to help pay off their loans.

I thank you for your time and hope that these suggestions have assisted you with choosing different avenues to solve our caregiver shortage.

Kind Respects,

[redacted]

From: Michelle Benson [redacted]
Date: Thursday, August 10, 2023 at 7:06:25 PM UTC-4
Subject: Habilitation Hours for My Minor Son
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello,

I want to start by saying how grateful I am that my son has had the opportunity to participate in the parent provided habilitation goals program. My son has been a participant for almost 2 years. It has been a tremendous blessing to my son as I am able to work specifically on his goals with him. Because I am with my son the most I am able to continually work on his goals and have those goals on the forefront of my mind.

I would like to kindly ask for an extension of this program. It would be a very big challenge for my family to find a provider in just a few short months that we would feel comfortable with. In all honesty, I don't know that we would be able to even use a third party provider for my son. Currently my son is involved in different therapies (speech and OT) as well as sports and other community involvement along with school and family events. I can't realistically see a provider being able to spend the time my son needs to reach his goals in between all his activities resulting in little to no services given to my son.

I feel it will be a huge disadvantage for my son if the parent provider program is discontinued and I truly hope there can be consideration to extend the program.

Thank you,
Michelle Benson

From: christina Guerrero [redacted]
Date: Thursday, August 10, 2023 at 3:22:33 PM UTC-4
Subject:
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To Whom it may Concern, My name is Christina I am a single mother with a child with autism.

Being a parent paid providing make such a big difference in our lives and so many other lives of families .This program has the ability to allow me to give my special needs child full care that she deserves. Children look up to someone who is consistent in their life. You can't even imagine how many times ive got calls saying they have inadequate staffing . So budgeting for this is so small compared to what's going to happen when this goes away. You can't put a price tag on these kids. It's so hard, it's so stressful, and it's so heartbreaking for our kids that they have to deal with the stress of their parents' financials because the state is letting them down.

Having this has brought complete stability and comfort to our family, and it gives my daughter a really positive environment to grow in as well. So that's the big benefit for us.

due to the extreme shortage to care challenges by allowing payments to parents to serve as paid caregivers for our minor children ensures our kids will receive high quality of care while increasing accessible to care providers.

I never thought that I would get to be my daughters caregiver. I've always had to worry about the kind of care that she was receiving and making sure that she in the best environment that she can be in and now, now I've been able to have that chance. I've been able to give my daughter such a good positive and consistent environment to be in and to see and watch her grow . That money is already there and allocated for our children, so why can't they just allow the parents to use that money it's there and it's waiting on our children? It's really frustrating and disheartening because we've seen such positive results and it’s not just my family. It’s multiple families throughout Arizona who have seen just the most amazing and exponential growth in their children because just being able to have their parents care for them. Please dont take this away. make this permanent.

Regards ,
Christina
Sent from my iPhone

From: Kiya Johnson <[redacted]
Date: Thursday, August 10, 2023 at 2:56:29 PM UTC-4
Subject: Parent caregiver message please read my concern
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Please continue the program for parents to provide care to their minor children, I have kids with disabilities and being able to fine care BESIDES myself is basically impossible there's a shortage of direct care workers. Also no one understands your disabled child, like you do. Daycares won't tolerate them do to their disabilities. If this program ends families will really lose & the support will stop because bad enough there's really no direct care workers. It's horrible. The stress is unbelievable worrying what's next.....it's so much better to know, YOU CAN REPLIE ON YOURSELF AS THEIR PARENT TO GET THE JOB DONE AS THE DIRECT CARE WORKER.

Sent from Yahoo Mail on Android

From: Genoveva Salas
Date: Thursday, August 10, 2023 at 1:58:45 PM UTC-4
Subject:
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Buenos dias soy genoveva salas acabo de tesivir una carta diciendo que ahcccs ya no va a permitir alos padres que realicen el trabajo de habilitación yo no estoy de acuerdo y quisiera que si lo podamos realizar los padres ese trabajo en mi caso yo vivo lejos de Phoenix y nunca e encontrado un proveedor que pueda venir a donde yo vivo es por eso que yo tome las clases para aserlo yo misma el trabajo no es justo que nos quiten a los padres el poder trabajar con nuestros propios hijos asta ahorita ya tengo más de un año esperando un proveedor para respit y no lo e encontrado por vivir un poco lejos de Phoenix y mi hijo nesesita todos los servicios y yo lo puedo aser alcontrario enves de quitarnos habilitación deberían de dejarnos poder trabajar también respit nosotros mismos grasias atentamente genoveva salas madre de un hijo con incapacidades especiales que no puede trabajar en ningún otro trabajo para cuidar asu hijo por favor no nos quiten este trabajo gracias dios los bendiga

From: Jessi [redacted]
Date: Thursday, August 10, 2023 at 4:00:35 AM UTC-4
Subject: Fragile families
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To Whom It May Concern:

My family has personally been affected by the caregiver shortage that our state and nation have battling for years. Prior to Covid this was a dire issue and with the flexibility waiver we have been able to persevere through these trying times and flourish.

From the moment you find out you are expecting you envision this little person conquering the world. You imagine what they are going to look like, what personality they will have, who they are going to become, and what traditions and principles you are going to teach them. You see them being straight A students, who have the same interests as you so you can bond. As a teenager they cause a little mischief but nothing horrible because you are going to raise them with dignity and love. You envision them getting older and moving out though it may pain you to see them make this transition. College years are going to lead to an amazing career. Eventually you see them getting married and having children, buying a house and growing old. Each of these passing thoughts are followed by years of milestones celebrating all their accomplishments. It's the American dream for all parents. The reality of this vision is our children are each different and don't come with a manual. We as parents make mistakes, we live with constant concern if we are making the right decisions. Eventually our children find their own path and it's our responsibility to guide them as they get older and always want better than what previous generations had come to be.

As a parent of two disabled children, my envision is constantly evolving. My American dream was altered shortly after their birth. I have come to celebrate milestones that other parents don't understand. It started when my oldest was young and couldn't talk. With diligent assistance I cried when my four-year-old was finally able to say "ellow (yellow)" and "love ew" (love you)". When my youngest was continuously sent home in first and second grade for having accidents. I wondered if he would ever fully be able to use the restroom independently. Now at 11 years old he is practicing using the restroom out in the community. I celebrate my 12-year-old finally being able to follow a shower step sheet instead of having hand over hand assistance. I celebrate my child's AASA's being at a level one (severely behind with a score of 2471) because it was a few points better than last year. These are all tiny progresses that I have to see as wins that nobody understands.

With these wins comes fears and concerns for their future. My oldest cries because people make fun of him and tell him he is different on the inside as well as the outside. Another child has already made a video of him on social media naming him the SPED kid. I pray that people will see him for more than his disability and that he can live a happy life. I often wonder who will take care of them when I pass or can no longer do it myself. I ask my brother and pray he truly understands when I stress that it will be a lifelong commitment. I no longer dream of them becoming doctors but pray they will someday learn to read and write so they can obtain a job. I no longer imagine grandchildren but pray for my children to become as independent as possible. As my world has been altered and my envision evolves, I can tell you what I have learned in the last 12 years. I have learned patience, I have learned the true meaning of unconditional love and advocacy, I have learned not to compare others success with our own because we are making waves and most of all I have learned early intervention is the key to all our success.

Habilitation is the key to early intervention. It allows my children to focus on daily living skills that will eventually provide a more independent lifestyle that they deserve. By not allowing parents to continue this lifeline of service we are hindering our fragile children and doing a great injustice to their overall wellbeing. The successful milestones I provided examples to you of were not due to another service provider but due to my diligent determination to assist my children. Providers have proven time and time again to be unreliable, inconsistent, and not properly trained to handle the unique situations that present themselves in our day to day lives. As a habilitation provider, I am willing and passionate about providing services that meet their needs. I am able to fill the gap of care with quality services to see my children continue to progress into healthy, happy adults.

I heard a lot about parent burnout and mental health issues but what we failed to discuss was our children's mental health and feelings of burnout. For a neurodivergent child the world can seem overwhelming and give a sense that they don't belong. These feelings can and will cause burnouts, meltdowns, and effect their overall mental health. If we are able to provide a consistent, stable environment that is enriched with opportunities to grow and fit in these issues decline. By allowing myself and other parents to provide habilitation services we are providing such environments to fill the gap between atypical and typical peers. This lets children feel less isolated from the world than allows them to prosper in their communities.

Thank you for your time. I hope this has given insight to the struggles and feelings parents of special needs go through. I also hope we can continue to see accomplishments in our community by allowing parents to provide habilitation services.

Sincerely,

Jessica Grace

From: Patty Garza [redacted]
Date: Thursday, August 10, 2023 at 12:36:54 AM UTC-4
Subject: AHCCCS/DDD Hab
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hi to whom it may concern,
I'm writing on behalf of my son [redacted]. He is 13 years old, Autistic, non-verbal, has sensory processing disorder & seizure disorder. I am currently working with Milestone Pediatrics to provide Habilitation for my son. These past years working with the company has taught me & my son a lot. A lot of my sons goals are more on a personal level, toileting, bathing. So I'm happy that I am able to help my son with these ADLs, as these goals are very personal. I really hope that you take into consideration that by allowing parents to work with our children with these types of personal goals has really made a difference. I've went from just doing these things for him, to having him to these ADLs to work towards his goals to become more independent. I really hope that having parents continue to provide Habilitation with their children continues.

Thank you,
Patricia Provencio (Garza)
[redacted]

---------- Forwarded message ---------
From: [redacted]
Date: Wednesday, August 9, 2023 at 11:20:44 PM UTC-4
Subject: CMS extension
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To Whom it May Concern,

On Wednesday August 2, 2023 CMS released a new State Medicaid Director Letter offering updated guidance to ensure continuity of key flexibilities implemented during the Covid-19 Public Health Emergency.

This letter automatically amends the expiration date of approved Appendix K provisions to be the later of November 11, 2023 or the effective date of amendments to underlying 1915(c) waivers to incorporate relevant PHE flexibilities. This ensures states, providers, and beneficiaries that there will be no disruption to the HCBS delivery system for PHE flexibilities the state requests to incorporate into ongoing HCBS waiver programs. No state action is required.

https://www.medicaid.gov/sites/default/files/2023-08/smd23004.pdf

This letter should be utilized by AHCCCS to determine the best course of action when implementing their new 1115 waiver amendment proposal for Paid Family Caregivers of minors. AHCCCS now has the ability to add a delayed start date to their new Paid Parent Caregiver program allowing the current flexibility to continue for as long as needed to ensure a reasonable transition to any permanent program changes to the service delivery of Habilitation or Attendant Care by parents of minor members beyond November, 2023.

CMS shared with Raising Voices Coalition in June 2023 that their requests of allowing parents of minors to be paid Habilitation providers and exceeding 40 hours per week of paid care per member is possible under the 1115 waiver amendment. We ask AHCCCS to strongly consider stakeholder feedback, our Coalition’s program adjustment requests, and individual member and family experiences when deciding on how to amend their current proposal to best align with the needs of the disabled minors in Arizona.

July 2023 - Paid Parent Caregiver Proposal Adjustment Request

Paid Parent Caregiver Proposal Adjustment Request July 2023 Dear AHCCCS and 1115 Waiver Team, As a parent …

Thank you,

[redacted]

From: **Jennifer Garcia**
Date: Wed, Aug 9, 2023 at 1:41 PM
Subject: File a Grievance in regard t Paid Parent Caregivers
To: <DDDCustomerS...@azdes.gov>

To Whom it May Concern:

I am the mother of a child who receives DDD and ALTCS services. I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which will go into effect November 2023, my son and many more like them will lose access to their Habilitation services or more than 40 hours a week of care by parent providers of minor members. The reason my son will not have access to their appropriately evaluated services is due to the DCW shortage. My agency has specifically stated that they will not be able to recruit, hire, and train enough providers to fill the gaps in service these new rules will create. The did not have enough providers before the pandemic and we all know that the work force has not and may never recover. By being a paid Parent Caregiver I am able to work through our habilitation with consistency and success. This will all come to a halt if they do not include HAB to continue (as well as ATC)in the proposal that has been drafted. Also I am aware that other states already have these programs in affect and if they can get approval from the federal government and laws that surround this why can't we? My sons quality of services will not be satisfactory with out this and it is my understanding that is one of your goals with this proposal.

Thank you for your time, I would like to request a TICKET NUMBER and a return phone call to address this grievance.
Sincerely,
Jennifer Garcia

From: Arianna Mitchell [redacted]
Date: Wednesday, August 9, 2023 at 6:29:52 PM UTC-4
Subject: Consumer Comment.
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello I just want to add as a parent who has provided habilitation since a little after covid happened, if I was not able to work with one of children I would not have known how far behind she was with alot of different aspects especially with learning.

Alot of these companies and school districts are nor honest about our children's progress and need. My child's needs have not been met this entire time of receiving ALTCS and DDD services. If we, as parents, are not able to have the availability to help our children due to life's demands and living expenses, we don't have opportunities for that same amount of time for our children.

Supplementing support for parents to work with their children is a very needed service that the state of arizona should not even be suggesting to remove. If the percentage it so small for parents who are providing the services I'm not quiet sure why habilitation is being a service opted to be stopped. While attendant care is still willing to be provided by family members.

The reason in the AHCCCS zoom meeting behind this suggestion was due to a lack of socialization for children with habilitation being provided. While I find that highly improbable and no evidence to make these claims exist, I find that habilitation is done outside of hours that children have to coexist with other children and people in the world. Habilitation hours are very short-term in my childs case. As part time work. 1 to 4 hours max a day is whats allowed to be billed. So I dont understand out of a 24 hours day how habilitation is causing decreased socialization. Especially when services are benefiting a child and being provided by the people who know that child best. Not just doing the service because we were hired to do so and write it on paper as documentation for the state, but because we can afford to provide the service by being paid to do so.

Ahcccs should focus on where and how dollars are being spent through DDD/ALCTS and their vendors first and foremost. DDD has not provided my child with a caseworker who has completed anything in the DDD Ahcccs manual besides vendor calling. DDD never attended a

IEP meeting, never made sure the medications my child was taking was the correct prescription need, never help get the state board of education involved for my child when I was fighting the school system. DDD never did anything with my complaints I submitted to their customer service email, the governor's office, the supervisors of the caseworker, no one ever did anything to have policy enforced by DDD.

When reading the entire 826 pages of the DDD ahcccs policy I was made aware of how under serviced my child really was. If you want to take the dollars away from parent to have a "family support" in place that's optional then you should be mandating the job necessities of the program you are given it to. Taken complaints seriously and listening to the feedback that you are receiving. This program is by far the worst management I've ever seen. And I know this is more off subject of why we should keep habilitation for parents to work with their children, however making the people in charge of ahcccs decisions aware of the issues with the contractors in place, also plays a role in our needed being. Something else should be done with the funding that you are trying to take away from our families. To which have been services us and our children's needs two fold for two plus years now.

I don't understand how taking funds from parents providing any type of service is harming or misusing federal dollars. When in fact the system in place already has caused this issue and made special needs children the last priority in this system being ran by AHCCCS.

Ddd does not help with issues of providers and consistency. None of you can have children within the altcs system or you wouldn't even be suggesting this as a option. And if you do have children under this system having any service provided why are you not standing up and speaking for these disabled children? Why are you not at board meeting raising your voice about the discrimination and despicable caseworker we have for our children?

Whatever ahcccs decides to propose to the federal government only the minimum will only be completed by the states program in Arizona. Which leads me to ask exactly where you all are trying to tie funding to.

Attendant care is a more hourly needed service to which should definitely help families and children. I definitely say if a incapacitated child or adult is in needed of someone to care for them around the clock why not have family or parents do that service. The services are being provided, money is being made to support that service and then the funds are being allowed to help the family in a circle. It's definitely unharmful and not misful. So why would habilitation be?

For instance in my situation I have multiple children with disabilities and only two of which can qualify for DDD altcs services. However that does not stop a parent like me from having multiple appointments for those other children. It doesn't stop me from having to work part time to take care of the responsibilities that the state can't help with. It doesn't stop me from having to attend speciality clinics for those children. And honestly the only benefit that has been a good help is the home therapy session. When they do happen. If you all want to take money from the families that have been using and depending on it then you should be making sure it's going to a place that like the FBI in a sense. A contractor that will over look the services that are not being providing in the appropriate manner for all special needs children and adults. If our child needs speech two times a week and doesn't have it over a month and vendor calls have been placed, then action aganist that program should be happening with those dollars. Services should not be provided the sporadic way they are and tax dollars including being paid by my self, are being used on those half done services.

Honestly that's what I would love to see happen if you take the small percentage of funds away from families for habilitation then place thise funds to a agency not facilitated by this states regimen and provide it to a agency that would not be compromised to enforce the laws and policy in place for these children and their needed services which are not being provided especially in rural areas. In my case buckeye arizona. No one comes this way and if someone does work this way it's not for long term as it is supposed to be.

This system has failed our special children enough and the actions you all are taking at the moment are causing more of that to happen. Funding should be placed in a needed area if it's going to be disbursed in a different manner. That should be the biggest focus of where and how it will be used to create the best outcome for the public who is using the service. Not the state to mis use them and possibly use them for "family support" if they want it as a resource. Put the dollars where they need to be going. To our children and their educational and therapeutic needs.

From: **Tara Mackey** [redacted]
Date: Tue, Aug 8, 2023 at 5:46 PM
Subject: Grievance regarding the proposal to end the parent provider program
To: <DDDCustomerS...@azdes.gov>

Good evening,

I am a parent of 2 children who receive DDD and ALTCS services. I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which would go into place in November 2023, my child and many more like them will lose access to their Habilitation services or more than 40 hours a week of care by parent providers of minor members. The reason my child will not have access to their appropriately evaluated services is due to the DCW shortage. I also used to provide services to others on DDD/ALTCS prior to being allowed to work as a DCW for my own children and I'd like to understand why I'm qualified to work with others (adults and minor children) but not considered qualified to work with my own children. I can work with someone else and pay more than I earn in order to do so for childcare and worry about if anyone reliable will be able to show up for my own children on DDD/ALTCS, or I can work with my own sons and use my earnings to pay for experiences such as family photos, swim lessons, or adaptive sports, etc which will enrich their lives and allow opportunities to help strengthen them, learn new skills to interact with others, and to keep them safe. I can also then afford to pay a babysitter for my other children so that I can take my sons one on one to go do fun things and work on their goals in the community. I have a Master's degree in healthcare administration and a degree in pre-medical sciences. My husband is an ICU nurse in a nurse practitioner program. How are we not qualified to provide life skills and habilitation instruction to our own children? I believe this rule to be discriminatory and based on our relationship to our disabled children, and am contemplating an EEOC discussion based on this.

I have passed all background, motor vehicle record and fingerprinting criteria, I've done all training pertinent to the job of habilitation provider, I am CPR and first aid certified. If I am credentialed to work with others in this role, am I not also qualified and credentialed to work with my own minor children?

Thank you for your time, I would like to request a TICKET NUMBER as well.

Sincerely,

Tara Mackey, MHA, BS, DCW
[redacted]

From: Kelly Pichitino [redacted]
Date: Wednesday, August 9, 2023 at 2:09:08 PM UTC-4
Subject: Minor Child & parent feedback
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To Whom It May Concern,

I am writing this morning to be a voice and advocate for my young child who is not able to speak and communicate for himself, due to his disability. My child is under the age of 12 and has several disabilities. We reside in Pima County and have recently been approved for DDD/AHCCES ALTEC services after 7 long years of advocating for approval. So since he was three years old.
If my child could verbally speak and communicate with you in regard to the current proposal and the HAB parent provider plan going away in November.
I would imagine he would say this:
I do not want a stranger coming into our home and my space to help me with the most private areas of my life. My parents already help me. I am a young child and do not feel comfortable having someone other than my mom or dad help to shower and bathe me and help me work towards my personal HAB goals. I do not want an assigned worker, that is a stranger to me to come here and help me get dressed or brush my teeth. I only feel safe with my parents. I am taught about stranger danger, and because of MY disability, the only people that I am safe, comfortable, and feel most supported with are my parents. Other people do not know me, that causes me stress, and that affects me. I am a vulnerable child, please do not take away or make another change that is disruptive to my life, that would be having another or new worker come in and try to help me reach my goals. My mom does that now, she helps me reach my goals and I love her for that.
****
I know in my heart that is what my child would communicate to you. Parent burnout doesn't happen when it's your child. Burnout happens when you have to advocate for the right to get your child the services they deserve to have because of disability.
Burnout happens when the people in charge do not hear us and when they stop listening to our parents.
Burnout happens when you go unheard. Burnout happens when you go through agency and agency, work after worker because they can not meet the needs of your disabled child.
Burnout happens when the doorbell won't stop ringing because of all the in and out of the

many different therapists and HAB, ATC, workers.
We, parents, have respite but still, our children are not comfortable nor are we, able to truly get that respite that we need, we are anxious and worried if our children are safe and being cared for properly. Parents know best, please consider not making any changes to something that is currently working. Why stop something, make changes, and go backward in time? Parents need to be paid for proving HAB because, yes, there is a worker shortage, we are filling that problem, we go through training and an onboarding process. We even have to get a background check, CPR certification, and other training to work with our own children. Being a paid provider is what is best for a minor child with a disability, it is what is best for my child. Let the parents have a choice, as to what is best for their child and who provides the care. No one is forcing us parents to become HAB providers, we choose this. We are already entrusted with their education, we should be trusted with providing HAB to our very own children. Again, please do not take this away, it lessens any burnout that we may face.

Thank you,

Mrs. Pichitino

From: **Susan Morgan (Suzie)**[redacted]
Date: Tue, Aug 8, 2023 at 12:36 PM
Subject: Grievance
To: <DDDCustomerS...@azdes.gov>

I am a parent of a child who received DDD and ALTCS services. I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which would go into place in November 2023, my child and many more like them will lose access to their Habilitation services by parent providers of minor members. The reason my child will not have access to their appropriately evaluated services is due to the DCW shortage. My agency has specifically stated that they will not be able to recruit, hire and train enough providers to fill the gaps in service these new rules will create. I am requesting a ticket number.

Susan Morgan

From: **Jen Christianson** [redacted]
Date: Tue, Aug 8, 2023 at 10:51 AM
Subject: Grievance
To: DDDCustomerS...@azdes.gov <DDDCustomerS...@azdes.gov>

To whom this may concern

I am a parent of two children who receives DDD and ALTCS services. I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which would go into place in November 2023, my children and many more like them will lose access to their Habilitation services or more than 40 hours a week of care by parent providers of minor members. The reason my children will not have access to their appropriately evaluated services is due to the DCW shortage. My agency has specifically stated that they will not be able to recruit, hire and train enough providers to fill the gaps in service these new rules will create.
In fact they are unable to provide respite providers. In addition due to the lack of DCW we are required by the agency to sign that if a provider calls off or does not show they are not liable. One of our children that receives ALTCS was adopted from foster care. Having multiple providers that are not consistent and often do not show or call off last minute create more trauma for my daughter.
This will not create isolation as she is in school full time. We are able to work on her hab goals in the community. If my husband or I are unable to continue as her hab provider another provider would not be able to take her into the community to work on goals.
She is enrolled at ACCEL due to her behaviors. She has been "kicked out" of multiple schools due to her behaviors. However her behaviors are controlled with us (parents) due to her knowing she is safe with us. She was placed with us at the age of 7 and is now 16. Removing parents as an option for habilitation provider will create further trauma for her and she will regress.
Thank you

Jennifer Christianson

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From: Jenna Parker [redacted]
Date: Tuesday, August 8, 2023 at 7:36:31 PM UTC-4
Subject: Parents as Paid Providers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Good afternoon,

I would like to address my concerns of parents as paid providers. This benefit has been started to ensure that through the pandemic services were still in place. This benefit has been a disservice to our members and a reward to the parent, parents assess themselves, and members deserve unpaid support.

This benefit has been a great disservice to our members. The purpose of the services we provide are meant for multiple people to work with the members regarding areas that they need extra support with. For example, making a snack. Parents would work on this as well as providers. That would give our members multiple times to work with someone regarding an area of need. Now, parents are working with the member once (if that) and the member is not receiving enough assistance in such areas. I see examples of this by lack of progress over long periods of time.

Secondly, parents constantly call requesting more hours. Not because the member needs more help but because the parents need more income. If what they request is not granted, we as support coordinators are fired. I can't imagine the day when a family calls DES to say they want food stamps, they may not qualify but they insist they receive $1000 a month. That is what parents as paid providers are like. All of our assessments should be eliminated if this benefit to the parents continues. Our assessments mean nothing at this point, the parents assess themselves.

Lastly, don't our members deserve people in their corner that aren't paid to be there? When I began here that was one thing that stuck with me while in training. Our members are mistreated and taken advantage of by many, now their families are just as guilty of exploiting our members as a stranger.

--
Jenna Parker

Support Coordinator
District East Behavioral Health Unit
Human Services Specialist III
Division of Developmental Disabilities
125 E Elliot Rd, Chandler, AZ 85225

[redacted]
https://ddd.azdes.gov/Organization/DDD/DDDProviderSearch

From: **Google Form** [redacted]
Date: Tue, Aug 8, 2023 at 2:12 PM
Subject: New form response notification

To [redacted] [redacted]

Your form has a new entry. Here are all the answers.

What AHCCCS meeting did you attend?8/2/2023**How did you hear about this meeting?**Colleagues and email**After seeing this presentation, how well do you understand the information we discussed?**2**Overall, how would you rate this presentation?**1**How was the length of the presentation?** Too short**Help us improve!How can we improve this presentation for future public meetings?**Very one-sided. I didn't see the REAL questions or remarks from SC's that have to deal with Agencies that call families and tell them they can get paid to care for their child(s). Parents of minors should not be paid to do their job. This is a disservice to member(s), and a lot of the times the members are going without their HCBS services while parents are just getting paid. Also, I have seen an increase of anger, frustration and abuse with minors with parents as paid providers. I have been in meetings with HCBS Supervisor's that act as the members lawyer telling SC's what they should have. SC's don't need to be harassed anymore than they already are as this job is already unbearable. In one week I got 2 requests for increase habilitation from parents stating that they need more money. Not that they need a reassessment, but that they need more money, so they need more ATC or Habilitation hours.

From: **Jadie Almonte** [redacted]
Date: Tue, Aug 8, 2023 at 11:27 AM
Subject: Grievance
To: DDDCustomerS...@azdes.gov <DDDCustomerS...@azdes.gov>

To whom this may concern,

I am a parent of a child who receives DDD and ALTCS. I would like to file a grievance against DDD and AHCCCS regarding the current paid parent caregiver proposal. Under this proposal my child would lose his habilitation services November 2023. My family is not comfortable allowing strangers in our home AND also living far out in Estrella Mountain Ranch/Goodyear not one provider would even travel to my area pre-Covid. There are NO providers to cover if the parent caregiver provider program ends. My son would be the one to suffer greatly and his quality of life would take a turn for the worse as I will not be able to provide services myself and i would also need to work away from the home to help support my family. We would not be able to find help for him- we couldn't in the past so i know we won't now. So many kids in Arizona like him will be left with nothing! This program needs to be extended for another year until a more solid plan is in place or keep this program exactly as is so we can help/watch our kids thrive.
Thank you for taking the time to read this.

Kind Regards,
Jadie Almonte
(Mom to 13 year old with cerebral palsy & epilepsy)

From: Regina Harris [redacted]
Date: Tuesday, August 8, 2023 at 5:12:42 PM UTC-4
Subject: negative impact of Parents of Paid Providers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Good afternoon,

I would like to address the pending policy of Parents as Paid Providers.
I am a Support Coordinator and I would like to share the negative effects I have seen on kids and families when parents are paid providers.

I think this program had good intent but I have seen several situations that have had a negative effect on the family and more importantly the member. It changes the relationship and now the parents view the kiddo as a job. Listening to both Town Hall sessions I was quite saddened about how parents were speaking about their children. I am a parent of a kid with a disability, a SC so I feel that I bring a unique perspective.

There are many kids withs with significant needs but as SC we are getting parents calling us with statements such as "my friend gets X hours of Attendant Care and I don't get any, I received a call from an agency saying I can get paid to take of my child and I want to be paid, I saw on a parent Group Facebook Group that the average of Hab is X and we only get X so I want more hours...

Only 5 minutes ago I received an email from a Mom who is a stay at home Mom and stated she would like ATC and the email is quite obviously scripted from an agency.

I have two members that have Hab Goals concerning dental hygiene. The parents were paid to teach teeth brushing and both families didn't teach their kids and in both cases the members had to have extensive dental work due to teeth rotting because of the lack of teaching. There is no accountability on the parents' part.

I have several parents ask for more hours based on wanting their income to increase and not on Hab Goals increased - and that state that they need more money. The kids are losing out because the parents are not vested in teaching skills but instead focus on additional money. They often demand more hours based on what they heard or read in parent groups, "most parents are getting 20 hours of Hab" so they want to have what other parents have. When SC try to explain that the goals determine the time they get upset and demand to speak to Supervisors and then badger them to get what they deem as their right.

I have a case that was transferred to me and one of the goals was to teach "Self calming techniques". I asked the Father who was the paid provider what were the ways he taught his son self calming and he stated "I told him to shut up".

The agencies are not providing any Teaching Strategies - which is quite common. The parents have no training and do not seek out any resources on how to teach any of the goals.

I have several friends that are SC and they all have the same view that it is hurting the member. If you would like to discuss this further with me or would like additional SC to speak to concerning this I am happy to provide additional information and SC information.

Kind regards,

Regina Harris

HSS III

DES/DDD/Mesa Office

125 E Elliot Rd, Chandler, AZ 85225

Mail drop: 2E62

[redacted]

[redacted]

[redacted]

https://ddd.azdes.gov/Organization/DDD/DDDProviderSearch

From: Jessica Taylor [redacted]
Date: Tuesday, August 8, 2023 at 4:25:35 PM UTC-4
Subject: Parent Provider Program
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To Whom It May Concern,

I am a parent of a special needs boy and we utilize the parent provider habilitation program. We were told that the program may end in November 2023 and this is very concerning for us. This program has been so beneficial for our 9 year old son. We are able to really focus on reaching his life skills goals since we started the program. It helps keep us motivated and organized with his goals and we have seen (and can easily track) a lot of progress so far. We have always struggled to find long term hab workers and now the workforce is more scarce than ever before. All kids thrive on consistency and strong and trusting relationships. Until we can guarantee that these hab positions can be filled by caring, qualified, and long term caretakers, the Parent Provider Program needs to be extended to ensure that our special needs kids are getting all of the help they deserve.

Thank you for your consideration.

--
Jessica Taylor

From: Lindsey Unger [redacted]
Date: Saturday, August 12, 2023 at 1:53:57 AM UTC-4
Subject: AHCCCS Forum Regarding Caregiver Benefits for Parents
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>
Cc: Joanne Norwood [redacted]

My name is Lindsey Unger and I am writing to you in support of parents still being able to receive caregiver benefits.

Ever since my son was little I would ask why I couldn't be hired as a respite or habilitation provider for my child. I have experience as a caregiver, a Bachelor's of Science degree, and experience working in a Special Education classroom. All of these experiences really increased my awareness of what it takes to educate and help a child with a disability, and it can be a very challenging experience, depending upon the child.

When I found out that I could receive caregiver benefits I decided to do so to help provide for my family since the work-life balance of trying to raise a family that includes a child with a disability, has been very hard for me. During the years after my son was diagnosed with Autism I became homeless, divorced, became a single mom without the support of my ex-husband, struggled to find steady employment, and have faced multiple struggles that seem to be undening. I know that being a parent can be difficult, but at times this experience seems unnecessarily difficult.

I'm not sure how to explain it but when I became a mom my mind became overly focused on my children and that desire to care for my child has never left me. I think people call it mom instinct. When I found out that my child was disabled those feelings and emotions of wanting to protect my child became even more enhanced. Being able to become his caregiver has helped our relationship a lot by relieving some of the stress I deal with about trying to find work that goes along with raising my children.

I also felt that it helped our relationship by being able to be trained as a habilitation provider. It's really helped me to focus more effectively on my son and how to help him. I think that it has also made parenting him feel less overwhelming because I know that I have a support system from my agency that trained me and that in effect helps me help him to grow and develop in certain aspects of his life.

I hope that my story helps you understand why allowing parents to receive caregiver benefits can benefit not only the parent but more importantly, help the development of their child that they are caring for.

If you are concerned at all about parents abusing this employment then I would encourage you to consider the following ideas for healthy limits and boundaries.

- Set hours based upon the severity of the disability.
- Make sure parents are filling out notes and participating in training.
- Consider the parents education and ability level when hiring them and making sure that they are able to work with their child.
- Check to see if the parent is struggling to find employment and could this work help them to stabilize their family life.
- Check to see if the child is able to respond better to their own parent when dealing with severe behaviors or other developmental challenges.

I hope that this story and these suggestions help.

Sincerely,
Lindsey Unger
-

From: shawnece domasin
Date: Friday, August 11, 2023 at 7:33:26 PM UTC-4
Subject: Advocacy
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To whom it May concern, My name is Shawnece Domasin. I am the mother of a beautiful special needs little boy. I want to use my time to speak up and speak out not only for my child and out family but also other families whom reside in Arizona. These resources that were put in place only for the pandemic have truly been a blessing but to find out it is ending makes me so sad for all the beautiful children and families out there who will suffer without this program. We are in 2023 and it is time Arizona gets with the time. There is no doubt there is a MASSIVE shortage of caregivers, providers,therapists, Doctors, nurses etc. Taking away habilitation hours, ATC parent providers will be detrimental to those already struggling. It is not easy for our children or us. Wondering who will take your child who will watch them while you work and try to put food on the table. My son was denied at 5 separate daycares do to his needs not being able to be met. Who better then their own parent to care for them. California is far ahead of the times and I feel Arizona really needs to step it up and get on bored. When you live in a small town like Kingman Az, the resources are few and far between. We travel 4 plus hours for specialty appointments. When you have a child with needs such as my son that include: Epilepsy, Autims level 3 (severe) cortical dysplasia bilaterally (top 2 layers of his brain didn't from hence the cause of the seizures, unknown genetic issues that cause damage to the mitochondrial DNA, we need to be able to care for them, they despise change it sets them off. I have been caring for my son since he was born, change for him is so hard! Taking away parents as paid caregivers will affect so many families especially single families such as myself. Trying to find a job to work with hours I need around caring for my son is next to impossible. Please do not let these babies and their families down. Many of us will be left stuck or homeless because we have no income. Our babies will regress, they deserve just as much love and care as the next.

Sincerely a concerned mother.
Thank you for your time.

From: Micheal Sherwood [redacted]
Date: Friday, August 11, 2023 at 6:41:51 PM UTC-4
Subject: Parents as paid care givers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Please make this bill permanent
I would love to be my son's caregiver he needs
One on one with a parent more than one on one with a stranger
Please and thank you
Sincerely Michael Sherwood

From: Jamie Veprek
Date: Tuesday, August 8, 2023 at 1:10:15 PM UTC-4
Subject: Parents as Paid Caregivers Story and Feedback
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To Whom it May Concern,

I am writing today to discuss my experience being a paid parent caregiver to my minor children. Overall, this program has been very beneficial for our family in a multitude of ways, and we are hopeful that this program will become a permanent offering for our children and the community.

My family is unique in many ways. I have 4 children, 2 biological and 2 adopted. My 3 daughters have disabilities and utilize wheelchairs and other mobility aids on a daily basis. 2 of my daughters are on long-term-care and receive PT, OT, and speech, as well as AHB, attendant care, and respite hours. Due to the emotional needs of my adoptive children, having caregivers in and out of our house was never a good choice for our family. Not only did it trigger survival behaviors that were not healthy for my children, but it also impaired their ability to successfully attach and bond to me, which is so important for their emotional safety and development. Additionally, due to the extraordinary numbers of children within the special needs community that experience abuse, having other caregivers dress and care for my children never felt like a safe choice. I have always chosen to work with my daughters myself. This allows me to work with them consistently, with no gaps in service. It allows us to work during all hours of the day, and in a multitude of situations, which allows them to make much more substantial growth and development. My children are thriving, happy, and successful because of this.

We are very active members of the community. My children participate in weekly homeschool co-op, dance, working with horses, have weekly playdates, and so much more.

They have played wheelchair basketball and baseball. We go on fieldtrips frequently with other children. Because I have three daughters that use wheelchairs, it is impossible for someone else to transport them. The fact that I am able to be home with them is exactly why they are able to be so active and have so much involvement with friends and in the community. They are able to socialize, get exercise, and actively participate, because I am able to transport them, help them use the restroom, and help them work on their goals while we are out-and-about.

I am a single mother parenting my children. I am a strong advocate for my children and know them better than anyone else on this planet. I have been there every day, for every aspect of their care. I have been the one at every single appointment, and I know their medical history by heart. However, because of our therapy, schooling, and tutoring schedule, it is not in the best interests of my children or my family for me to work outside of the home. You would be paying someone else to provide subpar care to my children, while I work, instead of allowing me to be home, providing them with consistent, caring, and extraordinary care myself. My children are healthy and thriving because I am able to be home, providing their attendant and habilitation care, and helping them meet their goals for independence and daily living.

I hope that this email helps you see the importance of continuing to allow parents to provide their children with both attendant and habilitation care on a permanent basis. Our family has benefited in so many ways from this program, and I know my daughters will continue to thrive and have long-term success in life because of the opportunities it affords them. Thank you so much for your time and attention to this matter. Please reach out with any questions.

Sincerely,

Jamie Veprek

From: Ashley Pihlman [redacted]
Date: Monday, August 7, 2023 at 11:19:48 PM UTC-4
Subject: Parents as caregivers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello, I'm writing to submit more comments about the proposal regarding parents as caregivers. I've taken the liberty of contacting Mesa Community College and they answered my questions about their AHCCCS scholarship.

The student in receipt of the scholarship agrees to work for a long term care facility or in HCBS (with any age) after their program is completed. This was a proposed solution to the direct care worker shortage. Should the proposal as is pass, disallowing certified & trained parents from providing habilitation, as of November our children will no longer have habilitation services. There are not habilitation workers available for all DDD minors. We could be waiting upwards of 1-2 years to even see an increase in the workforce.

I've heard about the family support unit being available to train parents to provide habilitation in lieu of outside hab providers. This looks like AHCCCS does not care about our children receiving habilitation in a timely manner, nor do they care about caregiver's burnout among parents if parents are being exploited for unpaid care services while AHCCCS fails to increase the workforce.

Another concern was social isolation among DDD members. Parents as caregivers allowed our children more freedom and ability to socialize, not less. Removing parents as providers and not having a plan to increase the workforce for 1-2 YEARS is going to ensure our children are socially isolated due to the loss of income AND no hab workers.

Please keep parents as caregivers providing habilitation, attendant care, and remove the 40 hour limit. There are no workers and our children deserve their services being fulfilled in a timely manner now.

From: Karen Meza [redacted]
Date: Monday, August 7, 2023 at 10:21:26 PM UTC-4
Subject: Habilitation program
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hi! ,
My daughter is nonverbal speaking it’s very difficult to trust someone especially in these days. Habilitation program is helping my daughter how to communicate for daily living with my patience and love. My daughter doesn’t distinguish good and evil, if something happened to her, she won’t be able to tell me.

From: Dani Rodriguez [redacted]
Date: Monday, August 7, 2023 at 8:15:39 PM UTC-4
Subject: To Whom It May Concern
To: [redacted],
[redacted], [redacted],
waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>, [redacted]

Dear Ms. Heredia and CMS officers,

Please do not end the parent provider program for habilitation and attendant care.

As a former caregiver myself I know first hand how high the turnover is in this industry, caregivers will leave because of various reasons including minimal pay, emotional distress, or odd work hours just to name a few.

Speaking as a parent, this turnover is extremely harmful to our children as they require consistency to thrive. When a provider leaves my child is thrown into distress because the person he learned to trust left causing trust issues, not only that but I'm expected to fill in the gaps as we wait for a new provider. Because of these inconsistencies I was forced to leave my career. Not to mention I am able to provide care during the hours of the day that others don't want to work.

This program offers parents hope, it offers consistency for our kids, and it allows for parents to step in and do the job others aren't willing to do for the modest pay being offered.

There has been talk about the concern of a lack in social interactions if parents are their providers and this program has allowed for quite the opposite. Because I am capable of being my son's provider I can take my son out to socialize in the community. He is more comfortable socializing because he feels safe with me as his parent which offers more meaningful interactions. Additionally, outside therapies like Speech and Occupational offer those outlets for socialization in a capacity not overwhelming to our kids.

Being able to be my son's provider is a blessing that has afforded us the opportunity to pay our bills and not wonder how we're going to do so month after month, we don't have to wonder if we can trust the next provider who enters our homes, and our children feel most comfortable learning from their parent who is not only consistent but familiar to them. This includes personal care goals like potty training or bathing, things I'm sure you wouldn't want a stranger coming in to help your child with either.

Like many other parents, we ask that you please maintain this program permanently.

From parent to parent or even citizen to representative, we're speaking for those who cannot speak for themselves, please continue giving our children a voice and a fighting chance at thriving. Please do not end the parent provider program for habilitation and attendant care.

Thank you,

Daniela Muench

From: **Marie Dumesnil** [redacted]
Date: Sun, Aug 6, 2023 at 1:51 PM
Subject: Arizona Habilitation Paid Parent Providers + Proposed Solution

To: [redacted]

Dear AHCCCS, CMS and 1115 Waiver Team,

Following the 8/2 AHCCCS Public Forum on the proposed Permanent Parent Provider Program, I would like to share some important points on the potential impact of no longer allowing parents to provide Habilitation services for their minor children.

1- Risks

Parents are quite concerned that the only reason being given for not allowing parents to provide habilitation services is that it might lead to social isolation for the member/minor child (**even though no data exists regarding this claim for minor children**). While it might be a valid concern, after listening to public feedback, you surely understand that if minor members lose their habilitation parent provider on 11/11/2023, the **repercussions will go well beyond social isolation for the member.**

Impact on the member and their family:

- Potential loss of financial security for parent and member

- Increased stress for the member and their caregiver, in families who are alread managing extraordinary levels of stress every day due to medical conditions, schedules packed with therapies and medical appointments, etc.
- If a new and capable DCW is indeed available at the right time for the right number o weekly hours, this will still mean a complete and sudden change in caregiver for the member. This will lead to potentially disastrous regressions in members with autism and other developmental disabilities. These are members who thrive on routine and consistency due to their condition.
- Most likely, there will be no immediate DCW available (or not for the right number o hours), leading to even more isolation and regressions
- If parents have to find other ways to be financially secure and work outside the home, th members are also more at risk to not receive care at all, including care outside of Habilitation (Occupational, Physical, Speech, Feeding therapy, etc).

Impact on AHCCCS and other organizations:

- Due to the continued DCW shortage, you will see an important increase in number of grievances and quality of care complaints for DDD and AHCCCS
- There will be a shift to WIC, SNAP, and other community resources such as churches and non-profits that assist with rent, utilities and food boxes due to loss of income for some families.

Proposed solution:

If the main concern is member isolation, a simple solution is to require that socialization/community goals be a part of every DDD Person Centered Service Plan. These goals are documented and supervised by DDD and agencies, and reviewed quarterly with DDD service coordinators to assess progress.

2- Benefits of parents as Habilitation Providers

I want to highlight the unique benefits of parents providing habilitation for their minor children, outside of increased financial stability and consistent, uninterrupted habilitation services. Our children with special needs are spending a lot more time than typical children with third-party care providers. My own child, in addition to her time in school, spends more than 3 hours/week in therapies, and that's not accounting for extra-curricular activities. As parents of children with special needs, the ability to be habilitation providers (and not just attendant care providers) has multiple benefits:

- spend time with our children and not add yet another caregiver/therapist to the already very long list
- witness and quantify progress
- identify areas of strengths and opportunity in a natural setting
- be empowered to play an active role in our children's development
- receive proper training to best support and develop our children according to their unique needs

- strengthen the family unit

Note how Habilitation (per DDD definition) “provides methods and training to increase a member’s ability to become more independent and improve upon life skills”, whereas Attendant Care only provides “a trained direct care worker (DCW) to assist a member to create or maintain safe and healthy living conditions”. Habilitation and Attendant Care do not have the same impact on the member or parent, **with habilitation clearly having a goal of increasing the member’s ability to be independent, therefore gradually reducing caregiver burnout.**

3- Long term impact

Finally, in the meeting, AHCCCS participants brought up that we need to be mindful about the long term impact of this proposed permanent program on members and caregivers, not just the short term. Allowing parents to continue to provide habilitation to their children would have the following long-term benefits for everyone involved:

Members

Improved chance for the members to have **better independence and self reliance in the future**, thanks to consistent, uninterrupted habilitation services in a natural environment, at the time when the service is the most impactful (toileting, hygiene, safety in and out the house, home care skills, social skills, etc.)

Caregivers

Improved chance for the parents as they are aging to not have to care for their adult child, **therefore reducing caregiver burnout.**

AHCCCS/DDD/Agencies

More DCWs becoming available, as **trained parent providers will be highly skilled to care for other children and adults**

In conclusion, we as parents urge you to include Habilitation as part of the permanent Parent Provider program, for the well-being of your members and their families in the short and long term.

Sincerely,
Marie Dumesnil

From: **mandy Pleis** [redacted]
Date: Sat, Aug 5, 2023 at 3:18 PM
Subject: Re: Parents as Paid Habilitation providers

To: [redacted]
Cc: [redacted]

To Whom It May Concern,

I am a parent provider for habilitation for my 10year old grandson. I have saw the points that have been surfacing for cancellation of this program. One of them being that we as parent providers will not give the socialization aspect of the goals set forth and, that these children will suffer with no socialization. This couldn't be further from the truth. Most of my habilitation goals with my grandson are in fact socialization. I do get him out in public. I take him shopping with me, I take him to the parks, I take him to his schooling, I take him to the gas station and out to eat, and, out to do fun things as well. You see we as parents have the ability to be able to work on these goals on a daily basis in the hours that are available during the day and evenings. I cannot see that I will be able to find a caregiver who is willing to work from 6am to 8:15am, then stop, come back at 1pm and work with him from 1pm until 9pm 3 days a week. Or one that is willing to give me a 10-hour day on Sundays for that matter. We as parents have these abilities. This matches his school hours, his time he has available. There is no way I will ever find anyone to match his schedule with school included and his therapies are on all of the other days of the week with the exception of Saturdays and Sundays. On Sundays we do our main grocery shopping, on Saturdays we plan fun things to do. The entire time I am working with him on the socialization piece, life skills, and manners. I am preparing him for a life of self-care such as shopping on his own, not being afraid or suffering anxiety in public settings, speaking to others and being polite.
Then there is the aspect of his hygiene. My 10-year-old grandsons' goals also consist of self-care and hygiene. I personally don't want a stranger or a non-parental entity in the restroom with him. Let alone helping walk him through showering. This is not okay. What it does teach him is that it is okay to be with naked with strangers and allow them to not only watch you but, help you by touching. There is no time that this is okay. No matter what! don't understand where the ending of the parent as paid providers/ habilitation program is a good idea. This program has allowed me to be employed, raise my Autistic grandson, work on his goals, not have a stranger in the bathroom with him, give him his comfort, and privacy. As well as not go homeless doing so. I am a grandparent with Permanent Guardianship, and a huge responsibility which I take incredibly seriously. I know his needs, his moods, his schedule, his comfort zone, how to take him out of his comfort zone, how to keep him socialized. All so as an adult he can become a productive member of society.
I would like to know how this is a good idea to end these programs that are helping so many of our children, and keeping our parents employed and not on welfare programs ect. It is allowing these children to be raised with love, care, and, learning skills that will last long after we as paid providers are no longer around. We have to look at what the taking of such an amazing program will do to our future generation of disabled children and what the ramifications of our actions for not acting on behalf of them would be to the future of society. Also, how many parents if this program goes away end up unable to work due to having to be caretakers as it is, the welfare system gets flooded with all new food stamp and cash assistance applications, AHCCCS is applied for as well. I ask you please don't allow this to happen to our children.
Sincerely,
Mandy Pleis
[redacted]

From: Brianna Munster [redacted]
Date: Sunday, August 6, 2023 at 4:56:24 PM UTC-4
Subject: Parent Provider
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Good Afternoon,

I am a parent provider for my daughter and me being the parent provider has given my daughter who has Autism a consistent person in the house, who knows her and what would motivate her, I have had a few providers for my other son before he passed away and since being with DDD he had about maybe 4 or 5 different providers and every time they had to learn his behaviors and ticks that he had to help him as a provider, and My daughter craves the stability of having one consistent person there for her who can help her through and can make it more personal for her. Parent providers are a great asset to have especially since there is a shortage of caregivers that would not give her the stability that she needs or craves as a child with Autism.

Thank you for your time and consideration.
Brianna Munster
[redacted]

From: Mary Fulfer [redacted]
Date: Sunday, August 6, 2023 at 10:32:22 AM UTC-4
Subject: Habilitation (HAH) as a paid service for parent/guardians of minors
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To whom it may concern,

Please consider extending allowing parents to provide HAH services for their minor children. We moved to Az two years ago and have had a very difficult time finding respite care workers and HAH workers.

The agencies simply do not have enough staffing, post COVID. We had to find our own person to provide respite care, and then refer them to the agency because the agency did not have any staff to provide us those services.

Please consider continuing the allowance for parents to provide HAH services to minors. I fear if this is taken away, there will be no agency staff to fill this deficit in our child’s care plan.

Thank you.
Mary Fulfer

From: Tiffany Andersen <[redacted]
Date: Saturday, August 5, 2023 at 11:23:29 PM UTC-4
Subject: Parents as caregivers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To Whom it may concern,

I hope you will consider extending the time for parents to be habilitation workers for their own children with disabilities.

Over the last several years a I have been able to not only meet the needs of our daughter that we knew how to define but through continue education offered by your programs I have learned to identify and address other areas of concern, which in turn has resulted in substantial improvements in our daughters development well beyond what we were able to accomplish under the traditional habilitation programs.

When I look at the schedule of our daughters needs we do not believe anyone other than an adult member of the household would be able to fill those needs.

Being trained and paid while "on the job" has been an outstanding solution that otherwise would not have been possible.

To sum it up. For those parents who feel capable of assume these habilitation responsibilities for their own children, the current solution yields far superior results for both the clients and their families.

Thank you for reading.

Sincerely,

Tiffany Andersen

Get Outlook for iOS

From: Brittany Etcheverry [redacted]
Date: Saturday, August 5, 2023 at 12:46:30 PM UTC-4
Subject: Certified Parent Providers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Email and tell them to Keep parent providers for attendant care, habilitation and don't limit the number of hours these CERTIFIED parents are qualified to work!!!!

Parent's are the best people to be able to take care of our children. We want them to succeed. We need them to succeed. We care more than any other provider you can have for our children.

From: Karletta Chief [redacted]
Date: Saturday, August 5, 2023 at 12:22:33 PM UTC-4
Subject: comment
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

I am in support of 1115 Waiver Amendment which would allow parent providers to permanently continue attendant care services for their minor children for a maximum of 40 combined hours per week per eligible member. Although, we are currently not parent providers, we have been trying to get one parent certified to be parent provider and the agency is taking almost 6 months to get back to us. We always struggle to find attendant care providers and my husband left his job to care for our son during the pandemic. He never took advantage of this program because we were overwhelmed by lack of time to apply and trying to homeschool our 2 kids and care for a premature baby. Thank you.

From: jocelyn rider [redacted]
Date: Saturday, August 5, 2023 at 11:06:29 AM UTC-4
Subject: Public comment
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Our children, our children that are Disabled and unable to self advocate. Having security and reliability with parents, no call offs, no "no shows", no struggle on having to find providers to accommodate our children's needs. Being at harm to themselves and others around them, but yet feeling secure and safe around their parents. Having struggles, having meltdowns, having challenges that no one can control, but yet parents of the disabled know their child better than anyone on this planet and have that naturally ability to sooth our children.

Our children are not able to advocate for themselves so here we are standing strong providing full consistency, full dependability, hearts full of love, with never a dull moment . Yes we are legally entitled to care for our children, but why put a child through a situation where some if not all STRUGGLE with new routines, new people, and set our children up for meltdowns, struggles and tears? Why not give our children the option, why not give us parents a chance to actually change the world helping our children get through life struggles and challenges by knowing they have the reliable parents there, reliable time, reliable love, forever love.Never ever self isolating our children, we do our jobs as parent PROVIDERS plus MORE, we show them the world, we show them people, we show them new environments, we give them new opportunities every single day, every hour and every single day of their lives around the clock for the rest of their life. Why not give the parents a chance? A chance for a positive fulfilling life for families, our children, and having the stability to be financially okay to be able to do even MORE things with our children.

Parents have full authority and full responsibility for their disabled children, minors and adults. We will always work with our agencies and also never worry about burn out. It's a privilege to be our children's parent providers, we teach them, we help them, we love them, we show them this world. This will impact them to learn the way they know best, with comfort, joy and stability all in the same page and that will lead to positive bright futures that will be excelled.

They say everyone deserves a chance, and as a mother, as an Arizona resident, and as for my child, I honestly AM FOR PARENTS TO HAVE THE ABILITY TO BE PROVIDERS FOR MINOR CHILDREN. This one is for OUR CHILDREN, OUR NEXT GENERATIONS, OUR WORLD.

Thank you.

From: Dana Groom [redacted]
Date: Friday, August 4, 2023 at 10:22:54 PM UTC-4
Subject: Parent provider program/social isolation
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To whom it may concern:

Please consider the following accurate and true points as it relates to Habilitation and the concern around "social isolation"

1- If minor members lose their habilitation parent provider on 11/11/2023 without having another DCW, the repercussions will go well beyond social isolation:

- Potential loss of financial security for parent and member
- Increased stress for the member and their caregiver, in families who are already managing extraordinary levels of stress every day due to medical conditions, schedules packed with therapies and medical appointments, etc.
- If a new DCW is miraculously available (sometimes for 40 hours/day or more), this will still mean a complete and sudden change in caregiver. This will lead to potentially disastrous regressions in members with autism and other developmental disabilities. These are members who thrive on routine and consistency due to their condition.
- Most likely, there will be no immediate DCW available, leading to even more isolation and regressions
- If parents have to find other ways to be financially secure and work outside the home, the members are also more likely to not receive care at all, including care outside of Habilitation (Occupational, Physical, Speech, Feeding therapy, etc).

2- If the main concern is socialization, why not simply require that socialization/community goals be a part of every Person Centered Service Plan? These goals are documented, approved and reviewed quarterly with DDD service coordinators and supervised by agencies.

3- Also making a point that most of our children with special needs are already spending a lot more time than typical children with third-party care providers. My own child, in addition to her time in school, spends more than 3 hours/week in therapies, and that's not accounting for extra-curricular activities. As parents, being able to provide habilitation to our children allows us to spend quality time together, witness and quantify progress, identify areas of opportunity, play an active role in their development, and strengthen the family unit.

4-Finally, in the meeting, AHCCCS participants brought up that we need to think about the long term impact of this program on members and caregivers, not just the short term. Allowing parents to continue to provide habilitation to their children would have the following long-term benefits for everyone:

- Improved chance for the members to have better independence and self reliance in the future, thanks to consistent, uninterrupted habilitation services in a natural environment, as the time when the service is the most impactful (toileting, hygiene, safety in and out the house, home care skills, social skills, etc.)
- Improved chance for the parents as they are aging to not have to care for their adult child, therefore reducing burnout
- More DCWs becoming available as trained parent providers will be highly skilled to care for other children

Thank you for reading and considering these points.

Warmly,
Dana Groom
[redacted]
--
Sent from Gmail Mobile

From: Gabrielle Hampton [redacted]
Date: Friday, August 4, 2023 at 7:50:25 PM UTC-4
Subject: New CMS guidelines
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To whom this may concern

“Public comment and story”

Our children, our children that are Disabled and unable to self advocate. Having security and reliability with parents, no call offs, no “no shows”, no struggle on having to find providers to accommodate our children’s needs. Being at harm to themselves and others around them, but yet feeling secure and safe around their parents. Having struggles, having meltdowns, having challenges that no one can control, but yet parents of the disabled know their child better than anyone on this planet and have that naturally ability to sooth our children.

Our children are not able to advocate for themselves so here we are standing strong providing full consistency, full dependability, hearts full of love, never a dull moment . Yes we are legally entitled to care for our children, but why put a child through a situation where some, if not all STRUGGLE with new routines, new people, and set our children up for meltdowns, struggles and tears? Why not give our children the option, why not give us parents a chance to actually change the world helping our children get through life struggles and challenges by knowing they have the reliable parents there, reliable time, reliable love, forever love and never ever a parent burn out. Never ever self isolating our children, we do our jobs as parent PROVIDERS plus MORE, we show them the world, we show them people, we show them new environments, we give them new opportunities every single day, every hour and every single day of their lives around the clock for the rest of their life. Why not give the parents a chance? A chance for a positive fulfilling life for families, our children, and having the stability to be financially okay to be able to do even MORE things with our children.

Parents have full authority and full responsibility for their disabled children, minors and adults. We will always work with our agencies and also never ever ever worry about burn out. It’s a privilege to be our children’s parent providers, we teach them, we help them, we love them, we show them this world. This will impact them to learn the way they know best, with comfort, joy and stability all in the same page and that will lead to positive bright futures.

They say everyone deserves a chance, and as a mother, as an Arizona resident, and as for my child, I honestly AM FOR PARENTS TO HAVE THE ABILITY TO BE PROVIDERS FOR MINOR CHILDREN. This one is for OUR CHILDREN, OUR NEXT GENERATIONS, OUR WORLD.

Thank you.

Gabrielle Hampton
[redacted]

From: **Kelly Bertetto** [redacted]
Date: Tue, Jul 25, 2023 at 6:47 PM
Subject: Grievance
To: <dddcustomers...@azdes.gov>

I am a parent of a child who receives DDD and ALTCS services. I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which would go into place in November 2023, my child and many more like them will lose access to their Habilitation services or more than 40 hours a week of care by parent providers of minor members. The reason my child will not have access to their appropriately evaluated services is due to the DCW shortage. My agency has specifically stated that they will not be able to recruit, hire and train enough providers to fill the gaps in service these new rules will create.

Please note, this grievance is not a target or unfavorable matter against any single personnel, rather a systemic grievance against a pressing matter that is before the decision makers.

Thank you for your time. Kelly Bertetto

From: **Sara CdB** [redacted]
Date: Mon, Jul 24, 2023 at 11:00 PM
Subject: Grievance Against DDD/AHCCCS
To: <DDDCustomerS...@azdes.gov>

To Whom It May Concern:

I am a parent of a child who receives DDD and ALTCS services. I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which would go into place in November 2023, my child and many more like them will lose access to their habilitation services. The reason my child will not have access to their appropriately evaluated services is due to the DCW shortage. My agency has specifically stated that they will not be able to recruit, hire and train enough providers to fill the gaps in service these new rules will create.

The habilitation services I provide my child are far and beyond that of what a parent of a typical eight year old is responsible for. My child can still not dress/undress herself, she cannot clean herself after using the restroom, she cannot bathe herself, she cannot get food or drink for herself, etc., etc. These are life skills I have to either do for her or teach her in the hopes that some day in her future she might be able to do them. This takes MUCH more time than you can imagine. You want to take these paid hours away from me? I only get 15 hours a week, but it helps us survive. Before this program, we were never able to find a habilitation provider. The chances are slimmer now. So why would you hurt families that are already carrying such heavy loads?

I am requesting that you remove this clause from your proposal to make the Paid Parent Caregiver Program permanent. If you move forward with it, only families with attendant care will benefit. To qualify for attendant care means your child is medically complex as defined by archaic standards - meaning a gtube or a trach for example. That is unfair. My child is severely cognitively delayed AND has muscular dystrophy. She doesn't qualify for attendant care because her only medical equipment is a bipap and leg braces. Do you see how ironic and subjective this is?

I would like to request a TICKET NUMBER be assigned to my grievance.

Thank you,

Sara C de Baca
[redacted]

From: Sarah Blank <[redacted]
Date: Friday, August 4, 2023 at 6:18:04 PM UTC-4
Subject: Waiver 1115 feedback
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear Waiver 1115 team and AHCCCS,

I attended the 8/2 waiver feedback session. Thank you for including parent feedback and allowing parents to participate in the proposal process.

I appreciate the care and concern that went into creating this proposal.

I ask that you please include the option for parents to provide habilitation for their minor children. This would not be the automatic plan or the assumption. It would be included as an option when families cannot find or keep an outside provider. It is extremely difficult to find qualified providers that want to work with disabled children. It is hard to keep providers once they are hired. It is detrimental to the child's progress and development to have a swinging door of different providers. Many children with Autism struggle with transitions and changes in routine. It is imperative that their care be as consistent as possible.

Habilitation provided through the caregiver could also be an option when the child responds best to goals with the parent. As previously mentioned, consistency is important. This would particularly be the case with life skill goals, personal hygiene, and independence. Caregivers also have the ability to include social experiences and activities as part of the habilitation. This increases their opportunities to engage with peers, explore the world and gain independence.

As a parent of a child with disabilities, it is my goal to ensure that my child is as independent as possible. I want him to be happy and to successfully contribute to his community. I am not yet sure what success will look like for my child. There are many steps that we need to take to get there. I feel that meeting his habilitation goals will help him thrive and find that success.

Please add the option for parents to provide their minor children with habilitation to the Waiver 1115 proposal.

Thank you for your time and consideration,

Sarah Blank

From: Keri Chorpenning [redacted]
Date: Friday, August 4, 2023 at 4:01:11 PM UTC-4
Subject: Public comment: HAB Services for Son
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Good afternoon. I am reaching out to comment on the proposal to end the Parent's as Providers option for habilitation goals.

I am a formerly certified K-8 teacher with a masters degree. Both of my children were born with medical issues that required a parent for care at home, so I left my profession to raise these two great people. My second child qualified for long-term care around the age of one because of his significant disabilities.

I have had difficulties for years finding a provider and someone reliable for my 16-year-old son. The number of available providers who could maintain a consistent set of hours to help my severely disabled son grow in skillset and independence regarding feeding, locomoting through the home and community, and learning how to best utilize his service dog was extremely difficult.

His number of hours available for HAB work after school hours is limited due to fatigue, Dr appts, and weekly therapy times. Working around all these schedule conflicts makes for a complicated schedule.

I finally decided to obtain the certifications required to obtain employment through ARION to bridge this lack of personnel gap. I can honestly say my son has grown tremendously in skills with my employment through this time on task consistency. He only receives 16 hours weekly but has shown incredible progress since the spring.

Please consider continuing allowing and providing pay for parents to further their family members' independence goals. Our family was hampered by a lack of interested individuals to work within the home. I am here. And with me as now a care provider, I'm proud of what he's accomplished. He needs that consistency that was unavailable for years to him.

Thank you for listening,

Keri Jo Chorpenning

From: Cox [redacted]
Date: Friday, August 4, 2023 at 3:30:05 PM UTC-4
Subject: Parent Providers
To: [redacted],
waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Sandra,
I was just sent this (see photo below). Is this the committees response to not supporting HAB for parents to continue doing?

From: Mary McCauley [redacted]
Date: Friday, August 4, 2023 at 2:19:07 PM UTC-4
Subject: Public Comment
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello,

I am writing to express my concern that Habilitation care isn't in the draft proposal for ongoing parents as paid caregivers. As I know you have heard from other families, this would be a huge issue for us. Our autistic child receives respite care from another family member, and receives habilitation care from one of his parents. We are extremely cautious about who we let into our home and around our children. Our autistic son is very picky about people and it takes him an incredibly long time to warm up to people and gain their trust. The kinds of people we've hired outside of the home have not aligned with our parenting methods, our goals, and have not stayed long enough to form trust and consistency with our child. Furthermore, the types of goals he has for habilitation are extremely sensitive and personal in nature, and even if we found someone we trusted that would be consistent outside of the family, there's no way we would be comfortable with someone outside of our childs' parents providing support for these extremely sensitive and personal goals for our minor child. Allowing a parent to be a paid habilitation provider gives us the additional resources needed to focus on these goals and work towards improving them. If you take that away, we will not have any option for habilitation, and will lose the valuable resources that have allowed us to give our time and energy to these hab goals.

Thank you,

Mary

From: Morteza Talebi [redacted]
Date: Friday, August 4, 2023 at 11:02:36 AM UTC-4
Subject: Parents of Minors Program
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To whom it may concern,

I am a parent of a minor to whom I provide habilitation services. My five-year old son has a rare genetic syndrome and is on the Autism Spectrum Disorder. The Parents of Minors program has eliminated the challenges associated with finding a reliable and dedicated third-party provider for my son. In addition, the program has allowed my son to receive the assistance he needs during his daily routines to practice and acquire essential personal care and life skills. If this program were to end in November of 2023, my son would be left without a reliable, dedicated provider and would no longer have the opportunity to participate in meaningful, practical learning during his daily routines (e.g., meal times, bed time, potty time).

Please reconsider extending this program or making it permanent to allow parents to provide the highest quality of care and assistance to their minor children.

Thank you,

Mehrsa Aghajafari
[redacted]

From: Tara Mackey [redacted]
Date: Friday, August 4, 2023 at 7:56:57 AM UTC-4
Subject: CMS document regarding extension of parent caregiver program
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Please see the attached CMS document regarding extension of appendix K and 1115 demonstration waiver flexibilities:

https://www.medicaid.gov/sites/default/files/2023-08/smd23004.pdf?
fbclid=IwAR30G7Clc84xaqt76J7e4g5O-KeO8TGu29FRLqN286-NLS-

7JsLtVVPjqn4_aem_AVpeP1DvJR_aQ-
8tkmEmpMNcLNdF74tFOcvNOSPaICRwa7thMM2f9Hw06j1eVjGSoZA&mibextid=Zxz2cZ

From: delilah sadik [redacted]
Date: Thursday, August 3, 2023 at 11:25:26 PM UTC-4
Subject: Parents as providers input (parent)
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello, I am a parent of two autistic children and I am writing to you in regards of the changes that would impact my family and I's situation. Taking away this schedule that we have in place would highly affect my children's routine. I feel like it is very necessary for this to stay in place because we are able to provide the best care for our children by having the opportunity to provide habilitation for them. Parents know their children's wants and needs best and having this change will impact our routine and it will also cause a shift in the way we provide care to our children to our best knowledge. Providing habilitation to my children has given me the opportunity to grow and learn from experience and being able to do that gives them great success. I am advocating for my children for their best. I do not want just anyone to come in and not know what my children's needs are and I feel like they will not be able to provide them with them meeting their goals. I feel like if you take this away they will regress and that will cause a significant set back. Thank you for giving me the opportunity to speak upon this and I hope you take my thoughts into consideration.

Sent from my iPhone

---------- Forwarded message ---------
From: **Myers, Carrie** [redacted]
Date: Thu, Aug 3, 2023 at 3:57 PM
Subject: RE: Parents as Paid Caregivers Material
To: Susan Kennard <susan....@azahcccs.gov>

Hi Susan

The services referred to throughout the presentation were attendant care, habilitation, and homemaker services. What about home health nursing services? Is that included in this waiver proposal?

Thanks!

Sincerely,
Carrie Myers
Director
[redacted]
Bayada Home Health Care
7250 N 16th St.
Suite 301
Phoenix, AZ 85020

From: John <[redacted]
Date: Thursday, August 3, 2023 at 6:25:12 PM UTC-4
Subject: Urgent Ahcccs and 1115 waiver team
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Good Afternoon,
My name is Holly Brittain and I am the Mother to a beautiful Non Verbal autistic 4 year old daughter [redacted] Firstly thank you for allowing us to email and send out feedback, concerns and quest

The Paid Parent provider program has done miracles for our family in so many ways. My Daughter is considered to be on the severe end of the spectrum. Before the Pandemic we weren't able to find any providers. She was being kicked out of every daycare we placed her in and the reasons were either her needs are to high or she wasn't meeting the milestones with the rest of the program.

Since then I had to quit my job and be a stay at home mom since we couldn't find child care while I was at work. That took a hit to our family financially but on the other side I was able to see how much my daughter was progressing with me being there.

Since becoming her Habilitation Provider she has gotten out into the public much more, even met a few friends on her own. She is almost completely potty trained and started understanding safety, stranger danger. She's starting to understand self care and hygiene as well. Her social anxiety has decreased easing up the meltdowns that are associated with the anxiety. I believe all this is happening because I am lucky enough to be her provider. I know my daughter and I'm teaching her life skills for the future so she won't I have to depend on me or anyone. This program has showed me that she isn't just capable of learning that she is learning and Thriving.

Instead of having strangers in and out of her home causing said anxieties mentioned and added stress of the revolving door of strangers coming and going helping my non verbal your child with private and intimate duties. I don't feel comfortable having complete strangers helping her dress, use the restroom, bathe as those are part of her Hab goals. Instead I could be home with her helping her.

In just over 3 short months we are going to be pushed off a cliff with shortage of dcw workers and if we do get a worker they won't stay long. If Habilitation is excluded from the proposal I'll be forced to go back to work and troubleshoot different daycares. If they will even take her and then I'm afraid we will loose all progress [redacted] has made this far. Or we will be again forced with the added financial difficulties in order for me to be home with [redacted]

With all that being said I'd like to again thank you for reading this and I hope you take my story to heart because there are hundreds of other families just like us.

From: Susan Luks [redacted]
Date: Thursday, August 3, 2023 at 6:16:49 PM UTC-4
Subject: [redacted]
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hi ! My name is Susan Luks I am the mother of [redacted]. I have been his paid provider since covid and it has changed our lives. Since this policy was in effect he has always received his services. We no longer have to worry about people canceling or there schedule not work with our etc. the best part is I take this money and take him on weekly outings in the community to work on his goals, this is something I couldn’t do before . Please permanently keep this in effect.
Thank you
Susie luks

From: Lori mouer [redacted]
Date: Thursday, August 3, 2023 at 4:23:16 PM UTC-4
Subject: Waiver proposal public Input
To: Lori mouer <lorimouer@gmail.com>, waiverpublicinput@azahcccs.gov
<waiverpublicinput@azahcccs.gov>

I'd like to comment on the proposed removal of HAB. Families like ours with kids who have immunodeficiency disorder and are medically fragile are unable and/or unwilling to allow providers in our home. When my son was a baby, he contracted RSV from a respite provider who had been told to "please, call in sick if you have ANY symptoms" because of my sons issues. He spent the better half of the year in and out of the hospital because of that illness.

Prior to becoming a parent provider, we hadn't utilized services for approx 7 years. The last provider we had, I found her asleep in my sons room while my son was on home-based oxygen. I can no longer trust others to care for my son.

Since I've started doing HAB for my son, his vocabulary has dramatically increased. His speech is clearer and his articulation has improved. His homework has become easier and transitions are smoother between tasks. He's getting out and having play dates with friends and family(yes this is a hab goal), he's being taught how to make eye contact and engage in conversations with others, amongst just becoming a well-rounded kid. I'm the only person who loves and cares about my son enough to put all my efforts into teaching him these goals. However, if I can't collect a paycheck for doing them, then I'm forced to find employment outside of our home. I truly believe we've all been living a happier, healthier life since implantation of this program.

Thank you for your time,

Lori Mouer

From: Jada Lewis [redacted]
Date: Thursday, August 3, 2023 at 3:52:43 PM UTC-4
Subject: Parents as Paid Providers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello,
I wanted to share my story and beg for Arizona to not let this program slip through the cracks.

My son, [redacted] is six years old and has Down Syndrome. He is non-verbal, does not eat solid food, and is not yet potty trained. He requires a lot of instruction, reminders, and repetitions to learn anything.

This program allows me to help him through all these daily habits that most people take for granted. I am able to spend time teaching, showing, and training.

We have been denied entry to summer camps, daycares, after-school programs, and church offerings because of his disability. He has made some amazing progress but he continues to struggle to completely become independent on most everyday tasks.

Using a 3rd party caregiver is almost always out of the question. Typically they are irresponsible, don't understand my son's true needs, and are very inconsistent. With myself as the paid provider, I have the ability to help him with much more consistency and precision.

I beg for at least an extension because the November deadline is just terrifying. We need the time to make sure he gets the care he DESERVES!

We've been left in the dust for far too long. Please don't take this away too.

--
Jada Lewis

◦

To Whom It May Concern:

I am the mother of a child who receives DDD and ALTCS services. I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which would go into place in November 2023, my son and many more like him will lose access to their Habilitation services or more than 40 hours a week of care by parent providers of minor members. The reason my son will not have access to their appropriately evaluated services is due to the DCW shortage. My agency has specifically stated that they will not be able to recruit, hire and train enough providers to fill the gaps in service these new rules will create.

It is my belief that this new proposal is intentional in discriminating against and specifically targets parent providers. Should my son lose Habilitation services due to this new proposal he will without a doubt suffer, have setbacks and will regress on learned skills and working towards new goals.

I look forward to speaking with someone soon about my concerns. Thank you for your time.

Respectfully,

Sommer Walter
[redacted]

From: **Jennifer Garcia** [redacted]
Date: Wed, Aug 2, 2023 at 3:28 PM
Subject: Parent Paid Providers

To: Susan Kennard [redacted]

After listening to the forum I think it is VERY important to include HAB in this proposal. Most parents have HAB hours over ATC and getting people to come and do HAB is near impossible. As far as data goes I can only imagine how low the numbers were of members getting the services they need provided for before the parent providers was allowed as compared to now with parent providers the members. We are making progress and getting the services so that they (our children) can get out of the system. Constancy is key for children with disabilities, HUGE and trying to find people and if you do they quit does not service the member. So I know I am not alone in saying that ATC and HAB need to both be in this proposal, unless you are rolling all HAB hours into ATC hours.

Also it was said that there is a federal law that we have to abide by and that is why we just cannot continue. Why is it that other states like CA have done parent paid providers for minors long before covid? If it's a federal issue they would have the same problem, yes? Definitely something to look into.

Lastly if the family serves program is taking monies that could be put towards including HAB that is something to look at. Parents need help with HAB and ATC and getting the skills accomplished more than they need a family services representative. Having HAB and ATC continue as paid parents is serving the members and assuring they can move forward with their goals with a consistent care giver.

Thank you all for your time and help and all you do for this community we truly do appreciate

your support.

Sincerely,
Jennifer Garcia

From: Chantelle Boley [redacted]
Date: Thursday, August 3, 2023 at 9:18:03 AM UTC-4
Subject: Parent provided habilitation
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello,

My name is Chantelle Boley-Van and I provide Habilitation services for my son. He is 15. I was made aware of the changes trying to be made to stop parents being able to provide services. We only have 9 hours per week of paid services for habilitation so are not affect by the 40 hours a week. Raising any child is a lot of work but adding special needs brings challenges that are not typical. Simple tasks become huge milestones. Some goals take years to even begin to see progress. As parents with special needs children, we already have to work on our children’s goals daily, we already put the time and effort in for surpassing the hours we get paid for. My argument to not take away paying parents parents as providers is this, if we are already working on the goals and we already have the emotional component that our children may never fully by “typical”, then wouldn’t it be beneficial to give us parents a little extra help? My other argument is that finding providers outside my home has been a challenge since my son was little. Honestly they usually didn’t know what to do with my son or how to get him to work on his goals it was basically just about the same as a babysitter. They would cancel constantly, or quit the company and so the turnover rate was a large amount. Or they couldn’t find providers who could work our schedule or drive to our home. We had gone over a year a few times with finding a provider through the various companies. I obviously will always be here, I won’t quit, I know how to work with my son. Again, we only receive 9 hours a week so it’s not a lot but it helps my just take designated time to focus on my son and his goals.

Thank you for your time,

Chantelle Boley-Van

Sent from Yahoo Mail for iPhone

From: sara Vaughan [redacted]
Date: Thursday, August 3, 2023 at 1:59:42 AM UTC-4
Subject: Parents as Caregivers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello and thank you in advance for taking the time to read this email,

It means a lot to me that you are advocating for those who cannot, our children with disabilities. My son, [redacted] was diagnosed with Autism at three years old and we have been so grateful for the services that have been provided through DDD. He receives numerous therapies each week, health care coverage that allows our family to support his extra needs and he was even able to attend a DTS summer camp for the first time this summer using some of his respite hours for the first time in many years. The reason I include all these details is that the summer camp, especially, is the first time we have been able to get any sort of respite for him due to the worker shortage. He had an AMAZING time at camp and hopes to attend again next summer! Although we missed him around the house, it was also a few hours I was able to take care of all the rest of the demands life has for our family and his four other siblings. I am very grateful that you are including ATC hours in the waiver being proposed and agree that although it is absolutely our responsibility as parents to care for our children, it is also very beneficial to have the ATC hours to receive some compensation for the extra hours spent giving more individualized care to [redacted]. [redacted] has five year old identical twin sisters who are already surpassing him in many daily living skills that [redacted] isn't even close to mastering, such a toileting. Isaac will be ten in September. Not only can he not toilet independently, but he also wets the bed most nights which requires daily laundering of bedding; this has been happening for years as he leaks out of pull ups. He cannot brush his teeth or shower independently, tie his shoes or fasten pants that aren't an elastic waistband.

In regards to the worker shortage for respite, we have also experienced little to no luck with workers to provide HAH. Before COVID we were sent two women to interview, several months apart. The first was a much older woman who was very cross and just wanted to sit at the kitchen counter and bark orders at [redacted] so we respectfully declined her services. The second was a much younger girl who we agreed to have work with [redacted]. She arrived late most days and was extremely unprofessional in both her appearance and behaviors. She used words in our home we do not use and continued to use them even after we asked her not to. She would bring canned fruit to our home and eat it as breakfast out of the can while she was working with [redacted]. Managing her and her incompetence was a job within itself for me and little HAH was taking place. All this being said, the need for proficient HAH workers is vital for the member, our children. I STRONGLY insist HAH be included in the waiver so that parents can continue to provide this service for their children. Isn't some HAH better than no HAH with the worker shortage? This is what they will get if this option is eliminated. We had big gaps with no providers at all before I was able to provide HAH for [redacted] and I believe this will be the case again if it is not included in the waiver.

Some background on myself: I have a Bachelor's Degree in Education. I worked for HOPE Group after college providing HAH and Respite for several clients with Autism before I had children of my own. I have taught in many classrooms, of all ages and learning abilities and I am now the mother of 5. Without sounding conceited, I have far more insight and credentials than most HAH providers that would potentially be sent our way. I understand the concern for isolation if parents continue as caregivers, but parents also naturally teach their children in the real world in a way that is much more natural for the child than leaving their home/family with a stranger to go out into the world and be influenced by the unknown. If parents cannot continue as caregivers in the capacity that they have been, then I propose the consideration of specific credentials being met to allow this option to take place. I understand all providers may not have a college degree, but if parents were required to meet certain criteria (above and beyond) to be a paid provider for their child, it would further the parent's knowledge on how to meet the need of their child and/or other clients they provide services to. Although I will continue to provide HAH to [redacted] whether I receive compensation or not, it truly is crucial to these children to have the daily, one-on-one care and attention to learn these life skills if they ever want a chance at independence on their own someday. My guess is that [redacted] HAH hours will go unused if parents as caregivers of HAH is eliminated because despite the attempts to recruit more workers, there will still not be enough...and certainly not enough by November 11th.

Along with inexperience, gaps of service/continuity is a huge issue with providers. I once recruited my own HAH/respite worker. She was a Para at an elementary school who had glowing reviews and was more than perfect for the job. She willingly did all the training and became certified to provide care for [redacted] She worked with him for the summer and they got along great....but then school started again and she went back to her full-time job. So, three months a most. It was great while it lasted but then we were back to square one. She worked with him here and there a little during school breaks but nothing consistent and certainly not long or frequent enough to make any strides in his goals. Does long term consistency and continuity of care not hold any weight in this decision to include HAH in the waiver? Parents are the MOST influential presence in their child's life. They are the most consistent and know their child best; they also typically meet their needs without the child having to ask for it. What better teachers to help these children achieve their goals?

In attending the forum today, another participant made an excellent point saying that if the parents who actually want to provide care as a paid worker for their child accept another provider instead of doing it themselves, she could potentially be taking away a provider from another family/child who may not want (or are unable) to provide care for their child. Allowing parents to be paid caregivers was a genius solution to a pandemic problem that has continued to benefit these children in desperate need of workers. Taking this option away would be a huge disservice to each of them.

Once again, I truly appreciate your time and willingness to consider adding HAH to the waiver. I believe it serves our children most...which should be the focus of all this - getting them the most we can in the time we have with them.

Have an amazing day!

Sara Vaughan
aka [redacted] mom
[redacted]

From: Regina Gutierrez [redacted]
Date: Wednesday, August 2, 2023 at 9:13:36 PM UTC-4
Subject: parent as paid caregiver comments
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

I really hope that I can still submit a comment. Since we have been apart of this program my sons life and our families life changed for the better. [redacted] is able to have all his services meet by family that he knows and is comfortable with. There is never a gap in care or random "call outs" or constant turn over of nurses leaving.

When our son had in home nursing there was never consistency. Nurses would come and go constantly. We would go months without help. This would impact our family negatively financially because we would have to miss work to get him to appointments/ therapies. Now we can ensure he gets to his appointments and also we don't have to worry about a job not understanding that our child's needs are chronic and they don't just get better in months.

It's a struggle being a parent of a disabled child. I used to work in healthcare and go figure they weren't understanding at all of my son's condition. They would deny my request off for his therapies and that would impact him negatively.

This program means so much to us and to so many other families who have disabled minor children.

This is my son. His name is [redacted]. He is ex 24 weeker and is a miracle. If he could talk I'm sure he would tell you that ever since this program came he's been able to have his parents with him and that he has achieved so much since having us provide care.

From: Brittany [redacted]
Date: Wednesday, August 2, 2023 at 8:58:57 PM UTC-4
Subject: Paid parent proposal
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello, to whom it may concern:

This proposal to end the paid parent program would be DISASTROUS for SO many families, if not all of them. Unless you have a child with a disability, you do not understand the level of unfairness and undeserved lack of care these children receive from immature and inexperienced caregivers who do not truly care to work toward meeting habilitation goals for

these young children….The audacity of some of these workers to show up in unacceptable conditions for work…. The lack of mere respect by calling out last minute or not showing up consistently or at ALL. No one will care about these disabled kids and be consistent in working in their goals like us parents are. My child has been able to go out to socialize so much more with this program because I have been home more and able to take him out. He is THE MOST comfortable with me placing demands on him by working on his goals. He struggles with strangers and high turnover rates, as do MANY other disabled children. Even a typical child or adult would struggle with new strangers constantly in their home space. Please do not end this paid parent program. Cap it at 40 hours if you will but DO NOT END IT!!!!!!!

Brittany Powers

From: Christina Sandez [redacted]
Date: Wednesday, August 2, 2023 at 8:56:07 PM UTC-4
Subject: Permanent Amendment 1115
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

As an active parent in the care of my child being able to get paid has been and is beneficial. Up to today nurses are not available and they also have life or get sick to. It's difficult to find nurses on short term notice. My regular job doesn't understand the care of a sick child, hospital stay, countless appointments. There is not enough nurses to cover extra shifts that come up. If my nurse gets sick there would not be any one available to cover. Which means I must call in to work. Can't get FMLA or excuse absences because I have not yet been with the past a year. Of course I rather take care of my daughter myself 24/7 but pay isn't much which means I still have to cover the other half. No one will ever take care of my child better than me. My daughter is much happier when she is with her mom. This program has helped me and my family stay up flot with bills. It is very beneficial for patient as for the parent. I lost my job in 2021 for to many absences, companies do not understand care of a sick child, they just want you to do your job regardless of anything else. Its hard situation to be in , not having income takes a toll in life and we can't relay on anyone else (nurses). During COVID-19 it was bad and it still is. Please keep problem going the best care givers is us the parents, these patients are our live.

Sent from Yahoo Mail on Android

From: Nichole Fernandez [redacted]
Date: Wednesday, August 2, 2023 at 8:45:47 PM UTC-4
Subject: 1115 Waiver Amendment - Public Comment
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

Thank you for the opportunity and forum to provide comments and feedback about this program. I attended the second public comment forum today and I am extremely grateful for all your hard work and efforts to create a permanent program for Paid Parent Caregivers.

As a parent of a disabled child who is a DDD and ALTCS member and who receives habilitative and respite services, I appreciate the opportunity to provide additional comments relating to what was discussed today. Please consider the following:

1. Social Isolation Concern for Habilitative Services:
During the first public comment forum, I asked in Chat for data about isolation, but it was either unavailable or not disclosed in the second public comment forum. Instead, with actual finger quotes, we were told that social isolation has been "researched" and found that it has its roots in childhood. There was no data for this statement, and no indication of whether this information was provided by disabled adults giving a retrospective view or by disabled children via self-report or some other source.

My 9-year old child sees two therapists three days a week in our home (and many other people outside of it), and really needs down time from interacting with people in ways that center her disability (e.g. that take her away from playing and/or “other” her from her siblings) or that require her to advocate for her needs with non-family members. As stated in my prior comments and feedback, for us, right now, social isolation is not a primary concern nor an overarching aim of current habilitative goals.

While social isolation is a valid concern, it should not be the driving force for a policy that removes parents as potential providers of habilitative services. Surely, there are a range of other parameters that can be put in place to meet the need for social interaction, but the complete removal of parents as HAB providers is incredibly limiting to the members who benefit from it.

2. Parent Providers as Primary DCW Workforce/Burnout Concerns:
Alex shared the concern of over-reliance on parent providers as a primary DCW workforce, and I really appreciate this concern and the efforts to diversify the workforce beyond parent providers. I hadn't previously considered this view, and recognize it as completely valid.

At the same time, please consider there is a lost cost of time and effort that parents expend to identify good agencies, interview potential HCBS providers, and train those new providers, only to have to start all over again when providers leave service. The process of having to find the "right" provider and then having to train them all over again dissuaded me from replacing the provider we lost in January of 2020.

Additionally, the ongoing concern about Covid and other communicable illnesses being brought into our home when our only full-time working parent works from home has dissuaded us further from replacing the second provider we lost to a career change during the PHE.

For now, a parent providing HCBS for my child is what is best for our entire family. In the absence of non-family providers, I have often felt incredibly strained by trying to meet the rising costs of living working a flexible, part-time, unstable contract job, being unable to look for more stable work because of my child's needs, and adequately meeting her needs while working from home with no available providers.

The Paid Parent Provider program alleviates all of these worries and allows me to place my primary focus on meeting my child's needs and provides access to direct care we have otherwise been without for 3.5 years.

3. Maximizing Access by Maximizing Choice:
While it is a valid concern to not want to rely on parent providers as a primary source of the DCW workforce, continuing this program allows a much wider range of choices for members and member families and provides more routes to direct access to services.

If the goal is maximizing member choice, as I believe was stated several times during this forum, a strong concern must also be raised about the discussion of agencies having a method for reporting when members decline a potential non-family provider. Members and their families must reserve the right to decline providers for reasons that are valid for that member without fear or worry of being penalized for doing so.

Thank you for your time and consideration! Our community looks forward to our continued collaboration to create a permanent program that best serves DDD and ALTCS members in Arizona.

Thank you!

From: Alfonso Figueroa [redacted]
Date: Wednesday, August 2, 2023 at 7:49:37 PM UTC-4
Subject: Parents as paid providers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello,

My name is Jesus Figueroa and my son [redacted], was recently diagnosed with Autism and was accepted into the ALTCS program earlier this year. I am writing to voice my concerns about the possibility of losing the ability to provide habilitation care for my son. [redacted] is a very typical autistic child in the fact that he doesn't always connect well with people he does not know. He currently receives therapies from his preschool and a therapy center outside of school where both of these places tell us just how much he struggles to connect with others. Being able to provide him the extra habilitation care at home as a parent has helped [redacted] so much in the short time we have been able to do so. If we had to go through the process of finding another person to try and provide this care it would be an extensive and extremely stressful (not just for us, but for [redacted] as well) process. As parents, we try and do our best for our children and being able to provide [redacted] with his habilitation care has been an extra blessing in our lives, we would hate to lose this. The added income from this service that we receive allows us more opportunities to purchase tools and other essentials that can help [redacted] with everyday living that would not be possible in our budget otherwise.

I hope you take the time and truly think through the repercussions of parents losing the ability to provide habilitation care; because I know for a fact there are many others in the same position that would be devastated if they were to lose this.

Jesús Alfonso Figueroa

Sent from my iPhone

Sent from my iPhone

From: Erin m [redacted]
Date: Wednesday, August 2, 2023 at 7:48:30 PM UTC-4
Subject: Parents as paid providers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To whom it may concern:

My name is Erin Milburn and my 4 year old son, [redacted], was recently diagnosed with Autism and was accepted into the ALTCS program earlier this year. I am writing to voice my concerns about the possibility of losing the ability to provide habilitation care for my son. [redacted] is a very typical autistic child in the fact that he doesn't always connect well with people he does not know. He currently receives therapies from his preschool and a therapy center outside of school where both of these places tell us just how much he struggles to connect with others. Being able to provide him the extra habilitation care at home as a parent has helped [redacted] so much in the short time we have been able to do so. If we had to go through the process of finding another person to try and provide this care it would be an extensive and extremely stressful (not just for us, but for [redacted] as well) process. As parents, we try and do our best for our children and being able to provide [redacted] with his habilitation care has been an extra blessing in our lives, we would hate to lose this. The added income from this service that we receive allows us more opportunities to purchase tools and other essentials that can help [redacted] with everyday living that would not be possible in our budget otherwise.

I hope you take the time and truly think through the repercussions of parents losing the ability to provide habilitation care; because I know for a fact there are many others in the same position that would be devastated if they were to lose this.

Thank you for your time and consideration and please feel free to reach out if there is anything else that I can do for this.

Erin Milburn

Sent from my iPhone

From: Carson Romo [redacted]
Date: Wednesday, August 2, 2023 at 6:24:44 PM UTC-4
Subject: Input/Concerns
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello,

I am a supervisor with DDD. I have some concerns and suggestions for the proposal.

Issues with parents as DCW- concerns are more chances for abuse and exploitation, less chance for socialization, some parents not really following through with the services, morally feels wrong to pay parents to be a parent. Some kids do better listening to someone other than their parents, and it shows consistency of expectations beyond just the family household.

We have had parents lie about their schedules in order to get services, or they ask for the service when they are capable of caring for their child. Some are also trying/thinking to say their kid can't do something so they can change from HAH to ATC in order to continue getting paid.

It’s hard to assess and follow policy with parents as DCW for minor children, it gets messy and causing conflict between DDD staff and the families/agencies. Agencies are telling families they are entitled to 40hrs/wk, and they want the money. Families are only wanting 40 so they can get paid the full amount, but if sometimes assess more based on what they are saying they only want 40hrs since that’s all they get paid, so conflict of what is actually needed and thus also showing parents/guardians are capable of caring for their kid and don’t need the hours.

The policy for DDD has us follow that ATC is not needed if there is no barrier to parents/natural support providing care, yet this amendment is letting parents who are capable of caring for their kids get ATC. If we go this route to make this permanent, we need extreme clarification and stipulations on how this works.

There are some families that are using them appropriately, but there is an alarming amount abusing this flexibility.

When you say a parent can get paid for this service, they feel entitled for it, and it’s confusing for us (DDD staff) to follow policy like I stated earlier and seems like we should just give it to them, which is why I propose a new service with an amount (40hrs/wk) we can automatically give them to use as needed.

If we go the route of parents as DCW for ATC, we need to do away with support coordinators assessing services, there should be a single service that we can give to families with the amount they want and can do HAH or ATC within it. Or something like that, because the conflict on what's appropriate/needed can be a lot. Or again, need some serious clarification on policy and what counts for it, so it's easier to assess.

If parents can get paid, it should be stipulated that an outside provider should be constantly looked for in order to fulfill the need, and parents should stop being provider altogether then or only do whatever the new provider can't fill until all the hours can be filled by an outside provider. And if a provider ever leaves, then parent can get paid again until it's filled again.

If they refuse the help (outside provider), then do they actually need the service then? It shows they are capable of caring for their child and their needs. That's why maybe we should rid the assessing part if they are just going to get paid to care for their kids. We've had so many get overturned within DDD or in appeals process, even though the parent doesn't want an additional provider, they stated they can care for their kid, but they want to get paid. Again huge concern here for abuse/exploitation of their kids.

On the abuse topic, many injuries and things akin to reporting, may go under reported since no outside person/or less outside people sees the child, and parents don't want to tell on themselves.

There is also the concern of what parents can do as parents vs when they are the provider. Some may make their kid wear a harness, physically be able to pick up their kid, etc, which they can do, but as a provider they can't do that; it'd be a rights restriction they would have to get approved for, and many probably wouldn't get approved. Again, it would also likely go under reported when those are occuring.

That's all I have for now. Thank you,

Carson Romo (She/Her)

From: Jason Turner [redacted]
Date: Wednesday, August 2, 2023 at 6:12:56 PM UTC-4
Subject: Continue habilitation
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

I am the parent of a minor son with Down syndrome who my wife provides Habilitation services for. She started this in April 2020 during the PHE. I am writing to ask that you **PLEASE INCLUDE HABILITATION** in the 1115 Waiver Amendment. We do not have attendant care hours, but my wife (his mother) works with him on his Habilitation so that he can become an independent adult in the future. We have never been able to find a non-parental provider to come and provide Habilitation with my son. I work full time and my wife is our son's full time caregiver. I would be so disappointed if she had to find a job outside the home instead, while there is NO ONE to support my son. This would be a severe hit to our family in terms of his cognitive development.

The immediate implementation of this in November would not provide time to find a caregiver, as there is such a shortage. At least extend the implementation to the original ARPA program end date of September 2024. Better yet, include Habilitation services in the amendment.

Thank you for your consideration and the impact this amendment would mean to Arizona families like mine if implemented immediately, without Habilitation.

He needs habilitation goals of getting ready for school, showering after school, learning to cook dinner, bedtime chores and routine.   Learning tasks associated with these goals. Good luck finding a habitation specialist that is willing to come to our home from 5:30am to 7am to teach morning routine, then leave during school hours. Then come back again at

3:30pm and stay through dinner until bedtime at 8pm. This doesn't exist. It doesn't exist at all. He needs 24 hour care. He is learning these valuable tasks to become more independent and function as an adult.

My wife went through a lot of training to become a habitation specialist and my son does qualify for attendant care. This is a rushed implementation and there is no way there are habilitation specialists to fill all these needs. He is not isolated. He goes to school and attends GiGis playhouse, Down Syndtome network events, Miracle league, and I coach his Special Olympics team as a volunteer coach for multiple sports. He attends Civitan day program 8-12 during the summers and has speech therapy 2 times a week. He also goes to church weekly. He has a severe cognitive disability, impulsivity, flight risk, and has been kicked out of several programs due to leaving the facility and once the police were even called.

He needs habilitation goals and my wife is trained and knows him best as is the best person for the job.

Jason Turner

From: Gina B [redacted]
Date: Wednesday, August 2, 2023 at 6:07:06 PM UTC-4
Subject: Aug 1, 2023 public forum and input
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello
My name is Gina Blair
I was on the call today but was no selected to Read my statement so I am sharing it here with you all.

First off, I want to thank everyone at DDD for several things. The first thing is, is that this parent provider program which has afforded so many parents to be able to be home and more present with their children who need their extra care, love and support. Thank you for always wanting to be in the forefront of supporting our families.
Second, is that without DDD services over the years, my son, who is a prime example of how early intervention and sustained services like habilitation works, would not be doing all the amazing things that he's doing now.

He started today at west-mec in the auto collision program and is a senior in high school.

Hard to believe without speech, therapy, physical therapy, occupational therapy, habilitation, and all the other amazing services that DDD provides, he would probably still be nonverbal, and in a very dark spot.
I am eternally grateful for the services DDD provides !

I'd like to take a moment now and talk about how being a parent provider has helped my son grow exponentially the last 2 1/2 years.
We all know that sadly there is a high turnover rate with DCW workers as a whole, but especially Hab and attendant care providers. Before being allowed to be my son's parents provider, we would either have providers quit or not even show up for their first day or we would go very long times without have providers. At some points, we would even go 9+ months without providers as there just wasn't any providers available. Being able to have me as his provider of his services, provided the consistency and continuity of care he has needed and has helped him grow through goals and make great progress that he hasn't been able to do in a long time.

The talk of doing away with parent providers, specifically for habilitation, would not only affect my family, but many many others here and Arizona. So I ask you to please reconsider this and realize what a huge benefit it has been for not only my family, but so many others. I understand after looking at some data that the costs may seem higher associated with parent providers. However I ask you to keep in mind that many parents were like myself and With out providers for attended care and habilitation for extended periods of time. So this will make the figures look higher now as the parents are utilizing all of the hours their child is assigned.

Thank you again for all of your time and energy you have spent on this issue. I am incredibly grateful again for everything you have provided my family over the years.

Sincerely,
Gina Blair

From: Zahraa Salih [redacted]
Date: Wednesday, August 2, 2023 at 6:06:01 PM UTC-4
Subject: Habilitation services
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello,

Habilitation has major positive impact on my daughter who requires extraordinary all day long effort , from taking care of all her needs as a kid plus all tremendous effort to deal with a child with autism, a lot of commitment and combination of all type of intensive training and effort on daily basis, without any of that she will have ongoing regressions back to zero improvement.

The importance of consistency and intensive adhering for these efforts will impacting my daughter life.
Habilitation has major positive impact on her so far for improving her independency and learning.

without habilitation program, we will have major negative impact of my daughter needs.

From: Daniel Gardner [redacted]
Date: Wednesday, August 2, 2023 at 5:57:33 PM UTC-4
Subject: Parents as Paid Caregivers Proposal Draft Considerations
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Good afternoon.

I am an Autism parent and parent provider attending AHCCCS's Parent as Paid Caregiver Hearing. While I hoped to have the opportunity to verbalize my perspective during the meeting, the number of attendees limited my ability to do so. As such, I have drafted a summary of my talking points on the subject. I will be as succinct as possible in conveying the necessary information I would like to have considered in extending the waiver to provide parents the ability to be a paid caregiver for minor children as has been the case for adult children since before the healthcare emergency.

Having parent providers creates jobs that wouldn't otherwise exist. This should be kept in mind when considering the budget available to continue to serve special needs children. These tax dollars are going to great use as there are parents, willing to work, whose special needs children require so much attention, that the parent would not otherwise be able to maintain a job. Allocating funds to allow for parent providers gives these parents a productive way to contribute economically, keeping them from relying on more costly government assistance which would be more expensive. Maintaining parents' autonomy to provide support can reduce the number of vulnerable special needs children in systems like group homes to promote stability. In economic terms, paying parents to support their own special needs children creates jobs and is less costly to existing tax-payers than reliance on other government programs that would be used in the absence of having parent providers. This proposal will be effective to reduce the impact of the DCW shortage. Due to Article 9 and safety requirements, having parent providers brings more awareness and education on special needs that wouldn't otherwise be there and means that a larger number of the population are CPR certified which saves lives. Abuse statistics have shown that special needs children are among the most vulnerable. Parent providers allow for parents for foster a safe environment for children to obtain necessary attendant care and habilitation, reducing unnecessary reliance on third parties with which a trusting relationship have not been built. While these vulnerable children are safest with their own parents, having parent providers allows more options for special needs parents to choose direct care workers that would promote safety and be a good fit for their children.

I believe this panel to share my understanding of the value in maintaining paid parent providers of minor children and appreciate your efforts in extending this waiver permanently. This said, there are significant gaps in the proposal that I would like advocated for in the pitch to CMS:

-If it is not possible to remove the 40 hour limit, Ii would be beneficial for the development of special needs children to allow parents to collaboratively provide services in excess of 40 hours. For example, my son receives 60 hours, in total of services that are shared between my wife and myself who are both care providers. It would be beneficial, in the absence of available dependable DCWs, for parents in my situation to be able to continue to provide these hours of support so that my son can continue to get this support. Caregiver burnout is not a factor in this as the extraordinary care is split between my wife and I so I would like it proposed to allow parents to each contribute up to 40 hours each per child rather than a per-child limit. Socialization is not a factor as my child is engaged in school and Church. Reducing paid-parent care reduces the availability of necessary care provided to my child. There is a shortage of DCWs and mine and my wife's support is pivotal in my son's care and development

-If parent-provided habilitation is still to be provided for adult children, what is the rationale for minor children not being able to receive the same service from paid parents? With a DCW shortage, this change means my son will not receive necessary habilitation as the DCWs aren't available to provide the service if we do not provide it ourselves. The lack of habilitation is going to have a significant detrimental ripple effect on my son that carries over into our understaffed schools which are already ill-prepared to educate special needs kids.

Please consider revising the proposal to advocate for habilitation and less restrictive hour-limits provided by parent providers. Let me know any way that I may be of assistance as this is a subject I am immensely concerned about.

Daniel Gardner
[redacted]

From: Hilari Howard <[redacted]
Date: Wednesday, August 2, 2023 at 5:33:29 PM UTC-4
Subject: Request for HAH service extension
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello,
Thank you for hosting this forum today and considering a variety of perspectives. Our agency has received feedback from almost all of our parent providers of minor children that their member's services would be interrupted if habilitation was not included in the waiver amendments. We agree with their concerns and believe that parent providers of minor children should be able to provide both HAH and ATC services.

We have seen a steady rate in community-based services compared to home-based services since starting EVV and prior to the parent-provider program; indicating that parents of minor children are also rendering services in a variety of public places, community settings, and amongst their children's peers. When assessing our minor member's goals, almost all of them have at least one peer-to-peer or community-based goal. The parent providers are still encouraging their children to participate in their community, meeting all of the industry standards for DCWs, and exceeding our EVV expectations compared to non-parental DCWs.

Of the minors using this program at our agency, 93% of them receive HAH from their parent provider and 41% of our minor members do not receive ATC services. All of our members would either experience a 50% reduction in their services or would experience a total halt in their services until we are able to find a provider/providers able to perform their services. Already facing a DCW shortage, we expect it to take longer than 4 months to recruit, train, and match providers to our minor members so that they do not experience a gap in services. By not allowing parents to provide habilitation, we expect additional strains on the DCW shortages; and it's the members who will feel it the most when they aren't able to access their habilitation services in a timely manner.

Please make additional provisions to continue the parent-provider program as is in the waiver, with both attendant care and habilitation as parent-provided services.

Hilari Howard
Chief Executive Officer
Absolute HCBS

www absolutehcbs.com [redacted] [redacted]

From: Amanda Shuler [redacted]
Date: Wednesday, August 2, 2023 at 5:23:18 PM UTC-4
Subject: Paid Parent Waiver 1115 Feed Back
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To Whom It May Concern:

I attended the Public Form on the 1115 Waiver on 08/02/2023... First and foremost, I am a grateful parent to be able to provide HAB for my autistic son. In today's society it takes two incomes to make ends meet. This program has provided an opportunity for me to provide a service that is extraordinary to my son on a daily basis as well financially provide for him and our small family. His HAB goals and routine start before school and after school meaning there is a gap in HAB hours which makes it difficult to retain an outside HAB provider whom most likely will not stay for that kind of schedule. If the paid parent for HAB goes away, I will not be able to find a provider to come in on the odd hours in-between his speech and occupational therapies and other appointments. Even if I were to find a HAB provider, and having yet another individual come into our home is NOT ideal in our situation as he is susceptible to illness and yet will have another challenging appointment on our schedule. If the paid parent HAB program goes away, this will force me to a difficult workforce that is not willing to work with our difficult schedule. My partner and son's father does work a full-time, professional job the workforce, so ultimately the extraordinary circumstances and appointments fall on me for our son. If I have to go back into the workforce, I will have no choice but to put my son in an after-school program which is NOT ideal for multiple reasons, make adjustments to his speech and occupational therapy sessions, and will possibly have to pull him out of school for speech and OT where-as he currently has his therapies after school. This makes it incredibly challenging to go back into the workforce and may put our family into a difficult financial situation again if I am no longer a paid parent HAB provided. My son has come a long way with me providing HAB. Burn out has never been an issue with myself, and yes, I have a duty to provide care for my child, but the care goes far beyond raising a child that does not have a disability that makes a being in the outside workforce and a career challenging for myself. PLEASE, reconsider discontinuing the paid parent HAB program!! Other employers are not willing to work with our difficult schedules! Participating in this program has provided so much growth for my son and myself and will make things for our family much more difficult!

Very Respectfully,
Amanda S.

From: Ross, Cheryl-SQL [redacted]
Date: Wednesday, August 2, 2023 at 4:30:29 PM UTC-4
Subject: Habilitation for Daughter
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To whom it may concern:

I would like to continue doing Habilitation with my daughter. I am with her much of the time and have made tremendous progress in the last 6 years I have been working with her. Please do not change this program. Because of the area in which we live, it is almost impossible to find an outside provider.
Thank you,

Cheryl Ross ([redacted] mom)

From: Janet Mizrahi [redacted]
Date: Wednesday, August 2, 2023 at 4:12:35 PM UTC-4
Subject: Must of Necessity for my Son
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

HI Janet, I have made a few edit to your comment. I have included it below. Please let me know if you have any questions.

Hi, my name is Janet. My son turned 5 years old and he has delays in different aspects, one of the delays is in Adaptive Skills. This impairs [redacted] ability to cope with his environment.
He is not able to be independent, especially in the areas of feeding, dressing, bathing and toileting. [redacted] feels more comfortable in his natural environment such as his home. I am providing habilitation services care and assistance to maximize my son's potential for independence. [redacted] benefit from strong, loving, and supportive relationships and proximity to family members who truly understand his needs.
My son with developmental disabilities, who lives at home often, need supports in order to build important skills. Some of the skill building includes development of social skills, assistance with activities of daily living, and educational assistance. By continuing providing those services, [redacted] will reach the goals, will be less dependent and leading healthy and happy live.

Sent from Yahoo Mail for iPhone

From: Kylee Van Pelt [redacted]
Date: Wednesday, August 2, 2023 at 4:11:33 PM UTC-4
Subject: 1115 Waiver Comment
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello there,

I am in high hopes that Habilitation services will extend the implementation timeline back to September 2024 in advocacy for my young twin cousins with autism and their younger sister with a developmental disability who all receive HCBS services. Cutting this timeline shorter than expected will leave their mother in a detrimental situation in the midst of a provider shortage; this will of course also negatively affect many other families too. As part of the Community Relations team at Absolute HCBS, I also feel the need to advocate for our current members and providers who rely on the parent provider program and habilitation. Thank you for your time and consideration.

Sincerely,

Kylee Van Pelt
Community Relations Content Specialist
Absolute HCBS

www.absolutehcbs.com | [redacted]

From: **Morgan Seleski** [redacted]

Date: Tue, Jul 25, 2023 at 8:00 PM
Subject: Grievance against AHCCCS and DDD
To: <DDDCustomerS...@azdes.gov>

Good evening, I am the parent of member [redacted]. He receives both DDD and ALTCS services.

I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which would go into place in November 2023, my child and many more like them will lose access to their Habilitation services or more than 40 hours a week of care by parent providers of minor members. The reason my child will not have access to their appropriately evaluated services is due to the DCW shortage. My agency has specifically stated on numerous occasions that they will not be able to recruit, hire and train enough providers to fill the gaps in service these new rules will create. This will leave us without a habilitation provider to complete his assessed hours.

I would like to request a TICKET NUMBER to continue to follow up on the status of this formal grievance.

Thank you in advance,
Morgan Seleski

Sent from my iPhone

From: **Patricia Pastrano** [redacted]
Date: Tue, Jul 25, 2023 at 6:34 AM
Subject: Grievance DDD HAB PARENT CAREGIVER HOURS
To: DDDCustomerS...@azdes.gov <DDDCustomerS...@azdes.gov>

I am a parent of a child who receives DDD and ALTCS services. I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which would go into place in November 2023, my child (or state your relation) and many more like them will lose access to their Habilitation services or more than 40 hours a week of care by parent providers of minor members. The reason my child (or state your relation) will not have access to their appropriately evaluated services is due to the DCW shortage. My agency has specifically stated that they will not be able to recruit, hire and train enough providers to fill the gaps in service these new rules will create. Thank you for your time, I would like to request a TICKET NUMBER for following my grievance

Sincerely,
Patricia Pastrano
Mom of [redacted]

From: **Bradley Dorman** [redacted]
Date: Tue, Jul 25, 2023 at 11:14 AM
Subject: Grievence - Parent Caregiver Proposal
To: DDD Customer Service Center - DES <DDDCustomerS...@azdes.gov>

I am a parent of a child who receives DDD and ALTCS services. I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which would go into place in November 2023, my child and many more like them will lose access to their Habilitation services.

The reason my child will not have access to their appropriately evaluated services is due to the DCW shortage, specifically in Flagstaff Arizona. My agency will not be able to recruit, hire and train enough providers to fill the gaps in service these new rules will create.

Thank you for your time, I would like to request a TICKET NUMBER so I can follow this grievance.

Kindly,
Sarah Dorman

From: **Darla Nelson** [redacted]
Date: Mon, Jul 24, 2023 at 10:07 AM
Subject: Grievance
To: <DDDcustomers...@azdes.gov>

To whom it may concern:

I am a parent of a child who receives DDD and ALTCS services. I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which would go into place in November 2023, my child and many more like them will lose access to their Habilitation services or more than 40 hours a week of care by parent providers of minor members. The reason my child will not have access to their appropriately evaluated services is due to the DCW shortage. My agency has specifically stated that they will not be able to recruit, hire and train enough providers to fill the gaps in service these new rules will create.

When you do reach out to me, I would like a TICKET NUMBER for my grievance before the end of our call.

Thank you for your time,

Darlene Nelson
[redacted]

Mother of a daughter both born at 23 weeks and with a genetic mutation called [redacted] [redacted].

From: **CANDACE TIERNEY** [redacted]
Date: Mon, Jul 24, 2023 at 10:10 AM
Subject: Grievance regarding the paid parent caregiver proposal
To: <DDDCustomerS...@azdes.gov>

I am a parent of two children who receive DDD and ALTCS services. I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which would go into place in November 2023, my children and many more like them will lose access to their Habilitation services or more than 40 hours a week of care by parent providers of minor members. Both of my children are autistic and have elopement and self-injurious behaviors. Due to these challenges, they need close supervision to maintain safety. The reason my children will not have access to their appropriately evaluated services is due to the DCW shortage. My agency (ADDS) has specifically stated that they will not be able to recruit, hire and train enough providers to fill the gaps in service these new rules will create.

Thank you for your time, I would like to request a TICKET NUMBER please.

Sincerely,
Candace

From: **mary shoop** [redacted]
Date: Mon, Jul 24, 2023 at 10:30 AM
Subject: Notice of Grievance
To: DDDCustomerS...@azdes.gov <DDDCustomerS...@azdes.gov>

Hello,

I'm a parent of a child who receives DDD and ALTCS services. I'd like to file a grievance against DDD and AHCCCS regarding the current paid parent caregiver proposal. Under this proposal, which would go into place in November 2023, my child and many more like them will lose access to their habilitation service hours that are currently being filled by parent providers. Due to the DCW shortage, my child will not have access to her needed services. We have been with three different agencies over the past few years prior to the parent provider program, and all have struggled to find qualified, skilled workers in our area, willing to work the schedule we needed. We have, in the past, have had large gaps in habilitation services, due to lacking availability of providers, as well as the high rate of turnover of providers. This has proven to be at the detriment of my child. These agencies have stated that they will not be able to recruit, hire and train enough providers to fill the gaps in service these new rules will create.

Thank you for your time. I would like to request a ticket number to have on record for this grievance.

Mary Mavros

From: **Irma Lozano** [redacted]
Date: Mon, Jul 24, 2023 at 11:17 AM Subject:
Paid Parent Caregiver proposal. To:
<DDDCustomerS...@azdes.gov>

To whom it may concern,

Greetings, “I am a parent of twin boys whom receives DDD and ALTCS services. I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which would go into place in November 2023, my children and many more like them will lose access to their Habilitation services or more than 40 hours a week of care by parent providers of minor members. The reason my children will not have access to their appropriately evaluated services is due to the DCW shortage. My agency has specifically stated that they will not be able to recruit, hire and train enough providers to fill the gaps in service these new rules will create.

I would like to request a TICKET NUMBER as soon as possible.

Thank you for your time. Stay safe and God bless.

Irma Lozano

From: **Meghann Hodge** [redacted]
Date: Mon, Jul 24, 2023 at 2:05 PM
Subject: Parent Provider
To: dddcustomers...@azdes.gov <dddcustomers...@azdes.gov>

Good afternoon,

I am a parent of a child who receives DDD and ALTCS services. I would like to file a Grievance against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which would go into place in November 2023, my child and many more like them will lose access to their Habilitation services or more than 40 hours a week of care by parent providers of minor members. The reason my child will not have access to their appropriately evaluated services is due to the DCW shortage. My agency has specifically stated that they will not be able to recruit, hire and train enough providers to fill the gaps in service these new rules will create. And will likely go out of business when these changes take effect.

My daughter has had nothing but issues with getting access to her services she is approved for due to lack of employees in all types of services. She was on a waiting list for 3 months before getting any Speech therapy. After 6 months with a wonderful provider, the therapist moved and now we have been left with no replacement and no services for almost 3 months. She waited nearly 7 for Occupational Therapy just to have many cancellations, changes in providers, and then another therapist move and she lose services. She has been in a waiting list for physical therapy since January of this year and has never been placed with a provider due to lack of staffing.

We had to cancel her respite hours and get them though her primary insurance because we searched for months and we're unable to find a provider, and even with her primary insurance finding respite providers are few and far between. The sole reason my child is able to receive Habilitation consistently is because I am able to provide this for her. I was trained the same way as all other workers, and have a therapy background and with the time and commitment I have been able to provide to my daughter to work on her goals, and not worry about my old job getting in the way of working with her, we have seen huge improvement! We have seen more success and improvement in many areas in the few short months I have been providing Habilitation than in the almost 12 months of her receiving a combination of many other therapies.

This success has been due to:

Consistency of services, consistency in her provider, ability to do these things naturally in her home setting at the times she would typically do these things she needs full support with (eating, toileting, bathing, dressing, social skills, appropriate play with siblings without aggression etc) so it does not feel like work, and the comfort and safety of doing these things with a trusted and familiar person and not a stranger. My child is very closed off from unfamiliar people and it makes working on goals twice as long because it takes months before she trusts the person and by then we are switching providers for one reason or another.

This parent provider program has been a life saver for myself, my child, and thousands of other families!

Thank you for your time, I would like to request a ticket number for my email claim to remain updated.

From: Loretta Leyvas [redacted]
Date: Wednesday, August 2, 2023 at 1:35:19 PM UTC-4
Subject: Hours for children
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Parents of younger children should be able to bill hour for their own children on HAH and Attended Care. I is hard to get worker and hard to be out working with children.

Loretta Leyvas

Sent from Yahoo Mail for iPhone

From: Michael Reuwer [redacted]
Date: Wednesday, August 2, 2023 at 1:32:42 PM UTC-4
Subject: Keep parents as paid caregivers.
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

As a parent of a child who receives DDD and ALTCS services I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility, and it has been extremely beneficial to our family and my child. I would like to share my personal experiences and feedback based on my review of the current proposal for a permanent Paid Parent Caregiver program. This program has been vital for our family. We would not be able to survive without the income from this program. 2 of my 4 children have a disability and require an extreme amount of care. I am the best person for the job and this program has insured that they have received the best care.

Under the current proposal, the request of an ongoing program option which allows parents of disabled minors in Arizona to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies is not being met. Please consider updating the proposal based on the following questions, suggested solutions, and personal experiences.

Should Habilitation be included in the Paid Parent Caregiver Program?

We have heard the concerns about member isolation and lack of community involvement if parents continue as Paid Parent Caregivers facilitating their child's Habilitation services. Respectfully the parent caregiver community proposes the following solutions:

Examine available research and personal feedback statements from members and their families to evaluate the true potential impacts of social isolation and community involvement when parents of disabled children provide Habilitation services. The parent caregiver community's collective experience is that members who have parents facilitating their Attendant Care and Habilitation services have experienced greater member social engagement and community involvement over the last three years. Parent caregivers now have an increased ability to take their children to sporting team practices, community events, movie theaters, all ability parks, church activities and libraries. This is because parent providers can perform the appropriately trained and qualified supports in the correct time and location that is applicable to each member.

Implement precise guidelines to facilitate generalization for all Habilitation providers regardless of the DCW's familial status. Habilitation services are designed to have goals where data is collected to evaluate if those goals need to be changed, have been met, or need to be addressed differently. For a goal to be considered met, a member should be demonstrating that they are able to successfully meet that goal outside of the timeframe with a provider in one setting. This is referred to as generalization. The effective implementation of generalization with the pediatric IDD population would lessen, if not eliminate, any complications with adult transitional services. Under this model a program that includes parents as paid Habilitation providers would actually assist and improve in the success of adult transition. There are times when disabled children work successfully with different types of providers in clinics or schools, but the parents are not carrying the work over at home. This can happen for a variety of reasons. Having parents as

Habilitation providers would help ensure the child's goals are congruent and carried over in the home and community setting. This will give the member a better chance of independence as they transition through different life stages. With generalization policies in place, Habilitation services being performed by parent providers will actually help facilitate successful transition into adulthood.

We know from provider agency data that "the top 3 issues regarding recruiting and retaining career non-family caregivers are schedules of the client members, interest in the position and finding qualified applicants." Most members have Habilitation goals and ADLs that are most appropriately delivered throughout the natural routine of their day. A parent provider is uniquely available in the morning, after school or in the evenings when each member is motivated and focused on the pertinent task. If a non-family provider is available their schedules typically allow them to work in longer time chunks that are not always the most ideal for the member and creates artificial goal or ADL practice. Continuity of care and greater member outcomes can be associated with consistently provided Habilitation care by parent providers who have the greatest ability to be flexible and available for their member children.

Should parent providers be limited to 40 hours a week of paid care per child?

We have heard the concerns of AHCCCS regarding the potential for a difficult adult transition to non-family supports once parent caregivers are no longer able or willing to help facilitate the disabled member's care. The parent caregiver community would like to propose the following collaborative solution to create a win-win scenario:

- Create a program provision that outlines an extraordinary circumstances clause and the application process that allows parents to provide over 40 hours of paid care per week of authorized and evaluated services per member. These extraordinary circumstances could include, but are not limited to:
    - The lack of a non-parent DCW being available in the last 3 months to fill the member's assessed hours that exceed 40 hours per week. Ongoing DCW searches should continue to be made by the member's agency to fill the assessed hours beyond 40 hours per week of Attendant Care and Habilitation.
    - The expressed desire made by a member for a parent caregiver to facilitate their assessed DCW hours so that their Article 9 rights are honored.
    - The profound disabilities and/or significant behaviors of a member where a non-family provider is not equipped to provide DCW support. This determination can be made through a stakeholder team approach, including but not limited to the member's, DDD Support Coordinator, DDD Nurse, DDD Supervisors, Behavioral Plan Experts, Parents / Guardians, Psychologist, or Medical Doctor.
- Form equality between all Family Provider Programs by allowing all Direct Care Workers, regardless of familial relationship or member age, to provide up to 16 hours of paid care per day. This will allow for employee equality across the lifespan of the member and limit the potential anti-family provider rhetoric currently present within state policies and DDD Support Coordination culture. All evaluations of hours should be based on member needs regardless of who is providing the services to create uniform implementation of all applicable HCBS services by the DCWs available to fulfill those hours.
- The Family Support Program currently in this proposal addresses caregiver burnout. It is one of the available solutions to facilitate further community support within the disability and caregiver community that will provide greater access to non-profits facilitating counseling services, support groups and meet up activities.
- Reevaluate Respite reimbursement rates to also address caregiver burnout. If Respite services are not available to the member or their family, parent burnout will continue to be an issue regardless of parents having the option of providing Attendant Care or Habilitation hours. With a comprehensive Paid Parent Caregiver Program in place non-family DCW providers will have greater flexibility to provide Respite services to these same families.

How should current evaluation protocols, training and practices be updated to facilitate equality for all members when accessing member needs?

AHCCCS has stated their intention to amend applicable policy, further suggested action on this topic includes:

- Forming a committee of community and department stakeholders to amend and critique current DDD and AHCCCS policies and need assessment forms so that the most effective and efficient implementation of this permanent option is utilized moving forward.
- Provide appropriately determined training and program implementation to DDD and ALTCS Support Coordinators so that Attendant Care and Habilitation hours are equitably evaluated based on the member's needs and to remove organizational bias of familial providers across the member's lifespan. Specifically investigate and determine appropriate DDD staffing needs and training for the members served in rural areas and those from minority backgrounds.

Create the option for private sector Support Coordination. Other states have this option within their Medicaid services, and this could be an additional feature in our DDD portfolio to allow for the member's needs to be best evaluated.

In conclusion, Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. By not allowing parents of minors to provide Habilitation and Attendant Care services or work over 40 hours a week most of the minor disabled community in Arizona will be underserved. A comprehensive Paid Parent Caregiver program validates the irreplaceable work that parents provide in their homes and communities.

Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves all DDD and ALTCS members in Arizona.

Thank you!

Kind Regards, Mike Reuwer

From: Elizabeth Sanchez [redacted]
Date: Wednesday, August 2, 2023 at 1:15:42 PM UTC-4
Subject: HAH decision. Please hear my story.
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello, my name is Elizabeth Sanchez and I am a mom of 2 children on the spectrum, 3 total. I am writing today in response to the possible end of parent provider act.

My son [redacted] was diagnosed at the age of 2. WE advocated to get him the services he needs to thrive, and over the years we have finally found some consistency in his care. After ABA, we started looking into Hab and Respite Care for [redacted] while at home. Over the span of 2 years, we tried many times to get providers to our home that would fit our schedule. Even the rare times we were able to have someone assigned, their lack of consistency of showing up heavily affected [redacted]. He thrives from certain people and schedules in his life, and every time we tried a new Hab or Respite provider, and them all of a sudden be gone, it would cause major regressions.

And then of course when the pandemic hit and services weren't provided in home, we didn't have any options. When we learned about the Parent Provider Act and was approved, it was a game changer for my son. I have been able to work with him every day on life skills and social skills that we couldn't before. Since starting, he has surpassed several goals because of the consistency of our work together.

I am asking that this act be continued. Please don't stop us from being able to continue progress in his skills and goals. He needs this program. And I can imagine that if I have had this much success that there are many other families out there that could finally have some consistent therapy.

Thank you,

Elizabeth Sanchez

From: Taylor Foley [redacted]
Date: Wednesday, August 2, 2023 at 1:13:52 PM UTC-4
Subject: Parent Provider Program- Arizona needs this program!
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

I want to share my concerns as a parent of a severely disabled Autistc child. My child has a unique profile of autism called Pathological Demand Avoidance (PDA). In short, PDA is a nervous system disability in which the person has a low threshold of tolerance and is constantly in a state of fight/flight. Their system is in constant survival mode and overdrive to keep them safe. Whether or not there is actually a threat, their nervous system responds as if a bear was charging at them. Neurologically, PDA brains are constantly in their limbic system.

In order to function, PDA brains need 24/7, constant, undivided attention and co-regulation to feel safe and to access other areas of the brain besides the limbic system.

I am a licensed speech language pathologist (SLP) who previously loved working with children. However, my son's needs are so extreme that I had to leave my job in order to care for my son. We are grateful for the respite and habilitation hours through AHCCCS. Repite hours are helpful but my son's needs extend beyond what a respite worker is able to provide. PDA kids will often only accept help from one person, usualy the mother.

For this reason, I have become a parent provider. My son will not respond to an outsider provider for habilitation needs, as requests/demands trigger his nervous system to fight/flight. We currently receive 14 hours of habilitation, however, my son requires full time care that well exceeds 40 hours a week.

I am writing to advocate to continue the parent provider program. It has saved our family to be able to make my full time time caring for my son, as I had to quit my career job. Further, there is an enormous shortage of respite/habilitation workers. Cutting this program would be devastating to families with disabled children.

Please vote to keep this program in place to help families with disabled children.

Thank you,

TaylorFoley
FormerSLP
Current Parent Provider for my son

From: Audra Frazier [redacted]
Date: Wednesday, August 2, 2023 at 12:53:24 PM UTC-4
Subject: KEEP HAB HOURS FOR PARENTS!
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

I am fighting to keep HAB HOURS FOR PARENTS. As a mother to a son with special needs, I have been working with him and his goals more than anyone that can be provided for me. I have tried 2 agencies that haven't been able to provide ANYONE for RESPITE OR HAB for my son. There is no one to complete the job, except ME at times. I know it is my duty as a mother to help my son, but there are no workers to provide help with HAB goals, therefore I should be able to clock in for that time.

Thank you for listening and considering keeping HAB hours for PARENTS!

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Thank you,

Audra Frazier

From: CANDACE TIERNEY [redacted]
Date: Wednesday, August 2, 2023 at 12:17:43 PM UTC-4
Subject: Plea for a person-centered consideration - Please do not limit care options
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

My two ASD children need frequent verbal prompts in an effort to complete age-appropriate tasks and they need supervision for their potty and hygiene challenges as well as unsafe and elopement behaviors.

Finding a competent, compassionate, and local provider with the desire and availability to work in 10-15 minute increments to aid with these challenges has thus far been an impossible task.

Because there are not any available providers in or willing to travel to my area (85085), I have opted to become a parent provider. I have completed all available and required trainings to be as effective as possible. I use the payments received as a parent provider to have a teen babysitter provide care for my other children while I focus all of my attention to help provide guidance on the areas of need in the area of habilitation for my minor member. This opportunity has been a blessing because prior to this, the habilitation teaching I was doing as a 'natural support' wasn't as consistent nor helpful to my minor member (as my attention was divided and opportunities were less frequent). Being a parent provider for habilitation is a positive tool for members and their families. Two of my children (6 years old) struggle with wiping independently, bathing, & several hygienic needs that leave their bodies unclothed and exposed during times of support. This is another huge positive that the parent provider program assist with (comfort and safety of members).

My questions to those in authority…

How will the proposed elimination of parents providers doing habilitation benefit members that do not have an alternative provider?

How will the limitation of 40 hours of care to parent providers benefit members that do not have an alternative provider to assist with any hours in excess if 40?

Candace

From: Autism Awareness [redacted]
Date: Wednesday, August 2, 2023 at 12:01:11 PM UTC-4
Subject: Stopping Parents from Providing Hab Hours
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

As parents with two children with disabilities, We are writing you to voice our sincere concern in regard to the upcoming decision on limiting and/completely stopping parents from providing Hab ours for their children. This will be an absolute devastation to us parents with children with special needs. We rely on the ability to provide this service to our children and make some money doing so. When you have children with special needs getting a 9-5 job is next to impossible unless you are very wealthy. We ask that please Do Not take away our ability to provide for our children and be able to get some money to feed them while doing so. Thank you for your time, we hope you will be thinking if the thousands of families who need this to be their for their kids with special needs and still survive.

Best,
Larry G

Sent from my iPhone, please excuse any misspelled words or improper punctuation. Thank you.

From: R ** [redacted]
Date: Wednesday, August 2, 2023 at 11:55:01 AM UTC-4
Subject: regarding changes to Parent Provider Program
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello,
I am a Parent Provider reaching out regarding the recent proposed changes to the Ahcccs Parent Provider Programs. I am also a Direct Care Provider for other disabled individuals through two separate agencies.
Being a parent provider providing Habilitation to my Asd adult son was the best experience we ever had with providers. Before I stepped in to take on the role, we constantly lost providers and he was even put in unsafe situations with providers twice. He never met any habilitation goals because they never worked on them much. They mostly took him out, later I would find to their house or to run their errands. Because of this he began to avoid providers and refuse to work with them. We lost many providers due to his behaviors and also his psychiatric symptoms as he also has PANDAS, which causes extreme behaviors.With me we worked on all goals consistantly and we created new ones like using coping skills in public. I took the time to break down tasks and use his favorite things as motivators. He has been consistantly meeting his goals, can do his online classwork mostly on his own and can go many public places without a meltdown. I gained so much experience with him that I was able to start working with other clients after I was laid off of my job. I have even begun training in ABA to better help my son and others. My experience working with my son has made dealing with my clients behaviors so easy. My son and I have a strong trust between us and he feels safe working with me instead of a stranger. The extra income also pays for his medical expenses as his autoimmune specialist does not take insurance. He is on many supplements to treat chronic infections and autoimmunity , totaling hundreds of dollars as month. It is because of this treatment we have been able to keep him out of a group home setting. Without treatment his behaviors become too extreme for us to manage. In addition I suffer from a serious autoimmune condition and have many medications I must take that have a high cost. I dont know how we will manage with the loss in income, and I cannot work two jobs outside the home and still care for my son, get him ready for more providers and take care of my other children. He is not eligible for attendant care. Many of usnparent providers will be stuck in this situation if you eliminate habilitation and reduce attendant care hours.
Eliminating parent providers wont solve the problems in this industry which includes unsteady hours, low pay, lack of training and no benefits. As a provider I still see this going on. Theres no sick pay so we cannot take days off without suffering financially. One of the agencies I work with only pays job coaches 15 to 16 hourly and as a result cannot find job coaches, so cannot put its members to work successfully. I would recommend fixing these problems instead, as doing so would attract more workers.

I truly appreciate the parent provider program and want to thank you for having this wonderful program. Please keep it the way it is to help us special needs families have consistancy and safety for our children.

Sincerely,
Rebecca Laurin Lungu

From: Brenda Sharkey [redacted]
Date: Wednesday, August 2, 2023 at 11:41:45 AM UTC-4
Subject: Re: DDD Grienvance
To: Waiver Public Input - AHCCCS <waiverpublicinput@azahcccs.gov>,
[redacted]

Hi,

I'm a parent of a child who receives DDD and ALTCS services. I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which would go into place in November 2023, my child and many more like them will lose access to their Habilitation services by parent providers of minor members. The reason my child will not have access to their appropriately evaluated services is due to the DCW shortage. In the 5+ years of having these services, there has ALWAYS been a shortage of workers & it has gotten worse since COVID.

I'd like someone to respond to me with a ticket number regarding my concerns. I want to know what the plan is to get a sufficient amount of workers to provide HAB services if parents of minors are no longer allowed to.

-Cindie Wisener
[redacted]

From: Ivie Manalo [redacted]
Date: Wednesday, August 2, 2023 at 11:34:17 AM UTC-4
Subject: Parent Providers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

I am reaching out as a parent of a child with disabilities who utilizes DDD and ALTCS programs in Arizona. Over the last 3 years we have participated in a Public Health Emergency Flexibility which has allowed parents of minors with disabilities to be Paid Parent Caregivers. This program has assisted our child with disabilities and our family with continuity of care, stable employment for labor performed, reduction in caregiver burnout and improved quality of life for my disabled child and many more like them. Prior to 2020 parents of adults with disabilities could provide these services but parents of minors were unable.
Because of the Direct Care Worker shortage, the option for our disabled children to receive support from non-family providers is less accessible than ever before. AHCCCS has seen this concern and created a proposal for a permanent Paid Parent Caregiver Program through our Arizona 1115 Waiver. This proposal is currently under the public feedback period and their intention is to submit this Waiver Amendment to CMS for approval sometime in August 2023. While this proposal is a massive step in the right direction and the Arizona disability and caregiver community is extremely grateful for their proactive initiative, this proposal roughly cuts member access to those participating in the current flexibility in half. This reduction of access to these services would take place in November 2023, if this proposal is approved by CMS prior to that date. The proposal, as is currently written, excludes parents of minor members from being paid Habilitation providers or facilitate more than 40 Hours a week of Attendant Care services.

For your information all hours that parents of disabled minors currently provide are evaluated based on need based member assessments for our children who qualify for extraordinary and institutional level care. Parents are also required to be hired and trained as Direct Care Worker employees supervised by a provider agency. Parent providers have the same regulations and requirements as other non-family direct care workers.

A parent caregiver grassroots initiative has formed which is supported by many other disability stakeholders and organizations. They are asking for this permanent waiver to include a few adjustments and compromises so that this program can be available to all DDD and ALTCS members moving forward.

We are requesting your action and support as we work to negotiate and evaluate the best version of this permanent option with AHCCCS. We would appreciate your outreach to AHCCCS and the Governor to inquire about the current proposal and ask why the requests of the parent caregiver community have not been included thus far. Our desire is to have continuity of care for our disabled children with the best possible health outcomes throughout their lives as we find balance in utilizing this permanent program option. Included below are some additional resources for your reference.

If you have any further questions feel free to contact me directly or our grassroots leaders at www.raisingvoicescoalition.com

Our “Ask”
Our Proposal Adjustment Requests
CMS Perspective on Paid Family Caregivers
Correspondence with CMS Regarding our Requested Proposal Adjustments
June 2023 Press Packet and Parent Stories
AHCCCS Proposal

Thank you for your time and the work you do serving the citizens of our state!

--

Iviensan (Ivie) Manalo, MD, FAAD, FACMS
[redacted]

From: Austin Osiecki [redacted]
Date: Wednesday, August 2, 2023 at 5:00:10 AM UTC-4
Subject: Paid Parent Caregiver program comments
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

As a parent of a child who receives DDD and ALTCS services I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility, and it has been extremely beneficial to our family and my child. I would like to share my personal experiences and feedback based on my review of the current proposal for a permanent Paid Parent Caregiver program.

My daughter was born March 2019 with Down syndrome and an atrioventricular heart canal defect. We had the tough job of keeping our precious girl healthy until it was time for open heart surgery. Because she continued to grow, her surgery was pushed out to May of 2020 and with COVID, 95% of our therapies through AZEIP had been via Zoom. She was offered respite but due to her health, we were not willing to have someone else we were not familiar with, in our home. We reached out to our family for respite help, but no one wanted to in fear of getting her sick. Friends all have their own families to care for and were also afraid of getting her sick.

We now know my daughter has Down syndrome, repaired heart defects (AVSD, VSD, ASD), repaired hernias, hypotonia (decreased muscle tone), decreased mobility so she requires and ambulatory device when out in public as well as SMOs (braces for her ankles), PICA (eating things that are not food), sensory processing disorder (will only tolerate specific purees, textures, movements), and we are evaluating for Autism. When she was screened for preschool, she put anything she could in her mouth and ended up very sick 2 days later. She needs constant supervision for choking hazards in addition to the many other hazards she is unaware of, but not limited to just illness.

We have thankfully found someone that is willing to provide respite for us. Our catch is that we need to save up to be able to pay for her required training and certifications. She will only be working for us and due to the travel time for her, this is the right thing to provide us service. So, for the first time in 4 1/2 years, there is finally a glimmer of someone trustworthy in our eyes to care for our daughter. Now, trying to find someone that we trust to do HAB care, I don't even know where to begin. The hours are sporadic, some of our goals are intimate (bathing, changing, diapering) and I am not willing to subject my non-verbal daughter to a stranger for that kind of care. Also, requesting someone to come into our home during those intimate hours that my family is connecting over meals and night-time routines, is just unsettling.

My daughter was approved for ALTCS and DDD shortly after her heart surgery in 2020. When she turned 3, and we transitioned, we were not given any verbal information from our service coordinator regarding habilitation or attendant care. I had finally learned about it in one of the Facebook groups I was a part of. When I requested the evaluation from my service coordinator, she refused and claimed that all care I was providing to my daughter at that time was natural supports. I was upset because looking at my friends with typical kids, my daughter's age, they were doing so much more than her, feeding themselves, pulling up their pants, putting an object on the shelf, drinking from a straw and didn't need the bottle, and many others. The next meeting, October 2022, I finally wrote out to her exactly what I wanted so she finally agreed to the evaluation, and received 12 hours of HAB. She manipulated most of our goals to be and "end goal" rather than a step to get to that goal so when reporting, our progress looks minimal at best. If you know kids with disabilities, you know that we consider inch-stones to be a pretty big deal and they should all be celebrated and worked towards, not just the big mile-stones.

November 2022, I was laid off, so I decided to do the habilitation hours myself. Once we started, I realized how many other goals we should be working on for an almost 4-year-old so she finally granted a few more goals. When I mentioned ATC, she advised that it was only approved to parents with disabilities that prevent them from caring for their child. At this point, I was grateful for what she evaluated and approved so I left it at that despite what others were approved for. Our meeting in May 2023, I mentioned adding a few more goals as my daughter was now 4 and things are starting to click. She refused, stating that the goals I suggested were fantastic and well in line for goals of a child at her development level but she wasn't going to award her with the hours because she isn't showing significant progress in current goals. Excuse me, but this is why I requested the goals to be broken down rather than just showing the end goal. After shedding a few tears and telling her that I was going to appeal her decision, she ultimately allowed a few more hours. We are currently at 27 hours, which I am very thankful for, although I know the evaluation process is extremely unfair. Now, to not only find someone to help us with these hours, that are mostly nighttime, but we are located in the very far southeast valley where quality care is hard to find. Our last meeting, July 2023, we spoke of these new proposed changes. She admitted to me that she did not agree with the parent program and that most parents are in it for the financial gain. She thinks most parents are fraudsters. I replied back to look around her and that we clearly are not living the lavish life. We frequently require support from my in-laws to keep our vehicles running and power on. At the end of the meeting, she advised that if the program goes away, she will consider an ATC evaluation. I'm truly not sure what to think. The amount of inconsistencies being told. And these examples I've given are from one person.

In regards to my daughter's recent progress, we dropped feeding therapy because it was turning into something traumatic for her. We have been in and out of feeding therapy since she was born. She has NEVER advanced with a professional's guidance, from birth to now. We stopped feeding therapy in April 2023, and she is now bringing the spoon to her mouth with a plate on her tray and drinking out of a straw. 6 months ago, she was having sensory issues with different spoons and would shake violently if she didn't like it, she wouldn't even touch the spoon with one finger, all food had to be out of the plastic container they came in, and she would only drink milk from a bottle. She would not have made any of these advancement with another individual, professional or not. This is due to consistency and trust and this is what most of our goals are based upon. Since I am able to provide her care and not seek full-time outside employment, we are able to get out of the house to take advantage of hippotherapy (horse therapy, I highly suggest you check out Manes & Miracles - fantastic organization), aquatic therapy, swimming lessons, music therapy, homeschooling meet-up groups, frequent zoo and museum trips, and walks to the park. If we lost this, most of these extra activities will not work for our family.

Please consider our requests and know how positive this program has been for our children and the enrichment of their futures.

Under the current proposal, the request of an ongoing program option which allows parents of disabled minors in Arizona to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies is not being met. Please consider updating the proposal based on the following questions, suggested solutions, and personal experiences.

Should Habilitation be included in the Paid Parent Caregiver Program?
We have heard the concerns about member isolation and lack of community involvement if parents continue as Paid Parent Caregivers facilitating their child's Habilitation services. Respectfully the parent caregiver community proposes the following solutions:

> Examine available research and personal feedback statements from members and their families to evaluate the true potential impacts of social isolation and community involvement when parents of disabled children provide Habilitation services. The parent caregiver community's collective experience is that members who have parents facilitating their Attendant Care and Habilitation services have experienced greater member social engagement and community involvement over the last three years. Parent caregivers now have an increased ability to take their children to sporting team practices, community events, movie theaters, all ability parks, church activities and libraries. This is because parent providers can perform the appropriately trained and qualified supports in the correct time and location that is applicable to each member.
>
> Implement precise guidelines to facilitate generalization for all Habilitation providers regardless of the DCW's familial status. Habilitation services are designed to have goals where data is collected to evaluate if those goals need to be changed, have been met, or need to be addressed differently. For a goal to be considered met, a member should be demonstrating that they are able to successfully meet that goal outside of the timeframe with a provider in one setting. This is referred to as generalization. The effective implementation of generalization with the pediatric IDD population would lessen, if not eliminate, any complications with adult transitional services. Under this model a program that includes parents as paid Habilitation providers would actually assist and improve in the success of adult transition. There are times when disabled children work successfully with different types of providers in clinics or schools, but the parents are not carrying the work over at home. This can happen for a variety of reasons. Having parents as Habilitation providers would help ensure the child's goals are congruent and carried over in the home and community setting. This will give the member a better chance of independence as they transition through different life stages. With generalization policies in place, Habilitation services being performed by parent providers will actually help facilitate successful transition into adulthood.
>
> We know from provider agency data that "the top 3 issues regarding recruiting and retaining career non-family caregivers are schedules of the client members, interest in the position and finding qualified applicants." Most members have Habilitation goals and ADLs that are most appropriately delivered throughout the natural routine of their day. A parent provider is uniquely available in the morning, after school or in the evenings when each member is motivated and focused on the pertinent task. If a non-family provider is available their schedules typically allow them to work in longer time chunks that are not always the most ideal for the member and creates artificial goal or ADL practice. Continuity of care and greater member outcomes can be associated with consistently provided Habilitation care by parent providers who have the greatest ability to be flexible and available for their member children.

Should parent providers be limited to 40 hours a week of paid care per child?
We have heard the concerns of AHCCCS regarding the potential for a difficult adult transition to non-family supports once parent caregivers are no longer able or willing to help facilitate the disabled member's care. The parent caregiver community would like to propose the following collaborative solution to create a win-win scenario:

> Create a program provision that outlines an extraordinary circumstances clause and the application process that allows parents to provide over 40 hours of paid care per week of authorized and evaluated services per member. These extraordinary circumstances could include, but are not limited to:
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> > The lack of a non-parent DCW being available in the last 3 months to fill the member's assessed hours that exceed 40 hours per week. Ongoing DCW searches should continue to be made by the member's agency to fill the assessed hours beyond 40 hours per week of Attendant Care and Habilitation.
> >
> > The expressed desire made by a member for a parent caregiver to facilitate their assessed DCW hours so that their Article 9 rights are honored.
> >
> > The profound disabilities and/or significant behaviors of a member where a non-family provider is not equipped to provide DCW support. This determination can be made through a stakeholder team approach, including but not limited to the member's, DDD Support Coordinator, DDD Nurse, DDD Supervisors, Behavioral Plan Experts, Parents / Guardians, Psychologist, or Medical Doctor.
>
> Form equality between all Family Provider Programs by allowing all Direct Care Workers, regardless of familial relationship or member age, to provide up to 16 hours of paid care per day. This will allow for employee equality across the lifespan of the member and limit the potential anti-family provider rhetoric currently present within state policies and DDD Support Coordination culture. All evaluations of hours should be based on member needs regardless of who is providing the services to create uniform implementation of all applicable HCBS services by the DCWs available to fulfill those hours.
>
> The Family Support Program currently in this proposal addresses caregiver burnout. It is one of the available solutions to facilitate further community support within the disability and caregiver community that will provide greater access to non-profits facilitating counseling services, support groups and meet up activities.
>
> Reevaluate Respite reimbursement rates to also address caregiver burnout. If Respite services are not available to the member or their family, parent burnout will continue to be an issue regardless of parents having the option of providing Attendant Care or Habilitation hours. With a comprehensive Paid Parent Caregiver Program in place non-family DCW providers will have greater flexibility to provide Respite services to these same families.

How should current evaluation protocols, training and practices be updated to facilitate equality for all members when accessing member needs?
AHCCCS has stated their intention to amend applicable policy, further suggested action on this topic includes:

> Forming a committee of community and department stakeholders to amend and critique current DDD and AHCCCS policies and need assessment forms so that the most effective and efficient implementation of this permanent option is utilized moving forward.
>
> Provide appropriately determined training and program implementation to DDD and ALTCS Support Coordinators so that Attendant Care and Habilitation hours are equitably evaluated based on the member's needs and to remove organizational bias of familial providers across the member's lifespan. Specifically investigate and determine appropriate DDD staffing needs and training for the members served in rural areas and those from minority backgrounds.
>
> Create the option for private sector Support Coordination. Other states have this option within their Medicaid services, and this could be an additional feature in our DDD portfolio to allow for the member's needs to be best evaluated.

In conclusion, Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. By not allowing parents of minors to provide Habilitation and Attendant Care services or work over 40 hours a week most of the minor disabled community in Arizona will be underserved. A comprehensive Paid Parent Caregiver program validates the irreplaceable work that parents provide in their homes and communities.

Click here to connect with the Arizona parent led grassroot initiative leaders: www raisingvoicescoalition.com

Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves all DDD and ALTCS members in Arizona.

Thank you!

CMS perspective on the above noted requested program adjustments and paying Legally Responsible Individuals:

June 28, 2023 - Email Correspondence between CMS and Raising Voices Coalition: https://drive.google.com/file/d/10CPccmIY7gEr5vq9C6vIaKmncSQOV7kc/view?usp=share_link

May 23, 2023 - Transcription of National Meeting between CMS Leaders and Parent Advocates:
https://docs.google.com/document/d/1h02v6Yk7frWGADcqKgm1zmd0uquMNfW3Jcd0zjHCxOk/mobilebasic?

fbclid=IwAR2QLqbwJMQQRz0nj-XqhYzlFlkQbUV5wnyAyv98hivRVYpCjaYHhLBCzYg

Studies and data that support the changes being requested:

Data results from a 2023 Arizona survey of parents who have children with disabilities:
https://docs.google.com/document/d/16PZOk99caDUitg0XmQKqEv2mxXOBeaRywSD_zmjAnYw/edit?

usp=sharing

A report on the current caregiver crisis by the National Association of Homecare and Hospice: https://www.hcaoa.org/uploads/1/3/3/0/133041104/workforce_report_and_call_to_action_final_03272023.pdf

Higher satisfaction of paid supports for adults and minors with disabilities when care is received from paid family providers:
https://www ncbi nlm.nih.gov/pmc/articles/PMC1089106/

A comparison of healthcare utilization when children receive paid care by a family member vs non-family provider:
.https://www.jpeds.com/article/S0022-3476(23)00106-3/fulltext

Youth with Autism Spectrum Disorder have less ED visits and patient outcomes when patient providers are involved: https://www reliasmedia.com/articles/148366-autism-spectrum-disorder-in-the-emergency-department
https://www.psychiatrist.com/jcp/mental/child/youth-with-autism-in-the-emergency-department/

An evaluation of parent provider involvement in generalization of children with autism: https://www.sciencedirect.com/.../abs/pii/S0891422205000958

Impacts of the caregiving relationship: https://academic.oup.com/gerontologist/article/56/6/1102/2952858

State Approaches to Reimbursing Family Caregivers of Children and Youth with Special Health Care Needs through Medicaid - NASHP
https://drive.google.com/file/d/1TSt-Rj95DTn711EV8UTq7YqF0yoo0j8u/view?usp=sharing

Thank you for your time and considerations,

Austin Osiecki

From: Allison Katz [redacted]
Date: Wednesday, August 2, 2023 at 1:18:50 AM UTC-4
Subject: Public Comment Parent Provider Program
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

As a parent of a child who receives DDD and ALTECS services I have participated in the Paid Parent Caregiver program under the Covid-19 flexibility, and it has been extremely beneficial to our family and my child. I have a Masters degree in Social Work and have worked in the field for nearly 15 years. I worked for the same agency for almost 10 of those years and I thrived in my job. I was given excellent performance reviews, created and chaired committees, and even won Employee of the Quarter. I thrived at work throughout many of life's milestones, including becoming a mom and beginning to raise my children. However, that upward trajectory took a severe dive when my son started to miss milestones and finally was given a Level 3 Autism diagnosis. I was no longer able to take on extra projects, be relied upon to take on leadership roles, or able to consistently be available due to my son's schedule of multiple therapies and various appointments. When I was laid off in October 2023 I was told my counterpart at another office would be taking over my duties as her schedule allowed it. What was not said but implied was despite my years of dedication my schedule, due to my child's needs, was the reason I was not chosen to stay. As a parent of a child with special needs, it is nearly impossible to find a job, let alone have a career, that will allow for the constant unpredictability of caring for a child with special needs. I know this because I tried for months to find something that would allow me to do both. I do not have the luxury of simply staying home to care for my high needs child but I also do not have the option of taking on a normal job. I was not told of the Paid Parent Caregiving Program until January 2023, despite being enrolled in DDD and ALTECS since 2021, but when I did I was overcome with gratitude. I finally felt supported and heard, that a program was available that could actually help me and my family. A program that would give my family the support to allow me to have the time and energy to help my child.

However, I was soon told that despite the program originally being projected to end in September 2024, the Habilitation portion had now been moved up to end in November 2023. I was devastated when I was told this. I had to advocate for months to receive adequate hours for my nonverbal child from DDD. I was finally in a place where I emotionally felt comfortable because I had finally found a program where I, as a parent, felt supported. A program that understood what support parents actually needed but it was being taken away and, like everything else, I now have to fight for the support our family needs for my child's needs. Even though there are parents begging for this program to stay, as well as being overwhelmingly supported by the parents, the justification to end this program is fear of parental isolation. This program has been a gift and does not cause parental isolation, the lack of support and understanding is what isolates parents. Not having programs that actually help parents is what isolates us.

Prior to 2020 the Habilitation and Attendant Care programs had many issues of unprofessionalism, inconsistent care takers, and under trained providers. The lack of available providers caused stress and anxiety to parents who were left scrambling to search, on their own, for appropriate providers. As far as has been communicated, there has been little move to fix these issues that riddled the program for years prior. What this tells me is that this move to strip the program of parent providers is not rooted in concerns for parental isolation or the best interests of the child and instead in something else entirely.

I implore you to not leave families scrambling by getting rid of this program prematurely in November 2023, when it was communicated multiple times it would go until September 2024. I further implore you to use this time to instead consider ways of making this extremely favored program permanent. Parents have overwhelmingly informed you that they want this program to stay. By adding additional requirements for agencies to support parents' development and requiring more training to be a provider you could not only solve the isolation issue by boosting agencies to provide a safe supportive community to parents, but equip parents with the tools to effectively support their children with a disability.

Thank you,
Allison Katz

From: Lisa BROTHERS [redacted]
Date: Tuesday, August 1, 2023 at 9:41:42 PM UTC-4
Subject: Habilitation for minors
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To Whom it may concern,

I am writing in response to the pending decision for paid parent/guardian HAH for minors.

My daughter is a recipient of this service and has been since her left hemispherotomy leaving her with significant deficits requiring one on one care. This service has provided her with great results in addition to her weekly therapies. This service enables the member to work on selected goals in conjunction with therapies and to maximize the potential for progress. This service has been a huge positive in my daughters progression and as she has regained some functions this has provided her with a sense of gaining back some of her control and confidence. This service provides members the added services needed to regain self importance and the feeling of community contribution.
My daughter has required over 40 hour per week of HAH. The importance and consideration of having family members providing these services is the level of comfort, trust and reliability to these members. My daughter was nonverbal and any other caregiver other than myself would not have been able to understand, notice and have adequate response to her needs as we do because we know her. This service should remain in place for these members, they should have a choice in who cares for them.
Thank you,
Lisa Brothers
Sent from my iPhone

From: Karen Szilagyi [redacted]
Date: Tuesday, August 1, 2023 at 9:23:58 PM UTC-4
Subject: Habilitation Services
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To Whom It May Concern:

I am writing to talk about Habilitation services and how crucial these services are for my son who has Down syndrome. One of the most important goals and the end result of most everything we do is to have him become independent, safe and thriving in a community and in particular a community with typical individuals. Until the last few years, we have only been able to use 10% (at most) of his habilitation hours. It is almost impossible to find someone capable of working with my son, responsible and willing to work very few hours for very little pay.

His current hab goals include street safety, public restroom manners, and self-regulation. The disability community needs to keep the habilitation hours they have and if there is a family member living with them that can do the work, this needs to remain in place if we have any hope of continuing to work on goals that will last them a lifetime. The changes in November will not work and I am asking that an extension be granted to allow paid parent providers of minors to continue.

The community, city, state, and world will benefit from having our children grow up as contributing members of society. It starts when they are young and the long-term benefits of meeting goals will help our children later in life when we are not here to guide them. I hope everyone's comments and feedback are listened to. It will be a detrimental situation for many families if these services end.

Karen Szilagyi

[redacted]

From: Hillary Ceja [redacted]
Date: Tuesday, August 1, 2023 at 8:59:06 PM UTC-4
Subject: Parent Provider Program
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

My 15 year old son has severe autism, adhd and a cognitive impairment. This causes him to need 24/7 supervision. He has been a client of ALTCS/DDD since he was 3 years old. During the first 8 years of his enrollment with ALTCS/DDD it was very difficult to find and maintain providers. Every agency I contacted stated that providers were scarce and when we did find one they were overwhelmed with my son's needs and thus had a high turnover rate. This caused him to go without service for the vast majority of his enrollment as a client. This caused me to have issues with punctuality and consistency while trying to work. Since the parent provider program began during covid has been the only time he's been able to have a consistent provider in me and I have had a consistent income to provide for him.
There are hundreds of other special needs families in this same situation. Ending or reducing the parent provider program will have devastating effects on these families. Other states are able to maintain parent provider programs long before the pandemic that are funded in the same way as Arizona's. There is no reason Arizona needs to turn its back on its most vulnerable residents.

Sent from my iPhone

From: Ashley [redacted]
Date: Tuesday, August 1, 2023 at 8:49:17 PM UTC-4
Subject: program
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello, my name is Ashley and I am a mother/caregiver to my son Aiden and wanted to explain a little on how this program has benefited Aiden.

Aiden is a 5-year-old nonverbal autistic child with a lot of sensory issues and challenges ahead of him. you see Aiden is the type of child that absolutely needs a schedule for his day-to-day tasks, so he doesn't get overwhelmed, he also does not like change. He's very antisocial and is scared of most people, He also lives in a very small and rural area in Morenci Az. If you have never heard of this town, you could look it up and quickly see its small and no specialist or anything that helps autistic children are anywhere close to this town.
When Aiden got into this program not only did it help keep him comfortable with his over-stims but it also helped him thrive in so many other ways possible. Even though he is Non verbal he has two speech therapists that have helped him start signing some words. Because it's so hard to get any help from anyone for him and the fact that it takes him a Very long time to be semi okay with a new person, not everyone or company is willing to take on Aidens needs like this program has. Because of the 40-hour weekly program Aidens needs can be met and the potty training is still possible for him. I don't think November is enough time for this change and ask that you consider extending the program to allow paid parents to minors continue.

Thank you for your time.

Ashley

From: Jackie Taylor [redacted]
Date: Tuesday, August 1, 2023 at 8:47:10 PM UTC-4
Subject: Habilitation provided by parents comment
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

I am a registered nurse and biological mother of three children with special health care needs. My family has had benefits through the DDD for fourteen years. During most of this time, my children have had both habilitation and attendant care services.

Finding quality providers that continue to show up on a regular basis and provide quality care to my children has been difficult. I have always recruited, interviewed and supported all my own providers through the onboarding process at whichever agency we were working with at the time. Through the years, we have met some great people. They stay for a time or season and before long, move on to a better opportunity. I can not blame them. Working with special needs children is difficult and when they are paid minimum wage, there are many more glamorous jobs out there.

With COVID, providers were few and far between. We lost all our providers when the pandemic started. How do my husband and I both work when we have developmentally disabled children at home? They need constant supervision. My job was in very high demand as an ER nurse. I continued to work and my husband had to stay home to care for the kids. I am sure this is the case for most families.

During this time, we created plans and routines to work consistently on each child's habilitation goals. Before long, we bagan to look at the positives in life and realized that although there was so much devastation going on in the world, we had this opportunity to fully focus on what our kids needed.

Through my husband and I providing the majority of our children's habilitation, we have seen consistent progress. We are no longer having long periods of regression as we did in the past when there were gaps in care providers. Our oldest is an adult and has gained skills that he was unable to obtain with outside providers coming in to provide his care. Community skills have been more accessible because we are comfortable and confident in taking our adult son out to teach him about the world. There are no barriers that we frequently have with outside providers (not enough time to go in the community, no reliable transportation, not showing up for a shift, lack of funds to do activities in community, and more). I understand that there is some concern that these adults will not progress beyond needing their families. The reality is, some of these adults may never get to the point regardless, however, some of them may and if those young adults have the potential to do so, who is going to support them and push them harder than their own parents.

We want nothing more than to see our children and adults be successful and live as independently as possible. The best opportunity for my children to do so is for my husband and I to continue to provide their habilitation services for them with the support of the DDD to help me stay motivated and healthy myself in order to do so.

Please allow me to also explain my position as a Registered Nurse of twenty years and an advocate for special needs families. I have worked with children in the Phoenix area as a nurse in different capacities for eighteen years. As a pediatric nurse, I have worked with several families who benefit from DDD. Over the past three years, many parents that I interact with have had similar experiences to ours when caring for their special needs children. Many of these families have a parent that is staying home to care for their disabled child(ren) although they have a degree and the ability to make far more money in the community. My husband, a former grocery store manager, a good friend who is middle and high school special education teacher, three friends who are also nurses; all of these people are out of the work force and caring for their special needs children because there are not competent, reliable caregivers available in our community to provide for these children. Taking away the parent provider habilitation program will not provide these children with more services. Many children will lose the habilitation that they are consistently being provided. Parents will have an increased stress level, as they are required to still work these HAB goals for their child without pay and finances will be strained as the parent provider will not have less income.

Taking parents out of the equation is not the answer. Let's look at the lives of these individuals! They are special members of our society that deserve the support to be successful! If parents are helping these important individuals, then why change what is working? Because the date says so? It is much more logical to work on pressing issues instead of placing a significant amount of focus on fixing a system that is not broken.

Thank you for your time and consideration!

Jackie Taylor
Mother of [redacted]

From: Stacy Lee Maturo [redacted]
Date: Tuesday, August 1, 2023 at 8:24:57 PM UTC-4
Subject: Habilitation Hours are Important
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To Whom it may concern,

Hi, my name is Stacy Maturo and my daughter [redacted] receives Habilitation hours from myself. This has definitely helped my daughter learn how to control her emotions and behavior. For example, she is learning how to patiently wait her turn for structured activities. This is a very important skill to have all so she can use it in various settings, like school and going to appointments.
I really hope the Habilitation hours don't stop because my daughter has made progress throughout the years.
Giving my daughter what she needs while we are at home helps because she's definitely the most comfortable.
My daughter was diagnosed with Necrotizing Enterocolitis when she was 1 1/2 months old. Her little body swelled up including her belly and ears. Most of her small intestines died off, resulting in Short Gut Syndrome and she has a G tube for feeding. She's working on eating regular food, but the special formula she's on is keeping her alive. I beg you, please don't cut the Habilitation hours. My daughter needs this constant help from myself so that she can be the most independent person she can be. I am grateful she is alive and with hard work and persistence I know she will do great things.

Sincerely,
Stacy Maturo
[redacted]

From: Ali Wyant [redacted]
Date: Tuesday, August 1, 2023 at 7:49:57 PM UTC-4
Subject: Paid Parent Providers for Habilition
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To Whom it May Concern,

I am asking that you extend the current set up of parents as paid providers for their children regarding habilitation. This program has benefited my child personally as we are able to spend focused time each week on important life skills that will further benefit her later in life. If this program were to be canceled, we would be forced to try to find outside help, and that is almost impossible to provide good, consistent outside help to help with my child.

Please reconsider this change and keep it. Making this change as soon as November is way too soon for us as families to be able to find something or someone else to help. This would be a disservice to our community and our children. Please keep this program in place.

--
Ali Wyant

From: Angela Garcia [redacted]
Date: Tuesday, August 1, 2023 at 7:15:12 PM UTC-4
Subject:
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

I would like to voice my concerns in taking HAB from parents. Since covid the benefits of being able to actually work with my son has been a positive impact on my son . He has made so much progress in his goals. My son is autistic he does not like change. I would hate for him to regress. Please also consider the safety of our homes aswell. Thank you for your time..

Angela Garcia [redacted]

[redacted]

From: Therese [redacted]
Date: Tuesday, August 1, 2023 at 7:08:05 PM UTC-4
Subject: Paid Parent Caregiver input
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

As a parent of a child who receives DDD and ALTCS services I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility, and it has been extremely beneficial to our family and my child. I would like to share my personal experiences and feedback based on my review of the current proposal for a permanent Paid Parent Caregiver program.

My daughter, Samantha, is the shining light of every room she walks into. She is loved by all and just happens to have Down syndrome and low vision as well as several other conditions that require regular medical appointments. She is also trying to find gainful employment. You can imagine how busy this keeps us! My husband and I regularly rearrange our work schedules and take time off from work to get her to appointments. She is also not safe alone so is not left in our home without supervision. We do not have regular respite/hab and **have not had adequate coverage for years.**

Under the current proposal, the request of an ongoing program option which allows parents of disabled minors in Arizona to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies is not being met. Please consider updating the proposal based on the following questions, suggested solutions, and personal experiences.

Should Habilitation be included in the Paid Parent Caregiver Program?
We have heard the concerns about member isolation and lack of community involvement if parents continue as Paid Parent Caregivers facilitating their child's Habilitation services. Respectfully the parent caregiver community proposes the following solutions:

1. Examine available research and personal feedback statements from members and their families to evaluate the true potential impacts of social isolation and community involvement when parents of disabled children provide Habilitation services. The parent caregiver community's collective experience is that members who have parents facilitating their Attendant Care and Habilitation services have experienced greater member social engagement and community involvement over the last three years. Parent caregivers now have an increased ability to take their children to sporting team practices, community events, movie theaters, all ability parks, church activities and libraries. This is because parent providers can perform the appropriately trained and qualified supports in the correct time and location that is applicable to each member.

2. Implement precise guidelines to facilitate generalization for all Habilitation providers regardless of the DCW's familial status. Habilitation services are designed to have goals where data is collected to evaluate if those goals need to be changed, have been met, or need to be addressed differently. For a goal to be considered met, a member should be demonstrating that they are able to successfully meet that goal outside of the timeframe with a provider in one setting. This is referred to as generalization. The effective implementation of generalization with the pediatric IDD population would lessen, if not eliminate, any complications with adult transitional services. Under this model a program that includes parents as paid Habilitation providers would actually assist and improve in the success of adult transition. There are times when disabled children work successfully with different types of providers in clinics or schools, but the parents are not carrying the work over at home. This can happen for a variety of reasons. Having parents as Habilitation providers would help ensure the child's goals are congruent and carried over in the home and community setting. This will give the member a better chance of independence as they transition through different life stages. With generalization policies in place, Habilitation services being performed by parent providers will actually help facilitate successful transition into adulthood.

3. We know from provider agency data that “the top 3 issues regarding recruiting and retaining career non-family caregivers are schedules of the client members, interest in the position and finding qualified applicants.” Most members have Habilitation goals and ADLs that are most appropriately delivered throughout the natural routine of their day. A parent provider is uniquely available in the morning, after school or in the evenings when each member is motivated and focused on the pertinent task. If a non-family provider is available their schedules typically allow them to work in longer time chunks that are not always the most ideal for the member and creates artificial goal or ADL practice. Continuity of care and greater member outcomes can be associated with consistently provided Habilitation care by parent providers who have the greatest ability to be flexible and available for their member children.

Should parent providers be limited to 40 hours a week of paid care per child?
We have heard the concerns of AHCCCS regarding the potential for a difficult adult transition to non-family supports once parent caregivers are no longer able or willing to help facilitate the disabled member’s care. The parent caregiver community would like to propose the following collaborative solution to create a win-win scenario:

1. Create a program provision that outlines an extraordinary circumstances clause and the application process that allows parents to provide over 40 hours of paid care per week of authorized and evaluated services per member. These extraordinary circumstances could include, but are not limited to:
    a. The lack of a non-parent DCW being available in the last 3 months to fill the member’s assessed hours that exceed 40 hours per week. Ongoing DCW searches should continue to be made by the member’s agency to fill the assessed hours beyond 40 hours per week of Attendant Care and Habilitation.

    b. The expressed desire made by a member for a parent caregiver to facilitate their assessed DCW hours so that their Article 9 rights are honored.

    c. The profound disabilities and/or significant behaviors of a member where a non-family provider is not equipped to provide DCW support. This determination can be made through a stakeholder team approach, including but not limited to the member’s, DDD Support Coordinator, DDD Nurse, DDD Supervisors, Behavioral Plan Experts, Parents / Guardians, Psychologist, or Medical Doctor.
2. Form equality between all Family Provider Programs by allowing all Direct Care Workers, regardless of familial relationship or member age, to provide up to 16 hours of paid care per day. This will allow for employee equality across the lifespan of the member and limit the potential anti-family provider rhetoric currently present within state policies and DDD Support Coordination culture. All evaluations of hours should be based on member needs regardless of who is providing the services to create uniform implementation of all applicable HCBS services by the DCWs available to fulfill those hours.

3. The Family Support Program currently in this proposal addresses caregiver burnout. It is one of the available solutions to facilitate further community support within the disability and caregiver community that will provide greater access to non-profits facilitating counseling services, support groups and meet up activities.

4. Reevaluate Respite reimbursement rates to also address caregiver burnout. If Respite services are not available to the member or their family, parent burnout will continue to be an issue regardless of parents having the option of providing Attendant Care or Habilitation hours. With a comprehensive Paid Parent Caregiver Program in place non-family DCW providers will have greater flexibility to provide Respite services to these same families.

How should current evaluation protocols, training and practices be updated to facilitate equality for all members when accessing member needs?
AHCCCS has stated their intention to amend applicable policy, further suggested action on this topic includes:

1. Forming a committee of community and department stakeholders to amend and critique current DDD and AHCCCS policies and need assessment forms so that the most effective and efficient implementation of this permanent option is utilized moving forward.

2. Provide appropriately determined training and program implementation to DDD and ALTCS Support Coordinators so that Attendant Care and Habilitation hours are equitably evaluated based on the member's needs and to remove organizational bias of familial providers across the member's lifespan. Specifically investigate and determine appropriate DDD staffing needs and training for the members served in rural areas and those from minority backgrounds.

3. Create the option for private sector Support Coordination. Other states have this option within their Medicaid services, and this could be an additional feature in our DDD portfolio to allow for the member's needs to be best evaluated.

In conclusion, Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. By not allowing parents of minors to provide Habilitation and Attendant Care services or work over 40 hours a week most of the minor disabled community in Arizona will be underserved. A comprehensive Paid Parent Caregiver program validates the irreplaceable work that parents provide in their homes and communities.

Click here to connect with the Arizona parent led grassroot initiative leaders:
www.raisingvoicescoalition.com

Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves all DDD and ALTCS members in Arizona.

Thank you!

Therese Derivan
Samantha's mom

From: Jessica Salcido [redacted]
Date: Tuesday, August 1, 2023 at 7:01:51 PM UTC-4
Subject: DDD ending HAB hours for minors
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To whom it may concern,

I am deciding to write this letter to address my concern for the current on going decision to end HAB hours for parents to take care of minors.

First I want to tell you a little about my daughter Sophia. She is 4 years old and I am the primary parent that stays at home with her. She is currently diagnosed with cerebral palsy, hip dysplasia, epilepsy, dysphasia, and is primarily g tube fed. Right now Sophia currently sees 6 doctors at Phoenix Children's Hospital, as well as an Eye specialist and Pediatrician. She also has 4 therapy sessions she attends weekly at Desert Valley Pediatric Therapy Clinic. She defiantly has a busy schedule with many appointments and therapies to attend. She currently cannot talk and uses an AAC device but is not fluent with it just yet. So for others it's hard for her to express her needs or what's wrong, as a parent I can quickly understand what she needs. Sophia gets nervous around unfamiliar faces since she has had plenty of lengthy hospital stays for illnesses and complications. I know I am not the only parent with children that are just like Sophia.

Secondly I want to talk about how well this HAB program works for Sophia. She is able to work directly with me on all her long term goals and needs daily. Since I take her to her therapy appointments I know exactly what Sophia is working on in the clinic and can incorporate those into our at home routine. She works well again with familiar faces and defiantly took some time to get used to her therapists and actually cooperate at therapy to achieve her goals. I am also aware of how hard it is to find people to work these house with such shortage on employees. Or I have noticed they're schedule changes and we have to end up finding someone else and having Sophia take the time to get adjusted to them, and that sets her back on her goals in therapy. Overall it's just a big cycle and with me being able to be a consistent and familiar face it benefits her very well.

I am also aware that they are cutting back parents hours for minors to a maximum of 40 hours a week. With other children who have similar needs to Sophia's I can sympathize with the frustration this might bring. They constantly need around the clock care even during the night when they have feedings or suctioning that is required like Sophia. All of this cannot be done with a maximum of 40 hours between 1 or 2 parents combined. I strongly believe this decision to cut hours should be revised, since DDD coordinators carefully determine the hours needed for each individual you know that it's hours that are needed and are not getting abused in any way.

I strongly believe an extension should be made as I don't think November is enough runway for this change. It makes parents like myself struggle to be able to find a third party provider to work with my daughter which I know will be a struggle since there is a shortage. An extension is defiantly needed for us parents.

I appreciate you taking the time to read my letter, I know it's long but I felt I needed to strongly address these main concerns. Thank you.
Sincerely, Jessica Salcido

From: Maria Rossie [redacted]
Date: Tuesday, August 1, 2023 at 6:57:48 PM UTC-4
Subject: Waiver
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

I think it is imperative to have parents and family members be able to provide Respite and Habilitation services for their family.

There is still a shortage of qualified and dedicated people for all the clients in need.

Sincerely,

Maria Rossie
Sent from my iPhone

From: Sylvia McBride [redacted]
Date: Tuesday, August 1, 2023 at 4:49:51 PM UTC-4
Subject: Waiver 1115- Parents as Paid Providers comment
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To Whom It May Concern-

Prior to the pandemic, we were blessed to find a habilitation provider for our autistic daughter. Towards the end of 2021, we noticed a decrease in our providers's ability to come regularly due to finding a "higher paying job" & it affected our family greatly since we could not find a new habilitation provider who could remain consistent for our daughter. She regressed in her goals & I began working tirelessly to help her recover. I became certified in March 2022 to become her provider while we continued to search for an outside provider to take over. We would secure a provider, who just weeks later would leave to go to another higher paying job. Our agency offers competitive pay rates & we still had a hard time keeping a habilitation provider for our daughter. I continued to work on her goals around the clock while also stressing to find someone who could be a good fit for our family that could work for more than 2-3 months. Our daughter has gained back a lot of the goals we have for her that she regressed from while we were struggling to find a provider for her. I still continue to work hard to see her growth, and the hardship of still trying to find a habilitation provider who works for us more than a few months is still an ongoing issue.

Our family desperately needs her to have this consistency. I will always continue to work with my daughter, and the financial support we received for our family as a result of the parents paid provider program absolutely made it possible for us to give our daughter experiences and therapy tools we otherwise cannot afford.

Our family is pleading for the parents as paid providers program to continue with Habilitation included in the waiver. Currently the waiver does not cover HAH/Habilitation and we hope this can be reconsidered. Our family is so thankful for the blessing it has been for the last year, especially since we have yet to find someone who can support my daughter the way I have. Please consider making it possible for families all over that currently benefit from this, because I know many others I am in close contact with feel the same and are also struggling to find help. Without being able to provide habilitation for all of our children they will fall through the cracks and parents will continue to struggle.

Thank you for your time, I truly appreciate it and look forward to the public forum.

-Sylvia McBride, current parent HAH provider

From: Karina Quijada [redacted]
Date: Tuesday, August 1, 2023 at 4:29:49 PM UTC-4
Subject: Regarding parent providers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To whom this may concern :

Hello my name is Karina Quijada I have a daughter who was diagnosed with severe Autism , intellectual disability and epilepsy. The reason that I'm writing to you all today is regarding the concern I have of this change that wants to take in effect in November of 2023. There are many reason why I believe this shouldn't end on a personal note I have always experienced rejection because I have a daughter with special needs it has been very difficult to find people who actually have the patience and experience to work with kids like my daughter. As parents we are well aware of the needs of our kids and I personally have educated myself on different subjects so I can help my daughter become as independent as possible I am sure there couldn't be anyone better than me to teach her and guide her so we can get the best possible outcome there could be. I really think this transition would not benefit at all these children who need to be educated in a daily basis the same things either because they forget or because they have very very different social skills communication skills. My daughter Victoria is also non verbal and it is difficult for other people to understand her and I have taught her sign language but not everyone is willing to take that extra step to teach themselves all these things ñ. You have to have a purpose to do this you have to like it and have a heart for it … unfortunately this world is full of cruel people who even mistreat these kids because they know they will not say anything. There are so many things that you also have to protect them from it's scary now a days trying to find someone to help you and seeing that there is no one . I beg that you all reconsider this decision for the sake of these children
Please feel free to contact me if any further information is needed

Thank you

From: ahida de la toba [redacted]
Date: Tuesday, August 1, 2023 at 3:52:14 PM UTC-4
Subject:
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hi my name is Aida de la Toba I am a mother of a teenage boy . he's currently 14 years of age he has autism and speech delay . My son has a hard time understanding and speaking . processing things because of his disabilities. He will be going to high school in 9th grade. he is facing hard and new challenges and will in high school and throughout his coming future .

In covid times my son and I were introduced to Services one of them is attended care/ habilitation this service has come to be a wonders and essential in his daily living.

He he has progress quite a bit since he has the service. He has included habilitation in his routine day at home. When leaving home for school ,with family in the community. My son has been presented with things that he has had to learn. To listen and be patient and work hard. To understand and resolve things that are complicated for him. They have become goals in his life. Over time they have become wonderful the smile the happiness he has had in completing goals that he has worked on every day. And to listen to your son tell you lets goooo! I did it. That leaves a lot to say. If he applies effort and time .He can achieve everything . And can continue working on the goals that remain to be achieved.

It is difficult to find my son. A direct caregiver worker. He is very attached to his mom and dad sisters . If he goes out is with his sisters and Mom and Dad. Or at home he just likes his family to be there.

I think November is not long enough. For my son to reach and complete goals. And goals that he can have later on. please I request an extension to allow the child paid providers to continue to help their son / daughter.

Thank you

From: Denisse Santoyo [redacted]
Date: Tuesday, August 1, 2023 at 3:03:25 PM UTC-4
Subject:
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Buenos dias,me gustaría seguir con el programa que sea permanente para nuestras familias

From: Jess [redacted]
Date: Tuesday, August 1, 2023 at 2:56:14 PM UTC-4
Subject: Making Parents as Paid Caregivers Permanent
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To whom this may concern,

I was given notice that there is a motion to make the ability for parents to be paid caregivers a permanent option in the state of Arizona and that comments and imput of current paid caregivers would be welcome to this email.

I am a parent of two autistic children. One of which receives attendant care and habilitation care through ALTCS and the other is in the application process for receiving benefits through ALTCS. I am a paid parent caregiver. I agree with making permanent the ability for parents to be paid caregivers for their children for both attendant and habilitation hours.

My child does not do well with change and it is in his best interest to have a consistent caregiver to meet his needs. Depending on schedules and life changes of a non-parent caregiver he may go through multiple caregivers if a parent is not allowed as a paid caregiver. Each new person would need an introductory period where they get to know him and vice versa before any productive work can take place. Autistic children do not take change well or easily and each change can possibly bring regression of learned skills that would require additional care to work through. As the parent I have a unique perspective of what approaches will work best in teaching him new life skills that a stranger would need a longer transitional period of getting to know him to learn.

I also have more motivation to keep him safe and respect his boundaries as a parent. Minors with disabilities are more likely to encounter abuse and that abuse unfortunately does happen at times in industries meant to care for their medical needs including caregivers. A quick Google search will show unfortunate cases of this happening as well as the statistics of how a peron with disabilities is 4 to 10 times more likely to be abused. Although statistics very what I have found is that every statistic I've looked at about this shows that a person with disabilities is far more likely to be abused. Here is a site with research on this matter for reference
https://disabilityjustice.org/justice-denied/abuse-and-exploitation/

Due to my child's lessened ability to communicate, he may not be able to relate if any abuse were to occur and instead the abuse would continue and would more than likely manifest in behavioral issues that would then require additional treatment. With me, his parent, as his caregiver I know he is safe and it is when children, especially children with disabilities like autism, feel safe that they can truly grow and make progress.
I hope my thoughts on this matter helped. Please know if you would like to hear from me further. If you need to contact me my phone number is [redacted]. Email works well for me too. Thank you for your time.
Sincerely,
Jessica Hooker

From: Rebekah C. [redacted]
Date: Tuesday, August 1, 2023 at 2:44:46 PM UTC-4
Subject: Why Paying Parents to Provide Habilitation is a Great Solution to the Labor Shortage
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Why Paying Parents to Provide Habilitation is a Great Solution to the Labor Shortage

To whom it may concern,
I am writing to let you know why I support parents being paid Habilitation providers for their own children.

When my son was just a little over two years old, he began receiving Habilitation and Respite services in our home in Tucson, AZ. We were fortunate at the time to have a friend of a friend who was interested in working with us. It was a huge adjustment having a stranger in our home full time, but we believed that it would be to our child's benefit. While there were positives, there was a whole slew of challenges that came with essentially managing a full-time employee in our home. I certainly didn't receive training on how to go about that. Brigitte became an extension of our family and there was certainly a hole left behind when she moved on. How do you explain to a 2 ½ year old with autism and developmental delays that this person who has been such a huge part of his life is suddenly gone? We tried to play it off as normal, but it is anything but normal.

The agency we were working with found another provider, Sunshine, to take her place doing HAB and Respite. She worked very well with my son. She was a mother of a child with special needs as well, and while she probably would have preferred to work with her own son, that was not an option in 2017. Once again, my son grew very attached to her as she became like part of the family. She had health issues that often impacted her ability to consistently fulfill her role though. And eventually left after working with us for a little over a year right as my mother was beginning cancer treatment and I desperately needed Respite. There was another provider, Sydney, who took on some of the HAB and Respite duties while Sunshine was with us. She left after a short time but returned in 2019 when I reached out to her to let her know that Sunshine was too sick to work. We also connected with Mariah through the agency who was a HAB and Respite provider as well. At this time, I was also caring for my mother who had stage 3 pancreatic cancer.

My stress level was very high during this season and apparently it impacted my interactions with Sydney. She became disgruntled and I received a call from the agency addressing matters that would have made more sense for Sydney and I to talk through, but she never brought them up. Mariah left I believe because she took another job. Ultimately, I had to make the difficult decision to pause services for my son because the trying to manage the interpersonal relationships the providers felt overwhelming while I was trying to care for my dying mother. I could not bear bringing yet another stranger into our home and training them on how to work with my son in our home during that very difficult time. Not only was I caring for my mom, but I also have two other children. My boys were 2 ½, 3 ½ and 9. My 9 year-old had just been diagnosed the year before with ADHD. It was A LOT to say the least.

You might think that is the agencies job to train the providers, which they do to some level, but there is a large time commitment on the parent's part making sure that the provider knows how to manage your child's meltdowns, what the household routine's look like and just generally filling them in on many details about your unique child's quirks. It is physically and emotionally taxing. It takes untold hours and when you are tapped out from everything else life is throwing your way it can seem like too much.

When COVID hit there was clearly a time when services were on hold in general. We were afraid to have people coming into our home at one point, but as things began to open up we started Respite again. There wasn't a provider that was available on a regular basis though, so we had a lady who barely spoke English come to our home a few times. It was less than ideal, but we didn't have any other choice. I almost forgot that there were 3 other young ladies who did HAB for a little while during COVID. Lori, Carolyn and other girl who only came a few times.

After waiting months for our agency to find a regular Respite provider I finally asked our DDD Support Coordinator to do a vendor call to see if there was another agency that could fill the role. It took a little time, but we heard back from an agency that we weren't familiar with about a young lady who had never worked with children who have special needs, but she was available for regular shifts. We met Karen and decided to give her a chance. She is nice, but she is not the best fit. My son needs someone who can set firm boundaries with him and that is difficult for her. The agency is less than professional, but as I said, we didn't really have a choice.

In the meantime, my son started school we recognized that he needed one on one support, especially for mealtimes, but also with toileting and a variety of other activities, but the school where he was didn't allow outside providers and did not provide 1:1 support. We received a call from an agency that said they were new to Tucson and that they would be able to offer a HAB provider who could attend school with our son. This seemed like a dream come true! We began looking into other schools that would allow a HAB person to go with my son and found one that seemed like a good fit. We met the HAB provider, Brad, at school and I spoke to him for a few minutes before passing my son off. The BCBA had been getting to know my son and was going to train Brad, but I'm not going to say that it was a comfortable feeling putting my son in the care of more strangers. They added another RBT to do HAB in the afternoons with my son at school, but she was not there every day.

Within a matter of a couple of weeks, Brad began to have health issues and he stopped coming. My son was really struggling with the open layout of the campus and was darting off every time they transitioned from their classroom. After 6 weeks, without having consistent HAB providers working with him, the school admitted that they were not able to handle my son. They offered to have him come for one hour a day (and continue to pay full tuition) since that is how long it would take before they would be leaving the classroom. As a side note, the school had been holding meetings with the BCBA, her supervisor, the principal, and another woman several times trying to come up with a solution without ever addressing the concerns with me. Mind you, that none of them had known my son for more than 8 weeks. The final straw came when I had to demand to be included in one of their meetings where they all brainstormed for about an hour and ultimately concluded there was nothing they could do and in passing shared that my son had nearly walked out the front door of the school to the street the week before. Long story short, I pulled my son out of that school, I fired the agency that was providing HAB and brought my son home to teach him myself. I have a MAED in Special Education. I know my son better than anyone else, I am by far the most qualified person to teach him.

After that I really wasn't sure that I ever wanted to utilize HAB services again. I did reach out to our original agency summer of 2022 to see if they had someone who could work on goals with my son at camp. We met Andrea, who seemed like she would be good. She did some things well and others were a struggle for her like getting my son out of the bathroom to participate with the other children. It was a short-term situation being centered on working with him while he was at day camp, but once it was over, my opinion of HAB services was not any better.

Recently, my son was approved for 30 hours of HAB a week based on his summer day camp schedule. I spoke to Karen, and she said that she would like to do it. Later she said she could only do it for a couple of weeks though. Karen has been doing Respite for my son for about a year and a half now. And while we like her, we have concerns about her ability to properly care for him. She recently gave my son 12-day old chicken nuggets that were in the refrigerator. The date was on the container that they were in, but somehow it didn't register with her that those were not safe for him to eat. Thank God he didn't get food poisoning.

So now I have the choice of taking a risk and trying to find yet another stranger to come into my home to work with my son for 30 hours a week, adding to the current stress I am dealing with personally due to my dad's passing this morning, doing HAB with my son myself, or not doing HAB at all. What would you choose?

Please thoughtfully consider continuing to pay parents to provide Habilitation services for their children. There are many reasons as you can see from my letter why this is a positive solution to the labor shortage this industry has been facing long before COVID ever came on the scene. If you have questions, please feel free to contact me.

Thank you,
Rebekah Clark
[redacted]

From: Lindsay Stephens [redacted]
Date: Tuesday, August 1, 2023 at 2:36:27 PM UTC-4
Subject: Please extend Parent Habilitation Hours
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>, Lindsay Stephens <lrstephens@gmail.com>

To Whom it may Concern,

Hello there, My name is Lindsay Stephens and I am a mother of a beautiful spirited young lady named Journey. I have been Journey's Habilitation provider for a little over a year now. The Parent Providers of Minors Program has been a complete blessing and necessity for Journeys growth and development this last year. Journey has been able to conquer many goals due to her comfortability with me guiding her. Some of which have been personal hygiene goals that Journey would not have felt comfortable working on with someone other than myself. Journey has many sensory struggles and works really hard to overcome, however, I need to step in often to assist her. These are skills and tasks that don't get conquered unless they are worked on in exact step by step patterns. Because I am her parent, I have gained a supernatural skill to see things before they happen! Because I know Journey so well I am able to anticipate when Journey would need extra assistance and guidance . This allows Journey to feel more successful. It is wonderful to see her gaining self confidence as well as learning how to take care of herself more independently. Because I am a Parent Provider, I am able to assist Journey in all hours of the day or night. Having the flexibility to have a provider to respond to Journey's needs when she needs it is vital. We are able to conquer more because the moments are real and not simulated, so she doesn't feel like she is taking a class. She is simply living life and learning by my guidance in how to take care of herself and become a successful safe member of our community. I really enjoyed taking the classes required for me to be a provider for Journey. It helped refresh my safety knowledge which not only made me a better asset to Journey, but the rest of my family , and essentially to the community we live in. Also walking through the language and edicte of how to treat a member was wonderful. I was refreshed to be walking alongside people who genuinely believe in people first and I came out of that class feeling like a stronger voice for Journey and our family.

Please STRONGLY consider extending the Parent Providers for Minors Program. This program has been Vital for Journey's success. I ask for it to become PERMANENT. Thank you for your time and consideration.

Yours truly,
A grateful Parent Provider of Minors,
Lindsay Stephens
[redacted]

From: Flora Khosho [redacted]
Date: Tuesday, August 1, 2023 at 1:45:20 PM UTC-4
Subject: Parent provider
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hi my name is Falura khosho and I am my son's provider [redacted]. I never used to be his provider however, his provider who he had for 13 years had to quit, and I am guessing it's due to my sons size and aggressions that she was not used to in the past. It is almost impossible to find someone to be a caregiver for my son because he is strong and he is a big kid 230 pounds big. He has behavioral issues, so it's almost impossible for anyone to want to work with him other than myself, his mom, and at this point of his life, things like teaching him how to bathe himself, and personal hygiene is some thing I think a 17-year-old would be embarrassed for another person, other than his mother to teach him. Due to my circumstances, my personal story is I I'm not able to work another job except this one because my sons needs need to be met and if I was to lose the half hours and zero people to work the half hours our household income will change drastically. My son is also on a special diet, so that income really needs to come in. I would ask to consider allowing parents to be the providers for their children, especially those who have the older kids, which will be almost impossible to find someone to work with them or for the parent to feel they could trust them, especially because my son is nonverbal. Thank you. .FALURA khosho
Sent from my iPhone

From: Evelyn Camarillo [redacted]
Date: Tuesday, August 1, 2023 at 1:38:55 PM UTC-4
Subject: Celyne Ava Camarillo
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To whom it may concern,
I wanted to let everyone know how habitation has helped my family. My name is Evelyn Camarillo I am 31 years old. I have a daughter named [redacted] She is three now. She was diagnosed autistic level three at the age of 1 1/2 . At the time I work for the sheriffs office I was a Detention officer, while being pregnant. I attended the Academy with her. I had my baby early two months exact. I put her in a child care and last year November 2022. I was told that they cannot handle her because of her autism. I took a step down from my job and I did not know where else to go. I was scared because all I wanted to do was provide for my child and give her the best I can, a big part of me felt like I was nothing in life like all my dreams have gone away and fear consumed me. I ended up quitting my job and tried to get the help for my daughter. She is ambitious and she is thriving with ABA therapy and habilitation 40 hours a week has provided my family the help they need with the money that is given to me I am able to give my family a little of what I had before, I know too many ending this program for parents is OK. This is my life. I didn't choose to have an autistic child, but I will fight for her till the very end and do everything in my power to keep her achieving each goal I ask of you guys to please keep this habilitation Program for his parents to have at least something for children to give. Many of us do not qualify for low income or food stamps but with the high rise of everything going up the little we get, we can provide our children. I asked for you guys to please keep these 40 hours of habilitation , going to help us as parents thrive. We were blessed to have children that just needed a little bit more loving and honestly it's very hard I married but I have a husband in the military and it's the hardest thing to ever do alone.

From: alicia stancil [redacted]
Date: Tuesday, August 1, 2023 at 1:38:50 PM UTC-4
Subject: My family's view on Habilitation
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello, my name is Alicia and I am currently a parent provider for both of my children with Autism, Adhd, PiCA and Epilepsy for my oldest son. We were very happy to find out that I could be a parent provider for my children here in Arizona, as we have had not so great experiences before. Whether it be that my oldest is physically aggressive to people, things being damaged in our home by outside people, or said people being homophobic and having an issue with the fact that we are a 2 mom household. Also the hours needed for Habilitation is morning and pm hours to include weekends. I don't know about anyone else but I don't think many people will want to work those types of hours. Also since being in Arizona my youngest son has already been physically injured by a therapist who was trained and supposed to know what to do with my special needs children. But I'm supposed to trust random strangers with caring for my children? I'm home with my children, I would have to be home even if an outside person came into my home so how does this benefit my family or any other family. Then we also run the risk of an outside person bringing sickness into our home and exposing our entire family to it. Lastly we live on the military base which means the person would have to get access to base and I can't speak for anyone else, but speaking for myself I'm supposed to sign and give permission for them to come on a military base and take responsibility for their actions while they are here? That doesn't seem like a good idea in my book.

With great respect,

Alicia

Sent from Yahoo Mail for iPhone

From: Jessi Baird [redacted]
Date: Tuesday, August 1, 2023 at 1:36:31 PM UTC-4
Subject:
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello,

I am writing to tell our story and why being able to be the parent provider for my daughter's Habilitation hours is such an important thing. We live in rural Pima County. With our location being so far outside of city limits and in the middle of nowhere, we spent an exuberant amount of time waiting for a provider that was willing to provide HAB care for my daughter. That never happened. We never had vendor calls answered. It wasn't until this program, allowing parents to become the providers, that we finally had the ability to make a difference enough, that I could provide her care. Being paid to teach her daily living skills that she otherwise, could not grasp because I couldn't spend the time with her while always chasing the next gig job to pay the bills. Now, I dont have to do that so that I can focus on her needs, and not how she is missing out on needed help because of where we live. Taking this program away, would mean having to go back to chasing jobs to be able to pay the bills again, doing my daughter a disservice and once again, leaving her in the shadows with no help to better her life as she grows. I can't imagine that I am the only one who feels this way, more so I can't imagine we are the only family that lives too far for vendors to actually want to take us on.

This program should not end. It should become a permanent solution to a problem I'm sure the state doesn't even realize it has.

Thank you for your time,
Jessi Baird

From: Michelle Garcia [redacted]
Date: Tuesday, August 1, 2023 at 1:06:43 PM UTC-4
Subject: Parent Providers of Minors:
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>
Cc: [redacted]

Good morning,

I would like to provide some information regarding being a parent provider for a minor to take in consideration of not ending this program in November. We have had trouble getting providers to answer vendor calls to provide the services. It's been almost 2 years since we have had a provider in our home, and no one answers the vendor call. Thankfully, we have been able to provide the services as being a paid provider so that our Autistic daughter does not miss out on any of her approved services.

Our daughter receives Habilitation and Attendant Care each week. With the ability to being a parent provider for her, I can help her work on her goals each week and for the past 2 years. Without this program, she would not have the ability to work on goals to help her and she would be even further behind than she already is. For Habilitation we receive 12 hours a week to help her work on goals such as hygiene, cooking, exercising, counting money, and going out to stores to use these goals. My daughter receives these each because I am there to help her and not cancel on her or her not having a representative available before of the lack of providers available and especially in our rural area.

We have had long-term challenges finding a consistent third-party DCW Caregiver for my daughter. It's been at least 2 years that we have had one in our home. I was fortunate enough to find the Parent Provider program to be able to help my daughter with her needs. Then about a year and half ago her needs drastically changed, and I was able to obtain 23 hours ofattendant care to help her. Her services are vital to her well being and without having someone in place, she would be in disservice.

Even now, we have had a vendor call for a Respite provider, which a parent provider cannot do, and we have yet to obtain that, and the vendor calls constantly go unanswered. Also, when there is a vendor call for Habilitation or Attendant Care a new agency wants to sign up a parent provider and train them because they do not have employees, and I must tell them no, because I'm already a parent provider. We haven't had the ability to obtain a Speech Therapist as well, because of scheduling and availability in our area.

With the parent provider coming to an end in November, that is not enough time for this change to be able to find a third-party vendor to get Habilitation, Attendant Care or Respite in place for our daughter and she will be lacking these services for the time being without having the parent provider available.   We need to keep this program in place for all of people involved because it is a benefit to have in the households that are unable to obtain providers.

Please extend the program as the special needs community needs to have consistency and stability in their lives to help maintain their normalcy they know.

Thank you,

Michelle Garcia

From: **Shalyn Galdones** [redacted]
Date: Sat, Jul 29, 2023 at 4:38 PM
Subject: Grievance
To: <DDDcustomers...@azdes.gov>

Hello,
I am a parent of a child who receives DDD and ALTCS services. I would like to file a grievance against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which would go into place in November 2023, my child and many more like them will lose access to their Habilitation services. The reason my child will not have access to their appropriately evaluated services is due to the DCW shortage. My agency has specifically stated that they will not be able to recruit, hire, and train enough providers to fill the gaps in service these new rules will create.
I would like to request a ticket number for this grievance.
Thank you for your time,
Shalyn Galdones

From: Hussein Ali [redacted]
Date: Tuesday, August 1, 2023 at 12:59:50 PM UTC-4
Subject: Hi
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

That not enough we need partners hab to be longer please we need partners servies ther kids
Regards

Sent from Yahoo Mail for iPhone

From: Meagan Lougee [redacted]
Date: Tuesday, August 1, 2023 at 12:37:54 PM UTC-4
Subject: Pandemic/Parents as Paid Caregivers for Their Minor Children
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Thank you so much taking the time to read this personal account for parents as Paid providers.

I am the mother of three special needs kids each requiring 1:1 care and attention. We are fortunate enough to have fabulous support coordinators and therapist come to our home and support our kids. My children need assistance with basic daily needs including toileting, eating, dressing, following directions, and staying safe, and not hurting others.

Habilitation is critical in the care of our children and I contribute my children's success and better quality of health to the hab hours we have received. we recently had several doctor appointments that showed the work she was doing with her provider to help her to use the bathroom helped to prevent chronic and serious complications that other kids with similar conditions have. We were able to avoid costly surgery and considerable emotional damage.

While helping my child use the bathroom several times a day is very important, it is a delicate matter. We have a very difficult time finding Hab Providers that care for our kids we can trust in our home, and that my kids feel comfortable with to help them daily. Unfortunately, we are still in an employment crisis. When we do find a provider they are usually underpaid or are unable to stay more than a few months. As a parent, I have to continue the job of many providers until we find someone new. The accountability in the hab goals and notes and meetings with the support coordinator help me organize their needs and make adjustments as needed.

Furthermore, with 3 special needs kids—- all needing attention. It is overwhelming for them to have several outside help in the home. Often times one child will feel extra clingy to their parent and refuse to work with the provider. Having parents as the provider it allows the child to continue with their progress and maintains the family unit. It also allows me to work with one child while a provider works with a second child. Many of the hab goals are needed during the morning and evening hours, it is overwhelming to have several people in the home during that time.

I encourage you to follow the lead of other states in allowing parents to be paid providers for their special needs kids and ease the strain of raising special needs kids.
Best Regards,
Meagan Lougee

From: **Rachel Bunney** [redacted]
Date: Mon, Jul 31, 2023 at 11:04 AM
Subject: grievance
To: <DDDCustomerS...@azdes.gov>

Hello,

I am a parent of a child, [redacted], who receives DDD and ALTCS services. I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which would go into place in November 2023, my child and many more like them will lose access to their Habilitation services or more than 40 hours a week of care by parent providers of minor members. The reason my child will not have access to their appropriately evaluated services is due to the DCW shortage. My agency, Arion Homecare, has specifically stated that they will not be able to recruit, hire and train enough providers to fill the gaps in service these new rules will create. Thank you for your time.

Respectfully,
Rachel Marquardt

From: Violet Aird [redacted]
Date: Tuesday, August 1, 2023 at 11:54:11 AM UTC-4
Subject: From a Members point of view
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

This is from a disabled persons point of view….

Please read and consider their voice

From a members point of view…

I want to talk about choice. Choice is power. Choice is dignity. There is one choice someone should always have. That is the ability to control who touches you, your belonging, activities, and choices. Taking away that is wrong. Wrong is an understatement. Taking away that choice is a power play. It says in my world. My disabled world. That you don't trust me or those responsible for making decisions for me. That is the greatest insult ever. Especially since the state and cms both claim I have person centered and individual choice in my care.

Having a disability doesn't take this away. Neither does having a guardian. I should edit that there are even human rights that a guardian can't take away without good reason. It seems to me one of those fundamental rights is the right to control who is privy to personal and private information and who you hire to do adls and IADLs.

My biggest fear is my dsp or support worker won't see me. That they will see someone so disabled that they struggle with independent living skills. There is something profoundly undignified about needing assistance. Any assistance be it wiping bottoms or helping me with laundry or even making meal plans. I have to let this person into my life, often someone I don't know with no choice. The undignified part is I have no choice. I NEED assistance. I have to work with this person. The state decided I can't use my family member, not me. Choice is power and choice is dignity. Everytime I choose someone to work with me is another who can abuse, neglect, and exploit me. Whether I pay them, the state pays them, or my family pays them.

Some people I really like are going to testify against this. They may think the guardian or family member is likely to get away with abuse, neglect, or exploitation. I don't know why they think a family member is statistically more likely to get away with these things. Because here is the truth. I am a vulnerable person. The state says so. My family says so.

Best Regards,
Violet

From: Maryanne Bectold [redacted]
Date: Tuesday, August 1, 2023 at 10:12:45 AM UTC-4
Subject: Parents/Paid Caregivers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hi
Parents as paid Caregivers makes the most sense because , parents actually know their child the best and spend an awful amount of time training someone new how to work best with their child to quickly get to work on goal's instead of spending so much time on building rapport with their child and then they don't last long, only to train yet another worker . Our child gets used to one worker finally, and then they move on to a higher paying job .
A lot of what kids need to work on is private, like showering.
Bottom line it should be a Choice, if agencies cannot get enough quality people to be consistent in our kids lives. Parent should have the choice to be paid caregivers.
Thank you

Sent from my iPhone

From: Louise Turner [redacted]
Date: Monday, July 31, 2023 at 6:56:01 PM UTC-4
Subject: Include Habilitation in 1115 Waiver Amendment!
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

I am the parent of a minor son with Down syndrome who I provide Habilitation services for, beginning in April 2020 during the PHE. I am writing to ask that you **PLEASE INCLUDE HABILITATION** in the 1115 Waiver Amendment. We do not have attendant care hours, but I work with him on his Habilitation. I have never been able to find a non-parental provider to come and provide Habilitation with my son, as I do not work outside the home in order to provide all his care. This would be a severe hit to our family financially AND in terms of his cognitive development.

The immediate implementation of this in November would not provide time to find a caregiver, as there is such a shortage. At least extend the implementation to the original ARPA program end date of September 2024. Better yet, include Habilitation services in the amendment.

Thank you for your consideration and the impact this amendment would mean to Arizona families like mine if implemented immediately, without Habilitation.

Louise Turner
[redacted]

[redacted]4394

From: Fernando Islas III [redacted]
Date: Monday, July 31, 2023 at 5:17:16 PM UTC-4
Subject: Parent Habilitation Provider
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

My spouse is the Parent Habilitation provider for my 5 yoa son that is on the spectrum. My son is not great with new people especially temporary college students. He doesn't engage in activities and does what he can to avoide others. His mother is his comfort zone and only learns and engages in activities with her. It would continue to be beneficial for my son if his mother remains his Parent Habilitation provider. I am afraid and extremely concerned for my son if this changes.

For my son's sake and other children under the same circumstances, I high encourage to keep this program for as long as possible.

Thank you for your understanding.

From: Savanna Lester [redacted]
Date: Monday, July 31, 2023 at 5:14:49 PM UTC-4
Subject: Paid caregiver Concerns
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>
Cc: [redacted]

My name is Jill Ressler and I am a parent provider for my 15 year old daughter, [redacted] [redacted]. (DOB [redacted])
[redacted] has Down Syndrome and is also a survivor of AML leukemia. She lived for 7.5 months at Phoenix Children's Hospital fighting cancer and is healthy at this time.
As a result of her health issues and delays due to DS, I needed to stop my career that had resulted from my graduate education.
The parent provider program has been very helpful to my daughter and my family. I can provide her services when it is very difficult to get and maintain providers due to the demands of the certification and maintenance of that certification.
I'm aware that there is a discussion that habilitation hours are being considered being withdrawn from parent providers. This concerns me greatly. I am unable to get providers certified to do these services for my daughters. One of her goals, for example is helping her with her morning routine. Her delays make getting ready for school on time very difficult. I would have an impossible time having a provider arrive at my home from 5:30 am-7:30 am to complete this goal.

From: Savanna Lester [redacted]
Date: Monday, July 31, 2023 at 5:04:05 PM UTC-4
Subject: Paid Caregiver concern
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>
Cc: [redacted]

I am a parent of a child who receives DDD and ALTCS services. I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which would go into place in November 2023, my child (or state your relation) and many more like them will lose access to their Habilitation services or more than 40 hours a week of care by parent providers of minor members. The reason my child will not have access to their appropriately evaluated services is due to the DCW shortage. My agency has specifically stated that they will not be able to recruit, hire and train enough providers to fill the gaps in service these new rules will create. Please let me know the next steps.

From: Savanna Lester [redacted]
Date: Monday, July 31, 2023 at 4:59:14 PM UTC-4
Subject: Paid Provider
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>, Jamie Gregory
[redacted]

Iam a parent of a child who receives DDD and ALTCS services. I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which would go into place in November 2023, my child and many more like them will lose access to their Habilitation services or more than 40 hours a week of care by parent providers of minor members. The reason my child will not have access to their appropriately evaluated services is due to the DCW shortage. My agency has specifically stated that they will not be able to recruit, hire and train enough providers to fill the gaps in service these new rules will create.Thank you for your time, I would like to request a ticket number for this grievance

From: **Laura Vaterlaus** [redacted]
Date: Mon, Jul 24, 2023 at 9:30 PM
Subject: Grievance against DDD and AHCCCS and requesting a TICKET NUMBER
To: <DDDCustomerS...@azdes.gov>

I am a concerned parent, of a child with autism. I recently started the process of getting services put in place for my 5 year old son who was diagnosed with autism.

I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which would go into place in November 2023, my child and many more like them will lose access to their Habilitation services or more than 40 hours a week of care by parent providers of minor members. The reason my child will not have access to their appropriately evaluated services is due to the DCW shortage. I have had several potential agencies specifically state that they will not be able to recruit, hire and train enough providers to fill the gaps in service these new rules will create.

Before having children, I worked as a Hab, respite, and Attendant care service provider for 6 years. In my years supporting families of children with special needs through DDDs services, I saw first hand the unique trials these families face in regards to finding service providers.
Several of the families I worked for lived in rural communities and went without any workers other than myself for years. I worked 30 plus hours for one family alone to prevent them from loosing hours and ensure my client was able to get the therapy he needed. Between my regular clients and various agencies needs I worked over 50 hours a week regularly and they always asked for more. Location is one of many reasons why finding competent, caring, and reliable workers is difficult for these families.
I now live in a rural community and am unable to find workers for my child. I have several friends in my community in a similar situation.
I believe in having outside help from trained service providers. I was that person for my entire young adult life, and I would invite that opportunity for my child if we could find a suitable and willing provider.

However, when there are no providers available, or it better suits the families particular situation, we should be to be able to work with our children as their service providers.
I understand the concerns that have been voiced about how parents may abuse the system, but I have seen first hand how the benefits far outweigh the risks. These individuals and their families need the ability to provide services for their children.
I would like to request a TICKET NUMBER so we can further discuss the issue.

Warm Regards,
Laura Vaterlaus

From: Angela Wojtowicz, NMD [redacted]
Date: Monday, July 31, 2023 at 3:45:29 PM UTC-4
Subject: Arizona 1115 Demonstration Waiver - Public comment
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Habilitation from parent providers is so important. As a parent provider for my 15 year old daughter with Down Syndrome, I would like to voice my concern. While I am glad AHCCCS is looking to include the ability of parents to provide attendant care permanently, it does not include habilitation. Both attendant care and Habilitation are so important for our families. It has made such a difference for us to know that one of us can afford to be home and give my daughter the attention and care she needs. Our family has been living paycheck to paycheck for the past 15 years, to make sure our daughter has the care and attention she needs. FInally with paid parent provider ability for Habilitation, I could get paid for the work I do with her, and this has given us some much needed breathing room financially. To me it makes no sense to have a stranger come in and care for your child, while the parents can be doing the same job. I have put my career on hold to be able to be here for my daughter, since other jobs do not allow the flexibility needed to be available when my daughter needs me. Something I can not plan ahead for or schedule in. Arizona Section 1115 Demonstration Waiver Amendment must be updated to contain both attendant care and habilitation by parent providers. I have seen my daughters confidence and ability grow exponentially in the year that we have had parent provider habilitation. This is in the best interest of all of our society, because our children will grow into adults, and the more they can do for themselves and learn through habilitation as children, will allow them to be competent, confident and self-sufficient adults, to the very best of their ability.
Thank you!
Angela Wojtowicz, NMD

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Dr. Angela Wojtowicz
Naturopathic Medical Doctor (NMD)

[redacted]

From: Nicholas Holmes [redacted]
Date: Monday, July 31, 2023 at 3:39:57 PM UTC-4
Subject: 1115 Waiver Amendment
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Good afternoon,

As a parent provider of habilitation services for my minor child it is imperative for my family to continue to be able to bill hab services. Home and Community based services are vital to the disability population and not allowing habilitation to be billed will be a huge detriment as I am currently her main caregiver.

We live in a fairly remote area and have not been able to find a provider since COVID and still have not been able to post COVID.

I request the following.

- Amend the Arizona 1115 Demonstration Waiver to allow parents of minor DDD and ALTCS members to be paid providers with the same requirements and limitations of other DCW providers.
- State Legislation that authorizes parents of any DDD and ALTCS member to provide Attendant Care and Habilitation services for their minor children with the same requirements and limitations of other DCW providers. The legislation would require AHCCCS to issue an amendment to the Arizona 1115 Demonstration Waiver to support this permanent program adjustment.

Nicholas Holmes
[redacted]
[redacted]

From: Kevin Dunham [redacted]
Date: Monday, July 31, 2023 at 2:52:10 PM UTC-4
Subject: Waiver
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

I have recently read about the new waiver if voted in would allow parents to provide attendant care hours for their child but will not allow HAB hours to be provided by parents. I am VERY concerned about this because I have not been able to find a HAB provider for my daughter Emma in over 2 1/2 years and recently decided that if I didn't do it myself the hours would be lost and more importantly the benefit she receives from HAB services would be lost as well!

I just encourage you to add HAB services to this waiver so that we as parents can provide the services for the most vulnerable in our state until their are workers that are willing to work with these precious people.

Thank you for your consideration and I urge you to do the right thing for our kids

Ginger Dunham (mother to Emma)
Sent from my iPhone

From: MaryEllen Crawford [redacted]
Date: Saturday, July 29, 2023 at 4:04:14 PM UTC-4
Subject: 1115 Waiver Team
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

Thank you to you and AHCCCS for your time and hard work on creating a permanent program for Paid Parent Caregivers. I am a parent of a child who receives DDD and ALTEC services and I currently participate in the Paid Parent Caregiver Program. I would like to share my experience on why this program is so important to my family, especially the ability to provide Habilitation.

By the time my child reached age four, they had 15 different therapists and Direct Care Workers in their life. Currently I am still looking for consistent help, my option was to become trained as a direct care worker or for my child to not get those services. The training this program has already provided is invaluable and will continue to improve their life and learning. We have tried countless other therapy and learning techniques and nothing has shown progress like Habilitation, for the first time we are seeing new skills instead of decline. If parents lose the option to do Habilitation we will lose our progress. The Paid Parent Caregiver program is also the only option for me to work, I am college educated and had to recently decline a side job due to the inability to find consistent care and the amount of support my child needs. I will always choose my children first, we as parents are willing to do the work and learn the same requirements to be held to the same standards.

We commend adding the "home care training family support service" to the proposal. I believe the better trained and supported we are will improve the care we can provide and further support our children toward their full potential to be as independent as possible. My agency has done a wonderful job getting me the skills to not only assist my child but gain confidence and knowledge to carry that over to our other therapies, specialists and schools. We are the bridge that connects all the parts, making us stronger will only increase the chance our minor children will be closer to being independant adults. We understand the concerns of burn out all too well. There are not enough Direct Care workers and that includes respite. Taking away our ability to be trained, supported and an active part of our agencies does nothing to increase respite or provide additional support. Please consider looking into additional options to increase respite.
We also understand the concern of how our children will transition to others assisting and teaching them as well. Again, no one wants to see our children reach those milestones more than us. Our journey may look different, but we want the same for our disabled kids as everyone wants for their non-disabled kids. To have the best opportunity to become as happy, healthy and well adjusted individuals as they can be. Habilitation has allowed more time and opportunity to grow skills on my child's schedule and comfort. They have chronic pain and every day is meeting them where they are at and adjusting our schedule accordingly. We could not do that for someone outside the home who needs a set schedule to work. Our child was able to attend a friend's birthday party, get through both OT and ST with me in the waiting room for the first time and participate in a family game. This program has produced more independence and less stress for my child, it has not inhibited them or my family

I appreciate you taking the time to read and consider the viewpoint of parent providers. You can also connect to an Arizona parent led grassroots initiative at:
www.raisingvoicescoalition.com

Thank you!
MaryEllen Crawford

From: Annette Trujillo [redacted]
Date: Friday, July 28, 2023 at 9:41:19 PM UTC-4
Subject: Parent caregiver
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello,
I am a parent provider for my daughter. Among many things, she is unable to properly tend to her personal hygiene needs, so being a parent caregiver has enabled me to provide the level of care and assistance she requires. Because of this provision, I am able to dedicate the time, effort and consistency our daughter requires. Thank you for your consideration.
Annette Trujillo
[redacted]

From: sarah maichl [redacted]
Date: Friday, July 28, 2023 at 7:42:16 PM UTC-4
Subject: Waiver 1115
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Good afternoon,
First I would just like to take the time to say thank you for hearing us. The special needs community is severely lacking options for our special kiddos and adults. As a single mother with zero family support or help in any way this program has helped me keep a roof over my daughters head. I have a 4 year old daughter with spastic quad cp caused by meningitis encephalitis at 12 days old. She is full care as she is non verbal non mobile and has intellectual and global delays. Her father is an addict and not involved. His family is also not involved. My family has relocated back to Ohio so I have no support system in anyway. With being the sole caregiver and provider for my daughter I am unable to hold a job. I was recently let go in May from my current employer due to attendance. Having no help I had to call out more than was allowed and was terminated. Having a special needs child and very little options this paid provider program that includes atc and hab has really helped me keep my daughter safe. I do appreciate all the time and patience this has taken. Thank you for listening to all of our stories and helping us advocate for our special needs children.

Thank you
Sarah Maichl
[redacted]

480-408-3882

From: Alan Beaudrie [redacted]
Date: Friday, July 28, 2023 at 7:00:56 PM UTC-4
Subject: Waiver Public Input
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

I am a parent with a DDD and ALTCS recipient currently participating in the Paid Parent Caregiver program under the Covid-19 Flexibility. This program has been extremely beneficial to my disabled child and our family. I would like to share my observations, experience and feedback pertinent to the current proposal for a permanent Paid Parent Caregiver program.

The rest of this letter after this paragprah is a form letter - but the form letter also encapsulates our experience. Our main issues with DCW prior to parents being able to provide hab were: 1) finding a quality DCW. First, they were incredibly hard to find anyone, let alone someone who actually worked well with our child. These people often cancelled, upsetting our child who liked routine and schedule, and then later, once he got used to them, they would leave for a better job. 2) Just when we could get them trained and I felt like I could leave them alone with our child, they would leave to take another job. I personally invested countless hours training them myself to get them to work with our child. It was very frustrating for me and our child having to constantly retrain someone to provide a minimally effective service (in comparison to what I can provide my child). 3) We understand that being a DCW is a hard job and the hab people we had could go get the same amount of pay or higher at a much less stressful job. Right now, as everyone is well aware, ANY employer in AZ is having a hard time finding quality, long-term workers. I actually laughed out loud when I read that one of the arguements against having parents as paid providers was that they will work harder at getting DCW's. It will even be worse than before the pandemic in finding QUALITY DCW's. Thank you for reading this.

Under the current proposal, the request of the disability and caregiver community for an ongoing program option which allows parents of disabled minors in Arizona to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies is not being met. Please consider updating the proposal based on the following questions, suggested solutions, and experiences.

Should Habilitation be included in the Paid Parent Caregiver Program?
We have heard the concerns about member isolation and lack of community involvement if parents continue as Paid Parent Caregivers facilitating their child's Habilitation services. Respectfully I would like to proposes the following solutions:

1. Examine available research and personal feedback statements from members and their families to evaluate the true potential impacts of social isolation and community involvement when parents of disabled children provide Habilitation services. The parent caregiver community's collective experience is that members who have parents facilitating their Attendant Care and Habilitation services have experienced greater member social engagement and community involvement over the last three years. Parent caregivers now have an increased ability to take their children to sporting team practices, community events, movie theaters, all ability parks, church activities and libraries. This is because parent providers can perform the appropriately trained and qualified supports in the correct time and location that is applicable to each member.

2. Implement precise guidelines to facilitate generalization for all Habilitation providers regardless of the DCW's familial status. Habilitation services are designed to have goals where data is collected to evaluate if those goals need to be changed, have been met, or need to be addressed differently. For a goal to be considered met, a member should be demonstrating that they are able to successfully meet that goal outside of the timeframe with a provider in one setting. This is referred to as generalization. The effective implementation of generalization with the pediatric IDD population would lessen, if not eliminate, any complications with adult transitional services. Under this model a program that includes parents as paid Habilitation providers would actually assist and improve in the success of adult transition. There are times when disabled children work successfully with different types of providers in clinics or schools, but the parents are not carrying the work over at home. This can happen for a variety of reasons. Having parents as Habilitation providers would help ensure the child's goals are congruent and carried over in the home and community setting. This will give the member a better chance of independence as they transition through different life stages. With generalization policies in place, Habilitation services being performed by parent providers will actually help facilitate successful transition into adulthood.
3. We know from provider agency data that "the top 3 issues regarding recruiting and retaining career non-family caregivers are schedules of the client members, interest in the position and finding qualified applicants." Most members have Habilitation goals and ADLs that are most appropriately delivered throughout the natural routine of their day. A parent provider is uniquely available in the morning, after school or in the evenings when each member is motivated and focused on the pertinent task. If a non-family provider is available their schedules typically allow them to work in longer time chunks that are not always the most ideal for the member and creates artificial goal or ADL practice. Continuity of care and greater member outcomes can be associated with consistently provided Habilitation care by parent providers who have the greatest ability to be flexible and available for their member children.

Should parent providers be limited to 40 hours a week of paid care per child?
We have heard the concerns of AHCCCS regarding the potential for a difficult adult transition to non-family supports once parent caregivers are no longer able or willing to help facilitate the disabled member's care. I would like to propose the following collaborative solution to create a win-win scenario:

1. Create a program provision that outlines an extraordinary circumstances clause and the application process that allows parents to provide over 40 hours of paid care per week of authorized and evaluated services per member. These extraordinary circumstances could include, but are not limited to:
    a. The lack of a non-parent DCW being available in the last 3 months to fill the member's assessed hours that exceed 40 hours per week. Ongoing DCW searches should continue to be made by the member's agency to fill the assessed hours beyond 40 hours per week of Attendant Care and Habilitation.
    b. The expressed desire made by a member for a parent caregiver to facilitate their assessed DCW hours so that their Article 9 rights are honored.
    c. The profound disabilities and/or significant behaviors of a member where a non-family provider is not equipped to provide DCW support. This determination can be made through a stakeholder team approach, including but not limited to the member's, DDD Support Coordinator, DDD Nurse, DDD Supervisors, Behavioral Plan Experts, Parents / Guardians, Psychologist, or Medical Doctor.
2. Form equality between all Family Provider Programs by allowing all Direct Care Workers, regardless of familial relationship or member age, to provide up to 16 hours of paid care per day. This will allow for employee equality across the lifespan of the member and limit the potential anti-family provider rhetoric currently present within state policies and DDD Support Coordination culture. All evaluations of hours should be based on member needs regardless of who is providing the services to create uniform implementation of all applicable HCBS services by the DCWs available to fulfill those hours.
3. The Family Support Program currently in this proposal addresses caregiver burnout. It is one of the available solutions to facilitate further community support within the disability and caregiver community that will provide greater access to non-profits facilitating counseling services, support

groups and meet up activities.

4. Reevaluate Respite reimbursement rates to also address caregiver burnout. If Respite services are not available to the member or their family, parent burnout will continue to be an issue regardless of parents having the option of providing Attendant Care or Habilitation hours. With a comprehensive Paid Parent Caregiver Program in place non-family DCW providers will have greater flexibility to provide Respite services to these same families.

How should current evaluation protocols, training and practices be updated to facilitate equality for all members when accessing member needs?
AHCCCS has stated their intention to amend applicable policy, further suggested action on this topic includes:

1. Forming a committee of community and department stakeholders to amend and critique current DDD and AHCCCS policies and need assessment forms so that the most effective and efficient implementation of this permanent option is utilized moving forward.
2. Provide appropriately determined training and program implementation to DDD and ALTCS Support Coordinators so that Attendant Care and Habilitation hours are equitably evaluated based on the member's needs and to remove organizational bias of familial providers across the member's lifespan. Specifically investigate and determine appropriate DDD staffing needs and training for the members served in rural areas and those from minority backgrounds.
3. Create the option for private sector Support Coordination. Other states have this option within their Medicaid services, and this could be an additional feature in our DDD portfolio to allow for the member's needs to be best evaluated.

In conclusion, Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. By not allowing parents of minors to provide Habilitation and Attendant Care services or work over 40 hours a week most of the minor disabled community in Arizona will be underserved. A comprehensive Paid Parent Caregiver program validates the irreplaceable work that parents provide in their homes and communities.

Click here to connect with the Arizona parent led grassroot initiative leaders:
www.raisingvoicescoalition.com

Thank you for your time and consideration! The disability and caregiver community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves all DDD and ALTCS members in Arizona.

Thank you!

CMS perspective on the above noted requested program adjustments and paying Legally Responsible Individuals:

June 28, 2023 - Email Correspondence between CMS and Raising Voices Coalition:
https://drive.google.com/file/d/10CPccmIY7gEr5vq9C6vIaKmncSQOV7kc/view?usp=share_link

May 23, 2023 - Transcription of National Meeting between CMS Leaders and Parent Advocates:
https://docs.google.com/document/d/1h02v6Yk7frWGADcqKgm1zmd0uquMNfW3Jcd0zjHCxOk/mobilebasic?fbclid=IwAR2QLqbwJMQQRz0nj-XqhYzlFlkQbUV5wnyAyv98hivRVYpCjaYHhLBCzYg

Studies and data that support the changes being requested:

Data results from a 2023 Arizona survey of parents who have children with disabilities:
https://docs.google.com/document/d/16PZOk99caDUitg0XmQKqEv2mxXOBeaRywSD_zmjAnYw/edit?usp=sharing

A report on the current caregiver crisis by the National Association of Homecare and Hospice:
https://www.hcaoa.org/uploads/1/3/3/0/133041104/workforce_report_and_call_to_action_final_03272023.pdf

Higher satisfaction of paid supports for adults and minors with disabilities when care is received from paid family providers:
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1089106/

A comparison of healthcare utilization when children receive paid care by a family member vs non-family provider: .https://www.jpeds.com/article/S0022-3476(23)00106-3/fulltext

Youth with Autism Spectrum Disorder have less ED visits and patient outcomes when patient providers are involved: https://www.reliasmedia.com/articles/148366-autism-spectrum-disorder-in-the-emergency-department
https://www.psychiatrist.com/jcp/mental/child/youth-with-autism-in-the-emergency-department/

An evaluation of parent provider involvement in generalization of children with autism:
https://www.sciencedirect.com/.../abs/pii/S0891422205000958

Impacts of the caregiving relationship: https://academic.oup.com/gerontologist/article/56/6/1102/2952858

State Approaches to Reimbursing Family Caregivers of Children and Youth with Special Health Care Needs through Medicaid - NASHP
NASHP-State-Approaches-to-Reimbursing-Family-Caregivers-of-CYSHC-through-Medicaid_highlighted.pdf

NASHP-State-Approaches-to-Reimbursing-Family-Caregivers-of-CYSHC-through...

From: Tori Brinkley [redacted]
Date: Friday, July 28, 2023 at 5:17:09 PM UTC-4
Subject: Mathew Giles
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

I just want to state that I’m a caregiver for my son it hard to find a job with my son needs. He is current can’t attend school or daycare won’t except him so I’m write this letter to let you know that the company I work for his is good and I would love to continue been his paid care giver --
Sent from Gmail Mobile

From: Jody Brigham [redacted]
Date: Friday, July 28, 2023 at 4:53:15 PM UTC-4
Subject: Parent providers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To Whom It May Concern,

For years many parents have been relegated to staying home with a disabled child because there are no caregivers available. Today, most families require a two person income to survive, staying home because you have no other option makes it challenging for many of us. By being paid as a caregiver for my son, we have been able to have a much better lifestyle. We are no longer struggling financially and I am getting paid for what I have been doing for free for nearly a decade. I think that it just makes sense to continue this program. We now have the opportunity to receive respite services occasionally because the agency now has workers that are not scrambling to provide services to many, many families. PLEASE sign the amendment to continue this service. THANK YOU!

Jody Brigham

From: Matthew Hernandez [redacted]
Date: Friday, July 28, 2023 at 3:32:05 PM UTC-4
Subject: Paid Parent Provider Feedback
To: Waiver Public Input - AHCCCS <waiverpublicinput@azahcccs.gov>
Cc: [redacted]

Hello,

Sending this on behalf of [redacted]

* I am a parent of a child who receives DDD and ALTCS services. I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which would go into place in November 2023, my child and many more like them will lose access to their Habilitation services or more than 40 hours a week of care by parent providers of minor members. The reason my child will not have access to their appropriately evaluated services is due to the DCW shortage. My agency has specifically stated that they will not be able to recruit, hire and train enough providers to fill the gaps in service these new rules will create. I appreciate your time and consideration of these issues.

Thank you,

Matthew Hernandez
[redacted]

[redacted]

From: Judy Rieck [redacted]
Date: Friday, July 28, 2023 at 2:48:12 PM UTC-4
Subject: Paid parent provider waiver request for minor children
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To whom it may concern,

I am a paid parent provider to my minor child. I adopted my grandson who is diagnosed with non-accidental abusive head trauma (shaken baby syndrome).

Being able to care for my child is a blessing. Being able to be paid to care for my child allows for a reduced stress environment for my child which, in-turn provides my child a better quality of life. Stress brings on more health complication for a child with medical complexity fragile progressive diagnoses.

This also improves his quality and consistency of care. No one loves my child like I do. It is a rare find to actually find a qualified caregiver for a child that is medically fragile with no medical training willing to work as an attendant care provider.

In fact, for the last 9 years my home as been a revolving door for attendant care providers (atc), as well as, home health nurses for my child. Most don't stay, this position is either a stepping stone for a qualified candidate or a fear factor for a overwhelmed unqualified person.

I implore you to make paid parent provider's to minor children a permanent solution to this caregiver crisis, without restriction to member qualified hours for the betterment for the member.

Respectfully,
Judy Rieck

From: **Valerie Johnson** [redacted]
Date: Thu, Jul 27, 2023 at 11:04 AM
Subject: File a Grievance Against DDD and AHCCCS
To: <DDDCustomerS...@azdes.gov>

I am a parent of two children who receive DDD and ALTCS services. I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this
proposal, which would go into place in November 2023, my children and many more like them will lose access to their Habilitation services or more than 40 hours a week of care by parent providers
of minor members. The reason my children will not have access to their appropriately evaluated services is due to the DCW shortage. My agency has specifically stated that they will not be able
to recruit, hire and train enough providers to fill the gaps in service these new rules will create.

Thank you for your time, I would like to request a TICKET NUMBER please.

Thank you,

Valerie Johnson
Cell: [redacted]

From: **Cindie** [redacted]
Date: Thu, Jul 27, 2023 at 2:26 PM
Subject: Ticket number requested - Grievance regarding discontinuation of the parent provider program
To: <DDDCustomerS...@azdes.gov>

Hi,

I'm a parent of a child who receives DDD and ALTCS services. I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which would go into place in November 2023, my child and many more like them will lose access to their Habilitation services by parent providers of minor members. The reason my child will not have access to their appropriately evaluated services is due to the DCW shortage. In the 5+ years of having these services, there has ALWAYS been a shortage of workers & it has gotten worse since COVID.

I'd like someone to respond to me with a ticket number regarding my concerns. I want to know what the plan is to get a sufficient amount of workers to provide HAB services if parents of minors are no longer allowed to.

-Cindie Wisener
[redacted]

From: **Brittany** [redacted]
Date: Fri, Jul 28, 2023 at 3:39 AM
Subject: Grievance
To: <DDDcustomers...@azdes.gov>

My child receives DDD and ALTCS services. I would like to file a grievance against DDD and AHCCCS regarding the proposal to end the Paid Parent Caregiver proposal in November 2023. My son will lose access to their Habilitation services by me, his mother. This is an outrage because my son NEEDS this program and needs ME. If this program ends, my son will totally LOSE access to their appropriately evaluated services is due to the DCW shortage. My agency has specifically stated that they will not be able to recruit, hire and train enough providers to fill the gaps in service these new rules will create. This could be viewed as discrimination!! These children with disabilities and delays need SIGNIFICANT assistance daily and the lack of DCW is being ignored ….. why? These hired employees work for a month or less then quit or don't even show up at all, or are not properly qualified and trained, OR there's just NO ONE available! And my son goes without necessary medical services!!! This parent program can not end. This parent program needs to become permanent.

**** I NEED A TICKET NUMBER FOR MY GRIEVANCE PLEASE. PLEASE PROVIDE A TICKET NUMBER ASAP!!****

Brittany Powers

[redacted]

From: **Jennifer Foster Degillo** [redacted]
Date: Thu, Jul 27, 2023 at 3:12 PM
Subject: Grievance
To: DDD Customer Service Center <dddcustomers...@azdes.gov>

I am a parent of a child who receives DDD and ALTCS services. I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which would go into place in November 2023, my child and many more like them will lose access to their Habilitation services or more than 40 hours a week of care by parent providers of minor members. The reason my child will not have access to their appropriately evaluated services is due to the DCW shortage. My agency has specifically stated that they will not be able to recruit, hire and train enough providers to fill the gaps in service these new rules will create.

Thank you for your time, I would like to request a TICKET NUMBER regarding this.

Thank you ,

Jennifer Foster-Degillo

From: **JaNel Stewart** [redacted]
Date: Wed, Jul 26, 2023 at 3:55 PM
Subject: Grievance -DDD and AHCCCS
To: <DDDCustomerS...@azdes.gov>

Hello, I am a parent of 2 children who receive DDD and ALTCS services. I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which would go into place in November 2023, my two children and many more like them will lose access to their Habilitation services. We would be losing access to 87 hours of combined Habilitation. We have already gone a full year of not being able to find a provider and were unaware this program existed until 2022 due to our support coordinator never mentioning it as an option. We have also been looking for providers more recently since May 2023 and have not found any providers. Parents should not be capped at 40 hours a week of care by parent providers of minor members when there aren't providers to take over the rest of the hours. Under this proposal my children will not get the services they need. The reason my children will not have access to their appropriately evaluated services is due to the DCW shortage. My agencies do not have enough providers to fill the gaps in service these new rules will create.

Thank you for your time, I would like to request a TICKET NUMBER for this grievance.

JaNel Stewart
[redacted]

From: **Carrie Goettl** [redacted]
Date: Thu, Jul 27, 2023 at 8:29 AM
Subject: Ending parent providers for HAB
To: <DDDCustomerS...@azdes.gov>

To whom it may concern:
Good morning g! I am a parent providers for my son with Cerebral Palsy. I am filing a grievance about the end of these paid parent HAB positions. We live in [redacted] Az, and are somewhat rural. We have only hired family respite providers due to the lack of providers in our area, and the past experiences we have had with outside providers. Our son has finally been able to get more servicing than ever with this paid parental option. He is finally making progress in his goals, even if slowly, and enjoys the time with his parent.
As parents, we are the perfect providers for our child. We already know them, their needs, how they communicate (Communication is key with our guy, who is non verbal), which has taken us years to get down, and will set an outside person back for a while. We know how to work around their needs, get them out of funks quickly, and the things that motivate them. At this point, for our family to have someone new come in, it would be a setback for months, as the communication battle ensues, then a parent has to step in to interpret, placing a block in that particular goal, the client has to become adjusted to a new person and new hours that he has to be engaged for. While at home, we try to keep a schedule, but if he is off or refuses, we can come back to it when he's more cooperative, or we can just work when we knos he is going to cooperate. The clients receiving these service are so scheduled, sometimes, that flexibility is a must.
Please, for the benefit of our children and adults with special needs, and their families, please make paid parental HAB providers permanent.
Thank you for your considerations!

Sincerely,

Carrie Goettl
[redacted]

From: **Sophia Chacon** [redacted]
Date: Wed, Jul 26, 2023 at 11:06 PM
Subject:
To: DDDCustomerS...@azdes.gov <DDDCustomerS...@azdes.gov>

I am a parent of a child who receives DDD and ALTCS services. I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which would go into place in November 2023, my child (or state your relation) and many more like them will lose access to their Habilitation services or more than 40 hours a week of care by parent providers of minor members. The reason my child will not have access to their appropriately evaluated services is due to the DCW shortage. Thank you for your time.
Sophie Chacon
[redacted]

From: **Brianne Rosa** [redacted]
Date: Wed, Jul 26, 2023 at 9:56 PM
Subject: Grievance
To: <DDDCustomerS...@azdes.gov>

Good evening,

I am a parent of a child who receives DDD and ALTCS services. I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which would go into place in November 2023, my child and many more like them will lose access to their Habilitation services or more than 40 hours a week of care by parent providers of minor members. The reason my child will not have access to their appropriately evaluated services is due to the DCW shortage. Of greatest concern is the loss of attendant care hours with the 40 hour cap. My son has specific high needs surrounding his disability. Many of those hours are general supervisor overnight. Our service coordinator has attempted to submit a vendor call and the one agency that responded was attempting to have an attendant care worker who was 18 years old, who has no specialized training in my sons special needs. Not only is there a shortage in DCW, there is a shortage of highly trained DCW. Allowing an untrained and inexperienced provider to care for my son overnight is a risk I am unwilling to take. I urge that the proposal be amended to not limit hours parents can provide services for their children. This change will be detrimental.

Regards,
Brianne Rosa

From: **Allyse Morel** [redacted]
Date: Wed, Jul 26, 2023 at 11:53 PM
Subject:
To: <DDDCustomerS...@azdes.gov>

I am a parent of a child who receives DDD and ALTCS services. I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which would go into place in November 2023, my child and many more like them will lose access to their Habilitation services or more than 40 hours a week of care by parent providers of minor members. The reason my child will not have access to their appropriately evaluated services is due to the DCW shortage.

Thank you for your time, I would like to request a TICKET NUMBER and callback,

Allyse Morel
[redacted]

From: **Rebekah C.** [redacted]
Date: Wed, Jul 26, 2023 at 10:43 PM
Subject: Grievance
To: <DDDCustomerS...@azdes.gov>
Cc: Rebekah C. [redacted]

To whom it may concern,
I am a parent of a child who receives DDD and ALTCS services. I would like to file a grievance against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which would go into effect in November 2023, my child and many more like him will lose access to their Habilitation services or more than 40 hours a week of care by parent providers of minor members. The reason my child will not have access to their appropriately evaluated services is due to the DCW shortage. Prior to the pandemic we had issues with finding reliable and emotionally healthy people to provide these services as well. My agency has specifically stated that they will not be able to recruit, hire and train enough providers to fill the gaps in service these new rules will create. One agency I spoke to on July 20, 2023 (UCP) regarding HAB services put my son on a waitlist but told me that they already had over 500 hours of services that they were unable to staff.

Thank you for your time. Please confirm receipt of my grievance and provide a ticket number for my records.

Sincerely,
Rebekah Clark

From: **Melissa Furrier** [redacted]
Date: Thu, Jul 27, 2023 at 12:43 PM
Subject: GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal
To: <DDDCustomerS...@azdes.gov>

I am a parent of a child who receives DDD and ALTCS services. I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which would go into place in November 2023, my child and many more like them will lose access to their Habilitation services or more than 40 hours a week of care by parent providers of minor members. The reason my child will not have access to their appropriately evaluated services is due to the DCW shortage. My agency has specifically stated that they will not be able to recruit, hire, and train enough providers to fill the gaps in service these new rules will create.
Thank you for your time, I would like to request a TICKET NUMBER for this GRIEVANCE.

Thank you,
Melissa Furrier

From: Deanna Karn [redacted]
Date: Friday, July 28, 2023 at 1:33:49 AM UTC-4
Subject:
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To whom it may,

My name is Deanna karn, I am my daughter's paid caregiver. I think making this service permanent would help a lot of families who can't find proper care for their special needs children. For me, personally, it's helped a lot. 2 years ago, I was in a [redacted] accident which left me unable to [redacted] due to a [redacted] injury. It's allowed me to both be a stay at home mom, and get paid for it by working with my daughter. The cost of living has skyrocketed and we can no longer live on one paycheck. Please consider making this service permanent.

From: Julie [redacted]
Date: Friday, July 28, 2023 at 12:25:08 AM UTC-4
Subject: Please continue the program
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>
Cc: Jennifer Kemp [redacted], Sarah Donoghue [redacted]

Hello,
I have severely Autistic twins that didn't receive habilitation therapy until I became their provider. We would get a provider and they wouldn't last a shift, they always claim it's too much. Our twins have made exceptional advances since I started working with them.
I don't understand why you are ok to pay a stranger to come into our home who will turn around and break our twins hearts by leaving but not pay parents who have their children's best interest at heart.
Please reconsider
Thank you

From: cynthia keethler [redacted]
Date: Thursday, July 27, 2023 at 11:03:14 PM UTC-4
Subject:
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

I am in favor of keeping paid caregivers such as myself permanently. I have a [redacted] year old that I'm doing rehabilitation and this is income for those of us who can't work because of our special needs children. Please don't dissolve this program. Thank you for reading this

Cynthia keethler

From: Julie Perez [redacted]
Date: Thursday, July 27, 2023 at 8:17:13 PM UTC-4
Subject:
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

I think it will be a great plan to have the parents to become permanent to priovide services for our child it really is amazing working with our child the good communication skills and the good awesome visuals and schedules and positive reinforcers have been really good for our child our child is getting through our service and is very happy to work with the parents thankyou also my child loves her routines

---------- Forwarded message ---------
From: Cindie [redacted]
Date: Thursday, July 27, 2023 at 5:16:03 PM UTC-4
Subject: Paid Parent Provider Feedback
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

As a parent of a child who receives DDD and ALTCS services, I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility, and it has been extremely beneficial to our family and my child. I would like to share my personal feedback based on my review of the current proposal for a permanent Paid Parent Caregiver program.

The elimination of the paid parent provider program will negatively impact my [redacted] old daughter because of the following reasons:

1) It's hard to find QUALITY & RELIABLE hab workers. This was the case before, during, and post-COVID. Even if we find a good worker, most don't stay very long for various reasons (school, change of career, moving, etc.)

2) A lot of my child's hab goals have to do with bathing & toileting. I don't want just anyone helping her with these very intimate/personal tasks. I would prefer to do these things myself with her as a parent Hab provider.

I know that parent burn out has been mentioned in forums. However, I have experienced the opposite. Getting my agency support for HAB goal creation and validation for my work with my child has been empowering. In addition, I believe it's benefited my relationship with my child.

In conclusion, Habilitation services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. By not allowing parents of minors to provide Habilitation services, most of the minor disabled community in Arizona will be underserved. A

comprehensive Paid Parent Caregiver program validates the irreplaceable work that parents provide in their homes and communities.

Sincerely,

Cindie Wisener

From: Danielle Robertson [redacted]
Date: Thursday, July 27, 2023 at 4:11:06 PM UTC-4
Subject: Paid Parent Providers Of Minors
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hi there. I'm emailing my public comments in advance regarding the paid parent providers of minors 08/21/23 deadline. I myself am a DCW for my child, who is on the autism spectrum and lives with other medical and developmental disabilities. This program greatly benefits my child, the member, in many positive ways. My son has been doing great with the consistency, familiarity, schedule and routine he has gotten accustomed to from the services provided to him in the program. My son has overcome daily obstacles and is thriving so much since I have been able to give him the one on one care and attention he is comfortable with and needs. My son struggles with being comfortable/receiving consistent care with other people providing services and it has been a long-term struggle over many years in finding a consistent third-party DCW/caregiver for this member. The member has adapted and shown amazing progress! I would love to continue to provide him the services he needs and see him continue on this positive path he is on! I feel that November is not enough of a runway for this change, and I ask that an extension be granted to allow paid parent providers of minors to continue. Thank you for taking the time to read this, we appreciate your time!

Sincerely, Danielle Robertson

From: [redacted]
Date: Thursday, July 27, 2023 at 2:09:43 PM UTC-4
Subject: Parents working with their Children
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Greetings,

I am a parent of a child with autism. He is now [redacted] years old had he was diagnosed when he was [redacted]. It has been a long journey for us and many times I had to quit my job because I could not find a worker to help him out home with Habilitation and ABA. There is currently a shortage of workers. The job does not pay well, and a lot of young many people would rather work at Mcdonald's then deal with a difficult child in a difficult situation. Parents are really the most qualified to care for their own child. They care the most and will be the most committed. The agency has to pay someone anyway why not pay the parent? I just wanted to share my thoughts.

sincerely,
Steve C

From: **Shannon Behnke** [redacted]
Date: Mon, Jul 24, 2023 at 10:12 AM
Subject: Grievance notification
To: <DDDCustomerS...@azdes.gov>

To whom it may concern,

I am a parent of a child who receives DDD and ALTCS services. I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which would go into place in November 2023, my child and many more like them will lose access to their Habilitation services or more than 40 hours a week of care by parent providers of minor members. The reason my child will not have access to their appropriately evaluated services is due to the DCW shortage. My agency has specifically stated that they will not be able to recruit, hire and train enough providers to fill the gaps in service these new rules will create. I appreciate your time and consideration of these issues.

Thank you,

Shannon Behnke

From: **Heather** [redacted]
Date: Mon, Jul 24, 2023 at 10:45 AM
Subject: Parent Providers proposal grievance
To: <dddcustomers...@azdes.gov>

Good morning,

I would like to fila a grievance against DD and AHCCCS regarding the current paid parent caregiver proposal. Per this proposal, effective Nov of 2023 my child will lose access to habilitation services. There is a shortage of providers, has been and remains today. Prior to parent providers being approved, my son was eligible for habilitation and NEVER received it due to this shortage. My agency has shared they will not be able to fill the gaps in care due to recruiting, hiring and training these new rules will create. There was a gap prior to parent providers and this gap was filled by parent providers. The new proposed rules will eliminate habilitation services for our children, making us go backwards in progress for our children. Currently there are many, like me and my son, who is now receiving services (habilitation) thanks to parent providers.

Thank you for your time in reading this and addressing it with your team. I would like to request reply with a ticket number as well please.

Thank you again

Heather

From: Tracy Stewart [redacted]
Date: Thursday, July 27, 2023 at 1:05:20 PM UTC-4
Subject: Parent Provider Program 40 hours and Habilitation Services
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS Public Input,

I am writing this letter to express my concerns not only as an agency owner of over 20 years, but as a parent of an individual who receives DDD services.

I have observed and participated in the Paid Parent Caregiver program under the Covid-19 flexibility and in my opinion it has been extremely beneficial to the members we serve. I would like to share my organization's experience and my own personal feedback based on my review of the current proposal for a permanent Paid Parent Caregiver program.

During the recent public forum, we learned about the decision of AHCCCS to discontinue parents from providing Habilitation starting November 2023 and I have significant concerns regarding this. The focus of DDD has always been to support our members to be as independent as possible and we do this by writing outcomes that support them increasing their overall skills. Each member that is approved for DDD services goes through an assessment as a team. The team sits together to come up with person specific outcomes that the provider implements. The assessment pursuant to policy has never been based on who the provider is, but yet the specific need, achievements and abilities of the member. I heard Dara state that the concern of parents being Habilitation providers is burnout and that they will limit the member from participating in community activities or doing things that potentially a non-parent provider would. I disagree with this statement. Since this program flexibility started, I have been a part of countless member assessment meetings. I have seen our members flourish by becoming more independent, having less behaviors, expressing more of a willingness and doing more than they ever have been. I have seen allegations of abuse and neglect significantly reduce. In evaluating the reasoning behind this, it is that the member trusts their parents and through this trust the member participtes in activities they would not do if the trust was not there. When a non-parent caregiver is hired, this caregiver views this as a job and there is turnover. With a parent provider there is no turnover. It takes extensive time for the member to build a relationship with the caregiver and more importantly to trust the caregiver. The caregiver has to get to know the member and what they like to do. Parents are also not as willing to allow the member to participate in activities until they have a trust in the caregiver, which also limits the member. We are all parents, think about letting a stranger take your child in a vehicle, out in the community and to go places not even really knowing them. It takes time to build that trust. With the parent provider the trust is instant with the member, thus creating more opportunities for learning, participating and becoming more independent. In my opinion, parents are taking this seriously and they are implementing the outcomes. For many with the extra income they have been able to resign from other work positions and stay at home to focus 1:1 with the individual. This is why there is less abuse and neglect and more progress and achievements with the member. In my opinion, parents of minor children should be allowed to provide Habilitation and Attendant Care services just like the adult population. What is critical here is training the support coordinators to truly assess. If at a meeting, the Support coordinator sees that a parent is burned out or a parent is not implementing the Habilitation outcomes as they should be, then the Support Coordinator needs to address this with a supervisor and a CFT meeting held to address DDD concerns and reassess the need of the member. If needed, DDD could recommend the agency recruit for an outside provider. It should be on a case by case basis versus a global policy.

As an agency, I am also concerned of the negative impacts to agencies and members and their families if Habilitation is not allowed to be worked by parents of minor children. As everyone is aware, there is truly a caregiver shortage. We are an agency that actively recruits on many job platforms, social media, colleges and universities and word of mouth. We get people who apply, but due to the extensiveness of the onboarding process the applicant does not follow through. Each provider has to go through several training classes, complete a new hire packet, be fingerprinted, obtain a notary and that takes time. Also the positions are not full-time and many are split shifts. Finding providers who want to work 2 hours here and there is very difficult. Arizona has seen a spike in the average minimum wage jobs. Most fast food is paying $18.00 to $20.00 per hour. Direct Care providers require more than a minimum wage job and we are competing with those making it even more difficult. My question to AHCCCS is with an abrupt stop to allowing parents of minor children to provide Habilitation, what are the plans to ensure no gap in services? If unable to provide Habilitation, Parents will be returning back to regular jobs and DDD has a requirement to ensure services that are assessed are implemented. Agencies will have a significant reduction in income which means less funds being able to be used for marketing campaigns and less resources to recruit and train providers. I fear that AHCCCS may not fully grasp the challenges that will come from parents not being able to work Habilitation.

Another point to discuss is that DDD’s policy has always been that Attendant Care should not be given to younger members. For most of our members, Attendant Care is not an assessed service. The focus has always been to give our younger members the opportunity to become more independent during the years they are learning and absorbing and growing. That is

Habilitation. At our agency, 80% of our parent providers of minor children only have Habilitation hours. If AHCCCS stops the ability of these parents to provide services, the agency will need to recruit providers and fill shifts from a nonexistent applicant pool. That means our members will not be given the continued opportunity to learn and grow and we will see significant regression, increase in behaviors and as we all know recoupment takes longer. This decision of AHCCCS is going to have a significant negative impact on our members, and they need to re-evaluate the program to be based on the adult DDD program and not the spouse program.

I would also like to address the cap of 40 hours per week. Currently in the adult population, the assessment is not based on who the provider is but yet the needs of the member. Parents of adult members are allowed to work over 40 hours per week if the agency is willing to pay a non reimbursable expense of overtime. DDD and AHCCCS have stated they are concerned with burnout of parents of minor children. The question is – what is the difference between an adult parent and a minor parent. There is no difference. DDD has implemented a cap that a provider cannot work more than 16 hours per day to ensure that caregivers are not burned out. Agencies work closely with families to ensure there is no burnout. I feel that the entire Parent program should be based on the current adult program which does not limit the parent. AHCCCS needs to also understand that over 90% of members with disabilities have divorced parents. This is nationwide statistics. The member has shared custody between parents and each parent household is different and each household requires supports. Splitting hours between two parents is going to be a hardship for the family, especially in a divorce. Additionally how is DDD and agencies going to ensure that the parents are not splitting between other agencies as we do not have access to other agencies billings. Also are step parents included if married as they have not legally adopted. There are so many unanswered questions regarding this. DDD has always been responsible for the assessment of the member. The agencies have always been responsible for employing the caregiver without restrictions. Let agencies employ the caregiver, whether it be a parent provider or a non-parent caregiver and allow us to permit working over 40 hours if that is what is right for the member. Ask yourself, currently non-parent providers for adults and children can work more than 40 hours and parents/guardians of adults can work more than 40 hours – why is it different for parents of minor children? Keep consistency and keep it the same. If DDD is going to mandate this, my strong recommendation to ensure that we are not hurting our community is to grandfather in all parent providers of minor children prior to a date to allow them to bill more than 40 hours and those hired after a certain date to be restricted.

Medicaid has clearly stated that they allow all states to have a parent provider program with no restrictions. They will accept parents of minor children working more than 40 hours and providing Habilitation services under our 1115 waiver. Since the implementation of this program, there are less cases of abuse and neglect, members now have stability of providers with less turnover, services are being implemented fully as per assessments, and our members are thriving and becoming more self sufficient through opportunities they have never had before. Isn’t that what the purpose of our services are?

I truly hope that AHCCCS mirrors the parent provider of minor children program with the adult program that is currently in place. Allow parents to work more than 40 hours per week if that is what is right for the member and include both Habilitation and Attendant Care. The key factor here is our support coordinators truly doing proper assessments and ensuring services are being implemented as approved and assessed. Please consider the direct implications on our members and their families regarding these two issues. There will also be significant implications on agencies that are already struggling with hiring and staffing solutions and recovering from a global pandemic. I truly urge AHCCCS to amend the proposal to include allowing parents of minor children to work more than 40 hours per week and to provide Habilitation services.

Thank you for your time, understanding and support.

Tracy Stewart

Executive Director of Affinity Family Care

Parent to a Member as well

Email: [redacted]

[redacted]

[redacted] AZ [redacted]

Business Phone: [redacted]

[redacted]

[redacted]

Remember you're Never Alone with Affinity

---------- Forwarded message ---------
From: Cori Contreras [redacted]
Date: Thursday, July 27, 2023 at 1:05:09 PM UTC-4
Subject: Re: Fwd: Grievance CC
To: Matthew Hernandez [redacted], Waiver Public Input - AHCCCS <waiverpublicinput@azahcccs.gov>

Hello,

I do not wish for this grievance to be closed until an amendment is proposed to address this need.

Cori Contreras
[redacted]
Member name- [redacted] Contreras

[redacted]

---------- Forwarded message ---------
From: **Cori Contreras** [redacted]
Date: Mon, Jul 24, 2023 at 10:56 AM
Subject: Grievance CC
To: <dddcustomers...@azdes.gov>

I am a parent of a child who receives DDD and ALTCS services. I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which would go into place in November 2023, my child and many more like them will lose access to their Habilitation services or more than 40 hours a week of care by parent providers of minor members. The reason my child will not have access to their appropriately evaluated services is due to the DCW shortage. My agency has specifically stated that they will not be able to recruit, hire and train enough providers to fill the gaps in service these new rules will create.

Thank you for your time, I would like to request a TICKET NUMBER.

Cori Contreras
Re: [redacted] Contreras

---------- Forwarded message ---------
From: **Brittany** [redacted]
Date: Mon, Jul 24, 2023 at 12:08 PM
Subject: Grievance claim.
To: <DDDcustomers...@azdes.gov>

Hello

My child receives DDD and ALTCS services. I would like to file a grievance against DDD and AHCCCS regarding the proposal to end the Paid Parent Caregiver proposal in November 2023. My son will lose access to their Habilitation services by me, his mother. This is an outrage because my son NEEDS this program and needs ME. If this program ends, my son will totally LOSE access to their appropriately evaluated services is due to the DCW shortage. My agency has specifically stated that they will not be able to recruit, hire and train enough providers to fill the gaps in service these new rules will create. This could be viewed as discrimination!! These children with disabilities and delays need SIGNIFICANT assistance daily and the lack of DCW is being ignored ….. why? These hired employees work for a month or less then quit or don't even show up at all, or are not properly qualified and trained, OR there's just NO ONE available! And my son goes without necessary medical services!!! This parent program can not end. This parent program needs to become permanent.

**** I NEED A TICKET NUMBER FOR MY GRIEVANCE PLEASE. PLEASE PROVIDE A TICKET NUMBER ASAP!!****

Brittany Powers

From: CRISTINA
Sent: Monday, July 24, 2023 2:07 PM
To: waiverpu...@azahcccs.gov
Subject: Concern about HAB

Hi . My name is Cristina Garcia, I'm a Parent provider who does ATC and HAB for my son, he is [redacted] years old, has severe Autism, he is Non-verbal , before they aloud us to provide services for our children we had a very hard time finding providers for our son , and when we found some our son was never conforta with it.   Now my son is a [redacted] and I don't feel confortable bringing a strange person home to help him to take a shower or clean himself when he go to the restroom , also my teenage daughter also request that we avoid having strangers in the house . Having a stranger at home every day will be very uncomfortable for the hole Family. Also wanted to add that my son is never isolated as our family goes out to eat, to church and part of the HAB goals is taking him to do some of their favorite activities to relax his anxiety. Last, I would like to state that since I started to do HAB with my son we started to see resulta with his goals , because I have more opportuniti to be with him and not working outside home full-time
Thank you for your attention in this matter
Cristina

From: MIKE MARQUARDT [redacted]
Date: Thursday, July 27, 2023 at 11:29:47 AM UTC-4
Subject: please maintain the waiver program as is
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello,

My name is Mike and I am a father to a special child who receives DDD and long term care services. My son was born with a rare de novo genetic mutation that has greatly affected our family. He cannot walk, sit, crawl or talk. He has a feeding tube and a trach. Prior to having [redacted], my wife and I both worked full-time jobs. In fact, my wife left her teaching career [redacted] [redacted] to be home with [redacted] full-time as our jobs were constantly disrupted due to [redacted] surgeries, therapies, illness/hospitalizations, and disruptions in home health nursing care. My wife was making a sizable income with fully paid health benefits for our family, but the constant disruptions in his home health nursing (often 3-4 months in between providers) and dr appointments left us with little choice but to have her stay home to care for [redacted]. Since she has been home, I have been able to work with fewer disruptions and the stress on our family and marriage has decreased. Sure, we have far less expendable income, but the decrease in stress, less arguing, and more time with our son who has a life-limiting condition is worth the sacrifices we have had to make.

We are so grateful for the paid parent program as it allows my wife to still bring in income for our family and to be paid for services that a stranger would ultimately provide who does not understand the intricacies of our son. Furthermore, because our son is not only delayed but also medically complex, she (or a home health nurse) would have to be constantly available. Unfortunately, our home health nursing hours have been drastically cut since moving to Arizona, which really leaves us no other choice than my wife staying home with [redacted] full-time. Although [redacted] is enrolled in school and loves school, he is absent often due to appointments and frequent illness that comes with immobility and a trach.

We depend on my wife to provide services to our son and I plead with you to maintain the paid parent provider program without the limitation of 40 hours a week as my wife is serving our son day in and out. She is the best to help [redacted] meet his habilitation goals while also caring for his medical needs. We ask you to continue to allow parents to provide these services. She relayed to me that the reason to limit the hours to 40 and get outside community members to provide habilitation is to give parents a "break" but that is really not an option for many families. My wife would have to supervise anyone caring for our son since he needs suctioning, tube feeds, oxygen monitoring etc. He can't be left alone with anyone who has not gone through rigorous medical training and this is something not outlined in Habilitation or Attendant Care training, nor are they being hired to complete medical care. It simply doesn't make sense or afford my wife a break. It would only further set us back financially as she would be "supervising" (unpaid) and still unable to work outside the home. Additionally, our son doesn't always have a set schedule. Once a month, he cries for several days (neurological issue). Would an outside provider just come and watch him cry during his set habilitation hours? Or would we cancel that person's shift? It would make more sense for my wife to tend to [redacted], then complete habilitation once he is calm. Many people with special needs need a flexible schedule that parent providers can flow with versus a set schedule from an outside provider.

Cutting the hours and limiting parents to Attendant Care would hurt our family and many others. Already, many families can't find respite providers who should be more hirable than Habilitation providers (given the difference in responsibility), so the state would be causing more hours to be unfilled by providers, thus a greater burden falling onto families. The BEST case scenario would be to allow the provisions to stay as they currently are and revise the respite program to actually have enough providers to give us hard-working parents a break. Please find it in your heart to consider families like ours and keep the current provisions of more than 40 hours and habilitation in the hands of the most qualified candidates- the parents.

Thank you,
Mike Marquardt
cell: [redacted]
text: [redacted]
[redacted]

From: Ariana Thude [redacted]
Date: Thursday, July 27, 2023 at 10:55:42 AM UTC-4
Subject: Additional comments on waiver 1115
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

As this is an ever-evolving discussion, I am submitting additional comments that I feel are pertinent to consider as discussions are being made about what provisions to continue for the CMS waiver 1115. The most concise version of this is that it would be cheaper to pay parents to be the habilitative provider when no other provider could be found than to have them put in facilities at earlier ages. You can read my entire remarks below, as you can see from what is written it is a public response that was posted to my blog, so there will not be additional posts for you personally to read, but the rest of the material is pertinent to this discussion. Respectfully, Ariana Thude

Yesterday afternoon, I read the public response from Raising Special Kids about AHCCCS 1115, the proposed CMS waiver that seeks to extend some provisions allowing parents to provide attendant care to their children, while discontinuing others, namely allowing parents to become the paid habilitative therapy providers. I feel it is important for me to share my thoughts, but I also do not have time to finesse my writing to the degree I might in other circumstances, as I have been and will continue to be working on tasks related to my hiring as the one-to-one aid for my son in his school district as he transitions back into that environment.

For our son, it is a necessary accommodation to provide the least restrictive environment that he have a person he already cooperates with safety instructions from working with him in the school environment until he generalizes that cooperation to staff there. We asked for and wanted his RBT to go in with him, and the school district communicated that their policy prohibits outside therapists from working with students inside the classroom.

So here I am spending time and planning on giving up more profitable financial opportunities I could have had to provide the support necessary for my son to flourish as his one-to-one for the first year until he can generalize cooperation of safety instructions to his teacher and permanent one-to-one.

So I don’t have a lot of time right now to sound polished, collected, artistic, or anything other than a mom who sometimes feels bone tired, and I will ask each of you bear patiently with that.

On the surface, the scenario I am describing might seem to support the argument that insisting hab providers be someone other than the parents promotes generalization. But the reality is he’s worked with dozens of therapists in other disciplines (ABA, NMT, PT, OT, ST, and even HAB) who were not me over the years, and it has only been a more recent development within the past year that he will generalize critical safety instructions to anyone other than me. So, I do not believe his struggles with generalization are related to lack of exposure to other people, but rather the specific symptoms of his disabilities in general.

When our son was first approved for habilitative therapy, we could only find someone to do 10 of the 40 hours he was assessed for. So I did the other 30 unpaid.

My son is potty trained because of me and that unpaid work (that took a year of work, and still required reinforcers for years to ensure cooperation up until about [redacted] ago.) He no longer smears poop on the walls because of me and that unpaid work. And so, so much more that I don’t have time to write here, but feel free to stick around and read some posts from the past 5 years or so if you want a comprehensive list.

After he was out of his diapers, his physical therapist at the time looked at me and she said “we never thought we’d see the day.” All of his PT/OT/ST services were at the same location at that point, so there was a coordinated “we” behind that statement. Everyone who will ever work with our son in any environment has and will continue to benefit from work I did for free because we couldn’t find providers.

I have a kiddo with a history of hours a day of self-harming. I have a kiddo who would try to use his entire body weight to push through someone like a football player for upwards of an hour to get what he wants. A kiddo who couldn’t calmly or safely take “no” for an answer for years. A kiddo who to this day has risk assessment comparable to that of a kiddo under 18 months of age. A kiddo with challenges so severe people would say things to me like this quote as I remember it from his [redacted] developmental pediatrician (who is truly fabulous!) after the first 2 hours she spent assessing him: "When I first read your paperwork, I thought you were exaggerating- but you weren't!" A kiddo who wouldn’t keep his clothes on when therapists were present (he now can for an entire day of therapists in home because of paid work I did in hab), who would frequently grab his genitals and start stroking regardless of who was in the room. A kiddo who at one point required 2 adults to his one to provide almost all therapy services.

That second person was me. And I wasn't paid for that either.

We wanted hab providers other than me to fill all of his hours, but we haven't had anybody to do most of his hours other than me for [redacted] of his [redacted] years he has been assessed as meeting medical necessity for hab.

Of course every success [redacted] has would be absolutely impossible without all of the therapists who have worked with him (and I am grateful to each and every one of them), but it is also true it would have been impossible without the work I did for *free* during his [redacted] years, without the work that I have been paid for the past [redacted] -but will no longer be able to afford to do for free if we can't find a provider.

Work that will then go undone.

I understand the concern expressed by Raising Special Kids that if parents are allowed to remain providers, it may promote atrophy in the work force of habilitative providers. But for families of individuals like my son, that atrophy might not be going anywhere because the challenges can be beyond what a person paid at the level of habilitative therapy wants to deal with. And, until the rules governing habilitative workers being able to make up hours that are canceled are changed, that may continue even for other individuals. Currently, if a family cancels the therapy because of an illness or an emergency, the hab therapist cannot make up those hours and will not be able to have an opportunity to earn those wages, so if they need that money to support themselves, this job won't provide them with the stability of income they need.

We've had people turn down being our son's habilitative therapist once they learned the details of his needs and challenges. And even though he hasn't done any self-harming in any setting in more than [redacted] weeks now, it still takes him so long to learn certain skills we may continue to struggle to find individuals with the patience to fill all of his hours.

So many skills our son currently has he wouldn't if I hadn't been working with him. He may have needed to be in a facility at a young age if he were in a family where one parent couldn't afford to stay home and provide that support for free.

So my belief based on my personal experiences is that in order to provide the best outcomes to individuals with disabilities, especially those who have severe behavioral challenges, there needs to be at a minimum a provision allowing for the parent to become the paid provider if no other provider can be found. I feel like for individuals with challenges like my son, there is an increased risk of need for placement in a facility outside of the home without a paid option for the parent to step in when no other provider can be found.

I think having provisions in place requiring documentation that a hab provider cannot be found is appropriate to substantiate the need, but it is my hope that the AHCCCS Administration and other stake holders in this process will hear the needs of families such as mine as they are fine-tuning the draft of proposals submitted to CMS and at a minimum include a provision allowing for parents to be the habilitative provider if no other provider is willing to take the case.

---------- Forwarded message ---------
From: Jenny Mullins [redacted]
Date: Thursday, July 27, 2023 at 10:18:54 AM UTC-4
Subject: Data request/Feedback about 1115 Waiver- Parents as Paid Providers
To: waiverpublicinput@azahcccs.gov [redacted], Jakenna Lebsock
[redacted], sara.salek[redacted]
Zane Garcia Ramadan [redacted], [redacted]
[redacted], marcus.johnson[redacted]
[redacted], dara.[redacted]
zdedolph[redacted] carmen.heredia[redacted]
<carmen.heredia , alex....[redacted]
lgibbs[redacted]

Hello all,

I am so grateful for all the work that everyone receiving this email is doing to support DDD members who are minors. It is so very appreciated!

I have submitted feedback about the 1115 Waiver that AHCCCS is proposing to CMS. I wanted to submit additional feedback and ***request current data that DDD or AHCCCS has collected on how many parents are DCW vs how many non-parent DCWs are currently in place.***

I know that this data has been requested multiple times by myself and other advocacy organizations, and it has not been provided. ***Therefore, I would like to formally request the current data from 2023 on how many current DCWs are parent providers of minor children as well as how many DCWs are non-parent providers.*** Can you please email that to me prior to the next DDD feedback session on August 2?

Today at a DDAC meeting it was stated by DDD leadership that there are "approximately 50,000 members and 40,000 DCW." It was also implied that the lack of DCW who are not parents is not that big of a problem.

However, the reason there are approximately 40,000 DCWs is because of how many PARENTS of minors are providing this service for their children. If parents are eliminated as DCWs, it will lead to a huge shortage!

We have requested the data from DDD and AHCCCS to show that there are enough non-parent DCWs to meet the demand for 50,000 or more members.

If AHCCCS does not amend Its proposal to CMS based on stakeholder feedback, this will immediately lead to gaps in care and a HUGE shortage of habilitation providers.

Your help in gathering this requested data will help us better understand the DCW shortage that exists if parents are no longer able to be habilitation providers.

I have been told that agencies are now required to report in the Skynet System how many DCW are parents vs non-parents. If agencies are reporting this to AHCCCS or DDD, then there should be a way to pull this data and make it publically available.

If there is another way to request this data or a form that I need to fill out, please let me know.

Thank you so much for your help in gathering this data. We truly want to make this program one that meets the needs of all members and appreciate all of your time and efforts to support DDD members.

Jenny Mullins
Co -Founder / Program Director
Special Education and Civil Rights Advocate
Council of Parent Attorneys and Advocates (COPAA) Member

ADVOCACY 31nine
[redacted]
Direct Line: [redacted]
Amplifying Your Voice

WANT TO MAKE AN IMPACT IN THE LIVES OF VULNERABLE KIDS?:
[redacted]

---------- Forwarded message ---------
From: Aj Lindner [redacted]
Date: Thursday, July 27, 2023 at 3:30:37 AM UTC-4
Subject: Fwd:
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

I am a concerned community member and have a personal relationship with a DDD and ALTCS recipient currently participating in the Paid Parent Caregiver program under the Covid-19 Flexibility. This program has been extremely beneficial to this disabled child and their family. I would like to share my observations, experience and feedback pertinent to the current proposal for a permanent Paid Parent Caregiver program.

Under the current proposal, the request of the disability and caregiver community for an ongoing program option which allows parents of disabled minors in Arizona to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies is not being met. Please consider updating the proposal based on the following questions, suggested solutions, and experiences.

Should Habilitation be included in the Paid Parent Caregiver Program?
We have heard the concerns about member isolation and lack of community involvement if parents continue as Paid Parent Caregivers facilitating their child's Habilitation services. Respectfully I would like to proposes the following solutions:

1. Examine available research and personal feedback statements from members and their families to evaluate the true potential impacts of social isolation and community involvement when parents of disabled children provide Habilitation services. The parent caregiver community's collective experience is that members who have parents facilitating their Attendant Care and Habilitation services have experienced greater member social engagement and community involvement over the last three years. Parent caregivers now have an increased ability to take their children to sporting team practices, community events, movie theaters, all ability parks, church activities and libraries. This is because parent providers can perform the appropriately trained and qualified supports in the correct time and location that is applicable to each member.

2. Implement precise guidelines to facilitate generalization for all Habilitation providers regardless of the DCW's familial status. Habilitation services are designed to have goals where data is collected to evaluate if those goals need to be changed, have been met, or need to be addressed differently. For a goal to be considered met, a member should be demonstrating that they are able to successfully

meet that goal outside of the timeframe with a provider in one setting. This is referred to as generalization. The effective implementation of generalization with the pediatric IDD population would lessen, if not eliminate, any complications with adult transitional services. Under this model a program that includes parents as paid Habilitation providers would actually assist and improve in the success of adult transition. There are times when disabled children work successfully with different types of providers in clinics or schools, but the parents are not carrying the work over at home. This can happen for a variety of reasons. Having parents as Habilitation providers would help ensure the child's goals are congruent and carried over in the home and community setting. This will give the member a better chance of independence as they transition through different life stages. With generalization policies in place, Habilitation services being performed by parent providers will actually help facilitate successful transition into adulthood.

3. We know from provider agency data that “the top 3 issues regarding recruiting and retaining career non-family caregivers are schedules of the client members, interest in the position and finding qualified applicants.” Most members have Habilitation goals and ADLs that are most appropriately delivered throughout the natural routine of their day. A parent provider is uniquely available in the morning, after school or in the evenings when each member is motivated and focused on the pertinent task. If a non-family provider is available their schedules typically allow them to work in longer time chunks that are not always the most ideal for the member and creates artificial goal or ADL practice. Continuity of care and greater member outcomes can be associated with consistently provided Habilitation care by parent providers who have the greatest ability to be flexible and available for their member children.

Should parent providers be limited to 40 hours a week of paid care per child?
We have heard the concerns of AHCCCS regarding the potential for a difficult adult transition to non-family supports once parent caregivers are no longer able or willing to help facilitate the disabled member’s care. I would like to propose the following collaborative solution to create a win-win scenario:

1. Create a program provision that outlines an extraordinary circumstances clause and the application process that allows parents to provide over 40 hours of paid care per week of authorized and evaluated services per member. These extraordinary circumstances could include, but are not limited to:
    a. The lack of a non-parent DCW being available in the last 3 months to fill the member’s assessed hours that exceed 40 hours per week. Ongoing DCW searches should continue to be made by the member’s agency to fill the assessed hours beyond 40 hours per week of Attendant Care and Habilitation.
    b. The expressed desire made by a member for a parent caregiver to facilitate their assessed DCW hours so that their Article 9 rights are honored.
    c. The profound disabilities and/or significant behaviors of a member where a non-family provider is not equipped to provide DCW support. This determination can be made through a stakeholder team approach, including but not limited to the member’s, DDD Support Coordinator, DDD Nurse, DDD Supervisors, Behavioral Plan Experts, Parents / Guardians, Psychologist, or Medical Doctor.
2. Form equality between all Family Provider Programs by allowing all Direct Care Workers, regardless of familial relationship or member age, to provide up to 16 hours of paid care per day. This will allow for employee equality across the lifespan of the member and limit the potential anti-family provider rhetoric currently present within state policies and DDD Support Coordination culture. All evaluations of hours should be based on member needs regardless of who is providing the services to create uniform implementation of all applicable HCBS services by the DCWs available to fulfill those hours.

3. The Family Support Program currently in this proposal addresses caregiver burnout. It is one of the available solutions to facilitate further community support within the disability and caregiver community that will provide greater access to non-profits facilitating counseling services, support groups and meet up activities.

4. Reevaluate Respite reimbursement rates to also address caregiver burnout. If Respite services are not available to the member or their family, parent burnout will continue to be an issue regardless of parents having the option of providing Attendant Care or Habilitation hours. With a comprehensive Paid Parent Caregiver Program in place non-family DCW providers will have greater flexibility to provide Respite services to these same families.

How should current evaluation protocols, training and practices be updated to facilitate equality for all members when accessing member needs?
AHCCCS has stated their intention to amend applicable policy, further suggested action on this topic includes:

1. Forming a committee of community and department stakeholders to amend and critique current DDD and AHCCCS policies and need assessment forms so that the most effective and efficient implementation of this permanent option is utilized moving forward.

2. Provide appropriately determined training and program implementation to DDD and ALTCS Support Coordinators so that Attendant Care and Habilitation hours are equitably evaluated based on the member's needs and to remove organizational bias of familial providers across the member's lifespan. Specifically investigate and determine appropriate DDD staffing needs and training for the members served in rural areas and those from minority backgrounds.

3. Create the option for private sector Support Coordination. Other states have this option within their Medicaid services, and this could be an additional feature in our DDD portfolio to allow for the member's needs to be best evaluated.

In conclusion, Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. By not allowing parents of minors to provide Habilitation and Attendant Care services or work over 40 hours a week most of the minor disabled community in Arizona will be underserved. A comprehensive Paid Parent Caregiver program validates the irreplaceable work that parents provide in their homes and communities.

Click here to connect with the Arizona parent led grassroot initiative leaders:
www.raisingvoicescoalition.com

Thank you for your time and consideration! The disability and caregiver community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves all DDD and ALTCS members in Arizona.

Thank you!

CMS perspective on the above noted requested program adjustments and paying Legally Responsible Individuals:

June 28, 2023 - Email Correspondence between CMS and Raising Voices Coalition:
https://drive.google.com/file/d/10CPccmIY7gEr5vq9C6vIaKmncSQOV7kc/view?usp=share_link

May 23, 2023 - Transcription of National Meeting between CMS Leaders and Parent Advocates:

https://docs.google.com/document/d/1h02v6Yk7frWGADcqKgm1zmd0uquMNfW3Jcd0zjHCxOk/mobilebasic?fbclid=IwAR2QLqbwJMQQRz0nj-XqhYzlFlkQbUV5wnyAyv98hivRVYpCjaYHhLBCzYg

Studies and data that support the changes being requested:

Data results from a 2023 Arizona survey of parents who have children with disabilities:
https://docs.google.com/document/d/16PZOk99caDUitg0XmQKqEv2mxXOBeaRywSD_zmjAnYw/edit?usp=sharing

A report on the current caregiver crisis by the National Association of Homecare and Hospice:
https://www.hcaoa.org/uploads/1/3/3/0/133041104/workforce_report_and_call_to_action_final_03272023.pdf

Higher satisfaction of paid supports for adults and minors with disabilities when care is received from paid family providers:
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1089106/

A comparison of healthcare utilization when children receive paid care by a family member vs non-family provider: .https://www.jpeds.com/article/S0022-3476(23)00106-3/fulltext

Youth with Autism Spectrum Disorder have less ED visits and patient outcomes when patient providers are involved: https://www.reliasmedia.com/articles/148366-autism-spectrum-disorder-in-the-emergency-department
https://www.psychiatrist.com/jcp/mental/child/youth-with-autism-in-the-emergency-department/

An evaluation of parent provider involvement in generalization of children with autism:
https://www.sciencedirect.com/.../abs/pii/S0891422205000958

Impacts of the caregiving relationship: https://academic.oup.com/gerontologist/article/56/6/1102/2952858

State Approaches to Reimbursing Family Caregivers of Children and Youth with Special Health Care Needs through Medicaid - NASHP
https://drive.google.com/file/d/1TSt-Rj95DTn711EV8UTq7YqF0yoo0j8u/view?usp=sharing

---------- Forwarded message ---------
From: cherry anne macasieb [redacted]
Date: Wednesday, July 26, 2023 at 11:39:58 PM UTC-4
Subject: 1115WAIVER
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

I am a concerned community member and have a personal relationship with a DDD and ALTCS recipient currently participating in the Paid Parent Caregiver program under the Covid-19 Flexibility. This program has been extremely beneficial to this disabled child and their family. I would like to share my observations, experience and feedback pertinent to the current proposal for a permanent Paid Parent Caregiver program.

Under the current proposal, the request of the disability and caregiver community for an ongoing program option which allows parents of disabled minors in Arizona to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies is not being met. Please consider updating the proposal based on the following questions, suggested solutions, and experiences.

Should Habilitation be included in the Paid Parent Caregiver Program?
We have heard the concerns about member isolation and lack of community involvement if parents continue as Paid Parent Caregivers facilitating their child's Habilitation services. Respectfully I would like to proposes the following solutions:

> Examine available research and personal feedback statements from members and their families to evaluate the true potential impacts of social isolation and community involvement when parents of disabled children provide Habilitation services. The parent caregiver community's collective experience is that members who have parents facilitating their Attendant Care and Habilitation services have experienced greater member social engagement and community involvement over the last three years. Parent caregivers now have an increased ability to take their children to sporting team practices, community events, movie theaters, all ability parks, church activities and libraries. This is because parent providers can perform the appropriately trained and qualified supports in the correct time and location that is applicable to each member.
>
> Implement precise guidelines to facilitate generalization for all Habilitation providers regardless of the DCW's familial status. Habilitation services are designed to have goals where data is collected to evaluate if those goals need to be changed, have been met, or need to be addressed differently. For a goal to be considered met, a member should be demonstrating that they are able to successfully meet that goal outside of the timeframe with a provider in one setting. This is referred to as generalization. The effective implementation of generalization with the pediatric IDD population would lessen, if not eliminate, any complications with adult transitional services. Under this model a program that includes parents as paid Habilitation providers would actually assist and improve in the success of adult transition. There are times when disabled children work successfully with different types of providers in clinics or schools, but the parents are not carrying the work over at home. This can happen for a variety of reasons. Having parents as

Habilitation providers would help ensure the child's goals are congruent and carried over in the home and community setting. This will give the member a better chance of independence as they transition through different life stages. With generalization policies in place, Habilitation services being performed by parent providers will actually help facilitate successful transition into adulthood.

We know from provider agency data that “the top 3 issues regarding recruiting and retaining career non-family caregivers are schedules of the client members, interest in the position and finding qualified applicants.” Most members have Habilitation goals and ADLs that are most appropriately delivered throughout the natural routine of their day. A parent provider is uniquely available in the morning, after school or in the evenings when each member is motivated and focused on the pertinent task. If a non-family provider is available their schedules typically allow them to work in longer time chunks that are not always the most ideal for the member and creates artificial goal or ADL practice. Continuity of care and greater member outcomes can be associated with consistently provided Habilitation care by parent providers who have the greatest ability to be flexible and available for their member children.

Should parent providers be limited to 40 hours a week of paid care per child?

We have heard the concerns of AHCCCS regarding the potential for a difficult adult transition to non-family supports once parent caregivers are no longer able or willing to help facilitate the disabled member’s care. I would like to propose the following collaborative solution to create a win-win scenario:

Create a program provision that outlines an extraordinary circumstances clause and the application process that allows parents to provide over 40 hours of paid care per week of authorized and evaluated services per member. These extraordinary circumstances could include, but are not limited to:

The lack of a non-parent DCW being available in the last 3 months to fill the member’s assessed hours that exceed 40 hours per week. Ongoing DCW searches should continue to be made by the member’s agency to fill the assessed hours beyond 40 hours per week of Attendant Care and Habilitation.

The expressed desire made by a member for a parent caregiver to facilitate their assessed DCW hours so that their Article 9 rights are honored.

The profound disabilities and/or significant behaviors of a member where a non-family provider is not equipped to provide DCW support. This determination can be made through a stakeholder team approach, including but not limited to the member’s, DDD Support Coordinator, DDD Nurse, DDD Supervisors, Behavioral Plan Experts, Parents / Guardians, Psychologist, or Medical Doctor.

Form equality between all Family Provider Programs by allowing all Direct Care Workers, regardless of familial relationship or member age, to provide up to 16 hours of paid care per day. This will allow for employee equality across the lifespan of the member and limit the potential anti-family provider rhetoric currently present within state policies and DDD Support Coordination culture. All evaluations of hours should be based on member needs regardless of who is providing the services to create uniform implementation of all applicable HCBS services by the DCWs available to fulfill those hours.

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Provide appropriately determined training and program implementation to DDD and ALTCS Support Coordinators so that Attendant Care and Habilitation hours are equitably evaluated based on the member’s needs and to remove organizational bias of familial providers across the member’s lifespan. Specifically investigate and determine appropriate DDD staffing needs and training for the members served in rural areas and those from minority backgrounds.

Create the option for private sector Support Coordination. Other states have this option within their

Medicaid services, and this could be an additional feature in our DDD portfolio to allow for the member's needs to be best evaluated.

In conclusion, Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. By not allowing parents of minors to provide Habilitation and Attendant Care services or work over 40 hours a week most of the minor disabled community in Arizona will be underserved. A comprehensive Paid Parent Caregiver program validates the irreplaceable work that parents provide in their homes and communities.

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Thank you for your time and consideration! The disability and caregiver community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves all DDD and ALTCS members in Arizona.

Thank you!

Cherry Anne Duterte
[redacted]

PS
I as a parent of a minor with HAB services, is concern with how my son's health and behavior will affect him when there is different people coming to in & out of our home to provide services if you removed Habilitation from parent provider .. Aside from the fact he has low immune system, I don't want it to happen that he will be sick every now and then.. If you will removed habilitation it's like your removing my son's continuity of care for him when other will give him the service.. And how can we become an effective parent when we will not see how their goal will change when other person will handle them.. If there is a case we don't know how to handle them and if they only listen to the habilitation provider how can we manage them.. there is also goals that need personal hygiene, I will not take it that someone will teach my son to wash his private part .. I wish you can take consideration to not remove the habilitation service comes November 2023..thank you

From: Nikki Chapman [redacted]
Date: Wednesday, July 26, 2023 at 10:27:42 PM UTC-4
Subject: Comments for the forum
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello,

Thank you for allowing me to comment on the forum. My husband and I have recently started habilitation with our son and we have seen some great improvements with goals that cannot be worked on in his other therapies, life skills, toileting, stranger danger, swimming, and more. Being able to work on these goals has provided us the opportunity to connect with our son and teach him to be aware, respectful, independent, and motivated. It is wonderful to see our son make such great progress and learn and grow as an individual.

It has also been great to build a better working relationship with our DDD coordinator and attendant care provider. They have allowed us to learn more about programs available for our son as well as develop appropriate goals. They have also been caring and available for questions at any time. Their input has been very useful.

We realize that a lot of the goals we work on with him can be done without receiving pay, but in these tough economic situations, it has been very helpful to have the additional income. We would like to continue hab goals at home as paid caregivers to not only help our son but our family. We ask you to reconsider and urge you to keep this program as it helps not only the children but the parents to work with their kids and watch them learn from their caregivers inside their homes or in public settings.

Thanks,
Nicole and David Chapman

---------- Forwarded message ---------
From: **Abby Gibson** [redacted]
Date: Mon, Jul 24, 2023 at 10:05 AM
Subject: New Proposal Regarding Habilitation
To: <DDDCustomerS...@azdes.gov>

To Whom it May Concern:

I am a mother of chidlren who receives DDD and ALTCS services. I would like to file a grievance against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which would go into place in November 2023, my children and many more like them will lose access to their Habilitation services or more than 40 hours a week of care by parent providers of minor members. The reason my children will not have access to their appropriately evaluated services is due to the DCW shortage. My agency has specifically stated that they will not be able to recruit, hire and train enough providers to fill the gaps in service these new rules will create.
I have already experienced the detriment this staffing shortage will cause *particularly with my son* [redacted]*. I was unable to find anyone to provide Habilitation services for him.*
My provider would line up interviews and people wouldn't show, or would reschedule on multiple occasions, only to never respond again.
I interviewed ***one*** *person in almost three months of waiting.*
Finally, I decided to become his Habilitation provider myself. I also was then able to provide Habilitation for my other two children. Since I have been able to give them consistent Habilitation services they have grown exponentially and I know they are consistently being pushed to do more.
WIthout this program my children would still be without Habilitation as it is still incredibly difficult to find habilitation providers currently, especially for the hours my children require. I also am the most constant and consistent provider they could ever ask for. We're not relying on someone else to show up and do the work.

Please record my grievance and provide me with a case number for my records.

Thank you,

Abby Gibson

---------- Forwarded message ---------
From: **Amanda Marquez** [redacted]
Date: Mon, Jul 24, 2023 at 10:10 AM
Subject: Grievance
To: dddcustomers...@azdes.gov <dddcustomers...@azdes.gov>

I am a parent of a child who receives DDD and ALTCS services. I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which would go into place in November 2023, my child and many more like them will lose access to their Habilitation services or more than 40 hours a week of care by parent providers of minor members. The reason my child will not have access to their appropriately evaluated services is due to the DCW shortage. My agency has specifically stated that they will not be able to recruit, hire and train enough providers to fill the gaps in service these new rules will create.

Thank you for your time, I would like to request a TICKET NUMBER to ensure this grievance has been filed.

Thank you,
Amanda Marquez

[redacted]

[redacted]

[redacted]

[redacted]

---------- Forwarded message ---------
From: **Brandy Coleman** [redacted]
Date: Mon, Jul 24, 2023 at 8:37 PM
Subject: Filing a grievance against DDD and AHCCCS
To: dddcustomers...@azdes.gov <dddcustomers...@azdes.gov>

I am a parent of a child who receives DDD and ALTCS services. I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which would go into place in November 2023, my child and many more like them will lose access to their Habilitation services or more than 40 hours a week of care by parent providers of minor members. The reason my child will not have access to their appropriately evaluated services is due to the DCW shortage. My agency has specifically stated that they will not be able to recruit, hire and train enough providers to fill the gaps in service these new rules will create.
Thank you for your time, I would like to request a TICKET NUMBER be sent to me upon receipt of this email.

Thank you

Brandy Coleman parent of [redacted] Coleman

From: **Holly** [redacted]
Date: Mon, Jul 24, 2023 at 10:06 AM
Subject: File a Grievance against DDD & Ahcccs
To: dddcustomers...@azdes.gov <dddcustomers...@azdes.gov>

Good Morning,

I am a parent of a child who receives DDD and ALTCS services. I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which would go into place in November 2023, my child and many more like them will lose access to their Habilitation services or more than 40 hours a week of care by parent providers of minor members. The reason my child will not have access to their appropriately evaluated services is due to the DCW shortage. My agency has specifically stated that they will not be able to recruit, hire and train enough providers to fill the gaps in service these new rules will create.

Thank You,
Holly Brittain
[redacted]

---------- Forwarded message ---------
From: **sarah maichl** [redacted]
Date: Mon, Jul 24, 2023 at 10:32 AM
Subject: Grievance
To: <DDDCustomerS...@azdes.gov>

Good Morning

“I am a parent of a child who receives DDD and ALTCS services. I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which would go into place in November 2023, my child and many more like them will lose access to their Habilitation services or more than 40 hours a week of care by parent providers of minor members. The reason my child will not have access to their appropriately evaluated services is due to the DCW shortage. My agency has specifically stated that they will not be able to recruit, hire and train enough providers to fill the gaps in service these new rules will create.

Thank you for your time, I would like to request a TICKET NUMBER.

Sarah Maichl
[redacted]

From: **Sarah Blank** [redacted]
Date: Mon, Jul 24, 2023 at 10:59 AM
Subject: Grievance
To: <DDDCustomerS...@azdes.gov>

Good morning,

I am a parent of two children who receive DDD and ALTCS services. I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which would go into place in November 2023, my children and many more like them, will lose access to their Habilitation services or more than 40 hours a week of care by parent providers of minor members. The reason my children will not have access to their appropriately evaluated services is due to the DCW shortage. My agency has specifically stated that they will not be able to recruit, hire and train enough providers to fill the gaps in service these new rules will create.

I would like to request a ticket number in response to my grievance.

Thank you for your time,
Sarah Blank

From: Malia Leyvas [redacted]
Date: Wednesday, July 26, 2023 at 3:35:30 PM UTC-4
Subject: Parent Caregivers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Good Afternoon,

I would love it if you would permanently allow parents to remain as paid caregivers. My son has Down Syndrome/non-verbal and a heart condition and needs 24/7 care. He was trached his first [redacted] years of life and it was always hard to get respite and hab. Even after his trach got removed it has always been a struggle to get respite/hab relief. Since Covid there has been no luck in finding caregivers for my son. I also live in [redacted] and it is extremely difficult to find anyone to provide respite/ hab because of my location. I have been fulfilling all my sons needs/care with no help. I am a single mother and also have a teenager and would really benefit if you continue to let parents stay as permanent caregivers. I also was wondering if siblings would be able to provide respite when they are of age and go through training when parents need extra help. Thank you for allowing this program and for parents input. I really hope it gets approve because it is a big help for parents.

Thank you,
Malia Leyvas

From: Dawn Penninger [redacted]
Date: Wednesday, July 26, 2023 at 2:50:28 PM UTC-4
Subject: paid parents
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To whom it may concern,
I believe that you should keep parents as paid caregivers. So many of us can't work. I as a parent can't work. It would be nice if it didn't go against our SNAP benefits

From: JaNel Stewart [redacted]
Date: Wednesday, July 26, 2023 at 2:36:39 PM UTC-4
Subject: Parent Caregiver Program
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

I am a parent that has two children who receive DDD and ALTCS services combined they need and utilize (ATC 57 hours, Habilitation 87 hours) . I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility for less than 1 year as my Support Coordinator never told me about the program even though we had no provider for a year because we could not find an available provider to work the hours. I found out from a fellow mom about the Paid Parent Caregiver Program. I am upset that I didn't find out about this program sooner when we had no provider for a year and I am upset that after just finding out about the program less than a year ago, it seems it is ending after it has been extremely beneficial to our family and both of my children. If the program ends as it currently is, I know I will be without a provider again with little to no hope of finding one and my two children are the ones who will suffer. I would like to share my personal experiences and feedback based on my review of the current proposal for a permanent Paid Parent Caregiver program.

Under the current proposal, the request of an ongoing program option which allows parents of disabled minors in Arizona to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies is not being met. Please consider updating the proposal based on the following questions, suggested solutions, and personal experiences.

Should Habilitation be included in the Paid Parent Caregiver Program?
Absolutely! My children are improving as specific goals are worked on individually. We have goals that focus on community involvement and social outings to help them out in the community and at home. If it ends, there aren't enough providers to fill this vacancy. With school starting up we work on Habilitation goals from 6am-7:25am when school starts. There are no providers willing to come at 6am for a shift that is less than an hour and a half. Additionally we work on Habilitation Goals after school from 2pm-9pm. We have been unable to fill this late night shift as we cannot find providers willing to work until 9pm. And again we need providers for both our children with disabilities. As a parent I have a degree in Recreation Management and Youth Leadership from [redacted]. I was also an EMT, CPR/First Aid/AED Instructor, and a lifeguard instructor. Perhaps your concern with Parents providing Habilitation could be responded to by requiring more caregiver training. As of now I have been more qualified than any providers we have had in the home and therefore I am doing an excellent job meeting the needs my children have to help them overcome life skills that are needed.

Should parent providers be limited to 40 hours a week of paid care per child?
No! Again we have a major issue with there not being enough providers in our state. If hours are

assessed for the child, the child needs the hours and limiting those hours only hurts the child not having their needs met. Please remember everything here is about meeting the child's needs. So it shouldn't matter the number of providers there are, just as long as the child's assessed hours are being met. It shouldn't be capped at 40 hours a week for anyone, it should only be capped at the number of hours that the child was assessed for. If you are unwilling to change the 40 hour a week cap per child, please consider making it 40 hours each or per person and not 40 hours per parent unit. A dad should be able to work 40 hours and a mom should be allowed to work 40 hours independent of each other. Between my two children they utilize ATC 57 hours and Habilitation 87 hours; the way you are proposing a 40 hour limit, we would need providers for 64 hours yet we went a year with no providers at all because we couldn't find one, not much has changed since when looking for providers. We have been looking for providers since May this year and still have not had anyone to interview. In my experience trying to get providers, the providers are unable to do the hours or they only want regular daytime hours and children are in school during those times but care is needed day and night.

You have the power to help our disabled children get the help they need. Whatever your decision, please don't cut anything off cold turkey and leave our children with no help for days, months, and years on end. That's how it was before the Paid Parent Caregiver Program and we can't go back to the way it was with no providers to help our children. Please consider a minimum 12 month grace period to allow us parents time to figure out how to implement any changes to this program you are making. Then please schedule a followup at 12 months to see if your changes were successful and best for the children or if the changes you made are failing them due to a lack of providers in the state.

Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves all DDD and ALTCS members in Arizona.

Thank you,

JaNel Stewart
[redacted] AZ
[redacted]

From: **Jenny Mullins** [redacted]
Date: Tue, Jul 25, 2023 at 9:11 PM
Subject: File a Grievance- Lack of DCW available
To: DDD Customer Service Center - DES <DDDCustomerS...@azdes.gov>

Hello,

I am a parent of a child who receives DDD and ALTCS services. My child's name is [redacted] Mullins [redacted] [redacted]. My current agency is AZA United.

I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which would go into place in November 2023, my child and many more like them will lose access to their Habilitation services or more than 40 hours a week of care by parent providers of minor members. The reason my child will not have access to their appropriately evaluated services is due to the DCW shortage. My agency, AZA United has specifically stated that they will not be able to recruit, hire and train enough providers to fill the gaps in service these new rules will create.

I would like to request a TICKET NUMBER for this grievance so that I know this matter is being dealt with.

Thank you for your assistance!

Sincerely,
Jenny Mullins

From: Kellye Marie [redacted]
Date: Friday, August 18, 2023 at 11:34:35 AM UTC-4
Subject: Continue Parent Program
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Good Morning,

I am a parent of an autistic [redacted] year old little boy. I am his paid provider to help him acquire skills that peers his age already have. Who better to help him than the person who loves and cares about him most than anyone in the world? There aren't an abundance of health providers willing to do what we as parents are doing. Why take that away from parents and children who need their parents help? It's not about the money because trust me when I say we as parents would give every single cent we have if it meant our children didn't have to struggle the way they do. Unfortunately, that's not reality so please continue to allow parents to be the providers for their children. You're paying someone either way so why not the people who love them and want the best for them?

Thank you,

Kellye

From: Ann Garcia [redacted]
Date: Friday, August 18, 2023 at 11:16:12 AM UTC-4
Subject: RE. LONG TERM CARE PROPOSAL
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

hello were are commenting about the long term care proposal to cut the program for the attended care for parents. iam a mother whose husband is taking care of our disabled daughter who was born completely disabled..she is [redacted] now and she has cortical vision impairment, development delayed,she cannot walk or talk or sit up or eat by herself she is totally dependent on us to take care of her completely she has neuropathy issues she has cerebral palsy and signs of scoliosis she is gtube fed and her immune system can get compromised due to anyone who is sick or has a virus..we cannot have a provider come into our home due to [redacted] medical conditions and i have family staying with us as well and they are disabled as well we completely benefit from this program due to dad not being able to work cause [redacted] needs 24hr care from someone who knws her cries, her wants,her needs, or if she needs something else, dad is certified and knows exactly what she needs and wants..I feel like the patient or child with these disabilities dont have a VOICE TO BE HEARD AND I AM HERE TO STAND FOR MY DAUGHTER AND I AM COMING TO YOU AS MOTHER THAT IF U TAKE AWAY THESE BENEFITS OUR CHILD WILL BE WITHOUT THE RIGHT CARE THEY NEED...I DONT TRUST ANOTHER PERSON OR "CAREGIVER" COMING IN PRETENDING THEY R REALLY THERE FOR MY CHILD AND THERE ONLY THERE FOR PAY...PLEASE CONSIDER EXTENDING THE PROGRAM AS WE AND ALL PARENTS DESERVE TO B ABLE TO DO THIS PROGRAM AND FEEL THAT THERE CHILDS NEEDS ARE MET THANKS FOR HEARING ME OUT ON THIS MATTER...PLEASE CONSIDER THE CONSEQUENCES AND THE WAY THE CHILD WILL BENEFIT...

A MOTHER WITH A VOICE

---------- Forwarded message ---------
From: L Bright [redacted]
Date: Friday, August 18, 2023 at 11:04:18 AM UTC-4
Subject: Parent CareGiver Pay
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Good Morning,

I am writing this in response to public opinion query. It is my opinion that no person understands the needs of a special needs child other than their parent or guardian. Provision of monies to direct family or legally appointed caregivers addresses the following:

1. Allows the parent/guardian to remain at home to care for their special needs child as opposed to the parent/guardian having to seek employment outside the home
2. Assures continuity of care delivery to special needs children with complex chronic conditions and acute exacerbations of these conditions
3. Mitigates disruption in care delivery for special needs children therefore minimizing errors in care or unintentional harm to the child due to change in caregivers over the course of time
4. Early identification in change of conditions of the special needs child that may be “subtle” but critical in nature. The parent/ guardian is more likely to notice changes in condition that may result in hospitalization if not addressed sooner than later
5. Provides peace of mind for the parent/guardian that they may remain home with their special needs child and not have to fret if the peripheral caregiver will be late, call-off duty, have no knowledge of the medical and psycho-social history of the child and quite frankly not be “invested” in providing care with compassion, kindness and grace
6. Individuals who may be coming in a setting to care for a special needs child do not have the expertise, knowledge and training in caring for special needs children’s developmental and behavioral health needs in addition to the medical care they require.

With over 40 years of nursing experience, including over a decade as a Board Certified Family Nurse Practitioner it is my professional and personal opinion it is incumbent upon our community leaders to utilize critical thinking, sound judgement, and objective data in evaluating their decisions that impact those with serious, chronic conditions; especially within the special needs pediatric population.

Respectfully submitted,

LuAnn Bright, RN, BSN, MSN, FNP-BC

From: Stefney Crawford [redacted]
Date: Friday, August 18, 2023 at 10:51:17 AM UTC-4
Subject: Parents as paid providers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

8/20/2023

To whom it may concern,

This is a topic I am extremely passionate about. Although my child is now an adult, this issue is critically important for parents of minor children that are providing paid care for their children. Providing paid care for their minor children should remain in place. I cannot tell you through the years the number and times of extreme hardship I personally faced (and others I know in a similar situation), by NOT being provided this option. WE know our children the best. If that is something that we are able to do for our children, by all means, please allow us this opportunity!! Many times I was literally left stranded by inept providers, providers that didn't show, ongoing and last minute scheduling conflicts. This led to lost opportunities for both my child/myself, from emotional distress, to financial insecurity, to job loss, and many, many other distressing situations. The list goes on and on. This is not right, and damages on so many levels, and creates a ripple-down effect. There is no reason, if our schedule allows, that we shouldn't be paid providers! Our lives are altered beyond people's comprehension because of the challenges we are faced with raising children with disabilities. There is no question about that! Don't make our already difficult and challenging situation harder and more demanding by taking away this lifeline and option! Unless you have had a child in this situation, you really cannot fully comprehend all of the different variables and difficulties we as parents face! Both parent and child benefit immensely by allowing and providing this option. Let the people that are most qualified (the parents), have this choice and opportunity! Should you have additional questions or want additional information regarding this, feel free to reach out to me.

Sincerely,

Stefney Crawford

From: Mandy Pleis [redacted]
Date: Friday, August 18, 2023 at 9:51:03 AM UTC-4
Subject: Parent as paid providers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

I have to say that this program has given me, a Grandmother/Permanent guardian of my grandson, the ability to be able to better care for him. The program itself as proposed today is invaluable. I am able to afford, without collecting any welfare benefits for my family to live. I have the ability to work his habilitation goals as a part of our daily lives, every day. I can provide the consistency that is necessary for an Autistic child and his proper development, without interruption periods over and over again, of getting to know someone and open up, due to his social emotional needs. We all know caregivers come and go quickly and never stay the same. There are no gaps of time left infilled due to staffing shortages. This is months and months. The child doesn't go without. The goals are started over and over again with inconsistent teachings and confusion by him.
Also, this program allows me as a parent paid caregiver to be able to work with him on his schedule. I will never find a caregiver for habilitation willing to work with his hours. They would have to be live ins honestly. I work his habilitation such as showering at 6:15am and his use of problem solving daily life skills until 7:50am. He then begins school and is not home until 1:15. At which time a caregiver would have to be willing to come back to my home by 1:15pm and stay with him working going out in public for social aspects, and, working on reading facial cues and emotion support, as well as, teaching him how to request for his needs, until 9pm at night 2 days a week and give up their own Sundays 12 hours to work with him. Or attend social functions on a Sunday 12 hours and every other week change part of the schedule to Wednesday as well, to allow for his other therapies and work around school hours. There is no way I could remotely find a person to give that amount of teaching and instruction, and, time to my child in my complete care. Please understand the value of this program doesn't just mean lazy parents. It means the ability of us to care for our children, not rely on people who won't show, and, get fired from jobs due to no one to provide the hours for our children, we aren't all putting any strain on the welfare system, and, the future of alot of these children can and will be future taxpayers with incomes of their own due to these teachings. Without this program many parents would have to be on the welfare system for the lack of income due to the lack of providers and care givers there is and the scheduling that would be the child's availability in real life. We and our kids deserve to be able to live and learn and progress, not back tread, and, suffer. The pandemic caused alot of bad, but, in other aspects alot of good came from it to. Let's not destroy the hope and of a brighter future for our children.

Sincerely
Mandy Pleis
[redacted]

From: Dave [redacted]
Date: Friday, August 18, 2023 at 3:07:18 AM UTC-4
Subject: Caregiver Benefits for Parents Program
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To Whom It May Concern:

We are writing to you to ask and plead that you keep and continue the Caregivers Benefits for Parents program as is.
Prior to this program, we had difficulties finding the right provider, habilitator and a special needs educator for our son. When we find one, it proved to be difficult for my son to warm up and adjust to having a stranger or new person working with him at home. Turnover was high and it would take months before we'd find another provider with experience and is properly trained to help with our son.

Since this program started, we have been able to get family members trained and certified to help care for, supervise, educate and assist with our son's daily needs and routine. Working with familiar people has not been an issue and our son has thrived in his various therapies.

Please continue this program as it provides peace of mind for all parents of children enrolled in DDD and ALTCS.

Sincerely,
Dave Dizon

From: Kennia Rivera [redacted]
Date: Thursday, August 17, 2023 at 7:47:50 PM UTC-4
Subject: Padres proveedores
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Buenas tardes! Soy madre proveedora. Muy agradecida con l oportunidad d atender y trabajar p mi Hija.. atendiendo todas sus necesidades, q uno como madre, sabe hasta donde llegamos.. y es una ayuda económica p esta situación q estamos viviendo, todo a la Alza y así estar siempre al cuidado d nuestra familia sin salir d casa! Ojala y esa propuesta ya quede permanente d que todos los padres nos quedemos , a trabajar con nuestros hij@s, mejor con nosotros q con otras personas q no los conocen nuestros nin@s.. De ante mano Gracias!!.

From: AZA United [redacted]
Date: Thursday, August 17, 2023 at 4:44:34 PM UTC-4
Subject: Public comment and position statement
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

AZA United supports continuation of the current Parent Provider program, at least through September 2024 as AHCCCS and DDD had previously assured us. We feel strongly that a sudden change in November that no longer allows parents to provide Habilitation would be extremely detrimental for many families and the system of care as a whole. There are currently thousands of parents across the state participating in this program, and it is virtually impossible to replace those services with non-parent providers that quickly. Additionally, we have collectively observed the significant benefits that this program offers children when parents can participate in services if that is what they feel is best for their child.

We believe that having a mix of services from parents and non-parents can help create a more consistent approach with improved continuity and flexibility to help meet the child's needs through different stages and transition phases. Therefore, we support the notion of making Habilitation a permanent option for parents in the new AHCCCS waiver, in addition to Attendant Care. We hope to participate in any future policy discussions that may determine any limits regarding the amount of service hours that parents can provide, as well as any other new requirements that seek to ensure that these services are as or more impactful as they would be if done by a non-parent provider.

Aaron Blocher-Rubin, PhD, BCBA

President & CEO

Arizona Autism United (AZA United)

On Thu, Aug 17, 2023 at 11:04 AM Marlena Tholen [redacted] wrote:

> Brenda,
>
> Sorry about that, I am working with All Aboard Services.
>
> Marlena Tholen

---------- Forwarded message ---------
From: **Marlena Tholen** [redacted]
Date: Wed, Aug 16, 2023 at 10:24 AM
Subject: GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal
To: DDDCustomerServiceCenter@azdes.gov <DDDCustomerServiceCenter@azdes.gov>
Cc: Marlena Tholen [redacted]

I am a parent of a child who receives DDD and ALTCS services. **I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal.** Under this proposal, which would go into place in November 2023, my child and many more like them will lose access to their Habilitation services or more than 40 hours a week of care by parent providers of minor members. The reason my child will not have access to their appropriately evaluated services is due to the DCW shortage and many providers not available in my area.

Marlena Tholen [redacted] Tholen)

On Wed, Aug 16, 2023 at 3:22 PM Marlena Tholen [redacted] wrote:

Hi Brenda!

My child's information is:

[redacted]

I had spoken to several agency's quite some time ago, my apologies for not having a list, but I could not find any that would service in-home care in [redacted]. They don't come out this far east. I became a parent provider in [redacted] and that has been working out well and I would hate for my son to lose that benefit.

Thank you for reaching back out, I truly appreciate it. Have a great day!

Marlena Tholen

[redacted]

From: Candice Leigh [redacted]
Date: Thursday, August 17, 2023 at 2:08:48 PM UTC-4
Subject: Pro keeping parents on for habilitation permanently
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

There are more benefits for the children having parents be allowed to work habilitation with the kids. Please consider the following from a parent who had habilitation done by an outsider compared to doing it myself.

Pros to having parents be able to provide habilitation:

1. Parents are more readily available and can provide consistency. Outside habilitation providers cancel and change too much.

2. Parents can be available when the child is ready to do habilitation. It gives a sense of flexibility to the child, which many of these children need.

3. The parents already have a bonded relationship with the child and knows the child's quirks and needs. It allows them to provide a more unique service to the child.

4. The funds are already going to habilitation providers, why not allow the parent to be the provider? It doesn't make a difference financially.

5. There aren't enough providers to service all the children. For most services there is some kind of wait list. Parents can provide the service without a wait list.

I am requesting habilitation to be permanently available for parents to provide these services.

From: Heather Burns [redacted]
Date: Thursday, August 17, 2023 at 12:59:48 PM UTC-4
Subject: Parent paid provider input
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Good morning,

I'm writing this morning to share my testimoy/ comments on the changes being made to parents as paid providers initiative.
Our family had some wonderful respite/habilitation/attendant care providers for our 2 kids that receive services but then they moved away. We worked with 3 different agencies as well as had the support coordinator put out vendor calls trying to get them a new provider for a year but to no avail. After the support coordinator sent out yet another vendor call and the only calls I received all 3 places told me the only thing they could do was get me set up as a parent provider as there was no one available to cover our needs.
I have now been my kiddos provider for habilitation and attendant care for a year now, but while doing this we are still actively listed with several agencies trying to get a respite provider that will then be able to take over doing the habilitation once they have bonded with our kids. I check in with the agencies to see how the search is going but each time am told there just isn't anyone available so I continue to do the care. I have no problem doing it as long as needed.
My concerns with this change of removing habilitation is that 1) we are unable to get someone else in to do the job because there simply isn't enough people accepting these jobs at the agencies 2) a lot of the agencies promise qualified people who have worked with special needs kids and receive training but the last several people sent to me had little experience watching kids and zero experience with special needs kids and only worked 1 or 2 shifts before quitting. 3) if we don't have someone working their goals they will back slide in their abilities 4) if hours are not being used we are told they will get taken away which then I will have to fight to get them back if/ when we are able to get a provider. 5) needing to be a stay at home parent to care for our special needs kiddos has provided a financial burden on our family so having this option to earn income while helping our children learn new goals has also helped our family become more financially stable. Losing this option puts us back in the same situation with me needing to be home and not being able to go get another job. 6) In the public forum meeting it was stated that parents have a choice in who provides the care to their kids but by not including habilitation as one of the services then you are taking that right away from parents.

I'm happy you are working to make parents as paid providers a permanent option but for a lot of families if habilitation is not included in that option then we will not be able to be a paid provider for our kiddos as most parents providing services right now are providing habilitation services to their kids.
I also have no problem continuing to look for and interview additional providers to be their provider if that were to be a stipulation, its just while no one is available I feel I should be allowed to continue providing the service as my kids deserve to learn new skills and grow and they don't deserve to lose services because no one is available to work the needed hours.

If you have any questions for me you can reach me at my email: [redacted] or by phone at [redacted]
Thank you for your time.
Heather Burns

From: **Amy Staren** [redacted]
Date: Tue, Aug 15, 2023 at 9:11 PM
Subject: Paid Parent Caregiver Proposal Grievance
To: <DDDCustomerServiceCenter@azdes.gov>

Hello,

I am a parent of two children who receive DDD and ALTCS services. I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which would go into place in November 2023, my child and many more like them will lose access to their Habilitation services or more than 40 hours a week of care by parent providers of minor members. The reason my child will not have access to their appropriately evaluated services is due to the DCW shortage.

Thank you for your time, I would like to request a TICKET NUMBER for this grievance.

Sincerely,
Amy Staren

From: Gina Gillmore [redacted]
Date: Thursday, August 17, 2023 at 12:10:47 PM UTC-4
Subject: Habilitation
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To who it may concern,
I feel that no longer allowing parents to provide habilitation would be a huge disservice to the children. First of all there are not nearly enough of non family providers to help the children, therefore many children would go without much needed services.
Secondly by me being able to provide services to my two children, it helps supplement my income so I only have to work outside the home four days a week. Which gives me a extra day and flexibility to not only teach them much needed skills but time also to get them to needed therapies. If I was able to find a provider for services[which could take months}, it would be a strain on my family to try and find the time for them to come into my home,with me having to take on additional day and hours at mywork.
I feel as a society, it’s our responsibility to give the children much needed services to help them learn the to hopefully be able to take care of themselves and be self sufficient.
In closing, I would ask you to please consider the ramifications of discontinuing parent habilitation.
Sincerely,
Gina Gillmore

From: Carrie Goettl [redacted]
Date: Thursday, August 17, 2023 at 9:49:42 AM UTC-4
Subject: Habilitation care from parents
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To Whom it May Concern,

As a parent of a child with multiple disabilities, I have to admit I am so grateful to have the opportunity to provide HAB services to my son. It has allowed us to naturally and systematically meet his goals. He has made more progress at this as it has become a precious and cherished time between us. We are able to work on thew goals throughout the day as they naturally need to be addressed in typically situations, as opposed to brushing his teeth, dressing, cooking meals all when it isn't natural to do so. It also gives him a break from the "therapy" feeling of a kid who has many hours of that a week.

As his parent, I intimately know his needs and am able to take him in the community and see that those are met and encourage him to use his communication device, to develop boundaries, and skills he needs.

I have been frustrated that supervisors have tried to deny him hours that relate to him using his communication device, or try to compose goals that are not at all what we are trying to express as far as behavior and respecting the space of others.

Raising Voices Coalition and parents of minor DDD members across Arizona ask you to join with us to request changes to the AHCCCS Paid Parent Caregiver Proposal in order to provide a permanent solution that will provide equitable care to all minor DDD members.

Extraordinary Care and Ordinary Care are currently being evaluated for minor DDD members by individual Support Coordinators through assessments for Attendant Care and Habilitation hours based on their personal discretion and ideology because the current standardized tool provided for their use by DDD covers cradle to grave development instead of age appropriate developmental standards.

Under the current proposal put forth by AHCCCS for a permanent Paid Parent Caregiver Program in Arizona, there is no framework to define Extraordinary Care and Ordinary Care of minors. The current intention of AHCCCS is to build in safeguards that allow for Ordinary Care. However these safeguards would create unequal access to Extraordinary Care to some DDD and ALTCS members based on their individual needs assessments.

According to CMS which gives the framework for all states to create Medicaid waiver programs that provide appropriate supports for their members, Extraordinary Care is defined ‘as care exceeding the range of activities that a Legally Responsible Individual (parent of a minor or spouse) would ordinarily perform in the household on behalf of a person without a disability or chronic illness of the same age, and which are necessary to assure the health and welfare of the participant and avoid institutionalization. If the state allows Legally Responsible Individuals to provide waiver services, it must establish criteria that define extraordinary care.’ In addition, Ordinary Care is defined as, ‘the typical responsibility of a Legally Responsible Individual ordinarily provided to people, with or without a disability or chronic illness.’

(page 121 [redacted])

In public forums regarding the new Paid Parent Caregiver Proposal there has been discussion between AHCCCS leaders and community members around Ordinary Care and the roles of Legally Responsible Individuals. AHCCCS leaders are currently proposing program restrictions (40 hour weekly cap on Attendant Care and removal of Habilitation) for Parents Providers of members under the age of 18. This would limit access to authorized care hours currently performed by the parent providers.

In order for Extraordinary Care to function equitably in Arizona, AHCCCS leaders need to define Extraordinary Care and create new evaluation tools for Support Coordinators to use in the evaluation of Attendant Care and Habilitation for minors. This is necessary for Arizona's permanent program which allows parents of minors to perform paid waiver services because disabled minors have unique Extraordinary Care needs at each stage of development.

We can no longer operate within a system that leaves these determinations up to individual Support Coordinators without the correct framework to support their understanding of Extraordinary Care. Families in Arizona have experienced a wide degree of evaluation inconsistency and discrimination across the minor DDD member population under the current lack of appropriate evaluation tools.

The framework to define and evaluate Extraordinary Care through the individual planning process should be built into the evaluation tools for services instead of the blanket regulation of a permanent Paid Parent Caregiver Program.

The Raising Voices Coalition Requested Changes to the Paid Parent Caregiver Proposal and parent caregivers across Arizona believe that these changes will allow for Extraordinary Care and Ordinary Care of minors to be appropriately evaluated throughout their years of development regardless of who provides the service hours.

If you have any further questions feel free to contact me directly or our grassroots leaders Brandi Coon and Lauryn VanRooy.

[redacted]

Thank you for your consideration as we collaborate to create the most optimal program to serve the needs of our minor members.

Thank you,

Carrie Goettl
[redacted]

From: Melinda Rubio [redacted]
Date: Wednesday, August 16, 2023 at 6:19:29 PM UTC-4
Subject: Input on Proposal
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

My name is Melinda. **My daughter is disabled.** Since she is a non-verbal disabled [redacted], I have not been comfortable allowing a DCW, who is a stranger, to be alone with my daughter while her father and I go to work (due to the fact that if her DCW did or didn't do something to/for her she would not be able to let us know). So while my husband has continued to work, I have not been able to go back to work since her birth but in [redacted], **I became my daughters DCW** for habilitation and attendant care full time. Now our household has two incomes again after three years with only one.

This is why my family and I are thrilled to hear that there is a proposal to take the temporary COVID-19 relief of allowing parents to become paid DCW for their children and make it a permanent opportunity for disabled children and their families.

- Disabled children would be in the care of their parents which sets up the perfect environment for those children to thrive as they will be supported by the person who cares for them most. (No DCW would be as motivated as the parent would be to stay on top of the child's occupational, speech & physical therapies etc)
- Families, like mine, that have given up income in order to care for their disabled child will be able to have income again while still being able to support their disabled child's demanding needs throughout the day.
- Companies hiring parents as Direct Care Workers will have some relief from the high turnover that comes with the difficult job of being a DCW.

I strongly believe that both attendant care and habilitation should be offered to the parents. I attended the 8/2/23 forum and it was stated that allowing parents to provide habilitation will not be in the proposal because they believe that having a DCW would create a more sociable environment for disabled children as well as preventing parents working as DCW from experiencing burnout. **Speaking from experience, this is why I disagree with the decision to leave out habilitation.**

- I am able to take my daughter to the library, park and play dates. A company assigned DCW would not be able to do those things. They would just be at home by themselves.
- If habilitation is offered to parents they will have the choice to take it but if they feel like they will experience burnout then they can deny that option and get a company assigned DCW instead. Having the option will allow parents to decide what limitations they may or may not have without taking away from the parents who would love to provide habilitation and have been doing so since the parents as paid DCW opportunity started.
- Families like mine can still have the opportunity to have full time income.

Thank you for your time in reading this and thank you for allowing us families who are a part of the parents as paid DCW to provide their feedback on this proposal.

Melinda Rubio

[redacted]

From: Caroline Conner [redacted]
Date: Wednesday, August 16, 2023 at 6:14:17 PM UTC-4
Subject: Paid Parent Provider Comments
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Paid parent provider habilitation is absolutely necessary to keep in place permanently. Eliminating the program would be detrimental to families and their children who need it.

From: Arturo Rodriguez [redacted]
Date: Wednesday, July 26, 2023 at 2:03:36 PM UTC-4
Subject: 1115 Waiver Amendment Feedback
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>
Cc: Beatriz Benitez [redacted]

Hello,

This email is regarding the plans to amend the 1115 waiver making the Parents as Paid Providers for minors a permanent program. Our agency is Casa de Rosa LLC, and we are currently an HCBS vendor for the Pima/Tucson region. We have been present in the last two Public Comment Forums with this discussion to hear stories as well as gather more information about the topic before sending out an official opinion.

From our end, the 1115 waiver allowed many of the families that we service to get through the social, health, and financial hardships that came from the Covid-19 Pandemic. Since the Pandemic, some of our families have decided to continue with the Parents as Paid Providers program due to the increase in flexibility they have in their family structure. For example, some families with younger children can continue to have financial stability because a parent is able to provide services at home, as opposed to having to decide to forego an income so they can provide the same level of care. Furthermore, many parents who have historically struggled to obtain a provider due to the current provider shortage we have, can have an income while covering the holes in the member's schedule.

Leading up to the open forum we had asked the families that we serve their thoughts about the 1115 waiver amendment and one trend for parents that decided not to take advantage of the program as due to concerns of an end date where they would have to disrupt their new lifestyle and go back to seeking employment elsewhere. Similarly, some parents were concerned about leaving their current employment and then not being able to return once the program is over. A permanent implementation of the 1115 waiver would give parents the ability to decide how they can best and consistently meet the needs of their members and for their family. We wish you the best in the waiver amendment process and are happy to provide any assistance during the process.

Thank you,

Arturo Rodriguez M.A.

[redacted]

[redacted]

Phone: [redacted]

Fax: [redacted]

[redacted]

From: **Katherine Rodriguez** [redacted]
Date: Mon, Jul 24, 2023 at 2:58 PM
Subject: File a Grievance against DDD and AHCCCS

To: DDD Customer Service Center - DES <DDDCustomerS...@azdes.gov>, <C...@azahcccs.gov>

Katherine Rodriguez representative for
[redacted] **Rodriguez**
Ahccs id #[redacted]
[redacted]

Hello
I am a parent of a child who receives DDD and ALTCS services. I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which would go into place in November 2023, my son and many more like them will lose access to their Habilitation services or more than 40 hours a week of care by parent providers of minor members. The reason my son will not have access to their appropriately evaluated services is due to the DCW shortage. My agency has specifically stated that they will not be able to recruit, hire and train enough providers to fill the gaps in service these new rules will create.We barely can get any services now this would be detrimental to our life's we parent providers feel discriminated on because of this proposal we are the only ones that can provide services because of this shortage and because of the level of safety we want for our child. We hope to come to a positive resolution in this proposal.

From: Luisa Guzman [redacted]
Date: Tuesday, July 25, 2023 at 9:54:48 PM UTC-4
Subject: Re hrs for parents
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello! I just wanted to introduce myself, My name is Luisa Guzman.

I wanted to give my personal opinion about the "US" that work (providing services for my our own children. This is very important that you keeps this going as us parents are able to be home and provide services for our own. Some of us parents have children that are very sensitive autism or Down syndrome children that need us parents at home. I hear a lot of outside caregivers abusing special needs children, because us parents are out working. This opportunity that was given to us parent is the best! I enjoy being and working with my special needs child. I know my child will be safe when I'm home with them. If this is taken away, I wouldn't even be able to work right outside my home. Just thinking so many things can happen well I'm out. So please let us parents keep working with our own children. Thank you.
[redacted]

From: Holly Shuster [redacted]
Date: Tuesday, July 25, 2023 at 7:56:42 PM UTC-4
Subject: Parent of Paid Provider Program
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Good afternoon,

As a friend and family member of several ALTCS members and also a employee of DDD I would like to express my concerns.

I attended a public forum and believe the current proposal should remain as is AND not permanent - to be offered while the workforce is expanded to meet the members needs.

For my friends and family they all have become paid caregivers for their minor children (with the exception of one) when they did not NEED these services and the family circumstances did not change compared to the circumstance prior to the PHE. What did change was pressure to become providers for their children from vendors who take a cut of the pay allotted. They were contacted by these vendors directly to become providers. This alleviated them (the vendors) from hiring providers. These vendors told them that they do these things for their children anyway so they may as well be paid. They coached them in what to say during assessments to increase hours for attendant care. So both they were not responsible for hiring needed caregivers because they had a built in workforce and they contributed to a false "need". In my personal were to go away tomorrow not one of my friends or family members would choose to have an outside caregiver come in to help. So is this really a need?

Vendors have a built in workforce with parents and are incentivized to push for as much paid care as possible. This is an artificial inflation of "need". I would like to see concrete evidence of what service levels were for children before the PHE compared to now and the reasons for the increases explored. Qualitative research so that stories are told from both families and DDD employees would identify real issues and problems resolved.

Parents are legally obligated to care for minor children and the current DDD assessments do not consider several nuances to determine the need for attendant care services. "Extraordinary" care to needs to be able to be measured in some way for support coordination to be able to assess as a medically necessary service. Without this tool existing this is just waste of funds.

I feel this process has allowed wide spread fraud with no way to determine if / what the attendant care needs for a child really are. Support Coordinators have been directed to not ask about the providers. Not to inquire about days and times of billing. However, when it is assessed as a supervision need due to parents work schedules (or whatever they have communicated) then how can those parents turn around and be the provider?

The friends and family I have used to be a support and provide respite for each other to avoid caregiver burnout. Now as thy are paid caregivers they no longer seem to have the time to help each other out. Which is another great concern - Parents being both parents and now providers are now more likely to have caregiver burnout and these same vendors who gladly take the attendant care and habilitation hours now have no respite for them. The vendors take no additional responsibility but are reaping the benefits of this program much more than members and their families.

I have countless examples as a support coordinator and supervisor with DDD. Here are a few.

For instance I have been asked for 120 hours a week of ATC for a 6 year old so that mom, dad, and grandmother will all have full time jobs. This is said out loud by parents all the time - not based on the members needs. They fired the SC and supervisor once the service assessment came back at under 40 hours per week.

This is a often employed tactic that is being communicated all over forums and has drastically changed the landscape of care coordination. Support coordinators are no longer feeling that they are able to be helpful and give the families the support they need but rather the enemy - as Arizona's network vendors and families now feel that the support coordinator is the barrier to hours assessed.

I have been asked to assess toileting, cleaning, and dressing habilitation goals for 3 year olds (clearly not extraordinary care as all 3 year olds need help for this). Been told that they need someone to bath, do laundry, clean up after them, and feed them with no reason as to why as a parent they cannot meet this need for their 3 year old. Age appropriateness is not in any DDD assessment at this time.

I have seen parents tell me the member cannot do something they clearly demonstrate so that habilitation hours will not be changed. To the detriment of the member saying right in front of them that they don't know how to do something - seeing them be deflated because if they said they were successful maybe the goals would change / hours.

These are not the minority, rather the majority of requests. I do not see real benefit rather a hindrance to the quality of care of the members.

I feel the current program should not be extended - families have been well aware of the ending for months and the opposition is not for lack of providers but the loss of personal finances - which is EXPLOITITVE of our most vulnerable members (children). The network of vendors need to focus on real hiring and retention of employees to benefit everyone.

Thank you,

Holly Shuster

From: **SEBASTIEN DUMESNIL** [redacted]
Date: Mon, Jul 24, 2023 at 10:43 AM
Subject: Grievance
To: DDDCustomerS...@azdes.gov <DDDCustomerS...@azdes.gov>

Dear Sir or Madam,

I am a parent of a child who receives DDD and ALTCS services. I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which would go into place in November 2023, my child and many more like them will lose access to their Habilitation services or more than 40 hours a week of care by parent providers of minor members. The reason my child will not have access to their appropriately evaluated services is due to the DCW shortage. My agency has specifically stated that they will not be able to recruit, hire and train enough providers to fill the gaps in service these new rules will create.

Thank you for your time, I would like to request a TICKET NUMBER for this matter.

Sebastien Dumesnil
[redacted]

From: Kin Counts [redacted]
Date: Tuesday, July 25, 2023 at 5:58:17 PM UTC-4
Subject: Paid Parent Providers For Minor Children
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

My name is Kin Counts. I am a members' advocate, as well as a parent provider for my [redacted] child,who is in the system since diagnosed at age [redacted]
Pertaining to the subject concerned,
I would like to comment and asked ,

1. Isn't it lawfully for parents to take care of their children till they turn 18? Why are parents EXPECTED to be paid for taking care of their minor children?
Most parents had been doing this for years with services and DCW services . Yes, we do have a shortage of DCW at most times, but it IS NOT ZERO availability.
Where does natural support in place, since parents are providing services?!
2. If parents are paid to take care of the minor children, parents are given the choice to not have external providers.
3. How are our members' being protected if parents fraud the system?
4. If this program is allowed, isn't it a reflection that DDD (Division of Developmental Disabilities) isn't doing its job of providing appropriate help for our members? That DDD is a failure?
And I am well aware that DDD is doing a lot for our members, and trying very hard to detain DCWs.
5. How are our members protected? External DCWs are mandatory reporters.They are able to report concerns where there were concerns, like an extra pair fo eyes.

Last but not least, isnt it simply that parents should be parents , and not become service providers for their minor children? Of course, there are members who need more help. But shouldnt that be when there are medical concerns involved? OR families in RURAL areas, where help can be limited?
I urge that this program should be carefully reviewed , and not become a loophole for frauds, that Parents of MINOR children EXPECT to be paid!
Thank You.

Respectfully and Sincerely,
Kin Counts

" See The Potential ."
" I am Different. Not Less."

From: Tiffany Starcevich [redacted]
Date: Tuesday, July 25, 2023 at 3:25:58 PM UTC-4
Subject: Benefits of being a parent provider
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team

As a parent of a child who receives DDD & ALTCS services I have participated in the paid parent program under the Covid-19 flexibility and it has been extremely beneficial for our family and for my daughter who is Autistic nonverbal on the spectrum 3. Little background on my daughter she struggles with any routine changes anything having to do with new people anything that makes her feel different. She has meltdowns because she doesn't understand change. She's nonverbal so she gets frustrated that she cannot express herself or advocate for herself. Being her mother I am voice and I will advocate as much as her voice needs to be heard. Finding help and services came very hard for us until we found the right Psychologist who showed us the way. Once we got approved through DDD & ALTCS we had the most trouble with finding help. My daughter is very aggressive and has problems with change and having new people come into our home that would only last one week if they even showed up. We needed a reliable source for my daughter and the only program that has worked milestones is the Parent Provider Program. My daughter is speech impaired so having strangers come into our home does not help because they don't understand her and when she isn't understood she gets very upset which turns into a meltdown which makes her very aggressive. My daughter is thriving with this program because she is able to work on her goals with her mother which gives her confidence and helps her to want to do better and try harder each day. The provider shortages and the negativity that goes on is not something that our children with special needs deserve. Not being able to find a DCW for over 9 months is an issue for our children when this is something that they need to be consistent and have everyday. This is why we should be able to keep the Paid Parent provider program ongoing. Only the parents of there children know what is best for them. There are so many different stories and voices that need to be heard. I really hope that you take each and everyone's voices into consideration. Parent provider program is something that is very important and that needs to remain to help our minor children thrive through this crazy world that we call life. Thank you

From: Anthony Tinaglia [redacted]
Date: Tuesday, July 25, 2023 at 1:58:53 PM UTC-4
Subject: Parents as Paid Providers for Habilitation
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello,

I'd like to share some feedback regarding the topic of potentially removing the parents as paid providers for Habilitation after 11/2023.
As a Father of a [redacted] year old Autistic child I can say that I am grateful that the great state of Arizona has allowed me the opportunity to work as both a Habilitation and Attendant Care Provider for the last [redacted] years.
Recently many of us have learned that the Habilitation privilege is possibly going away soon. It's fair to say that 100 percent of us working as providers presently are very disappointed by this. My very first question is whom will replace me as a provider? From what I have learned through my DDD Support Coordinator, my conduit agency, and others in the special needs community is that there are next zero available private direct care workers. What's AHCCCS's strategy to replace us?

In our specific family my Son attends school from [redacted] daily then is in ABA therapy from [redacted]. My hours spent doing Habilitation and Attendant Care for him primarily occur on weekday evenings and weekends.
There are many other parents that are in a similar type of routine. Does AHCCCS really believe a DCW is going to want to work non-traditional business hours? The pay rates are not very competitive either and additionally a DCW is going to have to drive great distances back and forth to these jobs. This is not a very feasible opportunity for a DCW especially considering gas prices being as high as they are. This is a position tailor-made for willing parents and many of us feel that utilizing a DCW should just be an as-needed option. Another point as well that's not getting discussed enough is the financial aspect. Though it's not our children's fault in any way whatsoever, their disabilities prevent us from seeking many other employment opportunities. I have a degree from a well known university and am not able to work in my field anymore primarily due to the travel and business needs away from home. The Paid Parent Provider opportunity has allowed us to offset these financial losses in addition to the wonderful training I receive from my agency to support my Son. This has been one of the few blessings in disguise that have come about from the tragedy that the Covid 19 Pandemic was.

I politely ask that AHCCCS please allow the parents to continue to provide for both Habilitation and Attendant Care permanently.

Please let me know of any questions and if anyone would like to personally discuss any of this with me.

Sincerely,
Anthony Joseph Tinaglia

From: Darci Yeary [redacted]
Date: Tuesday, July 25, 2023 at 12:54:30 PM UTC-4
Subject:
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

As a parent of a child who receives DDD and ALTCS services I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility, and it has been extremely beneficial to our family and my child. I would like to share my personal experiences and feedback based on my review of the current proposal for a permanent Paid Parent Caregiver program.

My son is autistic and these services and the ability to be my son's provider have been invaluable. Indeed, he also qualifies for respite and because of the shortage of individuals for these types of positions, no one has been able to find an individual able to provide these services for my son. My DDD coordinator, agencies that have been assigned for respite pay, and myself have all been unable to attain anyone for this position. Removing the Paid Parent Caregiver program will make this an issue for many families in the area of HAH and Attendant Care and thus will directly impact the individuals in need as they will be unable to receive the services they need and have the legal right to receive.

Under the current proposal, the request of an ongoing program option which allows parents of disabled minors in Arizona to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies is not being met. Please consider updating the proposal based on the following questions, suggested solutions, and personal experiences.

Should Habilitation be included in the Paid Parent Caregiver Program?
We have heard the concerns about member isolation and lack of community involvement if parents continue as Paid Parent Caregivers facilitating their child's Habilitation services. Respectfully the parent caregiver community proposes the following solutions:

1. Examine available research and personal feedback statements from members and their families to evaluate

the true potential impacts of social isolation and community involvement when parents of disabled children provide Habilitation services. The parent caregiver community's collective experience is that members who have parents facilitating their Attendant Care and Habilitation services have experienced greater member social engagement and community involvement over the last three years. Parent caregivers now have an increased ability to take their children to sporting team practices, community events, movie theaters, all ability parks, church activities and libraries. This is because parent providers can perform the appropriately trained and qualified supports in the correct time and location that is applicable to each member.

2. Implement precise guidelines to facilitate generalization for all Habilitation providers regardless of the DCW's familial status. Habilitation services are designed to have goals where data is collected to evaluate if those goals need to be changed, have been met, or need to be addressed differently. For a goal to be considered met, a member should be demonstrating that they are able to successfully meet that goal outside of the timeframe with a provider in one setting. This is referred to as generalization. The effective implementation of generalization with the pediatric IDD population would lessen, if not eliminate, any complications with adult transitional services. Under this model a program that includes parents as paid Habilitation providers would actually assist and improve in the success of adult transition. There are times when disabled children work successfully with different types of providers in clinics or schools, but the parents are not carrying the work over at home. This can happen for a variety of reasons. Having parents as Habilitation providers would help ensure the child's goals are congruent and carried over in the home and community setting. This will give the member a better chance of independence as they transition through different life stages. With generalization policies in place, Habilitation services being performed by parent providers will actually help facilitate successful transition into adulthood.

3. We know from provider agency data that "the top 3 issues regarding recruiting and retaining career non-family caregivers are schedules of the client members, interest in the position and finding qualified applicants." Most members have Habilitation goals and ADLs that are most appropriately delivered throughout the natural routine of their day. A parent provider is uniquely available in the morning, after school or in the evenings when each member is motivated and focused on the pertinent task. If a non-family provider is available their schedules typically allow them to work in longer time chunks that are not always the most ideal for the member and creates artificial goal or ADL practice. Continuity of care and greater member outcomes can be associated with consistently provided Habilitation care by parent providers who have the greatest ability to be flexible and available for their member children.

Should parent providers be limited to 40 hours a week of paid care per child?
We have heard the concerns of AHCCCS regarding the potential for a difficult adult transition to non-family supports once parent caregivers are no longer able or willing to help facilitate the disabled member's care. The parent caregiver community would like to propose the following collaborative solution to create a win-win scenario:

1. Create a program provision that outlines an extraordinary circumstances clause and the application process that allows parents to provide over 40 hours of paid care per week of authorized and evaluated services per member. These extraordinary circumstances could include, but are not limited to:

1.
    a. The lack of a non-parent DCW being available in the last 3 months to fill the member's assessed hours that exceed 40 hours per week. Ongoing DCW searches should continue to be made by the member's agency to fill the assessed hours beyond 40 hours per week of Attendant Care and Habilitation.

    b. The expressed desire made by a member for a parent caregiver to facilitate their assessed DCW hours so that their Article 9 rights are honored.
    c. The profound disabilities and/or significant behaviors of a member where a non-family provider is not equipped to provide DCW support. This determination can be made through a stakeholder team approach, including but not limited to the member's, DDD Support Coordinator, DDD Nurse, DDD Supervisors, Behavioral Plan Experts, Parents / Guardians, Psychologist, or Medical Doctor.
2. Form equality between all Family Provider Programs by allowing all Direct Care Workers, regardless of familial relationship or member age, to provide up to 16 hours of paid care per day. This will allow for employee equality across the lifespan of the member and limit the potential anti-family provider rhetoric currently present within state policies and DDD Support Coordination culture. All evaluations of hours should be based on member needs regardless of who is providing the services to create uniform implementation of all applicable HCBS services by the DCWs available to fulfill those hours.
3. The Family Support Program currently in this proposal addresses caregiver burnout. It is one of the available solutions to facilitate further community support within the disability and caregiver community that will provide greater access to non-profits facilitating counseling services, support groups and meet up activities.
4. Reevaluate Respite reimbursement rates to also address caregiver burnout. If Respite services are not available to the member or their family, parent burnout will continue to be an issue regardless of parents having the option of providing Attendant Care or Habilitation hours. With a comprehensive Paid Parent Caregiver Program in place non-family DCW providers will have greater flexibility to provide Respite services to these same families.

How should current evaluation protocols, training and practices be updated to facilitate equality for all members when accessing member needs?

AHCCCS has stated their intention to amend applicable policy, further suggested action on this topic includes:

1. Forming a committee of community and department stakeholders to amend and critique current DDD and AHCCCS policies and need assessment forms so that the most effective and efficient implementation of this permanent option is utilized moving forward.
2. Provide appropriately determined training and program implementation to DDD and ALTCS Support Coordinators so that Attendant Care and Habilitation hours are equitably evaluated based on the member's needs and to remove organizational bias of familial providers across the member's lifespan. Specifically investigate and determine appropriate DDD staffing needs and training for the members served in rural areas and those from minority backgrounds.
3. Create the option for private sector Support Coordination. Other states have this option within their Medicaid services, and this could be an additional feature in our DDD portfolio to allow for the member's needs to be best evaluated.

In conclusion, Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. By not allowing parents of minors to provide Habilitation and Attendant Care services or work over 40 hours a week most of the minor disabled community in Arizona will be underserved. A comprehensive Paid Parent Caregiver program validates the irreplaceable work that parents provide in their homes and communities.

Click here to connect with the Arizona parent led grassroot initiative leaders: www.raisingvoicescoalition.com

Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves all DDD and ALTCS members in Arizona.

Thank you!

Sincerely,
Darci Yeary

CMS perspective on the above noted requested program adjustments and paying Legally Responsible Individuals:

June 28, 2023 - Email Correspondence between CMS and Raising Voices Coalition:
https://drive.google.com/file/d/10CPccmIY7gEr5vq9C6vIaKmncSQOV7kc/view?usp=share_link

May 23, 2023 - Transcription of National Meeting between CMS Leaders and Parent Advocates:
https://docs.google.com/document/d/1h02v6Yk7frWGADcqKgm1zmd0uquMNfW3Jcd0zjHCxOk/mobilebasic?fbclid=IwAR2QLqbwJMQQRz0nj-XqhYzlFlkQbUV5wnyAyv98hivRVYpCjaYHhLBCzYg

Studies and data that support the changes being requested:

Data results from a 2023 Arizona survey of parents who have children with disabilities:
https://docs.google.com/document/d/16PZOk99caDUitg0XmQKqEv2mxXOBeaRywSD_zmjAnYw/edit?usp=sharing

A report on the current caregiver crisis by the National Association of Homecare and Hospice:
https://www.hcaoa.org/uploads/1/3/3/0/133041104/workforce_report_and_call_to_action_final_03272023.pdf

Higher satisfaction of paid supports for adults and minors with disabilities when care is received from paid family providers:
https://www.ncbi.nlm nih.gov/pmc/articles/PMC1089106/

A comparison of healthcare utilization when children receive paid care by a family member vs non-family provider:
https://www.jpeds.com/article/S0022-3476(23)00106-3/fulltext

Youth with Autism Spectrum Disorder have less ED visits and patient outcomes when patient providers are involved: https://www.reliasmedia.com/articles/148366-autism-spectrum-disorder-in-the-emergency-department
https://www.psychiatrist.com/jcp/mental/child/youth-with-autism-in-the-emergency-department/

An evaluation of parent provider involvement in generalization of children with autism:
https://www.sciencedirect.com/.../abs/pii/S0891422205000958

Impacts of the caregiving relationship: https://academic.oup.com/gerontologist/article/56/6/1102/2952858

State Approaches to Reimbursing Family Caregivers of Children and Youth with Special Health Care Needs through Medicaid - NASHP
https://drive.google.com/file/d/1TSt-Rj95DTn711EV8UTq7YqF0yoo0j8u/view?usp=sharing

From: Cassandra Simonton [redacted]
Date: Tuesday, July 25, 2023 at 10:31:58 AM UTC-4
Subject: Parents as Paid Caregivers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>
Cc: Henny Mesones [redacted]

You don't know my son, and his story is j ustone of the many on the spectrum. He is a high needs autistic individual who just turned [redacted] this [redacted]. He was diagnosed with ASD when he was just [redacted] months old. Since then it's been a long, hard journey. Over the years, doctors have added a few more diagnosis's (ODD, ADHD, Anxiety, migraines), they've prescribed a great deal of medications (none that have worked), and they have advised the best they could. Life has been rough, to say the least. When we started our journey, he received speech therapy and occupational therapy for one hour each a week. He also received habilitation under the supervision of a BCBA for whopping 36 hours a week. The habilitation provider was not a family member. The 5-7 BCBA's that were assigned to us were not family members. The many OT's and SLP's were, again, not family members. During this time, none of his behavioral problems were alleviated, in fact, sometimes they would get worse as they all used their own methods and experiences to try to help. To this day, he is still not potty trained after one of the BCBA's failed to listen to reason, creating totally new problems that we, his parents, were left to help him overcome. During those years, many appointments and sessions had to be adjusted or outright cancelled because he developed such a poor sleep schedule that could not always be accommodated. Neither medications nor advice helped relieve this issue that we still struggle with at times. So we began patiently waiting for him to reach preschool age hoping that the SPED department could better help our family. To say that public school was a severe mistake is putting it lightly. Without taking up too much of your time with all of the details, our son developed severe anxiety, panic attacks, a worsening sleep schedule, and very selective eating. While in the classroom for those [redacted] years (three different schools), he learned no more than the alphabet and how to write his name.. Both of which I was also working on with him in our home. He spent most of his time in the SPED room or at the playground to not distract the other children with his "outbursts." When Covid started and the kids were all sent home, we realized very quickly that online learning was not going to work for him. We also knew that once school started in person again he would absolutely never wear a mask. So we decided as a family to homeschool him. During this time, we had no outsiders coming in to provide services for the first time in almost [redacted] years. We also had no virtual therapies because he wouldn't tolerate them. This quiet time for our family is what we consider our healing time. We had been fighting for him and his older brother (whom is also diagnosed with ASD and has his own journey) for so many years. Being able to just stop, assess, and figure out our own way has been the healthiest and most beneficial to both of the boys, and for our family as a whole. As soon as parents as providers became a thing, I was probably one of the first to be approved. I had already been a provider for a client whom I couldn't visit anymore because of covid. Therefore, I already had experience and all of the credentials and trainings I needed to start, which I still maintain to this day and hopefully for as long as he needs these services. Almost immediately I could see a difference in my little guy. He was willing to work for me and we could easily adjust our hours to our sleep schedule because we weren't relying on anyone else. My son went from being almost completely nonverbal to being able to effectively express his needs. He doesn't speak in full sentences (yet), but he can let anyone know what he wants or needs at any given time. We still struggle with his goals, but it's no longer because his providers or therapists can't get him to settle down and focus. It's now because the goal is simply still something we need to work on, but we do in fact work during every single session. His last panic attack happened in [redacted], he's slowly but surely eating new things, and his behavioral issues are down to what anyone would deem typical for someone who isn't as verbal as the majority of us. Some days aren't great, but we have more great days than we have bad.. and that's way more than I could have ever dreamed of if someone had asked me [redacted] years ago. I have never felt more confident in my son's future than I do now. Parents being paid to provide attendant care and habilitation for their own children is unconventional, but that doesn't mean it's wrong. Everything at some point was novel. We adapted because we needed to, but many of us have had very positive outcomes. Not only are these children thriving from the consistency of their parent providers, but parents who would otherwise be unemployable (given their children's hectic schedules and high needs) are now able to help provide for their families in more than one way (therapeutically and financially). Please consider allowing us to keep providing BOTH attendant care AND habilitation as parent providers. ESPECIALLY habilitation. You don't know our experiences enough to be able to say this isn't working for your members, our children.

Cassandra Simonton
Parent provider with Elite Community Services LLC
[redacted]

---------- Forwarded message ---------
From: Jessi [redacted]
Date: Tuesday, July 25, 2023 at 4:36:19 AM UTC-4
Subject: Considerations for your Paid Parent Provider Proposal
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

I am a parent of two children who receive DDD and ALTCS services. I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility, and it has been extremely beneficial to our family and my children who receive these services. Based on my review of the current proposal for a permanent Paid Parent Caregiver program I would like to give you, my feedback. Thank you for your time and consideration while reading my experience and suggestions.

A little background on myself and my family. In [redacted] I graduated from Apollo College as a Physical Therapy Technician and NFPT Personal Fitness Trainer. Right out of college I began working as a caregiver for Arion Care Solutions and a few other agencies. I did this for [redacted] years until moving to [redacted]. During my time in [redacted], I had two wonderful children, and my family grew to be a family of [redacted]. In [redacted], we moved back to Arizona. When we first came back, I had hopes of going back to being a caregiver but unfortunately due to pay wages and not having an insurance option I chose to work at [redacted] as a waitress. During my [redacted] years at [redacted] I worked my way up from being a waitress to an Employee Training Coordinator and an Assistant Manager. Though I loved my job and was working diligently on continuing my way up the ladder, I was struggling at home with some major decisions. In the end I chose to change careers and started working at [redacted] as an ABA Technician. Now I work as a Paid Parent Caregiver. I feel my knowledgeable background has given me insight to both sides of this situation and I am able to offer solutions that will assist with closing the gap on providers.

As we all know there is not only a caregiving crisis but a medical staffing crisis, a specialist crisis, a behavioral health crisis and a therapist crisis. All these areas are short staffed and Covid has only made the shortage worse. During our last public AHCCCS forum you had mentioned at one point we had extra caregivers and now we don't have enough. I know there is always going to be a flux in caregivers, but I was wondering if you have a timeline that shows these fluxes in caregiving. Are there correlations to the economy? Are these correlations related to the number of children being diagnosed? I ask for a couple of reasons. The first is, according to the CDC, approximately 1 in 36 children in the U.S. are being diagnosed with autism. As this number rises there's a chance more children are going to be in need of assistance. The second reason I ask is, how long did it take for the low caregiver status to get up to us having enough or more caregivers than we needed? This statistic should show you how long it's going to take to solve our current problem.

On August 18th some wonderful ideas were discussed to help with the caregiver shortage crisis. I think it is great to give an opportunity to someone who is going to medical school to have part of their loans paid for or forgiven. The issue is timing and execution to this plan. In 2007, George W. Bush signed a bill called "The Act" which included Public Service Loan Forgiveness. As years have gone by the Public Service Loan Forgiveness plan has been poorly executed and has caused so much concern that this year it was revised. I would like to know how you plan on implementing this type of program to caregivers, is it only going to be in the state of Arizona and how long will it take to actually have this program/bill signed into law? In negotiating terms to make new laws it may take years to reach an acceptable proposal. Meanwhile if this proposal is sent to CMS as it is currently written these new rules (40-hour limit and exclusion of HAB), it will go into place in November 2023. This will limit roughly 50% of the current program's participants' access to services. Our children can't wait years for a provider! It would seem more beneficial to continue with allowing parents to provide HAB services without a 40-hour limit and also create a bill that allows new non-parent providers to get their student loans paid.

Another idea to increase nonparent caregivers is to increase the rate of pay. In [redacted], I was making $1490 a year as a caregiver. This is below poverty level. I was required to drive my own vehicle all over the Phoenix metropolitan area and suburbs of Phoenix without mileage reimbursement. As well as take my clients on outings without mileage reimbursement. Hours of availability for my members were random. At times I would work 6-8 hours with a client and other times I was just there to give a shower and make them a meal which came to about 2-3 hours of work. If my member was sick or on vacation, I was left without a paycheck for that time which caused me to work for multiple agencies to make ends meet. I also didn't have the option to get medical insurance due to not being able to afford the cost it would be. When I looked into going back to caregiving in [redacted] the rate of pay wasn't much more, and nothing had changed. As a waitress I made more than a caregiver and was able to provide a better living situation for my family. After a year of employment, I was even offered health insurance that I could afford. Even as I hired dishwashers, bussers, grill cooks, retail workers, and hostess at [redacted] I started them out at a decent wage that was well beyond minimum wage standards. Most grill cooks and dishwashers start at $15 to $16 an hour and get three raises before their yearly anniversary. It begs to ask why someone would choose to be a caregiver to members with no relation to them if they can make more washing dishes. This is why pay raises and mileage reimbursements are crucial to closing the gap on the caregiver shortage.

You have conveyed concerns about parent burnout. A recent survey showed, on a scale of 1 to 100 with 100 being the highest possible level of stress a person can experience, the survey asked parent caregivers to rate their stress levels in the areas of Finance, Physical Health, Mental Health, Medical Management, Relationship, Employment, Time Management and Household Management. The reported mean stress level prior to the Parent Provider Program was 78. With the Paid Parent Provider program in place, parents evaluated their stress levels in the same categories at 32. I understand parent burnout is a concern but as the survey shows, taking advantage of this program has decreased our stress levels and allowed us to focus on the important priority of our children.

I'd like to share my story of coming close to being burnt out. When my [redacted]-year-old was born I remember being filled with joy and unconditional love for this little, tiny being that I was holding. As time went on, we began to notice milestones that weren't being met like his older siblings. He would scream bloody murder if you tried tummy time which caused him to not develop the strength to crawl. Once he did crawl, he was quickly standing and walking. Which we learned later affects a number of cognitive processes. He wouldn't hold eye contact. He wouldn't babble or speak. During his checkups with his primary pediatrician, I voiced my concerns but was quickly assured that it was normal because he was a boy and/or his older siblings were doing too much for him. I would go home and tell my [redacted]-year-old not to talk for him or try to pick him up, that he needed to learn these skills. As time went on things didn't improve and I had another child. My youngest was born [redacted] months after and he started down a similar path but wasn't as far behind in his milestones. When it came to my youngest's one year checkup we had started seeing a new primary and I mentioned to him that my youngest could talk but my other son wasn't. He referred me to a specialist. The specialist diagnosed him with an articulation disorder because he would smile and ordered speech therapy. During this six-week therapy we were told he made no progress and AHCCCS wasn't going to renew his referral. We were back at stage one with finding assistance. A glitter of hope was given when the therapist told us that if we sent him to developmental preschool, he would be provided speech services, so we applied. We were put on a waitlist for several months until an opening came. As kindergarten was approaching his speech improved slightly and his cognitive levels were very low. He was tested in kindergarten by the school psychologist and was diagnosed with a learning disability. They said even though he had been in school since he was [redacted] he didn't retain any of the information and was below his peers in speech, reading, math, phonics, etc. I again questioned if he should be evaluated for ASD or something else, and if I should search for outside assistance. I was reassured he would eventually catch up and that I didn't need to do anything. As school years passed, he fell further behind. At home he was still needing full assistance with daily living skills, social interaction, comprehension, and now aggression and frustration. I felt hopeless and scared for what the future might hold for him. You go to these school functions, and they talk about how early reading is the key to success and meanwhile my son is still trying to grasp the ability to talk and isn't reading at all. I felt like a failure as a parent, but I didn't give up. For [redacted] years I called everyone I could to get help finding and understanding what was going on. I searched for help from my doctor who couldn't find a specialist who took our insurance to see him. I sought help from the school to get more services. I sought behavioral health services, hoping they could give me some insight into what was going on. I went to advocates for disabilities trying to find out who I specifically need to ask for, what wording do I use, and questions do I ask. I even went to DDD and asked personally for a list of doctors who did evaluations for cognitive disorders and ASD. I spent hours on the phone, each one having my pleas go on deaf ears and send me down another rabbit hole.

It wasn't until right before Covid we finally found answers. By this time my son was [redacted] years old and severely behind in many areas. The doctor diagnosed him with autism level 2 and explained the reason he wasn't at a level 3 was because he was finally talking. I felt relieved knowing I wasn't crazy all these years. I cried because I finally had someone who listened and could tell me what was going on so I could help my son. But this feeling was short lived and began another uphill battle. After my son's diagnosis we were told to put in an application for DDD/ALTCS, request that he receive speech and OT therapy and get his MET for his IEP changed to autism. Now mind you I had clients that were autistic, so I knew a little about the diagnosis, but I didn't know everything, and I certainly didn't know it affects everyone differently. I was down another rabbit hole all alone trying to find out everything I needed to know about autism and what his future would hold. To be honest, as I sit here writing this letter, I am still not sure what the future holds. I try to make every opportunity accessible to my son so he will be able to lead a productive and independent life when he gets older. But as of right now we still don't know what productive is going to look like for him or what independence is going to look like. This is the main reason having a consistent, trained HAB provider is critical for his future.

The transition to early intervention and finding services during COVID was extremely stressful. To this day I remember being so overwhelmed with everything that was going on and all the information and lack of information I was given and trying to seek. I was working 16-hour shifts at [redacted] 5-6 days a week. I was setting up IEP meetings with the school only to be told they wouldn't change his MET and tried to discourage me from getting DDD/ALTCS services because they said no one ever gets approved the first time they apply and DDD/ALTCS is going to need more proof than the diagnosis. I felt defeated with the answers they gave me, but I continued to advocate for my son and seek help elsewhere. I applied for DDD/ALTCS and read everything I could get my hands on about autism. The process for DDD was quick. She called me and explained who she was and did the interview over the phone with me. We had to stop several times during this phone call because I was at work and had to take care of guests and the restaurant needs. She tried to explain the next step was her forwarding my application to ALTCS and who ALTCS was. To this day, I don't think I fully know the difference between DDD and ALTCS services, but she assured me they would help pay for his therapy and services. About a week later I received a call as I was grocery shopping from ALTCS going over the first portion of the interview. I remember having to stand in an aisle as she asked questions and constantly reminding my son to hold onto the cart so he wouldn't elope. He had passed the first portion of ALTCS and now we had to wait for the second portion. The second portion was done about a week or so later and he was quickly approved. At this time, I wasn't sure what all that meant but I was happy because to me it meant we were moving forward. Then came the quick hurdles I didn't expect, seeking services. Our DDD coordinator called and wanted to talk about the next steps. I remember I answered when I was on the grill line in the middle of lunch rush and explained I would have to call her back. Once the lunch rush had died down, I sat in the breakroom, quieting anyone who came in there so I could intently listen to what our next steps were. As she knew I was at work and didn't have much time to talk she quickly ran off our next steps of getting a referral for services, her sending out a vendor call for these services, me having 10 days to interview and pick these agencies and get back to her and if I hadn't, she would have to pick them for me. She went on about vendor calls and agencies for providers, our next meeting, how my son needed to be there, and so much more that my head was spinning at the end. I never realized as a caregiver the amount of work that goes into setting up and receiving services, but I was about to find out. Getting his pediatrician to write the scripts wasn't difficult because he had been seeing him since he was 3 years old and knew of our concerns. Setting up vendor meetings was very difficult with my work schedule though. Over the next 10 days I carried my phone with me everywhere. I would run to the back of [redacted] when I felt it vibrate just so I wouldn't miss a call from vendors. I set up meeting after meeting with anyone I answered just so I could pick the right one. Some meetings I was able to do on the phone as I was running a shift, constantly asking if they could excuse me so I could assist an employee. Others I was able to work around my already tight schedule and see in person. Once we picked our agencies for speech, OT and caregiving I thought the meetings would be over. I was wrong, then came more meetings with caregivers to find the perfect fit. It took many interviews, but we finally felt comfortable with our choice and providers.

I must also mention that prior to the start of our services my father was diagnosed with a rare form of pancreatic cancer that was in the fourth stage, my grandmother's health was increasingly getting worse, and I was planning my wedding. As you can tell I was overwhelmed with what life was handing me, but I was determined to not give up. Then came the Covid shut down right at the beginning of our services. We received an amazing, untrained caregiver with the heart of gold. She didn't know how to do the job, but she was willing to learn and was patient with my son. At times they would just sit in silence until he felt comfortable to talk to her. She would ask him questions to build a repertoire and then go home to try to gain knowledge on his interests so they could have things in common. She also assisted him on the computer with schooling since this was new to both my children, that way I could assist my youngest. Then during the end of the day, she would assist me with his habilitation goals. It was a little hectic but manageable with her assistance. Speech therapy was more challenging through the computer though. He struggled so much that I needed to sit with him to translate what was said. OT was horrendous. She would come in and request that we leave the room during their sessions. She seemed demeaning and rude from the very start and would send him into tears by the end of it. But I kept with her for several months. I didn't feel like I had a choice and assumed she was having a hard time adjusting to Covid as well and needed a break. As time went on though my caregiver started to notice the same thing during these sessions and expressed concern with the attitude and demeanor our OT was presenting. During one session she yelled at my son and told my caregiver that the behaviors my son was having weren't symptoms of autism but symptoms of an unruly child. We immediately ended services after this incident and needed to put out another vendor call for OT.

During this new vendor call I finally had enough experience to know what questions to ask. I wanted to make sure that the therapist was going to allow us to join in the session, that she understood autism and behaviors that we were trying to work on. After the first experience with OT therapy my son was reluctant to join in on sessions. He would cry and have a meltdown every time he had services and refuse to work with her. She was very patient through all this and understanding to his fear. She spent several months trying to have him understand that OT could be fun and not everyone was going to treat him horrible. I'm also happy to report OT is now his favorite therapy and we have had her for several years and have seen immense progress with his therapy.

As time went on, we were caught in a vicious cycle of trying to find a speech therapist during Covid. We would start to get to know one and then they would leave the company and we would be put on a waitlist or have to send out a vendor call. In a couple years span my son went through 5 speech therapists and oftentimes we would find out hours before the session started that we didn't have speech any longer. With these gaps in therapy, we saw regression and would oftentimes have to start his goals over which frustrated him. Another problem we ran into was the therapist not putting enough information into their notes so then the new therapist would want to work on things we mastered. This continued until a little over [redacted] when we started to receive services through Arizona Autism. Our speech therapist has been great at filling in the gaps with my son not receiving services and continues to work with him twice a week. For this I am very grateful.

After [redacted] months off of work I returned to a whole new world of problems. The hours were the same, but all protocols were different which led to stress at work. Life at home wasn't much easier. My grandmother had broken her hip and needed around the clock care, so I was trying to take care of her as much as possible. During this time her health started to deteriorate, and she needed oxygen among other assistance. I would get up early in the morning to go over and assist her with eating breakfast and getting dressed. On my lunch hour I would go make her lunch, assist her with doing her therapy exercises and check her oxygen levels. Then in the middle of my shift I would need to take another break to go assist her with dinner and get her into bed. Due to these breaks I needed to work longer hours to make up for the hours I was missing. I also was having to take time off of work every week for her doctor visits, her physical therapy and constantly running back and forth to the hospital when she caught covid or was having trouble breathing. I was trying to assist my father with his battle with cancer and be there as much as possible. Towards the end of his battle, I had to take care of him every weekend because my mother was mandated to go back to work at the hospital during covid and hospice wasn't available on the weekends due to staffing shortages. I was in a constant conflict with the school to get a new MET and had to hire an advocate to assist me. I wasn't able to be there for my children and when I was there, I was so exhausted from this stress. I missed therapies and assisting my sons with their schoolwork. I missed being a mother and a wife to my new husband. It seemed like the only time they saw me was when I was advocating for his needs or working on something for work at home. I was beginning to feel like a failure to everyone and wasn't taking proper care of myself. Then to add more stress to our situation my caregiver decided to go back to college and needed a new schedule. I began to have to take time off of work due to her schedule and at times her calling out and the agency not having someone to fill in. My work was suffering, my children were suffering, and I was suffering. During these days at home, I started to see more behaviors with my son than we had in the past. It was then that I started to look for a new career.

I had read about all the therapies one might need if they had autism and many parents swore by ABA therapy. I had tried several times to get this approved by DDD but was told it wasn't a therapy they provided. I was feeling so lost. I couldn't understand why DDD discontinued providing ABA therapy, but I knew somehow this could be the answer to a lot of my prayers with my son. Since there wasn't a way to provide this service, I discussed with my husband looking for a job in the field as a tech. I figured I could learn all the techniques and then bring them home to teach my son new skills. After a few months I began working at [redacted]. During my couple months of training, I continued to work at [redacted] part time and on an as needed basis. Life was finally starting to settle down and become normal again. My aunt started to help more with my grandmother, freeing up time to spend with my family. We decided instead of fighting the school we would just move our son to [redacted] and see what happens. My father had unfortunately passed shortly after my transition to [redacted]. Therapies were finally on track with the providers we have currently, and I felt like I could breathe again after struggling all year. Life had a couple more curveballs to throw at me though.

During the time I was advocating for my oldest son to get services from the school I began to see my youngest son struggling more often. He wasn't always the greatest reader and we had suspected he had dyslexia since kindergarten. As time went on this notion became more apparent but the school refused to do an evaluation. Due to this we had to work the channels and get an IEE. After waiting several months for this to happen we were able to take him in for some answers. The doctor was wonderful and spent several days observing him, asking us questions, and evaluating him before he came to his conclusion. He stated that my youngest did indeed have dyslexia but also dysgraphia, and dyscalculia as well as autism. I explained that I honestly thought all these years he was mimicking his older sibling. I knew he struggled with things at home and school, but I never guessed it was autism as well. Now I really felt like a bad parent, but I didn't give up hope. I knew now what I needed to do because of his older sibling and was prepared for all the stress that came with. We were able to quickly set him up all the same services as his brother. People we trusted and knew to be a great asset to our family.

The last curveball was our wonderful caregiver quitting the field so she could pursue her dream job. It was hard to think that someone you see five days out of the week and has been such an asset to your family is going to leave as soon as they find a replacement. We were heartbroken but very happy that the agency found someone within a couple months instead of years as I have seen other parents wait. Our new caregiver seemed nice and friendly. She was very talkative and excited to be starting as a caregiver because she had never been one. Since both my sons were her first clients, the agency agreed to have our old provider train her for 3 days so she would be comfortable. I felt blessed that we weren't going to have a gap in services but as soon after training I started to see some red flags. When I would drop my sons off from school, she would ask me if my youngest had any accidents at school or if my other son had worked on his coping strategies, and then she would state she needed to write that in her notes because she was going to clock out of HAB soon and clock into ATC. I had mentioned to her that HAB goals were meant to be worked on and notes were meant to be about the session she had. She would continually state she knew this, but it would be easier to write her notes at the beginning of the session than at the end. As time went on though I noticed my children weren't meeting their goals, they were regressing in certain areas and their behaviors had become worse. I also noticed on my days off that she was more interested in trying to give me her life story and be my friend than to work with my children. She would tell me about her love life, her past, how tired she was and all her financial problems, but I couldn't get her to work with my children. When communicating with my sons instead of offering redirection, role modeling what to say instead or prompting she would simply state "that's rude" or "you're being rude" to them. This confused my children and upset them very much because they didn't realize how they were being rude and thought she hated them.
Another thing I noticed right away was that the only thing she would do with my sons was watch tv as she was on her phone. When I tried to get her to engage in other activities with them, she stated this is all they want to do which I found odd because my sons are very active. I started to lay rules down on the time they spent on electronics hoping this would

solve this problem, but it didn't. I was continuously being the one who was providing services for my children while she sat on the couch. I was the one asking my youngest son if he needed to use the restroom, I was the one working on coping strategies, I was the one assisting with hygiene routines and communication. On the days I was supposed to have respite I would request my oldest son [redacted] years old) to come over and observe the situation and make sure his brothers were ok. He continuously reported that the caregiver was on her phone the whole shift and only interacted with the boys if he requested it. I also noticed that during my children's therapy instead of working with the other child she would sit at the table on her phone. One time she was supposed to be assisting me on an outing to buy them new clothing but instead of watching my son who elopes she followed me around. When I politely asked her to get him, she yelled across the store for him and then said he was with his father and continued to follow me around. After this incident I became more concerned with the quality of care my children were receiving and her being unreliable. I started to have to take time off my new job to stay home. I went from working 40 hours a week to 12 hours. The last incident put my child in a harmful situation. My youngest son had a doctor appointment that day and my oldest was upset that he had to stay home with our caregiver alone. I tried explaining to him that I didn't have a choice and I would be back right after the appointment. As you can imagine this didn't go over very well and he started to have a meltdown as we walked out the door. After being gone for an hour, I came home to my son being outside all by himself screaming, crying, and hitting the garage door. When I came through the front door, I found our caregiver on her phone watching The Game of Thrones! I asked her what had happened, and she replied that he ran out of the house to try to catch my car and then blew up when I wasn't there, so she left him outside to cool down. I was very upset, but I needed to calm down my son before I could do much more. This process took forever. Once he calmed down, I immediately asked her to leave and contacted our agency. Due to this incident I had to quit my job. For a while I did wait to see if they could find another caregiver but as time passed it was easier for me to become their caregiver than to wait much longer.

I gave you this insight into our life to let you know, parents aren't burnt out from taking care of their children but constantly having to advocate for them and make severe sacrifices to make sure they get the opportunities they deserve. Prior to becoming a paid caregiver, I didn't have much time to create bonding relationships with my children or my husband, I was constantly working. My schedule was overruled with taking care of ill family members and working around everyone's needs. I didn't have any time for myself or to take care of my household. Though I have an amazing support system, I was failing at every aspect of my life. Now I have time to use my respite hours appropriately, I have quality time with my children and family, I feel comfortable in the care they are receiving, I feel confident in managing my household, mental health and wellbeing. This program has given us all a new take on life.

If you are seeking ways to stop parent burn out don't take away this program that has helped families like mine instead offer other options. Be transparent in all the services that are out there for our members to become successful at being independent. Please don't make us continue to jump through unnecessary hoops or hear from other members the services that our members could get to help with their disabilities. Be open on your website about clear options to getting evaluated for disabilities that are available for low-income families. Give extensive training to DDD coordinators and caregivers so that they may adequately do their job and not cause confusion or hinder care. Increase respite reimbursement pay rates so if parents need more selfcare they may receive it. Provide more grants to programs like Care 4 the Caregiver to help them expand the services they currently offer. Provide counseling and/or psychology services to parents and family members of DDD/ALTCS members. Have DDD routinely check up on family members to see if they need any other resources or assistance and how they are feeling. If we come together as a community, we will be able to succeed in taking care of our members instead of if we worked individually.

I would also like to mention it would be beneficial to expand on companies that service our community and offer increased wages and benefits to medical staff who specialize in disabilities. Phoenix continues to be the 5th largest city in the nation. Phoenix metro continues to gain ground quickly among the largest U.S. cities ranked by population. In 2019, Mesa Arizona (suburb of Phoenix) became the first U.S.'s first Autism Certified City, denoted by the international Board of Credentialing and Continuing Education Standards. Knowing this, it seems impossible to believe that our members are severely overlooked in our community for services. My son has undergone three counselors and is currently on many waitlists for services. The turnover rate in mental health services is worse than in food service. His last counselor left since the company was shutting down this service and sent us a list of counselor providers. As such the list only had six companies that offered behavioral health to the autism community. Most councilors ask many questions before agreeing to provide services to see if you are a good fit for each other. Due to this, most counselors won't offer services to my son because they don't specialize in autism. We had to wait over [redacted] to be seen by [redacted] and are currently waiting another [redacted] months for our next appointment just to go over my son's cognitive report and how we can better serve him. We also have been on a waitlist for behavioral therapy for a year now. I have diligently called companies to seek services only to be told they don't accept our insurance and Mercy Care isn't accepting new contracts and they are short staff and don't have someone to provide services. Our behavioral health case manager gives us monthly updates on the situation with the same results. If we focused more on expanding behavioral/mental health and medical staff that specialize in disabilities, we could pursue everly intervention on our most fragile members. This would alleviate and/or decrease isolation, seclusion of care, hospitalization, regression, unnecessary complications, higher costs, and premature mortality.

Isolation was another concern you had for our members. Isolation may have many different effects on people. It may cause low self-esteem, depression, anxiety, sleep problems, substance abuse, high blood pressure, heart disease, diabetes, and increase stress and your risk of dementia. This was a topic they shared research on relating to members with disabilities, but it can affect anyone in these manners. A study was also shared related to adults with disabilities and family providers from 2019 but no such study has been done currently on children and family providers. It was mentioned that this study would take too long to obtain and that is why they were going off of the adult one. I propose a survey be sent through DDD/ALTCS email to all members asking related questions. It should include age of member, age of parent, are they paid providers or not, are they currently seeking for outside providers and if so how long have they been seeking services, do they feel burnt out, do they take members out in the community, and if so where, are the members HAB goals able to be obtained out in the community and then do they have any suggestions on how to improve services. This way you could get an accurate observation on many different topics. I also have research studies that I think will be helpful in your decision-making process. A recent study from Berkelely.edu showed, "Those who received paid support from family members reported higher satisfaction with paid care and had either better or no worse outcomes on self-reported quality measures. Moreover, positive effects of respite may not occur if individuals or their family members do not trust others to provide quality care. Paid family caregivers have also been associated with neutral or positive outcomes, such as fewer hospital admissions and fewer institutional placements."

(Newcome, supra note 2; A.E Benjamin and Ruth E. Matthias, Comparing Consumer-and- Agency directed models: California's In-Home Supportive Services Program 24(3) Generations 85-87 (2000), available at http://laborcenter.berkelely.edu/homecare/pdf/benjamin_01.pdf.)

It is worth mentioning that previous to becoming their provider my children weren't out in the community as often due to their caregivers not having a license or vehicle to transport them. As I write this, the caregiver who provides respite for my children doesn't have a license or a vehicle to take them out into the community either. I feel my children felt more isolated when they had our last caregiver who didn't engage with them than they feel with me providing constant engagement and taking them out in the community to engage with peers. In our experience, with the flexibility of myself providing habilitation and attendant care service, my children have the opportunity to be out in the community more and with their peers. Not only am I able to take them to the park, to the library, out to a restaurant, to their favorite stores or events to assist with obtaining the goals, I have also been able to add future activities that they enjoy to their schedule. My eldest has shown interest in the military for years. This coming [redacted] he will finally be able to join the [redacted] as a cadet. In the [redacted], he will be learning leadership skills and building character among other wonderful teachings. He is also joining a football team which will teach him about being a team player, good sportsmanship, and how to interact with his peers appropriately while building his social skills. My youngest enjoys playing chess and is very excited to have the opportunity to join a chess club taught by a Master chess player. He also just joined the Special Olympics swim team and is excited about competing in a sport he loves. These new opportunities wouldn't be available without the flexibility I have as a paid parent provider. Since I am continuously with my children throughout the day, I am able to adjust their service hours to be flexible in changes with their schedule. This gives them access to the maximum number of activities and gives them an opportunity to grow and have fun. To us this is as important as therapies and habilitation goals because you are only a child once.

A suggestion to assist with these concerns of isolation and encourage more involvement in the community would be to mandate every member who has habilitation services to have a goal that must be done in the community. There are a variety of options to pick from for all ages. This would be a better option to promote social interaction for our members. I also suggest revising your current rules to include that caregivers must have their license and a vehicle to take members on outings. This would also help encourage more community engagement for members as they would have access to actually getting out in the community. Though I must mention that this revising might dwindle the current caregiver status and cause more harm to the caregiver crisis we are currently in.

It was mentioned on several different occasions about 80-year-old parents taking care of their children. During my time as a caregiver, I only saw this happen on one occasion and it was with an adult member. According to the CDC, the national average for women to start families is 27.2 years old. In 1970 the average was 21 years of age and in 2000 it was 25. Though there is a slight uptick in the last three decades, it is highly unlikely that 60-year-old women will be the average age for a woman to start having children any time soon. Most parents will be more than capable of meeting their minor children's needs as caregivers and as mentioned above Paid Family Caregivers have been associated with positive outcomes.

(CDC.gov)

Just recently I was mandated to take a course on neglect and child abuse from DDD as part of my ongoing training. This document was revised on 10/20/2020. According to the National Survey on Abuse Against People with Disabilities 67% of the people with developmental disabilities have or will be the victims of abuse in their lives. From 2017 to 2019 a person with disability were victims of 26% of all nonfatal violent crimes, while accounting for about 12% of the population. The violent victim rate went up four times than the rate of a person without a disability. A person with cognitive disabilities had the highest rate of violent victimization (83.3 per 100) among the disability types measured. Only 19% of rape or sexual assaults against someone with a disability were reported to the police, compared to the 36% of those against a person without a disability. Out of 100 cases of abuse against people with developmental disabilities 33 were reported, 17 were investigated, 10 were arrested and 5 were prosecuted, meaning 95% go unprosecuted. These are very terrifying statistics for anyone to read. In a more recent study on abuse and neglect prevention, it showed a decrease since the implementation of Paid Parents Providers in 2020. In the last 5 years, 18% of the families reported a DDD and/or AHCCCS grievance against a non-family provider. This is in contrast with 2% of grievances with DDD and/or AHCCCS being made against a parent in the last 5 years. 80% of the members see at least 2-4 mandatory reporters on a weekly basis. This doesn't include mandatory reports that children see in a school or medical setting. Provider agency owners or founders collected a second survey that stated out of 20 agencies surveyed, 18 were located

in Maricopa County, 1 in Pinal County and 1 in Pima County. Fifty percent of the agency employees are Paid Parent Providers. 72% of the members are disabled minors and 28% are disabled adults. The survey showed in the last 5 years an average of 12 abuse or neglect grievances per agency have been filed by agencies with DDD/AHCCCS regarding a non-parent provider. In the last 5 years 0 grievances on average, have been filed with DDD/AHCCCS regarding abuse or neglect by parent providers of disabled minors.
Looking at these studies it shows how beneficial the Paid Parent Program is and how **including HAB and no inclusion on hours is beneficial** to continuing this decrease in victimization on our members.

(Information came from the participant guide of Recognizing and Reporting Abuse, Neglect, and Exploitation of Vulnerable Populations from Division of Developmental Disabilities.
https://www.ncjrs.gov/ovc archives https://www.google.com/url?client=internal-element-cse&cx=015849196504226064512:uyit-fm6gna&q=https://bjs.ojp.gov/library/publications/crime-against-persons-disabilities-2009-2019-statistical-tables&sa=U&ved=2ahUKEwjZ5YeQtqWAAxWOJUQIHaqDDW8QFnoECAIQAg&usg=AOvVaw3uIAN6_ajvIizFnMMnK_Tj

https://docs.google.com/document/d/16PZOk99caDUitg0XmQKqEv2mxXOBeaRywSD_zmjAnYw/edit?usp=sharing

Through a survey, Parents of children with disabilities rated their satisfaction level regarding the care their disabled children receive as well. The scale was 1 to 5 with 5 being the highest level of satisfaction they could receive. Parent Providers were rated at 4.5 and non-family providers were rated at 2.4. 99% of parents of minor DDD and/or ALTCS members believe that Paid Parent Providers have been beneficial for their families. It also showed 81% of parent providers to be employed by a provider agency have a two-year employment average. Whereas 64% of non-parent DCW providers have a year or less of employment on average. I do realize that the temporary Paid Parent Provider program for minors has only been in place since 2020 and most parents were utilizing this option due to lack of knowledge until 2021. I believe this shows the longevity of this program and how it affects employment and ultimately the quality of care our members receive. The data that was collected stated from 2018-2020 members had 279 hours of attendant care, 258 hours of habilitation, and 371 hours of respite go unused that were assigned to them due to lack of providers. These numbers reflect mostly the pre-covid era. In 2021-2022 members had 200 hours of attendant care, 116 hours of habilitation, and 446 hours of respite that were assigned but not used due to lack of providers. As you can see there was an increase of utilization in attendant care and rehabilitation that directly correlated with the option of Paid Parent Provider. Unfortunately, respite hours went up due to agencies not being able to find caregivers. Agencies are having a hard time finding non-family caregivers due to scheduling conflicts, interest in the position and finding qualified applicants.

2023 Survey Summary

When we were a family of [redacted] I had to work three jobs to survive at times. People would ask how I did it? I didn't see another option and would do whatever it takes to see my children thrive. I am their mother, and this is what a mother is supposed to do. During the forum, we were asked to provide examples of how we provide extraordinary or additional support as a parent habilitation provider outside the scope of a typical parent. My question though is what is considered a typical parent? Parents of all types of children go far and beyond to see their children thrive. I don't see myself as special or extraordinary but as a mother determined to help her children succeed in life. Maybe when you asked that question you were meaning I should compare what a typical parent does for their 12 and 11 year old as opposed to myself. This means we would need to look at examples of what a typical 11-12 year old can do for themselves. A typical 11-12 year old can wake up on time without being told to do so. They are able to complete household chores like laundry, sweeping and mopping, doing the dishes, cleaning their room, the kitchen and bathroom. They understand instructions that involve three or more steps. They can hold meaningful conversations with adults and peers. They know how to use the phone. An 11-12 year old is organized and can manage a budget, be able to solve problems with more than one variable, write stories, do homework on their own and read age-appropriate books and material. They have basic first aid skills and can watch their younger siblings for short amounts of time. They are able to make their own lunch and cook basic meals. They can fully dress themselves appropriately and complete all grooming tasks. As a typical parent for my children's ages, I shouldn't have to assist with any of these tasks mentioned above but I do on a regular basis.

Habilitation services are designed to have goals where data is collected to be evaluated if those goals need to be adjusted, have been met, or need to be addressed differently. For a goal to be considered met, a member must be able to successfully demonstrate this goal outside the time frame with a provider in one setting. This is referred to as generalization. For most members this includes goals that can't be done in the community. My children currently have objectives to address hygiene (showering, brushing their teeth, combing their hair and dressing properly), and laundry duties (washing, drying, folding and putting their clothes away properly). These objectives cannot be obtained in a public setting or with peers. Another goal that can be difficult to obtain in the community and often happens more at home is picking up after themselves. Each child is given a one-step direction on picking up their room or any other environment they have belongings and putting their items away properly. As time goes on this goal will include two step instructions and so on until they are able to pick up after themselves without being prompted to do so. We also have a goal that involves my children to be able to learn how to utilize a computer and participate on one. At times this involves social interaction with peers by zoom but mostly it is teaching them to properly use a computer.

Other habilitation goals can be done in the community and as a parent habilitation provider I encourage this and use it as a way of measuring generalization and mastery of these skills. Currently my youngest son has been working on using the restroom and not having any accidents. When we first started this goal, it consisted of being fully hands on. I would ask and give reminders every hour and assist with wiping and washing his hands afterwards. Then as time went on, I would continue asking and give reminders to use the restroom and observe him wiping himself and washing his hands. I also reminded him to ask for assistance if needed. The next step was to give reminders to wipe and wash his hands and let him advocate when he needed to use the restroom at home. Now we are working on generalizing this skill to the community. My son unfortunately has a cleanliness issue with restrooms outside the home and will have accidents instead of using the restroom. I'm teaching generalization for the restroom by teaching my child to self-advocate that he doesn't like a restroom and asking if he needs to use the restroom and giving reminders while in public. He has come a long way with this goal and in the near future we hope to master it.

My oldest son has two objectives that we also utilize in all settings in his life, coping skills and comprehension. I have taken an intense approach with these goals by working on them hourly and any time the opportunity presents itself. Every hour he picks out a coping skill he would like to practice, and we do it for about 5-10 minutes or longer if he chooses. These skills can be taking a walk, drawing or coloring, listening to music, taking a break, discussing what is on his mind, applying pressure to himself in a hug, exercising, and taking deep breaths, just to name a few of his favorites. Before the practice and after we discuss how we are feeling so we are able to identify our feelings and self-regulate. When a problem arises, we also discuss how big our problem is and what we can do to come to a solution. Practicing this skill has helped immensely with knowing what to do when he feels overwhelmed or frustrated. With assistance he is able to identify his feelings, self-advocate and come up with solutions after calming down. This has lowered his meltdowns and outbursts which has opened up opportunities to enjoy more of the community and situations he wasn't able to before.

Another goal we work on in the community for generalization and mastery for both children is communication skills. My eldest is learning how to advocate for himself in an appropriate manner and with the proper tone of voice. We practice this in our home with a volume meter sign that shows the different volumes of your voice and examples of when it is appropriate to use those levels, reminders of these levels during conversations and redirection when levels aren't appropriate. As for advocating for himself he is prompted to ask for assistance when needed and express his wants and needs without using curse words. Before we go on outings to the park, family festivities, or other outside places we discuss these communication practices and role play situations that he might have or has had difficulty with. During our outings I am there to assist with developing his communicating skills by offering reminders, prompts, redirection and praise. As time goes on we will add to this goal and have him work on eye contact, maintaining a two to three way conversation and so on.

My youngest son has come a long way with communicating in an appropriate manner and observing initial greetings from others. Since he struggles with beginning, continuing, and ending a conversation as well as advocating for himself, we decided to break this into steps. Currently we are working on observing initial greetings from others and self advocating in an appropriate manner. In the beginning, he struggled with ignoring people when they greeted him or talked to him. We practice this skill daily by greeting each other, provoking others to greet him (family and friends), role modeling what a greet looks like, reminders to greet politely, having him answer the phone when family or friends are calling, and role playing scenarios that he might see out in the community. Then we practice these skills out in public to help with generalization. As for self advocating in an appropriate manner we use the same techniques by asking him questions, redirecting him when he isn't polite, discussing how he feels and how others may feel when he doesn't communicate appropriately, role modeling how to express yourself, role playing scenarios that have or could come up and how to handle them, etc. This has opened up a window of communication and self worth that we utilize as we continue to work on all parts of communication.

As you can see throughout this letter my children are very much involved in the community during habilitation services and beyond. I would also like to mention that my children consistently attend school, speech therapy, occupational therapy, and routinely see doctors for vision and regular check ups. They attend church on Sunday and Wednesday for religious instruction classes and are an active part of the special olympics. Each of the above places not only provide a sense of connection to the outside community but are mandated reporters that my children see 7 days a week.

Effective implementation of generalization for my children actually lessens, if not eliminates, any complications with the adult transitional services. With the collaboration of multiple entities I am able to provide early intervention which I wasn't able to carry over from therapies/school prior to becoming a Paid Parent Provider. This has, and if capable will continue to give my children a better chance of independence as they transition through life and will help facilitate a successful transition into adulthood. If habilitation services are interrupted this will only hinder our members (my children) from progressing with their goals of obtaining independence as they get older.

Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves DDD and ALTCS members in Arizona.

Best Regards,

Jessica

CMS perspective on the above noted requested program adjustments and paying Legally Responsible Individuals:

June 28, 2023 - Email Correspondence between CMS and Raising Voices Coalition:
https://drive.google.com/file/d/10CPccmIY7gEr5vq9C6vIaKmncSQOV7kc/view?usp=share_link

May 23, 2023 - Transcription of National Meeting between CMS Leaders and Parent Advocates:
https://docs.google.com/document/d/1h02v6Yk7frWGADcqKgm1zmd0uquMNfW3Jcd0zjHCxOk/mobilebasic?fbclid=IwAR2QLqbwJMQQRz0nj-XqhYzlFlkQbUV5wnyAyv98hivRVYpCjaYHhLBCzYg

Studies and data that support the changes being requested:

Data results from a 2023 Arizona survey of parents who have children with disabilities:
https://docs.google.com/document/d/16PZOk99caDUitg0XmQKqEv2mxXOBeaRywSD_zmjAnYw/edit?usp=sharing

A report on the current caregiver crisis by the National Association of Homecare and Hospice:
https://www.hcaoa.org/uploads/1/3/3/0/133041104/workforce_report_and_call_to_action_final_03272023.pdf

Higher satisfaction of paid supports for adults and minors with disabilities when care is received from paid family providers:
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1089106/

A comparison of healthcare utilization when children receive paid care by a family member vs non-family provider:
.https://www.jpeds.com/article/S0022-3476(23)00106-3/fulltext

Youth with Autism Spectrum Disorder have less ED visits and patient outcomes when patient providers are involved:
https://www.reliasmedia.com/articles/148366-autism-spectrum-disorder-in-the-emergency-department
https://www.psychiatrist.com/jcp/mental/child/youth-with-autism-in-the-emergency-department/

An evaluation of parent provider involvement in generalization of children with autism:
https://www.sciencedirect.com/.../abs/pii/S0891422205000958

Impacts of the caregiving relationship: https://academic.oup.com/gerontologist/article/56/6/1102/2952858

State Approaches to Reimbursing Family Caregivers of Children and Youth with Special Health Care Needs through Medicaid - NASHP
NASHP-State-Approaches-to-Reimbursing-Family-Caregivers-of-CYSHC-through-Medicaid_highlighted.pdf

NASHP-State-Approaches-to-Reimbursing-Family-Caregivers-of-CYSHC-through...

From: Paula Raso [redacted]
Date: Tuesday, July 25, 2023 at 2:21:01 AM UTC-4
Subject: Parent let Habilitation Services
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>, Saul Rascon [redacted], Paula Raso [redacted]

To Whom and May Concern,

I'm writing this to beg you to please not discontinue parent let habilitation services. It's extremely tough to raise a child with special needs and the parent let habilitation program has been a blessing in our lives. Parent let habilitation has made things easier for my entire family.

For years we have struggled with finding services for our son and at times it seemed like a revolving door for therapists as they did not stick around for very long. This issue only led to setbacks in my Child's care plan and a lot of troubles for my family due to increased behavioral issues in my son. With the state allowing parents to lead Habilitation services this opened an opportunity for a company to train me and to provide me with tools and resources to tackle my son's habilitation needs. In the last year I have seen immense growth in my son because I have been able to work with him on a daily basis on his habilitation goals, of course the state only pays for so many hours but it's the parents that work many more hours to provide our children with the best possible opportunity to a normal life. Also the income that comes into the home allows me to spend on additional resources and experiences that only broaden my Childs habilitation learning.

I do not believe that a young college kid that has very little real world experience and for the most of them no child care experience, will be a better at teaching my child habilitation skills than his mother who has nothing but the absolute best intentions for him.

I ask you to please consider the damage that this will have on our children who are already at a disadvantage in this world, and the added stress that this decision to remove the parent-let habilitation program will have on so many families, mine being one of them.

Kindest regards,

Paola and Saul Rascon parents of [redacted]

From: Kim Evans [redacted]
Date: Monday, July 24, 2023 at 11:44:21 PM UTC-4
Subject: Public Input for 1115 Waiver Team
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

July 23, 2023

Dear AHCCCS and 1115 Waiver Team,

I am a concerned community member and have a personal relationship with a DDD and ALTCS recipient currently participating in the Paid Parent Caregiver program under the Covid-19 Flexibility.

This program has been extremely beneficial to this disabled child and their family. I would like to share my observations, experience and feedback pertinent to the current proposal for a permanent Paid Parent Caregiver program.

Before the Paid Parent Caregiver program began under the Covid-19 Flexibility, I saw the stress and strain first hand of one set of parents providing for their disabled child largely due to constantly trying to find, train and retain in-home caregivers. Some of the caregivers that were found by the agencies were chronically late. Most while competent could not continue for more than a few months due to the low salary. I saw burnout and hopelessness take a toll on these parents.

When the Parent Paid Provider program began, these parents were able to provide more financial stability for their family. It relieved stress in that they were able to hire someone to clean the home a couple of times per month as the mother was providing 18 hours of care per day for her severely handicapped child. More social interaction with the community was able to be had as they were able to buy a vehicle that would carry their wheelchair bound son. Overall this program has provided security for their son as well as their family.

Under the current proposal, the request of the disability and caregiver community for an ongoing program option which allows parents of disabled minors in Arizona to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies is not being met. Please consider updating the proposal based on the following questions, suggested solutions, and experiences. Should Habilitation be included in the Paid Parent Caregiver Program? We have heard the concerns about member isolation and lack of community involvement if parents continue as Paid Parent Caregivers facilitating their child's Habilitation services. Respectfully I would like to propose the following solutions:

1. Examine available research and personal feedback statements from members and their families to evaluate the true potential impacts of social isolation and community involvement when parents of disabled children provide Habilitation services. The parent caregiver community's collective experience is that members who have parents facilitating their Attendant Care and Habilitation services have experienced greater member social engagement and community involvement over the last three years. Parent caregivers now have an increased ability to take their children to sporting team practices, community events, movie theaters, all ability parks, church activities and libraries. This is because parent providers can perform the appropriately trained and qualified supports in the correct time and location that is applicable to each member.

2. Implement precise guidelines to facilitate generalization for all Habilitation providers regardless of the DCW's familial status. Habilitation services are designed to have goals where data is collected to evaluate if those goals need to be changed, have been met, or need to be addressed differently. For a goal to be considered met, a member should be demonstrating that they are able to successfully meet that goal outside of the timeframe with a provider in one setting. This is referred to as generalization. The effective implementation of generalization with the pediatric IDD population would lessen, if not eliminate, any complications with adult transitional services. Under this model a program that includes parents as paid Habilitation providers would actually assist and improve in the success of adult transition. There are times when disabled children work successfully with different types of providers in clinics or schools, but the parents are not carrying the work over at home. This can happen for a variety of reasons. Having parents as Habilitation providers would help ensure the child's goals are congruent and carried over in the home and community setting. This will give the member a better chance of independence as they transition through different life stages. With generalization policies in place, Habilitation services being performed by parent providers will actually help facilitate successful transition into adulthood.

3. We know from provider agency data that "the top 3 issues regarding recruiting and retaining career non-family caregivers are schedules of the client members, interest in the position and finding qualified applicants." Most members have Habilitation goals and ADLs that are most appropriately delivered throughout the natural routine of their day. A parent provider is uniquely available in the morning, after school or in the evenings when each member is motivated and focused on the pertinent task. If a non-family provider is available their schedules typically allow them to work in longer time chunks that are not always the most ideal for the member and creates artificial goal or ADL practice. Continuity of care and greater member outcomes can be associated with consistently provided Habilitation care by parent providers who have the greatest ability to be flexible and available for their member children. Should parent providers be limited to 40 hours a week of paid care per child? We have heard the concerns of AHCCCS regarding the potential for a difficult adult transition to non-family supports once parent caregivers are no longer able or willing to help facilitate the disabled member's care.

I would like to propose the following collaborative solution to create a win-win scenario:

1. Create a program provision that outlines an extraordinary circumstances clause and the application process that allows parents to provide over 40 hours of paid care per week of authorized and evaluated services per member. These extraordinary circumstances could include, but are not limited to:

a. The lack of a non-parent DCW being available in the last 3 months to fill the member's assessed hours that exceed 40 hours per week. Ongoing DCW searches should continue to be made by the member's agency to fill the assessed hours beyond 40 hours per week of Attendant Care and Habilitation.
b. The expressed desire made by a member for a parent caregiver to facilitate their assessed DCW hours so that their Article 9 rights are honored.
c. The profound disabilities and/or significant behaviors of a member where a non-family provider is not equipped to provide DCW support. This determination can be made through a stakeholder team approach, including but not limited to the member's, DDD Support Coordinator, DDD Nurse, DDD Supervisors, Behavioral Plan Experts, Parents / Guardians, Psychologist, or Medical Doctor.

2. Form equality between all Family Provider Programs by allowing all Direct Care Workers, regardless of familial relationship or member age, to provide up to 16 hours of paid care per day. This will allow for employee equality across the lifespan of the member and limit the potential anti-family provider rhetoric currently present within state policies and DDD Support Coordination culture. All evaluations of hours should be based on member needs regardless of who is providing the services to create uniform implementation of all applicable HCBS services by the DCWs available to fulfill those hours.

3. The Family Support Program currently in this proposal addresses caregiver burnout. It is one of the available solutions to facilitate further community support within the disability and caregiver community that will provide greater access to non-profits facilitating counseling services, support groups and meet up activities.

4. Reevaluate Respite reimbursement rates to also address caregiver burnout. If Respite services are not available to the member or their family, parent burnout will continue to be an issue regardless of parents having the option of providing Attendant Care or Habilitation hours. With a comprehensive Paid Parent Caregiver Program in place non-family DCW providers will have greater flexibility to provide Respite services to these same families.

How should current evaluation protocols, training and practices be updated to facilitate equality for all members when accessing member needs?

AHCCCS has stated their intention to amend applicable policy, further suggested action on this topic includes:

1. Forming a committee of community and department stakeholders to amend and critique current DDD and AHCCCS policies and need assessment forms so that the most effective and efficient implementation of this permanent option is utilized moving forward.

2. Provide appropriately determined training and program implementation to DDD and ALTCS Support Coordinators so that Attendant Care and Habilitation hours are equitably evaluated based on the member's needs and to remove organizational bias of familial providers across the member's lifespan. Specifically investigate and determine appropriate DDD staffing needs and training for the members served in rural areas and those from minority backgrounds.

3. Create the option for private sector Support Coordination. Other states have this option within their Medicaid services, and this could be an additional feature in our DDD portfolio to allow for the member's needs to be best evaluated. In conclusion, Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS.

By not allowing parents of minors to provide Habilitation and Attendant Care services or work over 40 hours a week most of the minor disabled community in Arizona will be underserved. A comprehensive Paid Parent Caregiver program validates the irreplaceable work that parents provide in their homes and communities. Click here to connect with the Arizona parent led grassroot initiative leaders: www.raisingvoicescoalition.com

Thank you for your time and consideration!

The disability and caregiver community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves all DDD and ALTCS members in Arizona.

Thank you!

Kim Evans
Family Member of DDD and ALTCS Recipient

CMS perspective on the above noted requested program adjustments and paying Legally Responsible Individuals: June 28, 2023 - Email Correspondence between CMS and Raising Voices Coalition: https://drive.google.com/file/d/10CPccmIY7gEr5vq9C6vIaKmncSQOV7kc/view?usp=share_link May 23, 2023 - Transcription of National Meeting between CMS Leaders and Parent Advocates: https://docs.google.com/document/d/1h02v6Yk7frWGADcqKgm1zmd0uquMNfW3Jcd0zjHCxOk/mobilebasic?fbclid=IwAR2QLqbwJMQQRz0nj-XqhYzlFlkQbUV5wnyAyv98hivRVYpCjaYHhL BCzYg Studies and data that support the changes being requested: Data results from a 2023 Arizona survey of parents who have children with disabilities: https://docs.google.com/document/d/16PZOk99caDUitg0XmQKqEv2mxXOBeaRywSD_zmjAnYw/edit?usp=sharing A report on the current caregiver crisis by the National Association of Homecare and Hospice: https://www.hcaoa.org/uploads/1/3/3/0/133041104/workforce_report_and_call_to_action_final_03272023.pdf Higher satisfaction of paid supports for adults and minors with disabilities when care is received from paid family providers: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1089106/ A comparison of healthcare utilization when children receive paid care by a family member vs non-family provider: .https://www.jpeds.com/article/S0022-3476(23)00106-3/fulltext Youth with Autism Spectrum Disorder have less ED visits and patient outcomes when patient providers are involved: https://www.reliasmedia.com/articles/148366-autism-spectrum-disorder-in-the-emergency-department https://www.psychiatrist.com/jcp/mental/child/youth-with-autism-in-the-emergency-depart ment/ An evaluation of parent provider involvement in generalization of children with autism: https://www.sciencedirect.com/.../abs/pii/S0891422205000958 Impacts of the caregiving relationship: https://academic.oup.com/gerontologist/article/56/6/1102/2952858

State Approaches to Reimbursing Family Caregivers of Children and Youth with Special Health Care Needs through Medicaid - NASHP https://drive.google.com/file/d/1TSt-Rj95DTn711EV8UTq7YqF0yoo0j8u/view?usp=sharin

From: Kelly Bertetto [redacted]
Date: Monday, July 24, 2023 at 10:48:29 PM UTC-4
Subject: HELP needed: Parent Paid Provider Program
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

As a parent of a child who receives DDD and ALTCS services I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility, and it has been extremely beneficial to our family and my child. I would like to share my personal experiences and feedback based on my review of the current proposal for a permanent Paid Parent Caregiver program.

[redacted], a name you probably don't know personally. She is my [redacted] year old daughter. She is disabled and has been since was very young. She was born at only [redacted] weeks gestation. She is a MIRACLE! She had a 10% chance of survival and her twin brother had roughly a 30% chance of survival. Her dad served [redacted] years in the [redacted]. I've been a single mom (110% SINGLE MOM) since the twins were [redacted] years old. I am the sole provider and caregiver for the twins. When the twins went from Early Intervention to Long Term Care, I was very unfamiliar with all the ins and outs of what AZ had to offer my disabled children. I kind of just went with the flow. Over the years we've had numerous providers. Some that we trusted VERY much and could rely on. Some providers were not so great. I would even recruit some on my own. I know my twins had Habilitation goals as we discussed them in the meetings, but it wasn't until I became a parent provider that I realized the training they all received. However, having providers on an inconsistent basis and at different times of the day/evening (depending on when I was home from work) didn't really give my kids the benefits of the Habilitation they were to receive per the state of AZ. The providers wouldn't be at therapies with me to see the proper ways to work with the kids. The providers wouldn't be there for 1 hour in the mornings when it was in the kids routine to work on a Hab goal. When the providers were at my home, it would sometimes be more of a babysitter type than someone who was actually WORKING with my kids on their goals. It ended up being more work for me, as I was still doing my daily routines with the twins, plus having to train the providers, and more work when they left as most of them did poorly at completing a task. When the pandemic hit and we were trained to be caregivers, I could actually put the notes in and see the progress...things changed for my twins 110%. Moreso for my daughter [redacted]. I received so many compliments from her teachers and school staff when she returned to school on how much she's excelled and progressed during the pandemic (where most "Typical" children suffered with setbacks). I can ONLY attribute it to me being her provider. I was able to dedicate the time I wasted training providers, cleaning up after providers to my kids. I was there EVERYDAY to work on goals. Not just the occasional shifts a caregiver could work. Since I've worked with my daughter on the HAH goals since I was her provider, she has achieved and grown so much with her goals. She is now able to help brush her teeth for 2 minutes, before she would hardly let the provider touch her mouth without screaming for me. She can brush tangles out of her hair, another goal she didn't get any progression from her providers. She can now assist with transfers from her wheelchair to multiple surfaces. Why is this? Having an outside provider come to the home once or twice per week to work on something that only occurs within the hour parameters they are available is useless. When my daughter is at a certain part of her day and wants to work on her goal of using her device to communicate, am I supposed to say...Oh please hold and let me call a provider to help with your hab goals? I'm HERE and working with her. All these examples are things I've dealt with BEFORE the pandemic. Now we have a caregiver shortage EVERYWHERE! How would I even find a provider? I've had feelers out with the agency that I'm employed through for YEARS and they can't even find qualified people to work. Getting rid of parent provided habilitation would be a sad scene. Sure our kids would still get the services provided by us now that we are all qualified to provide it, but the only ones benefiting would be the state, as they would not be paying for services that our kids qualified for and so dearly need, because there will be no one to provide the services. And there will be no way to track goals daily as us parents will not be tracking as providers. I'm sure you've heard this before, but the reality is, not many people would choose working with disabled individuals, changing diapers, transfering dead weight, showering young adults when they could go to work in a fast food restaurant for more money.

Under the current proposal, the request of an ongoing program option which allows parents of disabled minors in Arizona to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies is not being met. Please consider updating the proposal based on the following questions, suggested solutions, and personal experiences.

Should Habilitation be included in the Paid Parent Caregiver Program?
We have heard the concerns about member isolation and lack of community involvement if parents continue as Paid Parent Caregivers facilitating their child's Habilitation services. Respectfully the parent caregiver community proposes the following solutions:

1. Examine available research and personal feedback statements from members and their families to evaluate the true potential impacts of social isolation and community involvement when parents of disabled children provide Habilitation services. The parent caregiver community's collective experience is that members who have parents facilitating their Attendant Care and Habilitation services have experienced greater member social engagement and community involvement over the last three years. Parent caregivers now have an increased ability to take their children to sporting team practices, community events, movie theaters, all ability parks, church activities and libraries. This is because parent providers can perform the appropriately trained and qualified supports in the correct time and location that is applicable to each member.

2. Implement precise guidelines to facilitate generalization for all Habilitation providers regardless of the DCW's familial status. Habilitation services are designed to have goals where data is collected to evaluate if those goals need to be changed, have been met, or need to be addressed differently. For a goal to be considered met, a member should be demonstrating that they are able to successfully meet that goal outside of the timeframe with a provider in one setting. This is referred to as generalization. The effective implementation of generalization with the pediatric IDD population would lessen, if not eliminate, any complications with adult transitional services. Under this model a program that includes parents as paid Habilitation providers would actually assist and improve in the success of adult transition. There are times when disabled children work successfully with different types of providers in clinics or schools, but the parents are not carrying the work over at home. This can happen for a variety of reasons. Having parents as Habilitation providers would help ensure the child's goals are congruent and carried over in the home and community setting. This will give the member a better chance of independence as they transition through different life stages. With generalization policies in place, Habilitation services being performed by parent providers will actually help facilitate successful transition into adulthood.

3. We know from provider agency data that "the top 3 issues regarding recruiting and retaining career non-family caregivers are schedules of the client members, interest in the position and finding qualified applicants." Most members have Habilitation goals and ADLs that are most appropriately delivered throughout the natural routine of their day. A parent provider is uniquely available in the morning, after school or in the evenings when each member is motivated and focused on the

pertinent task. If a non-family provider is available their schedules typically allow them to work in longer time chunks that are not always the most ideal for the member and creates artificial goal or ADL practice. Continuity of care and greater member outcomes can be associated with consistently provided Habilitation care by parent providers who have the greatest ability to be flexible and available for their member children.

Should parent providers be limited to 40 hours a week of paid care per child?
We have heard the concerns of AHCCCS regarding the potential for a difficult adult transition to non-family supports once parent caregivers are no longer able or willing to help facilitate the disabled member's care. The parent caregiver community would like to propose the following collaborative solution to create a win-win scenario:

1. Create a program provision that outlines an extraordinary circumstances clause and the application process that allows parents to provide over 40 hours of paid care per week of authorized and evaluated services per member. These extraordinary circumstances could include, but are not limited to:
    a. The lack of a non-parent DCW being available in the last 3 months to fill the member's assessed hours that exceed 40 hours per week. Ongoing DCW searches should continue to be made by the member's agency to fill the assessed hours beyond 40 hours per week of Attendant Care and Habilitation.
    b. The expressed desire made by a member for a parent caregiver to facilitate their assessed DCW hours so that their Article 9 rights are honored.
    c. The profound disabilities and/or significant behaviors of a member where a non-family provider is not equipped to provide DCW support. This determination can be made through a stakeholder team approach, including but not limited to the member's, DDD Support Coordinator, DDD Nurse, DDD Supervisors, Behavioral Plan Experts, Parents / Guardians, Psychologist, or Medical Doctor.
2. Form equality between all Family Provider Programs by allowing all Direct Care Workers, regardless of familial relationship or member age, to provide up to 16 hours of paid care per day. This will allow for employee equality across the lifespan of the member and limit the potential anti-family provider rhetoric currently present within state policies and DDD Support Coordination culture. All evaluations of hours should be based on member needs regardless of who is providing the services to create uniform implementation of all applicable HCBS services by the DCWs available to fulfill those hours.
3. The Family Support Program currently in this proposal addresses caregiver burnout. It is one of the available solutions to facilitate further community support within the disability and caregiver community that will provide greater access to non-profits facilitating counseling services, support groups and meet up activities.
4. Reevaluate Respite reimbursement rates to also address caregiver burnout. If Respite services are not available to the member or their family, parent burnout will continue to be an issue regardless of parents having the option of providing Attendant Care or Habilitation hours. With a comprehensive Paid Parent Caregiver Program in place non-family DCW providers will have greater flexibility to provide Respite services to these same families.

How should current evaluation protocols, training and practices be updated to facilitate equality for all members when accessing member needs?
AHCCCS has stated their intention to amend applicable policy, further suggested action on this topic

includes:

1. Forming a committee of community and department stakeholders to amend and critique current DDD and AHCCCS policies and need assessment forms so that the most effective and efficient implementation of this permanent option is utilized moving forward.

2. Provide appropriately determined training and program implementation to DDD and ALTCS Support Coordinators so that Attendant Care and Habilitation hours are equitably evaluated based on the member's needs and to remove organizational bias of familial providers across the member's lifespan. Specifically investigate and determine appropriate DDD staffing needs and training for the members served in rural areas and those from minority backgrounds.

3. Create the option for private sector Support Coordination. Other states have this option within their Medicaid services, and this could be an additional feature in our DDD portfolio to allow for the member's needs to be best evaluated.

In conclusion, Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. By not allowing parents of minors to provide Habilitation and Attendant Care services or work over 40 hours a week most of the minor disabled community in Arizona will be underserved. A comprehensive Paid Parent Caregiver program validates the irreplaceable work that parents provide in their homes and communities.

Click here to connect with the Arizona parent led grassroot initiative leaders:
www.raisingvoicescoalition.com

Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves all DDD and ALTCS members in Arizona.

Thank you!
Kelly Bertetto

CMS perspective on the above noted requested program adjustments and paying Legally Responsible Individuals:

June 28, 2023 - Email Correspondence between CMS and Raising Voices Coalition:
https://drive.google.com/file/d/10CPccmIY7gEr5vq9C6vIaKmncSQOV7kc/view?usp=share_link

May 23, 2023 - Transcription of National Meeting between CMS Leaders and Parent Advocates:
https://docs.google.com/document/d/1h02v6Yk7frWGADcqKgm1zmd0uquMNfW3Jcd0zjHCxOk/mobilebasic?fbclid=IwAR2QLqbwJMQQRz0nj-XqhYzlFIkQbUV5wnyAyv98hivRVYpCjaYHhLBCzYg

Studies and data that support the changes being requested:

Data results from a 2023 Arizona survey of parents who have children with disabilities:
https://docs.google.com/document/d/16PZOk99caDUitg0XmQKqEv2mxXOBeaRywSD_zmjAnYw/edit?usp=sharing

A report on the current caregiver crisis by the National Association of Homecare and Hospice:
https://www.hcaoa.org/uploads/1/3/3/0/133041104/workforce_report_and_call_to_action_final_03272023.pdf

Higher satisfaction of paid supports for adults and minors with disabilities when care is received from paid family providers:
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1089106/

A comparison of healthcare utilization when children receive paid care by a family member vs non-family provider: .https://www.jpeds.com/article/S0022-3476(23)00106-3/fulltext

Youth with Autism Spectrum Disorder have less ED visits and patient outcomes when patient providers are involved: https://www.reliasmedia.com/articles/148366-autism-spectrum-disorder-in-the-emergency-department
https://www.psychiatrist.com/jcp/mental/child/youth-with-autism-in-the-emergency-department/

An evaluation of parent provider involvement in generalization of children with autism:
https://www.sciencedirect.com/.../abs/pii/S0891422205000958

Impacts of the caregiving relationship: https://academic.oup.com/gerontologist/article/56/6/1102/2952858

State Approaches to Reimbursing Family Caregivers of Children and Youth with Special Health Care Needs through Medicaid - NASHP
https://drive.google.com/file/d/1TSt-Rj95DTn711EV8UTq7YqF0yoo0j8u/view?usp=sharing

[redacted]

From: Deanna Gile [redacted]
Date: Monday, July 24, 2023 at 9:11:15 PM UTC-4
Subject: PUBLIC FEEDBACK from July 18th Meeting
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To Whom It May Concern:

Again, I want to express my sincerest gratitude for the paid parent program. Without the temporary measures put in place for me to provide my daughter, [redacted] care, and be paid to earn an income for that care, I'm confident my daughter would not be as healthy, strong, and made as many gains as she has. Frankly, without the temporary measures Arizona put in place, I'm not sure she would be here today.

I am extremely appreciative to those of you working feverishly to pursue the waiver program so that I may continue in this capacity - caring for her needs, in the absolute best way possible, and receiving a steady income while doing so. This will be such a relief. I only hope that the limit of the 40 hour parent maximum will be reconsidered and eliminated so that [redacted] needs can be met, as best as they possibly can.

During the meeting on July 18th, you expressed some information you would like to learn from us, as parents.

How has my member child's hours been unfairly assessed by a biased Support Coordinator due to the parent provider program being an option over the last 3 years?

While I am not certain there was malice in all of these situations, there are certainly many learning opportunities and inconsistencies within the DDD system.

When the pandemic began it was a learning process for most support coordinators, parents and DDD staff. Initially [redacted] was assessed by the hours I personally would provide for her and not necessarily based on her entire needs. As we continued to meet each 90-days the hours were assessed and grew greater and greater the more time [redacted] spent with me, ultimately ending with 168 hours per week of Attendant Care. However, only 112 hours of that total were approved to the ATC agency because of the "policy" that skilled hours, regardless of if they are waived [during the pandemic], must be deducted from the non-skilled hours - THIS WAS NOT AN ACTUAL POLICY, and those hours were reduced from my daughter's bank erroneously.

When a new SC was assigned [redacted] ATC hours were reduced to 112 without a new assessment which caused huge concern. I went through a lot of back and forth with the SC and her supervisor relating to various needs being left off the assessment (brief changes were reduced, PM grooming omitted, supervision removed entirely, etc) and ultimately I told them if they decided they didn't want to assess her the hours that was fine, but I wanted the document reflected the appropriate needs regardless. I was told the hours must match the needs and they couldn't assess needs without hours. They kept giving me excuses that "I couldn't work supervision hours" and trying to make other excuses to not assess her properly. The SC was very interested in giving [redacted] a fair assessment, it was the guidance of her supervisor that was negating the proper unbiased assessments. During a meeting with the SC and her supervisor in an effort to appease me the supervisor approved 168 ATC hours if I signed a MRA waiving skilled hours. This, of course, was also not the correct course of action. When I received the MRA and saw that I would be legally held responsible if [redacted] died in anyone else's care but my own, I was terrified to sign it. It was at this time I decided to contact outside counsel. Through the help of outside counsel and DDD legal team together, it was determined that skilled hours do not negate attendant care hours; the 56 hours [redacted] was already assessed for her SKILLED needs, that require a skilled provider, were to be granted in addition to the 168 attendant care hours. **This totals 224 weekly combined skilled/unskilled service hours.**

Why is it important to our members and families that Habilitation be included in this program?

Although my daughter does not receive HAB services, I believe it is an integral part of the Paid Parent Caregiver program. In this example you shared that it is vitally important for many of these goals to be provided in social settings with other people and that can be better served by a stranger provider than a parent provider. Do you have enough providers willing and able to take on these members and help them meet and fulfill their goals as diligently as their parents? Some of these child members, due to their condition, kick, hit, bite, run, elope, smear feces, scream, undress in public, need support with intimate skills such as bathing, dressing, using the bathroom. Do you think that once assigned to a case, the first time a stranger. making $19.00/hr with no benefits, has feces smeared on them will come back? Do you think they will take on that case to begin with? Then what happens? That member simply goes without the service because the parent is no longer an option as a provider (a parent that you, the state, already invested training and time into) and they are now out of the home working two-three jobs to make ends meet. Many of these parents are already thinking of creative ways to give their kids the best experiences and now they can - because they are home with them, they are compensated to be able to be there for their child and invest the time in their child when before they couldn't - for nearly all of we have to choose to pay our bills which comes with one-three jobs, because we can't afford to choose to stay home because there will be no home.

Recommendations requested, from a system perspective, on how you could unroll Habilitation and/or the 40 hour limitation to create the least amount of disruption as possible for the members if their program stays as it is currently proposed.

I would recommend that there be a clause with a variety of factors taken into consideration and if the member falls into one of those then the parent can be considered for additional hours.

For example: If a member has a certain number of weekly hours unstaffed, the parent(s) can be considered to have additional hours granted.

If a member lives in a certain area, where DCWs are limited, the parent(s) can be considered to have additional hours granted.

I would also recommend that prior to a mass removal of hours (or HAB services), that there be a DCW identified to transition these hours/services to, and ensure that DCW is committed to the member (perhaps after working a trial of two weeks), before parent hours (or HAB services) are reduced (or eliminated). This would require all members to be transitioned on a case by case basis or in a phased approach, perhaps from low needs, to moderate needs, to high needs members, however, it would allow for the system to set members and their family up for success rather than simply pulling the rug out with no identified support to relieve us. Additionally, I would also recommend backup support(s) also be identified and in place at this time, so that parents are not pulled from their paying jobs to care for their child members when experiencing DCW shortage/staffing challenges resulting in huge stressors on how to pay rent and bills.

Recommendations on what you can do to help us prevent caregiver burnout / Concerns for relying heavily on parents:

Parents have always been, and will always be, relied on heavily (or solely) to care for our children, it is just whether or not we will be compensated for our efforts. The first question asked in the assessment process is what informal support(s) the member has - meaning UNPAID support. While, as parents of children like ours, who have a variety of needs, we would absolutely love to be that soccer mom and cheer mom, running around unpaid, sipping our Starbucks in the pickup line at school chatting with all the other moms about our weekends and what our kids want to be when they grow up. For us, our reality is locking our refrigerator so that our child doesn't eat all day long because their body doesn't know when it's full, cleaning feces off the walls and floors because you decided to go to the bathroom yourself, changing the diaper of a [redacted] year old, monitoring oxygen saturations to ensure that your child is breathing and so much more. We do not have this luxury of being just a parent, and frankly having a choice of being paid or unpaid is just an additional stressor. WE WOULD NOT TRADE OUR CHILDREN or the care we provide them for the world, but we do need to have consistent income. Eliminating HAB for parents as a paid support, or capping parents to provide 40 hours weekly attendant care does not cure caregiver burnout, it leaves the opportunity for WAY more stress in our world, because then we have to figure out how to work outside the home, how to be home, how to have an income, and how to ensure how our child receives the care they need simultaneously. It is impossible.

Here are some recommendations on specific ways to help with caregiver burnout:

In my situation specifically: Eliminating the proposed limitation of Parent ATC Hours allows my daughter's other parent to become a provider as well, offering the ability for them to take time off from their primary job (unpaid with FMLA) to take our daughter to the occasional doctor, therapy, or other appointments that currently all fall on me. It also allows for a more even distribution of coparenting time than is currently allocated.

Eliminating the proposed limitation of Parent ATC Hours and omitting HAB for parent providers: When a DCW or a Skilled Nurse does not show up to a shift, quits, or is simply not available for the hours for the child member's needs, it automatically falls on the child's legal guardian - their parents. If the parent has the ability to be compensated for those hours, and not be limited to a certain number of hours, this will provide the parent with a safety net knowing they will be able to provide care for their child and contribute to the household expenses which is vitally important for both the member and the parent. While this does not specifically cure burnout it does help with financial stress.

Identifying members as low needs, moderate needs, and high needs members based on their assessed needs then by low-high priority for staffing needs and helping to staff those cases in that order, if possible. Also, actually follow the DDD guidelines and go out of network when the time frame designates that can be done, most families do not know that there is a policy that if staffing has not been found within a designated time that DDD must use out of network providers to meet their needs. Most just continue going without the coverage, continuing to burn themselves out more and more and more.

Provide support groups for parents of child or adult members.

Extend mental health services to parents of child or adult members.

Continue to extend AHCCCS healthcare to parents caregivers. Educate the AHCCCS team better on the parent program so that services are not withdrawn in error.

Train DDD staff or roll-out staff wide memos when policies change, are updated or are eliminated so that all DDD workers are assessing consistently across the board and we, as parents, do not have to keep fighting for what our members deserve.

Concerns relating to the socialization of members:

I absolutely share this fear and concern. In the past years of quarantine and isolation it has become very lonely, not only for my daughter but for me. Thankfully, I have been able to come up with 'out of the box' ways of helping [redacted] socialize while maintaining her health and as the years have gone by, I continue to get better and better at resourcing, and finding different ideas. Just some of the things we have been able to successfully do while maintaining her health are:

- [redacted] was enrolled in several ongoing sessions of a program through Integrative Touch called TeleFriends, where she met with two girlfriends weekly virtually and they explored music, played games, chatted about their week and so much more. This was also a great opportunity for [redacted] to be able to sustain virtual activity. Although the program is currently on pause, it is one she absolutely loves!
- I was able to successfully introduce her to a new friend from the special needs community. Her mom is willing to do a Covid test prior to them coming to our house which really helps ease our fears for [redacted] contracting illnesses. She comes and spends the night and they do crafts and have Starbucks!
- We research times and days where venues are the least busy and visit them during

those times so she still sees and has the opportunity to interact with people just on a lesser scale.

Again, I appreciate your support for us as parents to be able to provide the care for our children that they desperately need and deserve. I hope you will take into consideration our feedback to eliminate the limitation on parent providers and also to retain parents as paid providers for HAB services.

Thank you again.

Deanna Gile

From: Raj Sundar [redacted]
Date: Monday, July 24, 2023 at 9:00:51 PM UTC-4
Subject: Plea to make Parent provider of minor Habilitation Services permanent
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Good evening,

Recently, I heard about the possibility that Arizona DDD/AHCCCS could potentially stop funding the parent providers of minors programs for Habilitation services.

As a recent parent provider of a minor, I sincerely urge Arizona AHCCCS to not only refrain from canceling this program but also urge to make this program permanent. Here are some major concerns that I (as a parent) have experienced from (non-Parent) Direct care workers with regard to providing services to my son.

- Lack of availability of Direct care workers - In the last few years, it has been a huge challenge to find suitable direct care workers for my son.
- Competency - As parents, we know how our children function and have their best interests at all times. From past experiences, direct care workers (if and when available) do not provide the same level of knowledge/skills or care to the special needs that my son requires. As a result, the habilitation goals are seldom achieved.
- Reliability - All three of the direct care workers whom we had for my Son had reliability issues. There were frequent no-shows, late arrivals, and lack of communication. Children do not do well with such behaviors.
- Safety - I know direct care workers receive training from their agencies but there is always a fear of safety/security when children are alone and around with adults who are not from their family. We see incidents in daily news about horrific things happening in our communities and consequently, there is always a constant worry.
    - Reduction of time with Family - Since children are already going to school, having a worker provide habilitation service, often reduces the family time and interaction that a child has with his/her parents and family. Often habilitation service includes transportation (in addition to the targeted skill goal) which adds to the time.

I just listed a few of the key factors on why and how parents play a crucial developmental and skill-building role in our exceptional kid's evolving lives.

Humbly, requesting the AZ DDD/AHCCCS decision-makers to consider this plea and make an informed decision about the continuation of this program. This program has really been helpful for my son in not only improving his skills but also strengthening the bond and family values.

Best Regards,
Rajesh

From: Fauzia Rajabally [redacted]
Date: Monday, July 24, 2023 at 6:11:11 PM UTC-4
Subject: Parents as Paid Caregivers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

I had attended the first meeting for Parents as Paid Caregivers. Some feedback below;

During and after the Pandemic due to the fact that Parents were allowed to care for their minor children brought about a stability in the field of caregiving. With the shortage of staff and constant turnover of providers this was very beneficial. The agencies were able to source Providers who worked certain hours in combination with Parents to provide a solid foundation. There were many Parents who refused to let anyone in their home and the same was with certain caregivers who were reluctant to work in the field.

Currently we are still dealing with a shortage of Caregivers despite agencies offering them higher hourly wages. It seems to be the standard of employment that Caregivers feel that they can come and go whenever they want. We interview, hire, train offer sign on-bonuses and still see them fall off within a few months for one reason or another for us to restart the process of hiring.

As far as minor children are concerned, I share the view with many others that this is part of raising your child whether they are special needs or not. Caring for your minor child is all part of the Parenting process. Why do parents now want to be paid for this? It could be that they are not happy with their caregivers and have left their jobs to be a full-time caregiver.

As agencies we witness the negotiations for rates and hopping from agency to agency to get more and more money. Despite the AARPA Funding which was a blessing as many Caregivers went from $14 to almost $20 an hour, this pattern continues as some Parents are very demanding.

However, we cannot put everyone in this category and strongly encourage the State to consider extending this rule with the intent to make it permanent so Parents can have the option of caring for their minor children. Respite should still be given to Parents to give them a break with the fill in caregiver.

Thanks

Fauzia Rajabally
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Phone [redacted]
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Email: [redacted]
Web: www.azcareproviders.com

---------- Forwarded message ---------
From: Deanna Gile [redacted]
Date: Monday, July 24, 2023 at 6:10:18 PM UTC-4
Subject: What the Parent Paid Caregiver Program means to me and how the 40 hour cap would effect our family
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

What the Parent Paid Caregiver Program means to me:

My name is Deanna Gile and my daughter is [redacted], is [redacted] years old: loves all things cat, chatting with her girlfriends on the computer, listening to Miley Cyrus, Taylor Swift and Harry Styles, enjoys being read to, and looking through magazines. She also likes a good Starbucks run, going bowling, and shopping at her favorite toy store, Mildred and Dildred. While she sounds like a typical teenager she is extremely medically fragile, severely immunocompromised, and has numerous diagnoses related to her extreme premature birth that left her with her [redacted] brother passing away after four short hours of life. As her mom, and primary caregiver, I have to be extraordinarily careful in any and all interactions to keep her safe and healthy - donning masks, washing hands, using hand sanitizer, keeping distance from others in public - both in a pre and post pandemic world.

Firstly, I want to express my sincerest gratitude for the paid parent program. Without the temporary measures put in place for me to provide her care, and be paid to earn an income for that care, I'm confident my daughter would not be as healthy, strong, and made as many gains as she has, frankly, I’m not sure she would be here today, without the temporary measures Arizona put in place. So thank you again for this amazing program. Additionally, I would not have been able to pay my bills nor my rent, which would have resulted in so many additional stresses and challenges, as you can imagine, again thank you.

Currently, [redacted] is assessed and approved for over 200 hours weekly between both skilled and unskilled services (attendant care and skilled/nursing care), due to her high needs and severe risks. [redacted] can never be left alone, but not only that she can never be left unsupervised due to a compromised airway, even caregiver bathroom breaks are difficult, because in a matter of seconds her airway can become compromised. Due to the lack of caregivers (both skilled and unskilled) available in Arizona, but specifically in our area, [redacted] hours could never be so closely met without the parent paid caregiver program.

Prior to the pandemic [redacted] **was assessed for 56 skilled nursing hours**, and was also going to public school with another approximate **40 skilled nursing hours provided by the public school district** (all, ultimately, *paid for by the state*). Unfortunately, due to SC oversight and misunderstanding of the programs offered she was never offered the attendant care assessment. Of the 56 skilled hours approved for at home, over 40+ skilled hours weekly on a routine basis were unstaffed. We as parents NEVER were able to take a single respite hour from the 600 hour nursing respite bank provided to offer us a break. There was also a constant threat by the DDD nurse to "cancel nursing services" because we were not utilizing them as they were assessed, despite it being an issue to have the agency staff them.

When the pandemic began it was a learning process for most support coordinators, parents and DDD staff. [redacted] **was finally assessed based on her needs and risks** for Attendant Care at 24/7 care (168 hours/week). Through the help of outside counsel and DDD legal team together, it was determined that skilled hours do not negate attendant care hours; the 56 hours [redacted] was already assessed for her needs, that require a skilled provider, were to be granted in addition to the 168 attendant care hours. **This totals 224 weekly combined skilled/unskilled service hours.**

As I'm sure you can imagine, staffing 224 hours weekly, including overlap of services, is no small effort to keep a child who is medically fragile living a quality life in her home. This is our ultimate family goal: a quality life at home, forever. This requires keeping her safe, maintaining skin integrity, safely socializing in this new world, proactive care to keep her healthy (with minimal to no hospital admissions due to illness), all while maintaining balance to help her enjoy activities to lead a quality life.

I, being her primary caregiver, have provided [redacted] care 24/7 for her entire life, with a small break during my divorce, which was the most stressful time in my life. During this time, I was not a reliable employee, often having to call in or leave early due to [redacted] health or staffing challenges by our nursing agency. There has always been a shortage of nurses, despite [redacted] having a primary nurse, due to her own personal life issues she was not reliable and there was no available back up coverage. Throughout the entire time we have lived in Arizona and [redacted] has been receiving services, there has never been

continuity of care and I have always had to be available to take care of her needs at a moment's notice. Even if a nurse was found for the case, they may not have been found to be competent to provide the level of care [redacted] needed to maintain her health and remain in the home, additionally avoiding lengthy in-patient ICU admissions. It takes a special skill set to provide [redacted] care, she is not a case where a retired hospital nurse can come and sit bedside, taking notes, and charting all day, there is a great deal of involved care required for her case, and unfortunately for in home care nursing it is EXTREMELY hard to find those nurses due to low pay, less than desirable benefits, treatment from the staffing agency, and so much more.
It was less than a year before the pandemic that I worked in this capacity then the pandemic began; I found the pandemic to be a blessing. All I wanted was to continue to be able to stay home with [redacted], keep her safe (and alive!), provide her care, and be able to keep a roof over our heads doing it. The temporary flexibilities put in place allowed me to do just that.

The paid parent program has allowed me to stay home with [redacted], care for her, keep her safe, healthy, thriving and growing in leaps and bounds. During the pandemic [redacted] extremely involved care fell on me with minimal to no help, which at the time we had no idea would go on to last three years. At the end of those three years I was exhausted; in this post-pandemic world, I know I can not do all of her care myself, [redacted] needs a team, but I also know that the team needs me 100% of the time, which is far more than 40 hours per week proposed as a cap for parents. I also know that at a moment's notice I need to be available for [redacted] to provide her care in the absence of anyone on her team. The Covid19 virus is still circulating and could be life threatening for [redacted], as well as any respiratory illness could be life threatening for [redacted] - this is why it is so important that there not be a cap for parents, specifically in the case of [redacted], and those other children like her, if she were to go to a facility she would be exposed to a plethora of germs, which would highly likely result in an abundance of in-patient ICU admissions, paid for by her state community plan. Prior to moving to Arizona, she spent so much time in the ICU due to the contracting respiratory illness. Now, and even more so since the pandemic, she has been able to maintain a level of health like we have never seen before, all due to the ability for me to stay home with her and be her primary caregiver and the reduced stress due to the ability to have income while working in that capacity.

With the guidelines as they are today, [redacted] hours are already unmet by an average of 24 hours weekly, these unstaffed hours will go up with the new limits proposed to be placed on the program for parent caregivers, and even more so in the absence of a parent caregiver program entirely.

Thank you for your time.
Deanna Gile

From: Jennifer Walters [redacted]
Date: Monday, July 24, 2023 at 5:44:24 PM UTC-4
Subject: Feedback for Program for Proposal
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Good afternoon, I'm Jennifer Walters. I have a [redacted] year old on the program that is diagnosed with 22q and Autism and is also non-speaking. I want to say thank you to AHCCCS for this amazing program and everything you do for our children and just share a little bit about our experience. We just moved to a small town in northern Arizona a year ago. When we first spoke with our support coordinator, she was surprised that my son had habilitation and attendant care services and shared with me that for the most part, No one in northern Arizona had these services. She told us that it usually takes years here to even get a speech, occupational or physical therapist and there would probably be no way to get a provider for habilitation, attendant care, respite or other services like music therapy. We still have not been able to find an OT, PT, music therapist or respite provider since moving to [redacted]. But, thankfully, due to the parent provider program, I am able to work with him for the habilitation and attendant care. My son has home-based and community-based goals and has made huge improvements in all areas as well as maintained an active social life. We actually started a social club in [redacted] for children with disabilities, which I feel is a better option for socialization, rather than removing habilitation from the current plan. If habilitation is not included in the permanent plan, my son will not have another provider for this service and will most likely lose all of the amazing progress he's made. I ask that you please consider adding habilitation to the plan and remove the 40 hour restriction for parent providers.

From: Cristina [redacted]
Date: Monday, July 24, 2023 at 5:07:27 PM UTC-4
Subject: Concern about HAB
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hi . My name is Cristina Garcia, I'm a Parent provider who does ATC and HAB for my son, he is [redacted] years old, has severe Autism, he is Non-verbal , before they aloud us to provide services for our children we had a very hard time finding providers for our son , and when we found some our son was never conforta with it. Now my son is a teenager and I don't feel confortable bringing a strange person home to help him to take a shower or clean himself when he go to the restroom , also my teenage daughter also request that we avoid having strangers in the house . Having a stranger at home every day will be very uncomfortable for the hole Family. Also wanted to add that my son is never isolated as our family goes out to eat, to church and part of the HAB goals is taking him to do some of their favorite activities to relax his anxiety. Last, I would like to state that since I started to do HAB with my son we started to see resulta with his goals , because I have more opportuniti to be with him and not working outside home full-time
Thank you for your attention in this matter
Cristina
[redacted]

From: Chelsea Leppard [redacted]
Date: Monday, July 24, 2023 at 3:02:26 PM UTC-4
Subject: Suspending parents to provide HAB services.
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello,

I recently revived and email about parent no longer allowed to provide HAB services to their children. My name is Chelsea Leppard, and my son's is [redacted] [redacted]. Since I have been working with him he has learned to write his letters, numbers, name and follow directions. With my son I am motivated and can dedicated the time to make positive changes in his development, which I have proved. I am assuming i am not the only family that feel that not allowing parents to do HAB would be senseless and detrimental to the children that are in schedules with parents and are making huge progress. No one can tach my son like me. He was counting at [redacted], now following directions, and writing numbers and letters at [redacted]. I would like to formally appeal this if possible.

Best
Chelsea leppard
[redacted]

---------- Forwarded message ---------
From: [redacted]
Date: Monday, July 31, 2023 at 8:00:56 PM UTC-4
Subject: How should we build in program scaffolding for Extraordinary Care?
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To whom it may concern,

Extraordinary Care is defined as care exceeding the range of activities that a Legally Responsible Individual (parent or a minor or spouse) would ordinarily perform in the household on behalf of a person without a disability or chronic illness of the same age, and which are necessary to assure the health and welfare of the participant and avoid institutionalization. **If the state allows Legally Responsible Individuals to provide waiver services, it must establish criteria that define extraordinary care.**

Ordinary Care is defined as the typical responsibility of a Legally Responsible Individual ordinarily provided to people, with or without a disability or chronic illness.

Both of these definitions come from CMS which gives the framework for all states to create Medicaid waiver programs that provide appropriate supports that enable individuals with disabilities to live in their homes and communities.

While discussing the new Paid Parent Caregiver proposal for minors with disabilities in Arizona the discussion around Natural Supports and the rolls of Legally Responsible Individuals has come up from our Medicaid and DDD leaders. Specifically regarding the Attendant Care and Habilitation services that ALTCS and DDD authorize. Our state leaders are currently proposing program restrictions that would limit access to authorized care hours to minors due by their parent providers.

In order for Extraordinary Care to be defined and function correctly in Arizona, AHCCCS (Medicaid) leaders need to define and reassess our current evaluation tools for Attendant Care and Habilitation. This is necessary for a permanent program which allows parents of minors to perform paid waiver services in Arizona.

Individualized plans that evaluate appropriate services for each member by a Support Coordinator with clearly defined roles of Legally Responsible Individuals at different ages of a member's development is needed. We can no longer operate within a system that leaves these determinations up to individual Support Coordinators without the correct framework to support their evaluations of Natural Supports. Families in Arizona have experienced a wide degree of chaos and evaluation inconsistencies across the entire DDD population within Arizona over the last 3 years operating under the current flexibility.

The proposal change request that the Raising Voices Coalition and parent caregivers across Arizona are requesting will best support the balanced care needs of all Arizona minors with disabilities. It will allow for flexibility within the individual planning process as long as appropriate steps are taken to clearly define Extraordinary Care for disabled minors at different ages through a comprehensive overhaul of existing evaluation tools. The framework to define and evaluate Extraordinary Care on an individual basis should be built in the evaluation tools for services instead of the parameters of a permanent program which authorizes parents of minors to provide Attendant Care and Habilitation.

https://www.medicaid.gov/medicaid/benefits/early-and-periodic-screening-diagnostic-and-treatment/index.html

Brandi Coon
Co-Founder & Disability Advocate
website: raisingvoicescoalition.com
email: [redacted]

---------- Forwarded message ---------
From: Jill Ressler [redacted]
Date: Monday, July 24, 2023 at 1:48:15 PM UTC-4
Subject: feedback re: possible parent provider changes
[redacted]

Hello. I am writing as a parent provider of my 15 year old daughter with Down Syndrome. She is also a survivor of AML leukemia.

I am a mom who has a master's degree with a career that ended due to the needs of my daughter. (She lived for 7.5 months in the hospital) The parent provider program has been very helpful. I provide both attendant care and habilitation hours. I have found it very difficult to get other individuals to provide such services for my daughter. There are a lot of hoops to jump through to get certified to provide these services and stay certified. I have found that there are few people that want to jump through these hoops for this amount of pay.
If the parent provider program services for habitation discontinues, it would be a hardship for my daughter and for my family.

Please do all that you can to advocate for parents and individuals with special needs. Thank you.
Jill Ressler
[redacted]

Sent from my iPhone

From: Chelsea Leppard [redacted]
Date: Monday, July 24, 2023 at 3:02:26 PM UTC-4
Subject: Suspending parents to provide HAB services.
[redacted]

Hello,

I recently revived and email about parent no longer allowed to provide HAB services to their children. My name is Chelsea Leppard, and my son's is [redacted]. Since I have been working with him he has learned to write his letters, numbers, name and follow directions. With my son I am motivated and can dedicated the time to make positive changes in his development, which I have proved. I am assuming i am not the only family that feel that not allowing parents to do HAB would be senseless and detrimental to the children that are in schedules with parents and are making huge progress. No one can tach my son like me. He was counting at 2, now following directions, and writing numbers and letters at 3. I would like to formally appeal this if possible.

Best
Chelsea leppard
[redacted]

From: Olivia Fryer [redacted]
Date: Monday, July 24, 2023 at 12:39:26 PM UTC-4
Subject: November 2023 AHCCCS Proposes to END Parents of Minors as Habilitation Providers
To: [redacted]

Good morning

The Board of Autism Society of Greater Phoenix believes AHCCCS should request that CMS make permanent the temporary Paid Provider Program. AHCCCS should amend the Arizona 1115 Demonstration Waiver to allow parents of minor DDD and ALTCS members to be paid providers with the same requirements and limitations of other DCW providers. The State Legislation should authorize parents of any DDD and ALTCS member to provide Attendant Care and Habilitation services for their minor children with the same requirements and limitations of other DCW providers.

The current Parent Provider program allows parents of disabled minor children to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies. This program is crucial to families because of the lack of qualified providers available to serve those with DDD and ALTCS. Home and Community Based Services are necessary for those in Arizona who qualify for DDD and ALTCS and these children deserve caring, consistent, qualified direct care workers.

The social, cultural and systematic benefits that members will receive from this permanent program are significant and superior to the current DCW program. Changing circumstances require us as a nation to do better with the funds we manage, situations we face and members we serve. Parent caregivers have been the backbone of the Developmental Disability community for decades. Comprehensive Paid Parent Provider programs validate the irreplaceable work they provide on a daily basis in their homes and communities.

Our Board believes this change must happen to meet the needs of families who qualify for DDD and ALTCS. It is imperative that we acknowledge the struggle to find an adequate number of qualified compassionate caregivers for those with special needs. As the baby boomers age, the elderly and those with disabled children will compete for the same small group of providers. This shortage has created a growing gap between the demand for quality care and the available supply of caregivers. It is evident that the existing workforce cannot meet the increased demands. The most vulnerable of our population deserve the services that they qualify for and that those services be provided by qualified, consistent direct care workers. The scarcity of caregiver workers can have long-term negative effects on the development and well-being of children, especially those with special needs. We need an innovative solution, and we believe the Paid Parent Provider Program is that solution.

Please see the attached letter for additional information regarding the latest updates to the waiver.

Kind regards,

Olivia Fryer
[redacted]

[redacted]

---------- Forwarded message ---------
From: Sam Polley [redacted]
Date: Monday, July 24, 2023 at 11:29:25 AM UTC-4
Subject: Habilitation Information
[redacted]

Hello,

I received an e-mail from many of our habilitation parent providers to send to this e-mail address with some more information on our habilitation parent providers.

We feel that ending the ability for habilitation parent providers in November 2023 will be very challenging in many ways, with the most difficult assignment of finding habilitation providers for all of these members before that date. I do not feel it is realistic.

How many parent providers of minor members provide Habilitation services at your agency?
36

What is the total number of weekly Habilitation hours that parent providers of minors are currently providing? Roughly 350 hrs

Thank you,

Sam Polley

Admin

[redacted]

Admin

[redacted]

---------- Forwarded message ---------
From: Sue Tarr [redacted]
Date: Monday, July 24, 2023 at 9:26:13 AM UTC-4
Subject: habillitation
To: [redacted]

I don't even know where to start!
We as parents work so hard to keep
our loved ones safe.
My son has had so many bad experiences in other
homes. I am so blessed to have the ability
to be home and care for my son.
And to be able to help him through Habilitation
to better him by helping him to feel like he is
able to learn to cook,clean and help himself.
We don't get paid much at all. And your considering
taking it away? Why ? I don't understand ! i would think
you would want us to continue to make one life by one life
better and better. In this world so many struggle to make it.
To buy groceries and clothes and just enjoy some things.
And it seems that you continue to say. We are here to help!
And yet still take what little we have away! I enjoy teaching my son.
Is it hard work? Absolutely! but the gratification of seeing my eat what I
have helped him cook. And his room watching him as he cleans and folds his
laundry and guide him. You can't put a price on that.
And yet here we are! having to fight and write to keep what you
have the power to take away. Sad sad sad!. I believe you should be encouraging us
to continue to help and I believe better pay and giving us that a girl or that a boy. Now that is
as a government you should be doing. Please consider what you are about to
do to a lot of families. Our family members are at home, not on the street. thank you,

Sue Tarr

---------- Forwarded message ---------
From: Susan Kennard [redacted]
Date: Monday, July 24, 2023 at 9:02:22 AM UTC-4
Subject: Fwd: Parents as Paid Caregivers 1115 Waiver Amendment Community Forum Confirmation
To: [redacted]

[redacted]

[redacted] ***Voice Heard! View and register for a community event now!***

Susan Kennard

Administrator

Office of Individual and Family Affairs

Division of Community Advocacy and Intergovernmental Relations (DCAIR)

801 E. Jefferson

Phoenix, AZ 85034

MD9000

[redacted]

[redacted]

[redacted]

Website: www.azahcccs.gov

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---------- Forwarded message ---------
From: **irene donofrio** [redacted]
Date: Sun, Jul 23, 2023 at 10:56 AM
Subject: Re: Parents as Paid Caregivers 1115 Waiver Amendment Community Forum Confirmation
To: Susan Kennard [redacted]

Hello Susan, As a Parent and Caregiver of a 44 year old Man. My husband age 80 years old and myself 70 years are aging out of the System. I have extreme Anxiety of where he will end up
He has 2 sisters in Illinois who don't really want the burden of taking care of him when we are unable. They say Group Home
What are our options, and plans. We have a house that would be sold off if we the parents would have to go to a Nursing Home
What do you think? If he had his own place he would always need some one to check in on him. Please do a Workshop to address this issue. My stomach just gets sick when I see on the News, victims of Group Homes. He works part-time and is a Selective Mute. If he were placed in a Group Home where there is Mentally Ill individual with Anger Issues or Fragilly Ill Individual with issues of noise making it would frighten him. Please advise. Thank you, Irene Donofrio

On Fri, Jul 21, 2023, 6:49 PM Susan Kennard <no-r...@zoom.us> wrote:

---------- Forwarded message ---------
From: Angela Johnson [redacted]
Date: Monday, July 24, 2023 at 12:38:12 AM UTC-4
Subject: July 18th Public Forum and Habilitation Feedback
[redacted]

Dear AHCCCS and 1115 Waiver Team,

I attended the July 18th public forum and was extremely disappointed to learn that AHCCCS is not planning to include Habilitation in their permanent parent provider program. And, I was even more disappointed that if you continue to submit your program without including Habilitation, that parent providers will lose the ability to provide services for their children as early as November 2023.

First of all it is EXTREMELY UNREALISTIC for parents to find new providers for their children as early as November 2023. There just aren't enough providers available and willing to work. And, it's unrealistic for agencies to hire, train, and implement the number of DCWs between now and November 2023 that it would take to replace parent providers. If you move forward with this permanent program without including Habilitation, MOST of the minor disabled community in Arizona will be underserved. This seems like it goes against the mission of AHCCCS.

Currently, I am the Habilitation provider for my three disabled children. This program has been life changing for them and they've actually made huge strides in their goals (which wasn't happening before these flexibilities even when working with ABA providers). If Habilitation isn't included in the new permanent program, my children will likely go without Habilitation services. Prior to the flexibilities, my children were not able to do Habilitation because we couldn't find providers. I know you've thrown around ideas to recruit more DCWs, but it is just NOT realistic to think you can hire enough DCWs to replace parent providers. The past challenges with hiring providers and the past challenges with turnover of these providers have not gone away…there is a HUGE shortage currently of DCWs even with parents being able to do

Habilitation.

I know one of your concerns about including Habilitation was member isolation. My children are anything but isolated. They are out in their community all week long…with school, therapy appointments, park play dates, shopping, etc. My children work with and learn from others all day long. In fact, when they are home, they are maxed out on outsiders and don't like visitors because they've spent their day coping and regulating through all of the interactions they've had. Because of this, having a "stranger" DCW come in to work with them is absolutely going to impact their experiences and gains at school and their stamina for time in the community with our family. They will burn out because they are not comfortable having someone they don't know working with them on self care and other Habilitation goals in our home. When we're spending time in the community, I want it to be beneficial and quality time focused so that they're successful, I do NOT want it to be quantity focused (which is counter-productive and what it sounds like AHCCCS is striving for).

Many of my children's Habilitation goals are self care related (brushing teeth, wiping their bottoms, showering, getting dressed, etc). These are things that occur in our home and occur first thing in the morning, in the evenings, and scattered throughout the day. These things do not occur in a block of time that a typical DCW is available to work. And, due to some horror stories that I've heard, I am not comfortable with a complete stranger working on a lot of these self care goals with any of my children. They are extremely susceptible and do not have the ability or understanding to express their concerns should something inappropriate happen with the DCW. And, due to the constant turnover of DCWs, it is difficult for my children to become comfortable with a new provider. And, while adjusting to working with new providers (as turnover is a huge issue), they regress in their skills.

I remember in the meeting that it was suggested to compare working with our children on goals to what a parent of a non-disabled child would do working with their children. It sounded like it was implied that what parent providers do is just what a "normal" parent should/would do. Being the mother of three disabled children and two non-disabled children, I can tell you it's a night and day difference in every aspect of their lives. Simple things like brushing their teeth, wiping their bottoms, being able to wash their hands, etc. are extremely difficult for my disabled children. These goals take time and they make VERY slow progress…one step in the process may take months to learn. For my disabled children to learn a new skill, it often takes repeating hundreds of times to finally master. The work that parent providers do as Habilitation providers is invaluable and goes above and beyond what a parent of a non-disabled child would need to do for their children.

I urge you to please include Habilitation in your permanent provider program that you are submitting. The minor disabled community in Arizona is relying on you so that they can be successful and be able to utilize the services that they need and qualified for.

Thank you for your time.

Angela

---------- Forwarded message ---------
From: Marie Dumesnil [redacted]
Date: Sunday, July 23, 2023 at 7:37:17 PM UTC-4
Subject: Re: Habilitation and paid family caregiver program
To: [redacted]
Cc: Sebastien Dumesnil [redacted]

Dear AHCCCS and 1115 Waiver Team,

Following the 7/18 Public Forum, I would like to share some additional thoughts on the benefits of allowing parents to remain Habilitation providers for their minor children.

During the meeting, a point was raised that AHCCCS needed some examples of what extraordinary or additional supports Parent Habilitation Providers give to their child that is outside the scope of what a typical parent would do for their child. Here are some examples about our daughter, who will be 9 years old in September, and has Autism Spectrum Disorder. My husband is her Parent Provider. As a result of her condition, there are numerous tasks he supports her with that are outside of the scope of what a typical parent would do for a typical 9-year old.

Safety:

- Our daughter needs numerous reminders and pointers when it comes to safety in the home around electrical appliances, the kitchen, stairs, not opening the door to strangers, etc.
- Similarly, she still needs those reminders in the community: watching both ways when crossing the street, not talking to strangers, being safe on a parking lot, not eloping in a store, etc. We do have a handicap placard due to her eloping tendencies on parking lots. One of the goals my husband is working on is for our daughter to memorize our names and phone number, as well as identifying community helpers in case she gets lost.

Hygiene:

- Toileting: at this time, my daughter refuses to wipe after a bowel movement due to sensory issues. A Parent provider can not only help her with this very private task, but also work on finding ways to reduce her sensory issues (using gloves, etc.) in order for her to

gain toileting independence.
- Bathing: our daughter still needs reminders, help and supervision with showers and baths. She needs help adjusting the water temperature, supervision to avoid accidents due to her poor balance and coordination (she receives OT and PT services), and reminders/timers for things like not leaving the water running for too long, brushing her teeth, etc.

Communication:

Our daughter is semi-verbal, which means that she can communicate verbally but her communication is limited and not always functional. A lot of her communication is delayed echolalia (repeating words/sentences she has memorized from TV shows). My husband helps her work on specific communication goals throughout the day: prompting her to answer simple questions about her needs and wants, working on functional communication by recalling and retelling information about her day at school, practicing gaining attention using proper gesture/phrases instead of interrupting, practicing being polite, practicing back and forth interaction with board games, etc.

As you can see, these are extraordinary supports that a parent of a typically-developing 9-year old would not provide. These supports need to be consistent, part of the daily life and delivered in a safe, trusting environment. Any disruption to these supports would be extremely detrimental to our daughter's development and could potentially put her in physical danger.

I urge you to include Habilitation as part of the permanent Parent Provider program, for the well-being of your members and their families.

Sincerely,
Marie Dumesnil

On Thursday, July 13, 2023 at 06:26:39 PM MST, Marie Dumesnil [redacted] wrote:

Dear AHCCCS and 1115 Waiver Team,

I wanted to follow-up on my note below with some additional thoughts and comments regarding the need to include Habilitation as a service parents of minors DDD and ALTCS members can perform as certified DCW providers. In a SMAC meeting on 7/12, it was stated that AHCCCS strongly feels as though excluding parents as paid providers for Habilitation will encourage more community engagement and prevent social isolation of members, and that is the main reason given for not wanting to allow parents to provide Habilitation services for their child.

I think such a decision should be made based on data. Is there data supporting this statement? Our personal experience and the experience of many other families has been on the opposite end for the following reasons:

1- Minor children are required to receive an education, which is vastly happening in a community setting, with other children and adults
2- Most minor DDD/ALTCS members receive therapies such as Occupational Therapy, Physical Therapy, Speech Therapy, etc., all provided either outside of the home, or in the

home by a third-party
3- Many children participate in extra-curricular activities, adaptive or not (my child participates in Horse Therapy and Swimming, and just last week attended an event for children with special needs at the Scottsdale Ice Den)
4- When the parent is the Habilitation provider, the child actually has a greater chance to participate in community outings such as trip to the grocery store, and be able to work on goals such as safety, choosing healthy foods, counting money, etc.
5- Finally, many habilitation goals are based on home life and hygiene, and do not require the intervention of a third party or the community. In fact, most parents of children with a disability are extremely anxious about safety when it comes to involving a third-party in such private things as toileting and bathing.

I will also add that parents/guardians of adult children are indeed authorized to provide habilitation services, even though the same concern should apply around community engagement and social isolation.

Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves DDD and ALTCS members in Arizona.

Sincerely,

Marie Dumesnil

On Wednesday, June 28, 2023 at 09:52:39 PM MST, Marie Dumesnil [redacted] wrote:

Dear AHCCCS and 1115 Waiver Team,

I am a parent of a child who receives DDD and ALTCS services. Our family has participated in the Paid Parent Caregiver program under the Covid-19 Flexibility and it has been extremely beneficial to our family and my child who receives these services. Based on my review of the current proposal for a permanent Paid Parent Caregiver program I would like to give you my feedback. Thank you for your time and consideration while reading my experience and suggestions.

Our community of parent caregivers is asking for a permanent program that allows parents of disabled minor children to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies. Under the current program proposal this request is not being fully met. Please consider the following suggestion:

Include Habilitation as a service parents of minor DDD and ALTCS members can perform as a certified DCW provider. Parents of adult DDD and ALTCS members can currently perform both Attendant Care and Habilitation hours for their children and parents of the minor population would like this permanent option to mirror that program allowance. The DCW workforce shortage applies to Habilitation providers just as much as it does Attendant Care providers. Habilitation services fulfill the member's "personal care" needs by allowing them continual practice with their own personal care and rehabilitation. The only difference in Attendant Care and Habilitation personal care is that an individual receiving Habilitation can perform their personal care partially and needs assistance mastering these skills. There has been massive improvement to the IDD population in Arizona since parents of minors have been able to provide this service at the correct time and place that is applicable to the member. Parents being paid as Habilitation providers was allowed under the Covid-19 flexibility program and the ARPA program extension as a "personal care" service and we would like to continue to have it as a permanent option.

I want to tell you about our personal experience: we are lucky to have found one outside provider. However, she is only able to provide respite/habilitation 1 or 2 times/month for roughly 3 hours at a time. She lives in Mesa while we live in North Phoenix. This is far from meeting our child's requirement of 40 hours of Habilitation weekly (approved by DDD) to meet essential personal care and safety goals. These goals/tasks occur mainly before and after school and therapies, at times when outside providers are not available/willing to work. Additionally, some of these personal care tasks include hygiene/bathing, which are best supervised/taught by a family member for personal privacy reasons, especially for members such as my child, who needs to learn personal boundaries and what is appropriate/not appropriate. Additionally, safety goals are literally a question of life and death for our family, and we don't have the luxury to wait for a habilitation provider to be available in order to teach our child safety around the house (hot water. electrical appliances, opening the door to strangers), as well as in the community (crossing the street, talking to strangers, eloping, etc.). This is a goal that requires a lot of time and consistency.

Finally, many DDD/ALTCS members have Autism Spectrum Disorder, a condition that is characterized by a strong preference for routine and familiarity. For this reason, parents/family are truly the best caregivers for autistic members, as they provide consistency, familiarity and a safe, calming environment that is conducive to learning new skills. Discontinuing habilitation for parent providers would be extremely disruptive for members on the autism spectrum, and disruption would be synonymous with regression.

Going back to the main goals of the Demonstration proposal, you will see that habilitation should absolutely be included in order for the goals to be met:

- Mitigate DCW shortage and other access to care challenges by allowing payments to parents who serve as paid caregivers for their minor children,
- Increase member satisfaction and promote positive health and well-being outcomes for the target population,
- Extend an additional support service to restore, enhance, and maintain family functioning to preserve effective care for the member in the home and community, and
- Ensure that members receive high-quality care while increasing timely accessibility to care providers.

Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves DDD and ALTCS members in Arizona.

Sincerely,

Marie Dumesnil

---------- Forwarded message ---------
From: Barbara Vaiau [redacted]
Date: Sunday, July 23, 2023 at 6:35:02 PM UTC-4
Subject: Paid parent caregiver program
[redacted]

Dear AHCCCS and 1115 Waiver Team,

I just got approved as a parent provider under the habilitation program last week to become a parent care provider for my son. But it's really sad news to find out that this program will discontinue this November. I haven't had a respite provider in years due to shortages. I can't even hold a full time job and provide for my family due to my son's therapies and needs.

Despite all that, I still think it's worth it to spend more time helping my son. Nobody is able to help and advocate for my son better than I have. I paid for school out of my own pocket to learn to be an RBT so I can help him. I am currently attending [redacted] studying ABA and autism to be able to help other children with autism, especially my son.

To other people, it's just a job. But to me, this is my son, my world and I will never get tired of teaching him, advocating for him, and helping him even though it is the hardest thing I've ever had to do. The habilitation program not only motivates me to keep doing what I do which is helping my child. But it also helps alleviate some of the financial burden that comes with caring for a child with special needs.

Please don't discontinue this program. Nobody has helped my son reached his milestones faster than I have. I am his best care provider, not some stranger who only sees it as a job.

Thank you,

Barbara Auvaa Vaiau

---------- Forwarded message ---------
From: Ronna Chavez [redacted]
Date: Saturday, July 22, 2023 at 11:12:27 PM UTC-4
Subject: Parents as Paid Providers
[redacted]

Hello I am writing in regards to the Parents as Providers to Minors program that may be ending in November 2023. As a parent of 2 special needs children who benefit from this program this is a very stressful update I have recently been made aware of. With the shortage of Providers in all fields of support I have found it very difficult to provide consistency for my children who have had a revolving door of therapist recently. This programs allows for me to spend the necessary time with them to master skills they already have and continue to work on those they still struggle with. Compensation given by the program also allows for me to take more time away from my other place of employment and more time with my children setting them up for success in life. I ask that you reconsider any possible changes to the current program in place as it would add a level of stress and possible inconsistency to my children. Thank you.

Sent from Yahoo Mail on Android

---------- Forwarded message ---------
From: Grace RusseLL [redacted]
Date: Saturday, July 22, 2023 at 10:19:04 PM UTC-4
Subject: parent providers for habilitation and attendant care
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

to whom it may concern

i am grace necesario and i am a parent of a child with severe autism. currently, i am providing his needs for attendant care and habilitation. the money i am earning from it greatly helps our financial needs. i have heard that ahccccs/ddd is proposing that parent providers to end providing habilitation and limit the hours of attendant care to 40. i am humbly asking you to please reconsider this proposal as this would affect a lot of families including myself.

hoping for your kind consideration
grace necesario

---------- Forwarded message ---------
From: Andrea Palmer, NMD [redacted]
Date: Saturday, July 22, 2023 at 8:39:51 PM UTC-4
Subject: Feedback Regarding Paid Parent Caregiver Meeting on 7/18/23
[redacted]

Hello,

In response to the AHCCCS meeting on July 18th, 2023 I wanted to share some feedback regarding the Paid Parent Caregiver Program and the current proposed restrictions.

First, let me share a brief background to our family. We have three beautiful children aged 7, 4, and 2. Our 7 year old [redacted] is a DDD/ALTCS member and has severe intellectual disability and is unable to walk, talk, or complete any daily activities for himself (eating, toileting, bathing, playing). [redacted] **requires 24/7 care and supervision.** [redacted] **also requires frequent therapy and consistent and frequent opportunities to work on therapy goals (i.e. several times per day).**

I am a Naturopathic Doctor and my husband is DevOps Engineer. For the first 5 years of [redacted] life we both worked full time and had to rely on caregivers. **However, we were unable to find any caregivers through the agencies** and had to hire them as nannies and pay out of pocket. As we had more children the number of nanny candidates who wanted to work with a special needs child and additional children dried up. And we were still unable to find caregivers to work with our son individually through the state. In 2021 I lost my job and we made the decision for me to become [redacted] caregiver to provide him consistent Attendant Care and Habilitation. Since making this transition we (and his therapists and teachers) have observed some pretty big changes in [redacted], including:

- **Increased communication -** [redacted] can now appropriately answer "yes and no" to questions and can make choices with a switch or our hands.
- **Improved muscle tone**, as evidenced by **sitting independently and standing with minimal support**
- **Improved visual attending -** [redacted] has CVI and we have had to work on him looking at objects and he now will look towards someone saying his name and track toys!
- **Improved diet and weight gain -** I am now able to prepare homemade blended diet for [redacted] instead of relying on formula and his growth has improved!

Some questions came up in the meeting on July 18th that I would like to address:

1. What extraordinary or additional supports do Parent Habilitation Providers give to their child that is outside the scope of what a typical parent would do for their child?
    1.
        - ANSWER:
            - With our son's severe intellectual disability we are working with him on some very "basic" things right now to bolster his future independence. These things include standing with support; grasping objects for longer than 10 seconds; letting go of objects in a controlled manner,;visually tracking toys, books, etc. These things take quite a bit of frequent 1:1 attention and time to complete and they need to be completed in a relatively calm and quiet environment as our child gets overwhelmed in loud and busy environments (think grocery stores, kid play places, etc)
            - Now compare this to our 2 year old and 4 year old. Both are working on different developmental aspects, however, they can do that as they go about in life. They do not require nearly as much specific 1:1 attention to learn new skills. They can work on these skills anywhere and do not get easily overwhelmed. They do not require someone with training to teach them new skills.
            - What we do for our special needs child is probably what any parent would do for their special needs child, however, it is **very far from "normal" and is really an extraordinary effort.**

2. Why is it important to our members and families that Habilitation be included in this program?

1.
    - Our family is very grateful for the Paid Parent Caregiver program. This program has allowed my child to have a consistent caregiver. And not only does he have a "Mom" as his caregiver, but his Mom happens to also be a Physician with a higher level of understanding of the human body, neurology, health, and wellbeing than any caregiver that will be obtained through the State. **Restricting parents from being Habilitation providers will only hurt our son because he then either won't have a Habilitation provider (as is historically the case) or he will have one that isn't as qualified as his current Habilitation provider.**

3. Ideas on what they can do to prevent caregiver burnout.

1.
    - First, I want to state that **I felt more caregiver burnout when I was having to work AND try to manage inconsistent or nonexistent caregivers.** The toll this takes on mental health, stress, physical health, and ability to work is tremendous.
    - Ways to reduce caregiver burnout:
        - Increase Respite workforce
            - This summer I had the pleasure of having a school aide be our son's respite provider for a few hours per day, 5 days per week. This was very helpful over the summer break from school!
        - Find ways to increase summer programs for children with severe intellectual disability
            - Last summer we tried to find a summer program for our son but came up short as none of them would accept a child who required diapers and 1:1 feeding.
        - Create a counseling/therapy program for caregivers of DDD/ALTCS members with therapists who are knowledgable about the special needs world and the stress of caregivers

- Create support groups for caregivers of DDD/ALTCS members

ADDITIONAL COMMENTS

40 Hour per Week Restriction

It appears to be the choice of AHCCCS to limit parents to 40 hours per week. This is not a governmental requirement and is a restriction that will only hurt the member and the member's family.

This restriction is harmful because it will take away hours from qualified and able caregivers (parents) and give them to an **absent workforce**. **Our children *need* care *now*.** We can *not* wait for some theoretical ideas to maybe increase the caregiver workforce. Our entire Nation is at a serious caregiver shortage and you have, at your fingertips, individuals who are willing and ready to fill this role. **So please, let us fill this shortage for our children!**

Habilitation Restriction

Our son currently has 1 respite provider, 4 in home therapists, 3 school therapists, 1 teacher, and 4 aides. We are completely unconcerned about him developing difficulty learning from others or receiving care from others because I am his sole caregiver for ATC and HAB.

In addition to the above, because I am able to be his full time caregiver, I am able to take him on outings to improve his ability to be in different places and reduce isolation. This summer we have been to friend's houses, the community pool multiple times, the Arizona Museum of Natural history, the Phoenix Children's Museum, the Idea Museum, a trip to see his family (Grandparents, cousins, aunts, uncles), bike rides, various parks. **Prior to me being his full time caregiver I simply did not have the time to do all of these activities with him and he was absolutely more isolated from his community.**

Thank you for reading my feedback and your consideration regarding the Paid Parent Caregiver Program.

We hope that this program can continue without restriction to the member and their family!

Kindly,
Andrea Palmer, NMD

---------- Forwarded message ---------
From: Julia Sanchez [redacted]
Date: Saturday, July 22, 2023 at 8:13:53 PM UTC-4
Subject: padres cuidadores de hijos menores
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

A quien corresponda . Mi nombre es Julia Sanchez ,yo actualmente estoy trabajando con mi hijo,en sus habilitación y atender care,solo les pido que tomen en consideración de quitarle a los padres este beneficio prq en mi caso como madre soltera a sido de una gran ayuda tanto económica y lo mas importante que mejor cuidado para un nino especial que sus padres lo están cuidando o enseñando dia a dia a valerse por sí mismos y en mi caso yo daria mi vida pr lograr que mijo un dia sea capas de ser lo mas serca posible como cualquier nino o adulto normal en la vida diaria, nadie mas va ser mas paciente con ellos que cualquier otra persona que no sea su mama

o papa que ya sabemos el limite de tolerancia que nuestros hijos tienen con algunas cosas,lo digo pr mi hijo que su problema de agresión y comportamiento no lo deja concentrarse o enfocarse por mucho tiempo en una sola tarea y no solo eso cualquier nino con necesidades especiales o no siempre estarán mas seguros con sus padres ,que con cualquier otra persona,pr favor les pido que cualquier desision que tomen la hagan con el corazon y que diosito les ayude a tomar en cuenta desde el punto de vista de los padres,nosostros desde cualquier punto que se vea somos las personas correctas para hacer los servicios que nuestros ninos nesecitan ,gracias pr su ayuda.

---------- Forwarded message ---------
From: Kara Swierz [redacted]
Date: Saturday, July 22, 2023 at 5:18:24 PM UTC-4
Subject: Parent Paid Caregiver Progam
[redacted]

July 22, 2023

Dear AHCCCS and 1115 Waiver Team,

Reference: Parent Paid Direct Care Provider Program.

Good afternoon.

My name is Kara Swierz and I am a parent of a child with disabilities who receives services through DDD and ALTCS. As a parent of a child who receives DDD and ALTCS services, I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility for the past three years, and it has been highly beneficial to our child and family. I want to share my personal experiences and feedback based on my review of the current permanent Paid Parent Caregiver program proposal.

In the last month AHCCCS published their proposal for a Permanent Paid Parent Caregiver program. The public feedback phase is open until August 21, 2023. Under this current proposal AHCCCS intends to continue parents of minor members as paid ATC providers with a 40 hour weekly limit per member. Under this proposal **Habilitation will be REMOVED** as a service parents of minors can provide to their children after **NOVEMBER 2023**.

Prior to this proposal AHCCCS shared in documents and their website that the current flexibility, which includes parents of minors providing Habilitation, was extended under the APRA program until September 2024.

Please consider updating the proposal based on the following questions, suggested solutions, and personal experiences.

Should Habilitation be included in the Paid Parent Caregiver Program?

1. We have heard the concerns about member isolation and lack of community involvement if parents continue as Paid Parent Caregivers facilitating their child's Habilitation services. **Respectfully, I disagree**.

    a. I have reviewed current research and personal feedback statements from members and their families to evaluate the potential impacts of social isolation and community involvement when parents of disabled children provide Habilitation services. On the contrary, the collective community caregivers serving as Habilitation and Attendant care providers have experienced greater social engagement and community involvement over the last three years.

        i. As my daughter's Parent Paid Provider, I have been able to be creative, focusing on her Habilitation Goals in the community flexibly and meaningfully. Her goals are our goals; therefore, we are working together to develop functional independence in the home, school, and community. Because our goals are to increase functional independence, as her provider, I make a conscious and intentional effort to grow and generalize skills in the community. We are not isolated; on the contrary, we are getting out more than before COVID because we have goals that make us accountable to work on them daily.

2. Training is an area of contention to adequately provide a minor with skilled services as a direct care provider.

    a. I have my Doctorate as a Physical Therapist and an American Physical Therapy Association Board Certified Pediatric Specialist. I have 20 years of experience as a pediatric physical therapist in multiple settings. In addition, I have just completed a Masters in Special Education and a Graduate Certificate for Assistive Technology. My resume is robust; however, the role that provides the most significant merit and authorizes the most qualifications to service my child as a DCW is being her Mother. I have known every freckle, every birthmark, every doctor's appointment, procedure, diagnosis, and school assignment. I listen to her when others may not understand her words. When she doesn't verbalize her needs or wants, I can see them in her eyes. I am not my daughter's expert but a close second. Studies have shown that parents are their child's greatest advocates, historians, and diagnosticians. Although we have a fantastic service coordinator through DDD, a parent is their child's chief executive officer. This role is a privilege, and I take it very seriously. We are beyond qualified to be our child's DCW.

b. A parent is the most invested financially, spiritually, emotionally, and physically to their child's present and future. Therefore, the parent is motivated to offer high-quality services for their child to live their best life. I can't imagine a person loving my child more than me. I can't imagine a person investing their heart, soul, and mind into my child more than me. In addition, no single person on this earth knows my child as intimately as I. Therefore, as my daughter's Parent Provider, I offer more heartful and genuine care to my child than a stranger could ever replicate.

3. Provider agency data shows that "the top 3 issues regarding recruiting and retaining career non-family caregivers are schedules of the client members, interest in the position and finding qualified applicants." Most members have Habilitation goals and ADLs that are most appropriately delivered throughout the natural routine of their day. A parent provider is uniquely available in the morning, after school, or evenings when each member is motivated and focused on the pertinent task.

a. Additionally, my daughter's Habilitation goals and ADLs are personal and private. My daughter is almost 12 years old and should be offered the privacy, modesty, and dignity all young ladies are granted. Individuals with intellectual disabilities are 75% more likely to be physically or sexually abused than their peers without disabilities. Unfortunately, in the past, we had experienced incidences that harmed our daughter when we trusted and placed her with "Qualified Individuals." My daughter deserves to feel safe in her home and has the right to privacy and dignity while she works on strengthening her self-care and ADL skills. Our daughter has been taught to respect her body and that her doctors and parents are the only persons who should see her in her most vulnerable state. As my daughter's parents, we feel strongly about protecting her privacy by being the only individuals to support her ADLs and habilitation goals. Our daughter is sweet and vulnerable, and we do not trust a non-family, unfamiliar individual in our home to support our child in the most intimate skills.

4. Our daughter has a progressive genetic disorder. It is uncertain that she will live life into middle age. Because we understand how precious time is, we choose to spend as much of it together as possible. In addition, since I am physically capable and respect and nurture my daughter's independence and aspirations, I prefer to be her Direct Care Worker over a non-family provider.
5. Lastly, along with a genetic disorder, my daughter has Autism and Cerebral Palsy. She takes time to warm up to a new person and thrives with routine and a schedule. Her progress and daily emotions are dictated by reliability, consistency, and kindness. A parent is predictable and is always present. Non-family providers that are qualified and are a good fit for a child is like a needle in a haystack. Absenses and loss of services can negatively impact my daughter’s progress. My daughter's ADL and Communication skills would regress without consistency. Therefore, my daughter benefits from a parent being her Direct Care Provider instead of a non-family member.
6. Finally, my daughter has an autoimmune disease, severe food allergies, and is immune compromised. We choose to keep our house clean, fragrance-free, and allergy-free. It would cause undue stress for our home to have a stranger who doesn't follow these guidelines. We know our daughter and what is best to keep her safe. A non-family DCW will not be as authentic.
7. Burnout is possible; however, burnout is most notable when I repeat myself to unfamiliar workers in all settings, such as medical, school, and therapy staff. Often, the parent is undervalued in their child's care plan. However, a parent is the most essential member of the team. Being my daughter's Direct Care Worker, providing both

> Habilitation and Attendant care eliminates unnecessary conversations, training, and frustrations from non-family members unfamiliar with my daughter supporting her needs.

In conclusion, Habilitation and Attendant Care services should be delivered and received promptly by those in Arizona who qualify for DDD and ALTCS. Parents who choose to perform their child's Attendant Care and Habilitation carry the most significant investment and possess the most substantial understanding of the child's health history, strengths, and goals for their future. The Paid Parent Caregiver program allows organizations to follow a Person/Family-centered plan. By not allowing parents of minors to provide Habilitation and Attendant Care services, most of the minor-disabled community in Arizona will be underserved. A comprehensive Paid Parent Caregiver program validates parents' irreplaceable work in their homes and communities.

Click here to connect with the Arizona parent-grassroots initiative leaders: www.raisingvoicescoalition.com

Thank you for your time and consideration. Our community is highly grateful to the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves all DDD and ALTCS members in Arizona.

Best Regards,

Kara Ann Swierz, PT, DPT

James A Swierz, PT, DPT, MHA

---------- Forwarded message ---------
From [redacted] [redacted]
Date: Saturday, July 22, 2023 at 5:13:13 PM UTC-4
Subject: November 2023 AHCCCS Proposes to END Parents of Minors as Habilitation Providers
[redacted]

I am the mother of a child who receives DDD and ALTCS services and I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility. It has been extremely beneficial to our family and my child. I am the mother to my Autistic Son that is almost 4 years old. My son suffers from anxiety, autism, sensory disorders, behavior problems and is at harm of harming others and himself.

My son does have high sensory stress with anyone new coming over to visit us so I'm very concerned about trying to find a HAB provider without making him triggered for a meltdown. My sons happy place is his mother which is me, there personally is never no burn out for me because I would go above and beyond for my son. He has been on better behavior when I'm around, but when I'm not it's a complete huge meltdown which last from hour to even days.

The benefits of being a Parent provider has been a blessing not only to guide and help my son, but to also build a solid foundation of socializing and learning daily with his goals. I am a current student at [redacted] and do my classes (on my own time) majoring in criminal justice and it's been the best journey to be able to stay home care for my son and his goals plus do school in between when my respite provider comes to relieve me so I can study. I feel like the HAB ending will definitely cause a toll on us as a family and biggest toll on my son. We are just getting started as of April with HAB and it's been a blessing thus far. We have a routine structure, he is 24/7 care so both myself and my respite provider provide scheduling and take breaks as needed. We are very religious so we are also careful with who we let inside of our home and also very cautious about our health and well being, so even allowing a random stranger to be my child's provider would be a huge no for us.

We have learned, we have grew, and we are still growing as we speak by having the ability to stay home to help my son with his developmental delays and disabilities. By extending the parent provider program and making it a permanent task, it will guide us and protect us from any future mental health breakdowns, and even help prepare my son for his future with his day to day and hour by hour needs. We are hoping someone can read this in support of my son that can't advocate for himself.

Thank you very much for taking the time to read my email.

[redacted]

---------- Forwarded message ---------
From: Valerie Johnson [redacted]
Date: Saturday, July 22, 2023 at 3:41:05 PM UTC-4
Subject: 2023 Paid Parent Caregiver Proposal
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

As a parent of two children who receives DDD and ALTCS services I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility, and it has been extremely beneficial to our family and my children. I would like to share my personal experiences and feedback based on my review of the current proposal for a permanent Paid Parent Caregiver program.

I am a mother to two boys ages 5 and 7 who are both Autisitic. Both of my boys receive various services through the state, DDD ALTCs, speech therapy, occupational therapy, ABA therapy, feeding therapy, special needs education tutoring, adaptive sports programs, and more. Currently they both qualify for respite but there are no providers available. We have been waiting for a respite provider for over a year now. Last year my SC stated I could provide Habilitation as a parent provider and it has been life changing. Being able to work directly with my children to set and accomplish habilitation goals has increased their success 10 fold. My oldest son was not potty trained even after 3 years of full time ABA and now since creating that goal and working on it through habilitation we have made significant improvements, no more diapers! (I could cry). I was made aware that AHCCCS is concerned of caregiver burnout, if parents are providers. In my situation, I was able to cut my hours at work and provide habilitation and it has been the best outcome. Arizona is a pioneer and leader in their Healthcare policies, and how they treat the disabled community. I hope that the parent provider program for habilitation becomes permanent and sets the example for other states to follow. If the parent provided habilitation ends in November 2023, I fear I will not be able to find a habilitation provider, just like I cannot find a respite provider and it will significantly negatively impact my childrens progress and development.

Under the current proposal, the request of an ongoing program option which allows parents of disabled minors in Arizona to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies is not being met. Please consider updating the proposal based on the following questions, suggested solutions, and personal experiences.

Should Habilitation be included in the Paid Parent Caregiver Program?
We have heard the concerns about member isolation and lack of community involvement if parents continue as Paid Parent Caregivers facilitating their child's Habilitation services. Respectfully the parent caregiver community proposes the following solutions:

> Examine available research and personal feedback statements from members and their families to evaluate the true potential impacts of social isolation and community involvement when parents of disabled children provide Habilitation services. The parent caregiver community's collective experience is that members who have parents facilitating their Attendant Care and Habilitation services have experienced greater member social engagement and community involvement over the last three years. Parent caregivers now have an increased ability to take their children to sporting team practices, community events, movie theaters, all ability parks, church activities and libraries. This is because parent providers can perform the appropriately trained and qualified supports in the correct time and location that is applicable to each member.
>
> Implement precise guidelines to facilitate generalization for all Habilitation providers regardless of the DCW's familial status. Habilitation services are designed to have goals where data is collected to evaluate if those goals need to be changed, have been met, or need to be addressed differently. For a goal to be considered met, a member should be demonstrating that they are able to successfully meet that goal outside of the timeframe with a provider in one setting. This is referred to as generalization. The effective implementation of generalization with the pediatric IDD population would lessen, if not eliminate, any complications with adult transitional services. Under this model a program that includes parents as paid Habilitation providers would actually assist and improve in the success of adult transition. There are times when disabled children work successfully with different types of providers in clinics or schools, but the parents are not carrying the work over at home. This can happen for a variety of reasons. Having parents as Habilitation providers would help ensure the child's goals are congruent and carried over in the home and community setting. This will give the member a better chance of independence as they transition through different life stages. With generalization policies in place, Habilitation services being performed by parent providers will actually help facilitate successful transition into adulthood.
>
> We know from provider agency data that "the top 3 issues regarding recruiting and retaining career non-family caregivers are schedules of the client members, interest in the position and finding qualified applicants." Most members have Habilitation goals and ADLs that are most appropriately delivered throughout the natural routine of their day. A parent provider is uniquely available in the morning, after school or in the evenings when each member is motivated and focused on the pertinent task. If a non-family provider is available their schedules typically allow them to work in longer time chunks that are not always the most ideal for the member and creates artificial goal or ADL practice. Continuity of care and greater member outcomes can be associated with consistently provided Habilitation care by parent providers who have the greatest ability to be flexible and available for their member children.

Should parent providers be limited to 40 hours a week of paid care per child?
We have heard the concerns of AHCCCS on why they want to limit parents to 40 hours a week under the Paid Parent Caregiver Program. The parent caregiver community would like to propose the following collaborative solution to create a win-win scenario:

> Create a program provision that outlines an extraordinary circumstances clause and the application process that allows parents to provide over 40 hours of paid care per week of authorized and evaluated services per member. These extraordinary circumstances could include, but are not limited to:
>
> > The lack of a non-parent DCW being available in the last 3 months to fill the member's assessed hours that exceed 40 hours per week. Ongoing DCW searches should continue to be made by the member's agency to fill the assessed hours beyond 40 hours per week of Attendant Care and Habilitation.
> >
> > The expressed desire made by a member for a parent caregiver to facilitate their assessed DCW hours so that their Article 9 rights are honored.
> >
> > The profound disabilities and/or significant behaviors of a member where a non-family provider is not equipped to provide DCW support. This determination can be made through a stakeholder team approach, including but not limited to the member's, DDD Support Coordinator, DDD Nurse, DDD Supervisors, Behavioral Plan Experts, Parents / Guardians, Psychologist, or Medical Doctor.
>
> Form equality between all Family Provider Programs by allowing all Direct Care Workers, regardless of familial relationship or member age, to provide up to 16 hours of paid care per day. This will allow for employee equality across the lifespan of the member and limit the potential anti-family provider rhetoric

currently present within state policies and DDD Support Coordination culture. All evaluations of hours should be based on member needs regardless of who is providing the services to create uniform implementation of all applicable HCBS services by the DCWs available to fulfill those hours.

The Family Support Program currently in this proposal addresses caregiver burnout. It is one of the available solutions to facilitate further community support within the disability and caregiver community that will provide greater access to non-profits facilitating counseling services, support groups and meet up activities.

Reevaluate Respite reimbursement rates to also address caregiver burnout. If Respite services are not available to the member or their family, parent burnout will continue to be an issue regardless of parents having the option of providing Attendant Care or Habilitation hours. With a comprehensive Paid Parent Caregiver Program in place non-family DCW providers will have greater flexibility to provide Respite services to these same families.

How should current evaluation protocols, training and practices be updated to facilitate equality for all members when accessing member needs?

AHCCCS has stated their intention to amend applicable policy, further suggested action on this topic includes:

Forming a committee of community and department stakeholders to amend and critique current DDD and AHCCCS policies and need assessment forms so that the most effective and efficient implementation of this permanent option is utilized moving forward.

Provide appropriately determined training and program implementation to DDD and ALTCS Support Coordinators so that Attendant Care and Habilitation hours are equitably evaluated based on the member's needs and to remove organizational bias of familial providers across the member's lifespan. Specifically investigate and determine appropriate DDD staffing needs and training for the members served in rural areas and those from minority backgrounds.

Create the option for private sector Support Coordination. Other states have this option within their Medicaid services, and this could be an additional feature in our DDD portfolio to allow for the member's needs to be best evaluated.

In conclusion, Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. By not allowing parents of minors to provide Habilitation and Attendant Care services or work over 40 hours a week most of the minor disabled community in Arizona will be underserved. A comprehensive Paid Parent Caregiver program validates the irreplaceable work that parents provide in their homes and communities.

Click here to connect with the Arizona parent led grassroot initiative leaders: www raisingvoicescoalition.com

Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves all DDD and ALTCS members in Arizona.

Thank you!

Respectfully,

Valerie Johnson

[redacted]

---------- Forwarded message ---------
From: Katie Smith [redacted]
Date: Saturday, July 22, 2023 at 2:51:31 PM UTC-4
Subject: Parent Provider Program Feedback
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

As a parent of a child who receives DDD and ALTCS services I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility, and it has been extremely beneficial to our family and my child. I would like to share my personal experiences and feedback based on my review of the current proposal for a permanent Paid Parent Caregiver program.

Under the current proposal, the request of an ongoing program option which allows parents of disabled minors in Arizona to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies is not being met. Please consider updating the proposal based on the following questions, suggested solutions, and personal experiences.

Personal Experience:

My son currently receives habilitation services through which I am his habilitation provider. My son does not receive ATC as our main focus with him is to promote independence through teaching various skills in habilitation sessions. The paid parent provider program has allowed our family to target specific, yet critical skills that I would not be comfortable with a stranger assisting with. These skills include: toileting, showering, and dressing. All of which leave the child very exposed and susceptible to possible abuse from a stranger.

Aside from this, our habilitation hours are commonly done outside of normal work hours due to school and other various therapies. These hours include early morning hours starting as early as 6AM, evening hours between 5PM-9PM, and weekend hours. These hours have proven extremely difficult to fill in our search efforts prior to the parent provider program.

To address the concerns brought up during the prior forum in regards to ensuring independence of parents, increasing community engagement, and decreasing isolation I would like to point out a few examples of how the parent provider program gives the ability to do just that.

Independence: The trust that is already established between parent and child allows for more boundaries to be pushed in terms of meeting goals. We are able to include goals that focus more on self-care due to parent and child comfort. These self-care goals are critical to fostering life-long independence. Due to the intimacy of these goals there is a significant barrier with parent and child comfort in a stranger assisting with such goals.

Increase community engagement: The parent provider program provides the ability for children to be taken out in the community to practice social, communication, and safety goals. The parent is there to provide some support and comfort though familiarity as the child explores and engages in their community. A parent providing these services eliminates the steps needed to approve a provider to transport a child and care for them out of the child's home. This specific issue was one that I personally ran into multiple times when previously searching for a habilitation provider. Many will not or would prefer not to go through the process of being approved to transport a child, and therefore, the child is not able to work on goals out in the community.

Decrease isolation: One of the major points discussed in the forum was in relation to the isolation that may occur if a parent is the habilitation provider. This concern is easily mitigated due to the various therapies that families utilize for their children. I am just 1 of 8 providers of therapy to my son. My son has been creating relationships with his 7 other providers and has been exposed to many others through his years of therapy. He is also exposed to other caregivers and peers through school and extracurricular activities. Our habilitation goals allow us to venture out into the community significantly decreasing isolation.

Should Habilitation be included in the Paid Parent Caregiver Program?
We have heard the concerns about member isolation and lack of community involvement if parents continue as Paid Parent Caregivers facilitating their child's Habilitation services. Respectfully the parent caregiver community proposes the following solutions:

> Examine available research and personal feedback statements from members and their families to evaluate the true potential impacts of social isolation and community involvement when parents of disabled children provide Habilitation services. The parent caregiver community's collective experience is that members who have parents facilitating their Attendant Care and Habilitation services have experienced greater member social engagement and community involvement over the last three years. Parent caregivers now have an increased ability to take their children to sporting team practices, community events, movie theaters, all ability parks, church activities and libraries. This is because parent providers can perform the appropriately trained and qualified supports in the correct time and location that is applicable to each member.
>
> Implement precise guidelines to facilitate generalization for all Habilitation providers regardless of the DCW's familial status. Habilitation services are designed to have goals where data is collected to evaluate if those goals need to be changed, have been met, or need to be addressed differently. For a goal to be considered met, a member should be demonstrating that they are able to successfully meet that goal outside of the timeframe with a provider in one setting. This is referred to as generalization. The effective implementation of generalization with the pediatric IDD population would lessen, if not eliminate, any complications with adult transitional services. Under this model a program that includes parents as paid Habilitation providers would actually assist and improve in the success of adult transition. There are times when disabled children work successfully with different types of providers in clinics or schools, but the parents are not carrying the work over at home. This can happen for a variety of reasons. Having parents as Habilitation providers would help ensure the child's goals are congruent and carried over in the home and community setting. This will give the member a better chance of independence as they transition through different life stages. With generalization policies in place, Habilitation services being performed by parent providers will actually help facilitate successful transition into adulthood.
>
> We know from provider agency data that "the top 3 issues regarding recruiting and retaining career non-family caregivers are schedules of the client members, interest in the position and finding qualified applicants." Most members have Habilitation goals and ADLs that are most appropriately delivered throughout the natural routine of their day. A parent provider is uniquely available in the morning, after school or in the evenings when each member is motivated and focused on the pertinent task. If a non-family provider is available their schedules typically allow them to work in longer time chunks that are not always the most ideal for the member and creates artificial goal or ADL practice. Continuity of care and greater member outcomes can be associated with consistently provided Habilitation care by parent providers who have the greatest ability to be flexible and available for their member children.

How should current evaluation protocols, training and practices be updated to facilitate equality for all members when accessing member needs?
AHCCCS has stated their intention to amend applicable policy, further suggested action on this topic includes:

> Forming a committee of community and department stakeholders to amend and critique current DDD and AHCCCS policies and need assessment forms so that the most effective and efficient implementation of this permanent option is utilized moving forward.
>
> Provide appropriately determined training and program implementation to DDD and ALTCS Support Coordinators so that Attendant Care and Habilitation hours are equitably evaluated based on the member's needs and to remove organizational bias of familial providers across the member's lifespan. Specifically investigate and determine appropriate DDD staffing needs and training for the members served in rural areas and those from minority backgrounds.
>
> Create the option for private sector Support Coordination. Other states have this option within their Medicaid services, and this could be an additional feature in our DDD portfolio to allow for the member's needs to be best evaluated.

In conclusion, Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. By not allowing parents of minors to provide Habilitation and Attendant Care services or work over 40 hours a week most of the minor disabled community in Arizona will be underserved. A comprehensive Paid Parent Caregiver program validates the irreplaceable work that parents provide in their homes and communities.

Click here to connect with the Arizona parent led grassroot initiative leaders: www raisingvoicescoalition.com

Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves all DDD and ALTCS members in Arizona.

Thank you!

Katherine Smith

---------- Forwarded message ---------
From: Bradley Dorman [redacted]
Date: Saturday, July 22, 2023 at 2:28:07 PM UTC-4
Subject: Paid Parent Caregiver - Our Family's Perpsective
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

I am a parent of a child who receives DDD and ALTCS services and starting in May 2022, I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility. Being able to provide Habilitation services to our son has been extremely beneficial to our family and my child.

I live in Flagstaff, Arizona and our son, [redacted] has received DDD and ALTCS services for the last eleven years. Of those years, it has been a heavy burden on our family to find direct care workers to fulfill Habilitation, Attendant Care and Respite hours for our son.

This burden has continued to grow as our son gets older and the shortage of providers continues to be an issue, even more so in a small town. Our long time agency was not able to provide us with more than one qualified provider over the last several years, even when continually asking them to fill the hours. We did vendor calls for other agencies, yet no results were yielded. We are then tasked with recruiting our own providers, which is difficult and stressful.

Becoming a paid provider for our son has relieved much of that stress. As a direct care worker, I am able to provide increased consistency, resulting in meeting and making significant progress on his goals. In fact, during the past year we have seen more growth in his social interactions and his ability to communicate his needs and wants, than we have in the past five years.

I also have unique access as a live-in caregiver to work on goals that other habilitation providers can't, such as night-time/morning routines, dinners, church events, community events, family gatherings, etc.

If your concern is social isolation, please know that being a parent provider has increased his social interactions and his ability to be out in the community. I have found that some providers and agencies are unable or unwilling to transport, which leads to more isolation time in our home. Being a parent provider does not limit his access to people, it actually increases his access, thereby increasing his exposure to novel situations and people.

[redacted] works with a myriad of providers throughout his week when he receives ABA services, occupational therapy, speech therapy, and schooling. This assists with his generalization skills and exposure to different people. Being a parent provider does not change his interaction with non-family members.

I cannot emphasize enough that being able to provide habilitation services for our son has decreased my level of burn out and stress as a caregiver. I know that he is working on and accomplishing goals, he is safe, and there is consistency that facilitates growth. This brings peace of mind as I look towards his future, lessening my stress therefore giving me more energy and stamina to be his primary caregiver for the next 30-40 years.

Please consider keeping habilitation as a part of the parent provider program, it has been a positive game changer for our family and our son's quality of life.

Respectfully,

Sarah Dorman

---------- Forwarded message ---------
From: [redacted]
Date: Saturday, July 22, 2023 at 2:23:05 PM UTC-4
Subject: Hope you don't cancel services
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hope you don't cancel services

Sincerely
Nohemy Teran

---------- Forwarded message ---------
From: lupita moreno ballesteros [redacted]
Date: Saturday, July 22, 2023 at 1:29:48 PM UTC-4
Subject: Habilitation
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

I am sending this email because I do want to continue qualifying for my son, for me it is a lot of help because when you have a special child it is very frustrating and it is always good help thanks I hope you continue the program
Thank You

Enviado desde mi iPhone

From: Katherine Anderson [redacted]
Date: Friday, July 21, 2023 at 10:02:50 PM UTC-4
Subject: AHCCCS and 1115 Waiver Team
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

As a parent of a child who receives DDD and ALTCS services I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility, and it has been extremely beneficial to our family and my child. I would like to share my personal experiences and feedback based on my review of the current proposal for a permanent Paid Parent Caregiver program that includes habiliation.

This program has been a complete tranformation for my daughter and our family unit. It has allowed me to allocate a portion of my working hours outside the home, to work with her on important life skills, given her more confidence and emotional wellbeing and security, lowered anxiety levels resulting in faster goal mastery , and given her a more normalized home life as she doesn't have strangers invading her safe space day in and day out. For clarification I say "strangers" because unlike a school teacher or regularly seen therapist these care providers are a high turnover and therefore never bond or get to know my child well, nor us them. Unlike a school teacher or regular therapist that is outside the home, these strangers are invading a child's home which should always be a place where they can feel safe.

I would also like to address a couple other ideas about parent providers that have been mentioned, namely that parents are "receiving a paycheck for being a parent", or that the child will suffer social isolation and a lack of community involvement. If you believe that children receive valuable socializtion within a school system, then I fail to see how this would cause isolation or a lack of community involvement. If your concern is more about homeschooled or ESA children, then what you need to be aware of is that children who are learning outside of a school are actually significantly more active in the community than children who attend a school several hours a day. They actually leave the home everyday, not only learning and practicing daily life skills such as purchasing groceris as an example, but the homeschooling communites are filled with a plethora of activites. Homeschooling groups include everthing from park days where kids meet, play and socialize, to drama clubs, gaming clubs, sproting events, Co-Ops with various group classes, and much much more. Here is a link to our largest west valley non profit homeschooling group. It is private but you can get a glimpse of opportunites without joining. https://www.facebook.com/groups/WVHSN/ That being said, since the pandemic has ended and everything has opened back up, the extra hours that were spent at work are spent with her habilitation goals. The hours I would have spent working with her on those goals after work (prior to this program) are then available to take her to these activities. So you surely can see how ending this program will actually limit time for outside activities, not to mention increasing burnout for myself.

As far as "a parent receiving a paycheck for being a parent", what you need to understand is that we may be doing things that a parent might already teach a neurootypical child to do, but it takes a significantly more amount of time to do so, as they child needs more time to learn it. Also, there are many things we need to TEACH, that most neurotypical children pick up on their own naturally. The difference between an outside provider teaching these skills vs a parent is that the parent is already bonded to the child, and they feel less threatened, as well as the consitency because providers are either not available, there are gaps in care, and a high turnover rate.

Personally, if this ends I will end up trying to be a parent, habilitation provider and work 40 hours a week because I refuse to put her through the stress of rotating providers again. I am begging you, please do not end this program. Please consider the impact for our children, parents and family unit as a whole.

Under the current proposal, the request of an ongoing program option which allows parents of disabled minors in Arizona to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies is not being met. Please consider updating the proposal based on the following questions, suggested solutions, and personal experiences.

Should Habilitation be included in the Paid Parent Caregiver Program?
We have heard the concerns about member isolation and lack of community involvement if parents continue as Paid Parent Caregivers facilitating their child's Habilitation services. Respectfully the parent caregiver community proposes the following solutions:

1. Examine available research and personal feedback statements from members and their families to evaluate the true potential impacts of social isolation and community involvement when parents of disabled children provide Habilitation services. The parent caregiver community's collective experience is that members who have parents facilitating their Attendant Care and Habilitation services have experienced greater member social engagement and community involvement over the last three years. Parent caregivers now have an increased ability to take their children to sporting team practices, community events, movie theaters, all ability parks, church activities and libraries. This is because parent providers can perform the appropriately trained and qualified supports in the correct time and location that is applicable to each member.
2. Implement precise guidelines to facilitate generalization for all Habilitation providers regardless of the DCW's familial status. Habilitation services are designed to have goals where data is collected to evaluate if those goals need to be changed, have been met, or need to be addressed differently. For a goal to be considered met, a member should be demonstrating that they are able to successfully meet that goal outside of the timeframe with a provider in one setting. This is referred to as generalization. The effective implementation of generalization with the pediatric IDD population would lessen, if not eliminate, any complications with adult transitional services. Under this model a program that includes parents as paid Habilitation providers would actually assist and improve in the success of adult transition. There are times when disabled children work successfully with different types of providers in clinics or schools, but the parents are not carrying the work over at home. This can happen for a variety of reasons. Having parents as Habilitation providers would help ensure the child's goals are congruent and carried over in the home and community setting. This will give the member a better chance of independence as they transition through different life stages. With generalization policies in place, Habilitation services being performed by parent providers will actually help facilitate successful transition into adulthood.
3. We know from provider agency data that "the top 3 issues regarding recruiting and retaining career non-family caregivers are schedules of the client members, interest in the position and finding qualified applicants." Most members have Habilitation goals and ADLs that are most appropriately delivered throughout the natural routine of their day. A parent provider is uniquely available in the morning, after school or in the evenings when each member is motivated and focused on the pertinent task. If a non-family provider is available their schedules typically allow them to work in longer time chunks that are not always the most ideal for the member and creates artificial goal or ADL practice. Continuity of care and greater member outcomes can be associated with consistently provided Habilitation care by parent providers who have the greatest ability to be flexible and available for their member children.

Should parent providers be limited to 40 hours a week of paid care per child?
We have heard the concerns of AHCCCS on why they want to limit parents to 40 hours a week under the Paid Parent Caregiver Program. The parent caregiver community would like to propose the following collaborative solution to create a win-win scenario:

1. Create a program provision that outlines an extraordinary circumstances clause and the application process that allows parents to provide over 40 hours of paid care per week of authorized and evaluated services per member. These extraordinary circumstances could include, but are not limited to:
    a. The lack of a non-parent DCW being available in the last 3 months to fill the member's assessed hours that exceed 40 hours per week. Ongoing DCW searches should continue to be made by the member's agency to fill the assessed hours beyond 40 hours per week of Attendant Care and Habilitation.
    b. The expressed desire made by a member for a parent caregiver to facilitate their assessed DCW hours so that their Article 9 rights are honored.
    c. The profound disabilities and/or significant behaviors of a member where a non-family provider is not equipped to provide DCW support. This determination can be made through a stakeholder team approach, including but not limited to the member's, DDD Support Coordinator, DDD Nurse, DDD Supervisors, Behavioral Plan Experts, Parents / Guardians, Psychologist, or Medical Doctor.
2. Form equality between all Family Provider Programs by allowing all Direct Care Workers, regardless of familial relationship or member age, to provide up to 16 hours of paid care per day. This will allow for employee equality across the lifespan of the member and limit the potential anti-family provider rhetoric currently present within state policies and DDD Support Coordination culture. All evaluations of hours should be based on member needs regardless of who is providing the services to create uniform implementation of all applicable HCBS services by the DCWs available to fulfill those hours.
3. The Family Support Program currently in this proposal addresses caregiver burnout. It is one of the available solutions to facilitate further community support within the disability and caregiver community that will provide greater access to non-profits facilitating counseling services, support groups and meet up activities.
4. Reevaluate Respite reimbursement rates to also address caregiver burnout. If Respite services are not available to the member or their family, parent burnout will continue to be an issue regardless of parents having the option of providing Attendant Care or Habilitation hours. With a comprehensive Paid Parent Caregiver Program in place non-family DCW providers will have greater flexibility to provide Respite services to these same families.

How should current evaluation protocols, training and practices be updated to facilitate equality for all members when accessing member needs?
AHCCCS has stated their intention to amend applicable policy, further suggested action on this topic includes:

1. Forming a committee of community and department stakeholders to amend and critique current DDD and AHCCCS policies and need assessment forms so that the most effective and efficient implementation of this permanent option is utilized moving forward.
2. Provide appropriately determined training and program implementation to DDD and ALTCS Support Coordinators so that Attendant Care and Habilitation hours are equitably evaluated based on the member's needs and to remove organizational bias of familial providers across the member's lifespan. Specifically investigate and determine appropriate DDD staffing needs and training for the members served in rural areas and those from minority backgrounds.
3. Create the option for private sector Support Coordination. Other states have this option within their Medicaid services, and this could be an additional feature in our DDD portfolio to allow for the member's needs to be best evaluated.

In conclusion, Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. By not allowing parents of minors to provide Habilitation and Attendant Care services or work over 40 hours a week most of the minor disabled community in Arizona will be underserved. A comprehensive Paid Parent Caregiver program validates the irreplaceable work that parents provide in their homes and communities.

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Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves all DDD and ALTCS members in Arizona.

Thank you!
Katherine Anderson

CMS perspective on the above noted requested program adjustments and paying Legally Responsible Individuals:

June 28, 2023 - Email Correspondence between CMS and Raising Voices Coalition:
https://drive.google.com/file/d/10CPccmIY7gEr5vq9C6vIaKmncSQOV7kc/view?usp=share_link

May 23, 2023 - Transcription of National Meeting between CMS Leaders and Parent Advocates:
https://docs.google.com/document/d/1h02v6Yk7frWGADcqKgm1zmd0uquMNfW3Jcd0zjHCxOk/mobilebasic?fbclid=IwAR2QLqbwJMQQRz0nj-XqhYzlFIkQbUV5wnyAyv98hivRVYpCjaYHhLBCzYg

Studies and data that support the changes being requested:

Data results from a 2023 Arizona survey of parents who have children with disabilities:
https://docs.google.com/document/d/16PZOk99caDUitg0XmQKqEv2mxXOBeaRywSD_zmjAnYw/edit?usp=sharing

A report on the current caregiver crisis by the National Association of Homecare and Hospice:
https://www.hcaoa.org/uploads/1/3/3/0/133041104/workforce_report_and_call_to_action_final_03272023.pdf

Higher satisfaction of paid supports for adults and minors with disabilities when care is received from paid family providers:
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1089106/

A comparison of healthcare utilization when children receive paid care by a family member vs non-family provider: .https://www.jpeds.com/article/S0022-3476(23)00106-3/fulltext

Youth with Autism Spectrum Disorder have less ED visits and patient outcomes when patient providers are involved: https://www.reliasmedia.com/articles/148366-autism-spectrum-disorder-in-the-emergency-department
https://www.psychiatrist.com/jcp/mental/child/youth-with-autism-in-the-emergency-department/

An evaluation of parent provider involvement in generalization of children with autism:
https://www.sciencedirect.com/.../abs/pii/S0891422205000958

Impacts of the caregiving relationship: https://academic.oup.com/gerontologist/article/56/6/1102/2952858

State Approaches to Reimbursing Family Caregivers of Children and Youth with Special Health Care Needs through Medicaid - NASHP
https://drive.google.com/file/d/1TSt-Rj95DTn711EV8UTq7YqF0yoo0j8u/view?usp=sharing

An autistic child, or young adult, should never have to perceive themselves as patient; as somebody who has things doen to them or who needs to be in constant treatment. -

Dr. Steven Gutstein

From: Faye Watkins [redacted]
Date: Friday, July 21, 2023 at 7:57:44 PM UTC-4
Subject: Parent
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

As a parent, I would really like to continue the service of providing care for my daughter. I feel that it’s something simple like that. OK is cannot be there are not enough people out there to take care of her as well as other children. I feel that my daughter benefits more for me.

[redacted]

From: Brenda Sondersted [redacted]
Date: Friday, July 21, 2023 at 6:48:38 PM UTC-4
Subject: Feedback for Parent as Paid Providers of Minor Children
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello,
Thanks for allowing me the opportunity to share my thoughts on the proposal for Parents as Paid Providers.
I applaud AHCCCS for such targeted intervention for our families when the world turned itself upside down with COVID.
The change to parent paid providers for minors at that time did have a significant positive impact and really helped a lot of families during that difficult time. Kudos!!

The change also created a lot of strong emotions, feelings and opinions from Parents, Vendors and DDD Staff. I personally don't have an issue with whomever is chosen to be paid for performing the care as my interest is to ensure that the member receives the care or services that they need.

I would like to share some of my observations on how the Parents as Paid Provider flexibilities have changed things from the support coordination perspective so as you go forward you can possibly consider some of these things as you adjust your policies.

The change to paid parent providers over these past 3 years have created a significant shift in the relationship of the Support Coordinator with the Parents and the HCBS Vendors. Traditionally, the Support Coordinators conversations have been very positive working with families/or vendors to identify and assess current need and identifying supports to help. Previously Support Coordination was viewed as being helpful, always welcome and valuable to the families/teams. The families and teams seemed to want to collaborate with us and we were welcome in their homes. While not every family relationship has changed and time has gone by and parents are being paid now to care for their minor child there have been many occasions that the support coordinators have been met with challenges they never had to face before from parents. Behaviors from the parent have changed such as arguing, demanding and threatening statements trying to obtain more services and no showing for meetings.
Comments range from: "you can't change anything on the plan because I need the paycheck" , "you can't touch my hours" "You can't reduce/change the goal even though the member

mastered it because I would have to go get another job" SC's are hearing a huge shift in the language as in a lot of cases the conversations are no longer about what is needed for the member but what was needed by the parent. Indeed, during the pandemic many lost their jobs or struggled to care for their disabled family members with businesses, daycare and schools closed. However, now the schools are now back in session, daycare is open and the PHE has ended. Now it is more the norm that the parents do not want us to ever make any changes or adjustments to the PCSP service plan because they consider it "their paycheck". Some parents have the perception or have been told by vendors that the program means we have to pay them full time for caring for their child. Many are threatening and insistent because "someone told them that DDD will pay me and I was told you have to give me what I ask for" For a seasoned or unseasoned support coordinator it is difficult to coach a parent when you know you are being asked for 40 hours of direct programming or more for a young child on top of going to school for 30 hours per week. If you add therapies and any behavioral supports/ABA or extra curricular activities into the schedule some of these children as young as 4 are being programmed with paid services for 80 or more hours out of 112 waking hours. We have seen an increase in behavior and frustration in these children but parents are insistent in telling support coordination that they won't agree to changes because it is their "paycheck". SC's are reviewing the members schedule and physically showing the parent that there are no more hours to fit any additional services time in but they insist that they have to receive more, not to serve the member but to afford to live.
These are definitely new conversations and guidelines and timeframes would be very helpful.

Support Coordinators are now experiencing at PCSP meetings where they are being asked for additional service but the members needs have not changed, then the family begins to change the answers in regards to needs saying that the member is now at risk or wonders or can no longer do things for themselves that were historically not present and past documentation shows the member was independent or there were no concerns or barriers for the member. Now, the parent is saying that the member can't do anything for themselves, requiring constant supervision from the parent when they never have before with no reported illness, event or justification for the change. In a recent event a Parent told the support coordinator that the child can not feed themselves and the parent has to feed every meal to the child. However, during the meeting the SC is watching the child feed themselves cereal independently in front of them. Many of these embellishments are to try to justify the request for service increase to the ATC policy, not because the parent can say that the member has experienced a change in functioning, health or mental health needs.

As time moves forward with parents being paid we are seeing a significant challenge with the parents who are now asking to be paid for every task and every minute of the day with the under age child. We advise the parent of the eligibility requirements , need to consider age, functional ability, attention span and what other things are in the members schedule as we assess for services, Where before that conversation would be accepted now often the conversation turn into a refusal to cooperate because it is not meeting their need for their income and not because the member has service needs that are unmet. An example is a parent of a [redacted] year old asking for 40 hours of habilitation (member does not qualify for ATC or ATCS per policy) - because the parent says that they need a full time position and the vendor said she should be paid. They did not cite any new barriers or issues or extenuating needs of the member. They want us to develop 40 hours worth of habilitation goals for this [redacted] year old child. Mother says, I am with the child all the time, I am doing all of these things to care for them so I should be paid. for it. Parents are now demanding high hours of service just because of the parents' need for a certain level of income to live and get offended when we tell them we have to focus only on the members' needs. Policy is not very clear so the parent and vendor just keep creating new scenarios to try to get the service approved. Of course we want to authorize anything that the member qualifies for but not every child will qualify for ATC or ATC Supervision so now parents are asking for full time hours (40) for habilitation.

Clarification and modification of the ATC and ATC Supervision policy really would be beneficial for support coordination. It is important that we are able to ensure that manipulation does not occur to artificially inflate the needs now that the parent has a financial interest in the service plan not changing (ever) and ensure that they are not able to manipulate eligibility requirements.

Support Coordination could really benefit from clearer definition of what is parental role vs paid parent provider. Guidelines are really necessary for any parent paid services to ensure that parents are not overtaxing themselves,or over-programming a child in regards to service considerations and how much they are able to bill as a paid service for a minor child. Realistically, any parent can say children of certain ages require all the support on an attendant care assessment but mostly it is age related and not necessarily disability related so it is hard to justify or deny as we typically would have before parents were paid.
Policy has not changed yet and most children do not qualify for attendant care per the policy requirements. A lot of families were given 40 hours of attendant care during the pandemic and now that the PHE has ended and schools and daycare are open the parents are not wanting support coordinators to adjust or change anything on the service plan because it is their PAYCHECK. Many parents are now asking for attendant care when they never needed it before and there has not been any significant changes in the members' needs, health, mental health to balance out why more support is needed. SC's are getting calls from parents who say "vendor said that I should have attendant care, or 40 hours of HAH so you have to give it to me" "if you don't give me what I want I will just request a new support coordinator/file a grievance etc" when in most cases there has never been any discussion of need previously.

Another change is that some families are now not being home when the SC goes for their scheduled PCSP meetings because they did not want to have any discussion or make any changes. Some parents are just refusing to sign the service plan that the team agreed to and refusing to discuss anything because they don't want to lose any pay. Parents are saying things like " my vendor said to tell you that the member wanders or is now at risk so I am supposed to get paid to do attendant care" Previous history does not support that member wonders or is at risk per policy. There are no incidents and historically the child did not have any issues with wondering or confusion and did not have any new health issues. There are no reported changes or incident reports to support an increased need. Again, a difficult position for the Support Coordinator as historically the parent provided us with a picture of the members needs unbiased by any financial net gain so they were typically candid and honest. Now they have a vested interest in seeing that the same level of care is maintained and parents are not wanting to report functional skill gains because it is their employment and not because of the members' needs or growth. Clarity is also very much needed as to how to address the parent of a minor child who wants to be paid for every minute of the child's day would be very helpful to support coordination.

The conversations with vendors have changed as well since the pandemic. They have now become threatening to the support coordinators, bullying them to give more hours, they attempt to manipulate support coordinators by saying "well I have a child or I know other children who get attendant care, so you have to give it to the family" or "10 other SC's put the

service in so you're wrong and you need to enter the service anyway". The vendors have had it very easy signing up parents and now they want to make as much money as they are able by asking the parent to ask for every service the division offers. I understand that they are a business but they need to allow support coordinators to assess and do their job and generate conversations around eligibility not threaten the support coordinators. Sometimes Providers are refusing to accept members for service saying "10 hours a week is not enough to get or keep a provider". The challenge with that is some members only need 10 hours. Vendors are also talking to parents who have never wanted to be the paid provider and coercing them into being the paid provider. Some promise to find a provider to relieve them as soon as possible but then they never find a provider. They also get the parent to demand all services be reassessed and give them more service time directly after signing the parent up as their employee. In many cases lately they demanded reassessment but not during the PCSP meeting but outside of a meeting. In my most recent event the SC had just reassessed with parents and developed new goals just one a week prior. The Vendor is demanding that the parent be given more hours of service or additional services for needs that were never needed before or discussed at any of the members meetings. This creates exhausted and stressed out parents and a new crisis to manage. In some households the parent may not be the best candidate to provide the service because the parent is indicating that what they need is more hands on help or eyes on the member for safety or to address other duties. Support Coordination is then faced with a difficult conversation with the provider and vendor to say "we talked as a team and the goal was to get additional hand on or eyes on support for the member, how does making the parent the provider the paid support person meet the members needs?" Having that conversation without offending the parent is challenging. Typically after a period of time the parent is now dependent on the money coming in and then does not want the paycheck to end and wants to forgo the extra help, but yet each meeting they are still struggling with the same issues. You can see the catch 22.
Some Vendors are telling parents that they can get them full time hours per week paid services so that they do not have to go out of their home to work. Really hard to pull that off when you have a [redacted] year old who may have some areas of need that can be addressed but not up to a full time job worth weekly.

I 100% support the exemption of Habilitation Hourly from the parents as a paid program.
Many of the above mentioned problems will likely resolve if you are successful
with exempting habilitation hourly from the parent paid program.
I can imagine that you will definitely hear the opposite from MANY parents.

I totally agree that this service allows our members contact and connection with others rather than just their natural family. It also allows more eyes on the member to identify needs, strengths and for safety. It is possible in many cases the member may learn better from someone not their primary care provider. Mostly, it also allows for more information about the member to be shared with the team as to how the member works, learns and is growing or regressing from another perspective than the parent which has always been helpful to us in support coordination to justify need and detailed growth. Habilitation is often difficult to assess now with parents who are being paid. It is hard to get the parents to step out of the parental role and into the employee role of teaching the task for habilitation. Some of the parents look at everything they do, every prompt they give and want to be paid for all of their support of their child. It is hard for them to see the difference between their natural role as a parent (a job that never ends) but ALTCS HCBS service is about need. HAH is not designed to fill every learning need of a child all at once. It would be very difficult
and counterintuitive to program a young child with 40 hours of habilitation goals for a [redacted] year

old child who has a very short attention span. Very much the same difficulty is for children whose parents say they know how to do the task already but they just need reminders and the parent wants us to write a goal and assess for every prompt and every reminder they give through the day, which is not very realistic. For those reasons I absolutely support exemption of habilitation from the parent paid program.

Support Coordination would really benefit from a clearer Attendant Care and Attendant Care Supervision policies for underage children in regards to how to view the parental role now that parents will be paid, what is informal support and what is paid provider. If we no longer need to consider informal support for parent paid services, policy would benefit from clearer eligibility criteria and clearer guidelines for reasonable time frames for service assessment and it would be good to have ranges for different ages, We would benefit from clearer guidelines as to what constitutes justification for the services such as what documentation should we have? Do we need IRs, police reports etc if the parent says the member is at risk? Or do we just take the word of the parent. As an example, recently we had a parent say the member was at risk and needed to have attendant care supervision. Their reason was that there was one event when the member first moved to his new home many months ago, he walked across the street to the store and did not tell his mother. He never did it again per parent. Is one incident enough? We would really benefit from clarification on how we demonstrate that the member has an issue with wondering when we are assessing a young child. Most young kids are at risk for wondering which is why they need constant parental supervision. With the current policy we struggle with discussing a natural parental role vs paid support.

I hope I was able to share with you a good perspective of the changes that have occured since this Parent Paid flexibility was instituted. I sincerely hope it supports your policy changes to help balance out the changes in coordinating services for Paid Parents of Minors. I speak for many support coordinators when I say we would all love to once again have positive and supportive relationships with all of our families without the need for threats, bullying and fighting. Unfortunately, the Paid Parent program has created this shift in this relationship and we really need updated policy and guidelines to navigate these new challenges with supportive language but still be able to keep things realistically and appropriate for our members.

Thank you for your time and consideration of this information.
Respectfully,
Brenda Sondersted

--
Chandler Support Coordination
Division of Developmental Disabilities
DES Logo

[redacted]

Phone: [redacted] - main
Cell: [redacted]
Fax: [redacted]
des.az.gov

From: Michelle Mit[redacted]
Date: Friday, July 21, 2023 at 5:33:49 PM UTC-4
Subject: Parent Paid Provider
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello!

First, I'd like to thank you for offering this program for Parents of Special Needs kiddos to get paid to provide some of their care. My family just recently became aware, and were approved for this program. I have been at home with my son since the beginning of the pandemic, [redacted]. I have used all of my savings during this time to survive. Unfortunately, I was unaware of this program until this past Fall. It took from [redacted] 2022 until [redacted] 2023 for us to get processed thru DDD (they dropped the ball with our initial application)… however, I am SO grateful for the financial help!

I was on the recent call with AHCCCS regarding the possible end of this program. I would like to stress the importance of this program by sharing our story;

I am a single mom to my [redacted] year old son, who is ASD, ADHD, Anxiety, SPD, ID, and newly diagnosed with Dysautonomia. My son requires 24 hour Supervision at this time. My son is thriving since we have started online school (due to the pandemic), and 8 different therapies that he attends weekly. Prior to Covid I worked fulltime so he was unable to attend these current therapies because there was not enough time in the day, and I didn't have anyone to transport him. For over [redacted] years, and now with the help of the Parent Provider Program(PPP), I am able to transport him, help with his education because I can see where he is struggling throughout school, continue to help with ADL('HAB') goals, and also help him with homework from school and from his therapies… and get paid for some of my time. None of this would be possible without PPP!

I would like to believe that I could have a provider come into our home and do the same job that I am, however, we live in [redacted], AZ, and these providers are unheard of. It would be great if I could get back to my career, and bring home a great salary again… but HOW? Who will drive my son to 2-3 different therapies each day (he is [redacted] yo, doesn't drive, and may never be able to)? Who will sit with my son during school, and help him as he struggles daily? Who will do all the extra required out of class work during the day? Who can supervise my son for 10 hours each day while I am at work? Oh, and who will work on HAB goals EVERYDAY-7 days a week, ie… showering, dressing, grooming, meal prep, socialization, exercising, financial training, etc. . So, if you can guarantee a provider that is available 7 days a week… 60-70 hours/week, and will show up to work even when they are sick, or tired, or have personal appointments, etc… then I could agree that this program is no longer necessary… BUT, you cannot! Because these providers do not exist!

Please consider keeping this program, it is essential is SO many lives!

My son will be the one that will miss out on the many things that are helping him learn to become a more independent and self confident individual with disabilities.

Thank you,

Michelle Mitchell

[redacted]

[redacted]

From: buildupandencourage[redacted]
Date: Friday, July 21, 2023 at 5:02:38 PM UTC-4
Subject: Public comment- Paid Parent (extension for November l)
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello,

We would like to make comment on the November Parent Extension from the perspective of a Day Program. We are concerned about paid parent extensions because we see problems in declining socialization in some of our members and Guardians. As convenient as it seems that this program is, we have a member that is still waiting on returning to our DTA program because of this funding. She has expressed personally that she would like to return to our center and used to attend our program pre-covid. Her Aunt Guardian is now using the paid parent service and having her help babysit for grandkids/ cousins. During Spring we had a brief interaction with her in which she visited the [redacted] center where we have rented and saw her seemingly going to use the workout room. She stated "I miss everybody, I want to come back". The woman she was with stated they needed to leave because they were on her time (assumingely she was getting paid for taking the member and left with the member). We were confused by the woman's comment but happy to have bumped into our member. We have tried reaching out to the member's support coordinator and supervisor on the member's interest to return but have not heard back. We understand this support of paid parent funding is convenient but in more ways can be detrimental to the member's mental health and need for socialization. When we called the aunt/Guardian to follow up on the member's interest to return to her DTA, we were told the member was helping babysit with the aunt for the grandkids / cousins of the member but could possibly come back for once a week. Unfortunately, this was the clarification we received by the aunt, who is her Guardian. In not receiving correspondence from the Support Coordinator or Supervisor, they too could possibly be aware of these details. This aunt/Guardian of this member never gave support to the member financially for outings and always stated the member does not attend outings due to transportation, however she uses DDD habilitation/respite services frequently. This Guardian does not put the member's interests to heart, like in other members we know. We see that this funding could be helpful for a season or summer but not yearly.

We have another member who is Self-Guardian but the parent will not pay for outings for the member. She is not using the Paid Parent services right now but still isolates the member who has expressed through numerous online meetings that he is wanting to come back to the program. The SC has done so much trying to get him back in the program to socialize but the mom is now stating she does not like the [redacted] of the member who attends our program and wants to pull her son from the program because of this. She says she is willing to look at other options for him for socialization, but obviously due to the SC's dedicated support. I am not sure if this member will be attending anywhere because some parents lean on convenience a bit too much than the members best interests. This parent serves as another demonstration of holding on to finances that do not support community outings for the member unless it is free.

In yet another parent were the father luckily paid for outings for his son but often complained. His son lost weight with our program and was doing excellent, before Covid struck. We were online for quite a while due to The City of [redacted] closing [redacted] buildings where we [redacted], and we found our member was quickly gaining weight again. He loved getting out of the house in which his father used to say "If [redacted] could sleep here, he would". Our beloved member later died from a [redacted]. We were advised by his mother long ago that his doctor advised him to loose weight and we worked with this member having fun in sports and [redacted] in which he lost weight. Unfortunately, Covid Season happened and there was a disruption in focus and routine for fitness that brought on new challenges. He was a precious member that later skipped [redacted] in the [redacted] online because he would stay up late on his computer at night. [redacted] was something he loved but staying home did not help him. He gained a lot more weight that compromised his health and we were devastated by his loss. He lived to socialize and we can't help but think of the repercussions of this parent funding option and where it can lead. We saw some of our healthy, stable members that loved socialization and fitness, and later died (not due to Covid).

We lost another member who fell in depression during Covid and the Fiduciary saw her need for mental health and had her attend outings and seek psychological help immediately. She was cared for and not in a paid parent situation but she had a bad outcome from being isolated during Covid. She sadly died and was cared for by her surroundings, however our point is that friends, socializing and community are a vital priority for many members. We fear isolation will hurt some of the members who need this mental health aspect in their life's. This funding needs to address those who need it due to behaviors and not hinder the members who need an environment with others. It is within our society and culture to help cultivate and foster these relationships with others.

We have seen a problem in another member who has cut back on hours at the DTA and stays with grandparents. He now comes in to our center and is very different and isolated since Covid. He puts on his music w/headphones and no longer socializes with his peers as he used to. He is preoccupied by his music and he used to be a very lively, energetic and extremely extroverted individual. His socialization has diminished and he was watching alot of TV when we were meeting online. We feel the homebody experience is not going to help our members but put them more [redacted] as this member. He just had a [redacted] surgery and we are hoping he can maintain a healthier weight because we are silently concerned about his changes.

These are our expressed concerns based on experience. We also have another member who used to sit by the window at another program waiting for his transportation to get there so he could come to our day program as we start at [redacted] and end later. We assume the anticipation he expressed was because we offer music, dance, Zumba, etc. that help stimulate member's interest. He has been expressing to a member/friend who attends our program and to the friend's Guardian, that he wants to return. This member is self-guardian but the mother doesn't return calls and last stated that the home and other program was concerned about Covid exposure. This member has a mother that demonstrates a strong need for control and does not see the value of community, or for that matter take the member's requests and needs for socializing. This member used to like playing the [redacted] in our DTA band and loved entertaining in public at the [redacted] invitations, [redacted], etc. The member has showed frustration in the past at past meetings and hit staff at the other program but never exhibited behavior at our program. The company who provides his group home also provides his Day program and he unfortunately was over powered by his mother. We feel for him but can't do anything for him. The SC we used to meet with prior to Covid has experienced these same uncomfortable meetings with the mother's control over the member. In mentioning this situation, careful consideration needs to take place before allowing this parent funding to take place. DDD in its respected form, is an advocate for these members, and DES is respectfully focused on health (be it mental or fitness), please take heed to our advice as providers in what we experience.

During community outings we have to find at least one free outing because some parents/ Guardians do not see the value of community outings and hold control of the finances. We see this often and are concerned because members enjoy this interaction and it is unfortunate that some family do not support it. We see more problems coming from the extension of funding for parents like this… who do not value or support socialization. We feel this funding without good approach will lead to neglecting mental health where as DDD and providers have worked hard to support community involvement and social efforts for our members. Despite limited funding, our day program aims to build up and encourage the community of developmentally disabled adults and make the best use of time together. If children or adults with behaviors may benefit from this Parent Paid Program, we see it's value on special needed terms, however for children and adults who are harmonious around others, we see a distinct value and need for continued support in these areas. We speak humbly for their needs and strive to encourage the benefits of companionship through peers, community and adventures out of home, to benefit their mental health and well being. We strive to strengthen their interactions and social development. We feel seasonal funding is appropriate during summers or urgencies, or for those with long term caretaking needs such as tube feeding, etc. or behaviors that call for extended needs. DDD should take precaution in not leading a healthy maintained member group to isolation or lacking communal supports or proper outlets. As a provider, we would never want to hold back community involvement, in fact we want to cultivate friendships and healthy lifestyles. Implementing a parent paid program that does not infringe on the rights of the members due to pressed measures taken by the parent, this will take some work. Proper accountability measures need to be taken BEFORE implementing. Some guardians/ parents are beautiful advocates for the members, while other Guardians base interests on convenience and quickly down play the member's needs and wants. Please take our experiences into consideration as we do not want to tamper with the precious mental health of our members and incidentally promote an idea of isolation for those members not needing it.

Sincerely,
Margo Arvizu

[redacted]

---------- Forwarded message ---------
From: Jennifer Garcia [redacted]
Date: Friday, July 21, 2023 at 4:03:26 PM UTC-4
Subject: Parent Provider Provision
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To Whom It May Concern:

I am writing as a mother of an autistic child to explain why parent providers are so important. I have been a parent provider since a little after the program update was created during Covid. This provision has given my family the ability to truly help my child thrive and advance in his therapy without it I am scared to think where he would be in regard to his therapies. I don't know if you know, but being the parent of a special needs child is challenging to say the least and when you add in having to try to find someone to "help or aid" your child it's unattainable. Before I had the opportunity to do this I was never able to find a HAB provider that wasn't family to help me. When this program was created for parents I had no one at the time to help me, so basically I never found a provider before Covid unless they were family (which never lasted long).

Now we all know that the workforce has never been the same since Covid (no one wants to work) so to expect us to be able to find people who are acceptable to do this job is just not going to happen.

It is unreasonable to think that people will come and work at 6am until school starts then come back at 7pm to work a few more. Not to mention the nature of what my child needs help with us very personal like toileting and showering (things a stranger cannot do with my child) so if this was stopped for parents it would require me to find someone then sit and watch their every move (as they do the HAB) to make sure my child is safe. It seems very counter productive to do this when I can do it myself and get paid for it.

Let me give you an idea of what a day looks like for my child. On a [redacted] he starts school at [redacted] goes to [redacted]. Then comes home for [redacted] min then we go to occupational therapy at [redacted]. Then back home by [redacted]. On a [redacted] he has school than [redacted] hours of ABA which ends at [redacted]. This repeats on [redacted] and [redacted] then on [redacted] he has school then 2 hours of speech and feeding therapy which ends at [redacted]pm. This schedule does not include dentist or

doctors appointments child meltdowns or other challenges that family members may need which all have to be worked in. Do you think it will be easy or even an option to find someone to work around all of this (starting at 6am then back at 7pm daily)?
Not to mention having a full time job out of the house and do this is impossible, so by allowing us to work and help our children it has given our family hope that our son will be a functional member of society someday.

Another huge issue is the the safety of our children. How do you hire a stranger to accomplished toileting and showering with my child? Those are things that only a family member should do. We all know about the predators out there and how Arizona ranks on child trafficking in the United States. By taking this away from parents it would be forcing us to possibly hand over our kids over to be groomed by a predator. Then add in that our children are often non verbal or socialized enough to even stand up for themselves or even tell us what has happened to them. As a parent put yourself in my shoes and just think about what I am saying. Would you allow your non verbal child to be taken care of by a stranger in your home who is required to help them toilet and shower?
This program has helped so many families and children. Just look at the numbers of providers that are parents. Please take all of this into consideration please do put our children on the back burner to be left behind.

I appreciate your time on this.
Sincerely,
Jennifer Garcia

[redacted]

From: All Aboard Services [redacted]
Date: Friday, July 21, 2023 at 3:04:56 PM UTC-4
Subject: Wavier 1115 & Attachement L
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

HI

Where can i find a copy of the approved Waiver 1115 items such as the ATC billing during a hospital stay or the proposed

Also Attachment L for the home care training family support (family support) service as part of the HCBS benefit package

Thanks

Katie Krietemeyer
All Aboard Services, LLC
6859 E Rembrandt Ave #128
Mesa, AZ 85212
[redacted]

From: Bethany Moore [redacted]
Date: Friday, July 21, 2023 at 1:16:10 PM UTC-4
Subject: public comment- Bethany Page
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello,

My name is Bethany Page and I am writing to request that parents be allowed to continue to work as attendant care providers for their disabled children.

Before having my daughter I worked as a sign language interpreter. I worked in various settings, but primarily worked for universities interpreting for students. I was paid very well for my skill, and enjoyed my work.

Once my daughter was born, I was unable to return to work due to the high medical needs of my child; she is now [redacted] years old and I still have not returned to my former profession due to the high needs of my child. We home school her because of her medical needs as well and I am her primary caretaker; this has made going back to work, or earning any kind of income impossible for me.

Additionally, the medical needs of my child are very expensive, therapies, special foods, medical grade formula and vitamins all add up. The parent (as an attendant care provider) program has brought income back into my life after [redacted] years; we are no longer struggling to provide food or therapies for my daughter.

Despite several attempts to bring respite care, or other support into our home, I remain the only person who truly has the patience or capacity to care for my daughter. I am the best person for the job, because I am her Mother.

I ask that you please continue this program, it has been a lifeline for my family in already challenging times.

Sincerely,

Bethany Page

From: Sergio Quintano [redacted]
Date: Friday, July 21, 2023 at 11:54:37 AM UTC-4
Subject: RE: Parents as paid caregivers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Good Morning, I really believe these parents are taking away from our care providers the opportunity to work. DDD should hire all these parents on board through their agency called PPL, and not have to go apply through other agencies and take away job opportunities from caregivers. Since covid hit a lot of people became lazy to work and this was a way parents came into the picture wanting to work and care for their family member. I am really against it because forcefully the parents have to be employed through agencies and leaving out the providers without jobs. Eventually all these parents are going to want to work leaving all these caregivers thata certified and with experience without jobs, I myself have to deal with these parentes coming on board without certifications and all. The State is the one to blame for allowing this to happen.

From: Irma Lozano [redacted]
Date: Friday, July 21, 2023 at 11:18:24 AM UTC-4
Subject: Petition to add HABILITATION services to proposal for Parent Caregivers.
To: Waiverpublicinput@azahcccs.gov <Waiverpublicinput@azahcccs.gov>

> To whom it may concern,
>
> This letter is in reference to the Waiver For Parent Caregiver Program. I would like to share my personal experience and provide input as to why I feel Habilitation Services should be added to the waiver. I am a single mother of four boys. I was in an abusive marriage with their father for a bit over a decade. He finally left in [redacted] and we were divorced almost [redacted] years later.
>
> After he left the journey with my [redacted] year old fraternal twin boy's ASD diagnosis began. I was on a wait list for years to try to get them evaluated by a Developmental Specialist to get an official diagnosis. When I was finally given the appointment I traveled to [redacted], AZ for that appointment. I made that trip a few times until it got too hard, mostly financially, and I had to withdrawal her services. Ever since then I have been advocating and fighting for my children's needs and benefits. I have also educated myself, as well as the rest of my household, on how to help them achieve the best possible quality of life they can have even with their limitations and diagnosis.
>
> I have been out of a job since I was [redacted] months pregnant with my twins for many different reasons. My abusive ex-husband alone was a huge burden. He struggles with [redacted] and [redacted] due to his time as an active recruit of the [redacted]. When he left, he left our boys (I have all four boys) and I with a lot of trauma and a lot of financial problems. We have since been diagnosed with [redacted] due to the [redacted] and [redacted] we experienced. I have been working hard and been extremely adamant to rebuild myself and most importantly rebuild my children. For a long time I did hair (I am a licensed Cosmetologist) of friends and family to make a bit of money (I was only doing it a couple maybe a few times a month) when I was able to get my sister to babysit. I would also clean the house of a family friend. But I couldn't work part-time let alone full-time AND take care of my children, AND work thru my trauma AND make it to therapies, AND medical appointments, AND school meetings

and functions, the list goes on and on. Eventually even the side work I tried to pick up became too much and I had to stop. My dear mother whom I am more than grateful to be blessed with, supported her household (she lives in another town) and mine (including clothes and even occasional unnecessary stuff for the kids, like McDonald's). My mother is a Room Attendant (Housekeeper) and picked up extra rooms and worked over-time to make ends meet for both our households. Her work is extremely hard on the body AND mind and not once has she to this day complained. She is a saint and without her I don't know how things would be working out for my boys and I.

When the Pandemic hit and we were eventually allowed to start providinga services to our disabled underage children, it felt bittersweet because it is EXTREMELY unfortunate that this program came to be because the world was dealing with the Pandemic but for the first time in YEARS I had a steady income and I was able to eventually stop being a burden on my mother who is only getting older.

Being able to provide my children's Habilitation Services has given myself and my household a lot of peace for the following reasons. Beside the fact I have become a lot more financially stable, I have become a much better parent and provider. With all the knowledge and training I have acquired from the agency I am employed with, I am a lot more well prepared to help my children achieve the best quality of life possible for them regardless of their diagnosis or limitations. I don't just work with them during my scheduled hours. I work with them all day and most of the times my children don't even realize we are "working". I am convinced the opportunity to accomplish their HAB goals with them has helped me grow closer to my children. Some of us might know that with Autism a lot of the time it is extremely difficult maybe even impossible to make intimate connections with anyone. To truly bond with anyone. I feel I have been able to accomplished that with my boys.

I attended the webinar on July 18th, 2023 and one of the reasons given for not adding HABILITATION Services on the proposal was the fear of the lack of socialization. In my case my children go to school, which is when I am able to take care of my mental and physical health which is extremely important for all of us with loved ones with disabilities. Especially when that loved one is a minor child of ours that lives with us. After school there are occupational therapies, speech therapies, medical, and dental appointments. My children are pretty social, even with their Autism. Socialization is also something in their IEP's that is a goal to work on and they have been meeting their goals. Opportunities for Socialization is not an issue at all.

There is already so much going on every day in our lives and even for those fortunate to have their significant others support it is a job we have 24/7. For me being a paid caregiver for my children has given me knowledge and financially stability to be able to provide, care, and to provide all the skills and tools I can for them to have the best quality of life possible for them. To aide them in gaining their independence as they grow older. Even when I am gone.

I get so many compliments on how well they handle their days. How well they handle themselves in different environments. They have become more aware of the world around them, the world they live in. I just do not see how someone can achieve that, that isn't invested 110% in their members the way a parent is. I truly honestly believe my children would not be doing so good if it were a stranger working with them only on certain days and certain times.

Another point that has been brought up as to why HABS are currently not added is that it is the parents legal obligations to care for their underage children. Yes, I understand that BUT until I became their paid caregiver and have been taught how to break down things when they are being taught is something I had never learned or experienced elsewhere before. Also when we become parents of children with disabilities a much as anyone wants to say they learn just like anyone else, the truth is that is actually not the case. There is always something that needs some adjustment to accommodate the disability of the individual and by having the opportunity to work with my children I have learned how to properly give those accommodations and I have learned what "accommodations" for the children and any member with a disability actually are ok and what isn't. What works and what doesn't.

Another thing I'd like to share is that at one point I had asked my DDD case manager what would happen if at any point I wasn't allowed to do my children's HABS anymore. That if some stranger is supposed to come into our home which is already invading our privacy AND making the whole household uncomfortable, but with the hygiene goals (showering, toileting, changing clothes) how am I suppose to know this stranger won't take advantage of my children regardless of back ground checks? Someone just truly does not know. One of my boys is more severe than the other and he is non-verbal. My other son speaks but I doubt he would understand if some one was taking advantage of him. The response that was given to me was that I would have to be present the whole time the DCW would be working with my children. So in a day they get 3 hours each so I would have to sit there for 6 HOURS watching someone else do the work that I have already had training in and work that I could be doing. That just seems insane to me.

There is also the issue of shortage of Caregivers. Keeping us to continue to do the work we do is helping that issue and more of the individuals with Disabilities are getting the care, attention, and consideration they deserve.

I want to take the time now to thank you for the blessing in disguise we were given when the Pandemic hit, and I am asking that you reconsider and add HABILITATION services to the proposal. Thank you for your time. Stay safe and God bless you always.

From: Alejandra DS [redacted]
Date: Thursday, July 20, 2023 at 11:24:34 PM UTC-4
Subject: Hi
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hi I believe it would be a great opportunity for us parents to be able to do habilitation hours for our children since I couldn’t get any provider that was able to take in my sons schedule it was difficult for me to go to work or even keep a job. I hope this is consider it would be very helpful for parents like me. Thank you

From: GALAXYGAMER junior [redacted]
Date: Thursday, July 20, 2023 at 9:13:45 PM UTC-4
Subject:
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Quiero que las horas de abilitacion sigan siendo solo con los padres no quiero que alguien extraño cuide de mi hija por favor ampóllenos

From: Vale Leon [redacted]
Date: Thursday, July 20, 2023 at 8:43:24 PM UTC-4
Subject: Habilitation for parents
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello I decided to write this email to ask that they don’t take away habilitation for parents, my mother and my [redacted] sister need this since everything is raising, rent, food, insurance, health insurance etc, please don’t do this other parents depend on this job

From: Aisha Berrios Martinez [redacted]
Date: Thursday, July 20, 2023 at 7:34:19 PM UTC-4
Subject: Reconsider ending parent pay for habilitation
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To whom it may concern:
Please reconsider this proposal so that parents can continue providing Habilitation services for their loved ones after November 2023.
My child has shown significant improvement since I am able to provide his habilitation.
Ending parent paid habilitation will cause severe disruption and regression in those receiving care.
Please do what's best for the children and continue to allow parents to provide habilitation and receive pat for services!

Aisha Berrios Martinez
Please excuse any grammatical errors, this message is being sent from my iPhone with the intent of a speedy response.

From: Brittany Miller [redacted]
Date: Thursday, July 20, 2023 at 6:53:14 PM UTC-4
Subject: Public comment
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

After listening to the recent public forum on the parents as paid caregivers program, I wanted to add some additional comments and concerns.

- Parents expected to have til the end of Sept 2024 for habilitation services. I personally disagree with the removal of habilitation for countless reasons, even more so if it goes away in 4 months without giving parents enough time to adjust. There is not a workforce waiting in the wings to take over these services, and cutting them much earlier than families expected is not considering the family and DDD member's needs

-If hab is going to be removed, it should be done after Sept 2024, and phased out slowly by reducing hours every 90 days.

- I believe there should be a clause put in the proposal that if a member is without habilitation services for more than 3 months, and DDD cannot find a provider, the parent can take over and work those hours so the habilitation goal progress is not further disrupted for that member.

-Caregiver burnout was addressed, it has always been an issue long before the parent-provider option when families like mine went years without attendant care and habilitation hours being filled. One might argue why the sudden increase in concern for caregivers, in relation to them being paid. Burnout is significantly reduced when families can provide their child's care, and pay their bills. Respectfully, where was the concern when we were not being paid for caring for our exceptional children with high needs? The lack of respite providers is statewide and families have been overwhelmed for years. Paid care relieves stress and burnout. And the member's services are actually fulfilled.

Thank you for giving us the opportunity to share our feelings on this. Warm regards,

Brittany Miller

From: Jennifer Mittal [redacted]
Date: Thursday, July 20, 2023 at 6:34:56 PM UTC-4
Subject:
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Please do not end the parents as providers. Prior to me providing services for my son, we were never able to keep workers for him. He went at leat a year without any HAB and respite care. Once I took on his HAB hours, I took the time to focus on his goals. He has shown steady success. If I don't work with him he will either have no provider or possibly difficulty keeping one. Providers never stayed long in their position. I have been there for my son for [redacted] years as a provider and he looks forward to our time together. The money I earn doing HAB pays for our outings together. It has been the best and most fulfilling job I've ever had. Thank you Jennifer Mittal

From: Devinmarie Zuleski [redacted]
Date: Thursday, July 20, 2023 at 6:25:22 PM UTC-4
Subject: Hab
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello there!

My name is Devin Marie Zuleski.
I moved to the state of Arizona in [redacted]. I left California to come to AZ, when I left the state, I had been a special needs teaching assistant for [redacted] years and a habilitation provider for [redacted]. I came here and taught for a little over a year and a private school in [redacted]. It was a specials needs school. Beautiful ground, decent work environment but most of all I learned so many skills and techniques working with children on the autism spectrum. At this time I was also provide habilitation services for a consumer.

I left the teaching field in [redacted], when I gave birth to my son. My son was born a happy baby. By age [redacted] he was diagnosed with asd level 3, sleep apnea both neurological and blockage, global delay, sensory processing delays, non verbal, hyper mobility and suspected ehlers danlos (he isn't old enough to be tested for it). Anyhow, we quickly joined aziep and we were assessed and assigned speech and occupational therapy.

At this time we were also awarded 600 hours of respite. That was in [redacted]. None of those hours have ever been used. Reasoning no providers available.

When my son turned [redacted] we were transferred to ddd applied to altcs and we were approved. When we were assessed for habilitation I was so excited! I thought this will be easy, so I thought. I never had a problem finding clients to work for I shouldn't have a hard time finding a provider for my son. Boy was I wrong. I searched for a few month prior to us being accepted into altcs with no avail.

I continued my search and still do. Finding a provider is like finding a unicorn, and I believe it. I have been that unicorn for many families. But that is it, a good consistent provider is like a unicorn. They are out there but so hard to find. And if you do find that diamond in the rough can you really trust them?

Sadly feeling defeated, I became my sons provider. He deserves these services from someone that can be trusted and sees my son as more than a paycheck. That is me.

My son is currently [redacted] years old, he will be [redacted] in [redacted]. We have seen leaps and bounds since I started working with him on a daily basis in a habilitation environment. We are currently working on hygiene routines as our habilitation goals. Washing up in the tub, using the potty, brushing teeth, getting dressed. These are tasks that I don't not feel comfortable with a stranger doing. It's an invasion of our privacy, and I honestly don't trust anyone but myself, his dad and a few select family members bathing him or changing him.

Losing this habilitation program, would be devastating and disastrous. Thousands of children will lose services that will take months if ever to fill. As a parent, a former sped educator, and trained Hab provider we need this program. Our kids need this program. Their future depends on it. Don't take away something that is so successful. We are begging you.

Thank you for your time.

Devin Zuleski
[redacted]

---------- Forwarded message ---------
From: Cheryl Rawlings [redacted]
Date: Thursday, July 20, 2023 at 5:43:08 PM UTC-4
Subject: Parent provider feedback
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

As a parent of a child who receives DDD and ALTCS services I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility, and it has been extremely beneficial to our family and my child. I would like to share my personal experiences and feedback based on my review of the current proposal for a permanent Paid Parent Caregiver program.

Under the current proposal, the request of an ongoing program option which allows parents of disabled minors in Arizona to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies is not being met. Please consider updating the proposal based on the following questions, suggested solutions, and personal experiences.

Should Habilitation be included in the Paid Parent Caregiver Program?

We have heard the concerns about member isolation and lack of community involvement if parents continue as Paid Parent Caregivers facilitating their child's Habilitation services. Respectfully the parent caregiver community proposes the following solutions:

Examine available research and personal feedback statements from members and their families to evaluate the true potential impacts of social isolation and community involvement when parents of disabled children provide Habilitation services. The parent caregiver community's collective experience is that members who have parents facilitating their Attendant Care and Habilitation services have experienced greater member social engagement and community involvement over the last three years. Parent caregivers now have an increased ability to take their children to sporting team practices, community events, movie theaters, all ability parks, church activities and libraries. This is because parent providers can perform the appropriately trained and qualified supports in the correct time and location that is applicable to each member.

Implement precise guidelines to facilitate generalization for all Habilitation providers regardless of the DCW's familial status. Habilitation services are designed to have goals where data is collected to evaluate if those goals need to be changed, have been met, or need to be addressed differently. For a goal to be considered met, a member should be demonstrating that they are able to successfully meet that goal outside of the timeframe with a provider in one setting. This is referred to as generalization. The effective implementation of generalization with the pediatric IDD population would lessen, if not eliminate, any complications with adult transitional services. Under this model a program that includes parents as paid Habilitation providers would actually assist and improve in the success of adult transition. There are times when disabled children work successfully with different types of providers in clinics or schools, but the parents are not carrying the work over at home. This can happen for a variety of reasons. Having parents as Habilitation providers would help ensure the child's goals are congruent and carried over in the home and community setting. This will give the member a better chance of independence as they transition through different life stages. With generalization policies in place, Habilitation services being performed by parent providers will actually help facilitate successful transition into adulthood.

We know from provider agency data that "the top 3 issues regarding recruiting and retaining career non-family caregivers are schedules of the client members, interest in the position and finding qualified applicants." Most members have Habilitation goals and ADLs that are most appropriately delivered throughout the natural routine of their day. A parent provider is uniquely available in the morning, after school or in the evenings when each member is motivated and focused on the pertinent task. If a non-family provider is available their schedules typically allow them to work in longer time chunks that are not always the most ideal for the member and creates artificial goal or ADL practice. Continuity of care and greater member outcomes can be associated with consistently provided Habilitation care by parent providers who have the greatest ability to be flexible and available for their member children.

In my personal experience, I'm able to provide a consistent habilitation routine for my child with a busy schedule that manages school needs, goals, medical appointments, and therapy appointments. We work in our habilitation after school and then focus on her medical care. I'm not sure where we will find outside providers that are willing to work 2 hours at a time per day. Also,
several of my child's goals fit naturally into our home routine, such as cleaning up after herself. As parents were able to naturally fit in succession of these goals into our normal routine, which at mostly leads to the most success of the certain goals. Also, several of my child's goals are directly related to personal goals, such as toileting. As my child gets older, she will not be comfortable working with outside providers on these personal skills.

In terms of stable providers, I personally experienced years of in-home health providers with little stability. We had high turnover for my daughter's needs. We were not able to find a consistent provider who could thoroughly understand care for, and provide for my daughters changing needs due to their inconsistency. Prior to Covid, we experienced this for many years with several health providers coming in and out of our home. My child and our family are very tired of the disruption to our home environment.

Additionally, some of my daughter's primary goals are her therapy exercises. As her parents, we attend every therapy session with our daughter. We speak to the therapists, get direct feedback from them, and witness firsthand the types of exercise we should be working on at home. Outside providers do not do this. They are not in routine appointments with my child and they do not experience firsthand, the specific goals that my daughter should be working on. My child has very specific and special needs for speech therapy, feeding therapy and physical therapy. I am often known to take pages of notes during any one given therapy session. Because of these detailed tasks that we are asked to work on with her child, it is by far most beneficial for the parents to work on these habilitation goals with our children. We are directly in every therapy appointment, communicating with each uniquely specialized therapist, which is something no outside provider can do.

Should parent providers be limited to 40 hours a week of paid care per child?

We have heard the concerns of AHCCCS on why they want to limit parents to 40 hours a week under the Paid Parent Caregiver Program. The parent caregiver community would like to propose the following collaborative solution to create a win-win scenario:

Create a program provision that outlines an extraordinary circumstances clause and the application process that allows parents to provide over 40 hours of paid care per week of authorized and evaluated services per member. These extraordinary circumstances could include, but are not limited to:

The lack of a non-parent DCW being available in the last 3 months to fill the member's assessed hours that exceed 40 hours per week. Ongoing DCW searches should continue to be made by the member's agency to fill the assessed hours beyond 40 hours per week of Attendant Care and Habilitation.

The expressed desire made by a member for a parent caregiver to facilitate their assessed DCW hours so that their Article 9 rights are honored.

The profound disabilities and/or significant behaviors of a member where a non-family provider is not equipped to provide DCW support. This determination can be made through a stakeholder team approach, including but not limited to the member's, DDD Support Coordinator, DDD Nurse, DDD Supervisors, Behavioral Plan Experts, Parents / Guardians, Psychologist, or Medical Doctor.

Form equality between all Family Provider Programs by allowing all Direct Care Workers, regardless of familial relationship or member age, to provide up to 16 hours of paid care per day. This will allow for employee equality across the lifespan of the member and limit the potential anti-family provider rhetoric currently present within state policies and DDD Support Coordination culture. All evaluations of hours should be based on member needs regardless of who is providing the services to create uniform

implementation of all applicable HCBS services by the DCWs available to fulfill those hours.
The Family Support Program currently in this proposal addresses caregiver burnout. It is one of the available solutions to facilitate further community support within the disability and caregiver community that will provide greater access to non-profits facilitating counseling services, support groups and meet up activities.
Reevaluate Respite reimbursement rates to also address caregiver burnout. If Respite services are not available to the member or their family, parent burnout will continue to be an issue regardless of parents having the option of providing Attendant Care or Habilitation hours. With a comprehensive Paid Parent Caregiver Program in place non-family DCW providers will have greater flexibility to provide Respite services to these same families.

How should current evaluation protocols, training and practices be updated to facilitate equality for all members when accessing member needs?
AHCCCS has stated their intention to amend applicable policy, further suggested action on this topic includes:

Forming a committee of community and department stakeholders to amend and critique current DDD and AHCCCS policies and need assessment forms so that the most effective and efficient implementation of this permanent option is utilized moving forward.
Provide appropriately determined training and program implementation to DDD and ALTCS Support Coordinators so that Attendant Care and Habilitation hours are equitably evaluated based on the member's needs and to remove organizational bias of familial providers across the member's lifespan. Specifically investigate and determine appropriate DDD staffing needs and training for the members served in rural areas and those from minority backgrounds.
Create the option for private sector Support Coordination. Other states have this option within their Medicaid services, and this could be an additional feature in our DDD portfolio to allow for the member's needs to be best evaluated.

In conclusion, Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. By not allowing parents of minors to provide Habilitation and Attendant Care services or work over 40 hours a week most of the minor disabled community in Arizona will be underserved. A comprehensive Paid Parent Caregiver program validates the irreplaceable work that parents provide in their homes and communities.

Click here to connect with the Arizona parent led grassroot initiative leaders: www raisingvoicescoalition.com

Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves all DDD and ALTCS members in Arizona.

Thank you!
Cheryl Rawlings

---------- Forwarded message ---------
From: Amanda Marquez[redacted]
Date: Thursday, July 20, 2023 at 3:21:04 PM UTC-4
Subject: Parents as Paid Providers Feedback
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hi Director Heredia and Staff,

I appreciate all you are doing to implement the permanent Parent Provider Program but I feel it necessary to share my families experiences to help you understand just how important it is to include parent provided Habilitation in this program and to hopefully remove the 40 hour restriction.

My Autistic child has had services since he was 2 years old, he just turned 9 this year. We have been through about 4 Habilitation providers since that time because it is very hard to keep someone on for longer than 3 months and the rest of the time my son ends up on a waiting list without a provider at all due to the very real provider shortage. The providers that were sent to my home were subpar, inconsistent and for the most part unable to attend to my child's needs. Even when my child had a provider it was mandatory that I stay in the home with them and pretty much supervise them while they were supposed to be working with him. The providers were not able to work on his potty training goals or his bathing goals as my Autistic child would not allow them to get close to him during those private moments for weeks and would have a meltdown insisting for my help instead of theirs. So even on the rare occasion that a Habilitation provider was available to my child, I still had to do the work (unpaid) and that and the inconsistency of providers showing up and the inability to retain a provider for an extended period of time resulted in my inability to hold a steady job and provide for the family. By the time my child became comfortable enough with a provider to let them around his body they would quit within a month after that trust had been built.

The other issue I found is that when we were offered a Habilitation provider they were not a well suited match for my child's needs. My son is very active and is a runner as well, he needs to be watched 24/7 for safety purposes but some of the providers he was paired with were elderly, walking with a cane for support and unable to attend to his needs. One provider screamed at my son for jumping on the bed and almost falling into a dresser because she was unable to physically stand up from her chair to prevent him from hurting himself. Her screaming at him caused immediate trauma and he ran to me and clung to me until she left the house. I could not get him to stop crying for hours after she left. Another, Habilitation provider would call out sick multiple times a week and my son would have a meltdown everytime she didn't show up because he is aware of his Habilitation schedule and that lack of consistency was to much for him. She also would have mental health breakdowns in my home while providing services. She would randomly start crying in front of my child and he did not understand. He would think that she hated him but she would insist she just needed a mental health break. She only lasted a few weeks and of course I had to monitor her with my child because of her mental health breakdowns and I therefore could not work. Another Habilitation provider would come to the house and take multiple breaks (breaks are fine), but she would come back inside to work with my 4 year old child smelling like cigarettes and marijuana. I had to let her go and once again could not work. The next provider sent our way 3 years later (we were on a waiting list with vendor calls going out after each DDD meeting without any help or supports) was the same elderly woman who screamed at my child and could not assist him years prior so we of course had to turn her away for our child's safety. We remained on a waiting list for a Habilitation provider after that and never received one. I was uninformed regarding the Covid Parental Paid Provider Program and did not start utilizing that service until about 2 months ago.My child was still on a waiting list up until that time and since I have become his paid provider I have been able to dedicate my time to his Habilitation goals and we have made progress. It is my hope that we can continue making that progress without unneeded interruption. Without Habilitation in the Permanent Parent Paid Provider Program my son will once again regress as I have to scramble to take care of his needs while simultaneously working from home. This does not lessen parental burnout, removing Habilitation increases burnout in everyway. I will have to try to work from home while simultaneously caring for my child and hoping he doesn't have a meltdown while I'm on the phone with clients, my time is directed away from him so that I may financially provide for his needs and I cannot rely on an external Habilitation worker to show up consistently or even be able to handle my child or successfully work on his goals.

Another point I would like to bring up is that my child's Habilitation goals are not focused on social skills, they are solely focused on life function goals such as independent dressing, bathing, feeding and toileting goals. These goals are imperative as he needs to be able to achieve them to function in society which will one day increase his opportunities to socialize independently as an adult without relying on a provider. My child tries to understand what we have taught him in regards to stranger danger and appropriate touching. We have taught him that only Mommy or Daddy need be present when he is working on goals that render him vulnerable as a child. We have taught him this because we did not have a consistent provider and we have been working on these goals as a family all along. So now he has the mindset that no strangers are allowed to help him in the bathroom, the bath or with dressing. This is actually an amazing thing for him to know as it prevents him from being hurt by a stranger in any situation that would allow for that. Having an external provider come in would confuse his understanding of stranger danger and once again increase his vulnerability as a Special Needs Child. Not only that but it is very unlikely that he will allow a stranger to help him in these moments after having learned about Stranger Danger because his mind and thinking is very rigid and he does not understand that an external Habilitation provider is an exception to that rule. He is very keen on his privacy and as I stated before will only allow a parent to help him in these moments and I honestly as a parent can't argue that with him as it's his body and should most definitely be his choice. Please do not remove Parental Provided Habilitation for this reason.

I know one of the main reasons you are wanting to exclude Habilitation is that you are concerned about socialization but if we can not work on these lifeskill Habilitation goals first it well severely limit the amount of socialization he gets to experience in the present and in the future. There are many activities/schools etc that require a child to be fully potty trained or they cannot participate. Please understand that even the Habilitation goals that may not seem oriented towards social skills in this moment will help our children to achieve them in the future.

The hardship that removing Habilitation will place on parents and families such as mine is simple to understand in that our children will reject outside supports for personal care, hygiene and toileting goals and the progress the children have made and will continue to make with their parents will be diminished as parents have to scramble to find "consistent", "trustworthy" and "reliable" outside supports. Parents will have to focus their attentions on finding a source of income to replace the income they were receiving as providers and outside jobs require time away from the children who need their supports the most. Please don't do this to our kids. They will regress and parents will be burdened with not only burnout but extreme amounts of stress. Even if "external" Habilitation providers are brought in the parents will have to monitor them unpaid and it doesn't make sense.

If a child's Habilitation goals are focused on independence in self care your argument for socializing is not relevant as these goals are not meant to be achieved in a social situation and should be as private as possible for the mental health of both the children and the parents. These goals are just as important, if not as important as socialization goals and it feels as though you are completely disregarding the vulnerable children who have these specific self care goals for Habilitation. Parents are the best candidates to work on these goals with their Autistic children to ensure an understanding of body autonomy and stranger danger to prevent these kids from becoming familiar with the presence of a strange adult in the room with them, touching them in their most private areas. In a sense allowing strangers to assist our kids in these moments is a form of grooming that gets them comfortable with any adult who may claim that they are trustworthy or have permission to "touch" or kids. We are basically telling our kids that it is okay in special circumstances to allow strangers to touch them and that is something most of us as parents are not willing to allow in order to keep our children safe from predators. Please understand this and add Habilitation to this proposal to further ensure and protect the safety of our most vulnerable population.

I want to tell you of a real life scenario that occurred after my son had an "external" Habilitation provider. We decided to take him to the Great Wolf Lodge and he had become accustomed/comfortable with going to the bathroom around "strangers" so he pulled his pants down in front of everyone at the theme park as he prepared himself to go to the bathroom. He didn't think twice about it because he was used to doing this with his provider and also stand in providers. He did not understand the difference and he cried profusely when we tried to explain it to him because on one hand he was being taught it was okay with "HAB" providers but he didn't realize that it wasn't okay with just anyone. This is an example of how not allowing these children privacy sets them up for future issues and even problems down the line with the law (indecent exposure). All he wanted to do was go to the bathroom and he had been shown that it was okay around strangers. It is not okay for this very reason.

I want to tell you a real life story that has to do with the impact of inconsistent "external" Habilitation providers. My son had a provider when he was 3 that he had grown to love over the course of a few months. She could not handle the stress of the job and my child's meltdowns and so she decided to quit one day without notice and without a goodbye. My son waited for her to come to the home at the scheduled time for weeks and everytime she didn't arrive he would cry. I had to lie to him and tell him that she moved away to Montana to be with her family. He still cries over her 6 years later and asks me to book a flight to Montana to go visit her. He does not have the comprehension skills to understand this situation and so it still causes meltdowns 6 years later. Consistency is so important and choosing to offer incentives to college students to become HAB providers only makes this problem worse. It ensures that the providers will be temporary, that our special needs kiddos will develop a bond with them and then be let down over and over again. This is not a solution for the Autistic population that requires consistency to ensure that there is no regression. In fact this option all but ensures consistent trauma for Autistic children and the parents will be the ones who have to help them recover from trauma time and time again. This does not reduce parent burnout it increases it ten fold and many parents may forgo services all together to prevent repeatedly traumatizing their children. Parents being forced to choose between traumatizing their kids or electing for services should not be the proposed solution. Please hear the voices of parents with Autistic children as we have walked these difficult roads and know what is best for our kids. There is no provider more consistent, more loving and more motivated to see a child succeed than a Parent Provider.

I also wanted to touch base on the imposed 40 hour restriction. I will start with the assessment for needs performed by the Support Coordinator. In our situation over the years and with multiple Support Coordinators our child's assessment had never been based solely on need but instead reframed by the amount of hours the Support Coordinator usually can get approved by a Supervisor. I will use our last meeting as an example. My child was assessed with needs that were over 50 hours but as the Support Coordinator put it she needed to shave some of those hours off or they would most likely not be approved. With ATC she asked if I would like to remove one of the mealtimes and reduce laundering hours for my child who has accidents multiple times a day. She asked me to remove several important Habilitation goals to keep the hours under 25. She said this was common practice to make sure hours would be approved. I didn't think to argue it as this had been my experience with all Support Coordinators prior. So to be clear in no way were the actual needs of my child taken into consideration, rather, the hours that would be typically approved were granted. I just want to reiterate that if this process were based on my child's needs he would have many more hours and much more opportunity for success. I feel this assessment process needs to be looked at so the needs of each child are accommodated appropriately.

Even with the above mentioned process and the "shaving" of hours my child was assessed at above 40 hours of combined ATC and HAB services. It is important to note that even with the "shaving" of hours I will be accommodating my child's needs albeit unpaid which again causes unnecessary burden and stress upon myself as a parent and increases burnout because I have to simultaneously run a business because I need that income if I can not be paid as a provider for my time. As, I said I am still going to give my child that time as he very much needs it and trusts me and relies on me to provide what he needs. At this point he will not allow a stranger to assist with anything that crosses his privacy boundaries which in my opinion is a good thing and a wonderful step towards future independence. So making it mandatory to seek an outside provider would not work in our situation or in the situation of many families like ours. So the burnout for the parent will increase despite your "best efforts" to prevent it by taking away HAB in this proposal. So many children have become accustomed to their parents as providers and now this proposal seeks to destroy that consistency, that trust that has been developed between parent and child and it will disrupt not only the childrens worlds but the parents as well creating stress for the children(clients) and the parents. If this proposal goes through as is, this is guaranteed to happen as parents seek to keep up the consistency with their children and also seek external employment to maintain the household. For many of us changing up what is already working isn't an option as we know better than anyone how that will affect our children and will simultaneously cause trauma and regression. The Autistic population requires consistency and the only thing I have seen over the years are consistent changes in providers and the lack of them and that is not what my child needs to thrive and become a successful adult. My goal as a parent is not to have my child depend on others his whole life it is to teach him to be as independent as possible. Taking away Parental Habilitation and limiting the hours our children need is not a solution that will work. Habilitation teaches our children skills and Independence where Attendant Care allows us to do things for them. We need Habilitation for those kids who are capable of achieving independence.

In regards to socialization. Socialization should not be the focus of Habilitation for all kids. All kids do not currently have socialization goals and their needs for socialization are met in other ways. Music therapy, Outschool Socialization classes with kids across the country, classes with peers without disabilities, social outings, the park, swimming, family outings, playdates etc... Parents strive to ensure their kids needs are met in all areas including socialization so it is not necessary to imply that Habilitation be the key to our childrens socialization goals when many times our kids Habilitation goals focus on life skills and self care goals which cannot be worked on in a social environment and must require privacy. Habilitation goals are not the same for all children across the board, their individual are needs are assessed. If you are wanting to bridge socialization gaps for Special Needs kiddos please have more events and meetups for our children throughout the Valley. Swimming meetups, bowling, Minecraft, gaming, sports, holiday events, dance parties all of these would be amazing to help the minor Special Needs population and it's not easy to find events like these for kids under 18. Please add more of these and I'm sure many families will take part with their kiddos and new relationships between children will foster social growth. Every Special Needs event for kids under 18 is packed and many times they sell out. Add more events for our kids and this will remedy the socialization worries that you may have but please don't use HAB, our childrens needed services to attempt to satisfy socialization goals when many of our children's Habilitation goals are privacy/body based.

I ask you to consider what I have written as I know so many families who have the same issues as mine. Please consider our stories and understand the needs of our children by adjusting the proposal to include Parent Provided Habilitation and by allowing parents to work the hours allotted to our children. I promise you we love our kids and will work with them with or without pay but with pay you are guaranteed to relieve burnout as we won't also have to juggle side jobs simultaneously (that is burnout, I assure you but for my child I will keep going).

I hope that to ensure that parents don't experience "caregiver burnout" free counseling services could be put in place. Self Care workshops for caregivers can be implemented and external providers could still be provided by agencies on an as needed basis. The one thing that I find really helps caregiver burnout is already in place and that is respite. Please try to find more respite providers as we haven't been able to find one a reliable one in over 2 years.

Thank you and Blessings to you and all the families and kiddos,
Amanda Marquez

---------- Forwarded message ---------
From: Katie Morgan [redacted]
Date: Thursday, July 20, 2023 at 1:39:57 PM UTC-4
Subject: Continuing Parents as Paid Caregivers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To Whom It May Concern:

I am writing in support of continuing the Parents as Paid Caregiver Program under AHCCCS. This program has been an incredible opportunity for my family and many others whom I have met and worked with. Parents of special needs kids are already providing these services and the opportunity to be paid and to help offset some of the financial burden of having a child with special needs has been so wonderful.

My understanding is that it is also qualifying more people to provide these services for others, as more parents become certified and willing to provide the care to others. This can only be a benefit to the program!

Please consider making this program permanent!

---------- Forwarded message ---------
From: Shannon Zwible [redacted]
Date: Thursday, July 20, 2023 at 1:39:40 PM UTC-4
Subject: Habilitation (parent providers survey)
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To whom it may concern:

In response to the possible end of paid parent providers for habilitation services the following questions were asked:

How many parent providers of minor members provide Habilitation services at your agency?
I provide habilitation services for two children (my own) aged 7 and 9.

What is the total number of weekly Habilitation hours that parent providers of minors are currently providing?

A total of 50 hours per week.
1 child is assessed at 30 hours of need and the other is assessed at 20 hours of need.

Prior to the pandemic there were no providers accessible for these services as we need them in the early morning and evenings on weekdays and then on weekends. There are VERY few people willing to work with special needs children at all, let alone outside of the normal work week. It is impossible for the DDD to contract and train enough qualified individuals to cover all of these hours for all of these children by Nov 2023. Please please reconsider keeping parents as paid providers. We have made so much progress since this service has been made available to us.

Shannon-Lee Zwible
[redacted]

Sent from my Verizon, Samsung Galaxy smartphone
Get [Outlook for Android]

---------- Forwarded message ---------
From: Susan Kennard [redacted]
Date: Thursday, July 20, 2023 at 12:41:06 PM UTC-4
Subject: Fwd: Questions for AHCCCS Community Forum
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Submitting for inclusion.

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Susan Kennard

Administrator

Office of Individual and Family Affairs

Division of Community Advocacy and Intergovernmental Relations (DCAIR)

801 E. Jefferson

Phoenix, AZ 85034

MD9000

[redacted]

[redacted]

[redacted]

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---------- Forwarded message ---------
From: **Jessi** [redacted]
Date: Fri, Jul 14, 2023 at 8:52 PM
Subject: Re: Questions for AHCCCS Community Forum
To: Susan Kennard [redacted]

Hello Susan,
Yes, please submit my email. Thank you for doing this and taking the time to respond.

Best Regards,

Jessica

On Friday, July 14, 2023 at 08:30:06 PM MST, Susan Kennard [redacted] wrote:

Hi Jessi,

Thanks for taking time to connect with me on this important topic. There is a lot of information in our amendment request. You can find it [here](#). In this document, it also shares upcoming public forums, so you can have an opportunity to ask questions as well as submit your comments on our proposal.

I hope you will be able to attend one of the forums.

Below is the information for submitting public comments:

The public will have the opportunity to review and submit comments on the proposal at the public meetings and in writing via e-mail to [redacted] or mail to:

[redacted]
Phoenix, AZ 85034
Public comments will be accepted through August 21, 2023.

If you would like, I am happy to submit the email you sent me to the public comments email.

Please let me know if you would like me to do that.

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Susan Kennard

Administrator

Office of Individual and Family Affairs

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Phoenix, AZ 85034

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On Mon, Jul 10, 2023 at 9:41 PM Jessi [redacted] wrote:

> Good evening,
>
> I was wondering how AHCCCS proposes to address the caregiver crisis if they aren't going to allow parents to provide
> habilitation services? Currently, parents are able to provide habilitation services which has helped members, families, and agencies who aren't able to find caregivers. If this service is taken away, I am wondering how AHCCCS is going to address this issue of lack of support, progress on independence, and ultimately regression of goals. I have heard from many parents on social media that they are waiting up to or more than a year to find respite providers. Respite is a break, but habilitation is to help our members attain, keep or improve skills and functioning for daily living. Our members deserve someone who is consistent, reliable, knowledgeable of their needs and how to address them so they may see growth and success. Parent Paid Providers for attendant care and habilitation services are vital for this growth to happen.
>
> I also would like to know if AHCCCS plans to create a plan to train and maintain supervision of frontline DDD and ALTCS staff as they implement the paid parent program permanently? Language in this program policy should clarify that while non-family DCW providers are an option, Paid Parent Caregivers are also an equally suitable option. This permanent program option should be about which provider meets the needs of the member in the most efficient and safe way possible. Families across the state, especially those in rural areas and those from minority backgrounds, have experienced discrimination by state employees regarding this flexibility for a variety of reasons. An explicit explanation on how institutional change through training and monitoring of staff by AHCCCS and DDD leadership regarding this permanent program implementation would be very impactful in rebuilding those family, member, and Support Coordinator relationships.
>
> Thank you for your time and consideration on these issues.
>
> Best Regards,
>
> Jessica

---------- Forwarded message ---------
From: Ashia Taylor [redacted]
Date: Thursday, July 20, 2023 at 12:08:56 PM UTC-4
Subject: Regarding changes - parent providers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Good afternoon,
My name is Ashia. I am a proud mother of a 12 year-old daughter with developmental delays and a vision impairment. We are in [redacted] area. My daughter was diagnosed at early intervention age of 3. She has Jhoubert's syndrome. Her motor skills are delayed and she is unable to walk on her own. She requires continuous care and supervision. My daughter receives various services such as speech therapy, occupational therapy, and physical therapy. She has attendant care, habilitation and respite hours each week.
I am sending this email to share how much being a parent caregiver provider has meant to me and my daughter's well being.
I am a single mother, and primary parent, divorced since 2021. It has been a challenging time in my life raising my daughter, but I wouldn't take any of it back. I have worked as a behavioral health professional, and even then at times was difficult managing her care and running the household when working. During COVID I began to home school my daughter. When I became a parent provider she was thriving, better attaining her goals, and academically progressing. I had less stress of dealing with constant turnover of outside providers , and also the challenge of being in Pinal County area where it is difficult to find providers. I know that becoming a parent provider is proven to make all the world of difference in a child's life! Furthermore, I feel safer and moren stable now, because the income from being a provider has helped us tremendously! I have less stress and my daughter is happier!
I just wished that the HAB wouldn't be taken away. My daughter gets out in the community, and I have made sure we go places where she can be social, as well as gain her daily living skills. She takes swimming lessons, we go to ball games, out to eat, attend church functions and out to parks. I am devastated that I would have to have another strange person coming into my home just for HAB. Her father and I both are very cautious of trusting people with our now pre-teen daughter! I am already concerned and FEARFUL!
I am hoping that the powers that be will understand the significant impact of taking HAB hours away from parents will be!
I am asking to please allow parents to continue providing HAB and ATC services!. I would

also recommend that the Spoke choice app be allowable for us to log hours OUTSIDE the home in order to be able to do the HAB in the community, which seems to be a good option.

I appreciate your time in reading this email and I hope to see more good things happening to keep the parent provider program running and PERMANENT!

Thanks so much!

Blessings,

Ashia Taylor

---------- Forwarded message ---------
From: Susan Kennard [redacted]
Date: Thursday, July 20, 2023 at 11:12:08 AM UTC-4
Subject: Fwd: My son story and my corners
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

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Susan Kennard

Administrator

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---------- Forwarded message ---------
From: **Sarah Flick** [redacted]
Date: Wed, Jul 19, 2023 at 10:29 AM
Subject: Re: My son story and my corners
To: Susan Kennard [redacted]

My son did 3 years old non mobile. He as ATC put into pomace now. Will there be age limits up back into place? If so why?
He has hab I am the parent provider for him so i with him with my boyfriend at work he the only full time working parent. I work 2 pt time jobs events and weekends. So when not working i the one taking care of him. I looked into a medial based day care but they have a wait list of a year or more. He will only be going to pre-k at medial based school pert time in Aug. we have respit but I not allowed to work when they working with him. So why would you take away the hab support from a parent provider i under stand in about getting him ready for community but parents can do that as well by them out and working on community goals with their kidos. So this will meet the requirements that you're wanting for kido. Please consider this the Hab parent provider program allows parents to work their kidos goals while sending time and see how they grow instead seeing this from a direct care working but yet we do everything they do but it working better because we know why the kids do what they do and know how to hand the situation the same way if not better. If the Hab program was going to taking away then please consider adding a waver that will allow patients to be a provider has hab. Thank you

Sent from my iPhone

> On Jul 19, 2023, at 6:33 AM, Susan Kennard [redacted] wrote:

Good Morning Sarah,

I am sorry we were not able to get to your question yesterday. Please send me any questions you have, so I am able to assist you.

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Susan Kennard

Administrator

Office of Individual and Family Affairs

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On Tue, Jul 18, 2023 at 7:39 PM Sarah Flick [redacted] wrote:

> Susan,
> My hand was basically nearly most it not the either time towards the last hour of the meeting yet my corners were never heard nor was my question never asked I even commented in the private chat many time ask to talking after the person before was done. Nor was the concern bought up by Someone else. I understand we had short periods to talk afterwards i understand your time is important but so are my concerns and questions I would very much appreciate it you can get back to me so I can share my experience, tell you about my son Along with my concerns and questions that have. Please whenever you have free chance allow me to talk with you or even write you person letter to whoever gets this and can get back to me. Thank you and have great day.
> Sarah Flick
> Sent from my iPhone

---------- Forwarded message ---------
From: Susan Kennard [redacted]
Date: Thursday, July 20, 2023 at 9:21:00 AM UTC-4
Subject: Fwd: Parents as Paid Caregivers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Please include.

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Susan Kennard

Administrator

Office of Individual and Family Affairs

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---------- Forwarded message ---------
From: **Sherrine Hayward** [redacted]
Date: Wed, Jul 19, 2023 at 9:07 PM
Subject: Parents as Paid Caregivers
To: [redacted]

Dear Susan,

I am the mother of [redacted], a 26-year old young man with cerebral palsy, a seizure disorder, and cortical visual impairment. He is the oldest of my six children, and my husband and I are his full-time caregivers. He needs total care and is able to blink to answer yes, but the rest of his needs are completed by myself and my husband. As his younger siblings have gotten older, they have become certified to do respite and have been a tremendous help for our family. We appreciate that family members have been able to provide attendant care, respite and habilitation for him once he turned 18 years old. It would have been so incredibly helpful if we had been able to provide these services before he turned 18, though. I was so happy to hear that other family members with children under the age of 18 were able to become certified and were paid for their child's care during Covid. I am sad to hear of the upcoming changes that have been suggested.

First, our son needs more than 40 hours per week of care. He has always needed more than 40 hours of care per week. I was on the call yesterday and heard all of the comments and information that was presented. It is difficult to hear the things that were said. I understand that your concern is that families will be burnt out if they care for their child more than 40 hours each week but they care for them anyway. Being burnt out does not come from caring for our kids but from ALL of the hoops we have to continually jump through to get them the care they need. Burnout comes from not having enough money to care for them, the many doctor visits we have to attend, the supplies we have to fight for...the system. Being paid to care for our children is a gift. Further, when you take away a person's right to make that choice for themselves, you are taking away more of their freedom. As parents of children with disabilities, our choices are already completely limited. My husband is a school teacher. If we had had the ability to get paid for our son's care, I would not have been so incredibly stressed to find a provider in the first place. I was more burnt out before I had the opportunity to be his caregiver than I am now.

To have another person in our home is uncomfortable and difficult as they cannot provide the care that we can. I have trained so many young adults how to care for my son and most of them cannot do it. I had to stand by them every time they cared for him before he was 18 years old because they could not do it on their own. I had to remind them how to bathe him, lift him, wipe him, toilet him, g-tube feed him, put on his AFO's, wipe his eyes, wash his hair without getting soap in his eyes or water in his mouth so that he did not aspirate, make sure he did not fall, transfer him so as to not get a pressure sore, speak to him in a respectful way instead of ignoring him, ask him questions so that he can answer them appropriately with eye blinks, learn how to use his kangaroo pump, and a million other things. My own children have watched me for years do this and they are still learning how to do it appropriately. Yet, they know [redacted] and treat him as he is just like them. The challenge of a new provider is that it took me at least a month to teach them the basic skills and still many of them could not do it or quit. Finding a caregiver back then was difficult, but since he has turned 18, it has been impossible. There are just not enough providers. For this reason, my other children have become providers. Most families do not have this opportunity.

I also understand that another reason is to help families transition the care they give their children when the parents are elderly. There can be so many other systems in place to help with this. Why take away the hours when the children are young from the parents just to pay someone else? From the experience that I have had, caregivers that are family members and caregivers that are not still do the same things. Non-family members do not provide more social opportunities to children than their own family members. The same things need to be done! Social experiences can happen with respite providers or with church or school or even going to the grocery store. Full inclusion brings socialization, not the relationship of the person providing care for the child with special needs.

I also understand that the habilitation hours will be taken away. Habilitation is vital to these individual's growth! Who knows better how to do this than the family member? Nobody who has come into my home knows how to help my son with any of his habilitation needs; not one of them, and we had close to 20 providers before my son turned 18. I had to teach the providers many times how to do goals with my son and honestly, his own siblings have always known how to provide opportunities for my son to complete these goals in a very non-obtrusive way. I graduated as a Certified Therapeutic Recreation Specialist from ASU before I became a mom and habilitation goals are best completed when in a Least Restrictive Environment doing the things these kids normally do in their days. It does not happen with new people who sit down and make the kids work on goals. That is the least effective way to complete any goals.

Another thing that I have asked many times about that was not addressed in this meeting, but I feel should be addressed is the Clock In Clock Out requirement for family members. This is by far an extreme hardship in our family's lives. My son requires around the clock care and the last thing I think about is clocking out and clocking in. In the state of Arizona, this is not a requirement. DDD has the option to remove this requirement. Please take that into consideration. I cannot tell you how many times I have been changing my son's diaper or feeding him or bathing him, or when he has had a seizure, when my alarm has gone off to clock in or clock out. The stress that families are under is not something anyone can understand until you are in our shoes. I am not complaining. I absolutely love being a mother for all of my children. That is not the challenge. The challenge is the system of care for our children and young adults who are disabled. Everything we do for them is a fight. There is protocol, red tape, rules and so many restrictions that make it nearly impossible to keep our kids at home where they thrive and feel safe, loved and needed. Please, please take into consideration all that I am saying, I appreciate receiving income for my son. It has been the only way that we have survived. I once was told that I should not get paid for all of these hours because when did I expect to be a mom? That is a good question and it was so unkind at the same time. I am always a mom. Always. We all are. Yet, the care that these beautiful special needs children need is not that simple. Our "Mom" title is way more than that. We are moms first while being pediatricians, cardiologist, neurologists, urologists, physical therapists, speech and occupational therapists, nurses, dieticians, wound care doctors, specialists in fields we never imagined we would be. This is not simple. Our lives are complex. We are not fighting to get paid to stay home. We are asking to help us care for our own children. From the moment they were born, we have loved them more than anyone else. We can do it. We just need the support to do so. Please give us the opportunity to decide for ourselves how we would like our children to be raised,

Again, I thank you for taking the time to read this email. I know it is lengthy. Our kids truly do matter. They are so often overlooked but they have voices. I believe most of them would want to be cared for by their own parents more than anyone else. Please help us parents do that. I would really like to have a conversation about this. Please call me anytime.

Thank you,
Sherrine Hayward
[redacted]

---------- Forwarded message ---------
From: Stephanie Armijo [redacted]
Date: Wednesday, July 19, 2023 at 10:36:52 PM UTC-4
Subject: AHCCCS and 1115 Waiver Team feedback
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

As a parent of a disabled child who receives DDD and ALTCS services I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility, and it has been extremely beneficial to our family and my child. I would like to share my personal experiences and feedback based on my review of the current proposal for a permanent Paid Parent Caregiver program.

Under the current proposal, the request of an ongoing program option which allows parents of disabled minors in Arizona to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies is not being met. Please consider updating the proposal based on the following questions, suggested solutions, and personal experiences. **I will include my own personal testimony towards the end.**

Should Habilitation be included in the Paid Parent Caregiver Program?
We have heard the concerns about member isolation and lack of community involvement if parents continue as Paid Parent Caregivers facilitating their child's Habilitation services. Respectfully the parent caregiver community proposes the following solutions:

1. Examine available research and personal feedback statements from members and their families to evaluate the true potential impacts of social isolation and community involvement when parents of disabled children provide Habilitation services. The parent caregiver community's collective experience is that members who have parents facilitating their Attendant Care and Habilitation services have experienced greater member social engagement and community involvement over the last three years. Parent caregivers now have an increased ability to take their children to sporting team practices, community events, movie theaters, all ability parks, church activities and libraries. This is because parent providers can perform the appropriately trained and qualified supports in the correct time and location that is applicable to each member.
2. Implement precise guidelines to facilitate generalization for all Habilitation providers regardless of the DCW's familial status. Habilitation services are designed to have goals where data is collected to evaluate if those goals need to be changed, have been met, or need to be addressed differently. For a goal to be considered met, a member should be demonstrating that they are able to successfully meet that goal outside of the timeframe with a provider in one setting. This is referred to as generalization. The effective implementation of generalization with the pediatric IDD population would lessen, if not eliminate, any complications with adult transitional services. Under this model a program that includes parents as paid Habilitation providers would actually assist and improve in the success of adult transition. There are times when disabled children work

successfully with different types of providers in clinics or schools, but the parents are not carrying the work over at home. This can happen for a variety of reasons. Having parents as Habilitation providers would help ensure the child's goals are congruent and carried over in the home and community setting. This will give the member a better chance of independence as they transition through different life stages. With generalization policies in place, Habilitation services being performed by parent providers will actually help facilitate successful transition into adulthood.

3. We know from provider agency data that "the top 3 issues regarding recruiting and retaining career non-family caregivers are schedules of the client members, interest in the position and finding qualified applicants." Most members have Habilitation goals and ADLs that are most appropriately delivered throughout the natural routine of their day. A parent provider is uniquely available in the morning, after school or in the evenings when each member is motivated and focused on the pertinent task. If a non-family provider is available their schedules typically allow them to work in longer time chunks that are not always the most ideal for the member and creates artificial goal or ADL practice. Continuity of care and greater member outcomes can be associated with consistently provided Habilitation care by parent providers who have the greatest ability to be flexible and available for their member children.

Should parent providers be limited to 40 hours a week of paid care per child?
We have heard the concerns of AHCCCS on why they want to limit parents to 40 hours a week under the Paid Parent Caregiver Program. The parent caregiver community would like to propose the following collaborative solution to create a win-win scenario:

1. Create a program provision that outlines an extraordinary circumstances clause and the application process that allows parents to provide over 40 hours of paid care per week of authorized and evaluated services per member. These extraordinary circumstances could include, but are not limited to:
    a. The lack of a non-parent DCW being available in the last 3 months to fill the member's assessed hours that exceed 40 hours per week. Ongoing DCW searches should continue to be made by the member's agency to fill the assessed hours beyond 40 hours per week of Attendant Care and Habilitation.
    b. The expressed desire made by a member for a parent caregiver to facilitate their assessed DCW hours so that their Article 9 rights are honored.
    c. The profound disabilities and/or significant behaviors of a member where a non-family provider is not equipped to provide DCW support. This determination can be made through a stakeholder team approach, including but not limited to the member's, DDD Support Coordinator, DDD Nurse, DDD Supervisors, Behavioral Plan Experts, Parents / Guardians, Psychologist, or Medical Doctor.
2. Form equality between all Family Provider Programs by allowing all Direct Care Workers, regardless of familial relationship or member age, to provide up to 16 hours of paid care per day. This will allow for employee equality across the lifespan of the member and limit the potential anti-family provider rhetoric currently present within state policies and DDD Support Coordination culture. All evaluations of hours should be based on member needs regardless of who is providing the services to create uniform implementation of all applicable HCBS services by the DCWs available to fulfill those hours.
3. The Family Support Program currently in this proposal addresses caregiver burnout. It is one of the available solutions to facilitate further community support within the disability and caregiver community that will provide greater access to non-profits facilitating counseling services, support groups and meet up activities.
4. Reevaluate Respite reimbursement rates to also address caregiver burnout. If Respite services are not available to the member or their family, parent burnout will continue to be an issue regardless of parents having the option of providing Attendant Care or Habilitation hours. With a comprehensive Paid Parent Caregiver Program in place non-family DCW providers will have greater flexibility to provide Respite services to these same families.

How should current evaluation protocols, training and practices be updated to facilitate equality for all members when accessing member needs?
AHCCCS has stated their intention to amend applicable policy, further suggested action on this topic includes:

1. Forming a committee of community and department stakeholders to amend and critique current

DDD and AHCCCS policies and need assessment forms so that the most effective and efficient implementation of this permanent option is utilized moving forward.

2. Provide appropriately determined training and program implementation to DDD and ALTCS Support Coordinators so that Attendant Care and Habilitation hours are equitably evaluated based on the member's needs and to remove organizational bias of familial providers across the member's lifespan. Specifically investigate and determine appropriate DDD staffing needs and training for the members served in rural areas and those from minority backgrounds.
3. Create the option for private sector Support Coordination. Other states have this option within their Medicaid services, and this could be an additional feature in our DDD portfolio to allow for the member's needs to be best evaluated.

In conclusion, Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. By not allowing parents of minors to provide Habilitation and Attendant Care services or work over 40 hours a week most of the minor disabled community in Arizona will be underserved. A comprehensive Paid Parent Caregiver program validates the irreplaceable work that parents provide in their homes and communities.

Click here to connect with the Arizona parent led grassroot initiative leaders:
www.raisingvoicescoalition.com

My families story started when I was just 6 weeks pregnant. I started gushing blood and was rushed to the hospital fully expecting to learn I just lost my child. But to my shock I had not. I was diagnosed with a threatened miscarriage and sent home. One week went by and it happened again. Then it started becoming almost daily. I had to live in complete fear every single day that I was going to lose my child. At 20 weeks I was hospitalized and received multiple iron infusions and blood transfusions. I ended up having an emergency c section at 23 weeks 6 days in a hospital that does not deliver before 27 weeks. I had been in and out of the hospital more than 15 times. I had a placental abruption, chorioamnionitis, my daughters cord was shredded, and I was bleeding out. My daughter was a fighter from the very beginning. She was born at 1 lb 5 oz and is the youngest surviving baby ever to be born there. She had to be transferred immediately to a different hospital with the highest level NICU. She had a long 98 day stay where we almost lost her multiple times. Watching as doctors manually pump your child's chest while intubating is the most terrifying experience. As she started growing we realized there was more going on with her medically. She was diagnosed chronic lung disease, autistic, sensory processing disorder, global developmental delay, macrocephaly, accommodative esotropia, farsightedness, brachycephaly, reflux, dermatographia, possible absence seizures, she has an extremely rare double chromosome deletion and will be followed by genetics her entire life, she has muscle tone issues and falls a lot (we're in the process still of diagnosing Cerebral Palsy), BRCA2, and eczema. And this does not include anything from the NICU. My daughter, [redacted], has had a brain MRI that did show brain damage.

Due to our daughters extensive medical needs I had to give up my career and we were not able to make ends meet. Every month was a struggle just to pay the bills let alone buy food. My husband had to take a job in remote Alaska that keeps him up there for 3-6 months at a time. After that he comes home for 6 weeks before going back up. He works 7 days a week 12 hours a day, at minimum. We are originally from Washington state. Sadly, services there had a 2+ year waitlist. We knew we had to do something that would put our child in a better place to succeed. That is what prompted our move to Arizona. I was blown away by the services available. I had so much hope that we would set up [redacted] for her future. We moved here September 2020. It took a few months to get everything going. She finally received DDD and ALTCS. We had a very sweet support coordinator but never once did she even ask about HAB/ATC for our non speaking very high support needs child. After about one year with this coordinator I learned from other parents that the state of Arizona was allowing DDD/ALTCS to pay parents to be providers. I requested evaluations for our daughter but our SC was moving out of state and did not give us any heads up. We were sent to a few different SC's in the meantime who were just trying to fill a temporary position. Finally, we did get a permanent SC who did my daughters evaluations. I will admit during this time of waiting and frustration I learned from other parents how hard many SC's fight against parents being the paid providers. I brought up doing it once to our SC and she gave incorrect information about "natural supports" and thankfully I had learned DDD's policy and was able to give that to her. She said she would look into it but ignored it. My daughter, who at the time had barely one word communication, not potty trained, elopement risk, could not feed herself, has balance issues and falls a lot, many meltdowns, massive sensory overload, I can go on and on, was given 10 hours of HAB a week and I was told no ATC at first. When I started to question this I was getting a lot of pushback. I still do not understand why. I have a severely disabled high support needs child who was basically told was not important enough to be awarded the services she qualifies for. It took me continuing to talk for her SC to question one thing I said about how I have had to put my own health on the back burner that she said my daughter would be allowed 15 ATC hours a week. I have only recently learned this is an incredibly inaccurate way to assess for these needs. Please, understand this is a huge root of frustration for us as parents of children receiving DDD/ALTCS services. No two SC's have the same information. Many, like mine, seem to be biased against parents being paid providers, despite the state saying it has been okay. I have had to hide that I am my child's provider despite my child thriving with me providing these services.

Please listen to us parents when we explain how important providing our children HAB has been. I'll start with my daughters positives. I have been able to work on her goals with her and now have her potty trained at age 6.5 and she is still going strong at 7. She now will not only let me brush her teeth but now is attempting to do it on her own, and will ask for it now. I have been able to teach her how to say her first name when asked, before this she was unable to. We are at a point where we need to adjust her goals and start working on more personal care items. My daughter has become a much happier child overall as well. Much less meltdowns as well. Her health has been the best too. She does get sick a lot during the school year but over this summer has not been sick once. Reducing the outside world in our home has been a huge help for her. I would think a healthier child is a happier child who is more able to learn and participate.

For our family it has provided a small financial relief that allowed me to get a reliable inexpensive vehicle, that benefits our child as I now have something safe to take her to school in, to doctors appointments, as well as any other daily function. It allowed me the funds to provide her with a Christmas last year. I was not able to afford a tree but I was able to get her a few presents. It has given me a little extra that provided her with a hanging sensory pod, balancing stepping stones, sensory bath toys, better food options with her sensory processing disorder, as well as a second Amazon Fire Tablet that has been INSANELY helpful towards helping her learn to talk, count, and self regulate that helps her overall mental and physical wellbeing. It has given me, as not only a mother but a woman, a feeling of pride. Knowing I have been able to contribute not only towards my disabled child's overall care but to my families financial state. It allowed us a little extra that kept my husband home for 7 weeks last time instead of the usual 6 weeks. Our daughter and I miss our father and husband exponentially. If you take away HAB from us parents it will have detrimental effects on not only our families but our children. Before moving to Arizona I was very isolated with our daughter. I did not have any extra funds to provide her with the extra support needs she has. I am now able to do that. She has completely blossomed during this time. It gives me specific goals to work on that are working. It also keeps more eyes on our children with the every 3 month reviews. Thankfully my child is very well cared for, but I have heard horror stories of others that did have to intervene. Imagine if even one child was being abused or neglected that could have been caught in time to make a difference if you take this away. There are so many positives to continuing HAB for parents.

You stated isolation as being one reason you do not want parents to provide this. Please understand our children are not at home alone with us 24/7. My daughter attends school where she spends her days in multiple classes as well as therapies. She has a general education classroom, special education classroom, library, music, physical education, physical therapy, occupational therapy, speech therapy, and a reading group. That is only her days during the hours of 7:45 am to 2:00 pm. After that she has multiple doctor appointments, I am in the process of finding outpatient PT and OT, as well as accompanying me on daily tasks. I would like to start adding in more goals that also mean we have to work on them in public. If you remove parents from this we will have to take a stranger with us, and pay for them, to do the activities we need to work on. How will that help us at all if now we are not being compensated but are also paying out more? My daughter has learned to help me put items into the shopping cart at the grocery store, we are still working on her not eloping while out in public, but she is making improvements.

Please do not take this away from us. I have watched my child face death and come back. Yes, parent burnout is real. But you know what else is... worrying about bills as well as finding a provider who will even show up. Alleviating those two stresses significantly reduces parent burnout. We are allowed a little peace of mind that keeps us present mentally with our children. I am on the verge of starting very personal care goals with my child. Goals that I do not trust a stranger to provide. My autistic daughter thrives on consistency and routine. When our first vendor call was placed I received no calls for weeks and then finally did get one, but she did not speak English, which is our spoken language. How am I supposed to trust a stranger, who has the EXACT SAME TRAINING I DO, with my severely disabled child? A child that cannot tell me if something is inappropriate or if she is being mistreated. How would you do it? One parent said she asked her SC how she was supposed to do this and was told she would need to supervise. How is that benefitting anyone? So, instead of paying us to provide the best care possible for our children we have to spend that same amount of time, unpaid and stressing over bills, as well as watching a stranger to do the same job, but worse? How is that okay? I am trying to not get emotional but it is hard. This is not just a "job" for us. It is our children's lives. We are working hard to set them up for success for the day that we are no longer here to help them. Why take away a proven tool and asset for our disabled children and families?

Also, reducing our timelines from September 2024 to now November 2023 to have this set in place is disgusting. Most of us could not get providers to even respond to our calls and if someone could they would not be consistent. How are all of us supposed to remedy this in 4 months time? How am I supposed to hand over my minimally verbal, medically fragile, innocent to a fault child to a stranger who has absolutely not enough training to provide intimate physical care goals without supervision? Please take all of this into consideration. Removing HAB from parents will not help anyone.

I literally beg of you to please provide all of your SC's an SOP (standard operating procedure) for their jobs. Please provide proper training so that every parent and child is treated the same. At this time it truly feels like you know there is a huge DCW shortage and are trying to save money by cutting HAB and capping ATC to 40 hours. You know how hard it is for families to fill these voids therefore know how much you will save in the long run. Imagine being a parent of a medically fragile, medically complex, miracle child and feeling like you're being looked down upon because you fight to get your child what they should be due while having given up a career. But instead hear a different story from every SC. Please talk to agencies. Find out how hard society will also be affected. More than just parents may lose their jobs.

Please help put our disabled children and our families in a better position for all of our futures.

Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves all DDD and ALTCS members in Arizona.

Thank you!
Stephanie Armijo
[redacted]

---------- Forwarded message ---------
From: Amanda Burgos (she/her) [redacted]
Date: Wednesday, July 19, 2023 at 10:07:47 PM UTC-4
Subject: parent input
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

As a parent of a child who receives DDD and ALTCS services I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility, and it has been extremely beneficial to our family and my child. I would like to share my personal experiences and feedback based on my review of the current proposal for a permanent Paid Parent Caregiver program.

My son is 14 years old with severe autism. He is profoundly disabled by his autism and is non-verbal. In addition, he is an incredibly large child, 6'6" and 300 lbs. He has not been able to return to school since the start of the pandemic in March 2020. Because of the parent provider program I have been able to stay home and care for him. This would be impossible if not for this program. We have never been able to have a caregiver assist us because he has significant behaviors and direct care workers are not trained to handle a child as large and disabled as my son, William.

Under the current proposal, the request of an ongoing program option which allows parents of disabled minors in Arizona to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies is not being met. Please consider updating the proposal based on the following questions, suggested solutions, and personal experiences.

Should Habilitation be included in the Paid Parent Caregiver Program?
We have heard the concerns about member isolation and lack of community involvement if parents continue as Paid Parent Caregivers facilitating their child's Habilitation services. Respectfully the parent caregiver community proposes the following solutions:

1. Examine available research and personal feedback statements from members and their families to evaluate the true potential impacts of social isolation and community involvement when parents of disabled children provide Habilitation services. The parent caregiver community's collective experience is that members who have parents facilitating their Attendant Care and Habilitation services have experienced greater member social engagement and community involvement over the last three years. Parent caregivers now have an increased ability to take their children to sporting team practices, community events, movie theaters, all ability parks, church activities and libraries. This is because parent providers can perform the appropriately trained and qualified supports in the correct time and location that is applicable to each member.

2. Implement precise guidelines to facilitate generalization for all Habilitation providers regardless of the DCW's familial status. Habilitation services are designed to have goals where data is collected to evaluate if those goals need to be changed, have been met, or need to be addressed differently. For a goal to be considered met, a member should be demonstrating that they are able to successfully meet that goal outside of the timeframe with a provider in one setting. This is referred to as generalization. The effective implementation of generalization with the pediatric IDD population would lessen, if not eliminate, any complications with adult transitional services. Under this model a program that includes parents as paid Habilitation providers would actually assist and improve in the success of adult transition. There are times when disabled children work successfully with different types of providers in clinics or schools, but the parents are not carrying the work over at home. This can happen for a variety of reasons. Having parents as Habilitation providers would help ensure the child's goals are congruent and carried over in the home and community setting. This will give the member a better chance of independence as they transition through different life stages. With generalization policies in place, Habilitation services being performed by parent providers will actually help facilitate successful transition into adulthood.

3. We know from provider agency data that "the top 3 issues regarding recruiting and retaining career non-family caregivers are schedules of the client members, interest in the position and finding qualified applicants." Most members have Habilitation goals and ADLs that are most appropriately delivered throughout the natural routine of their day. A parent provider is uniquely available in the morning, after school or in the evenings when each member is motivated and focused on the pertinent task. If a non-family provider is available their schedules typically allow them to work in longer time chunks that are not always the most ideal for the member and creates artificial goal or ADL practice. Continuity of care and greater member outcomes can be associated with consistently provided Habilitation care by parent providers who have the greatest ability to be flexible and available for their member children.

Should parent providers be limited to 40 hours a week of paid care per child?
We have heard the concerns of AHCCCS on why they want to limit parents to 40 hours a week under the Paid Parent Caregiver Program. The parent caregiver community would like to propose the following collaborative solution to create a win-win scenario:

1. Create a program provision that outlines an extraordinary circumstances clause and the application process that allows parents to provide over 40 hours of paid care per week of authorized and evaluated services per member. These extraordinary circumstances could include, but are not limited to:

    a. The lack of a non-parent DCW being available in the last 3 months to fill the member's assessed hours that exceed 40 hours per week. Ongoing DCW searches should continue to be made by the member's agency to fill the assessed hours beyond 40 hours per week of Attendant Care and Habilitation.

    b. The expressed desire made by a member for a parent caregiver to facilitate their assessed DCW hours so that their Article 9 rights are honored.

    c. The profound disabilities and/or significant behaviors of a member where a non-family provider is not equipped to provide DCW support. This determination can be made through a stakeholder team approach, including but not limited to the member's, DDD Support Coordinator, DDD Nurse, DDD Supervisors, Behavioral Plan Experts, Parents / Guardians, Psychologist, or Medical Doctor.

2.

Form equality between all Family Provider Programs by allowing all Direct Care Workers, regardless of familial relationship or member age, to provide up to 16 hours of paid care per day. This will allow for employee equality across the lifespan of the member and limit the potential anti-family provider rhetoric currently present within state policies and DDD Support Coordination culture. All evaluations of hours should be based on member needs regardless of who is providing the services to create uniform implementation of all applicable HCBS services by the DCWs available to fulfill those hours.

3. The Family Support Program currently in this proposal addresses caregiver burnout. It is one of the available solutions to facilitate further community support within the disability and caregiver community that will provide greater access to non-profits facilitating counseling services, support groups and meet up activities.

4. Reevaluate Respite reimbursement rates to also address caregiver burnout. If Respite services are not available to the member or their family, parent burnout will continue to be an issue regardless of parents having the option of providing Attendant Care or Habilitation hours. With a comprehensive Paid Parent Caregiver Program in place non-family DCW providers will have greater flexibility to provide Respite services to these same families.

How should current evaluation protocols, training and practices be updated to facilitate equality for all members when accessing member needs?
AHCCCS has stated their intention to amend applicable policy, further suggested action on this topic includes:

1. Forming a committee of community and department stakeholders to amend and critique current DDD and AHCCCS policies and need assessment forms so that the most effective and efficient implementation of this permanent option is utilized moving forward.

2. Provide appropriately determined training and program implementation to DDD and ALTCS Support Coordinators so that Attendant Care and Habilitation hours are equitably evaluated based on the member's needs and to remove organizational bias of familial providers across the member's lifespan. Specifically investigate and determine appropriate DDD staffing needs and training for the members served in rural areas and those from minority backgrounds.

3. Create the option for private sector Support Coordination. Other states have this option within their Medicaid services, and this could be an additional feature in our DDD portfolio to allow for the member's needs to be best evaluated.

In conclusion, Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. By not allowing parents of minors to provide Habilitation and Attendant Care services or work over 40 hours a week most of the minor disabled community in Arizona will be underserved. A comprehensive Paid Parent Caregiver program validates the irreplaceable work that parents provide in their homes and communities.

Click here to connect with the Arizona parent led grassroot initiative leaders:
www.raisingvoicescoalition.com

Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves all DDD and ALTCS members in Arizona.

Thank you!
Amanda Burgos

Tucson AZ
[redacted]

---------- Forwarded message ---------
From: Amellaly Martinez [redacted]
Date: Wednesday, July 19, 2023 at 9:27:19 PM UTC-4
Subject: Habilitation provider for son
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello,

I am a parent provider for my son.
I believe habilitation should be a program to stay permanently.
It's so difficult to find providers who are actually willing to do the job. Most of the providers that agency's hire are college students that just want a temporary job and that affects our kids. They establish a connection then they provider leaves, we need someone consistent and reliable and who better than the parent. No one knows the chil best than the parent. This program has helped so many children establish and accomplish their goals. Plus I would not feel comfortable with a stranger helping my child undress himself or even take a bath. This program has helped so many parents with being financially stable with that little help of income. Please reconsider this decision.

---------- Forwarded message ---------
From: ASHLEY BRAMBLE [redacted]
Date: Wednesday, July 19, 2023 at 8:30:28 PM UTC-4
Subject: 2023 Paid Parent caregiver Proposal
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

As a parent of a child who receives DDD and ALTCS services I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility, and it has been extremely beneficial to our family and my child. I would like to share my personal experiences and feedback based on my review of the current proposal for a permanent Paid Parent Caregiver program.

Under the current proposal, the request of an ongoing program option which allows parents of disabled minors in Arizona to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies is not being met. Please consider updating the proposal based on the following questions, suggested solutions, and personal experiences.

After yesterday's meeting, I find it extremely necessary to speak up. Ending HAB for parent providers of minors is a huge disservice to our children. Most of the goals that are set for HAB for my child and other children are goals that occur during the natural routine of the day and are of a personal nature, like toileting, bathing, and so forth. My child wouldn't by any means be comfortable with a stranger helping him to learn those things nor would I be. Not to mention to find someone who is available and willing to come to my home in the early morning and evenings to do those things is/was impossible.

Ending HAB for parents with minor children so quickly does not allow time for agencies or AHCCCS to find providers to service all the families that are currently receiving HAB services, which will leave many children without HAB altogether.

Also as a single parent I am solely responsible for my child. His transportation, taking him to appts, therapies before school and after school, and have been his main caregiver since he left the NICU. I have not been able to find an employer who will allow me the flexibility I require to make sure my son gets all his vast needs met and in a timely manner. This program has allowed me to feel a sense of relief and less stressed out about how I'm going to afford to pay rent and afford food. Taking away HAB would take away that sense of relief and security that I will be able to keep a roof over my head and my child's increasing my stress and burnout.

I'm able to be a better and more present parent and caregiver to my child knowing he is getting the best care possible by someone who knows him, understands his needs and conditions, and how to best help him without the fear of a provider just not showing up or cancelling or in more cases than not, not being able to find anyone to fill the position in general.

Taking away HAB will do more harm to these children. Our children are exceptional and deserve to have exceptions made to make sure they are able to thrive in their everyday life. The HAB goals that most families have for their minor children are goals a typical family with a typical child wouldn't have to do. My son is 6 and a typical 6 year old can feed himself, pick up a cup and get a drink themselves, walk to the bathroom and go potty on their own, can wash their hair and body without needing assistance; my 6 year old can not do those things on his own. Would I love it if my son didn't need these services, absolutely but that's not the hand we were dealt. He has several diagnoses that prevent him from being able to do things a typical child his age can do and wouldn't require a parents assistance with. Your reasons in the meeting yesterday are invalid due to the statements listed above and by many other parents who have made similar comments to your department.

In conclusion, Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. By not allowing parents of minors to provide Habilitation and Attendant Care services or work over 40 hours a week most of the minor disabled community in Arizona will be underserved. A comprehensive Paid Parent Caregiver program validates the irreplaceable work that parents provide in their homes and communities.

Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves all DDD and ALTCS members in Arizona.

Thank you!

Ashley Green

---------- Forwarded message ---------
From: Nicole Noonan [redacted]
Date: Wednesday, July 19, 2023 at 7:39:35 PM UTC-4
Subject: Paid Parent Caregiver Program
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

As a parent of a child who receives DDD and ALTCS services I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility, and it has been extremely beneficial to our family and my child. I would like to share my personal experiences and feedback based on my review of the current proposal for a permanent Paid Parent Caregiver program.

Providing HAB for my daughter who is 8 years old and autistic has truly been one of the best things for our family. Finding providers we trust not only with our child but in our home who are also dependable feels nearly impossible! We already have providers such as respite care, occupational therapy and speech therapy in our home working with our daughter all week. Being the HAB provider gives me, my husband and our daughter peace of mind and a sense of normalcy. Some of the HAB skills are very private and personal, our daughter is most comfortable learning and doing those things with me and I'd have to agree- those skills are safest with a parent. We are seeing so much progress with our daughter's HAB goals, it would be detrimental to lose that. No provider cares more about my daughter and her progress than I do. Please, this is so disheartening, keep the Paid Parent Caregiver program.

Under the current proposal, the request of an ongoing program option which allows parents of disabled minors in Arizona to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies is not being met. Please consider updating the proposal based on the following questions, suggested solutions, and personal experiences.

Should Habilitation be included in the Paid Parent Caregiver Program?
We have heard the concerns about member isolation and lack of community involvement if parents continue as Paid Parent Caregivers facilitating their child's Habilitation services. Respectfully the parent caregiver community proposes the following solutions:

- Examine available research and personal feedback statements from members and their families to evaluate the true potential impacts of social isolation and community involvement when parents of disabled children provide Habilitation services. The parent caregiver community's collective experience is that members who have parents facilitating their Attendant Care and Habilitation services have experienced greater member social engagement and community involvement over the last three years. Parent caregivers now have an increased ability to take their children to sporting team practices, community events, movie theaters, all ability parks, church activities and libraries. This is because parent providers can perform the appropriately trained and qualified supports in the correct time and location that is applicable to each member.
- Implement precise guidelines to facilitate generalization for all Habilitation providers regardless of the DCW's familial status. Habilitation services are designed to have goals where data is collected to evaluate if those goals need to be changed, have been met, or need to be addressed differently. For a goal to be considered met, a member should be demonstrating that they are able to successfully meet that goal outside of the timeframe with a provider in one setting. This is referred to as generalization. The effective implementation of generalization with the pediatric IDD population would lessen, if not eliminate, any complications with adult transitional services. Under this model a program that includes parents as paid Habilitation providers would actually assist and improve in the success of adult transition. There are times when disabled children work successfully with different types of providers in clinics or schools, but the parents are not carrying the work over at home. This can happen for a variety of reasons. Having parents as Habilitation providers would help ensure the child's goals are congruent and carried over in the home and community setting. This will give the member a better chance of independence as they transition through different life stages. With generalization policies in place, Habilitation services being performed by parent providers will actually help facilitate successful transition into adulthood.
- We know from provider agency data that "the top 3 issues regarding recruiting and retaining career non-family caregivers are schedules of the client members, interest in the position and finding qualified applicants." Most members have Habilitation goals and ADLs that are most appropriately delivered throughout the natural routine of their day. A parent provider is uniquely available in the morning, after school or in the evenings when each member is motivated and focused on the pertinent task. If a non-family provider is available their schedules typically allow

them to work in longer time chunks that are not always the most ideal for the member and creates artificial goal or ADL practice. Continuity of care and greater member outcomes can be associated with consistently provided Habilitation care by parent providers who have the greatest ability to be flexible and available for their member children.

Should parent providers be limited to 40 hours a week of paid care per child?
We have heard the concerns of AHCCCS on why they want to limit parents to 40 hours a week under the Paid Parent Caregiver Program. The parent caregiver community would like to propose the following collaborative solution to create a win-win scenario:

- Create a program provision that outlines an extraordinary circumstances clause and the application process that allows parents to provide over 40 hours of paid care per week of authorized and evaluated services per member. These extraordinary circumstances could include, but are not limited to:
- The lack of a non-parent DCW being available in the last 3 months to fill the member's assessed hours that exceed 40 hours per week. Ongoing DCW searches should continue to be made by the member's agency to fill the assessed hours beyond 40 hours per week of Attendant Care and Habilitation.
- The expressed desire made by a member for a parent caregiver to facilitate their assessed DCW hours so that their Article 9 rights are honored.
- The profound disabilities and/or significant behaviors of a member where a non-family provider is not equipped to provide DCW support. This determination can be made through a stakeholder team approach, including but not limited to the member's, DDD Support Coordinator, DDD Nurse, DDD Supervisors, Behavioral Plan Experts, Parents / Guardians, Psychologist, or Medical Doctor.
- Form equality between all Family Provider Programs by allowing all Direct Care Workers, regardless of familial relationship or member age, to provide up to 16 hours of paid care per day. This will allow for employee equality across the lifespan of the member and limit the potential anti-family provider rhetoric currently present within state policies and DDD Support Coordination culture. All evaluations of hours should be based on member needs regardless of who is providing the services to create uniform implementation of all applicable HCBS services by the DCWs available to fulfill those hours.
- The Family Support Program currently in this proposal addresses caregiver burnout. It is one of the available solutions to facilitate further community support within the disability and caregiver community that will provide greater access to non-profits facilitating counseling services, support groups and meet up activities.
- Reevaluate Respite reimbursement rates to also address caregiver burnout. If Respite services are not available to the member or their family, parent burnout will continue to be an issue regardless of parents having the option of providing Attendant Care or Habilitation hours. With a comprehensive Paid Parent Caregiver Program in place non-family DCW providers will have greater flexibility to

provide Respite services to these same families.

How should current evaluation protocols, training and practices be updated to facilitate equality for all members when accessing member needs?
AHCCCS has stated their intention to amend applicable policy, further suggested action on this topic includes:

- Forming a committee of community and department stakeholders to amend and critique current DDD and AHCCCS policies and need assessment forms so that the most effective and efficient implementation of this permanent option is utilized moving forward.
- Provide appropriately determined training and program implementation to DDD and ALTCS Support Coordinators so that Attendant Care and Habilitation hours are equitably evaluated based on the member's needs and to remove organizational bias of familial providers across the member's lifespan. Specifically investigate and determine appropriate DDD staffing needs and training for the members served in rural areas and those from minority backgrounds.
- Create the option for private sector Support Coordination. Other states have this option within their Medicaid services, and this could be an additional feature in our DDD portfolio to allow for the member's needs to be best evaluated.

In conclusion, Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. By not allowing parents of minors to provide Habilitation and Attendant Care services or work over 40 hours a week most of the minor disabled community in Arizona will be underserved. A comprehensive Paid Parent Caregiver program validates the irreplaceable work that parents provide in their homes and communities.

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Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves all DDD and ALTCS members in Arizona.

Best,
Nicole Noonan

---------- Forwarded message ---------
From: Glennda Freeman [redacted]
Date: Wednesday, July 19, 2023 at 7:35:24 PM UTC-4
Subject: Agency Concerns
[redacted]

Dear AHCCCS Public Input,

I am writing to express my concerns as the Agency Owner of Rise Above Support Services, a small to medium-sized agency serving District West, Central, and East Districts with DDD.

Our agency has a total of 270 providers, out of which 64 are Paid Parents Providers offering services to children under 18.

A particular concern for us is the fact that out of the 64 Parent Providers, only 3 provide attendant care exclusively. This raises serious concerns as attendant care is not typically assessed for children, as they need to develop independence and not rely on others for their daily activities. Habilitation services are crucial for the development of our members, allowing them to lead more independent lives as they transition into adulthood.

To provide a more detailed breakdown of the data:

- 3 paid parent providers offer Attendant Care only.
- 16 paid parent providers offer both services.
- 45 paid parent providers provide habilitation only.

Currently, the total number of weekly hours billed for habilitation by our paid parent providers is 1007. Looking ahead to November, we will have 1007 weekly hours of services that need to be filled, requiring the hiring of 40-45 new providers.

However, I must emphasize that the hiring situation is unlikely to change between now and November. Being a smaller agency, this change to eliminate parents from providing the Habilitation service puts us in a challenging position of having to hire 45-50 providers before November, which is not feasible. Consequently, there will be 40-45 members within our agency facing gaps in habilitation service. This situation is likely to be more severe for other agencies. Additionally, hiring and training mass numbers of people will create significant financial strain for many agencies, including ours.

The loss of 1007 weekly hours of habilitation at $28.48 per unit equates to a loss of $28,679.36 per week for our agency until these hours are filled, totaling $114,717.44 per month. I must stress that expecting agencies to mass hire and pay for training while losing significant amounts of revenue each month until the hours are filled poses a major financial crisis.

During the recent public forum, we learned about the decision to discontinue parents from providing habilitation starting November 2023, and this has raised significant concerns for our agency. We have been struggling to hire providers, and while [redacted] mentioned targeting community colleges as a solution, I assure you that we have already explored this avenue extensively. We actively engage with community colleges, participate in job fairs, and maintain constant communication with them. Unfortunately, this approach has not yielded sufficient results, and I fear that AHCCCS may not fully grasp the challenges agencies like ours are facing.

Our agency receives around 60 applicants per month through various paid and promoted recruitment platforms, but due to several factors, we can only hire 1-3 people monthly. This highlights the magnitude of the hiring challenges we face. It is hard enough for our agency to find quality providers to fill shifts and cover gaps for our current families, let alone find replacement providers if we lose 30% of our entire workforce. These current parents are fully capable and qualified to continue to provide the needed services.

We already face agencies competing against each other for minimal applicants (1-3 per month) that we are able to hire. This decision to exclude habilitation will absolutely crush the provider network which is already facing a crisis. The ARPA bonus' and other programs and incentive ideas that were referenced, were helpful to get us through the last few years, but this amount will note even come close to covering the impact of the overall loss of the habilitation reimbursement.

I will not speak for other agencies, however if the data above is a baseline for most agencies in AZ that provide the same services, and with Rise Above being a small to medium sized agency, I am extremely concerned that we will have thousands and thousands of individuals and families with gaps in services which will be detrimental to them and their day to day lives. Agencies will face massive financial crisis's with the immediate loss of billing and we simply do not have the applicants, competitive pay advantages, training resources, nor the adequate time to interview and match applicants to appropriate families in order to fill these shifts by November.

We fought so hard to make it through the pandemic, we fought to make it through the EVV transition, we are just getting to a point of seeing business return to "normal" and for agencies and families to have this massive decision be made to not include habilitation on the waiver submission will be devastating. A potential loss of this magnitude ($114k in monthly billing) to an agency of my size will force us to make decisions with potential staff layoffs and more. It will take years for us to build back and hire that many staff and fill these services in our state, all for what? I can't even comprehend the negative consequences of this same situation happening to all agencies in AZ and the magnitude to our clients and families. We will need at least a year to notify families and hire staff to transition. I believe families will need this time as well.

I hope habilitation is included on the waiver as it stands today with no 40-hour limitation, however, if that is not going to happen, we would like to recommend a grand-father rule be put into effect where those parents currently hired and providing services can continue to do so moving forward, but no NEW paid parent providers after a certain date.

I urge AHCCCS to consider the implications of this decision on agencies and explore alternative solutions to address the hiring and staffing difficulties. Working together, we can strive for a more sustainable and effective approach that benefits the individuals we serve and ensures the continuity of vital habilitation services.

Sincerely,
Glennda Freeman
[redacted]

---------- Forwarded message ---------
From: Kelli Gabaldon [redacted]
Date: Wednesday, July 19, 2023 at 6:55:34 PM UTC-4
Subject: HAH Hab
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To whom it may concern:

I am a single mom to a 10 yr old little girl.She is autistic non-verbal and elopes. If I am not able to do my childs Habilitation,I feel she will experience regression. A lot of our goals are working on hygene. "Bathing,brushing teeth,toiletting,washing hands,brushing hair, ect. My daughters is autistic lvl3, more severe and is non-verbal,needs 24 hour care. Statistics have proven that 90% of nonverbal children with developmental delays are sexually abused. When asked to ahcccs how do I know my child would not be asbused by a dcw? The response was I would have to be present the whole time the DCW would be working with my child. So I have to watch someone do my childs Hab that I could be doing myself. Watching some stranger work 2-3 hours a day with me just sitting there for HOURS watching someone work with my child seems insane to me. Not to mention alot of our kids have very unusual schedules. Also with all the training and knowledge I have acquired as an employee has given me so many more tools to help my child thrive daily and have the best quality of life even when I am gone. My child has been thriving.. I put a lot of effort and hard work into giving my child the tools possible to be more independent. I just don't see how someone can achieve those things that isn't invested into her 100% the way I The parent am. I truly honestly believe my child would not be doing as good if it were a stranger working with her only on certain days and certain times. Sometimes the dcw showed up sometimes not. My child thrives with routine, consistancy,and compassion. We as parents went through the trainning and classes to learn how to provide habilitation to our children because Arizona could not get DCW's and now that so many of the kiddos are thriving, Ahcccs is gonna take away our ability to help and provide our children? Whats gonna happen when You pull parents from hab, and You Ahccs cannot provide hab dcw's just like you cannot provide respit dcws. Our kids suffer. I truly hope you look at how much this parents dcw helps these kids and parents.

Thank you for your time.

Kelli Gabaldon
Peoria,az
[redacted]

---------- Forwarded message ---------
From: Lisa Khoshaba [redacted]
Date: Wednesday, July 19, 2023 at 6:45:26 PM UTC-4
Subject: Comments on 1115 Waiver Program
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To Whom it May Concern,

My son is 5 years old with an ASD, communication, and global delay diagnoses. I recently decided to stay home with my kids. I also started working with him as a parent provider for a few hours a week since I now have the time. Below are reasons why HABILITATION services by a parent provider is the best and the only option for our family:

1. **Limitation on Daily Hours / Schedule** - We do two hours of Habilitation on most days. This was what we were allocated and so we can't just increase the hours. No one will drive or sign up for 2 hours of daily work. Having repetition of learning and tasks daily and splitting the hours out per day is the best way to execute trials and get my child (actually all children) to learn and retain information. With my sons disability, repetition is key. A parent is able to accommodate these hours easily in the existing daily family schedule. A regular provider is not.

2. **Pairing with Providers** - It takes my son about a month to pair with any provider to the point where he will listen to and/or trust the provider. With the amount of time for pairing, the efficiency of my child's work and effort is affected. He will achieve goals much slower with a stranger that with a parent at the helm of instruction. In addition, the reality is that there is high turnover in these types of roles and we end up starting over every six months or less further impacting efficiency and success.

3. **Community Locations** - Providers are usually unwilling to drive around town with us. We do much of my son's Habilitation work outside of the home, in the community, at places such as church, sporting events, restaurants, the library, etc. These venues give us the opportunity to take my son to places and practice coping, social, behavior, communication (and other) skills in real life places our family goes. It is unrealistic to expect a provider to drive around with us to various places, and or have a meal with us when we are practicing mealtime skills. Providers do not want to expend money for gas, especially to multiple locations. It's also very inefficient and awkward to have a third party tag along to places that

they otherwise would not want to attend (a child's birthday party, a class at the library, church services where they are not a member) when the parent is likely to attend and can then incorporate the Habilitation skills into the already planned activity. For example, my son struggles with coping with loud places, unfamiliar faces, crowds, etc. One of his goals is learning and applying effective coping strategies in these scenarios. I would not send a provider to a birthday party he was invited to for many obvious reasons. However, I am going to attend with him as his parent. While we are there, we are able to practice these coping techniques effectively in his natural environment. If I had a provider come to the home, they would not be able to practice them in the natural environment, we'd have to "manufacture" the environment and subsequently, the skills are less likely to be effective in the real world. Another example is that we work on toileting as a goal. We can master toileting at home, but is it really mastered if we are not practicing in unfamiliar restrooms and settings? Being able to work on these skills while at the library or at a restaurant enables us to truly set my son up for success. This is not possible with an agency provider, thus offering my son a lesser level of support.

4. **Education and Skillset** - As a parent provider, no one is more invested in my child's success. I take extra classes to better my own skillset and continue to help support my son's individual needs. I have taken time on my own to take literally hundreds of hours of classes from local and national providers such as Raising Special Kids, Care 4 the Caregivers, SARRC, A Day in Our Shoes, Full Spectrum, Trumpet Behavioral Health, and many more. I do this on my own time and my own dime (there is often a cost) and choose classes specific to what goals and programs we are working on with my child. This propels our success and helps my son achieve more. A regular provider would have zero vested interest in taking classes on their own time and it would be highly unlikely that the classes they would take would be directly related to what my specific child's disability and/or needs are. Most importantly, the provider would not pay for any such classes out of their own pocket. I am able to provider my son a HIGHLY skilled provider under the parent provider program whereas with the regular program the providers skillset is well below what he is getting today.

5. **Greater Results** - We've done ABA for several years and I've actually seen my child get better results with the goals and programs we run through Habilitation hours with his parent as the direct provider. For example, we used ABA for toileting and we saw regression each time they agency said he was ready to close out the goal. However, when I added it to our Habilitation goals for him, we have seen him truly go without any regression for the entire summer. This shows that when a parent who is skilled and knowledgeable executes the goals with proper training and strategies, the success rates are better. In our case, this is actually more effective for my son and produces stronger results.

I want to thank the decision makers and parties involved in making the program available. It's been transformational for my son. The best thing for my son would be to see it continue. Overall, if the parent provider program ends for Habilitation, we will likely not find a comparable replacement for my child, ultimately impacting his progress in life. Unfortunatley, even if we did, this creates more stress for my child meeting new providers, dealing with unneeded change, and not being able to get out into the community as much as he should. In the unlikely event we did find a provider for my child, I would need to be present the entire time to ensure that they are executing the goals the proper way, and to help my son feel confident with another person. The inefficiency is just paramount in this scenario and the impact falls squarely on the child who is in need of support. I cannot express strongly enough my concerns and my request that the team please consider scenarios like ours and understand that not including Habilitation hours in the new proposal will ultimately hurt the very children it is set out to help.

Sincerely,
Lisa Khoshaba

---------- Forwarded message ---------
From: Gina B <mom2twoinaz@yahoo.com>
Date: Wednesday, July 19, 2023 at 6:39:53 PM UTC-4
Subject: Input regarding 1115 waiver
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

As a parent of a child who receives DDD and ALTCS services I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility, and it has been extremely beneficial to our family and my child. I would like to share my personal experiences and feedback based on my review of the current proposal for a permanent Paid Parent Caregiver program.

While I am so incredibly grateful for the PPC program, I have tried to think of how it was before this program Was in place. We had not had a HAB or ATC providers jn many years. We had always been told by agencies that there was a shortage and or that there were no dcw's in our area. This made it very stressful on me as a parent to Try to find my own quality providers. Many times I would bring my own providers to the agencies we have been with over the years.
But the new PPC program helped us accomplish a lot of HAB goals while allowing me to be home with my son. I'm so grateful!!

Under the current proposal, the request of an ongoing program option which allows parents of disabled minors in Arizona to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies is not being met. Please consider updating the proposal based on the following questions, suggested solutions, and personal experiences.

Should Habilitation be included in the Paid Parent Caregiver Program?
We have heard the concerns about member isolation and lack of community involvement if parents continue as Paid Parent Caregivers facilitating their child's Habilitation services. Respectfully the parent caregiver community proposes the following solutions:

> Examine available research and personal feedback statements from members and their families to evaluate the true potential impacts of social isolation and community involvement when parents of disabled children provide Habilitation services. The parent caregiver community's collective experience is that members who have parents facilitating their Attendant Care and Habilitation services have experienced greater member social engagement and community involvement over the last three years. Parent caregivers now have an increased ability to take their children to sporting team practices, community events, movie theaters, all ability parks, church activities and libraries. This is because parent providers can perform the appropriately trained and qualified supports in the correct time and location that is applicable to each member.
> Implement precise guidelines to facilitate generalization for all Habilitation providers regardless of the DCW's familial status. Habilitation services are designed to have goals where data is collected to evaluate if those goals need to be changed, have been met, or need to be addressed differently. For a goal to be

considered met, a member should be demonstrating that they are able to successfully meet that goal outside of the timeframe with a provider in one setting. This is referred to as generalization. The effective implementation of generalization with the pediatric IDD population would lessen, if not eliminate, any complications with adult transitional services. Under this model a program that includes parents as paid Habilitation providers would actually assist and improve in the success of adult transition. There are times when disabled children work successfully with different types of providers in clinics or schools, but the parents are not carrying the work over at home. This can happen for a variety of reasons. Having parents as Habilitation providers would help ensure the child's goals are congruent and carried over in the home and community setting. This will give the member a better chance of independence as they transition through different life stages. With generalization policies in place, Habilitation services being performed by parent providers will actually help facilitate successful transition into adulthood.

We know from provider agency data that "the top 3 issues regarding recruiting and retaining career non-family caregivers are schedules of the client members, interest in the position and finding qualified applicants." Most members have Habilitation goals and ADLs that are most appropriately delivered throughout the natural routine of their day. A parent provider is uniquely available in the morning, after school or in the evenings when each member is motivated and focused on the pertinent task. If a non-family provider is available their schedules typically allow them to work in longer time chunks that are not always the most ideal for the member and creates artificial goal or ADL practice. Continuity of care and greater member outcomes can be associated with consistently provided Habilitation care by parent providers who have the greatest ability to be flexible and available for their member children.

Should parent providers be limited to 40 hours a week of paid care per child?

We have heard the concerns of AHCCCS on why they want to limit parents to 40 hours a week under the Paid Parent Caregiver Program. The parent caregiver community would like to propose the following collaborative solution to create a win-win scenario:

Create a program provision that outlines an extraordinary circumstances clause and the application process that allows parents to provide over 40 hours of paid care per week of authorized and evaluated services per member. These extraordinary circumstances could include, but are not limited to:

The lack of a non-parent DCW being available in the last 3 months to fill the member's assessed hours that exceed 40 hours per week. Ongoing DCW searches should continue to be made by the member's agency to fill the assessed hours beyond 40 hours per week of Attendant Care and Habilitation.

The expressed desire made by a member for a parent caregiver to facilitate their assessed DCW hours so that their Article 9 rights are honored.

The profound disabilities and/or significant behaviors of a member where a non-family provider is not equipped to provide DCW support. This determination can be made through a stakeholder team approach, including but not limited to the member's, DDD Support Coordinator, DDD Nurse, DDD Supervisors, Behavioral Plan Experts, Parents / Guardians, Psychologist, or Medical Doctor.

Form equality between all Family Provider Programs by allowing all Direct Care Workers, regardless of familial relationship or member age, to provide up to 16 hours of paid care per day. This will allow for employee equality across the lifespan of the member and limit the potential anti-family provider rhetoric currently present within state policies and DDD Support Coordination culture. All evaluations of hours should be based on member needs regardless of who is providing the services to create uniform implementation of all applicable HCBS services by the DCWs available to fulfill those hours.

The Family Support Program currently in this proposal addresses caregiver burnout. It is one of the available solutions to facilitate further community support within the disability and caregiver community that will provide greater access to non-profits facilitating counseling services, support groups and meet up activities.

Reevaluate Respite reimbursement rates to also address caregiver burnout. If Respite services are not available to the member or their family, parent burnout will continue to be an issue regardless of parents having the option of providing Attendant Care or Habilitation hours. With a comprehensive Paid Parent Caregiver Program in place non-family DCW providers will have greater flexibility to provide Respite services to these same families.

How should current evaluation protocols, training and practices be updated to facilitate equality for all members when accessing member needs?

AHCCCS has stated their intention to amend applicable policy, further suggested action on this topic includes:

Forming a committee of community and department stakeholders to amend and critique current DDD and AHCCCS policies and need assessment forms so that the most effective and efficient implementation of this permanent option is utilized moving forward.

Provide appropriately determined training and program implementation to DDD and ALTCS Support Coordinators so that Attendant Care and Habilitation hours are equitably evaluated based on the member's needs and to remove organizational bias of familial providers across the member's lifespan. Specifically investigate and determine appropriate DDD staffing needs and training for the members served in rural areas and those from minority backgrounds.

Create the option for private sector Support Coordination. Other states have this option within their Medicaid services, and this could be an additional feature in our DDD portfolio to allow for the member's needs to be best evaluated.

In conclusion, Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. By not allowing parents of minors to provide Habilitation and Attendant Care services or work over 40 hours a week most of the minor disabled community in Arizona will be underserved. A comprehensive Paid Parent Caregiver program validates the irreplaceable work that parents provide in their homes and communities.

Click here to connect with the Arizona parent led grassroot initiative leaders: www.raisingvoicescoalition.com

Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves all DDD and ALTCS members in Arizona.

If you have any follow up questions for me, please don't hesitate to reach out! [redacted]

Thank you!
Gina Blair

---------- Forwarded message ---------
From: Karla Dressen [redacted]
Date: Wednesday, July 19, 2023 at 6:06:59 PM UTC-4
Subject: Parent provider program
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

As a parent of a child who receives DDD and ALTCS services I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility, and it has been extremely beneficial to our family and my child. I would like to share my personal experiences and feedback based on my review of the current proposal for a permanent Paid Parent Caregiver program.

I have been my daughter [redacted] habilitation provider for over [redacted] and it has been a blessing in many ways. I will express some of them.

[redacted] has shown so much progress on her goals. Being able to be consistent and following a routine has allowed the progress in her goals.
I used to have a college student as a provider but she was missing a lot, she would get home and sit , play with her phone. I was constantly behind her remind her about the goals and making sure they were doing something related to [redacted] goals instead of having my daughter sitting and watching tv during her habilitation time.

Being a parent provider allows me to provide habilitation therapy to my daughter in a time when is convenient for me and my family and also allows me to take [redacted] to dance classes and library programs where is making new friendships and having social interactions. Being able to find a provider who cares is reliable and cares about my daughter goals is very hard and if the parent provider program gets cancelled it will have a great impact on my daughters progress.

Under the current proposal, the request of an ongoing program option which allows parents of disabled minors in Arizona to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies is not being met. Please consider updating the proposal based on the following questions, suggested solutions, and personal experiences.

Should Habilitation be included in the Paid Parent Caregiver Program?
We have heard the concerns about member isolation and lack of community involvement if parents continue as Paid Parent Caregivers facilitating their child's Habilitation services. Respectfully the parent caregiver community proposes the following solutions:

- Examine available research and personal feedback statements from members and their families to evaluate the true potential impacts of social isolation and community involvement when parents of disabled children provide Habilitation services. The parent caregiver community's collective experience is that members who have parents facilitating their Attendant Care and Habilitation services have experienced greater member social engagement and community involvement over the last three years. Parent caregivers now have an increased ability to take their children to sporting team practices, community events, movie theaters, all ability parks, church activities and libraries. This is because parent providers can perform the appropriately trained and qualified supports in the correct time and location that is applicable to each member.
- We know from provider agency data that "the top 3 issues regarding recruiting and retaining career non-family caregivers are schedules of the client members, interest in the position and finding qualified applicants." Most members have Habilitation goals and ADLs that are most appropriately delivered throughout the natural routine of their day. A parent provider is uniquely available in the morning, after school or in the evenings when each member is motivated and focused on the pertinent task. If a non-family provider is available their schedules typically allow them to work in longer time chunks that are not always the most ideal for the member and creates artificial goal or ADL practice. Continuity of care and greater member outcomes can be associated with consistently provided Habilitation care by parent providers who have the greatest ability to be flexible and available for their member children.

Should parent providers be limited to 40 hours a week of paid care per child?
We have heard the concerns of AHCCCS on why they want to limit parents to 40 hours a week under the Paid Parent Caregiver Program. The parent caregiver community would like to propose the following collaborative solution to create a win-win scenario:

- Create a program provision that outlines an extraordinary circumstances clause and the application process that allows parents to provide over 40 hours of paid care per week of authorized and evaluated services per member. These extraordinary circumstances could include, but are not limited to:

- The lack of a non-parent DCW being available in the last 3 months to fill the member's assessed hours that exceed 40 hours per week. Ongoing DCW searches should continue to be made by the member's agency to fill the assessed hours beyond 40 hours per week of Attendant Care and Habilitation.
- The expressed desire made by a member for a parent caregiver to facilitate their assessed DCW hours so that their Article 9 rights are honored.
- The profound disabilities and/or significant behaviors of a member where a non-family provider is not equipped to provide DCW support. This determination can be made through a stakeholder team approach, including but not limited to the member's, DDD Support Coordinator, DDD Nurse, DDD Supervisors, Behavioral Plan Experts, Parents / Guardians, Psychologist, or Medical Doctor.
- Form equality between all Family Provider Programs by allowing all Direct Care Workers, regardless of familial relationship or member age, to provide up to 16 hours of paid care per day. This will allow for employee equality across the lifespan of the member and limit the potential anti-family provider rhetoric currently present within state policies and DDD Support Coordination culture. All evaluations of hours should be based on member needs regardless of who is providing the services to create uniform implementation of all applicable HCBS services by the DCWs available to fulfill those hours.
- The Family Support Program currently in this proposal addresses caregiver burnout. It is one of the available solutions to facilitate further community support within the disability and caregiver community that will provide greater access to non-profits facilitating counseling services, support groups and meet up activities.
- Reevaluate Respite reimbursement rates to also address caregiver burnout. If Respite services are not available to the member or their family, parent burnout will continue to be an issue regardless of parents having the option of providing Attendant Care or Habilitation hours. With a comprehensive Paid Parent Caregiver Program in place non-family DCW providers will have greater flexibility to provide Respite services to these same families.

How should current evaluation protocols, training and practices be updated to facilitate equality for all members when accessing member needs?
AHCCCS has stated their intention to amend applicable policy, further suggested action on this topic includes:

- Forming a committee of community and department stakeholders to amend and critique current DDD and AHCCCS policies and need assessment forms so that the most effective and efficient implementation of this permanent option is utilized moving forward.

Provide appropriately determined training and program implementation to DDD and ALTCS Support Coordinators so that Attendant Care and Habilitation hours are equitably evaluated based on the member's needs and to remove organizational bias of familial providers across the member's lifespan. Specifically investigate and determine appropriate DDD staffing needs and training for the members served in rural areas and those from minority backgrounds.

- Create the option for private sector Support Coordination. Other states have this option within their Medicaid services, and this could be an additional feature in our DDD portfolio to allow for the member's needs to be best evaluated.

In conclusion, Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. By not allowing parents of minors to provide Habilitation and Attendant Care services or work over 40 hours a week most of the minor disabled community in Arizona will be underserved. A comprehensive Paid Parent Caregiver program validates the irreplaceable work that parents provide in their homes and communities.

Click here to connect with the Arizona parent led grassroot initiative leaders: www.raisingvoicescoalition.com

Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves all DDD and ALTCS members in Arizona.

Thank you!

Sincerely
Karla Dressen
[redacted]

From: Brittany [redacted]
Date: Wednesday, July 19, 2023 at 5:49:59 PM UTC-4
Subject: Permanent Parent Provider Feedback.
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

As the parent of a child who receives DDD and ALTCS services, I am under the impression that my feedback has been welcomed on the matter. This program has been life-changing for my disabled son and myself. Please listen to us parents on this matter, we are the ones fighting for our children to continue to have the assistance they DESERVE.

Should Habilitation be included in the Paid Parent Caregiver Program?

We have heard the concerns about member isolation and lack of community involvement if parents continue as Paid Parent Caregivers.

> Listen to personal feedback statements from members and their families to evaluate the true potential impacts of social isolation and community involvement when parents of disabled children provide Habilitation services. There is nothing to worry about here. As a parent caregiver, I have been able to take my nonverbal level 2 autistic child out more than ever before with this program. He is thriving with increased outings weekly. I am here to state that parent providers can perform the appropriately trained and qualified supports in the correct time and location that is applicable to each member.
>
> Habilitation requires data collection to evaluate if my child’s goals need to be changed, have been met, or need to be addressed differently. For a goal to be considered met, a member should be demonstrating that they are able to successfully meet that goal outside of the timeframe with a provider in one setting. This is referred to as generalization. A program that includes parents as paid Habilitation providers would improve the success of adult transition because parents as Habilitation providers would help ensure the child's goals are congruent and carried over in the home and community setting. This will give the member a better chance of independence.
>
> We know from provider agency data that “the top 3 issues regarding recruiting and retaining career non-family caregivers are schedules of the client members, interest in the position and finding qualified applicants.” Most members have Habilitation goals and ADLs that are most appropriately delivered throughout the natural routine of their day. A parent provider is uniquely available in the morning, after school or in the evenings when each member is motivated and focused on the pertinent task. If a non-family provider is available their schedules typically allow them to work in longer time chunks that are not always the most ideal for the member and creates artificial goal or ADL practice. Continuity of care and greater member outcomes can be associated with consistently provided Habilitation care by parent providers who have the greatest ability to be flexible and available for their member children.

Should parent providers be limited to 40 hours a week of paid care per child?

I believe to limit at 40 hours is discriminating against children under extraordinary disabling circumstances. Allow parents to provide over 40 hours of paid care per week of authorized and evaluated services per member. These extraordinary circumstances could include, but are not limited to:

- The lack of a non-parent DCW being available in the last 3 months to fill the member's assessed hours that exceed 40 hours per week. Ongoing DCW searches should continue to be made by the member's agency to fill the assessed hours beyond 40 hours per week of Attendant Care and Habilitation.
- The expressed desire made by a member for a parent caregiver to facilitate their assessed DCW hours so that their Article 9 rights are honored.
- The profound disabilities and/or significant behaviors of a member where a non-family provider is not equipped to provide DCW support. This determination can be made through a stakeholder team approach, including but not limited to the member's, DDD Support Coordinator, DDD Nurse, DDD Supervisors, Behavioral Plan Experts, Parents / Guardians, Psychologist, or Medical Doctor.

Form equality between all Family Provider Programs by allowing all Direct Care Workers, regardless of familial relationship or member age, to provide up to 16 hours of paid care per day. This will allow for employee equality across the lifespan of the member and limit the potential anti-family provider rhetoric currently present within state policies and DDD Support Coordination culture.

Reevaluate Respite reimbursement rates to also address caregiver burnout. If Respite services are not available to the member or their family, parent burnout will continue to be an issue regardless of parents having the option of providing Attendant Care or Habilitation hours.

How should current evaluation protocols, training and practices be updated to facilitate equality for all members when accessing member needs?

AHCCCS has stated their intention to amend applicable policy, further suggested action on this topic includes:

Forming a committee of community and department stakeholders to amend and critique current DDD and AHCCCS policies and need assessment forms so that the most effective and efficient implementation of this permanent option is utilized moving forward.

Provide appropriately determined training and program implementation to DDD and ALTCS Support Coordinators so that Attendant Care and Habilitation hours are equitably evaluated based on the member's needs and to remove organizational bias of familial providers across the member's lifespan. Specifically investigate and determine appropriate DDD staffing needs and training for the members served in rural areas and those from minority backgrounds.

Create the option for private sector Support Coordination. Other states have this option within their Medicaid services, and this could be an additional feature in our DDD portfolio to allow for the member's needs to be best evaluated.

Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. The lack of non-relative/non-pqrent employees scarce with an EXTREMELY high turnover rate. By not allowing parents of minors to provide Habilitation and Attendant Care services or work over 40 hours a week most of the minor disabled community in Arizona will be utterly underserved. A comprehensive Paid Parent Caregiver program validates the irreplaceable work that parents provide in their homes and communities.

Thank you, Brittany Powers

From: Isaac Holwager [redacted]
Date: Wednesday, July 19, 2023 at 5:49:58 PM UTC-4
Subject: Habilitation Helps Our Children
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

As a parent of a child who receives DDD and ALTCS services I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility, and it has been extremely beneficial to our family and my childen. I would like to share my personal experiences and feedback based on my review of the current proposal for a permanent Paid Parent Caregiver program.

Under the current proposal, the request of an ongoing program option which allows parents of disabled minors in Arizona to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies is not being met. Please consider updating the proposal based on the following questions, suggested solutions, and personal experiences.

I have five young children aged [redacted], and [redacted]. Our [redacted]-year-old is on the autism spectrum. Our [redacted]-year-old twin girls are on the autism spectrum. Our [redacted]-year-old twins are too young to be diagnosed but are currently in early intervention. There is a high possibility our family will have 5 children on the autism spectrum. Currently, only our [redacted]-year-old twins receive DDD/ALTCS services. My husband and I both work full-time and hold advanced degrees. The paid parent caregiver program pays significantly lower than our normal jobs. We choose to participate in it because it is very beneficial to our children and their development and the only way our kids can receive habilitation services. Between all of our kids we are seeing upwards of 40 medical specialists frequently to meet their needs. On top of that, every child is receiving some sort of therapy [speech, OT, PT] and/or multiple therapies. With this new proposal and removal of habilitation from the paid parent caregiver program there is no question that our girls will lose habilitation services for three primary reasons:

1. There is a major shortage of providers, especially in our rural area. We were lucky to even find a respite provider. The only providers available are typically available in the late evening, after our children are already asleep, because they have daytime jobs that they work.
2. It takes months for our girls to accept a provider into our home (even with highly qualified professionals such as an occupational therapist) and they have shown a strong history of low performance for anyone other than their parents. We (and them) are also uncomfortable with strangers working on a good portion of their goals such as toileting and dressing, and

3. As stated above, our family schedule is incredibly complicated. We are able to plan habilitation around our schedule. We can wake up in the early morning and work on goals with the girls then immediately wake the rest of our family. We can find pockets of time within our normal day-to-day to work on habitation goals. We cannot do that with an outside provider. **We would have to reduce their hours by at least 90%** as that is the only time we can guarantee we can be available (versus the fluidity of finding time as it becomes available). With the respite program, we find time to ensure a work-home-life balance. I believe one of the largest arguments against allowing habitation is concern for our well-being. I can assure you that removing habilitation from our lives will be nothing but detrimental to our family, will result in a significant loss of much-needed habilitation time, and will overall leave our family in a much worse situation than when we first became involved with DDD/ALTCS. As we speak to other families with one or more children with special needs, it seems their sentiment matches ours. Our girls are making great progress with us in the parent provider habilitation program. It hurts our hearts that we will lose so much potential for their futures. It leaves us bewildered, confused, disappointed, and feeling a bit abandoned by DDD and ALTCS. Please consider including habitation in the paid parent provider program.

Should Habilitation be included in the Paid Parent Caregiver Program?
We have heard the concerns about member isolation and lack of community involvement if parents continue as Paid Parent Caregivers facilitating their child's Habilitation services. Respectfully the parent caregiver community proposes the following solutions:

1. Examine available research and personal feedback statements from members and their families to evaluate the true potential impacts of social isolation and community involvement when parents of disabled children provide Habilitation services. The parent caregiver community's collective experience is that members who have parents facilitating their Attendant Care and Habilitation services have experienced greater member social engagement and community involvement over the last three years. Parent caregivers now have an increased ability to take their children to sporting team practices, community events, movie theaters, all ability parks, church activities and libraries. This is because parent providers can perform the appropriately trained and qualified supports in the correct time and location that is applicable to each member.
2. Implement precise guidelines to facilitate generalization for all Habilitation providers regardless of the DCW's familial status. Habilitation services are designed to have goals where data is collected to evaluate if those goals need to be changed, have been met, or need to be addressed differently. For a goal to be considered met, a member should be demonstrating that they are able to successfully meet that goal outside of the timeframe with a provider in one setting. This is referred to as generalization. The effective implementation of generalization with the pediatric IDD population would lessen, if not eliminate, any complications with adult transitional services. Under this model a program that includes parents as paid Habilitation providers would actually assist and improve in the success of adult transition. There are times when disabled children work successfully with different types of providers in clinics or schools, but the parents are not carrying the work over at home. This can happen for a variety of reasons. Having parents as Habilitation providers would help ensure the child's goals are congruent and carried over in the home and community setting. This will give the member a better chance of independence as they transition through different life stages. With generalization policies in place, Habilitation services being performed by parent providers will actually help facilitate successful transition into adulthood.
3. We know from provider agency data that "the top 3 issues regarding recruiting and retaining career non-family caregivers are schedules of the client members, interest in the position and finding qualified applicants." Most members have Habilitation goals and ADLs that are most appropriately delivered throughout the natural routine of their day. A parent provider is uniquely available in the morning, after school or in the evenings when each member is motivated and focused on the pertinent task. If a non-family provider is available their schedules typically allow them to work in longer time chunks that are not always the most ideal for the member and creates artificial

goal or ADL practice. Continuity of care and greater member outcomes can be associated with consistently provided Habilitation care by parent providers who have the greatest ability to be flexible and available for their member children.

How should current evaluation protocols, training and practices be updated to facilitate equality for all members when accessing member needs?
AHCCCS has stated their intention to amend applicable policy, further suggested action on this topic includes:

1. Forming a committee of community and department stakeholders to amend and critique current DDD and AHCCCS policies and need assessment forms so that the most effective and efficient implementation of this permanent option is utilized moving forward.
2. Provide appropriately determined training and program implementation to DDD and ALTCS Support Coordinators so that Attendant Care and Habilitation hours are equitably evaluated based on the member's needs and to remove organizational bias of familial providers across the member's lifespan. Specifically investigate and determine appropriate DDD staffing needs and training for the members served in rural areas and those from minority backgrounds.
3. Create the option for private sector Support Coordination. Other states have this option within their Medicaid services, and this could be an additional feature in our DDD portfolio to allow for the member's needs to be best evaluated.

In conclusion, Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. By not allowing parents of minors to provide Habilitation and Attendant Care services most of the minor disabled community in Arizona will be underserved. A comprehensive Paid Parent Caregiver program validates the irreplaceable work that parents provide in their homes and communities.

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Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves all DDD and ALTCS members in Arizona.

Thank you!

Erica Holwager (and family)

From: Jill Ressler [redacted]
Date: Wednesday, July 19, 2023 at 5:48:04 PM UTC-4
Subject: Hab hours for parent providers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello. I am grateful to provide my feedback regarding hab hours for parent providers. I have a daughter with Down Syndrome who is also an AML leukemia survivor. She lived for [redacted] months at [redacted] hospital fighting cancer.
We're doing all that we can to provide a big world for our kiddo. We have found it next to impossible getting providers to take care of her so I discontinued my employment. I can not find providers to complete habilitation hours. Please reconsider your stance in insisting that strangers should provide habilitation coverage. I am unable to find providers that will provide this coverage. Your understanding would be so appreciated.

Warmly,
Jill Ressler

[redacted]

From: CANDACE TIERNEY [redacted]
Date: Wednesday, July 19, 2023 at 5:29:36 PM UTC-4
Subject: Parent feedback
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

As a parent of two children who receive DDD and ALTCS services, I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility, and it has been extremely beneficial to our family and my child. I would like to share my personal experiences and feedback based on my review of the current proposal for a permanent Paid Parent Caregiver program.

Our two ASD children have elopement and aggression behaviors that leave many would-be providers feeling overwhelmed and unwilling to provide services. As a parent provider, I've taken and utilized training opportunities seriously and applied them to providing Habilitation for my special children. The funds I've received from helping them build skills has been used to hire a lesser qualified neighborhood babysitter to care for my other children while I focus on the child's special needs and development. Hiring a non-parent provider that is kind, patient, skilled, and willing to drive to our home and work for 15 minutes at a time to build a skill has been a 'unicorn' staffing challenge that several agencies have yet to fill for our family (and sadly, for many other families in our area).

Under the current proposal, the request of an ongoing program option which allows parents of disabled minors in Arizona to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies is not being met. Please consider updating the proposal based on the following questions, suggested solutions, and personal experiences.

Should Habilitation be included in the Paid Parent Caregiver Program?

We have heard the concerns about member isolation and lack of community involvement if parents continue as Paid Parent Caregivers facilitating their child's Habilitation services. Respectfully the parent caregiver community proposes the following solutions:

1. Examine available research and personal feedback statements from members and their families to evaluate the true potential impacts of social isolation and community involvement when parents of disabled children provide Habilitation services. The parent caregiver community's collective experience is that members who have parents facilitating their Attendant Care and Habilitation services have experienced greater member social engagement and community involvement over the last three years. Parent caregivers now have an increased ability to take their children to sporting team practices, community events, movie theaters, all ability parks, church activities and libraries. This is because parent providers can perform the appropriately trained and qualified supports in the correct time and location that is applicable to each member.
2. Implement precise guidelines to facilitate generalization for all Habilitation providers regardless of the DCW's familial status. Habilitation services are designed to have goals where data is collected to evaluate if those goals need to be changed, have been met, or need to be addressed differently. For a goal to be considered met, a member should be demonstrating that they are able to successfully meet that goal outside of the timeframe with a provider in one setting. This is referred to as generalization. The effective implementation of generalization with the pediatric IDD population would lessen, if not eliminate, any complications with adult transitional services. Under this model a program that includes parents as paid Habilitation providers would actually assist and improve in the success of adult transition. There are times when disabled children work successfully with different types of providers in clinics or schools, but the parents are not carrying the work over at home. This can happen for a variety of reasons. Having parents as Habilitation providers would help ensure the child's goals are congruent and carried over in the home and community setting. This will give the member a better chance of independence as they transition through different life stages.

2. With generalization policies in place, Habilitation services being performed by parent providers will actually help facilitate successful transition into adulthood.
3. We know from provider agency data that "the top 3 issues regarding recruiting and retaining career non-family caregivers are schedules of the client members, interest in the position and finding qualified applicants." Most members have Habilitation goals and ADLs that are most appropriately delivered throughout the natural routine of their day. A parent provider is uniquely available in the morning, after school or in the evenings when each member is motivated and focused on the pertinent task. If a non-family provider is available their schedules typically allow them to work in longer time chunks that are not always the most ideal for the member and creates artificial goal or ADL practice. Continuity of care and greater member outcomes can be associated with consistently provided Habilitation care by parent providers who have the greatest ability to be flexible and available for their member children.

Should parent providers be limited to 40 hours a week of paid care per child?
We have heard the concerns of AHCCCS on why they want to limit parents to 40 hours a week under the Paid Parent Caregiver Program. The parent caregiver community would like to propose the following collaborative solution to create a win-win scenario:

1. Create a program provision that outlines an extraordinary circumstances clause and the application process that allows parents to provide over 40 hours of paid care per week of authorized and evaluated services per member. These extraordinary circumstances could include, but are not limited to:
    1. The lack of a non-parent DCW being available in the last 3 months to fill the member's assessed hours that exceed 40 hours per week. Ongoing DCW searches should continue to be made by the member's agency to fill the assessed hours beyond 40 hours per week of Attendant Care and Habilitation.
    2. The expressed desire made by a member for a parent caregiver to facilitate their assessed DCW hours so that their Article 9 rights are honored.
    3. The profound disabilities and/or significant behaviors of a member where a non-family provider is not equipped to provide DCW support. This determination can be made through a stakeholder team approach, including but not limited to the member's, DDD Support Coordinator, DDD Nurse, DDD Supervisors, Behavioral Plan Experts, Parents / Guardians, Psychologist, or Medical Doctor.
2. Form equality between all Family Provider Programs by allowing all Direct Care Workers, regardless of familial relationship or member age, to provide up to 16 hours of paid care per day. This will allow for employee equality across the lifespan of the member and limit the potential anti-family provider rhetoric currently present within state policies and DDD Support Coordination culture. All evaluations of hours should be based on member needs regardless of who is providing the services to create uniform implementation of all applicable HCBS services by the DCWs available to fulfill those hours.
3. The Family Support Program currently in this proposal addresses caregiver burnout. It is one of the available solutions to facilitate further community support within the disability and caregiver community that will provide greater access to non-profits facilitating counseling services, support groups and meet up activities.
4. Reevaluate Respite reimbursement rates to also address caregiver burnout. If Respite services are not available to the member or their family, parent burnout will continue to be an issue regardless of parents having the option of providing Attendant Care or Habilitation hours. With a comprehensive Paid Parent Caregiver Program in place non-family DCW providers will have greater flexibility to provide Respite services to these same families.

How should current evaluation protocols, training and practices be updated to facilitate equality for all members when accessing member needs?
AHCCCS has stated their intention to amend applicable policy, further suggested action on this topic includes:

1. Forming a committee of community and department stakeholders to amend and critique current DDD and AHCCCS policies and need assessment forms so that the most effective and efficient implementation of this permanent option is utilized moving forward.
2. Provide appropriately determined training and program implementation to DDD and ALTCS Support Coordinators so that Attendant Care and Habilitation hours are equitably evaluated based on the member's needs and to remove organizational bias of familial providers across the member's lifespan. Specifically investigate and determine appropriate DDD staffing needs and training for the members served in rural areas and those from minority backgrounds.
3. Create the option for private sector Support Coordination. Other states have this option within their Medicaid services, and this could be an additional feature in our DDD portfolio to allow for the member's needs to be best evaluated.

In conclusion, Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. By not allowing parents of minors to provide Habilitation and Attendant Care services or work over 40 hours a week most of the minor disabled community in Arizona will be underserved. A comprehensive Paid Parent Caregiver program validates the irreplaceable work that parents provide in their homes and communities.

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Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves all DDD and ALTCS members in Arizona.

Thank you!

Candace

From: Lizbeth Byers [redacted]
Date: Wednesday, July 19, 2023 at 5:17:20 PM UTC-4
Subject: Habilitation for minors
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Many DDD/ALTCS members have Autism Spectrum Disorder, a condition that is characterized by a strong preference for routine and familiarity. As a parent I feel like you guys could care less about my child's well being and comfort the world for him is already so hard! No one will understand our living situations unless they are living it. My son loves routine and consistency we had to change providers so many times because they can't handle my son. One time a provider never showed up because her boyfriend broke up with her! No one will care for my child the way I do or have the patience that I have for him no matter how good you guys try to phrase it. For this reason, parents/family are truly the best caregivers for autistic members, as they provide consistency, familiarity and a safe, calming environment that is conducive to learning new skills. Discontinuing habilitation for parent providers would be extremely disruptive for members on the autism spectrum, and disruption would be synonymous with regression.
My son is [redacted], Autistic, intellectual impairment and non-verbal. I have a major issue with an unknown person working on the Habilitation goals I am currently working on with him. I do not want an unknown person teaching him to bathe, or go to the bathroom. Those are very personal items that I do not feel comfortable with someone else doing. Especially with him being non-verbal and his communication skills are severely lacking. I did not want to send him to a clinic based setting for ABA for similar reasons. Since he is unable to communicate with me, he is also unable to tell me if something is happening that should not be happening. If paid parent provider goes away, we will definitely take a financial hit (with some major financial modification) but I will not allow someone else to work on those very personal hygiene goals. Not to mention, my son has severe meltdowns that are near impossible to manage. I do not want an unknown person trying to navigate those. We do in home speech therapy and OT we are seeking in home ABA. We also go to parks, stores, zoo, aquarium etc My son is not lacking on outside interaction at all. Many kids have goals around hygiene that should remain private, and in addition to communication challenges, many autistic kids have no sense of danger, or of what is and isn't appropriate for them to share when it comes to their bodies. I feel like Arizona AHCCCS, ALTCS & DDD could care less about my child's well being and comfort the world for him is already so hard! No one will understand our living situations unless they are living it. I have been waiting for [redacted] months for a speech therapist. Kids with special needs are overlooked they are not a burden they are kids that need more assistance and attention than regular kids.

From: Amy Kitterman [redacted]
Date: Wednesday, July 19, 2023 at 5:13:11 PM UTC-4
Subject: Parent provider program habilitation
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

As a parent of a child who receives DDD and ALTCS services I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility, and it has been extremely beneficial to our family and my child. I would like to share my personal experiences and feedback based on my review of the current proposal for a permanent Paid Parent Caregiver program.

My son was diagnosed with Autism at the age of [redacted]. We were dealing with many scary situations regarding elopement, climbing and no regard for self-preservation. We were not able to leave the house and be around people without epic meltdowns, which made things like shopping or any interactions very difficult. He wouldn't be with anyone other than a select few family members. When habilitation and attendant care were offered we had to turn it down due to our son's inability to be around anyone other than me and my husband. Knowing this we struggled financially as I had to quite work to be home full time to be able to give him the best care possible as well as take him to different therapies, which were also just epic meltdowns as he was not comfortable being away from me or home. When the Parent Care Provider program was presented to me it was an answer to our many prayers. We had to live with family as we could not financially support ourselves on one income. The biggest blessing however has been the immense change this program has had in our son's life. With the help of our support coordinator we came up with goals that would help our son be successful out in the world away from home and be able to socialize. Working on these goals daily not only has made drastic improvements in my sons life but it has made it possible for us to work together as a team, get closer and have a better understanding of his needs and how best to help him be successful in life. Many of his Habilitation goals are regarding being out of the house in social situations as well as public locations where he needs to work on not eloping. This has been extremely beneficial in getting us out of the home and making many new friends and relationships. The goals that my son has are like I said mostly out of the home and while his is high risk of elopement I am very reluctant to ever trust a provider I do not know and who would only have limited interactions with our son weekly. As his mother i always have his best interest and safety in mind and would be much better suited to be aware of him at all times with no distractions, needed days off for sickness, vacations or emergencies like another provider may. When it comes to his attendant care goals and a few of his habilitation goals I am not comfortable having someone come into our home and be around my five year while he is learning to bath, go to the bathroom or dress himself. I hope that there is enough information brought forward to prove how much better it is to continue the parent provider program for both attendant care and habilitation. As parents we know our kid's needs, personalities and quirks better than anyone and already have a close constant relationship with our child, trust and stability is necessary for these children to be successful in their goals and relationships.

Thank you for your time and consideration!
Amy Kitterman

From: Laura Kimble [redacted]
Date: Wednesday, July 19, 2023 at 5:12:39 PM UTC-4
Subject: Please continue to support Arizona families
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

As a parent of a child who receives DDD and ALTCS services I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility, and it has been extremely beneficial to our family and my child. In fact, it has been the only way my child has been able to access habilitation services for the last [redacted] years. I would like to share my personal experiences and feedback based on my review of the current proposal for a permanent Paid Parent Caregiver program.

Arizona is a nationwide leader in how to treat, include and support individuals with disabilities and this has only increased in the last few years. Due to the difficulties in finding and hiring support professionals for my son, I have been so grateful that I have been able step in as his Habilitation provider, giving him the services he has been deemed to be entitled to and aiding in our family finances (also benefiting him) so that I can stay home and meet his needs. I wish there was another who could help us, give us support, or any break from the day to day up and downs of this unexpected diagnosis, but I truely don't know what we'll do if this, or only option, is taken away from him and our family.

Under the current proposal, the request of an ongoing program option which allows parents of disabled minors in Arizona to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies is not being met. Please consider updating the proposal based on the following questions, suggested solutions, and personal experiences.

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supports in the correct time and location that is applicable to each member.

2. Implement precise guidelines to facilitate generalization for all Habilitation providers regardless of the DCW's familial status. Habilitation services are designed to have goals where data is collected to evaluate if those goals need to be changed, have been met, or need to be addressed differently. For a goal to be considered met, a member should be demonstrating that they are able to successfully meet that goal outside of the timeframe with a provider in one setting. This is referred to as generalization. The effective implementation of generalization with the pediatric IDD population would lessen, if not eliminate, any complications with adult transitional services. Under this model a program that includes parents as paid Habilitation providers would actually assist and improve in the success of adult transition. There are times when disabled children work successfully with different types of providers in clinics or schools, but the parents are not carrying the work over at home. This can happen for a variety of reasons. Having parents as Habilitation providers would help ensure the child's goals are congruent and carried over in the home and community setting. This will give the member a better chance of independence as they transition through different life stages. With generalization policies in place, Habilitation services being performed by parent providers will actually help facilitate successful transition into adulthood.

3. We know from provider agency data that "the top 3 issues regarding recruiting and retaining career non-family caregivers are schedules of the client members, interest in the position and finding qualified applicants." Most members have Habilitation goals and ADLs that are most appropriately delivered throughout the natural routine of their day. A parent provider is uniquely available in the morning, after school or in the evenings when each member is motivated and focused on the pertinent task. If a non-family provider is available their schedules typically allow them to work in longer time chunks that are not always the most ideal for the member and creates artificial goal or ADL practice. Continuity of care and greater member outcomes can be associated with consistently provided Habilitation care by parent providers who have the greatest ability to be flexible and available for their member children.

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1. Create a program provision that outlines an extraordinary circumstances clause and the application process that allows parents to provide over 40 hours of paid care per week of authorized and evaluated services per member. These extraordinary circumstances could include, but are not limited to:

    a. The lack of a non-parent DCW being available in the last 3 months to fill the member's assessed hours that exceed 40 hours per week. Ongoing DCW searches should continue to be made by the member's agency to fill the assessed hours beyond 40 hours per week of Attendant Care and Habilitation.

    b. The expressed desire made by a member for a parent caregiver to facilitate their assessed DCW hours so that their Article 9 rights are honored.

    c. The profound disabilities and/or significant behaviors of a member where a non-family provider is not equipped to provide DCW support. This determination can be made through a stakeholder team approach, including but not limited to the member's, DDD Support Coordinator, DDD Nurse, DDD Supervisors, Behavioral Plan Experts, Parents / Guardians, Psychologist, or Medical Doctor.

2. Form equality between all Family Provider Programs by allowing all Direct Care Workers, regardless of familial relationship or member age, to provide up to 16 hours of paid care per day. This will allow for employee equality across the lifespan of the member and limit the potential anti-family provider rhetoric currently present within state policies and DDD Support Coordination culture. All evaluations of hours should be based on member needs regardless of who is providing the services to create uniform implementation of all applicable HCBS services by the DCWs available to fulfill those hours.

3. The Family Support Program currently in this proposal addresses caregiver burnout. It is one of the available solutions to facilitate further community support within the disability and caregiver community that will provide greater access to non-profits facilitating counseling services, support groups and meet up activities.

4. Reevaluate Respite reimbursement rates to also address caregiver burnout. If Respite services are not available to the member or their family, parent burnout will continue to be an issue regardless of parents having the option of providing Attendant Care or Habilitation hours. With a comprehensive Paid Parent Caregiver Program in place non-family DCW providers will have greater flexibility to provide Respite services to these same families.

How should current evaluation protocols, training and practices be updated to facilitate equality for all members when accessing member needs?
AHCCCS has stated their intention to amend applicable policy, further suggested action on this topic includes:

1. Forming a committee of community and department stakeholders to amend and critique current DDD and AHCCCS policies and need assessment forms so that the most effective and efficient implementation of this permanent option is utilized moving forward.

2. Provide appropriately determined training and program implementation to DDD and ALTCS Support Coordinators so that Attendant Care and Habilitation hours are equitably evaluated based on the member's needs and to remove organizational bias of familial providers across the member's lifespan. Specifically investigate and determine appropriate DDD staffing needs and training for the members served in rural areas and those from minority backgrounds.

3. Create the option for private sector Support Coordination. Other states have this option within their Medicaid services, and this could be an additional feature in our DDD portfolio to allow for the member's needs to be best evaluated.

In conclusion, Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. By not allowing parents of minors to provide Habilitation and Attendant Care services or work over 40 hours a week most of the minor disabled community in Arizona will be underserved. A comprehensive Paid Parent Caregiver program validates the irreplaceable work that parents provide in their homes and communities.

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Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves all DDD and ALTCS members in Arizona.

Thank you and best wishes,

Laura Kimble
mom and provider to [redacted], [redacted] yrs, Down syndrome & hip dysplasia

[redacted]

From: Celeste Freeman [redacted]
Date: Wednesday, July 19, 2023 at 4:49:24 PM UTC-4
Subject: Parents as paid habilitation providers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To whom it may concern:
I am a single mom of 2 amazing children. My youngest, [redacted] qualifies for habilitation and respite care. For the past few years I have been able to be his provider which has made a huge difference for my family. [redacted] works on skills directly in relationship to being a positive functioning family member and self care. I have been able to make wonderful progress with him because of this extra income. If habilitation is removed as an option for me to be a paid provider, I highly doubt I'd be able to find a qualified caregiver to fill this role. If I do, I'll have to leave him in their care to work outside of the home on weekends, disrupting crucial family bonding time. I will also lose the ability to get healthcare through my agency due to lack of monthly hours. Keeping habilitation as a parents as paid provider position will offer my family the comtinued support we need, especially since my kids father is currently [redacted] and cannot support me in any way. Removing this opportunity will place more stress on my family. I urge you to include habilitation as a part of the permanent parents as paid providers plan. I so appreciate all you do for the kids of our state! Thank you!
Celeste Freeman

From: Erica Holwager [redacted]
Date: Wednesday, July 19, 2023 at 3:54:16 PM UTC-4
Subject: Our Family Story and why not allowing habilitation will hurt us all
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

As a parent of a child who receives DDD and ALTCS services I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility, and it has been extremely beneficial to our family and my childen. I would like to share my personal experiences and feedback based on my review of the current proposal for a permanent Paid Parent Caregiver program.

Under the current proposal, the request of an ongoing program option which allows parents of disabled minors in Arizona to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies is not being met. Please consider updating the proposal based on the following questions, suggested solutions, and personal experiences.

I have five young children aged [redacted] and [redacted]. Our [redacted]-year-old is on the autism spectrum. Our [redacted]-year-old twin girls are on the autism spectrum. Our 1-year-old twins are too young to be diagnosed but are currently in early intervention. There is a high possibility our family will have 5 children on the autism spectrum. Currently, only our [redacted]-year-old twins receive DDD/ALTCS services. My husband and I both work full-time and hold advanced degrees. The paid parent caregiver program pays significantly lower than our normal jobs. We choose to participate in it because it is very beneficial to our children and their development and the only way our kids can receive habilitation services. Between all of our kids we are seeing upwards of 40 medical specialists frequently to meet their needs. On top of that, every child is receiving some sort of therapy [speech, OT, PT] and/or multiple therapies. With this new proposal and removal of habilitation from the paid parent caregiver program there is no question that our girls will lose habilitation services for three primary reasons:

1. There is a major shortage of providers, especially in our rural area. We were lucky to even find a respite provider. The only providers available are typically available in the late evening, after our children are already asleep, because they have daytime jobs that they work.
2. It takes months for our girls to accept a provider into our home (even with highly qualified professionals such as an occupational therapist) and they have shown a strong history of low performance for anyone other than their parents. We (and them) are also uncomfortable with strangers working on a good portion of their goals such as toileting and

dressing, and
3. As stated above, our family schedule is incredibly complicated. We are able to plan habilitation around our schedule. We can wake up in the early morning and work on goals with the girls then immediately wake the rest of our family. We can find pockets of time within our normal day-to-day to work on habitation goals. We cannot do that with an outside provider. **We would have to reduce their hours by at least 90%** as that is the only time we can guarantee we can be available (versus the fluidity of finding time as it becomes available). With the respite program, we find time to ensure a work-home-life balance. I believe one of the largest arguments against allowing habitation is concern for our well-being. I can assure you that removing habilitation from our lives will be nothing but detrimental to our family, will result in a significant loss of much-needed habilitation time, and will overall leave our family in a much worse situation than when we first became involved with DDD/ALTCS. As we speak to other families with one or more children with special needs, it seems their sentiment matches ours. Our girls are making great progress with us in the parent provider habilitation program. It hurts our hearts that we will lose so much potential for their futures. It leaves us bewildered, confused, disappointed, and feeling a bit abandoned by DDD and ALTCS. Please consider including habitation in the paid parent provider program.

Should Habilitation be included in the Paid Parent Caregiver Program?
We have heard the concerns about member isolation and lack of community involvement if parents continue as Paid Parent Caregivers facilitating their child's Habilitation services. Respectfully the parent caregiver community proposes the following solutions:

1. Examine available research and personal feedback statements from members and their families to evaluate the true potential impacts of social isolation and community involvement when parents of disabled children provide Habilitation services. The parent caregiver community's collective experience is that members who have parents facilitating their Attendant Care and Habilitation services have experienced greater member social engagement and community involvement over the last [redacted] years. Parent caregivers now have an increased ability to take their children to sporting team practices, community events, movie theaters, all ability parks, church activities and libraries. This is because parent providers can perform the appropriately trained and qualified supports in the correct time and location that is applicable to each member.

2. Implement precise guidelines to facilitate generalization for all Habilitation providers regardless of the DCW's familial status. Habilitation services are designed to have goals where data is collected to evaluate if those goals need to be changed, have been met, or need to be addressed differently. For a goal to be considered met, a member should be demonstrating that they are able to successfully meet that goal outside of the timeframe with a provider in one setting. This is referred to as generalization. The effective implementation of generalization with the pediatric IDD population would lessen, if not eliminate, any complications with adult transitional services. Under this model a program that includes parents as paid Habilitation providers would actually assist and improve in the success of adult transition. There are times when disabled children work successfully with different types of providers in clinics or schools, but the parents are not carrying the work over at home. This can happen for a variety of reasons. Having parents as Habilitation providers would help ensure the child's goals are congruent and carried over in the home and community setting. This will give the member a better chance of independence as they transition through different life stages. With generalization policies in place, Habilitation services being performed by parent providers will actually help facilitate successful transition into adulthood.

3. We know from provider agency data that "the top 3 issues regarding recruiting and retaining career non-family caregivers are schedules of the client members, interest in

the position and finding qualified applicants.” Most members have Habilitation goals and ADLs that are most appropriately delivered throughout the natural routine of their day. A parent provider is uniquely available in the morning, after school or in the evenings when each member is motivated and focused on the pertinent task. If a non-family provider is available their schedules typically allow them to work in longer time chunks that are not always the most ideal for the member and creates artificial goal or ADL practice. Continuity of care and greater member outcomes can be associated with consistently provided Habilitation care by parent providers who have the greatest ability to be flexible and available for their member children.

How should current evaluation protocols, training and practices be updated to facilitate equality for all members when accessing member needs?

AHCCCS has stated their intention to amend applicable policy, further suggested action on this topic includes:

1. Forming a committee of community and department stakeholders to amend and critique current DDD and AHCCCS policies and need assessment forms so that the most effective and efficient implementation of this permanent option is utilized moving forward.

2. Provide appropriately determined training and program implementation to DDD and ALTCS Support Coordinators so that Attendant Care and Habilitation hours are equitably evaluated based on the member’s needs and to remove organizational bias of familial providers across the member’s lifespan. Specifically investigate and determine appropriate DDD staffing needs and training for the members served in rural areas and those from minority backgrounds.

3. Create the option for private sector Support Coordination. Other states have this option within their Medicaid services, and this could be an additional feature in our DDD portfolio to allow for the member’s needs to be best evaluated.

In conclusion, Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. By not allowing parents of minors to provide Habilitation and Attendant Care services most of the minor disabled community in Arizona will be underserved. A comprehensive Paid Parent Caregiver program validates the irreplaceable work that parents provide in their homes and communities.

Click here to connect with the Arizona parent led grassroot initiative leaders: www.raisingvoicescoalition.com

Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves all DDD and ALTCS members in Arizona.

Thank you!

Erica Holwager (and family)

From: Melissa Furrier
Date: Wednesday, July 19, 2023 at 2:31:19 PM UTC-4
Subject: Parent Providers Habilitation
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

My name is Melissa Furrier. I am an RN, and a special needs mom. I have worked in maternal health and obstetrics for over [redacted] years at [redacted]. Nearly [redacted] years ago I gave birth to my incredible daughter. She came into this world with a number of surprises that we did not anticipate. She was diagnosed at [redacted] days old with an extremely rare chromosomal anomaly, Trisomy 9p. We were told that she was the [redacted] person in the world to ever receive this diagnosis. While this diagnosis was being presented to us, by a physician in the NICU that I worked with on a regular basis and knew me well, she asked if I planned on returning to work, my mother-in-law asked, "Will she be able to?" The doctor replied, "We will see how things go."

Over the course of the next [redacted] years, I learned how to be a special needs parent, it was an entire skill set that most people never acquire on their parenting journey. I had to learn how to be a physical therapy assistant, an occupational therapy assistant, and a speech therapy assistant, after the appointments were over the therapy was not. The therapist teaches the parents the exercises, and skills these children need, and we continue the therapies at home between appointments. Nothing can be accomplished in a one-hour appointment, it takes consistency and determination to reach these milestones that are so hard won by our tiny warriors. Fortunately, I already had the skills to help with the medical needs, and some of the advocacy skills nurses learn along the way became invaluable.

My daughter didn't walk until she was [redacted], didn't start using 3 world phrases until she was [redacted], and is still working on 5-word sentences. She has had [redacted] surgeries, [redacted] of which required complete immobilization at the age of [redacted] in a full body Spica cast for [redacted] months. She required around-the-clock care, changing diapers, repositioning every 2 hours to avoid pressure wounds, and medicating for muscle spasms and pain. One of our Habilitation goals is potty training. This is an ongoing skill we are working on to this day. She has frequent daytime accidents, that require personal care, clothing changes, and oh the laundry. Navigating the world with a child whose abilities are different takes more, more of everything. More energy, more emotion, more patience, more strength, more understanding.

Along with meeting her needs, I had to learn to meet my own needs under an entirely new set of circumstances. I have had to get past the embarrassment of public potty accidents, meltdowns, and when people try to talk to my child she responds in a way much younger than you would expect a child her age to. I have grown as a person, and I am proud of who I am today. My family dynamics changed, my role became more demanding and diverse. My ability to juggle my role as a bedside nurse was challenged. My relationships with friends and family changed, some for the better, some for the worse. But, I would do it all again for her, I am proud to be her mom, and will continue to fight for her and everything she deserves. She is my number one. Being able to be her Habilitation provider has made that role easier for all of us.

She is vulnerable, she cannot communicate the way children her age, or even how much younger children can. She doesn't understand safety, and right from wrong in the same way other children do. That is my role, to keep her safe, to protect and guide her. Only a parent can do that.

In [redacted] I became a habilitation provider for my daughter. The role utilizes a multidisciplinary approach that integrates therapy techniques from, occupational therapy, physical therapy, and speech therapy. I regularly communicate with her entire care team to meet the goals we set. This has allowed us to have a continuity of care that no one other than a parent can provide. We have made significant progress on potty training, bathing, dressing, transitions between activities, and using speech during activities of daily living.

We have been able to ingrate therapies and goals into everyday life and social activities that help normalize her life. Having the ability to provide this care for her has helped us integrate into the community more, and provide her with increased social interactions, for both herself and me. We have been able to find support and communities that fit our needs as a family and enhance our lives.

Our experience finding habilitation, respite, and other therapists has been challenging, vendor calls have been placed time and time again, often times with no response. I am not alone in this experience, countless families are placed with providers after waiting for months, only to lose the providers shortly after. This is very disruptive and creates more chaos than any amount of support it gives.

I'm immensely grateful for the opportunity to be able to work at home with my daughter and provide her with all of the things she needs to maximize her potential. We have to put our kids' needs first, and allowing a parent-provider program permanently that includes Habilitation is a step in the right direction. Please listen to the families of these children. We are what they need.

Thank you,

Melissa Furrier

From: Penny Muir [redacted]
Date: Wednesday, July 19, 2023 at 1:36:59 PM UTC-4
Subject: Parent Provider Program
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

As a parent of a child who receives DDD and ALTCS services I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility, and it has been extremely beneficial to our family and my child. I would like to share my personal experiences and feedback based on my review of the current proposal for a permanent Paid Parent Caregiver program.

My son has autism and cerebral palsy. He is [redacted] years old and has a neuro-typical, typically functioning twin brother. As a mother of twins, I have a unique perspective in that I know precisely what level of care can be attributed to my son's disabilities as compared to the care required for a child his age without disabilities. I am specifically disappointed that continued parent provider delivered habilitation is not included in your proposal. My son was granted habilitation about [redacted] years ago. For the first year, we worked with an agency who promised to find a provider and we waited....and waited....and waited. Finally, my husband went out and recruited a college student. It took more than a month to onboard with an agency but then we finally had a provider....until the agency decided to start assigning her to other families and we lost our coverage. So we started over. In total we have worked with four different agencies and have had six different care givers. Every single care giver was identified by my husband. We have experienced 3-12 month periods without a provider. We have experienced same day cancellations, requests to leave early, showing up late with no notice, and quitting without providing sufficient notice to locate a replacement. Habilitation is very important to us. We worry daily about how our son will survive when we are gone and how much of a burden we will leave to his twin brother. It is too important to be left to the chance that there is a well qualified non-parent provider available for continuous services.

Regarding concerns of social isolation and care giver burnout, you are correct that these are issues we face. There are just some places I will not take my son because it can become a dangerous situation for him. But this is even more true of a habilitation provider who is less experienced with him and also restricted from certain actions such as administering medication that can help him to calm down. My son has been skiing, to Disneyland, sailing, to the Grand Canyon, horseback riding, surfing, multiple water parks and has participated in many group activities. Generally, the activities that are successful are ones that were designed to be inclusive. Social isolation isn't because of us or my son, it's because of society. Whether the person delivering services is family or not will not change that. You are also correct that parents are burnt out. My son is up before 4AM on a regular (multiple times per week every week) basis. If he doesn't have constant supervision he does things like throwing glass into the garbage disposal, throwing non-waterproof toys into the pool, ripping up a king size mattress because of one lose thread, breaking his tablet. Yes, it's exhausting. We are on 24/7. Even if we have care providers, it's only certain hours of the day and you never know when coverage will be interrupted. If you want to prevent burnout, maybe ask people what they need and do that.

At this time, my family is fortunate enough to have resources in place such that we can afford to be a one income household so that my husband is available to care for my son. I know there is a legal obligation/expectation to care for your child. However, if you compare the time required for my typically-functioning son to my son with disabilities, it's well over 40 hours per week in additional care required. We don't "need" the money from the parent provider program but it sure has reduced the stress level in our family. We don't worry when things get broken, or when we have to spend nearly $1000 on a special needs stroller, or we pay for activities and have to leave because my son is having a rough time. We can also save for my son's future when we are no longer here to care for him. If my son needs the care and someone is going to be paid to do it, why does it matter if it's family (inlcuding parents) or not? The 40 hour cap seems arbitrary to me, particularly if both parents are providing care. If I were a family with fewer resources, I cannot think of a better way to improve the quality of life for the entire family, including the member.

Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves all DDD and ALTCS members in Arizona. This and the ESA program are literally the only things keeping us as residents of Arizona.

Thank you!
-Penny Simpson, mother to [redacted].

From: Jessica Nolte [redacted]
Date: Wednesday, July 19, 2023 at 12:57:06 PM UTC-4
Subject: Habilitation should be on 1115 Waiver
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Good morning,

Yesterday we had the public comment on the proposal to make parent provider permanent in the state of Arizona. This is a great accomplishment and will increase the quality of life of people with disabilities and their families.

Habilitation not being included is a HUGE mistake. There is no real reason why it shouldn't. The answers AHCCCS gives as to why are misleading at best. There is no data to support providing HAH increases isolation or burnout - the opposite is true. You have hundreds of parents sharing their experience on how it improved their quality of life and directly helped kids learn in the community.

Most HAH non-parent providers would not have the skills and safety awareness to take our kids out of the house, they just stay home working on goals because they and the caregivers are afraid of big meltdowns and/or elopement. A parent is uniquely qualified to understand the struggles of going into the community but also pushing for their kids independence and growth.

As to the question of how to prevent burnout out: providing mental health services for caregivers should be the first step. I currently receive therapy services through a non-profit organization Care 4 Caregivers and it has literally saved my sanity in many occasions. Finding programs like this will directly mitigate caregiver burnout by giving them a safe space to talk about the unique challenges of the disability community.

Another way is increasing Respite hours. During the pandemic respite was increase and it made a difference in my life and family. After years of looking for a provider we finally found someone that is a perfect fit for us - mind you I had to find and hire someone on my own since there was no one available with our agency. The only person they found came once or twice and then simply didn't show up or responded texts/calls.

I want to conclude by emphasizing there is a caregiver CRISIS, it's near impossible to find qualified providers and even when we find them they don't stay long term. College students are always moving and changing schedules, our kids need consistency and support from people they know and trust.

Please reconsider eclipsing Habilitation from the waiver and make the life of thousands of disabled kids brighter. The goal is independence and HAH is an amazing tool for it.

Sincerely,

Jessica Nolte

From: Kristal Van Boven [redacted]
Date: Wednesday, July 19, 2023 at 12:55:28 PM UTC-4
Subject: 1115 Waiver
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

As a parent of a child who receives DDD and ALTCS services I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility, and it has been extremely beneficial to our family and my child. I would like to share my personal experiences and feedback based on my review of the current proposal for a permanent Paid Parent Caregiver program.

Under the current proposal, the request of an ongoing program option which allows parents of disabled minors in Arizona to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies is not being met. Please consider updating the proposal based on the following questions, suggested solutions, and personal experiences.

A lot of my daughters hab goals are things she does in the home. Do they think a random hab provider should be teaching her to put her underwear/bra on the right way? What about bathing and cleaning up after? Should a stranger be doing that?

As a parent I feel like they could care less about my child's well being and comfort the world for her is already so hard! No one will understand our living situations unless they are living it. My daughter loves routine and consistency. No one will care for my child the way I do or have the patience that I have for her.

I have to say, not only am I super disappointed Hab isn't included but I was thinking we'd at least have until Sept 2024 now it sounds like we have until Nov 2023 which is 4 months. 4 months to try and find a good provider seems pretty impossible to me especially with our record on hab providers. The turn over is high and reliability none existent.

The high turn over rate of workers is detrimental on our children's comfort level and progress when they finally bond with a provider, get comfortable with them, begin making progress and then the provider leaves and is suddenly replaced with a stranger? This happened so many times to my daughter and it was so detrimental for her.

Please understand that taking away hours and stating "parent burnout" while knowing there is a DCW shortage you are removing the financial part for us that helps us not feel so burnt out. You are literally add extra stress as now we're even more worried about money and having to find a DCW who may cancel on us at any moments notice as well. How does that help our children at all?

In the end, I just feel very ignored

Thank you for your time,

Kristal Van Boven

From: Jennifer Renzulli [redacted]
Date: Wednesday, July 19, 2023 at 12:52:19 PM UTC-4
Subject: Paid Parent Habilitation Caregiver
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

My name is Jennifer Castine, I am a parent of a child who receives DDD and ALTCS services. I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility and it has been extremely beneficial to our family and my child who receives these services. Based on my review of the current proposal for a permanent Paid Parent Caregiver program I would like to share our story and give you my feedback. Thank you for your time and consideration while reading my experience and suggestions.

When COVID hit there was a lot of uncertainty. We already were struggling to find providers that actually showed up and put in the effort/cared. We had a lot of no call no shows, people being on their phones, being late/leaving early, the list goes on and on. We wasted SO much time finding a provider and then when they dropped off finding another one and going through the "get to know you" process all over again. The turnover rate of providers is very high. We were on a hamster wheel constantly going in circles. It was heartbreaking not only for me but for my son because transition isn't easy for him. He would get to know a provider and then they would leave and we would have to do it all over again. Many of his habilitation goals are regarding his Personal Care (showering, potty training, dressing, brushing teeth, etc.) which only added to the difficulty of having so many providers leave. His Personal Care goals for Habilitation are very private things and it was always difficult for him to have a stranger see him in such a way, for example on the potty. When parents were approved to become Habilitation providers for their children it changed our life in so many positive ways. Consistency for one, we created a routine so he knew what to expect each day during our Habilitation time. He thrived! Noone knows my son better than I do so it cut out the time wasted on "getting to know you" and he was comfortable with me working on his private Personal Goals. He made more progress with me than he has with any other provider. Not only has he made enoenormous strides but this has also helped our family financially. When my son was born, our family had the plan that my husband and I would go back to work full time. Well, life had other things in mind. With the amount of time and care my son needed I wasn't able to go back to work and that did have a financial impact on us. Since being able to do parent Habilitation it has given us that extra income that we put back into our son. During the past few years, we have been able to sign him up for drawing classes, Lego classes, sports and so many other things that allow him to just be a kid outside of school and therapy. I know seclusion was one of the concerns and I can assure you this program did quite the opposite for my son. He was able to engage more with his peers and the community. After attending the zoom meeting yesterday and hearing that if the current proposal passes as is we will loss Hab in November was heartbreaking especially originally think we had until September 2024. The idea of trying to find a reliable provider in 4 months is near impossible. If seclusion is a concern for Parent Hab, is it possible to put that 1 goal be required as a community outing or a social gathering? As for parent burnout, it will be more stressful finding a good reliable provider and worrying about my son regressing compared to being able to do it myself.

I know I am just one voice of many that this program has helped tremendously in more ways than one. Please help me help my son by keeping Paid Parent Habilitation.

Our community of parent caregivers is asking for a permanent program that allows parents of disabled minor children to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies. Under the current program proposal this request is not being fully met. Please consider the following suggestions:

> Include Habilitation as a service parents of minor DDD and ALTCS members can perform as a certified DCW provider. Parents of adult DDD and ALTCS members can currently perform both Attendant Care and Habilitation hours for their children and parents of the minor population would like this permanent option to mirror that program allowance. The DCW workforce shortage applies to Habilitation providers just as much as it does Attendant Care providers. Habilitation services fulfill the member's "personal care" needs by allowing them continual practice with their own personal care and rehabilitation. The only difference in Attendant Care and Habilitation personal care is that an individual receiving Habilitation can perform their personal care partially and needs assistance mastering these skills. There has been massive improvement to the IDD population in Arizona since parents of minors have been able to provide this service at the correct time and place that is applicable to the member. Parents being paid as Habilitation providers was allowed under the Covid-19 flexibility program and the ARPA program extension as a "personal care" service and we would like to continue to have it as a permanent option.

Habilitation services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. Parent caregivers have been the backbone of the Developmental Disability Community for decades. A comprehensive Paid Parent Caregiver program which includes Habilitation services validates the irreplaceable work that parents provide on a daily basis in their homes and communities.

Click here to connect with the Arizona parent led grassroot initiative leaders: www.raisingvoicescoalition.com

Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves DDD

and ALTCS members in Arizona.

Thank you!

Jennifer Castine

From: Elizabeth Jorgensen [redacted]
Date: Wednesday, July 19, 2023 at 12:27:28 PM UTC-4
Subject: Parents as Paid Providers Comment
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello -

I wanted to provide written comment on the 1115 Waiver

With the current allowance for parents as paid caregivers I have seen a large increase in parents who have never asked for ATC and call the support coordinators to request the service "so I can get paid." Many of these are families of very young children. They are not requesting due to lack of providers but because an agency has told them or another parent that they can get paid 40 hours to care for their child. I see the providers not trying as hard to find other support staff outside the parents and some actively recruit parents by calling which I fear my drastically reduce outside recruitment efforts for those parents who actually prefer outside help. There can be an open vendor call for RSP and they will contact the family and ask they to request ATC.

I think if this is going to continue there should be stricter parameters on eligibility. The assessment can be vague and parents often exaggerate times (60 minutes for cleaning daily, 30-60 minutes per meal daily, etc.) and it can be difficult to assess for what is more reasonable times when the family insists and is coached into saying thing. It was noted that this was for extraordinary demands yesterday on the forum but it was not clear what constitutes extraordinary. All parents of 3 year olds assist with dressing, grooming, cooking, laundry, cleaning etc. It is the normal demands of being a parent. I see this as a way to pay parents to take care of their kids. If a child has extensive needs that the parent cannot work, or the child has extensive needs over and above normal parenting responsibilities I think it would be different. I would love the rules and regulations to capture that so that the support coordinators can have more backing and understanding when they assess for services.that it is what is not considered normal for the age of the child. Otherwise it opens to interpretation and it is very hard to try to have assessments when parents are coached by outside advocates.

I would also like strict oversight from the agencies to ensure the services are being provided as requested. I also would love to have oversight and training with providers and families to remind them that they are responsible for Article 9 and following it when being paid. I find it highly unlikely that many paid parents of young children such as 3-5 are not restricting rights by time outs, saying no, do this then we can, etc. It is common nature of being a parent and teaching consequences at that age. I think the lines get blurred very easily between parent and paid and we need a way to make sure that the law is being followed.

Thanks,

Elizabeth Jorgensen Winslow

Support Coordination Supervisor
Division of Developmental Disabilities
[redacted]

[redacted]

[redacted]

From: Sophia Chacon [redacted]
Date: Wednesday, July 19, 2023 at 11:57:45 AM UTC-4
Subject:
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Good morning,
I attended yesterday's forum via zoom . I am shocked at how quickly things are changing for the Parent Provider program. I have a [redacted] year old son whom I provide HAB for.
My son [redacted] has ASD and is non verbal.To say the Parent Provider program is a blessing is an understatement. Before this program started , I struggled to find a Respite provider.I had one for two weeks who then quit for reasons unknown. Even then I was clearly very uncomfortable with a stranger working so closely with my son whom is unable to communicate any incidents to me. My boy is very friendly and trusting and that is actually one of our HAB goals, to make him aware of stranger danger and how to keep himself safe. I have worked closely with him on all of his goals to ensure my son's ability to be independent. Even now at [redacted] years old , he functions mentally at a [redacted] or [redacted] year old. He requires lots of patience , consistency and can get very angry or violent at times. Not a lot of people, besides a parent can handle these situations properly. I am not the least bit worried about parent burnout , there is no such thing in my mind. We have to function as parents of disabled children regardless.The monetary compensation allows me to stay at home and be a hands on parent for once in my life. With inflation and the high cost of living these days I am allowed to stay home and be less stressed and be able to focus more on my son, home and family.I can have more time ith my son to work on his goals and transition into adulthood with a familiar person. I feel a stranger can actually hinder the advancements we have made . I can put my hands on my child and show him how to brush his teeth, and wash properly behind his ears . I can sing to him and read to him at night when he has a hard time sleeping. I show him how to make his bed and which items to shower with. A stranger cannot. I will be here at 6 in the morning to wake him up for school and struggle to get him to school, a stranger will not.I will show him proper private hygeine techniques, a stranger will not do these thinscrepeatedly for an ASD child. It takes patience , commitment and lots of love to make these things work for a special needs child. Please take all of these factors into consideration when determining if the Parent Provider program will continue. It is much need for my child to succeed as an adult .
Thank you ,
Sophie Chacon

From: Holly [redacted]
Date: Wednesday, July 19, 2023 at 11:40:38 AM UTC-4
Subject: Please read Ahcccs and 1115 waiver team
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To Ahcccs and 1115 Waiver Team:

Hello! My name is Holly Brittain I am a mother to a [redacted] year old Level 3 non verbal Autistic Daughter. I have been lucky enough to have the opportunity to be my daughter Habilitation provider. I'm being her provider I've been able to get her out inyo the community and interact with her peers and other community members while making her feel safe, secure, and comfortable.

We have multiple Habilitation goals outside of our home like helping her learn to get safely to the car, getting in and out of the car as well as eloping. We have been working very hard in getting her to notify or remember to let us know when she is ready to transition. I feel as being her provider has empowered her to remember " I need to tell an adult I'm ready". I have noticed she is starting to understand that any adult that is within our group is a safe adult to go to when she's in the transitional period.

Another goal we've worked on outside of our home is stranger danger. She used to go up to any stranger and grab them and with my help being able to help her learn that has decreased by %50. I believe with me being home with her has helped her understand who is strangers are who isn't. Having an outside provider come in will restart all the progress in this specific goal. Having a stranger come in will tell her it's okay to approach strangers and it definitely is not especially in this day and age.

Since becoming her provider we have been so social and out in the community so much than it used to be. when we couldn't find an outside provider and I had to be at work away from her with no one to help her.

We have tons of goals at home as well, we have hygiene, dressing and potty training goals. I'm sorry I don't feel comfortable with a random person off the street coming in and doing these very personal tasks with my nonverbal child. My child is unable to tell me if someone has harmed them or touched them inappropriately and I just don't feel our family will benefit from

and outside source.

The financial aspect of all of this has afforded me to be able to be home with my daughter and not leave her with strangers. It has decreased everyone's anxieties in the home whether from have a consistent schedule and not worrying about our financial situation at much while watching the growth and the goals my daughter is consistently teaching with the help of me.

Please don't take Habilitation away, we as parents need it and our children deserve it. They don't deserve a constant in and out of strangers that aren't consistent and at the end of the who don't know and we can't trust with our non verbal little ones.

Please reach out if you have any questions
Thank you,
Holly Brittain.

---------- Forwarded message ---------
From: Kristen Willie [redacted]
Date: Wednesday, July 19, 2023 at 11:36:06 AM UTC-4
Subject: Parents as Paid Providers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

One of my main concerns, since HAH is not currently included in this plan, is that many families will request Attendant Care instead of Habilitation (which would likely be the more appropriate service). By keeping HAH out of this, we will likely see more being done **for** the members and less taught **to** the members resulting in increased dependence on the system, instead of learning skills to improve self help, socialization, etc. skills.

Thank you for the presentation and information presented. It was very helpful!

Kristen Willie
Human Service Unit Supervisor
Department of Economic Security
Division of Developmental Disabilities
[redacted]

DES Logo

Sign Up for Member Updates

DDD Actions Related to COVID-19

Provider Search: https://ddd.azdes.gov/Organization/DDD/DDDProviderSearch

From: Daniel Paula [redacted]
Date: Wednesday, July 19, 2023 at 2:38:00 AM UTC-4
Subject: Urgent: Maintain Comprehensive Care in the Parents as Paid Caregivers Program Proposal
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>
Cc: Susan.Kennard[redacted]

ATT: AHCCCS,
c/o Division of Community Advocacy and Intergovernmental Relations,
801 E. Jefferson Street, MD 4200 Phoenix, AZ 85034

Dear AHCCCS Team,

I trust this message finds you in good health. I write as a deeply concerned community member regarding the proposed amendment to the Parents as Paid Caregivers program.

I appreciate your intentions to compensate parents who tirelessly care for their Medicaid-eligible children. However, the proposal, as it stands, falls short of providing a comprehensive solution to the complex challenges at hand.

The focus on attendant care hours (ATC) seems too narrow when considering the full spectrum of parental caregiving, which often extends beyond specific hours and requires a 24/7 commitment. The real-life stories of numerous families in our community underscore this very fact. By not accounting for all needed hours, we risk undervaluing the time and effort parents put into their children's care.

The decision to exclude and subsequently eliminate habilitation hours, effective November 2023, raises substantial concerns. Habilitation services (HAB), crucial for helping children learn and maintain daily living skills, are integral to the care spectrum. The exclusion of these hours compromises the quality and comprehensiveness of care provided to these children.

There is no viable alternative now other than the parents providing HAB hours themselves.

Moreover, it’s distressing that there appears to be no data backing the assumption that excluding habilitation hours will alleviate the caregiver shortage in Arizona. Any amendment of this magnitude should be grounded in robust evidence, which appears absent in this case.

The scheduled elimination of habilitation hours in November 2023 threatens the continuity of care for children under this program. An abrupt interruption of such critical services may lead to potentially severe repercussions on the health and well-being of these children.

Finally, eliminating habilitation hours does not offer a sustainable solution to Arizona’s caregiver shortage. Instead, it places an undue burden on families, forcing them to provide essential services without any compensation.

This shift is not a solution but a penalty for families already under significant strain.

In our family’s specific situation, HAB represents 60% of the total weekly service hours. Unless this proposal is changed or the lack of DCW supply is magically resolved, this will become a free unpaid service the parents will provide. This is unfair and detrimental to families' mental and emotional health.

I urge you to revisit the proposal and expand its scope to cover **both** Attendant Care **and** Habilitation hours. By doing so, we can ensure a holistic approach that caters to the real needs of Arizona’s families and children.

To work toward a solution that truly benefits our community, you must amend the proposal, so we can build a program that offers comprehensive care, reflects our commitment to children and their families, and effectively addresses Arizona’s caregiver shortage.

Thank you for your consideration. I am excited to foster a dialogue that brings us closer to our shared objectives.

Yours sincerely,

Daniel and Drausia Paula
1212 East Zion Way, Chandler/AZ
85249 | [redacted]

From: Rebecca Buck [redacted]
Date: Wednesday, July 19, 2023 at 2:24:23 AM UTC-4
Subject: Parents as Paid Caregivers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

As a parent of a child who receives DDD and ALTCS services our family has participated in the Paid Parent Caregiver program under the Covid-19 Flexibility, and it has been extremely beneficial to us and my child [redacted]. I would like to share my personal experiences and feedback based on my review of the current proposal for a permanent Paid Parent Caregiver program.

[redacted] was born during the Covid-19 Pandemic and suffered a massive stroke at [redacted] days old. Once [redacted] was approved for HCBS services around [redacted] months old I had made mention that I heard parents were currently being paid for them and my service coordinator shut that idea down. I didn't know what what what yet so I left it at that. I later found out that she was required to at least do an assessment so I asked for one in writing. [redacted] was approved for 21 HAH hours. These are the hours the current proposal is set to not allow parents to do. I was eventually able to get an assessment done for the ATC hours after providing proof that I am disabled also because our service coordinator said that children under three don't qualify for ATC unless there is a special circumstance. [redacted] was approved for 24 hours of ATC. It has taken over 7 attempts at finding provider, most of which not lasting more than a day. Plus 4 different agencies to find a decent provider. Sadly she just found a better paying job and put in her notice. Her last day is [redacted]. I'd pay her the difference if I could. My [redacted] year old son is going to miss her dearly and I've never had to explain to him before that some people don't come back.

I really appreciate your work to make the Paid Parent Caregivers program permanent but it makes no sense to put limitations on Habilitation or who can collect how many hours. I'm confident that if you did an audit on how many DCW are actually available to meet the needs this proposal would create, the numbers simply aren't there.

Under the current proposal, the request of an ongoing program option which allows parents of disabled minors in Arizona to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies is not being met. Please consider updating the proposal based on the following questions, suggested solutions, and personal experiences.

Should Habilitation be included in the Paid Parent Caregiver Program?

We have heard the concerns about member isolation and lack of community involvement if parents continue as Paid Parent Caregivers facilitating their child's Habilitation services. Respectfully the parent caregiver community proposes the following solutions:

Examine available research and personal feedback statements from members and their families to evaluate the true potential impacts of social isolation and community involvement when parents of disabled children provide Habilitation services. The parent caregiver community's collective experience is that members who have parents facilitating their Attendant Care and Habilitation services have experienced greater member social engagement and community involvement over the last three years. Parent caregivers now have an increased ability to take their children to sporting team practices, community events, movie theaters, all ability parks, church activities and libraries. This is because parent providers can perform the appropriately trained and qualified supports in the correct time and location that is applicable to each member.

We know from provider agency data that "the top 3 issues regarding recruiting and retaining career non-family caregivers are schedules of the client members, interest in the position and finding qualified applicants." Most members have Habilitation goals and ADLs that are most appropriately delivered throughout the natural routine of their day. A parent provider is uniquely available in the morning, after school or in the evenings when each member is motivated and focused on the pertinent task. If a non-family provider is available their schedules typically allow them to work in longer time chunks that are not always the most ideal for the member and creates artificial goal or ADL practice. Continuity of care and greater member outcomes can be associated with consistently provided Habilitation care by parent providers who have the greatest ability to be flexible and available for their member children.

Should parent providers be limited to 40 hours a week of paid care per child?

We have heard the concerns of AHCCCS on why they want to limit parents to 40 hours a week under the Paid Parent Caregiver Program. The parent caregiver community would like to propose the following collaborative solution to create a win-win scenario:

Create a program provision that outlines an extraordinary circumstances clause and the application process that allows parents to provide over 40 hours of paid care per week of authorized and evaluated services per member. These extraordinary circumstances could include, but are not limited to:

The lack of a non-parent DCW being available in the last 3 months to fill the member's assessed hours that exceed 40 hours per week. Ongoing DCW searches should continue to be made by the member's agency to fill the assessed hours beyond 40 hours per week of Attendant Care and Habilitation.
The expressed desire made by a member for a parent caregiver to facilitate their assessed DCW hours so that their Article 9 rights are honored.
The profound disabilities and/or significant behaviors of a member where a non-family provider is not equipped to provide DCW support. This determination can be made through a stakeholder team approach, including but not limited to the member's, DDD Support Coordinator, DDD Nurse, DDD Supervisors, Behavioral Plan Experts, Parents / Guardians, Psychologist, or Medical Doctor.
Form equality between all Family Provider Programs by allowing all Direct Care Workers, regardless of familial relationship or member age, to provide up to 16 hours of paid care per day. This will allow for employee equality across the lifespan of the member and limit the potential anti-family provider rhetoric currently present within state policies and DDD Support Coordination culture. All evaluations of hours should be based on member needs regardless of who is providing the services to create uniform implementation of all applicable HCBS services by the DCWs available to fulfill those hours.
The Family Support Program currently in this proposal addresses caregiver burnout. It is one of the available solutions to facilitate further community support within the disability and caregiver community that will provide greater access to non-profits facilitating counseling services, support groups and meet up activities.
Reevaluate Respite reimbursement rates to also address caregiver burnout. If Respite services are not available to the member or their family, parent burnout will continue to be an issue regardless of parents having the option of providing Attendant Care or Habilitation hours. With a comprehensive Paid Parent Caregiver Program in place non-family DCW providers will have greater flexibility to provide Respite services to these same families.

How should current evaluation protocols, training and practices be updated to facilitate equality for all members when accessing member needs?

AHCCCS has stated their intention to amend applicable policy, further suggested action on this topic includes:

Forming a committee of community and department stakeholders to amend and critique current DDD and AHCCCS policies and need assessment forms so that the most effective and efficient implementation of this permanent option is utilized moving forward.
Provide appropriately determined training and program implementation to DDD and ALTCS Support Coordinators so that Attendant Care and Habilitation hours are equitably evaluated based on the member's needs and to remove organizational bias of familial providers across the member's lifespan. Specifically investigate and determine appropriate DDD staffing needs and training for the members served in rural areas and those from minority backgrounds.
Create the option for private sector Support Coordination. Other states have this option within their Medicaid services, and this could be an additional feature in our DDD portfolio to allow for the member's needs to be best evaluated.

In conclusion, Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. By not allowing parents of minors to provide Habilitation and Attendant Care services or work over 40 hours a week most of the minor disabled community in Arizona will be underserved. A comprehensive Paid Parent Caregiver program validates the irreplaceable work that parents provide in their homes and communities.

Click here to connect with the Arizona parent led grassroot initiative leaders: www.raisingvoicescoalition.com

Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves all DDD and ALTCS members in Arizona.

Thank you!

From: cynthia keethler [redacted]
Date: Wednesday, July 19, 2023 at 2:11:31 AM UTC-4
Subject:
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

I attended the webinar today and I have a [redacted] year old autistic son that I am rehabilitating. I am asking that you please extend this program to include us parents who are rehabilitating.

Thank you,
Cynthia

From: Nichole Fernandez [redacted]
Date: Wednesday, July 19, 2023 at 1:17:25 AM UTC-4
Subject: 1115 Waiver Amendment - Public Comment
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello.

I previously submitted a letter and also attended today's public comment forum in response to requests for public comment. I appreciate the opportunity to provide input and comments, and am grateful for the time and attention you are giving to this issue.

My daughter has had HAH and Respite services for years, but we lost both of our providers in early [redacted] and have been unable to replace them.

During that time, I have worked from home as an independent contractor for a nationwide resume company, which provided excellent flexibility, but I have recently had to begin looking for other work due to not having consistent, regular income. Because of a lack of knowledge of our SC or their CM, we have ATC hours approved, but not yet released, because they want a schedule of my work hours outside the home before they do so. But many fellow parent providers tell me their SCs say they are not allowed to use ATC hours to work. The lack of understanding about this program really needs to be addressed with specific training for all family support individuals.

I'm a new parent provider (for HAH only right now due to lack of ATC hours released) - going into my [redacted] week - and honestly really never set out to be one. However, as I both need to work and cannot work because someone needs to be here for my disabled child, this program covers both needs for now. The news today that HAH would end as of November 2023 was both worrying and disheartening.

For our family, HAH hours cover a specific subset of therapeutic goals and activities including stretching, massage, range of motion exercises, fine motor skill development, communication development, and self-care and hygiene activities. The department's guidelines for socialization and community involvement with someone other than a parent are just not appropriate for my [redacted] year old at this time. This feels like a concern and goal more oriented toward adult members, and I feel like HAH goals and guidelines need to be specific and separate for minor children versus for adult members.

When I left my job [redacted] years ago to first care for my disabled child, it was with full intent that I would one day return to my career. I would LOVE to work, but have embraced the sacrifice of being here for my child for as long as it's needed.

This program currently allows me to do so - at least until November 2023 with our current service hours. It is a wonderful thing, truly. But providing full-time care for a disabled child does leave me grappling with the opportunity cost of losing out on career advancements, having a large gap in employment, and being unable to have full-time employment because of a lack of availability of direct care workers.

The current lack of workers makes me concerned about what will happen in November and beyond, when there's a further need for providers due to parents being unable to provide HAH, but not enough workers to provide services.

Providing this direct care myself also really puts me face to face with my child's care in ways that are challenging, and very unique to caring for my disabled child versus my typical children. That is a valid concern for parent providers. At the same time, while care can sometimes can be outsourced, most times, it really does make a huge difference for a parent to provide these services for a child. A parent provides an in-depth knowledge, commitment, and continuity that is truly unique and extremely rare to find in providers who are not family members.

I really appreciate the opportunity to express these thoughts. I appreciate your work and time and advocacy on behalf of parent providers in Arizona.

Thank you sincerely for your time and effort.
~Nichole Fernandez

[redacted]
From: Kellie Barnard [redacted]
Date: Tuesday, July 18, 2023 at 11:59:37 PM UTC-4
Subject: Habilitation Services
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

My name is Kellie and I wanted to tell you about my [redacted] year old son. When he was [redacted] years old, we sat across from a team of doctors as they explained that my child had autism. We were told a list of things he would never be able to do. I researched for months every book I could get my hands on to figure out ways I would be able to both communicate and understand my son. As he got older, we once again sat across the room from a team of doctors as they informed us that not only did he have autism, but an intellectual disability as well. I can tell you, that as a mom, my heart shattered and I grieved over the child I had hoped to have to my new reality. We were again told all of the things my son would never be able to do, and all of the reasons why they weren't willing to even try to teach him how to read or write, or work on basic skills— because he wasn't capable. I felt lost and alone and didn't know where to turn. I again did all of the research I could possibly get my hands on. We decided to homeschool him where we could hire tutors that specialized in autism and intellectual disabilities. I researched every possible way to teach and tried everything I could. My son is learning to read, and write. He met milestones that doctors said he would never reach; because I care more about my child than any doctor in that room. I was willing to try when no one else would.

We put my son in multiple therapies… many services were in home and they would venture out into the public setting. They went with him everywhere working on goals and services. Though he grew a lot with the therapists, he fell into a deep depression. He was unable to explain what his therapists had said or done that made him upset. He closed off communication saying he no longer trusted people…. That his only friends took notes on him, and they were his therapists. Though he felt like he was benefitting from therapy, he felt different as he always had someone with him. He didn't want to be near friends because he didn't want to explain who this person was who followed him. He felt like they were invading a big part of his privacy. As a parent, we didn't know what was being said or how the goals were being carried out. We didn't understand how therapy— things that were supposed to help our son, could possibly spiral him into suicidal ideation. It was suggested that we pull him from therapy and start Habilitation instead, with me as his mom, being his provider. This was honestly the best thing we have ever done. Not only do I know and feel apart of his goals—

but I fight every day to research and find creative ways to meet his needs. I feel like I am better equipped with training and classes to be the best support for him. My son is very slowly coming out of his depression— he started smiling again. He explained that he feels like he can be more like a regular kid, because all kids have a mom. He doesn't feel the need to explain; he doesn't feel different. He is willing to talk to about his goals and how he feels about them because he feels like he can trust me.

I ask the board to please reconsider taking away the HAB role for Parent Providers. I understand that burnout is a concern, but I assure you that I feel more empowered and so does my son. It is so helpful to not have to worry about what is being said or done that he can't communicate effectively back. The classes and training have helped me so much in knowing how to deal with certain situations that have arisen that I didn't know what to do before. My family doesn't have to worry about mom having a second job anymore— it has been incredibly difficult to pull away from my son when he is in the middle of suicidal contemplation to have to go back to work— and pull my attention away from my son because "the therapist can handle it". As a parent, it is helpful to know that the person who he trusts and knows have fought for him since the beginning; is there when he needs them the most. He needs his mom and I ask that you don't take that away from him.

I ask that you reconsider taking away parents as a paid provider for habilitation services and consider the possibility of allowing parents to continue providing services for their children. If burnout is a concern, I would suggest that you offer support to parents in terms of therapy, training, and classes. Having Support Coordinators who reach out with resources for not only the child, but their families. I ask that coordinators be considerate of the families needs and goals and find resources to help them achieve those needs.

Thank you for taking the time to hear the stories of families like mine. Thank you for trying to find ways to support us.

Sincerely,
Kellie

From: Monique Magallanes [redacted]
Date: Tuesday, July 18, 2023 at 11:40:14 PM UTC-4
Subject: Parents as Paid Caregivers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hi there,

My name is Monique Magallanes. I am currently being paid as a Parent paid Caregiver for rendering several services to my disabled daughter. As we have had the opportunity to focus on her needs and skills daily, we have noticed a significant improvement in several ways. With me being able to stay at home and work on these goals and skills consistently, she has shown the most improvement. When we were utilizing other resources as the paid provider, we encountered several obstacles. One being, hardly having someone available on a regular basis, second, having several different providers, inconsistent providers and a lot of change making it difficult for my daughter to adjust to the changes and not having consistency in her daily routine.

Please consider extending Parents as Paid Caregivers permanently, giving us more of an opportunity to provide consistent high-quality care to those children that are in dire need.

Thank you for listening.

Sincerely,
Monique

From: Martha Sanchez [redacted]
Date: Tuesday, July 18, 2023 at 11:36:22 PM UTC-4
Subject: Habilitation
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Habilitation for our children should be automatically included in the proposal for parents as paid caregivers.
The need to provide socialization from an outside source instead of it being offered by the parent who knows the child better than anyone else is not a valid reason for exemption.
As a parent I know my daughters limitations and though we work at them I focus on her strengths and she feels genuine support. Socialization from an outsider can be accomplished through a group setting provided by the parent without causing stress for the child who them may regress.

From: Susie Turrey [redacted]
Date: Tuesday, July 18, 2023 at 11:24:51 PM UTC-4
Subject: 2023 Paid Parent Caregiver Proposal
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

I am a parent of an adult child who receives DDD and ALTCS services. I did not have to participate in the Paid Parent Caregiver program under the Covid-19 Flexibility as my son just turned [redacted] years old pre-Covid. However, as a parent who has a child with IDD I understand why this service is extremely beneficial to other families and their child/children who qualify. An Arizona parent- led grassroot initiative leaders have taken the time to break down the proposal. I hope you carefully read the below and then allow parents, who have minor children who qualify for this program, the right to provide Habilitation and Attendant Care services. It makes complete sense.

Under the current proposal, the request of an ongoing program option which allows parents of disabled minors in Arizona to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies is not being met. Please consider updating the proposal based on the following questions, suggested solutions, and personal experiences.

Should Habilitation be included in the Paid Parent Caregiver Program?
We have heard the concerns about member isolation and lack of community involvement if parents continue as Paid Parent Caregivers facilitating their child’s Habilitation services. Respectfully the parent caregiver community proposes the following solutions:

1. Examine available research and personal feedback statements from members and their families to evaluate the true potential impacts of social isolation and community involvement when parents of disabled children provide Habilitation services. The parent caregiver community’s collective experience is that members who have parents facilitating their Attendant Care and Habilitation services have experienced greater member social engagement and community involvement over the last three years. Parent caregivers now have an increased ability to take their children to sporting team practices, community events, movie theaters, all ability parks, church activities and libraries. This is because parent providers can perform the appropriately trained and qualified supports in the correct time and location that is applicable to each member.

2. We know from provider agency data that “the top 3 issues regarding recruiting and retaining career non-family caregivers are schedules of the client members, interest in the position and finding qualified applicants.” Most members have Habilitation goals and ADLs that are most appropriately

delivered throughout the natural routine of their day. A parent provider is uniquely available in the morning, after school or in the evenings when each member is motivated and focused on the pertinent task. If a non-family provider is available their schedules typically allow them to work in longer time chunks that are not always the most ideal for the member and creates artificial goal or ADL practice. Continuity of care and greater member outcomes can be associated with consistently provided Habilitation care by parent providers who have the greatest ability to be flexible and available for their member children.

Should parent providers be limited to 40 hours a week of paid care per child?
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1. Create a program provision that outlines an extraordinary circumstances clause and the application process that allows parents to provide over 40 hours of paid care per week of authorized and evaluated services per member. These extraordinary circumstances could include, but are not limited to:
    a. The lack of a non-parent DCW being available in the last 3 months to fill the member's assessed hours that exceed 40 hours per week. Ongoing DCW searches should continue to be made by the member's agency to fill the assessed hours beyond 40 hours per week of Attendant Care and Habilitation.
    b. The expressed desire made by a member for a parent caregiver to facilitate their assessed DCW hours so that their Article 9 rights are honored.
    c. The profound disabilities and/or significant behaviors of a member where a non-family provider is not equipped to provide DCW support. This determination can be made through a stakeholder team approach, including but not limited to the member's, DDD Support Coordinator, DDD Nurse, DDD Supervisors, Behavioral Plan Experts, Parents / Guardians, Psychologist, or Medical Doctor.
2. Form equality between all Family Provider Programs by allowing all Direct Care Workers, regardless of familial relationship or member age, to provide up to 16 hours of paid care per day. This will allow for employee equality across the lifespan of the member and limit the potential anti-family provider rhetoric currently present within state policies and DDD Support Coordination culture. All evaluations of hours should be based on member needs regardless of who is providing the services to create uniform implementation of all applicable HCBS services by the DCWs available to fulfill those hours.
3. The Family Support Program currently in this proposal addresses caregiver burnout. It is one of the available solutions to facilitate further community support within the disability and caregiver community that will provide greater access to non-profits facilitating counseling services, support groups and meet up activities.
4. Reevaluate Respite reimbursement rates to also address caregiver burnout. If Respite services are not available to the member or their family, parent burnout will continue to be an issue regardless of parents having the option of providing Attendant Care or Habilitation hours. With a comprehensive Paid Parent Caregiver Program in place non-family DCW providers will have greater flexibility to provide Respite services to these same families.

How should current evaluation protocols, training and practices be updated to facilitate equality for all members when accessing member needs?
AHCCCS has stated their intention to amend applicable policy, further suggested action on this topic includes:

1. Forming a committee of community and department stakeholders to amend and critique current DDD and AHCCCS policies and need assessment forms so that the most effective and efficient implementation of this permanent option is utilized moving forward.

2. Provide appropriately determined training and program implementation to DDD and ALTCS Support Coordinators so that Attendant Care and Habilitation hours are equitably evaluated based on the member's needs and to remove organizational bias of familial providers across the member's lifespan. Specifically investigate and determine appropriate DDD staffing needs and training for the members served in rural areas and those from minority backgrounds.

3. Create the option for private sector Support Coordination. Other states have this option within their Medicaid services, and this could be an additional feature in our DDD portfolio to allow for the member's needs to be best evaluated.

In conclusion, Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. By not allowing parents of minors to provide Habilitation and Attendant Care services or work over 40 hours a week most of the minor disabled community in Arizona will be underserved. A comprehensive Paid Parent Caregiver program validates the irreplaceable work that parents provide in their homes and communities.

Click here to connect with the Arizona parent led grassroot initiative leaders:
www.raisingvoicescoalition.com

Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves all DDD and ALTCS members in Arizona.

Thank you!
Susie Turrey

From: Holly Jaramillo [redacted]
Date: Tuesday, July 18, 2023 at 10:49:29 PM UTC-4
Subject: A personal note.
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

I am writing today to ask you please don't cut out anything from the parent provider program. I couldn't even get a care worker before I was paid to take on the tasks. It's not about the money. It's about providing services for my son.
Respite. Habitation. Attendant care.
I don't even get these services. I requested respite, HAB and Atc. In December last year. My ap was lost found and lost again. Ddd workers quit and I was lost again.

For services. No one's reached out beyond a vendor call. My support coordinator doesn't step up and help facilitate issues. My support coordinator in absolutely inept.
If it wasn't for knowing my sons doctor and staff I would be in an absolute mess.
I was finally approved to provide services after months(!) of waiting. In [redacted]. This month!

…..

After coming on with my company, I work harder to provide him with better care. I feel more compassion and understanding from his perspective. I've taken more courses and have been way more involved since working with a parent provider company. They provide tools that I would have never thought of, or happened across.
I take this job seriously. I left my career behind to attend to my son. I can't imagine having to work out three different providers for each.
Am I burnt out. Absolutely. Do I get reminders about parent burn out and take a step back. Absolutely.
From the right perspective and for the right reason this system is working for us so far.
I still have no respite. No response of my support coordinator three months after months of waiting. There simply isn't enough available help (dcw).
All my sons therapies are on zoom calls because there isn't enough providers for basic therapy like speech and OT.

I would even provide for other parents if they needed me to that's how scare support is these

days. I left the medical field. I had an excellent career. It's not about the money. It's about the time and the hours needed to help make these children a part of future society.

Please. Don't take what we need most.
Holly Jaramillo

From: Sarah Flick [redacted]
Date: Tuesday, July 18, 2023 at 10:36:07 PM UTC-4
Subject: Meeting today
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To who may concern,
My hand was basically nearly most it not the either time towards the last hour of the meeting yet my corners were never heard nor was my question never asked I even commented in the private chat many time ask to talking after the person before was done. I understand we had short periods to talk afterwards i understand your time is important but so are my concerns and questions I would very much appreciate it you can get back to me so I can share my experience, tell you about my son Along with my concerns and questions that have. Please whenever you have free chance allow me to talk with you or even write you person letter to whoever gets this and can get back to me. Thank you and have great day.
Sarah Flick

Sent from Yahoo Mail for iPhone

From: Violet Aird [redacted]
Date: Tuesday, July 18, 2023 at 10:22:23 PM UTC-4
Subject: Habilitation Hours for Minors Program
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

As a parent of a child who receives DDD and ALTCS services I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility, and it has been extremely beneficial to our family and my child. I would like to share my personal experiences and feedback based on my review of the current proposal for a permanent Paid Parent Caregiver program.

Truly we live on the outskirts of the county and have not had stability or success in keeping any type of providers or even services for speech, occupation and physical therapies. By allowing us to be paid parent providers we have been able to maintain part time work in order to help our sons with disabilities thrive and become as independent as they can be.

Both kids are on the spectrum and don't adapt to strangers well and will much less let or want to be helped to dress and undress or help with hygiene by people they don't know as their hab goals center around these types of obstacles. One of our kids is non verbal. How will he be able to voice his concerns to us if a random direct care worker were to abuse him in any way? I feel that more problems will arise if you decide to take this route.

Under the current proposal, the request of an ongoing program option which allows parents of disabled minors in Arizona to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies is not being met. Please consider updating the proposal based on the following questions, suggested solutions, and personal experiences.

Should Habilitation be included in the Paid Parent Caregiver Program?

We have heard the concerns about member isolation and lack of community involvement if parents continue as Paid Parent Caregivers facilitating their child's Habilitation services. Respectfully the parent caregiver community proposes the following solutions:

> Examine available research and personal feedback statements from members and their families to evaluate the true potential impacts of social isolation and community involvement when parents of disabled children provide Habilitation services. The parent caregiver community's collective experience is that members who have parents facilitating their Attendant Care and Habilitation services have experienced greater member social engagement and community involvement over the last three years. Parent caregivers now have an increased ability to take their children to sporting team practices, community events, movie theaters, all ability parks, church activities and libraries. This is because parent providers can perform the appropriately trained and qualified supports in the correct time and location that is applicable to each member.
>
> We know from provider agency data that "the top 3 issues regarding recruiting and retaining career non-family caregivers are schedules of the client members, interest in the position and finding qualified applicants." Most members have Habilitation goals and ADLs that are most appropriately delivered throughout the natural routine of their day. A parent provider is uniquely available in the morning, after school or in the evenings when each member is motivated and focused on the pertinent task. If a non-family provider is available their schedules typically allow them to work in longer time chunks that are not always the most ideal for the member and creates artificial goal or ADL practice. Continuity of care and greater member outcomes can be associated with consistently provided Habilitation care by parent providers who have the greatest ability to be flexible and available for their member children.

Should parent providers be limited to 40 hours a week of paid care per child?

We have heard the concerns of AHCCCS on why they want to limit parents to 40 hours a week under the Paid Parent Caregiver Program. The parent caregiver community would like to propose the following collaborative solution to create a win-win scenario:

> Create a program provision that outlines an extraordinary circumstances clause and the application process that allows parents to provide over 40 hours of paid care per week of authorized and evaluated services per member. These extraordinary circumstances could include, but are not limited to:

The lack of a non-parent DCW being available in the last 3 months to fill the member's assessed hours that exceed 40 hours per week. Ongoing DCW searches should continue to be made by the member's agency to fill the assessed hours beyond 40 hours per week of Attendant Care and Habilitation.

The expressed desire made by a member for a parent caregiver to facilitate their assessed DCW hours so that their Article 9 rights are honored.

The profound disabilities and/or significant behaviors of a member where a non-family provider is not equipped to provide DCW support. This determination can be made through a stakeholder team approach, including but not limited to the member's, DDD Support Coordinator, DDD Nurse, DDD Supervisors, Behavioral Plan Experts, Parents / Guardians, Psychologist, or Medical Doctor.

Form equality between all Family Provider Programs by allowing all Direct Care Workers, regardless of familial relationship or member age, to provide up to 16 hours of paid care per day. This will allow for employee equality across the lifespan of the member and limit the potential anti-family provider rhetoric currently present within state policies and DDD Support Coordination culture. All evaluations of hours should be based on member needs regardless of who is providing the services to create uniform implementation of all applicable HCBS services by the DCWs available to fulfill those hours.

The Family Support Program currently in this proposal addresses caregiver burnout. It is one of the available solutions to facilitate further community support within the disability and caregiver community that will provide greater access to non-profits facilitating counseling services, support groups and meet up activities.

Reevaluate Respite reimbursement rates to also address caregiver burnout. If Respite services are not available to the member or their family, parent burnout will continue to be an issue regardless of parents having the option of providing Attendant Care or Habilitation hours. With a comprehensive Paid Parent Caregiver Program in place non-family DCW providers will have greater flexibility to provide Respite services to these same families.

How should current evaluation protocols, training and practices be updated to facilitate equality for all members when accessing member needs?

AHCCCS has stated their intention to amend applicable policy, further suggested action on this topic includes:

Forming a committee of community and department stakeholders to amend and critique current DDD and AHCCCS policies and need assessment forms so that the most effective and efficient implementation of this permanent option is utilized moving forward.

Provide appropriately determined training and program implementation to DDD and ALTCS Support Coordinators so that Attendant Care and Habilitation hours are equitably evaluated based on the member's needs and to remove organizational bias of familial providers across the member's lifespan. Specifically investigate and determine appropriate DDD staffing needs and training for the members served in rural areas and those from minority backgrounds.

Create the option for private sector Support Coordination. Other states have this option within their Medicaid services, and this could be an additional feature in our DDD portfolio to allow for the member's needs to be best evaluated.

In conclusion, Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. By not allowing parents of minors to provide Habilitation and Attendant Care services or work over 40 hours a week most of the minor disabled community in Arizona will be underserved. A comprehensive Paid Parent Caregiver program validates the irreplaceable work that parents provide in their homes and communities.

Click here to connect with the Arizona parent led grassroot initiative leaders: www.raisingvoicescoalition.com

Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves all DDD and ALTCS members in Arizona.

Thank you!

From: Devinmarie Zuleski [redacted]
Date: Tuesday, July 18, 2023 at 9:34:38 PM UTC-4
Subject: Hab
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

As a parent of a child who receives DDD and ALTCS services I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility, and it has been extremely beneficial to our family and my child. I would like to share my personal experiences and feedback based on my review of the current proposal for a permanent Paid Parent Caregiver program.

I have worked as a habilitation provider since 2009, I started as a provider in California to subsidize my income while I was going to school to be a special education teacher. I was with my first family for close to 7 years before relocating to Arizona in 2017. When I moved to AZ, I quickly signed on with an agency and became a provider.

I loved the flexibility this job gave me and skills I learned along the way. In 2018, I gave birth to my son. Later we learned he was a level 3 autistic, non verbal. As soon as we were given resources I tried to find a respite provider. At the age 2 with a level three diagnosis I couldn't find anyone. That was 2020. I still have 600 hrs of respite that have never been touched due to lack of providers.

When pandemic hit I was still providing care to another member while my son received nothing. Then came the parent provider program.

My son, since then has had consistently, he has met goals, he has grown, together we have grown. Our relationship has flourish because together, we learned some hard things.

Is it easy to be your child provider. Nope. It sure isn't. But as parents we don't see it as a paycheck. We see it as a constant in our child's life.

So come November when y'all take this program away, you will be taking the only constant thing my son has away. Progress will plummet. The parents have shown this works. Look at a the case note. Please consider keeping the habilitation programs not just for our parents but for the kids that are thriving.

Under the current proposal, the request of an ongoing program option which allows parents of disabled minors in Arizona to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies is not being met. Please consider updating the proposal based on the following questions, suggested solutions, and personal experiences.

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We know from provider agency data that "the top 3 issues regarding recruiting and retaining career non-family caregivers are schedules of the client members, interest in the position and finding qualified applicants." Most members have Habilitation goals and ADLs that are most appropriately delivered throughout the natural routine of their day. A parent provider is uniquely available in the morning, after school or in the evenings when each member is motivated and focused on the pertinent task. If a non-family provider is available their schedules typically allow them to work in longer time chunks that are not always the most ideal for the member and creates artificial goal or ADL practice. Continuity of care and greater member outcomes can be associated with consistently provided Habilitation care by parent providers who have the greatest ability to be flexible and available for their member children.

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The expressed desire made by a member for a parent caregiver to facilitate their assessed DCW hours so that their Article 9 rights are honored.

The profound disabilities and/or significant behaviors of a member where a non-family provider is not equipped to provide DCW support. This determination can be made through a stakeholder team approach, including but not limited to the member's, DDD Support Coordinator, DDD Nurse, DDD Supervisors, Behavioral Plan Experts, Parents / Guardians, Psychologist, or Medical Doctor.

Form equality between all Family Provider Programs by allowing all Direct Care Workers, regardless of familial relationship or member age, to provide up to 16 hours of paid care per day. This will allow for employee equality across the lifespan of the member and limit the potential anti-family provider rhetoric currently present within state policies and DDD Support Coordination culture. All evaluations of hours should be based on member needs regardless of who is providing the services to create uniform implementation of all applicable HCBS services by the DCWs available to fulfill those hours.

The Family Support Program currently in this proposal addresses caregiver burnout. It is one of the available solutions to facilitate further community support within the disability and caregiver community that will provide greater access to non-profits facilitating counseling services, support groups and meet up activities.

Reevaluate Respite reimbursement rates to also address caregiver burnout. If Respite services are not available to the member or their family, parent burnout will continue to be an issue regardless of parents having the option of providing Attendant Care or Habilitation hours. With a comprehensive Paid Parent Caregiver Program in place non-family DCW providers will have greater flexibility to provide Respite services to these same families.

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How should current evaluation protocols, training and practices be updated to facilitate equality for all members when accessing member needs?

Forming a committee of community and department stakeholders to amend and critique current DDD and AHCCCS policies and need assessment forms so that the most effective and efficient implementation of this permanent option is utilized moving forward.

Provide appropriately determined training and program implementation to DDD and ALTCS Support Coordinators so that Attendant Care and Habilitation hours are equitably evaluated based on the member's needs and to remove organizational bias of familial providers across the member's lifespan. Specifically investigate and determine appropriate DDD staffing needs and training for the members served in rural areas and those from minority backgrounds.

Create the option for private sector Support Coordination. Other states have this option within their Medicaid services, and this could be an additional feature in our DDD portfolio to allow for the member's needs to be best evaluated.

In conclusion, Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. By not allowing parents of minors to provide Habilitation and Attendant Care services or work over 40 hours a week most of the minor disabled community in Arizona will be underserved. A comprehensive Paid Parent Caregiver program validates the irreplaceable work that parents provide in their homes and communities.

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Thank you!

Devin Marie Zuleski. Thank you for your time

[redacted]

From: Holly [redacted]
Date: Tuesday, July 18, 2023 at 9:09:41 PM UTC-4
Subject: Dear Ahcccs and 1115 waiver team
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

As a parent of a child who receives DDD and ALTCS services I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility, and it has been extremely beneficial to our family and my child. I would like to share my personal experiences and feedback based on my review of the current proposal for a permanent Paid Parent Caregiver program.

Under the current proposal, the request of an ongoing program option which allows parents of disabled minors in Arizona to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies is not being met. Please consider updating the proposal based on the following questions, suggested solutions, and personal experiences.

As a mom of a severely autistic daughter being afforded the opportunity to be my daughter's Habilitation Provider has helped her tremendously. We are able to go out into the community and have contact with her fellow peers while I help her be more social, learn life skills and make sure she is safe. This program has allowed me to help my daughter meet goals while making sure she is safe and being taken care of instead of being handed off to a stranger that doesn't know her cues, her mannerisms, fears, likes ECT.

This has allowed our family to stay afloat while being able to provide my daughter with the necessary help she not only needs but deserves. If this program is taken away she will get an outside provider that doesn't get her, doesn't know her. I will have to return full time to work and not be able to give her the attention, time and life skills education I've been lucky enough to do. Please don't take away the Habilitation paid parent caregiver program . Our family depends on it for goals being met, growth, safety and comfort for a very anxious loving little girl.

Should Habilitation be included in the Paid Parent Caregiver Program?
We have heard the concerns about member isolation and lack of community involvement if parents continue as Paid Parent Caregivers facilitating their child's Habilitation services.
Respectfully the parent caregiver community proposes the following solutions:
Examine available research and personal feedback statements from members and their families to evaluate the true potential impacts of social isolation and community involvement when parents of disabled children provide Habilitation services. The parent caregiver community's collective experience is that members who have parents facilitating their Attendant Care and Habilitation services have experienced greater member social engagement and community involvement over the last three years.

Parent caregivers now have an increased ability to take their children to sporting team practices, community events, movie theaters, all ability parks, church activities and libraries. This is because parent providers can perform the appropriately trained and qualified supports in the correct time and location that is applicable to each member.

We know from provider agency data that "the top 3 issues regarding recruiting and retaining career non-family caregivers are schedules of the client members, interest in the position and finding qualified applicants." Most members have Habilitation goals and ADLs that are most appropriately delivered throughout the natural routine of their day. A parent provider is uniquely available in the morning, after school or in the evenings when each member is motivated and focused on the pertinent task. If a non-family provider is available their schedules typically allow them to work in longer time chunks that are not always the most ideal for the member and creates artificial goal or ADL practice. Continuity of care and greater member outcomes can be associated with consistently provided Habilitation care by parent providers who have the greatest ability to be flexible and available for their member children.

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The expressed desire made by a member for a parent caregiver to facilitate their assessed DCW hours so that their Article 9 rights are honored.

The profound disabilities and/or significant behaviors of a member where a non-family provider is not equipped to provide DCW support. This determination can be made through a stakeholder team approach, including but not limited to the member's, DDD Support Coordinator, DDD Nurse, DDD Supervisors, Behavioral Plan Experts, Parents / Guardians, Psychologist, or Medical Doctor.

Form equality between all Family Provider Programs by allowing all Direct Care Workers, regardless of familial relationship or member age, to provide up to 16 hours of paid care per day. This will allow for employee equality across the lifespan of the member and limit the potential anti-family provider rhetoric currently present within state policies and DDD Support Coordination culture. All evaluations of hours should be based on member needs regardless of who is providing the services to create uniform implementation of all applicable HCBS services by the DCWs available to fulfill those hours.

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Reevaluate Respite reimbursement rates to also address caregiver burnout. If Respite services are not available to the member or their family, parent burnout will continue to be an issue regardless of parents having the option of providing Attendant Care or Habilitation hours. With a comprehensive Paid Parent Caregiver Program in place non-family DCW providers will have greater flexibility to provide Respite services to these same families.

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In conclusion, Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. By not allowing parents of minors to provide Habilitation and Attendant Care services or work over 40 hours a week most of the minor disabled community in Arizona will be underserved. A comprehensive Paid Parent Caregiver program validates the irreplaceable work that parents provide in their homes and communities.

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Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves all DDD and ALTCS members in Arizona.

Thank you!
Holly Brittain
[redacted]

From: jennylynsullivan [redacted]
Date: Tuesday, July 18, 2023 at 8:34:44 PM UTC-4
Subject: Parents as paid caregivers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To Whom It May Concern:
My name is Jennifer Sullivan and I am currently a paid parent caregiver for my child, Grace-Anna Sullivan. I am writing to show my support and ask sincerely that this program be kept permanently. Previously I worked as a home health nurse and would often have to call out of work due to my special needs daughter not having anyone to watch her or tend to her numerous needs. After covid hit, I lost all of my respite providers. I was in serious danger of losing my job due to many callouts to care for our daughter. Since the parents as paid caregivers came into effect, I've been able to stay at home with our daughter and provide the care that she desperately requires. If this program becomes permanent, I will not have to worry about going back out into the workforce and worrying about who will care for our daughter. Please consider our story and so many others just like it. Please keep the parents as paid caregivers a permanent program!

Sincerely,
Jennifer Sullivan

--
Jenny Sullivan
[redacted]

From: Pamela Paulon [redacted]
Date: Tuesday, July 18, 2023 at 8:07:31 PM UTC-4
Subject: Former WV paid family hardship of care authorized provider
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Title 19 HCB waiver in WV allows for families to get paid for care AND to chose community members to provide care by using Public Partnerships,LLC as a fiduciary intermediary for submitting billing, doing background checks and ensuring that caregivers are cleared through each state's abuse and neglect registry and meets all eligibility requirements for First Aid, CPR, PPE and AED training as well as Positive Behavior Support and Crisis Planning.
My budget was quite adequate. Please support AZ families with special needs children all their lives and not just during pandemics.

From: Carrie Jahnke [redacted]
Date: Tuesday, July 18, 2023 at 7:53:49 PM UTC-4
Subject: re: parents of minor as paid providers
To: Waiver Public Input - AHCCCS <waiverpublicinput@azahcccs.gov>

Here are my comments/concerns/feedback:

As someone working for DDD here are my comments from my experience and that of my team:

1) parents are requesting to be the paid provider regardless of the medical necessity for services for their child (some provider agencies tell parents that they can get paid to take care of their kids- parents think they can get paid 24/7 and don't need to be unpaid as their parental obligation). Parents ask right off the bat to be the provider, especially those newly ALTCS and push back when told we have to assess the needs of their child.

-I am concerned that this service may be/or is abused by some parents/cause fraud or abuse, they may misrepresent their child's capabilities just to get the hours.

-Will attendant care supervision be included with this proposal? or just straight up attendant care for taking care of daily living skills?

2) Parents bully/intimidate Support Coordinators to try and give them hours that are not warranted because it is their "means of income". This harms the relationship between the families and DDD/Support Coordinators. It makes Support Coordinators want to quit/leave their jobs because of how they are treated, then we continue to have high caseloads and high turnover. Members get moved around from Support Coordinator to Support Coordinator.

3) It needs to be clearly defined on what "extraordinary" care is for a child/that warrants attendant care.

-Policy needs to be clear on what are the appropriate indicators/triggers for attendant care. And what is parental responsibility for caring for their child as a parental obligation (unpaid time).

4) There needs to be clear guidelines on assessing for attendant care for minor children if parents will be the paid provider

- need a better, more age appropriate assessment for minor children. Current assessment is more based on adults.
- Most children, especially those under 6 years of age need tasks completed for them (even neurotypical children), so by default wouldn't all children qualify? with that logic.
- communication to parents/families needs to be clear on what can be assessed and that the service is based on their child's needs (not that someone else gets x amount of hours, or that parent needs income).

- clear guidelines for parents as paid providers such as abiding by article 9 when they are providing care on the clock. How would parents follow article 9 if they need to take toys / personal items away from a child or discipline their child? Would article 9 prevent this since staff are not discipline / punish a member or take personal belongings away for a member

5) would there be anything in place to prevent families from becoming dependent on DDD?

- Our mission is to support Arizonans with developmental disabilities to live self-directed, healthy, and meaningful lives. Sometimes parents get too reliant on DDD services such as attendant care and not teach their child daily living/independent living skills (especially if there is money involved to keep the parent reliant on the income as the provider) or the parent is not inherently teaching their child skills.

6) I agree that members need interaction with others outside the home, so I am happy that habilitation is not a part of this proposal. Also, children sometimes listen better to others that are not their parents and will do better at doing goals. Good to get members out of the home and be around a variety of people in the community (if able/not bed-bound).

7) The family support/peer support services sounds like a great thing, something to help families connect with others, especially those who are new to DDD/ALTCS.

8) anything that will help decrease the DCW shortage? I feel that parents as paid providers may not help the situation much.

Carrie Jahnke
Human Services Unit Supervisor
Division of Developmental Disabilities
Department of Economic Security
125 E Elliot Rd, Chandler, AZ 85225
Mail Drop 2E62
[redacted]

Certified Google Workspace Guru
My hours are Monday-Friday 8:00am-4:30pm

From: Ariana Thude [redacted]
Date: Tuesday, July 18, 2023 at 7:28:24 PM UTC-4
Subject: Habilitation Needs To Be In Waiver To Meet Member Needs
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

My name is Ariana Thude and my son, [redacted] has multiple qualifying DDD diagnoses. He has complex behavioral and therapeutic needs, but has demonstrated progress through his therapies that have allowed him to gain skills he otherwise would not have had, thus reducing the cost of providing future services to him.

For the past three years, I have been getting paid as his primary hab therapist. Before that, I spent years doing it for free because he needed those skills, which is well above the level of care that is legally expected of a parent based on my level of understanding. I was doing that because we couldn't find therapists in our area who were both able and willing to act as his habilitative therapists. We have had therapists who interviewed with our family choose to reject his case and rather take the case of a kiddo who was considered to be higher functioning or with fewer behavioral needs once they learned about his specific needs.

Of the 8 years my son has been approved for hab, I have been providing those services for more than 10 hours a week (20-30) for **6** of those years. That's a long stretch of time where nobody else could be found. For me, as a parent, there is nothing I want more than for somebody else to be able to come and help him with these things because he does need that practice. But what he needs most is the skills, and if nobody else can be found who can do it, paying the parents to fill that role is better than the disabled individual going without. Which is what will happen for my son if this program expires.
I attended today's forum, and though I raised my hand early in, did not unfortunately have the opportunity to speak. What I heard in this forum was that AHCCCS did not include habilitation as an area where parents can be the direct care worker because they are concerned about the ability of disabled individuals to gain opportunities to practice working with others.

How does it help a disabled individual do that if there is nobody else willing or available to do so?

My son has gained skills that he would not otherwise have because of the work I have done with him, and everyone who works with him in the future will benefit from this because I have built opportunities for him to interact with others outside of the home into his hab goals and his hab work.

If hab services aren't included in this waiver for parents as direct care workers, I won't be able to continue to give him that support for free. Because in the current economy, we will now need me to work outside the home. So what that means for my son is that if the past is any indicator, he is unlikely to have anybody else working with him. And he will not gain those skills without necessary support. And that will increase the cost and difficulty level for anybody working with him in the future.
To me, it is more important that he have the skills and his therapeutic needs met regardless of who is meeting those needs.

As a mother, I want to add my voice to other parents in requesting that the AHCCCS administration include habilitative therapy as a service that parents can be the direct care providers for in their CMS waiver submission.

Thank you for your time.

Respectfully, Ariana Thude

From: Pricila Sampy [redacted]
Date: Tuesday, July 18, 2023 at 7:25:25 PM UTC-4
Subject: Feedback
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

As a parent of a child who receives DDD and ALTCS services I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility, and it has been extremely beneficial to our family and my child. I would like to share my personal experiences and feedback based on my review of the current proposal for a permanent Paid Parent Caregiver program.

My son is almost 8 years old and he is autistic and non verbal. He just now got partially potty trained. He is able to urinate in the potty when prompted but because of his stomach issues I am taking it slow when it comes to bowel movements. He is not communicating when he needs to go potty so any providers working with him need to prompt him to go and be on top of it otherwise he will not continue to improve. The problem is none of them are on top of it. None of them will offer water or food if I don't show up and remind them to do so. None of them will go an extra mile to make sure my kid is not just bored or sad but actually hungry sitting in a corner waiting to be fed. If I am not there, showing up and giving specific instructions (isn't that common sense?) on what they should do, they won't do anything. And do you know why? I am assuming they think no one is going to lay them off because we are a community that needs these services so much that we will basically take anything and put up with anything just because we need it. There's no quality. Not to mention consistency. Providers do not stick around.

I am a habilitation provider for my son now. I have seen so much improvement. I have been trained just like everyone else and I have a big bonus of knowing my kid better than anyone. I work on goals that some may consider "natural support" but I consider keeping track on things that he and I need to accomplish. We both have learned a lot and we both have accomplished a lot too.

As a parent provider, I go above and beyong for my kid. I know I am not doing the bare minimum just for a paycheck at the end of the month. I am also making sure my kid is comfortable because he does not feel comfortable completing certain tasks with providers.

One of many examples I have before Covid is a provider we used to have. She would work on goals with my kid for probably half an hour and the rest of it she would use her phone. And I know that because I have cameras in my house. Then every time I would come close, she would turn her phone off and pretend tbey are working on something. Do I need to be right there investigating and forcing this to happen every time?? I think people do take advantage of autism families for the reasons I mentioned above and also because some parents are not present and kids cannot really speak for themselves. I have to make myself present and I already know I cannot even think of pursing a career out of this because this is the level of care that my kid will have if I am not his provider. And this is just one example.

If I have the same training and have seen improvement in our lives, why can I not continue to be his provider?? Because of member isolation? We currently have community goals. We go outside every day and we wouldnt do so if it was anyone else but me. You know why? Because no one will be able to anticipate behaviors that I do as a mom when he is in public. My kid is a flight risk as so many others. He might not show any cues to someone who does not know him well. Even if they work with him for years, they would not be able to guarantee his safety to me. I just cannot trust that they would give him their utmost attention to him outside if inside they are not showing that so unfortunately I cannot trust my son with anyone outside our house but me. So if that is the point, I do not see the correlation. We do much more outside than if he had another provider. Actually I am the only one who ever worked on community goals with him. There is no isolation. He has also other therapies and activities during his day that are not Habilitation so I am not isolated either.

I say all this with sincere respect for anyone involved in this matter. I do appreciate every effort and every explanation. This is just my experience to give you some insight on why this is so important to us.

Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves all DDD and ALTCS members in Arizona.

Thank you!

Priscila Black

From: Ashley Pihlman [redacted]
Date: Tuesday, July 18, 2023 at 7:04:34 PM UTC-4
Subject: Re Public Input about 1115 waiver
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

I provided a letter about my experiences with habilitation as a parent provider but have additional questions and comments after the webinar today.

1) Will there be an update official definition of who qualifies for attendant care? Is there a definition for "extraordinary" care or natural supports?
2) How much of an increase in the workforce can we expect to see and when can we expect to see this?
3) There will be additional burden shifted to other state programs such as WIC, SNAP/EBT, school lunch programs, Mental health services due to burnout, etc. Is the state prepared to handle this shift?
4) Will there be additional staff hired and prepared to accept quality of care complaints and grievances when that influx begins after habilitation is excluded from the permanent parent provider program?
5) How will we mitigate DDD Support Coordinator burnout? Since the return of in person meetings, SC's are already dealing with bigger caseloads and issues. There will be an influx of issues with providers and it will fall on support coordinators to mitigate issues.
6) How will we mitigate caregiver's burnout when the habilitation program ends?
7) Family Unit Support feels like a huge waste of resources because we already have resources available to the community such as the autism society of phoenix and raising special kids providing these services.
8) What resolution will there be if we still do not have habilitation providers available?

I propose we keep habilitation in order to mitigate stress on families, DDD employees, etc and the family support unit can provide opportunities for members to participate in community outings such as movie tickets, sports tickets, concert tickets, etc (a limited number to those who request or wish to participate) to encourage more interaction in the community.

--
Ashley Pihlman

From: Rebecca Pimienta [redacted]
Date: Tuesday, July 18, 2023 at 6:44:26 PM UTC-4
Subject: parent as paid giver for minor child
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello I am a parent of three special needs children. Because of covid it came to light that parents need to be home to take care of a child that have special needs. With this program i was able to make a better life for my family we just bought a new home got off a lot of assist form the state. If this were to go away my family and many others would loose homes cars and stability, and now if this does go away the stress would go back on to the state and the government.

Thank you for your time

Forever grateful Rebecca Pimienta [redacted]

From: sarah Maydwell [redacted]
Date: Tuesday, July 18, 2023 at 6:23:36 PM UTC-4
Subject: Parents as Paid Caregivers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

I just wanted to give a comment/testimony as the Step-Parent of a minor child with disabilities and as a coordinator of those services for other families from a provider agency.

In the two years I've been coordinating services on a Provider Agency level, I have found it very difficult to hire caregivers that are not related to the minor children or to even retain those staff as many of the services involved do not have a large number of hours that aren't even guaranteed should the family cancel the day's scheduled services. I have found for many of the families I have supported during the Covid Relief exception have felt great relief being able to be that trained provider and know that someone will be able to be there, that they don't have a revolving door of caregivers that may call out, and with the shortages an agency may not even be able to have another caregiver come to cover.

As a step-parent, my child was on a waitlist for 3 years and only received services through DDD when her Uncle came of age to be able to be a provider. When he had to step down due to personal life happenings it would have been detrimental to her Father's and my ability to support and care for her had he not been able to take over her services due to the Waiver in place for Covid Relief. The shortages have only worsened since she first got those services through her family member. There are exceptions already in place in DDD Policies for Minor children to receive ATC services and we had all the check marks for the services, but no Non-Parent provider was available to do those services.

The ability to provide ATC services was so helpful. Without it, her father and I had to work opposite each other due to an inability to get DDD after school, a daycare that could care for her, or a babysitter or other family member. This made it so she did not see her parents at the same time except maybe once or twice a week on a good week, and I know many other parents have expressed the same to me. The introduction of the ATC parent provider allowed her father to be home for her when she got home from school, and she got to have meals together with both parents and do more activities as a family while meeting her extensive needs. Her overall demeanor showed improvement with being able to see her parents together regularly instead of just an improvement on the days our time off overlapped. We found not having to strictly be the only one providing care before or after working a full-time job reduced burnout as one Parent was now able to adjust their work schedule, and dedicate time to be home providing that care, and then when the other got home later, had been able to work together on the more challenging tasks of care. This made us feel we have been able to provide better care for her as a unit without feeling run down or alone.

I understand on a private and professional level regarding not including HAH services in this proposal, however, I feel it would be important to include it in some capacity. I absolutely agree with the importance of broadening the exposure to others in the community and to other adults to prevent a "sheltered" Member. I also understand that the staffing shortage extends to those HAH services, and having comments from provider staff state it is hard to stay working when those hours can be canceled at any time by the family or member, and frequently those hours are limited anyway from assessments and isn't sustainable for those providers to stay long term.

From: Martha Ontiveros [redacted]
Date: Tuesday, July 18, 2023 at 5:34:07 PM UTC-4
Subject:
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

I was 40 yrs old in 2001 when my son was in a horrific car accident which left him in a vegetative state. He was 17 and the 3rd oldest of 6. Since that day, We, brought Eric home 6 yrs later 2007 after his trach was removed. I left my job of 20 yrs working for Cigna in 2008 so that my children could move on to college and I would do caregiver Eric since I felt he was my son. Even though I took an enormous payout to staying home and depended a lot on my husband's work and support, I was able to AND am still capable of taking care of him. Eric continues to live here with is and I feel I may not be getting Respiratory, Med. Nurse, CNA, or yet alone MD. wages, the topic of whether or not we even get paid should not be an option. Eric is ONLYstill here today because of the care he gets from me and his family. The pay is what should be discussed, you can't put a price on that but you can pay what is rightfully just as well. Not to mention the horrific supply company's we r given. Thank god my husband retired. That helps pay for supplies needed because I get tired of calling them. They feel they arent an entity when indeed they r . But thats another problem. This state needs a whole lot of right principals be it political or not. Sincerely Martha Ontiveros, Erics mom

Sent from Yahoo Mail on Android

From: Jordan Kirk [redacted]
Date: Tuesday, July 18, 2023 at 5:09:05 PM UTC-4
Subject: Parent as paid caregiver
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To whom it may concern,

I highly recommend a permanent extension of payments to parents who serve as paid caregivers for minor children.

I am a parent of a child with autism and it has been invaluable for me to be his Hab. provider. I know, more than anyone, what he needs for assistance to learn life skills and to become more independent. And he has grown and improved tremendously with me as his provider. Plus, with the education provided and required, I am a much better parent providing what he needs.

Additionally, it was difficult to find a qualified and reliable Hab provider so essentially, I gave up a long time ago. It was time consuming and a hassle to find, train and monitor outside Hab providers. Then retrain new providers when the current ones stopped coming.

I am strongly requesting that you make this a permanent extension.

Thanks you,

Jordan Kirk
[redacted]

From: Justin Diamond [redacted]
Date: Tuesday, July 18, 2023 at 4:47:06 PM UTC-4
Subject: Including Habilitation hrs in ghe Paid Parent Providers Permanent Program
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

As a parent of a child who receives DDD and ALTCS services I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility, and it has been extremely beneficial to our family and my child. I would like to share my personal experiences and feedback based on my review of the current proposal for a permanent Paid Parent Caregiver program.

Under the current proposal, the request of an ongoing program option which allows parents of disabled minors in Arizona to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies is not being met. Please consider updating the proposal based on the following questions, suggested solutions, and personal.
My sons social skills and personal outings have increased tremendously since I have been able to work with him on Habilitation goals. He is Autistic and has a rare form of Epilepsy. Due to that, he has tremors on his hands and extreme weakness in his hands and feet along with sensitivity to his head. This along with the fact that he does not like to be touched by others has made it difficult to have outside providers. For the last 3 years I have been providing Habilitation services and working on grooming, bathing, feeding, dressings other home issues. Because of this he has gained tremendous confidence and it has given him the ability to go out and attend a public school, play baseball for the Miracle League of Arizona, attend movies and participate in an adaptive theater program with 30 other people. He recently was picked to play a lead character in tje Jungle Book. Taking away the HAB services in the parent provider program would have substantially negative effects.
Thank you.
Regards,
Diame Diamond

From: Heather Moore [redacted]
Date: Tuesday, July 18, 2023 at 2:20:00 PM UTC-4
Subject: Parents as paid providers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Re:Parents as paid caregivers

To Whom It May Concern:

Thank you for the opportunity to comment on the proposed amendment to the State's current Demonstration project.

I would like to support the amendment proposing to continue allowing parents to be paid providers. Unfortunately, I was actually unaware that this became available during covid so I just took advantage beginning this past May 2023. We have ALWAYS struggled to find competent and/or available respite or attendant care for our son, Grant, who is 15 years old. Fortunately, my husband now works from home and I am a teacher so we are able to care for him when he is not in school. The summer months are the most difficult for our family as there are very few camps for someone with Grants needs. Grant gets bored, he tends to regress on his goals, and I end up feeling frustrated and guilty.

This summer, being a paid caregiver, has made the summer more bearable. With the money we receive I am able to afford to take Grant out for excursions during the day and pay the way for someone to accompany me. Grant is much bigger than me these days and I often need to ask a friend or neighbor to help me move or position or change him. Being able to pay the entrance fee to a museum or take someone for lunch as a way of saying thank you(in ADDITION to being able to afford going somewhere with Grant) is possible as a result of this money. Also, it is not easy to travel, as a family, due to Grant's needs and the additional money has made it easier to stay in accommodations that actually accommodate Grant and the rest of us.

Initially I felt strange being paid to care for my own child but, at the end of the day, it is work and it does require extra money to care and provide for Grant. It also requires extra work and money to try and provide him with a life that is comparable to a "typical" child. Additionally, if this money is available to help children like Grant then it should still be used, whether the care is provided by a parent or someone else:)

Sincerely,

Heather Moore

From: Doris Lawson [redacted]
Date: Tuesday, July 18, 2023 at 2:12:49 PM UTC-4
Subject: Parents as paid caregivers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

I would like to add my approval to this measure. Parents of children who have disabilities often have to quit their job outside the home to care for these individuals. Paid caregiving will go a long way to preventing the family from losing income while allowing attention to be paid to the disabled children which will greatly increase their chances for an optimum outcome.There is a great shortage of attendant care workers for hire to do the job, so the parent is the logical person to hire. They are usually the ones who know the child best and will advocate for them to receive the best possible care.
Doris Lawson

From: KARA PORTNER Owner [redacted]
Date: Tuesday, July 18, 2023 at 12:30:34 PM UTC-4
Subject: Caregiver Benefits for parents for minors
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

While I appreciate that this money was available when Covid was very active. As a parent of an adult that receives these benefits, I have concerns that money will eventually run out. I don't see how it can be supported. When they are adults is when it really gets to be a problem and more of a burden to care for our adults with disabilities. Parents are generally responsible for their minor children anyway monetarily. I know I was. I just don't want the money to not be there for my adult with disabilities in the future or for these parents as their children become adults.

thank you

Kara Portner

From: Candi Gregoire [redacted]
Date: Tuesday, July 18, 2023 at 1:05:46 AM UTC-4
Subject: Parents paid caregivers for disabled children
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To Whom it May Concern:

I have been teaching habilitation skills to my 17 year old Autistic, Intellectually Disabled son. During this time I have received quarterly trainings on how to improve his skills through Positive Behavior training, social skills classes, First Aid, etc. It has been a very instructive and educational experience for me to provide these services. He has shown a lot of improvement and I hope these services continue for parents since it is a hardship for me to find someone else who can work with his many difficult behaviors.

Sincerely,

--
Candi Gregoire

From: mindee stevenson [redacted]
Date: Tuesday, July 18, 2023 at 12:57:52 AM UTC-4
Subject: To: Public Forum re: Parents as Paid Caregivers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

7/17/2023

To: The state of Arizona staff who are currently managing the program which allows parents to be paid caregivers to their minor children.

From: The Stevenson family - residing in Phoenix, Az.

This letter is to express our sincerest gratitude and thanks for beginning this program during the Covid year around 2020-2021. Our son receives services through the state since he was about 3 years old. "Michael" is now 13 years old. Through therapy, schooling, support groups, family and friends, we have watched our son reach milestones and continue to watch him reach many more. This would not be possible without such resources and we are beyond grateful.

As our son entered Covid times, we decided to try homeschooling due to him being immune compromised. Other key factors in our decision included certain behaviors our son exhibited (which always interfered with his learning) and schools being strained due to lack of staff and resources. Since "Michael" began elementary school, I have taken jobs here and there when possible. Some of the work I have done include working with individuals with disabilities as a hab/respite provider, substitute teaching, surveying and a short stint of volunteering for the Human Rights Committee through DDD. As I watched my son grow up, I had to finally face the realization that it became difficult to work due to his needs. I would often get several calls a month from his school prior to Covid due to the challenges that the staff was not equipped to deal with. During the month of October 2020, "Michael" started having seizures. Allowing me to work with "Michael" one on one with academics, gave me piece of mind knowing that I was trained in CPR as his caregiver. When your child is that young and going through something like that, it is not an easy thing to do to turn him back over to a school no matter how qualified and loving they might be. Once the seizures though began to subside and we were able to get them under control, we were ready to seek out respite help and continue with homeschooling. The program of habilitation/respite prior to Covid has been helpful to us but with some learned lessons over the years. Finding and obtaining a provider can be somewhat of a daunting task - there is high turnover. When Covid came around, the turnover was still high but there was the issue of a staff shortage. While I try and utilize the hab/respite program (as the desire is greatly there), the option to place my child in exciting summer schools, reputable schools, or fun camps, is not possible unless I am with him, or a hab or respite provider. As we head well into 2023, "Michael" will be 14 in a few months and has become as tall as me (5 foot). Now more than ever (or rather our current situation), is that I see placing "Michael" in a school setting to be both irresponsible and a safety concern for those around him. "Michael" is a funny kid. Those who meet him enjoy his sense of humor. In a lot of ways he's like a five year old who throws a fit now and again, but also much like a teenager who loves music, his guitar and tacos.

This letter is not only to express our gratitude but to request the program of parents as paid caregivers to their minor children to remain permanently within the state for families. This is an important program for the member - it gives them stability. It allows for opportunities in a different learning setting aside from the classroom. I think for some members, the life skills are what it's all about and for "Michael," he needs the practice and repetition on how to do those skills for years - yes, years. If I had a choice to have "Michael" know how to tie his shoes, be efficient in math, and have a love for reading, or, know how to independently feed himself or use the restroom, I'll pick the latter. "Michael" has a lot of learning to do and academics are definitely important to us but as he is getting older and we see that our goals for him may need to be adjusted slightly, we also see the reality of what is important for him to learn first.

Please consider making this program permanent. Thank you for your time!

Sincerely,
"Michael's" mom and dad

From: Rachel Bunney [redacted]
Date: Tuesday, July 18, 2023 at 12:42:56 AM UTC-4
Subject: public comment
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

As a parent of a child who receives DDD and ALTCS services, I have participated in the Paid Parent Caregiver program and it has been a blessing to our family and my special son. Thank you for the efforts being made to continue the Paid Parent Caregiver program.

My 5-year-old son was the 13th child born in the world with a very rare genetic mutation and he has both extreme medical complexities as well as global delays. Because of his ongoing health issues and developmental delays, it is very difficult to find diligent, qualified, and long-term DCW employees to work with my son.

I would like to address a couple of concerns in regard to limiting parents to a 40-hour work week as well as not allowing parents to continue to provide habilitation services for their children.

My son needs 24/7 care. He has a tracheostomy, gtube, high risk for aspiration, takes many medications and needs breathing treatments daily. For these reasons, I (or a nurse) need to be with my son at all times to ensure he is safe. I take my son into the community often to ensure he is interacting with the public, but I could never allow a Habilitation employee to take my son into the community without me for health, liability and safety reasons. My son has a genetic mutation that affects his sleeping patterns and causes random bouts of neuro-irritability (crying, thrashing, whimpering-causes unknown). The ability for me to log in and work on habilitation goals when he is awake and doing well is a huge benefit as parents can be flexible with day-to-day timing as opposed to a non-family member who would show up according to a schedule and the schedule certainly will not necessarily align with my son's random sleeping habits or mood disorder. Another reason given by the committee to limit parents from providing Hab services is to allow parents to have a break, but this simply doesn't apply to my son or many other DDD members that also have medical issues that need to be overseen by a trained and experienced adult. Another reason I and others feel uncomfortable hiring a non-family member is that many of our children are nonverbal (including my son) and are easily susceptible to being victimized or mistreated, thus propelling us to be highly involved during the habilitation services and thus, not affording parents a break from care. Although full-time caregivers need breaks, we do not need them at the expense of our child's well-being and safety. We also would not feel comfortable taking a break given so many of our kiddos are nonverbal or have medical needs we must oversee at all times. I implore you to please place serious consideration in allowing parents to continue to provide habilitation services as we see firsthand the strides our kids are making.

I would like to ask that you please reconsider limiting hours to 40 per week for parent caregivers. There are not enough qualified providers to fill the vacancies that are currently available. If parents are limited to 40 hours, the unfilled shifts would greatly increase, placing a burden on families. Many parents need Habilitation and Attendant Care hours filled in the evenings and weekends when the workforce availability is even lower. Specific to my child, ATC does not include allowing providers to administer g-tube feeds (and it is also not a qualifier for home health nursing either), so again, parents need to be very involved and can best care for their children.

Other states allow parents to work more than 40 hours per week, understanding that parents have been forced to leave the workforce to care for their disabled children and the shortage of qualified home aid workers creates a situation where many parents are unable to work outside the home. It would benefit everyone to allow parents to fill these hours so that children are getting the highest quality care and the state is filling the positions for our loved ones.

Again, I thank you for expanding this program and ask that you consider the difficulties we endure in finding consistent, qualified DCWs and ask that you allow parents to provide these services for our children.

Respectfully,
Rachel Marquardt

From: az4me1 [redacted]
Date: Monday, July 17, 2023 at 11:33:08 PM UTC-4
Subject: I say no to kids learning from parents
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

I don’t think young children would be served well by having their parents be their paid caregiver. My child is now an adult and can learn from me, but as a child, there is no way that they would have done well, they need an outside provider to properly help them.

From: Jessica Curry [redacted]
Date: Monday, July 17, 2023 at 9:48:03 PM UTC-4
Subject: Parents as Paid Caregivers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello,

Thank you for the opportunity to voice an opinion regarding the proposal to extend parents as paid providers to minor children.

The extension of allowing parents as paid caregivers is paramount for the well-being of the children involved and the family unit in which they reside. Caregivers are difficult to find on a consistent basis since COVID occurred (it was difficult to find them prior to COVID but extremely difficult now) and even more challenging to manage a long-term, stable, presence in the child's life to provide imperative habilitation, attendant care, and respite services.

Many children and families will be left without the support and resources that are absolutely essential in dealing with the challenges of living with disabilities should parents not be allowed to provide services to their children. The impact of losing this support will be detrimental to the family unit and ultimately a greater burden on our society.

Sincerely,

Jessica Curry
El Mirage, AZ

Sent from Yahoo Mail for iPhone

From: Jennifer Mueller [redacted]
Date: Monday, July 17, 2023 at 7:53:49 PM UTC-4
Subject:
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hi,
As caregivers I believe we need to be paid a decent wage . I take care of my sisterlaw full time 24/7 but you don’t get paid that way . It really needs to change . We the people that have family living with us and we take care of them need more benefits . When they get up at 2 am to use the restroom and your up helping you don’t get paid for that . There needs to be more hrs given and a raise .

Jennifer Mueller

From: Shane Castine [redacted]
Date: Monday, July 17, 2023 at 1:44:08 PM UTC-4
Subject: Paid Parent Caregiver
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

My name is Shane Castine, I am a parent of a child who receives DDD and ALTCS services. My wife has participated in the Paid Parent Caregiver program under the Covid-19 Flexibility and it has been extremely beneficial to our family and my child who receives these services. Based on my review of the current proposal for a permanent Paid Parent Caregiver program I would like to share our story and give you my feedback. Thank you for your time and consideration while reading my experience and suggestions.

When COVID hit there was a lot of uncertainty. We already were struggling to find providers that actually showed up and put in the effort/cared. We had a lot of no call no shows, people being on their phones, being late/leaving early, the list goes on and on. We wasted SO much time finding a provider and then when they dropped off finding another one and going through the "get to know you" process all over again. The turnover rate of providers is very high. We were on a hamster wheel constantly going in circles. It was heartbreaking not only for me and my wife but for my son because transition isn't easy for him. He would get to know a provider and then they would leave and we would have to do it all over again. Many of his habilitation goals are regarding his Personal Care (showering, potty training, dressing, brushing teeth, etc.) which only added to the difficulty of having so many providers leave. His Personal Care goals for Habilitation are very private things and it was always difficult for him to have a stranger see him in such a way, for example on the potty. When parents were approved to become Habilitation providers for their children it changed our life in so many positive ways. Consistency for one, we created a routine so he knew what to expect each day during our Habilitation time. He thrived! Noone knows my son better than we do so it cut out the time wasted on "getting to know you" and he was comfortable with my wife working on his private Personal Goals. He made more progress with my wife than he has with any other provider. Not only has he made enormous strides but this has also helped our family financially. When my son was born, our family had the plan that my wife and I would go back to work full time. Well, life had other things in mind. With the amount of time and care my son needed my wife wasn't able to go back to work and that did have a financial impact on us. Since my wife has been able to do parent Habilitation it has given us that extra income that we put back into our son. During the past few years, we have been able to sign him up for drawing classes, Lego classes, sports and so many other things that allow him to just be a kid outside of school and therapy. I know we are one voice of many that this program has helped tremendously. Please help me help my son by keeping Paid Parent Habilitation program.

Our community of parent caregivers is asking for a permanent program that allows parents of disabled minor children to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies. Under the current program proposal this request is not being fully met. Please consider the following suggestions:

> Include Habilitation as a service parents of minor DDD and ALTCS members can perform as a certified DCW provider. Parents of adult DDD and ALTCS members can currently perform both Attendant Care and Habilitation hours for their children and parents of the minor population would like this permanent option to mirror that program allowance. The DCW workforce shortage applies to Habilitation providers just as much as it does Attendant Care providers. Habilitation services fulfill the member's "personal care" needs by allowing them continual practice with their own personal care and rehabilitation. The only difference in Attendant Care and Habilitation personal care is that an individual receiving Habilitation can perform their personal care partially and needs assistance mastering these skills. There has been massive improvement to the IDD population in Arizona since parents of minors have been able to provide this service at the correct time and place that is applicable to the member. Parents being paid as Habilitation providers was allowed under the Covid-19 flexibility program and the ARPA program extension as a "personal care" service and we would like to continue to have it as a permanent option.

Habilitation services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. Parent caregivers have been the backbone of the Developmental Disability Community for decades. A comprehensive Paid Parent Caregiver program which includes both Habilitation and Attendant Care services validates the irreplaceable work that parents provide on a daily basis in their homes and communities.

Click here to connect with the Arizona parent led grassroot initiative leaders: www.raisingvoicescoalition.com

Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves DDD and ALTCS members in Arizona.

Thank you!

Shane Castine

From: Danaka [redacted]
Date: Sunday, July 16, 2023 at 7:05:05 PM UTC-4
Subject: A parent provider
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

I am a parent of a child who receives DDD and ALTCS services. I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility and it has been extremely beneficial to our family and my child who receives these services. We have been in this program about 18 months now, and still have not been able to find much support/caregivers at all. We have no respite provider, on waitlist for every service, finding any type of provider is scarce. My son needs 24/7 supervision, I have to provide this. This program has benefited us as a family, but also has greatly benefited him, by having a loving parent, provide habilitation an attendant care. It has provided stability to our family and help him grow and be more successful. I am able to work one on one with him to provide life goals and give him the safety from a loving parent.

Based on my review of the current proposal for a permanent Paid Parent Caregiver program I would like to give you some insight into my personal experience and feedback. Thank you for your time and consideration while reading my experience and suggestions.

Our community of parent caregivers is asking for a permanent program that allows parents of disabled minor children to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies. Under the current program proposal this request is not being fully met. Please consider the following suggested changes, reasonings and proposed solutions to the current proposal:

1. **Include Habilitation along with Attendant Care as services parents of minor DDD and ALTCS members can perform as certified DCW providers.**
    a. **Parents of adult DDD and ALTCS members can currently perform both Attendant Care and Habilitation hours for their children under a permanent program. The new program allowing parents of minor DDD and ALTCS members to be paid providers should mirror this currently operating adult program as it is the most comparable based on familial roles and responsibilities. Most parents of adult DDD and ALTCS members have full guardianship of the members they perform care for as their child's DCW and thus have a very similar legal responsibility as the parents of minor members.**

    b. **Parents who currently facilitate Habilitation services for their minor children are able to customize their working schedule based on the appropriate time and place for the member's goals to be performed. Habilitation hours will be extremely difficult to fulfill by non live-in providers due to scheduling requirements and limited hour availability of the members. According to the 2023 Raising Voices Coalition survey, "Provider agencies state that the top 3 issues regarding recruiting and retaining career non-family caregivers are schedules of the client members, interest in the position and finding qualified applicants." There has been massive improvement to the IDD population in Arizona since parents of minors have been able to provide consistent Habilitation services in the most appropriate time and place for the member.**

c. AHCCCS leadership has stated that they strongly feel as though excluding parents as paid providers for Habilitation will encourage more community engagement and prevent social isolation of members. According to the parent caregiver community the members receiving Habilitation services will most likely experience community isolation if the option for paid parent caregivers were to be removed for their minor children. Parents of minor children will be forced to find some kind of outside employment while their DDD and ALTCS member children experience skill or goal regression due to a lack of continuity in receiving Habilitation services. This is because of the DCW shortage already in place in our state.

d. According to the 2023 Raising Voices Coalition survey of parent providers of minor children in Arizona, "Eighty percent of members see at least 2 to 4 non-familial mandatory reporters (e.g. DCW providers or therapists) on a weekly basis in their home or a clinic for services authorized through DDD or ALTCS. This does not include the mandatory reporters children with disabilities interact with in schools or medical settings."

e. CMS has no restriction on Habilitation being performed by a legally authorized representative through our Arizona state plan. Parents being paid as Habilitation providers has been allowed under the Covid-19 flexibility program and the ARPA program extension and the parent caregiver community would like to continue to have it as a permanent option.

f. PROPOSED SOLUTIONS: (1) Include Habilitation as a service parents of minor members can permanently perform as trained and authorized providers. (2) Provide appropriate training and program implementation to DDD and ALTCS Support Coordinators so that Attendant Care and Habilitation hours are appropriately evaluated in order to remove organizational bias of parents of minors only being allowed to be paid Attendant Care providers. (3) Examine available research or conduct research to evaluate the impacts and potential social isolation concerns when parents of disabled children provide their state authorized care.

2. Remove the 40 hour restriction of Paid Parent Caregivers of minors.

a. Caring for a child who receives DDD and ALTCS services is not comparable to the needs and familial roles of a spouse performing personal care needs for an adult who qualifies for housekeeping or personal care services. Often adult spouses with disabilities have very different diagnosis and prognosis than minor children receiving DDD and/or ALTCS benefits. Parents of adult DDD and ALTCS recipients can currently perform their child's Attendant Care and Habilitation hours regardless of their guardianship status. The new permanent Paid Parent Caregiver Program for minor members should mirror the current adult DDD and ALTCS member program.

b. According to current AHCCCS policy and the PCSP document (page 16 of AHCCCS Exhibit 1620-10), parents of minors are also not required to fulfill their child's care or hours as paid or unpaid providers due to their classification of being an ALTCS / institutional level care recipient.

c. **While parents are participants in their child's 90 day DDD planning meetings and parents can request evaluations for Attendant Care, Nursing, Habilitation or Respite hours, parents are not able to determine the number of hours a member receives. These are determined by the DDD Support Coordinator and their supervisor based on the stringent evaluation process outlined by DDD policy and program management. All hours are given based on the individual care needs assessment of each member.**

d. **Parent caregiver burnout is a legitimate issue and concern for members and their families. If parents are restricted to only performing 40 hours of care per week it will create gaps in service for most members under the age of 18 and it will require parents of minor members to again perform unpaid labor due to the DCW shortage. According to the DDD call report from July 12, 2023 there are 630 members under the age of 18 needing Respite services, 202 members under the age of 18 needing Habilitation providers, and 74 members needing Attendant Care providers. These are the current need levels with the currently operating parent provider flexibility. These figures are most likely a gross underestimate of the true needs of members due to DDD Support Coordinators discouraging families from initiating call report requests so that the figures do not look worse than they currently are. Families also know that putting out requests on the call report is a futile effort due to the DCW caregiver shortage we are experiencing across the disability community in Arizona.**

e. **PROPOSED SOLUTION: (1) Remove the 40 hour restriction for Paid Parent Caregivers of minors. (2) Amend the spouse as paid caregiver program to be consistent with the parents of the adult member program with a limit of 16 hours a say of paid care so that all 3 programs are congruent. (3) Create a program provision that outlines an exception clause and application process regarding parents performing over 40 hours of care per week per member under extraordinary circumstances. (4) Require referrals be made within the DDD call report if a member child qualifies for over 40 hours a week of Attendant Care and Habilitation so that if or when an outside provider is available families receive that available outside support.**

3. **Create a plan to amend current AHCCCS and DDD policy and update training and practicing procedures of front line DDD and ALTCS staff as they implement this permanent program option for families across the state.**

a. Language in this program policy should clarify that while non-family DCW providers are an option, Paid Parent Caregivers are also an equally suitable option. This permanent program should focus on which provider meets the needs of the member in the most efficient and safe way possible.

b. Families across the state, especially those in rural areas and those from minority backgrounds, have experienced discrimination by state employees regarding this flexibility for a variety of reasons. An explicit explanation on how institutional change through training and monitoring of staff by AHCCCS and DDD leadership regarding this permanent program implementation would be very impactful in rebuilding those family, member, and Support Coordinator relationships.

c. PROPOSED SOLUTION: (1) Form a committee of community and department stakeholders to amend and critique current DDD and AHCCCS policies for the most effective and efficient implementation of this permanent option moving forward. Some examples of policies that need updating include, but are not limited to, DDD Medical Policy Manual 1240-A, 1240A-1, 1240A-2, and AHCCCS Medical Policy Manual Exhibit 1620-17. (2) Update the needs assessment process so that it is appropriately evaluating the needs of the members in their home setting vs an institutional level of care. This can be done by evaluating other state's assessments through the Arizona policy evaluation committee for this project.

Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. Parent caregivers have been the backbone of the Developmental Disability Community for decades. A comprehensive Paid Parent Caregiver program which includes both Habilitation and Attendant Care services validates the irreplaceable work that parents provide on a daily basis in their homes and communities.

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Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves DDD and ALTCS members in Arizona.

Thank you!
Danaka Stanger

From: Leilani Williams [redacted]
Date: Sunday, July 16, 2023 at 12:40:20 PM UTC-4
Subject: Parents as paid caregivers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

From the grandparent of a medically fragile 13 year old.

I think it’s important to continue payments to parents who serve as paid caregivers for minor children. The extreme shortage of caregivers makes it impossible to fulfill this need. Even pre Covid, our family had little to no care for 5 years prior.

Additionally, a fair living wage MUST BE considered for any person who does this work. We are asking individuals to do this often difficult job with an unfair and impossible to live on wages.

The minor medical community and their families, sadly is not going away. We must find a way to allow them live their best possible lives with respect, rest and kindness. This makes all the difference.

It should be said that the cost for these children to live in a group home or medical group home is 100 times higher than the cost to keep them home with paid caregivers.

Thank you for letting me speak to this matter.

Leilani Williams

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Kind Regards,

Leilani Williams

From: madeline silk [redacted]
Date: Sunday, July 16, 2023 at 11:01:11 AM UTC-4
Subject: Parents as paid providers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

I am a parent of a child who receives DDD and ALTCS services. I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility and it has been extremely beneficial to our family and my child who receives these services. Based on my review of the current proposal for a permanent Paid Parent Caregiver program I would like to give you some insight into my personal experience and feedback. Thank you for your time and consideration while reading my experience and suggestions.

Our community of parent caregivers is asking for a permanent program that allows parents of disabled minor children to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies. Under the current program proposal this request is not being fully met. Please consider the following suggested changes, reasonings and proposed solutions to the current proposal:

- Include Habilitation along with Attendant Care as services parents of minor DDD and ALTCS members can perform as certified DCW providers.

- Parents of adult DDD and ALTCS members can currently perform both Attendant Care and Habilitation hours for their children under a permanent program. The new program allowing parents of minor DDD and ALTCS members to be paid providers should mirror this currently operating adult program as it is the most comparable based on familial roles and responsibilities. Most parents of adult DDD and ALTCS members have full guardianship of the members they perform care for as their child's DCW and thus have a very similar legal responsibility as the parents of minor members.

- Parents who currently facilitate Habilitation services for their minor children are able to customize their working schedule based on the appropriate time and place for the member's goals to be performed. Habilitation hours will be extremely difficult to fulfill by non live-in providers due to scheduling requirements and limited hour availability of the members.

According to the 2023 Raising Voices Coalition survey, "Provider agencies state that the top 3 issues regarding recruiting and retaining career non-family caregivers are schedules of the client members, interest in the position and finding qualified applicants." There has been massive improvement to the IDD population in Arizona since parents of minors have been able to provide consistent Habilitation services in the most appropriate time and place for the member.

- AHCCCS leadership has stated that they strongly feel as though excluding parents as paid providers for Habilitation will encourage more community engagement and prevent social isolation of members. According to the parent caregiver community the members receiving Habilitation services will most likely experience community isolation if the option for paid parent caregivers were to be removed for their minor children. Parents of minor children will be forced to find some kind of outside employment while their DDD and ALTCS member children experience skill or goal regression due to a lack of continuity in receiving Habilitation services. This is because of the DCW shortage already in place in our state.

- According to the 2023 Raising Voices Coalition survey of parent providers of minor children in Arizona, “Eighty percent of members see at least 2 to 4 non-familial mandatory reporters (e.g. DCW providers or therapists) on a weekly basis in their home or a clinic for services authorized through DDD or ALTCS. This does not include the mandatory reporters children with disabilities interact with in schools or medical settings.”

- CMS has no restriction on Habilitation being performed by a legally authorized representative through our Arizona state plan. Parents being paid as Habilitation providers has been allowed under the Covid-19 flexibility program and the ARPA program extension and the parent caregiver community would like to continue to have it as a permanent option.

- PROPOSED SOLUTIONS: (1) Include Habilitation as a service parents of minor members can permanently perform as trained and authorized providers. (2) Provide appropriate training and program implementation to DDD and ALTCS Support Coordinators so that Attendant Care and Habilitation hours are appropriately evaluated in order to remove organizational bias of parents of minors only being allowed to be paid Attendant Care providers. (3) Examine available research or conduct research to evaluate the impacts and potential social isolation concerns when parents of disabled children provide their state authorized care.

- Remove the 40 hour restriction of Paid Parent Caregivers of minors.

- Caring for a child who receives DDD and ALTCS services is not comparable to the needs and familial roles of a spouse performing personal care needs for an adult who qualifies for housekeeping or personal care services. Often adult spouses with disabilities have very different diagnosis and prognosis than minor children receiving DDD and/or ALTCS benefits. Parents of adult DDD and ALTCS recipients can currently perform their child’s Attendant Care and Habilitation hours regardless of their guardianship status. The new permanent Paid Parent Caregiver Program for minor members should mirror the current adult DDD and ALTCS member program.

- According to current AHCCCS policy and the PCSP document (page 16 of AHCCCS Exhibit 1620-10), parents of minors are also not required to fulfill their child's care or hours as paid or unpaid providers due to their classification of being an ALTCS / institutional level care recipient.

- While parents are participants in their child’s 90 day DDD planning meetings and parents can request evaluations for Attendant Care, Nursing, Habilitation or Respite hours, parents are not able to determine the number of hours a member receives. These are determined by the DDD Support Coordinator and their supervisor based on the stringent evaluation process outlined by DDD policy and program management. All hours are given based on the individual care needs assessment of each member.

- Parent caregiver burnout is a legitimate issue and concern for members and their families. If parents are restricted to only performing 40 hours of care per week it will create gaps in service for most members under the age of 18 and it will require parents of minor members to again perform unpaid labor due to the DCW shortage. According to the DDD call report from July 12, 2023 there are 630 members under the age of 18 needing Respite services, 202 members under the age of 18 needing Habilitation providers, and 74 members needing Attendant Care providers. These are the current need levels with the currently operating parent provider flexibility. These figures are most likely a gross underestimate of the true needs of members due to DDD Support Coordinators discouraging families from initiating call report requests so that the figures do not look worse than they currently are. Families also know that putting out requests on the call report is a futile effort due to the DCW caregiver shortage we are experiencing across the disability community in Arizona.

- PROPOSED SOLUTION: (1) Remove the 40 hour restriction for Paid Parent Caregivers of minors. (2) Amend the spouse as paid caregiver program to be consistent with the parents of the adult member program with a limit of 16 hours a day of paid care so that all 3 programs are congruent. (3) Create a program provision that outlines an exception clause and application process regarding parents performing over 40 hours of care per week per member under extraordinary circumstances. (4) Require referrals be made within the DDD call report if a member child qualifies for over 40 hours a week of Attendant Care and Habilitation so that if or when an outside provider is available families receive that available outside support.

- Create a plan to amend current AHCCCS and DDD policy and update training and practicing procedures of front line DDD and ALTCS staff as they implement this permanent program option for families across the state.

- Language in this program policy should clarify that while non-family DCW providers are an option, Paid Parent Caregivers are also an equally suitable option. This permanent program should focus on which provider meets the needs of the member in the most efficient and safe way possible.

- Families across the state, especially those in rural areas and those from minority backgrounds, have experienced discrimination by state employees regarding this flexibility for a variety of reasons. An explicit explanation on how institutional change through training and monitoring of staff by AHCCCS and DDD leadership regarding this permanent program implementation would be very impactful in rebuilding those family, member, and Support Coordinator relationships.

- PROPOSED SOLUTION: (1) Form a committee of community and department stakeholders to amend and critique current DDD and AHCCCS policies for the most effective and efficient implementation of this permanent option moving forward. Some examples of policies that need updating include, but are not limited to, DDD Medical Policy Manual 1240-A, 1240A-1, 1240A-2, and AHCCCS Medical Policy Manual Exhibit 1620-17. (2) Update the needs assessment process so that it is appropriately evaluating the needs of the members in their home setting vs an institutional level of care. This can be done by evaluating other state's assessments through the Arizona policy evaluation committee for this project.

Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. Parent caregivers have been the backbone of the Developmental Disability Community for decades. A comprehensive Paid Parent Caregiver program which includes both Habilitation and Attendant Care services validates the irreplaceable work that parents provide on a daily basis in their homes and communities.

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Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves DDD and ALTCS members in Arizona.

Thank you!

Madeline silk

From: Andrea Palmer, NMD [redacted]
Date: Saturday, July 15, 2023 at 7:38:37 PM UTC-4
Subject: Paid Parent Caregiver Program Comments
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello!

We are so thrilled to hear that the Paid Parent Caregiver program may become permanent! We want to share some information about our son, our experience, and some opinions regarding the proposal!

Our son is 7 years old and is unable to stand, walk, or speak. He requires assistance for all of his activities as he is unable to feed himself, dress himself, use the toilet, obtain toys, wheel himself in a wheelchair, pull covers over himself in a bed, etc.

Until 2021 my husband and I were both working full time. The stress of finding a caregiver for your child who is unable to speak and has to rely on someone for all daily living is very heavy. But what is even heavier is when you *can't* find that person. That was our experience until the Paid Parent Caregiver program allowed me to stop working outside the home and start being a paid caregiver for our son. We went through *years* trying to find someone who was reliable *and* worth being around. In 5 years we only ever were able to obtain a total of *three* caregivers through the state and only *one* of those caregivers was reliable and trustworthy (and unfortunately she moved out of state).

Our family is thrilled that this program has the potential to become permanent as we feel it will help so many other families and children like ours. We are concerned, however, of some of the restrictions to the proposal.

First, let's discuss the 40 hour restriction. Our son requires 24/7 supervision and care. This is not a 40 hour per week job, nor should it be treated as such by the state. Some reasons that have been given by the state in support of this restriction include:

- Mirror the Paid Spouse Program
    - This is not a spouse program. This is a program for minor children. If this program is going to mirror any program, it should be the Paid Caregivers of Adult Children program, which does *not* have a 40 hour per week limit.
- Give the member the opportunity to receive services from an additional provider
    - I have watched how my son interacts with outside providers and therapists and am certain that he prefers his family and close friends to outside providers that he doesn't know. I am also certain that this is true of many children.
- Preserve the family unit and prevent caregiver burnout
    - I personally felt more burnout when I was trying to juggle my full time job AND try to manage unreliable and untrustworthy caregivers. My husband and I feel much more at ease now, knowing our son is having all of his needs met. We were fortunate this summer to have a respite provider help with our son while he was out of school and will utilize this service in the future (if we can find one) to avoid burnout.
- Conflict of interest due to parents being involved in the determination of Attendant Care Hours in the PCSP process
    Our son is unable to do anything for himself. There is no conflict of interest there, that is just the facts.

Second, let's discuss the exclusion of Habilitation Services. Some reasons that have been given by the state in support of this exclusion include:

- Exclusion of Habilitation will encourage more community engagement for members
- Concern of social isolation with parents as the paid Habilitation providers
- Some members are experiencing a lack of connection to outside providers or experiences outside the home.

Our son has only ever had one Habilitation provider in the 5 years before I became his Habilitation provider (they just aren't available). This provider was good and trustworthy, however, the only outside activities they did were going to the local park. This is wonderful, but let me give you a snapshot of what we have done just in the past few weeks during summer break. We have gone to the Arizona Natural History Museum, the IDEA museum, the Phoenix Children's Museum, the pool to meet with friends, houses of friends, Utah to see all his family and cousins, parks, and splash pads. And since I have been providing Habilitation services for our son his total communication has improved GREATLY. He can now answer yes/no questions with nodding his head yes or no. He can make choices by grabbing our hand or using a switch. He has learned 2 sign language signs. He stands with minimal assistance. He walks reciprocal steps for about 30 feet in the pool. He is visually attending to his name being called and toys. This boy is LEARNING and of course there is much that goes into that but having a qualified Habilitation provider who has active communication with his therapists and teachers is a HUGE part.

The Paid Parent Caregiver program has been a Godsend to our family and to our child who depends on someone else for everything. We want to express our gratitude to the state for this program and for considering it for a permanent program. We also want to strongly encourage the state the remove the restrictions and exclusions from this program as they are not going to have the positive impact that the state thinks they will have. At least not for our family.

With gratitude,
Andrea Palmer

From: Jessi [redacted]
Date: Friday, July 14, 2023 at 2:20:48 PM UTC-4
Subject: Paid Parent Providers Program suggestions
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

I am a parent of two children who receive DDD and ALTCS services. I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility and it has been extremely beneficial to our family and my children who receive these services. Based on my review of the current proposal for a permanent Paid Parent Caregiver program I would like to give you my feedback. Thank you for your time and consideration while reading my experience and suggestions.

Our community of parent caregivers is asking for a permanent program that allows parents of disabled minor children to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies. Under the current program proposal this request is not being fully met. During your last meeting it was mentioned a list of reasons why habilitation services weren't included in this proposal. The list of reasons were, AHCCCS felt strongly that the exclusion of habilitation from this program will encourage more community engagement for members, they were concerned about social isolation with parents as the paid habilitation providers and some members are experiencing a lack of connection to outside providers or experiences outside the home. Please consider the following suggestions and rebuttals to these reasons:

First, I would like to mention that previous to becoming their provider my children weren't out in the community as often due to their caregivers not having a license or vehicle to transport them. As I write this, the caregiver who provides respite for my children doesn't have a license or a vehicle to take them out into the community either. If having our members out in the community with caregivers is a concern, I would like to know if and when you plan on revising your current rules to include that caregivers must have their license and a vehicle to take members on outings. This would also help encourage more community engagement for members as they would have access to actually getting out in the community. Though I must mention that this revising might dwindle the current caregiver status and cause more harm to the caregiver crisis we are currently in.

I would also like to mention that my children consistently attend school, speech therapy, occupational therapy, and routinely see doctors for vision and regular checkups. They attend church on Sunday and Wednesday for religious instruction classes and are an active part of the Special Olympics. Each of the above places not only provide a sense of connection to the outside community but are mandated reporters that my children see 7 days a week.

As you know, all habilitation goals are catered to the members needs and prioritized by the severity of these needs that are critical to providing independence. For most members this includes goals that can't be done in the community. My children currently have objectives to address hygiene (showering, brushing their teeth, combing their hair and dressing properly), and laundry duties (washing, drying, folding and putting their clothes away properly). These objectives cannot be obtained in a public setting or with peers. Another goal that can be difficult to obtain in the community and often happens more at home is picking up after themselves. Each child is given a one-step direction on picking up their room or any other environment they have belongings and putting their items away properly. As time goes on this goal will include two step instructions and so on until they are able to pick up after themselves without being prompted to do so. We also have a goal that involves my children to be able to learn how to utilize a computer and participate on one. At times this involves social interaction with peers by zoom but mostly it is teaching them to properly use a computer.

Other habilitation goals can be done in the community and as a parent habilitation provider I encourage this and use it as a way of measuring generalization and mastery of these skills. Currently my youngest son has been working on using the restroom and not having any accidents. When we first started this goal, it consisted of being fully hands on. I would ask and give reminders every hour and assist with wiping and washing his hands afterwards. Then as time went on I would continue asking and give reminders to use the restroom and observe him wiping himself and washing his hands. I also reminded him to ask for assistance if needed. The next step was to give reminders to wipe and wash his hands and let him advocate when he needed to use the restroom at home. Now we are working on generalizing this skill to the community. My son unfortunately has a cleanliness issue with restrooms outside the home and will have accidents instead of using the restroom. I'm teaching generalization for the restroom by teaching my child to self-advocate that he doesn't like a restroom and asking if he needs to use the restroom and giving reminders while in public. He has come a long way with this goal and in the near future we hope to master it.

My oldest son has two objectives that we also utilize in all settings in his life, coping skills and comprehension. I have taken an intense approach with these goals by working on them hourly and any time the opportunity presents itself. Every hour he picks out a coping skill he would like to practice, and we do it for about 5-10 minutes or longer if he chooses. These skills can be taking a walk, drawing or coloring, listening to music, taking a break, discussing what is on his mind, applying pressure to himself in a hug, exercising, and taking deep breaths, just to name a few of his favorites. Before the practice and after we discuss how we are feeling so we are able to identify our feelings and self-regulate. When a problem arises, we also discuss how big our problem is and what we can do to come to a solution. Practicing this skill has helped immensely with knowing what to do when he feels overwhelmed or frustrated. With assistance he is able to identify his feelings, self-advocate and come up with solutions after calming down. This has lowered his meltdowns and outbursts which has opened up opportunities to enjoy more of the community and situations he wasn't able to before.

Another goal we work on in the community for generalization and mastery for both children is communication skills. My eldest is learning how to advocate for himself in an appropriate manner and with the proper tone of voice. We practice this in our home with a volume meter sign that shows the different volumes of your voice and examples of when it is appropriate to use those levels, reminders of these levels during conversations and redirection when levels aren't appropriate. As for advocating for himself he is prompted to ask for assistance when needed and express his wants and needs without using curse words. Before we go on outings to the park, family festivities, or other outside places we discuss these communication practices and role play situations that he might have or has had difficulty with. During our outings I am there to assist with developing his communicating skills by offering reminders, prompts, redirection and praise. As time goes on we will add to this goal and have him work on eye contact, maintaining a two-to-three-way conversation and so on.

My youngest son has come a long way with communicating in an appropriate manner and observing initial greetings from others. Since he struggles with beginning, continuing, and ending a conversation as well as advocating for himself, we decided to break this into steps. Currently we are working on observing initial greetings from others and self-advocating in an appropriate manner. In the beginning, he struggled with ignoring people when they greeted him or talked to him. We practice this skill daily by greeting each other, provoking others to greet him (family and friends), role modeling what a greet looks like, reminders to greet politely, having him answer the phone when family or friends are calling, and role-playing scenarios that he might see out in the community. Then we practice these skills out in public to help with generalization. As for self-advocating in an appropriate manner we use the same techniques by asking him questions, redirecting him when he isn't polite, discussing how he feels and how others may feel when he doesn't communicate appropriately, role modeling how to express yourself, role playing scenarios that have or could come up and how to handle them, etc. This has opened up a window of communication and self-worth that we utilize as we continue to work on all parts of communication.

In our experience, with the flexibility of myself providing habilitation and attendant care service my children have the opportunity to be out in the community more and with their peers. Not only am I able to take them to the park, out to a restaurant, to their favorite stores or events to assist with obtaining the goals, I have also been able to add future activities that they enjoy to their schedule. My eldest has shown interest in the military for years. This coming August he will finally be able to join the Civil Air Patrol as a cadet. In the Civil Air Patrol, he will be learning leadership skills and building character among other wonderful teachings. My youngest enjoys playing chess and is very excited to have the opportunity to join a chess club taught by a Master chess player. These new opportunities wouldn't be available without the flexibility I have as a paid parent provider. Since I am continuously with my children throughout the day, I am able to adjust their service hours to be flexible in changes with their schedule. This gives them access to the maximum number of activities and gives them an opportunity to grow and have fun. To us this is as important as therapies and habilitation goals because you are only a child once.

A suggestion to assist with these concerns of isolation and encourage more involvement in the community would be to mandate every member who has habilitation services to have a goal that must be done in the community. There are a variety of options to pick from for all ages. For older minors these could be assisting with grocery shopping, being able to order from a menu without assistance, etc. For younger minors this could mean learning how to interact with others at the playground, building social awareness through outings, learning to pick out which strangers (police, firemen, etc.) that you can trust, etc. This would be a better option to promote social interaction for our members. By proposing we interrupt our children's habilitation services by trying to find another caregiver and a reliable one who is properly trained would only spike the caregiving crisis we are already in. If this crisis continues, we are only hindering our members from progressing with their goals of obtaining some form of independence as they get older.

Another concern that was brought to my attention was the worry of parents being burnt out. I can assure you this isn't the situation. Previous to obtaining this position I was an assistant manager at a restaurant and worked 15 hour days, while trying to maintain a household, be present for therapies and meet my children's needs. This was very stressful due to the inconsistencies of not having a reliable provider. It came to a turning point when one of my children was left unattended outside by a provider. I knew at this point I needed to stay home. Now I am able to put all my focus on what matters, my children. I am present and actively a partner in their therapies so as to learn how to continue their growth. I am able to write our schedule around household duties and their activities so I can give personal attention to their needs. I am fully able to take breaks with respite instead of using those hours to make up hours I missed at work due to providers and therapies. Being a paid parent provider hasn't been a hindrance to our lifestyle but has actually opened up opportunities to be more present in my children's lives and progress in their goals. This has actually been a blessing that I will cherish and continue to cherish if it is made permanent.

As you can see from these examples my children are very much involved in the community during their habilitation services and when not receiving services. I appreciate the opportunity to share my family's experiences and suggestions in hopes that you will take them into consideration by allowing paid parent providers to continue to provide services as we have under the Covid flexibility program.

Best Regards,

Jessica Grace

From: Liliana Ras-sar Byers [redacted]
Date: Thursday, July 13, 2023 at 10:39:14 PM UTC-4
Subject: Habilitation for children under 18 , Parent paid providers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Many DDD/ALTCS members have Autism Spectrum Disorder, a condition that is characterized by a strong preference for routine and familiarity. For this reason, parents/family are truly the best caregivers for autistic members, as they provide consistency, familiarity and a safe, calming environment that is conducive to learning new skills. Discontinuing habilitation for parent providers would be extremely disruptive for members on the autism spectrum, and disruption would be synonymous with regression.

My son is 5, Autistic, intellectual impairment and non-verbal. I have a major issue with an unknown person working on the Habilitation goals I am currently working on with him. I do not want an unknown person teaching him to bathe, or go to the bathroom. Those are very personal items that I do not feel comfortable with someone else doing. Especially with him being non-verbal and his communication skills are severely lacking. I did not want to send him to a clinic based setting for ABA for similar reasons. Since he is unable to communicate with me, he is also unable to tell me if something is happening that should not be happening. If paid parent provider goes away, we will definitely take a financial hit (with some major financial modification) but I will not allow someone else to work on those very personal hygiene goals.

Not to mention, my son has severe meltdowns that are near impossible to manage. I do not want an unknown person trying to navigate those. We do in home speech therapy and OT we are seeking in home ABA. We also go to parks, stores, zoo, aquarium etc My son is not lacking on outside interaction at all. Many kids have goals around hygiene that should remain private, and in addition to communication challenges, many autistic kids have no sense of danger, or of what is and isn't appropriate for them to share when it comes to their bodies..

From: Amanda Marquez [redacted]
Date: Thursday, July 13, 2023 at 1:00:12 PM UTC-4
Subject: Feedback from a Concerned Parent
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hi Director Heredia and Staff,

I appreciate all you are doing to implement the permanent Parent Provider Program but I feel it necessary to share my families experiences to help you understand just how important it is to include parent provided Habilitation in this program and allow for parents to provide 16 hours a day of services; just as an outsourced provider is allowed.

My Autistic child has had services since he was 2 years old, he just turned 9 this year. We have been through a multitude of providers since that time because it is very hard to keep someone on for longer than 3 months. That seemed to be the average turn around for my child's providers when we could find them although sometimes it was 3 weeks. Each time my child would lose a provider he would end up regressing and obsessing over why his provider left him. Years later he still obsesses over providers who left when he was 3 and 4 years old. He has a mind that does not forget. For his mind it is almost like processing the death of a loved one over and over again with the exit of each new provider. He gets close to them, gets accustomed to them and thinks of them like family and then poof they disappear. There is no consistency. To top that off, the providers were always very inconsistent in showing up for work and would often times give no notice at all. This inconsistency would cause meltdowns every time it occurred which was usually once or twice a week if not more. Not only did it affect my child's progress but it caused me to lose income and not be able to hold a steady job because there was no telling when a provider would simply not show up or quit entirely. This lack of consistency caused chaos for my child and my family in so many ways. Then the provider shortage hit and my child did not have a provider for Habilitation, Attendant Care or Respite for 3 years. He was on a waiting list up until I learned of the Parent Provider Program 2 months ago and became his provider. My son's Support Coordinator(s) would constantly put out new vendor calls for services because no one was available or responding to us. 3 years without the needed services that my child absolutely qualifies for and needs is not acceptable and has caused my child to fall even further behind on his goals and life skills. I was doing my best to provide unpaid services for him while simultaneously attempting to work from home which was a nightmare situation that did not work out and has caused me to fall into debt as I could not find a provider to be with him while I worked. It seemed as though finding someone with hours flexible to any work schedule was an impossible task and so my son was the one who suffered for it and he remained without a provider for 3 solid years. I'll repeat it, no Habilitation, no Attendant Care and no Respite providers were available to accommodate him even though he qualifies for over 40 hours a week of these essential services.
Since, I found out about the Parent Provider
Program and have been able to provide both his Habilitation and Attendant Care services while simultaneously receiving an income from it. I have been able to consistently work on his goals without having to struggle to maintain external employment that allows me to work around my childs needs. My child has only had me as a Paid Provider for a little over a month but working on his Habilitation goals everyday has made a huge impact in such a very short time. As a parent I have noticed that we have made more progress than any other provider that he has had in the past because of the consistency allowed and the trust that he has with me.

Many of his Habilitation goals focus on areas of growth that require privacy and he would not feel comfortable at this age allowing a stranger to provide assistance on goals that pertain to his daily hygiene and potty training. He is a little human who desires a certain amount of privacy and that helps to keep him feeling dignified which is something that I as a parent can only provide because he trusts me and will allow my presence in those moments without feeling embarrassed or ashamed. Habilitation goals are so important for my child and allowing his most trusted person to assist him in achieving those goals is something that works. I know my situation isn't unique and that many other children and parents have the same issues. Please allow us to provide the Habilitation our children need so that they can grow up to be successful adults capable of independence.

I also wanted to touch on the 40 hour restriction. My child qualifies for over 40 hours of Hab/ATC. His needs have been assessed by his Support Coordinator and approved by her Supervisor. All of those hours are necessary for him to meet his goals and work towards independence and he needs so many hours because he was without services for such a long time (3 years). As I mentioned before, my child needs consistency or he will regress and he needs to trust his provider. There is no one in his life that he trusts more or that is more consistent than me. With me he will be successful, comfortable and happy. I hope you will understand that this is the case for most families like ours. If you were to cap the hours at 40 there would be no outside provider able to come in and work with our child because he would not let them near him to work on goals that include potty training and independent bathing. He understands that he wants his privacy and will not allow a stranger to violate that space. So capping the program at 40 hours just ensures that parents will do the work unpaid and continue to struggle to make ends meet. That is unnecessary stress on families who are already heavily burdened and doing their best to accommodate the needs of their children. Please allow us to provide the services our children have qualified for in full. It is so important for their success in the world.

Also, I know you have mentioned concerns about our children not getting enough social interaction but many kids have "Habilitation" goals that are aimed entirely at socialization and life skills like shopping, going to a library, interacting with other kids at a park etc ... Parents providing those socialization goals is helpful for the child as they are around someone they trust as they venture out more and more into a social climate. A child having a trusted parent with them can make the difference between success or failure. A child having a trusted parent with them decreases anxiety and allows for more confidence in social situations. I can also say from a personal perspective that my child has external providers come into the home for therapies, he is involved in out school classes for socializing with other kiddos across the country, he hangs out with his cousins and friends, has playdates etc... Socialization needs are absolutely being met.

I wanted to touch on Habilitation goals that require privacy. We teach young children about appropriate touching but for Special Needs kiddos that line can get blurred when we bring in outside providers. It is very difficult for my child to understand an outside provider being present with him in the toilet or on the bathroom at 9 yrs old. He is comfortable with his mom being there to help him in those scenarios especially after 3 years without a provider (he is not used to strangers in his personal space). Body autonomy is also very important to teach our kids especially while they are young and vulnerable.

If my child refuses to have an external provider work on goals such as bathing and potty training as a parent I must respect that right to privacy but knowing that he will allow me to work on those goals with him begs me to ask you to see this perspective for all of our kiddos who need to work on these types of goals to be successful in life. ATC is not working towards goals and so I plead that you allow Habilitation to be provided by parents so our children can learn independence and not reliance whenever possible.

Thank you for hearing my comments and I hope you will take them to heart before making your final decisions.

Thank you,

A Concerned Parent (provider)
(name withheld for child's privacy)

From: Jessica Nolte [redacted]
Date: Thursday, July 13, 2023 at 9:26:11 AM UTC-4
Subject: Paid parent provider
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Good morning,

My name is Jessica Nolte and I'm a parent provider for my two autistic kids. They are currently 7yo and 5yo. I am very happy to hear there is a plan to continue the parent paid provider past the pandemic exception, it shows the state sees the work we are doing and appreciate us. I do, however, strongly disagree with the random decision of excluding Habilitation services from the proposal.

Habilitation is a great service in AZ that is me at to increase independence for people with disabilities. This program works, I have personal experience with it. In the last two years I have been a provider my kids gained amazing skills like using utensils during meals times, working on changing their clothes by themselves, getting rid of diapers and learning higiene skills such as brushing teeth, washing hands and taking a bath. All those skills increase the likelihood of them being independent and having a more fulfilling life - which is the goal for any citizen and specially for kids with disabilities.

Excluding Habilitation with direct affect kids ability to receive services. There is a work crisis for state related services, it's nearly impossible to find anyone willing to do the hard work of working with disable individuals for the pay the state has currently. I don't blame them, it's hard work, but we can't let those individuals without services that they require. Having a parent provider gives the child the best chance to achieve their independence since parents are the most motivated people to make it happen.

Some reasons given for HAH not being allowed is that it can increase isolation. Being there os NO other options for providers this point is moot. Until the state can address the crisis it cannot use this excuse to prevent parents to exercise the ability to serve their children. In another point, Habilitation allows community goals such as safety, grocery shopping and social skills - working on those will directly combat isolation and work on inclusion and acceptance in the community.

Habilitation has been a blessing in my kids lives, taking away that service will severely impact their ability to successfully achieve their goals. I know the state wants the best for the children and their parents and I'm here as a witness that the best outcome is for parents to be able to provide HAH services for their children.

I hope you will have an open mind to see there is no good reason to prevent HAH to be part of this waiver and do the right thing by our most vulnerable children.
Sincerely,
Jessica Nolte

From: [redacted]
Date: Thursday, July 13, 2023 at 1:53:23 AM UTC-4
Subject: Paid Parent Provider Feedback
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To whom it may concern,

I would like to first thank you for listening and considering the feedback from those that this program was built for.

I would like to take a moment to introduce my son. My son's name is Jackson. He is 5, going on 6 in August. He was diagnosed as level 3, Non-verbal autistic. As I have learned through the years, autism is an umbrella term. It is not a one size fits all diagnosis.

For my son, it is an exceptionally difficult disability to navigate. He has not said a single word and has no way of communicating with me. His mental acuity is more on par with that of a 2 year old. He will express his food needs by bringing me the food item he wants. Other than that, he does not communicate.

On top of the communication barrier, he has intense meltdowns that can take hours to overcome. With him not being able to tell me what is bothering him, it is a continuous guessing game.

His attention span is also very limited. He will be able to focus on a task for a maximum of 1 minute.

Now, that you know a little about my son, I would like to express my thoughts about making the paid parent provider program a permanent solution.

I am my son's current HAB provider. His current goals consist of toileting, bathing, tooth Brushing, hand washing, holding hands and following directions, and putting pants on.

Could you imagine an unknown person coming in and bathing your child? Or taking their pants off to go to the bathroom?

I can not, in good conscience, allow an unknown person to provide those very very personal hygiene HAB goals, when my son does not possess the ability to tell me if anything is happening that should not be happening. That, to me, is a major safety concern for me.

Also, as stated before, he has meltdowns that can last hours. I have a hard enough time getting him through those, I do not suspect any other HAB provider would be able to navigate them, nor would they want to.

Due to my son's needs and lack of communication, I have opted to have in home therapies (Speech, ot, aba), so I can jump in when needed to help navigate the meltdowns. I opt to drive him to school instead of a bus, due to his non existent communication skills.

He does not miss out on any interactions outside of the home or with people outside of the family. He sees 3 therapists weekly and wr go to the store, parks, zoos, ect.

If this paid parent provider program is taken away, the one it will harm the most is my son. The funds I receive as his parent provider have allowed me to purchase additional items to help him with his therapies. These are items that I would not be able to budget in on our families salary. Items needed for special needs children a quite a bit more expensive.

I urge you, to please consider making this program permanent. Consider the safety risks for all those involved, mainly the children. Consider the consistency that the majority of Special needs children need, especially my son.

Thank you for taking the time to get to know my beautiful son and our journey. We both appreciate your consideration.

Thank you,
Nicole Mumbach

From: Suzy Eames [redacted]
Date: Tuesday, July 11, 2023 at 2:37:19 PM UTC-4
Subject: Parent Caregivers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

1. Parents do most of the caregiving even when they get a helper. Getting financial help helps the parent pay for the needs of the child.

2. I am a caregiver for my adult special needs child. My child is not a minor. They still need my help.

From: Karen Land [redacted]
Date: Monday, July 10, 2023 at 2:18:04 PM UTC-4
Subject: Paid caregivers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

I vote for parents to be able to be permanent caregivers. Since the pandemic I have been the caregiver for my children and they have not been able to find any other outside caregivers for my home. I take care of them anyway and the salary has benefited our lives. Being with them all the time, and not working an outside job has made us a closer family and happier as a whole.
Sincerely,
Karen Land
[redacted]

From: Julie Hahn [redacted]
Date: Friday, July 7, 2023 at 10:12:08 PM UTC-4
Subject: Please keep parent providers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello,
I'm writing to you because for the first time in five years my special needs twins have consistently received habilitation. Before we were able to offer the care we would have multiple people that should've been offering services not show up or quit because it's too much, thus causing more trauma damage to our twins, who are adopted.
They have made strides that would've never been possible. The fact that you allow us to be paid means I can be home helping our twins learn life skills instead of working outside of the home and them being in someone else's care that wouldn't run the habilitation program.
I implore you to continue this most beneficial program.
Thank you for your time and consideration,
Julie

From: Ana Reyes [redacted]
Date: Friday, July 7, 2023 at 9:50:06 PM UTC-4
Subject: Padres cuidadores proveedores
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Para mi a sido muy importante como proveedora de mi hijo me e informado de las necesidades y de la ayuda que mi hijo necesita juntos hemos trabajado en metas que pueden hacer que mi niño pueda ser independiente como madre es muy importante trabajar en las metas que mi niño necesita poniendo no sólo trabajo como habilitadora si no enseñándole con cariño y paciencia que una madre podría tener a su hijo ya que en casa es donde mejor se conoce las necesidades que cada Niño puede tener y trabajar con el diariamente dedicándole el mayor tiempo posible y atención en todo momento quien mejor que los padre para hacer esta habilitación con su propio hijo con los cuidados, paciencia pero sobre todo amor y cariño Gracias!!!!
Enviado ya que desde mi iPhone

From: Maribel Valenzuela [redacted]
Date: Friday, July 7, 2023 at 7:53:36 PM UTC-4
Subject: The Arizona Health Care Cost Containment System (AHCCCS)
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To whom it may concern,

I have been a parent provider for the past 2 years going on 3years.
I started when covid first started and my husband was laid off from his job of ten plus years. I then became the only and main source of income for my family.
We have two sons that have disabilities
(autism/aspergers/adhd/non-verbal w/ speech delay/odd/sensory processing disorder) i was struggling on how to better help our kids as they grew, help them on what i could provide them when they had a hard time socializing among many other difficulties that they continue to face in school, with their peers and with in the community.
I have better come to understand their diagnosis and I help our family come to understand them as well and help them interact with my boys ages nine years old and 5 years old.
In having this job I have become better informed of their diagnosis so I can be a better advocate for them with doctors, teachers and when I have to attend their I.E.P meetings. This job has given more to my family than I could have ever dreamed of since this is the field that I plan on going to school to specialize in.
I have not only helped my family move forward financially, have an income while still being able to be a Mom, being able to attend their school functions, having a closer connection with my sons, helping them grow and flourish and being a part of their growth.
This job has given me the tools to help my sons show them how to regulate themselves, help them advocate for himself since they struggle to communicate on their own.
this job has shown me how to make a pecs board, how to implement it , how do continue to integrate it in every setting because they trained me to do so and that has been the biggest blessing of all because i now get to hear my son voice when he talks when before it was hard to just find out all he wanted was a break, he wanted a certain cup.
When in a normal setting BCBA along with RBT in ABA therapy are only there for a certain amount of time while yes they do help but they dont and wont understand the time were we as parents need so desperately to have more than a 10-15 minute conversations on "what we can do better" in when it comes to our kids. i have been that parent with multiple RBT/BCBA ABA therapies watching my kids build a bond every time they "had to get a new therapist" due to "policies" than to just watch our kid or as it's said " the client" regress everytime that it is done and watch them slowly shut down and not want do try because whats the point in they will be gone every so often? the "client"(our kids) think there is no point that's when WE as parent providers come we don't leave the "client" and have to build a rapport or a bond because we already have it and from my own experience my kids or "clients" love to learn more with me than they ever did with any BCBA/RBT in ABA therapy because they are learning with US their parents/relatives.

One does not have to wait on a waitlist for months to years for a spot to open for therapies because we got trained to do that very thing that I myself have been waiting for over a year every time till I got trained to do this job I have now which is at home habilitation.
if it is cut off it will sent hundreds if not thousands of parents to waitlist, scrambling to find a company that will not only take their insurance but also put in a those wait list that are all on a

first come first serve which will also send all those children to regress all the progress that not only the parents worked hard to learn to teach their "clients" (kids) but the joy that we all as parents enjoy to learn to teach our kids in every setting, giving us as parent the feeling of we are giving solutions to our kids giving them help because before this opportunity of parent provider came i was that parent that stayed up to research, read, try and find help for our kids instead of being put on waitlist to get evaluated which takes a minimum of a YEAR for the diagnosis if you can find one that will take your insurance if not its out of pocket which is a few hundred dollars than you have to be put on more waitlist and go through more hoops Just to get started to help your child, this parent provider helps alleviate those waitlists or having to deny certain companies due to time frames because it doesn't fit into the daily lives of each parent/ family and sometimes you have to leave your child at a center with people you are not familiar with and in a place that you don't know nor comfortable with but have to when you have no choice.
Parent provider helps us parents with having to leave our child in a place and with people we don't know and in some cases that ends in more problems because those providers may not agree with family value, how you are raising your kids etc and they do call CPS when you have done nothing at all wrong but you have to endure all that because you want to help your child.

I will end with this parent provider has been and continues to be the biggest blessing and the most hands down enjoying job i have ever had the pleasure of learning finally this is a soon to be a career for myself because this has shown me that i am more than a mom i am damn good provider and will make an amazing asset to other parents in the Autism community along with in the educational system all thanks to the first step i ever took which was becoming a parent provider.
This program and opportunity should stay and be given to more parents.

Thank you so much for reading my statements and thoughts on this subject.

sincerely,

Maribel Zenteno| HAH provider and Para-profesional

From: Olivier Avalos [redacted]
Date: Friday, July 7, 2023 at 7:52:21 PM UTC-4
Subject:
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Yo no estoy de acuerdo

From: Chimi Morales [redacted]
Date: Friday, July 7, 2023 at 5:57:13 PM UTC-4
Subject: Parent Child Care System
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To whom this may concern,
I believe parental care for special needs children would be a wonderful thing. A parents love & attention towards their child is better than being put in the hands of a stranger. If you've ever seen on the news there's reports all over the media where these children are often neglected or not given the full care they need. Unlike a parents love which is unconditional & they always know what's best for them. They know the ups & downs as well as ins & outs of their child. Who else could better care for them? They understand their behaviors, know their health issues, to attitudes & likings. It's important the child is in a loving & safe environment also one they are comfortable & recognize as well. Especially as many of these children are not used to change. It is great to know that there may be a program like this beginning & it would absolutely be wonderful to see it go through!

From: Karla Bautista [redacted]
Date: Friday, July 7, 2023 at 3:19:25 PM UTC-4
Subject: Parents as Paid Caregivers azahcccs.gov
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello,

I am a special needs parent, my son is severely affected by cerebral palsy he is full care he also has a hearing loss and has cortical vision impermanent. It has been such incredibly difficult journey for me. Since I am a single parent his dad doesn't help physically or financially I have submitted child support but through all the efforts he doesn't pay. My son does attend school but misses half the year since he also gets severely sick for months. Sometimes unable to sleep at night because of how sick he gets. I have many times tried to go back to work but I struggle finding help. I have offered this position to many people but always seem to complain about the amount of work my son is. My aunt has said many times that she wouldn't want to do what I do it's to much work. People leave because he is to heavy or he has accidentally hurt them since he isn't able to control his body or strength. As I'm writing this to you I am sobbing. It's very hurtful and painful everything we have been through. I would give my life so my son wouldn't be disabled and he wouldn't suffer so much as he is every single day. I would 1,000% go back to a full time position but calling out because my son is sick has gotten me into a lot of trouble and I have been yelled at work because of this. Being able to be my son paid caregiver has given my son the ability to buy groceries clothes wipes his glasses special chairs for him, I was able to buy him a manual wheelchair since the insurance covered his electric but sometimes his electric need repairs and he is out of a chair. I am able to buy things that insurance isn't able to cover. I also pay for our rent and all of our bills. Removing this help from us will leave me and him unable to pay for anything. We would have to reapply for food stamps and go to government apartments and hopefully they can help pay for my rent.

Please allow us to continue to be our kids providers.

From: Amanda Burgos (she/her) [redacted]
Date: Friday, July 7, 2023 at 1:59:32 PM UTC-4
Subject: Paid Parent Caregiver program input
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

I am a parent of a child who receives DDD and ALTCS services. I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility and it has been extremely beneficial to our family and my child who receives these services. My child is 14 years old and has been unable to return to school since the pandemic. He is 6'6" and 300 lbs, is non-verbal and incontinent. He requires constant supervision and care. He has a compromised immune system and is not able to attend any day programs. Because of his immune system, having people from the community in our home is dangerous to my child. Since I am his primary caregiver, and have been unable to work outside the home because of my son's disabilities, the Paid PArent Caregiver program has been hugley impactful to my family. Based on my review of the current proposal for a permanent Paid Parent Caregiver program I would like to give you my feedback. Thank you for your time and consideration while reading my experience and suggestions.

Our community of parent caregivers is asking for a permanent program that allows parents of disabled minor children to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies. Under the current program proposal this request is not being fully met. Please consider the following suggestions:

1. Include Habilitation as a service parents of minor DDD and ALTCS members can perform as a certified DCW provider. Parents of adult DDD and ALTCS members can currently perform both Attendant Care and Habilitation hours for their children and parents of the minor population would like this permanent option to mirror that program allowance. The DCW workforce shortage applies to Habilitation providers just as much as it does Attendant Care providers. CMS has no restriction on this service being performed by a legally authorized representative. There has been massive improvement to the IDD population in Arizona since parents of minors have been able to provide this service at the correct time and place that is applicable to the member. Parents being paid as Habilitation providers has been allowed under the Covid-19 flexibility program and the ARPA program extension and we would like to continue to have it as a permanent option.

2. Remove the 40 hour restriction of Paid Parent Caregivers. Caring for a child who receives DDD and ALTCS is not comparable to the needs and familial roles of a spouse performing personal care needs for an adult who qualifies for personal care services. Parents of adult DDD and ALTCS members can currently perform some or all Attendant Care and Habilitation hours that their adult children qualify for under their PCSP. The new permanent Paid Parent Caregiver program should mirror the current adult DDD and ALTCS member program. There are no federal CMS barriers to parents working over 40 hours per week of paid care. AHCCCS limits every DCW provider to 16 hours of provided care in a 24 hour period, Parent Caregivers would like this same option so that the care of the member's evaluated hours can be fully fulfilled dependending on the availability of non-family and family DCW providers. If this restriction is not an option, a provision that outlines an exception clause and process is requested.

3. Create a plan to train and maintain supervision of front line DDD and ALTCS staff as they implement this permanent program option for families across the state. Language in this program policy should clarify that while non-family DCW providers are an option, Paid Parent Caregivers are also an equally suitable option. This permanent program option should be about which provider meets the needs of the member in the most efficient and safe way possible. Families across the state, especially those in rural areas and those from minority backgrounds, have experienced discrimination by state employees regarding this flexibility for a variety of reasons. An explicit explanation on how institutional change through training and monitoring of staff by AHCCCS and DDD leadership regarding this permanent program implementation would be very impactful in rebuilding those family, member, and Support Coordinator relationships.

4. Include a provision that allows foster children residing in DDD / CDH homes to receive Attendant Care hours that foster parents can be paid for as DCW providers. These children receive the general Habilitation allotment appropriate to their foster placement to fulfill their personal care needs. However, their individual need levels should be considered in their Habilitation and Attendant Care evaluations so they can receive all appropriate services by a DCW provider regardless if it is a paid foster parent or outside DCW.

Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. Parent caregivers have been the backbone of the Developmental Disability Community for decades. A comprehensive Paid Parent Caregiver program which includes both Habilitation and Attendant Care services validates the irreplaceable work that parents provide on a daily basis in their homes and communities.

Click here to connect with the Arizona parent led grassroot initiative leaders:
www.raisingvoicescoalition.com

Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves DDD and ALTCS members in Arizona.

Thank you!
Amanda Burgos
Tucson, AZ

From: christinamaria13@yahoo.com [redacted]
Date: Friday, July 7, 2023 at 1:56:01 PM UTC-4
Subject: Parents as Paid Caregivers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To whom it may concern,
Covid-19 changed a lot of lives. It destroyed a lot of lives, in many different ways. Some people lost their lives, some lost loved ones, some lost jobs, some lost the opportunity to experience a graduation or a prom, or even a funeral, and so on. So many terrible things happened to so many different people during the pandemic.
But I know of one amazing thing that happened. Parents in the Special Needs community were able to finally get paid to take care of their child. Parents who normally can't work, or can't work enough hours to survive, were able to ensure the safety and care of their children, and at the same time, be able make money to a little to help feed their children and help provide for their family.
For years we have struggled to figure out how to find a job that lets you work the hours you need, or make the doctors appointments and therapies that our kids need, or even struggle to find a provider who is willing, and able, to work for the pay rate and the hours that are provided. It usually took two to three months to find a provider, and they rarely ever stay very long.
please don't take this away from all the families that need it. Please don't make us go back to the struggle the way that it was. Being a special needs parent is hard, please don't make it harder, again.

Thank you.
Christina, Junior's Mom

From: rlechleite [redacted]
Date: Friday, July 7, 2023 at 1:32:38 PM UTC-4
Subject: To who it may cocern:
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

I HAVE BEEN TaweKING CARE OF MY granddaughter since she was born in 2001. She lives with me and I take care of her. We use the money I make to support her. We need this since I am on ss. And would have to move in a home and so would she. Please re consider this We would be state susupported.

THANK YOU

Sent from my Verizon, Samsung Galaxy smartphonerenee lechleiter and Faith lopez

From: sarah maichl [redacted]
Date: Thursday, July 6, 2023 at 5:16:40 PM UTC-4
Subject: Paid parent caregiver program
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

I am a parent of a child who receives DDD and ALTCS services. I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility and it has been extremely beneficial to our family and my child who receives these services. Based on my review of the current proposal for a permanent Paid Parent Caregiver program I would like to give you my feedback. Thank you for your time and consideration while reading my experience and suggestions.

I have a 4 yr old non mobile non verbal spastic quad cp daughter. She is full care. I have recently been let go from my previous employer due to all the call outs and days I just couldn't make it in. I have not been able to find any type of provider in the last 3 years. I have unused respite hours that have never been filled. I have posted ads on numerous sites, put in vendor calls and have tried to recruit college students with no luck. This program helps me keep a roof over my daughters head. I am a single mother with no help. My family has relocated back to the Midwest. My daughters dad's family isn't involved in any way. With the shortage of help I am not able to find employment with the limited availability that I have. This program is an asset to most families and habilitation needs to be included in this.

Our community of parent caregivers is asking for a permanent program that allows parents of disabled minor children to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies. Under the current program proposal this request is not being fully met. Please consider the following suggestions:

> Include Habilitation as a service parents of minor DDD and ALTCS members can perform as a certified DCW provider. Parents of adult DDD and ALTCS members can currently perform both Attendant Care and Habilitation hours for their children and parents of the minor population would like this permanent option to mirror that program allowance. The DCW workforce shortage applies to Habilitation providers just as much as it does Attendant Care providers. CMS has no restriction on this service being performed by a legally authorized representative. There has been massive improvement to the IDD population in Arizona since parents of minors have been able to provide this service at the correct time and place that is applicable to the member. Parents being paid as Habilitation providers has been allowed under the Covid-19 flexibility program and the ARPA program extension and we would like to continue to have it as a permanent option.
>
> Remove the 40 hour restriction of Paid Parent Caregivers. Caring for a child who receives DDD and ALTCS is not comparable to the needs and familial roles of a spouse performing personal care needs for an adult who qualifies for personal care services. Parents of adult DDD and ALTCS members can currently perform some or all Attendant Care and Habilitation hours that their adult children qualify for under their PCSP. The new permanent Paid Parent Caregiver program should mirror the current adult DDD and ALTCS member program. There are no federal CMS barriers to parents working over 40 hours per week of paid care. AHCCCS limits every DCW provider to 16 hours of provided care in a 24 hour period, Parent Caregivers would like this same option so that the care of the member's evaluated hours can be fully fulfilled dependending on the availability of non-family and family DCW providers. If this restriction is not an option, a provision that outlines an exception clause and process is requested.
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> Create a plan to train and maintain supervision of front line DDD and ALTCS staff as they implement this permanent program option for families across the state. Language in this program policy should clarify that while non-family DCW providers are an option, Paid Parent Caregivers are also an equally suitable option. This permanent program option should be about which provider meets the needs of the member in the most efficient and safe way possible. Families across the state, especially those in rural areas and those from minority backgrounds, have experienced discrimination by state employees regarding this flexibility for a variety of reasons. An explicit explanation on how institutional change through training and monitoring of staff by AHCCCS and DDD leadership regarding this permanent program implementation would be very impactful in rebuilding those family, member, and Support Coordinator relationships.

> Include a provision that allows foster children residing in DDD / CDH homes to receive Attendant Care hours that foster parents can be paid for as DCW providers. These children receive the general Habilitation allotment appropriate to their foster placement to fulfill their personal care needs. However, their individual need levels should be considered in their Habilitation and Attendant Care evaluations so they can receive all appropriate services by a DCW provider regardless if it is a paid foster parent or outside DCW.

Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. Parent caregivers have been the backbone of the Developmental Disability Community for decades. A comprehensive Paid Parent Caregiver program which includes both Habilitation and Attendant Care services validates the irreplaceable work that parents provide on a daily basis in their homes and communities.

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Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves DDD and ALTCS members in Arizona.

Thank you!
Sarah Maichl
[redacted]

From: Beth Menendez [redacted]
Date: Thursday, July 6, 2023 at 4:54:28 PM UTC-4
Subject: Paid Parent Caregiver Program
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

I am a parent of a child who receives DDD and ALTCS services. I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility and it has been extremely beneficial to our family and my child who receives these services. Based on my review of the current proposal for a permanent Paid Parent Caregiver program I would like to give you my feedback. Thank you for your time and consideration while reading my experience and suggestions.

Before I was able to become a parent provider, I struggled to find quality care for my son. I take care of my autistic low functioning son along with my disabled mother and a 3 year old daughter. My son is not able to get attendant care but is able to get 40 hours of Habilitation so that he can, one day, hopefully become a functioning adult.

Our community of parent caregivers is asking for a permanent program that allows parents of disabled minor children to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies. Under the current program proposal this request is not being fully met. Please consider the following suggestions:

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Thank you!

Beth Menendez

From: Jenny Mullins [redacted]
Date: Thursday, July 6, 2023 at 4:30:22 PM UTC-4
Subject: 2023 Paid Parent Caregiver feedback
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,
I am a parent of a child who receives DDD and ALTCS services, including habilitation, respite, and attendant care hours. My organization, *Advocacy31nine, also represents the collective voices of hundreds of foster parents who are also caregivers of children with special needs.*

I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility and it has been extremely beneficial to our family and my child who receives these services. My child has made significant gains since I have been able to provide habilitation and attendant care services for her. *We went for years without being able to find providers to fulfill all of her hours* so having the paid parent caregiver program has been extremely beneficial for our daughter.

Based on my review of the current proposal for a permanent Paid Parent Caregiver program I would like to give you my feedback. Thank you for your time and consideration while reading my experience and suggestions.

Our community of parent caregivers is asking for a permanent program that allows parents of disabled minor children to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies. Under the current program proposal this request is not being fully met. Please consider the following suggestions:

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Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves DDD and ALTCS members in Arizona.
Thank you!
Jenny Mullins
Co -Founder / Program Director
Special Education and Civil Rights Advocate
Council of Parent Attorneys and Advocates (COPAA) Member

ADVOCACY 31nine
~~www.advocacy31nine.org~~
[redacted]
Amplifying Your Voice

WANT TO MAKE AN IMPACT IN THE LIVES OF VULNERABLE KIDS?:
Advocacy31nine is now a Qualifying Foster Care Organization!

From: **gigi** [redacted]
Date: Thu, Jul 6, 2023 at 11:23 AM
Subject: Parent Paid Caregiver Forum

To: <susan....@azahcccs.gov>

Hello,

I have registered for this forum. In the event that I have to cancel, I wanted to provide a statement of support that I hope can be referenced or presented to the appropriate legislature/individuals.

Thank you and please see below.

Dear Committee,

I am writing this letter in support of permanently extending the AZ Parent Paid Provider/Caregiver Program. I want to begin by providing a very interesting and compelling case in support of this Program.

My name is Jillian Alahaydoian. I am a mother of two high needs autistic children who are members of this program and recipients of DDD services. I want to specifically speak in reference to my 13 year old (male) child who I will refer to as J. J is a limited verbal autistic child who also has PTSD, ADHD, Intermittent explosive disorder, and extreme aggression. He has had an emergency room stay of over 500 hours this year due to extreme injurious behaviors. He has tried to throw himself through a window, bash his head into the concrete, punch through walls, broke my finger, almost broke my nose, and threw tables at his family. He also has physically injured his teachers which resulted in him being sent to the ACES school. He has injured staff at Phoenix Children's hospital and had a 2-to-1 staff ratio with him during his stay there. During his time at the hospital, he had to be chemically and physically restrained multiple times daily. Up until very recently, J has had no outside workers as a result of no one being able to withstand his aggression. He has not been a candidate for ABA due to aggression and lack of workers. All of this information has been noted through DDD documentation and crisis intervention teams. Jayden has no other family here in Arizona, as we are not Arizona natives. Arizona is also a foreign state to him as we have only been here a few years. Thus, a group home setting would send him into extreme depression. Coupled with J's other issues, a group home at this time is not preferable. The parent provider program has allowed me to provide services to J that he would not be able to use due to the lack of a suitable worker. It has allowed me to stay home financially and give him full support that he needs also considering no outside after school program or daycare is equipped to handle his high level of needs. The parent provider program also allows J to use the services that he has been approved for through the state. Please note again that he has not ever had another person do attendant care and habilitation due to his level of aggression. If this program is taken away this will have a detrimental effect on J. While I realize J's case may not represent the norm, his story deserves to be heard because every child deserves a chance to remain with their family in the home setting.

Currently, J finally has a respite worker who happens to also be a supervisor at a group home and is fully trained to do therapeutic interventions if necessary. No other agency besides the current one J's worker is employed with, has allowed hands on interventions in extreme emergencies (J trying to crack his skull on the floor). Finding this level of worker is a needle in a haystack and while we are extremely blessed, many many families with very high needs children suffer and have no-one to provide respite/HAB/Attendant care. We ourselves have gone years without any workers and never even imagined we would get one due to the complexity of J's issues. Currently my son's aggression has decreased some and is more manageable due to medication changes and having this respite worker. However, I am in local forums where the cries of parents for workers go unheard. Parents plead for referrals and help because of the low availability and skill set of workers needed to provide services for their children. The parent provider program for many is the only thing allowing these families to remain united in the home due to the financial support it provides.

I am imploring that cases such as mine be referenced and taken into consideration. Thank you for your time.

From: Jimmy Vaughan [redacted]
Date: Thursday, July 6, 2023 at 2:43:42 PM UTC-4
Subject: Parents as Caregivers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello,

I absolutely support the continuation of Parents as Caregivers. Our child has autism and over the years we have had tremendous difficulty finding and retaining quality providers for our child. With my wife’s background in education along with all of the excellent training she has received we have seen such growth with our son. This program has been such a blessing to our son and we would love to see it continue in the future. Thank you for hearing us out and hopefully continuing with the program.

Thank you,

Jimmy Vaughan

Sent from my iPhone

From: Sara Vaughan [redacted]
Date: Thursday, July 6, 2023 at 2:16:04 PM UTC-4
Subject: Parents as Caregivers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

I STRONGLY support the continuation of Parents as Caregivers.
As a parent of a child with Autism, it is incredibly difficult to find providers for my child and the growth I have seen in him since I have been able to provide Habilitation and Attendant Care services to him is invaluable. The trainings I have received have helped me to be able to give him the services her needs despite the shortage of providers I could get for him in this field. Parents are the best teachers as the child feels most comfortable with them. To remove this service/option will be detrimental for many and the children will suffer most from the discontinuation of this amazing opportunity.

Thank you for your time,
Sara Vaughan

From: Patty W Loyer [redacted]
Date: Thursday, July 6, 2023 at 1:48:53 PM UTC-4
Subject: Parents as caregivers for minor children
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

This is such an important service to have in place.

In a world where this is a very specific job that not just anyone can do, it is very important. People who fill these jobs are few and far between, making them hard to come by, especially for families who live in remote regions of Arizona. Parents often are not able to be employed outside of the home due to the needs of their special needs child. Having an income will help them financially which will impact positively on the special needs child as well.

Sincerely,
Patricia W. Loyer, MAEd
Mother of Joey, Smith-Magenis Syndrome, www.prisms.org

From: Kelly Bertetto [redacted]
Date: Wednesday, July 5, 2023 at 9:35:49 PM UTC-4
Subject:
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

I am a parent of a child who receives DDD and ALTCS services. I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility and it has been extremely beneficial to our family and my child who receives these services. Based on my review of the current proposal for a permanent Paid Parent Caregiver program I would like to give you my feedback. Thank you for your time and consideration while reading my experience and suggestions.

I am a single parent of special needs twins that are 14 years old. The Paid Parent Caregiver program has made a huge impact in our family. It has also contributed to the success of my daughter's many achievements at home and school. Not only has it helped with her learning success, it has helped with her physical strength and has also shown to be the "healthiest" she's been in many years. Why is this? I am firmly attributing it to my ability to focus my time on her habilitation and attendant goals. I do not have to train numerous providers that come and go and don't really know my daughter as well as I do by being a parent. Before this program, I've had a number of providers that were "good". But the lack of care and training was apparent in many of them. When the pandemic hit, we lost everyone. Not only was it unsafe for us to expose ourselves to others that we don't know their whereabouts, but it was simply not available as the caregiving industry has seen a drastic decrease of available caregivers.

Although I'd love to share my daughter's accomplishments, I do want to take this moment to tell you of a very scary moment that could have changed our lives and had a grim ending. As parents of special needs children, we are so in tune with each and every sound, breath, emotion (as many children, like my daughter, are non verbal), wince, cough, beep from a machine, the list goes on. Call it our superpower, because most people don't know those special "signals" our children show. Recently, I was home with my daughter and I was just down the hallway and I heard her start to have difficulty breathing. I immediately ran to her aid and started pounding on her back to clear her airway. Thankfully she was able to cough and assist with clearing her airway. She aspirated her formula that is fed through her G-tube. She didn't even have anything in her mouth. Most people wouldn't know what she was choking on because she feeds through a tube in her stomach. I heard that breath sound over every other sound in my house and was there to administer aid in seconds. I can guarantee that if I had an outside provider here, they wouldn't have heard or noticed it as quickly. Not even sure they would be able to administer aid due to the lack of training or lack of practice in use of training, seeing most aren't in the medical field. I was able to go back to my home camera to watch those scary moments of her struggling to breathe, and me rushing to her side. I would love to share the video with you if you'd be interested to see it.

Our community of parent caregivers is asking for a permanent program that allows parents of disabled minor children to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies. Under the current program proposal this request is not being fully met. Please consider the following suggestions:

1. Include Habilitation as a service parents of minor DDD and ALTCS members can perform as a certified DCW provider. Parents of adult DDD and ALTCS members can currently perform both Attendant Care and Habilitation hours for their children and parents of the minor population would like this permanent option to mirror that program allowance. The DCW workforce shortage applies to Habilitation providers just as much as it does Attendant Care providers. CMS has no restriction on this service being performed by a legally authorized representative. There has been massive improvement to the IDD population in Arizona since parents of minors have been able to provide this service at the correct time and place that is applicable to the member. Parents being paid as Habilitation providers has been allowed under the Covid-19 flexibility program and the ARPA program extension and we would like to continue to have it as a permanent option.

2. Remove the 40 hour restriction of Paid Parent Caregivers. Caring for a child who receives DDD and ALTCS is not comparable to the needs and familial roles of a spouse performing personal care needs for an adult who qualifies for personal care services. Parents of adult DDD and ALTCS members can currently perform some or all Attendant Care and Habilitation hours that their adult children qualify for under their PCSP. The new permanent Paid Parent Caregiver program should mirror the current adult DDD and ALTCS member program. There are no federal CMS barriers to parents working over 40 hours per week of paid care. AHCCCS limits every DCW provider to 16 hours of provided care in a 24 hour period, Parent Caregivers would like this same option so that the care of the member's evaluated hours can be fully fulfilled dependending on the availability of non-family and family DCW providers. If this restriction is not an option, a provision that outlines an exception clause and process is requested.
3. Create a plan to train and maintain supervision of front line DDD and ALTCS staff as they implement this permanent program option for families across the state. Language in this program policy should clarify that while non-family DCW providers are an option, Paid Parent Caregivers are also an equally suitable option. This permanent program option should be about which provider meets the needs of the member in the most efficient and safe way possible. Families across the state, especially those in rural areas and those from minority backgrounds, have experienced discrimination by state employees regarding this flexibility for a variety of reasons. An explicit explanation on how institutional change through training and monitoring of staff by AHCCCS and DDD leadership regarding this permanent program implementation would be very impactful in rebuilding those family, member, and Support Coordinator relationships.

4. Include a provision that allows foster children residing in DDD / CDH homes to receive Attendant Care hours that foster parents can be paid for as DCW providers. These children receive the general Habilitation allotment appropriate to their foster placement to fulfill their personal care needs. However, their individual need levels should be considered in their Habilitation and Attendant Care evaluations so they can receive all appropriate services by a DCW provider regardless if it is a paid foster parent or outside DCW.

Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. Parent caregivers have been the backbone of the Developmental Disability Community for decades. A comprehensive Paid Parent Caregiver program which includes both Habilitation and Attendant Care services validates the irreplaceable work that parents provide on a daily basis in their homes and communities.

Click here to connect with the Arizona parent led grassroot initiative leaders:
www.raisingvoicescoalition.com

Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves DDD and ALTCS members in Arizona.

Thank you!

Kelly Bertetto
[redacted]
[redacted]

From: marina [redacted]
Date: Wednesday, July 5, 2023 at 12:12:21 PM UTC-4
Subject: Make Parent Provider Provision Permanent
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello,
Making Parent Provider Provision permanent would make a huge difference and would be a tremendous help to so many families with kids with special needs. Please consider doing that. It would solve an issue of the extreme shortage of providers and would help such families financially as well.

Have a great day!
Marina
(Hear my name)

From: Martha Sanchez [redacted]
Date: Wednesday, July 5, 2023 at 10:27:04 AM UTC-4
Subject: Parents as paid caregivers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

I am a parent. I am a caregiver. I am a family member. It is my job to see the world through my child's eyes. Explain the needs of my child to the community. But also realize that don't want to or don't care to understand our way of life. I am the one, as a parent who can understand and encourage, applaud and celebrate accomplishments. And it is my privilege to care for my child like no one else could ever.

From: minerva zaldivar zarco [redacted]
Date: Tuesday, July 4, 2023 at 1:49:30 PM UTC-4
Subject: Madre proveedora
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hola buen día, me gustaría externar mi gratitud por la oportunidad de formar parte del sistema de provisión permanente para padres y asi mismo deseando se nos permita continuar como cuidadores para nuestros hijos, ya que no hay mejor cuidado para ellos que el de su propia mamá. Una mamá capacitada, guíada y con el apoyo como siempre del equipo de nuestra supervisora, agencia y equipo de trabajo.

Gracias

Enviado desde mi iPhone

From: Margarita Villasenor [redacted]
Date: Monday, July 3, 2023 at 8:13:54 PM UTC-4
Subject: Guardian /caregiver
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To whom it may concern please reconsider the options of parents and guardians continue as caregivers. Since the pandemic ended. I have enjoyed been my grandchildren caregiver since mother passed away I have learn and understand their different disabilities I can not trust anyone else to do this job. I had other persons working as caregiver for them and did no accomplish any of their goals. Sincerely Margarita

From: making the parent provider provision permanent, will help the children to continously get the services without breaks. [redacted]
Date: Monday, July 3, 2023 at 7:42:37 PM UTC-4
Subject: parent provider provision permanent, enabling parents to continue to serve as paid caregivers to their minor children
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hi,

This amendment is much needed and will help the children get the uninterrupted services without breaks. This will help a lot as we do not have keep continuously searching for the providers who are inshortage and even when they are available they cannot match up the child's flexible timings.

Please consider amending this to make the parent provider provision permanent.

Thanks,

RAjeesha

From: munziba ahmed [redacted]
Date: Monday, July 3, 2023 at 5:45:39 PM UTC-4
Subject: Supporting the decision
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Good afternoon!

I am very happy and excited to hear that authorities are thinking to give parents chance permanently to work for their minor children.
I think it is a great decision for many effective reasons, first of all we are always having hard time of getting responsible , reliable providers, even when we are fortunate to get a good provider after months / year they sometimes they have different problem and we need to look for another provider which is really hard on the kids , most importantly I believe since we ,parents are the persons who stays almost whole time with kids,if we get a chance to give them services and if we get more training/ guidelines kids will get the most effective services .
I think that will be the best for the kids who need the service.
Thank you

From: Tan Rivers [redacted]
Date: Monday, July 3, 2023 at 5:26:55 PM UTC-4
Subject: Parents as paid caregivers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

This has been very helpful to my family. I am able to work from home while caring for my son and helping him with his goals. We don’t have to hire strangers that he may be uncomfortable working with. It alleviates having too many outside providers in our home as well. It would be great for parent providers to be a permanent solution.

Thank you

Tanisia Johnson

From: Darlene Jones [redacted]
Date: Monday, July 3, 2023 at 4:14:55 PM UTC-4
Subject: Parents as paid caregivers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Thank you for allowing the comment.

Parents of minor children should not be being paid to watch their children. We as parents that have been in this system for years have never ever in the past been paid for our minor children. Parents need to learn to take care of their children.

I could see if it is an extreme case of behavioral then maybe they may need a bit of habilitation in the home. These kids are in school getting services already.

Remember we are in a program that is trying to normalize these members. We need to make sure the parents are normalized. Parents need REAL jobs that pay a good wage and have benefits.

Thank you very much

From: Ofhelia Cosen [redacted]
Date: Monday, July 3, 2023 at 11:07:32 AM UTC-4
Subject: Make Parent Provider Provision Permanent
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello

I am a paid provider parent for my son. I really encourage the state to make Parents a permanent paid provider and my reason for this is because as a parent myself, I have known my son very well since the day of birth. But the main reason is the trust issue. With what this world is becoming today with many violence, threat, abuse , killing and prejudice. I feel that the child is in a better and safer hand with their own parents. For the safety of the Child/over guardian adult, the parent/guardian should be a permanent provider. DO THIS FOR THE CLIENT...

Ofhelia

From: Brock Lewis [redacted]
Date: Sunday, July 2, 2023 at 5:02:02 PM UTC-4
Subject: AHCCCS Public Comment: Make Parent Provider Provision Permanent - Comment
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To Whom This May Concern,

It would be a wonderful and needed addendum to keep parents as care providers for their special needs children. This provides the necessary needs for parents to provide the best life for their children.
As a parent of two boys with Autism, my understanding on how to help my sons has grown as I have participated in the necessary training.
These services are necessary for children with special needs. These provisions helps us provide activities and outings for our two boys beyond what we can already do.
I would implore you to keep parents as providers for their children. This is a blessing in many ways.

Brock Lewis
[redacted]

From: danie s [redacted]
Date: Sunday, July 2, 2023 at 9:41:36 AM UTC-4
Subject: Parents as paid caregivers to Minor Children
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello AHCCCS,

Having a child with a disability brings many challenges and many rewards. During the 7 years my child has been in services we have been through many providers that were not up to my expectations for what the HAH service are to help with and how it was supposed to be accomplished to see progress with my son.

I have been a parent provider since 2022 and have seen such an increase in DLS and independence with myself providing the services. I am proud to modify his goals with less prompts per task about every 60 days. I have seen my child gain more self confidence in the last year with myself as a provider.

I urge AHCCCS to approve parents as paid providers for minor children beyond the 2024 end date. Progress is what DDD services are for and help special needs children become the best they can be and productive citizens when they are 18.

That is what I have witnessed with my own eyes and wish to continue seeing progress. My child has a very hard time with change and feels he would take a huge step backward if this was not to be approved further.

Sincerely,

Danielle H

From: karen craig [redacted]
Date: Saturday, July 1, 2023 at 11:10:38 AM UTC-4
Subject: Please keep parent provision permanent
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello ,
Parent Provider Provision Permanent

Karen
Be you, stay True

From: Melissa MAYBRAY [redacted]
Date: Saturday, July 1, 2023 at 10:50:53 AM UTC-4
Subject: MAKE PARENT PROVIDERS PERMANENT
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

I am writing today to request parent providers be made permanent.
I am a solo mom..let me clarify I am a widowed mom of a child with a disability that impacts daily life. Needing care 24 hours hours a day while trying to work is not realistic. Being a paid caregiver guarantees my child will be taken care of and our needs are still being met financially. (Clearly higher pay would be more realistic but that's a different story). Being a parent of a disabled child is an24/7 job and I am asking that you continue to allow parents to be paid providers so our lives can continue to function.
Parent provider gives me the option of not needing to call out of work because caregiver canceled, my child is sick or has appt or there is an incidient, so don't need to call out of work. When I did work and had a 2nd parent in the home these things came up and it put my job and stability in jeopardy.
Being a paid provider has helped my son flourish, it has maintained stability and our life. The state is paying people to take care of our children so continue to pay us and keep that as an option. I know with our circumstances we wouldn't have made it this far after covid without it.

From: Robin LaVoie [redacted]
Date: Saturday, July 1, 2023 at 9:45:50 AM UTC-4
Subject: Public Comment: Parents as Paid Caregivers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

I support the AHCCCS request to permanently extend the parent provider provision, as well as the family support service called for in the request.

My son is 24, and has been in the DDD/ALTCS system since he was 3 years old. When he turned 18, I became a paid Attendant and Habilitation provider for him, and this has been life changing for our family. If I'd had the option to receive this support when he was younger, for the amount of "extraordinary care" I provided beyond typical child-rearing, it would have helped our family immensely. Like many families, we struggled (and still struggle) to find providers — seeing the services he qualified for on paper in the ISP (now PCSP) never fully fulfilled due to workforce shortages, high turnover, and low wages.

During the COVID crisis, I have no doubt that young families felt great relief in being able to be paid for these services when providers were not available. That lack of providers is something our state needs to work on, and in the meantime, parents should be allowed to be paid to provide this care. When there are no providers, parents step up —and when the PCSP calls for those support hours, parents should be compensated.

I am also very much in support of the "family support" service mentioned in this proposal. Although it is a relief financially to be paid as a parent provider, it adds additional stress to the family to be without those outside providers to take some of the burden and share strategies. This family support service is critical to maintaining the health and well-being of the entire family unit for all families who have qualified ALTCS members, and especially those who must take on the attendant care role in absence of outside providers.

Thank you,
Robin LaVoie
Fountain Hills, AZ

From: Thomas Nolasco [redacted]
Date: Friday, June 30, 2023 at 8:50:19 PM UTC-4
Subject: Feedback on Parent Caregiver Proposal
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

I am the father of a three-year-old child who receives DDD and ALTCS services. He has Down Syndrome, is Autistic, has had open heart surgery and four additional surgeries in his three short years. He is an absolute joy to be around for those who know him, despite his challenges. Developmentally, he tracks at around a 6–9-month-old developmental age depending on the skill. He's not yet walking, is learning to eat solids due to his low tone, and just received a walker to hopefully begin walking independently soon.

I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility and it has been extremely beneficial to our family and my child who receives these services. Based on my review of the current proposal for a permanent Paid Parent Caregiver program I would like to give you my feedback. Thank you for your time and consideration while reading my experience and suggestions.

Our community of parent caregivers is asking for a permanent program that allows parents of disabled minor children to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies. Under the current program proposal this request is not being fully met. Please consider the following suggestions:

1. **Include Habilitation as a service that parents of minor DDD and ALTCS members can perform as a certified DCW provider.** Parents of adult DDD and ALTCS members can currently perform both Attendant Care and Habilitation hours for their children and parents of the minor population would like this permanent option to mirror that program allowance. The DCW workforce shortage applies to Habilitation providers just as much as it does Attendant Care providers. CMS has no restriction on this service being performed by a legally authorized representative. There has been massive improvement to the IDD population in Arizona since parents of minors have been able to provide this service at the correct time and place that is applicable to the member. Parents being paid as Habilitation providers has been allowed under the Covid-19 flexibility program and the ARPA program extension and we would like to continue to have it as a permanent option. Prior to the Paid Parent Caregiver program, we did not have a habilitation provider as there was simply none available; This was with us contacting three agencies and seeking out a caregiver ourselves in addition to utilizing agency supports. Additionally, several of my son's goals involve teaching him skills to care for himself. This includes toileting, bathing skills and additional hygiene needs. Not only would he refuse to do this with someone he did not know well, but I would simply not feel comfortable with him working on these skills with a community habilitation worker, if we'd even be able to find one.

We also have been able to complete the assessed hours as it works for my child. If we plan to work on his habilitation goals for three hours that morning, but he is struggling with sensory overload or is unable or unwilling to participate in his habilitation goals, we are able to easily adjust our schedule and work on his goals at a later time. This would not be possible if we were not providing these services to him.

2. **Remove the 40 hour restriction of Paid Parent Caregivers.** Caring for a child who receives DDD and ALTCS is not comparable to the needs and familial roles of a spouse performing personal care needs for an adult who qualifies for personal care services. Parents of adult DDD and ALTCS members can currently perform some or all Attendant Care and Habilitation hours that their adult children qualify for under their PCSP. The new permanent Paid Parent Caregiver program should mirror the current adult DDD and ALTCS member program. There are no federal CMS barriers to parents working over 40 hours per week of paid care. AHCCCS limits every DCW provider to 16 hours of provided care in a 24 hour period, Parent Caregivers would like this same option so that the care of the member's evaluated hours can be fully fulfilled dependending on the availability of non-family and family DCW providers. If this restriction is not an option, a provision that outlines an exception clause and process is requested.

3. **Create a plan to train and maintain supervision of front line DDD and ALTCS staff as they implement this permanent program option for families across the state.** Language in this program policy should clarify that while non-family DCW providers are an option, Paid Parent Caregivers are also an equally suitable option. This permanent program option should be about which provider meets the needs of the member in the most efficient and safe way possible. Families across the state, especially those in rural areas and those from minority backgrounds, have experienced discrimination by state employees regarding this flexibility for a variety of reasons. An explicit explanation on how institutional change through training and monitoring of staff by AHCCCS and DDD leadership regarding this permanent program implementation would be very impactful in rebuilding those family, member, and Support Coordinator relationships.

4. **Include a provision that allows foster children residing in DDD / CDH homes to receive Attendant Care hours that foster parents can be paid for as DCW providers.** These children receive the general Habilitation allotment appropriate to their foster placement to fulfill their personal care needs. However, their individual need levels should be considered in their Habilitation and Attendant Care evaluations so they can receive all appropriate services by a DCW provider regardless if it is a paid foster parent or outside DCW.

Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. Parent caregivers have been the backbone of the Developmental Disability Community for decades. A comprehensive Paid Parent Caregiver program which includes both Habilitation and Attendant Care services validates the irreplaceable work that parents provide on a daily basis in their homes and communities. Being a parent provider has allowed my son to receive his assessed hours, have a provider (myself) readily available to provide the services, and we have seen a tremendous amount of progress with his independence and ability to communicate his needs.

Click here to connect with the Arizona parent led grassroot initiative leaders: www.raisingvoicescoalition.com

Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves DDD and ALTCS members in Arizona.

Thank you in advance for the time to read through, it is greatly appreciated.
Sincerely,
Thomas Nolasco

From: [redacted]
Date: Friday, June 30, 2023 at 6:09:03 PM UTC-4
Subject: Parent Caregiver Continuation
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Please continue to allow parents as providers for habilitation and attendant care. We live in a very small rural area and it has been hard to find someone to reliably help. The extra income really helps especially when we have been in between providers and I need to take more time off of my home business to care for my son's needs. Thank you for considering.

-Ailea Clarkson

From: Mandy Fenchak [redacted]
Date: Friday, June 30, 2023 at 5:40:40 PM UTC-4
Subject: We support Parents as Paid Caregivers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

We are writing to affirm our support of the Parents as Paid Caregivers permanent extension. We have never been able to find stable habilitation caregiving for our daughter, and being able to provide habilitation for her ourselves has been a GREAT benefit to her.

Sincerely,
Robert and Amanda Fenchak

From: Sherri Mitchell [redacted]
Date: Friday, June 30, 2023 at 5:02:26 PM UTC-4
Subject: Parents as Paid Caregivers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To Whom It May Concern:

I'm writing in support of The Arizona Health Care Cost Containment System (AHCCCS) requesting an amendment to the State's current Demonstration project to allow for the permanent extension of payments to parents who serve as paid caregivers for minor children, previously allowed through a temporary COVID Appendix K flexibility. The Agency is also proposing to establish a home care training family support (family support) service as part of the HCBS benefit package detailed in "Attachment L" of the State's approved STC document (Project Number 11-W-00275/9).
Under this Demonstration proposal, the agency will seek to:

- Mitigate DCW shortage and other access to care challenges by allowing payments to parents who serve as paid caregivers for their minor children,
- Increase member satisfaction and promote positive health and well-being outcomes for the target population,
- Extend an additional support service to restore, enhance, and maintain family functioning to preserve effective care for the member in the home and community, and
- Ensure that members receive high-quality care while increasing timely accessibility to care providers.

It is essential that parents and family members continue to have the ability to care for their children full time and be compensated accordingly. It is incredibly difficult to find caregivers with the labor shortage. Parents of children and adults with disabilities sacrifice darn near everything trying to care for their loved ones with special needs.

Please let me know if you have any questions. Thank you!

Sherri Mitchell
President & Founder

From: Jessica Ballesteros [redacted]
Date: Friday, June 30, 2023 at 3:24:07 PM UTC-4
Subject: Parents as paid providers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

My issue is that lack of people applying for this job. There is a huge decrease in people that want to apply to be a DSP. Also all that entails with the hiring process. I have seen people start the hiring process but never complete it due to so many demands. We have been so thankful to be able to provide the service of habilitation and attendant care. My DSP providers are immediate family members. It's upsetting that the service will be ending soon for parents to bill for their under age children. What will happen? They go without services until providers are placed? Who knows how long that wait list will be. There are wait lists everywhere for the lack of therapists for therapies. This will add to another waiting list for us parents. Thats why it's important we keep this permanent for parents to be able to assist with services.
Thank you so much!
Jessica Forgy

From: Trent Kendall [redacted]
Date: Friday, June 30, 2023 at 3:02:23 PM UTC-4
Subject: AHCCCS Public Comment: Make Parent Provider Provision Permanent
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

I understand you are accepting comments on allowing parent providers to provide habilitation services to their kids under 18. I would love to have someone else provide this service to my child but no provider has been able to recruit someone reliable to provide this service. So I must step up and do it. I have been looking for years and the only reliable person I found was someone I recruited myself and had them become a provider. They were great for 2 years but then moved away. I hope you consider allowing parents to provide this greatly needed service.

Thank you,

From: Claudia A [redacted]
Date: Friday, June 30, 2023 at 2:33:20 PM UTC-4
Subject: Cruz Espino
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hola soy madr
e de un hijo con Autismo y trabajo con el Hah y Atc mi hijo necesita asistencia para casi todo para darle medicamento hasta para pagar o para cualquier necesidad en la vida es muy importante que atc se quede Permanente una porque que mejor que su madre para ayudarle en la vida diaria segunda porque no es facil encontrar provedores desde covid haci que porfavor dejen atc para nosotros los Padres muchas gracias de antemano

Claudia Arenivar provedora para Arion Care solutions

From: Michelene Colette [redacted]
Date: Friday, June 30, 2023 at 1:49:59 PM UTC-4
Subject: AHCCCS-Paid Parents as caregivers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Good afternoon,

As the mother & legal guardian of a special needs adult I can honestly say that this has been 45 years of caring for and teaching living skills on a daily basis. Parents should be paid for this as if special needs individuals were put in group homes, the cost would be exponentially more than what caregivers on their own are receiving.

Please retain & vote to keep this.

Thank you,

Michelene Colette

Sent from my iPad

From: zulma ruiz [redacted]
Date: Friday, June 30, 2023 at 10:26:01 AM UTC-4
Subject:
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

I have a 12 year old daughter with special needs. She is on different meds and due to her syndrome she has behavior issues. It was really hard for me to work and find somebody to learn so much to take care of all my daughters needs. I was working very long hours and had to come home all the time due to my daughters needs. One time her sugar levels got so high and was very lethargic. The care taker didn't know the signs and my daughter was in hospital in ICU for 3 weeks. It could of been fatal. One day they told me about this program. And it has been a life saver for my daughter. I was able to quit my job and still provide a home for my daughter. Now we know my daughter is taken care of and the company I work for has been great on teaching me so I know more on how to help my daughter. So please take into consideration all the wonderful things this program does for all special needs kids. Parents always know what there child needs are. Also with having this program it is very good to have DDD and the companies we work for involved bc they offer resources if family needs them. They see the children are being taken care of.

Thank you!
Zulma Butler Ruiz

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From: rich allen [redacted]
Date: Friday, June 30, 2023 at 6:06:31 AM UTC-4
Subject: parents serving minor children
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

I'm absolutely in favor of parents being able to provide services for minor children.

take care
rich allen

From: Noor S [redacted]
Date: Friday, June 30, 2023 at 1:34:38 AM UTC-4
Subject:
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

I am a parent of a child who receives DDD and ALTCS services. I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility and it has been extremely beneficial to our family and my child who receives these services. Based on my review of the current proposal for a permanent Paid Parent Caregiver program I would like to give you my feedback. Thank you for your time and consideration while reading my experience and suggestions.

My child is fearful of people he doesn't know and even family members that he knows but that he doesn't see daily. Me being able to participate in being a parent caregiver has been a blessing as he is most comfortable with me. It has also helped our family so much since I am the one providing the care and I have been trained. This helps with our daily life so much. This

Our community of parent caregivers is asking for a permanent program that allows parents of disabled minor children to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies. Under the current program proposal this request is not being fully met. Please consider the following suggestions:

Include Habilitation as a service parents of minor DDD and ALTCS members can perform as a certified DCW provider. Parents of adult DDD and ALTCS members can currently perform both Attendant Care and Habilitation hours for their children and parents of the minor population would like this permanent option to mirror that program allowance. The DCW workforce shortage applies to Habilitation providers just as much as it does Attendant Care providers. CMS has no restriction on this service being performed by a legally authorized representative. There has been massive improvement to the IDD population in Arizona since parents of minors have been able to provide this service at the correct time and place that is applicable to the member. Parents being paid as Habilitation providers has been allowed under the Covid-19 flexibility program and the ARPA program extension and we would like to continue to have it as a permanent option.

Remove the 40 hour restriction of Paid Parent Caregivers. Caring for a child who receives DDD and ALTCS is not comparable to the needs and familial roles of a spouse performing personal care needs for an adult who qualifies for personal care services. Parents of adult DDD and ALTCS members can currently perform some or all Attendant Care and Habilitation hours that their adult children qualify for under their PCSP. The new permanent Paid Parent Caregiver program should mirror the current adult DDD and ALTCS member program. There are no federal CMS barriers to parents working over 40 hours per week of paid care. AHCCCS limits every DCW provider to 16 hours of provided care in a 24 hour period, Parent Caregivers would like this same option so that the care of the member's evaluated hours can be fully fulfilled depending on the availability of non-family and family DCW providers. If this restriction is not an option, a provision that outlines an exception clause and process is requested.

Create a plan to train and maintain supervision of front line DDD and ALTCS staff as they implement this permanent program option for families across the state. Language in this program policy should clarify that while non-family DCW providers are an option, Paid Parent Caregivers are also an equally suitable option. This permanent program option should be about which provider meets the needs of the member in the most efficient and safe way possible. Families across the state, especially those in rural areas and those from minority backgrounds, have experienced discrimination by state employees regarding this flexibility for a variety of reasons. An explicit explanation on how institutional change through training and monitoring of staff by AHCCCS and DDD leadership regarding this permanent program implementation would be very impactful in rebuilding those family, member, and Support Coordinator relationships.

Include a provision that allows foster children residing in DDD / CDH homes to receive Attendant Care hours that foster parents can be paid for as DCW providers. These children receive the general Habilitation allotment appropriate to their foster placement to fulfill their personal care needs. However, their individual need levels should be considered in their Habilitation and Attendant Care evaluations so they can receive all appropriate services by a DCW provider regardless if it is a paid foster parent or outside DCW.

Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. Parent caregivers have been the backbone of the Developmental Disability Community for decades. A comprehensive Paid Parent Caregiver program which includes both Habilitation and Attendant Care services validates the irreplaceable work that parents provide on a daily basis in their homes and communities.

Click here to connect with the Arizona parent led grassroot initiative leaders: www raisingvoicescoalition.com

Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves DDD and ALTCS members in Arizona.

Thank you!

From: Morgan [redacted]
Date: Thursday, June 29, 2023 at 11:45:38 PM UTC-4
Subject: Feedback on Parent Caregiver Proposal
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

I am the mother of a three-year-old child who receives DDD and ALTCS services. He has Down Syndrome, is Autistic, has had open heart surgery and four additional surgeries in his three short years. He is an absolute joy to be around for those who know him, despite his challenges. Developmentally, he tracks at around a 6–9-month-old developmental age depending on the skill. He's not yet walking, is learning to eat solids due to his low tone, and just received a walker to hopefully begin walking independently soon.

I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility and it has been extremely beneficial to our family and my child who receives these services. Based on my review of the current proposal for a permanent Paid Parent Caregiver program I would like to give you my feedback. Thank you for your time and consideration while reading my experience and suggestions.

Our community of parent caregivers is asking for a permanent program that allows parents of disabled minor children to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies. Under the current program proposal this request is not being fully met. Please consider the following suggestions:

1. **Include Habilitation as a service that parents of minor DDD and ALTCS members can perform as a certified DCW provider.** Parents of adult DDD and ALTCS members can currently perform both Attendant Care and Habilitation hours for their children and parents of the minor population would like this permanent option to mirror that program allowance. The DCW workforce shortage applies to Habilitation providers just as much as it does Attendant Care providers. CMS has no restriction on this service being performed by a legally authorized representative. There has been massive improvement to the IDD population in Arizona since parents of minors have been able to provide this service at the correct time and place that is applicable to the member. Parents being paid as Habilitation providers has been allowed under the Covid-19 flexibility program and the ARPA program extension and we would like to continue to have it as a permanent option. Prior to the Paid Parent Caregiver program, we did not have a habilitation provider as there was simply none available; This was with us contacting three agencies and seeking out a caregiver ourselves in addition to utilizing agency supports. Additionally, several of my son's goals involve teaching him skills to care for himself.

This includes toileting, bathing skills and additional hygiene needs. Not only would he refuse to do this with someone he did not know well, but I would simply not feel comfortable with him working on these skills with a community habilitation worker, if we'd even be able to find one. We also have been able to complete the assessed hours as it works for my child. If we plan to work on his habilitation goals for three hours that morning, but he is struggling with sensory overload or is unable or unwilling to participate in his habilitation goals, we are able to easily adjust our schedule and work on his goals at a later time. This would not be possible if we were not providing these services to him.

2. **Remove the 40 hour restriction of Paid Parent Caregivers.** Caring for a child who receives DDD and ALTCS is not comparable to the needs and familial roles of a spouse performing personal care needs for an adult who qualifies for personal care services. Parents of adult DDD and ALTCS members can currently perform some or all Attendant Care and Habilitation hours that their adult children qualify for under their PCSP. The new permanent Paid Parent Caregiver program should mirror the current adult DDD and ALTCS member program. There are no federal CMS barriers to parents working over 40 hours per week of paid care. AHCCCS limits every DCW provider to 16 hours of provided care in a 24 hour period, Parent Caregivers would like this same option so that the care of the member's evaluated hours can be fully fulfilled dependending on the availability of non-family and family DCW providers. If this restriction is not an option, a provision that outlines an exception clause and process is requested.

3. **Create a plan to train and maintain supervision of front line DDD and ALTCS staff as they implement this permanent program option for families across the state.** Language in this program policy should clarify that while non-family DCW providers are an option, Paid Parent Caregivers are also an equally suitable option. This permanent program option should be about which provider meets the needs of the member in the most efficient and safe way possible. Families across the state, especially those in rural areas and those from minority backgrounds, have experienced discrimination by state employees regarding this flexibility for a variety of reasons. An explicit explanation on how institutional change through training and monitoring of staff by AHCCCS and DDD leadership regarding this permanent program implementation would be very impactful in rebuilding those family, member, and Support Coordinator relationships.

4. **Include a provision that allows foster children residing in DDD / CDH homes to receive Attendant Care hours that foster parents can be paid for as DCW providers.** These children receive the general Habilitation allotment appropriate to their foster placement to fulfill their personal care needs. However, their individual need levels should be considered in their Habilitation and Attendant Care evaluations so they can receive all appropriate services by a DCW provider regardless if it is a paid foster parent or outside DCW.

Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. Parent caregivers have been the backbone of the Developmental Disability Community for decades. A comprehensive Paid Parent Caregiver program which includes both Habilitation and Attendant Care services validates the irreplaceable work that parents provide on a daily basis in their homes and communities. Being a parent provider has allowed my son to receive his assessed hours, have a provider (myself) readily available to provide the services, and we have seen a tremendous amount of progress with his independence and ability to communicate his needs.

Click here to connect with the Arizona parent led grassroot initiative leaders: www.raisingvoicescoalition.com

Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves DDD and ALTCS members in Arizona.

Thank you in advance for the time to read through, it is greatly appreciated.
Sincerely,
Morgan Seleski

From: Emily Mayhew [redacted]
Date: Thursday, June 29, 2023 at 10:02:35 PM UTC-4
Subject: Paid Parent Caregiver Program
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

I am a parent of an 11-year old boy, diagnosed with Down syndrome, who receives DDD and ALTCS services. I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility and it has been extremely beneficial to our family and my son who receives these services. Based on my review of the current proposal for a permanent Paid Parent Caregiver program I would like to give you my feedback. Thank you for your time and consideration while reading my experience and suggestions.

My experience: I began providing Habilitation services to my son in 2020. When the pandemic closed schools and required families like ours, with children in a vulnerable position, to shelter at home, we lost our most cherished habilitation provider. It was too risky to allow any providers into our home, even those we loved. While we struggled to navigate how services like therapies were going to take place, we also worried about our son regressing and losing the skills he worked (and continues to work) so hard to acquire. When word began to spread that parents, because of the pandemic, could be certified to continue habilitation services our family was beyond grateful. Since the birth of my son, we've been a single income household. His diagnosis was unexpected and we knew our son needed me at home so I quit my job and began the life of a special needs mom. We have, at times, struggled to make ends meet. Raising my son has been a full-time job and traditional paid employment has never been in the cards. Providing habilitation for my son has been a huge help to our family. Not only has it financially made life a little easier but being the provider has allowed him to progress in the goals we continue to set. I am better able to track his progress, make real-time adjustments with our DDD coordinator and celebrate when he has accomplished a goal. It's only a few hours of habilitation a day, but those few hours have helped him to grow and progress without the risk of regression AND they have given me and my family the security of living life without constant money worries.

My suggestions: Our community of parent caregivers is asking for

a permanent program that allows parents of disabled minor children to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies. Under the current program proposal this request is not being fully met. Please consider the following suggestions:

1. Include **Habilitation** as a service parents of minor DDD and ALTCS members can perform as a certified DCW provider. Parents of adult DDD and ALTCS members can currently perform both Attendant Care and Habilitation hours for their children and parents of the minor population would like this permanent option to mirror that program allowance. The DCW workforce shortage applies to Habilitation providers just as much as it does Attendant Care providers. CMS has no restriction on this service being performed by a legally authorized representative. There has been massive improvement to the IDD population in Arizona since parents of minors have been able to provide this service at the correct time and place that is applicable to the member. Parents being paid as Habilitation providers has been allowed under the Covid-19 flexibility program and the ARPA program extension and we would like to continue to have it as a permanent option.

2. Remove the 40 hour restriction of Paid Parent Caregivers. Caring for a child who receives DDD and ALTCS is not comparable to the needs and familial roles of a spouse performing personal care needs for an adult who qualifies for personal care services. Parents of adult DDD and ALTCS members can currently perform some or all Attendant Care and Habilitation hours that their adult children qualify for under their PCSP. The new permanent Paid Parent Caregiver program should mirror the current adult DDD and ALTCS member program. There are no federal CMS barriers to parents working over 40 hours per week of paid care. AHCCCS limits every DCW provider to 16 hours of provided care in a 24 hour period, Parent Caregivers would like this same option so that the care of the member's evaluated hours can be fully fulfilled dependending on the availability of non-family and family DCW providers. If this restriction is not an option, a provision that outlines an exception clause and process is requested.

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Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves DDD and ALTCS members in Arizona.

Sincerely,

Emily Mayhew
Glendale, Arizona

From: Pokémon Gamer2158 [redacted]
Date: Thursday, June 29, 2023 at 9:23:58 PM UTC-4
Subject: Parent Providers for Vulnerable Minors!!!
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Please continue to allow parents to provide HAB services to our minor children that have no providers available to replace us. Our children would suffer unnecessarily during their most vulnerable years and it would negatively impact their independence for years to come.

Brent Diggins

From: jeffrey pavone [redacted]
Date: Thursday, June 29, 2023 at 9:07:58 PM UTC-4
Subject: Please Help
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To whom it may concern,

I’m writing this because I wanted to let you know how much progress my 8 year old son has made since I’ve been his hab provider. My son has autism and it’s extremely hard to find my son quality help. Since I’ve taken over my son has made tremendous progress. I’ve been able to work less hours at work and dedicate more time to him bc I’m being compensated. If this was cancelled I would not be able dedicate all these hours working with him. My hab provider caring for angels and my ddd coordinator Tammy Villani have been such a huge help. We are all a great team. I’m begging you to please allow me to keep being my sons hab provider. He’s such a special boy and I have the patience and tolerance to work with him. We’ve came so far. I continually look for outside help for my son and I feel like there’s not enough professionals out there to meet all these children’s needs. I’m extremely grateful I get to work with my son. Please don’t change that.

Thanks,

Jeff Pavone

Sent from my iPhone

From: Melissa Blomstrand [redacted]
Date: Thursday, June 29, 2023 at 7:43:59 PM UTC-4
Subject: Minor Parent Providers should be a Permanent Solution
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

The Arizona Health Care Cost Containment System (AHCCCS) is requesting an amendment to the State's current Demonstration project to make the parent provider provision permanent, enabling parents to continue to serve as paid caregivers to their minor children. I am writing in support of this amendment as we would not have a provider at all if I didn't step up and take the trainings and provide the services to my minor child. We waited for over a year and never found a provider. Had I not had the training and the agency support my child would not know how to brush his hair or teeth, goes his shoes or cut his food. Autism is a lifelong disability and early intervention is key. Please don't that this away from families that already are fighting a life long uphill battle to ensure our children can survive independently when we are no longer here on earth. We have taken the action and jumped through many loops to be able to provide HAB as no one wakes was willing or able to.

Thank you for hearing our story,

Please vote to make this a permanent solution for families. It shouldn't be this hard to give our kids what they need and deserve. Without the provision we lose our training and team of experts that help our kids thrive.

A very Concerned parent provider of a MINOR

MBlomstrand

From: Derek Anderson [redacted]
Date: Thursday, June 29, 2023 at 7:16:09 PM UTC-4
Subject: Support for Arizona Section 1115 Waiver Amendment: Parents as Paid Caregivers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To whom it may concern,

I'm writing to strongly support the amendment permanently allowing parents as paid caregivers. We struggled to find/keep caregivers for our son on the autism spectrum, both due to our location further north in Phoenix and due to the rapid turnover in caregivers among agencies. This generally meant that our son was not able to receive allocated habilitation and attendant care services as there were no providers available to us. The ability to function as caregivers for these services ourselves allowed us to utilize time that would otherwise have had to be spent in other employment activities. Through this option, our son was able to receive additional direct care throughout the week provided by people who I consider the most effective at working with him regardless of their paid status. I would HIGHLY encourage this practice of parents as paid caregivers to be made permanent.

Sincerely,

Derek Anderson

From: melissa DIGGINS [redacted]
Date: Thursday, June 29, 2023 at 7:07:42 PM UTC-4
Subject: Parents as Paid Caregivers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To whom it may concern,

I am writing to provide input regarding the provision that currently allows parents to provide HAB services to their minor children. I understand that AHCCCS wants to end this provision and I am writing to explain why this should be a permanent option for families. My child has autism and will need therapy and related services for the foreseeable future. By ending the provision, you would essentially end my child's access to these necessary services. In the past we went months and years without necessary services due to lack of providers in our area. If I was not given the opportunity to be properly trained to provide these services to my son, he would be unable to access them. You see, we went through many long months of "waiting" for a provider and never found one!! They did "all calls" and "agency calls" and months just kept passing by with no prospects.

When Jaxon was 3 waited for over a year and had the whole DDD searching to locate providers unsuccessfully. We live in an area that is not accessible by public transportation and this "narrowed" the provider pool, we were told. After growing frustrated that my child was missing out on critical therapy and was falling significantly behind in social and functional skills, the window for parent providers opened. I have been properly trained and have a great team of support through the agency to help me help MY child. Taking this away now would significantly and negatively impact my disabled child's progress and have have lasting negative consequences for my son.
He would lose his provider, the DDD would be unable to find one and I would lose the team of experts that help craft the programming and implementation that has allowed Jaxon to grow and flourish. The current process is working better than anything has in the past.

Please consider making trained parents permanently able to provide these services to their minor children. There just are not enough providers and those of us that have struggled for years to get help will be back in that same boat again. We need the agency to train us and we need to help our children make sustainable and meaningful progress. We have their best interest in mind and will always work harder than a paid stranger will to ensure OUR CHILD can live independently when we will no longer be here on earth for them. If not for the parents that stepped up, our children would still be "waiting for a provider" that never becomes available.

Thank you, for changing this policy to ensure parents of minors can work to provide services to their children. This would be devastating to our family and so many others of this happens.

Thank you for listening,
Melissa Diggins
Proud parent

From: Victor Nava [redacted]
Date: Thursday, June 29, 2023 at 6:33:01 PM UTC-4
Subject:
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Por favor ,les pedimos que hagan permanente el cuidado de menores con pago. Es muy difícil para nosotros como papás encontrar a alguien de confianza con quién podamos dejar tranquilos a nuestros hijos con nesecidades especiales .Para nosotros como papás es una gran bendición poder cuidar a nuestros niños y poder tener una paga monetaria .

From: Gittel Goetz [redacted]
Date: Thursday, June 29, 2023 at 6:18:01 PM UTC-4
Subject: Parents as paid caregivers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hi, I became a paid caregiver for my daughter when Covid hit. My daughter is eight years old and has spina bifida, among other diagnoses. She is paralyzed from the waist down and in a wheelchair. She also has a feeding tube and requires catheterizations and bowel management.

I'm so grateful to be able to get paid for the work that I do for my daughter. It has lifted much financial stress from my household. I was able to stop working at my other job which had become too difficult as my daughter grew older. I am able to focus on what my child needs, and be there for my other family members as well.

Besides, I do not have other paid caregivers on a regular basis and I know it would be very difficult to find one that we are comfortable with and that my daughter likes as well. Now that she is older, she has a lot of opinions and it makes things more challenging. Her night routine is considered skilled nursing, and I'm not sure how possible it would be to even find a nurse who could come every night at the same time to do it. With the current set up, i am comfortable providing the care, my daughter is so happy to have me and the financial benefit is so helpful.

Please understand what we parents go through on a day-to-day basis. Any help that can be given to us to lift our burdens in any way is much appreciated.

Sincerely
Gittel Goetz

Sent from my iPhone

From: Bobby Marks [redacted]
Date: Thursday, June 29, 2023 at 6:14:05 PM UTC-4
Subject: Parents as paid caregivers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

I vote yes!

Sent from my iPhone

From: Andrea Sullivan [redacted]
Date: Thursday, June 29, 2023 at 5:14:05 PM UTC-4
Subject: Parents as paid providers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To whom it may concern,

I am writing as the mother of two boys with Autism, 10 year old who also has severe depression and ADHD and a 7 year old who also has epilepsy. I am currently a paid provider for Habilitation for both boys and it has been a blessing for them. You see, up until I become their paid provider, they never had HAB, most providers didn't actually work on hab goals with them after a certain point and it was left up to me to work with them myself anyways. Now that I've been able to be a paid provider my boys have been successful and consistently receive their weekly habilitation goals.

My oldest, Callen 10, never had any Habilitation until I started being his provider. It is extremely rare to find habilitation workers that will consistently and successfully work the goals with them. Therefore, our hours were not being used until I was able to be their paid provider.

I'm writing to you to consider making it permanent for parents to be paid providers as this has been critical in my two boys actually receiving habilitation services.

Please let me know if you need anything from me or have any questions.

Thank you,
Andrea Sullivan
[redacted]

From: zulma ruiz [redacted]
Date: Thursday, June 29, 2023 at 4:55:41 PM UTC-4
Subject: Parent provider provision
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Would like to say that it's a great program for parents to be able to stay in the home with all the children with disabilities. What better care then the parents to take care of there own children. And not have to leave with strangers. The income helps especially for the mortgage payment. I have been able to leave my job and care for my own child.

Thank you so much
Zulma Ruiz
[redacted]

From: Amanda Roth <[redacted]>
Date: Thursday, June 29, 2023 at 4:38:23 PM UTC-4
Subject: AHCCCS Public Comment-Makin Parent Providers Provision Permanent
To: [redacted]

To Whom it may concern,

I am writing to implore you to please make parent provider status permanent. I am the mother of a 3 year old with autism who currently provides Habilitation services for my child. We have also been approved for respite but since parents cannot be respite providers, we have been unable to find a respite provider despite multiple vendor calls that have taken place over the past year. If parents can no longer provide hab services either, I am afraid we will not be able to find a vendor for hab either.

These services can make a huge difference.

Thank you for your time,

Amanda Roth

From: Gina Schroeder <[redacted]>
Date: Thursday, June 29, 2023 at 4:35:31 PM UTC-4
Subject: Parent Caregivers
To: [redacted]>

Please continue to allow parents to be the provider for their minor children. This has been so amazing for our family and I hope it continues.

Thank You,
Gina Schroeder
[redacted]

From: Cindy Anderson <[redacted]>
Date: Thursday, June 29, 2023 at 4:34:52 PM UTC-4
Subject: Parent providers
To: [redacted]>

I definitely agree that having parents as caregivers is both beneficial to the children and the children. My kids don't like strangers coming into the house and telling them what to do. It was very contentious. My husband didn't like it either and often they would tell my kids to do something then sit on the couch and play on their phones.

It benefits the child to have someone they care about and know helping them achieve goals. Also the parents do the very same things and need the income to provide for their child's welfare. Too often a disabled child prevents the parents from being able to work outside the home!

Cindy Anderson

From: BECKY KUERSTEN <[redacted]>
Date: Thursday, June 29, 2023 at 3:59:09 PM UTC-4
Subject: Make Parent Provider Provision Permanent / AHCCCS
To: [redacted]

To Whom it May Concern:

I am writing to you today to please Make Parent Provider Provision Permanent / AHCCCS. I am a parent provider for my minor child, he is currently 15, and will be 16 on August 13, 2023. Since becoming a parent provider, it has been such a blessing to my family. At the beginning of COVID, I lost my HAH provider. She quit to go back to school, and I was literally talked into becoming my son's provider to continue with his HAH. So, I did everything I needed to do and became his HAH provider. It was really nice because I didn't have to worry about some stranger coming into my home and possibly bringing the COVID virus with them. Even today, three years later, I still don't like the idea of some stranger coming into my home. I would very much like to continue to be my son's HAH provider.

I also have to be honest in saying that since I am a paid parent provider, the money I make doing this for my son has helped my family significantly financially. It helps pay our bills (mortgage payment and monthly household bills) not to mention it definitely helps put food on our table. The money I make is also giving me the opportunity to make my car payments every month. It would be a devastating loss if I lost my parent provider status.

I don't want to sound like I'm begging you to keep this a permanent thing, but I do want to ask you to please consider it. I am certain that I am not the only parent who wants to make Parent Provider Provision Permanent as well.

Thank you for taking the time to read my email.

Becky Kuersten
Parent Provider for HAH for my minor child
[redacted]

From: Kerri KareBear <[redacted]>
Date: Thursday, June 29, 2023 at 3:12:38 PM UTC-4
Subject: Parents/caregivers
To: [redacted]

Getting paid to be my daughter... [redacted] caregiver has been a

game changer for my family and I. I was able to buy a forever home for my 20yr old daughter with autism...so she will never have to go into state care. Without this income I do not know how i will be able to stay home to take care of her or be able to keep my home and pay all of the bills being a single parent. PLEASE HELP SAVE THIS FUNDING! Thank you..
Kerri Alauria [redacted]
[redacted]

From: Brooke Bailey <[redacted]>
Date: Thursday, June 29, 2023 at 2:41:30 PM UTC-4
Subject: Parents as caregivers for their minor children
To [redacted]

Hello

I would like to voice my opinion on the ability of parents to be paid providers for their minor children. Caring for a child will special challenges requires a lot of a parent, often limiting their opportunities to work outside of the home and can become a financial burden that can cause many adverse effects on a family. Having the ability to care for their special needs child and be a paid providers gives these parents to not only earn some money and provider for their families, but it also allows for the special needs child to be cared for by one of the people that loves them the most and is the most familiar with their needs. Additionally, parents should not be limited my 40 hours a week or by services when providing for their special needs child. Caring for these children is more than a full-time job.

There is also already a great shortage of workers qualified and willing to provide in home care services, if parents were no longer able to care for their special needs child, there would not be a person available to replace them.

Thank you for listening,

Brooke Bailey

---------- Forwarded message ---------
From: Lisa Khoshaba <[redacted]>
Date: Thursday, June 29, 2023 at 2:10:52 PM UTC-4
Subject: Parent Provider Input on Waiver
To: [redacted]

Dear AHCCCS and 1115 Waiver Team,

I have participated in the Paid Parent Caregiver program under Covid-19 accommodations to provide HAB services for my disabled son. This opportunity has been supremely impactful to our family and most importantly my child. We have never been able to find quality providers that are reliable or qualified. With all the trainings I have taken on my own, I am now extremely well equipped to work on the Habilitation (personal and life skills) goals with my child. He is making great progress. He is making the most progress he ever has. He loves having a parent provide these services too vs a stranger.

Our community of parent caregivers is asking for a permanent program that allows parents of disabled minor children to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies. Under the current program proposal this request is not being fully met. Please consider the following suggestions:

- **Include Habilitation as a service parents of minor DDD and ALTCS members can perform as a certified DCW provider.** Parents of adult DDD and ALTCS members can currently perform both Attendant Care and Habilitation hours for their children and parents of the minor population would like this permanent option to mirror that program allowance. The DCW workforce shortage applies to Habilitation providers just as much as it does Attendant Care providers. Habilitation services fulfill the member's "personal care" needs by allowing them continual practice with their own personal care and rehabilitation. The only difference in Attendant Care and Habilitation personal care is that an individual receiving Habilitation can perform their personal care partially and needs assistance mastering these skills. There has been massive improvement to the IDD population in Arizona since parents of minors have been able to provide this service at the correct time and place that is applicable to the member. Parents being paid as Habilitation providers was allowed under the Covid-19 flexibility program and the ARPA program extension as a “personal care” service and we would like to continue to have it as a permanent option.

- Create a plan to train and maintain supervision of front line DDD and ALTCS staff as they implement this permanent program option for families across the state. Language in this program policy should clarify that while non-family DCW providers are an option, Paid Parent Caregivers are also an equally suitable option. This permanent program option should be about which provider meets the needs of the member in the most efficient and safe way possible. Families across the state, especially those in rural areas and those from minority backgrounds, have experienced discrimination by state employees regarding this flexibility for a variety of reasons. An explicit explanation on how institutional change through training and monitoring of staff by AHCCCS and DDD leadership regarding this permanent program implementation would be very impactful in rebuilding those family, member, and Support Coordinator relationships.

Habilitation **and** Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. Parent caregivers have been the backbone of the Developmental Disability Community for decades. A comprehensive Paid Parent Caregiver program which includes both Habilitation and Attendant Care services validates the irreplaceable work that parents provide on a daily basis in their homes and communities.

Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves DDD and ALTCS members in Arizona.

Thank you,
Lisa Khoshaba

---------- Forwarded message ---------
From: Susana Almaraz <[redacted]>
Date: Thursday, June 29, 2023 at 1:53:18 PM UTC-4
Subject:
To: [redacted]

Hello plz let us continue getting paid as we work with our children daily needs and wants plz plz counting paying us some of us depend on wht we make with our children to survive in life thank u--
Susana Almaraz

---------- Forwarded message ---------
From: Brittany Miller <[redacted]>
Date: Thursday, June 29, 2023 at 12:42:49 PM UTC-4
Subject: Public Comment on Paid Parent Caregiver Proposal
To: [redacted]

Dear AHCCCS and 1115 Waiver Team,

I am a parent of a child who receives DDD and ALTCS services. I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility and it has been extremely beneficial to our family and my child who receives these services. For the first time in my daughter's 13 years, she is receiving ALL of her approved services and making significant progress on her habilitation goals. **This flexibility has been a godsend for our family** and I am truly grateful for AHCCCS listening to families and now advocating for a permanent program. THANK you for your efforts.

Based on my review of the current proposal for a permanent Paid Parent Caregiver program I would like to give you my feedback. Thank you for your time and consideration while reading my experience and suggestions.

Our community of parent caregivers is asking for a permanent program that allows parents of disabled minor children to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies. Under the current program proposal, **this request is not being fully met**. Please consider the following suggestions:

Include Habilitation as a service parents of minor DDD and ALTCS members can perform as a certified DCW provider. Parents of adult DDD and ALTCS members can currently perform both Attendant Care and Habilitation hours for their children and parents of the minor population would like this permanent option to mirror that program allowance. The DCW workforce shortage applies to Habilitation providers just as much as it does Attendant Care providers.

Habilitation services fulfill the member's "personal care" needs by allowing them continual practice with their own personal care and rehabilitation. The only difference in Attendant Care and Habilitation personal care is that an individual receiving Habilitation can perform their personal care partially and needs assistance mastering these skills. There has been a massive improvement to the IDD population in Arizona since parents of minors have been able to provide this service at the correct time and place that is applicable to the member. Parents being paid as Habilitation providers were allowed under the Covid-19 flexibility program and the ARPA program extension as a "personal care" service and we would like to continue to have it as a permanent option. We spend years without habilitation providers available for my daughter and when we did find one miraculously, the turnover is terrible. By keeping the option of allowing parents to also perform habilitation services, the DDD member will make progress and have continuity of care. In regard to to her consideration of whether or not hab is a personal care service, many of my daughter's habilitation goals relate to reinforcing therapies and activities of daily living and of course life skills. Also, to my understanding, **there are no federal prohibitions under the 1915(c) waiver authority about using legally responsible individuals, including parents, for services other than personal care.** Personal care tends to be the service that comes up most frequently in the conversation about using parents as paid caregivers because those activities (assistance with bathing, dressing, feeding, etc.) are ones parents are very familiar with. **But a state could choose to authorize parents to deliver other services.** The same goes for the 40 hour/week threshold. C**MS doesn't have any restrictions on that.**

Remove the 40 hour restriction of Paid Parent Caregivers. Caring for a child who receives DDD and ALTCS is not comparable to the needs and familial roles of a spouse performing personal care needs for an adult who qualifies for personal care services. Parents of adult DDD and ALTCS members can currently perform some or all Attendant Care and Habilitation hours that their adult children qualify for under their PCSP. The new permanent Paid Parent Caregiver program should mirror the current adult DDD and ALTCS member program. AHCCCS limits every DCW provider to 16 hours of provided care in a 24-hour period, Parent Caregivers would like this same option so that the care of the member's evaluated hours can be fully fulfilled depending on the availability of non-family and family DCW providers. If this restriction is not an option, a provision that outlines an exception clause and process is requested. My daughter requires 24-hour care and supervision, limiting the hours I as a parent can provide will interrupt her services. There is a massive caregiver shortage and we spent years without attendant care providers. They are not just going to magically be available and if a parent is trained and willing to do the service, they should be able to work the allotted hours for their child. Just like they are able to for their adult disabled children.

Create a plan to train and maintain supervision of front-line DDD and ALTCS staff as they implement this permanent program option for families across the state. Language in this program policy should clarify that while non-family DCW providers are an option, Paid Parent Caregivers are also an **equally suitable** option. This permanent program option should be about which provider meets the needs of the member in the most efficient and safe way possible. Families across the state, especially those in rural areas and those from minority backgrounds, have experienced discrimination by state employees regarding this flexibility for a variety of reasons. I experienced prejudice last year over the fact that I was my child's DCW from her longtime support coordinator and sadly had to file a complaint with DDD and request a new one. Personal bias from support coordinators on parents working as paid parent caregivers needs to stop immediately and be addressed very seriously. Families like mine are already exhausted from the constant advocacy we have to do for our children. We do not need judgment, we need support. An explicit explanation on how institutional change through training and monitoring of staff by AHCCCS and DDD leadership regarding this permanent program implementation would be very impactful in rebuilding those family, member, and Support Coordinator relationships.

Include a provision that allows foster children residing in DDD / CDH homes to receive Attendant Care hours that foster parents can be paid for as DCW providers. These children receive the general Habilitation allotment appropriate to their foster placement to fulfill their personal care needs. However, their individual need levels should be considered in their Habilitation and Attendant Care evaluations so they can receive all appropriate services by a DCW provider regardless if it is a paid foster parent or outside DCW.

Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. Parent caregivers have been the backbone of the Developmental Disability Community for decades. A comprehensive Paid Parent Caregiver program which includes both Habilitation and Attendant Care services validates the irreplaceable work that parents provide on a daily basis in their homes and communities.

Click here to connect with the Arizona parent-led grassroots initiative leaders: www.raisingvoicescoalition.com

Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves DDD and ALTCS members in Arizona.

[redacted]

[redacted]

Brittany Miller
[redacted]

From: Cynthia Macluskie <[redacted]>
Date: Wednesday, June 28, 2023 at 5:42:55 PM UTC-4
Subject: Comment on Paid Parent Provider Program
To: [redacted]

The Board of Autism Society of Greater Phoenix believes AHCCCS should request that CMS make permanent the temporary Paid Provider Program. AHCCCS should amend the Arizona 1115 Demonstration Waiver to allow parents of minor DDD and ALTCS members to be paid providers with the same requirements and limitations of other DCW providers. The State Legislation should authorize parents of any DDD and ALTCS member to provide Attendant Care and Habilitation services for their minor children with the same requirements and limitations of other DCW providers.

The current Parent Provider program allows parents of disabled minor children to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies. This program is crucial to families because of the lack of qualified providers available to serve those with DDD and ALTCS. Home and Community Based Services are necessary for those in Arizona who qualify for DDD and ALTCS and these children deserve caring, consistent, qualified direct care workers.

The social, cultural and systematic benefits that members will receive from this permanent program are significant and superior to the current DCW program. Changing circumstances require us as a nation to do better with the funds we manage, situations we face and members we serve. Parent caregivers have been the backbone of the Developmental Disability community for decades. Comprehensive Paid Parent Provider programs validate the irreplaceable work they provide on a daily basis in their homes and communities.

Our Board believes this change must happen to meet the needs of families who qualify for DDD and ALTCS. It is imperative that we acknowledge the struggle to find an adequate number of qualified compassionate caregivers for those with special needs. As the baby boomers age, the elderly and those with disabled children will compete for the same small group of providers. This shortage has created a growing gap between the demand for quality care and the available supply of caregivers. It is evident that the existing workforce cannot meet the increased demands. The most vulnerable of our population deserve the services that they qualify for and that those services be provided by qualified, consistent direct care workers. The scarcity of caregiver workers can have long-term negative effects on the development and well-being of children, especially those with special needs. We need an innovative solution, and we believe the Paid Parent Provider Program is that solution.

Cynthia Macluskie

President

Autism Society of Greater Phoenix

---------- Forwarded message ---------
From: Amanda Marquez [redacted]
Date: Wednesday, June 28, 2023 at 5:32:59 PM UTC-4
Subject:
To: [redacted]

Dear AHCCCS and 1115 Waiver Team,

I am a parent of a child who receives DDD and ALTCS services. I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility and it has been extremely beneficial to our family and my child who receives these services. Based on my review of the current proposal for a permanent Paid Parent Caregiver program I would like to give you my feedback. Thank you for your time and consideration while reading my experience and suggestions.

Prior to the implementation of the Paid Parent Caregiver Program my child went 2 years without Habilitation and ATC services and the years prior to that he has workers come into the home that were extremely inconsistent (they would only show up a few days a week and quit without notice). My child was on a waiting list and he never received the help that he needed due to the shortage of providers and the lack of consistent in the few he had when he was very young. I ended up losing my job and I had to stay home to perform the duties of a DCW (HAB and ATC) without a paycheck prior to the implementation of the Covid program. My son's needs had to be fulfilled even when we could not find a single provider for multiple years. My being out of work to take care of my child has put my family in dire financial debt and the Paid Parent Caregiver Program has helped to remedy that by allowing me an income while my son's needs are being simultaneously met. My son has many special needs and requires full attention around the clock. He has been accessed at over 40 hours a week for DCW services and those hours are mandatory to provide him the supports he needs as an individual. I believe that Habilitation should absolutely be added as a part of this permanent program. Habilitation varies from ATC in that it allows me to teach my son how to care for himself and over time he has the opportunity to master the skills he needs to become a fully functioning adult in the world. His goals do consist of Self Care modalities, from bathing himself, feeding, cleaning and dressing. All of these skills if taught through habilitation will assist in his personal success as an independent human being. As his parent, I am the only individual he will allow to assist in his personal Habilitation goals as he is mentally aware and wants his privacy. He does not want strangers in the room when he is going to the bathroom, bathing or getting dressed and I feel that he has the right to make that decision. I feel that it is safer for him that a parent takes care of those specific needs as his DCW. I implore you to add Habilitation for children under the age of 18 to the permanent Parental Paid Provider Program. Many of our children's futures depend on the ability to teach through Habilitation goals so that our children can one day become successful and independent adults.

Our community of parent caregivers is asking for a permanent program that allows parents of disabled minor children to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies. Under the current program proposal this request is not being fully met. Please consider the following suggestions:

Include Habilitation as a service parents of minor DDD and ALTCS members can perform as a certified DCW provider. Parents of adult DDD and ALTCS members can currently perform both Attendant Care and Habilitation hours for their children and parents of the minor population would like this permanent option to mirror that program allowance. The DCW workforce shortage applies to Habilitation providers just as much as it does Attendant Care providers. Habilitation services fulfill the member's "personal care" needs by allowing them continual practice with their own personal care and rehabilitation. The only difference in Attendant Care and Habilitation personal care is that an individual receiving Habilitation can perform their personal care partially and needs assistance mastering these skills. There has been massive improvement to the IDD population in Arizona since parents of minors have been able to provide this service at the correct time and place that is applicable to the member. Parents being paid as Habilitation providers was allowed under the Covid-19 flexibility program and the ARPA program extension as a "personal care" service and we would like to continue to have it as a permanent option.

Remove the 40 hour restriction of Paid Parent Caregivers. Caring for a child who receives DDD and ALTCS is not comparable to the needs and familial roles of a spouse performing personal care needs for an adult who qualifies for personal care services. Parents of adult DDD and ALTCS members can currently perform some or all Attendant Care and Habilitation hours that their adult children qualify for under their PCSP. The new permanent Paid Parent Caregiver program should mirror the current adult DDD and ALTCS member program. AHCCCS limits every DCW provider to 16 hours of provided care in a 24 hour period, Parent Caregivers would like this same option so that the care of the member's evaluated hours can be fully fulfilled dependending on the availability of non-family and family DCW providers. If this restriction is not an option, a provision that outlines an exception clause and process is requested.

Create a plan to train and maintain supervision of front line DDD and ALTCS staff as they implement this permanent program option for families across the state. Language in this program policy should clarify that while non-family DCW providers are an option, Paid Parent Caregivers are also an equally suitable option. This permanent program option should be about which provider meets the needs of the member in the most efficient and safe way possible. Families across the state, especially those in rural areas and those from minority backgrounds, have experienced discrimination by state employees regarding this flexibility for a variety of reasons. An explicit explanation on how institutional change through training and monitoring of staff by AHCCCS and DDD leadership regarding this permanent program implementation would be very impactful in rebuilding those family, member, and Support Coordinator relationships.
Include a provision that allows foster children residing in DDD / CDH homes to receive Attendant Care hours that foster parents can be paid for as DCW providers. These children receive the general Habilitation allotment appropriate to their foster placement to fulfill their personal care needs. However, their individual need levels should be considered in their Habilitation and Attendant Care evaluations so they can receive all appropriate services by a DCW provider regardless if it is a paid foster parent or outside DCW.

Habilitation and Attendant Care services should be delivered and received in a timely manner by those in

Arizona who qualify for DDD and ALTCS. Parent caregivers have been the backbone of the Developmental Disability Community for decades. A comprehensive Paid Parent Caregiver program which includes both Habilitation and Attendant Care services validates the irreplaceable work that parents provide on a daily basis in their homes and communities.

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Thank you for your time and consideration! Our community is extremely grateful for the initiative of

AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves DDD and ALTCS members in Arizona.

Thank you!

Amanda Marquez

---------- Forwarded message ---------
From: Barba Family [redacted]
Date: Wednesday, June 28, 2023 at 5:24:43 PM UTC-4
Subject: 1115 Waiver
To: [redacted]

Dear AHCCCS and 1115 Waiver Team,

I am a parent of a child who receives DDD and ALTCS services. I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility and it has been extremely beneficial to our family and my three children who receive these services. Based on my review of the current proposal for a permanent Paid Parent Caregiver program I would like to give you my feedback. Thank you for your time and consideration while reading my experience and suggestions.

Our community of parent caregivers is asking for a permanent program that allows parents of disabled minor children to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies. Under the current program proposal this request is not being fully met. Please consider the following suggestions:

1. Include Habilitation as a service parents of minor DDD and ALTCS members can perform as a certified DCW provider. Parents of adult DDD and ALTCS members can currently perform both Attendant Care and Habilitation hours for their children and parents of the minor population would like this permanent option to mirror that program allowance. The DCW workforce shortage applies to Habilitation providers just as much as it does Attendant Care providers. Habilitation services fulfill the member's "personal care" needs by allowing them continual practice with their own personal care and rehabilitation. The only difference in Attendant Care and Habilitation personal care is that an individual receiving Habilitation can perform their personal care partially and needs assistance mastering these skills. There has been massive improvement to the IDD population in Arizona since parents of minors have been able to provide this service at the correct time and place that is applicable to the member. Parents being paid as Habilitation providers was allowed under the Covid-19 flexibility program and the ARPA program extension as a "personal care" service and we would like to continue to have it as a permanent option. ***My three children were not able to use their Habilitation hours prior to the Covid-19 flexibilities and it has made a world of difference for them to actually have a consistent provider. There is a HUGE shortage of workers right now and if this flexibility goes away, my children will once again be unable to use their Habilitation hours and regression will occur quickly. Not only was/is it hard to find a provider (months and months of searching), but it's HARD to find one that stays (most last a month or two). My children thrive on consistency and having someone new in their home working with them is very triggering and causes regression. And, many of my children's goals are personal care that they only feel comfortable working on with a parent, not a stranger.***

2. Remove the 40 hour restriction of Paid Parent Caregivers. Caring for a child who receives DDD and ALTCS is not comparable to the needs and familial roles of a spouse performing personal care needs for an adult who qualifies for personal care services. Parents of adult DDD and ALTCS members can currently perform some or all Attendant Care and Habilitation hours that their adult children qualify for under their PCSP. The new permanent Paid Parent Caregiver program should mirror the current adult DDD and ALTCS member program. AHCCCS limits every DCW provider to 16 hours of provided care in a 24 hour period, Parent Caregivers would like this same option so that the care of the member's evaluated hours can be fully fulfilled depending on the availability of non-family and family DCW providers. If this restriction is not an option, a provision that outlines an exception clause and process is requested.
ate services by a DCW provider regardless if it is a paid foster parent or outside DCW.

3. Create a plan to train and maintain supervision of front line DDD and ALTCS staff as they implement this permanent program option for families across the state. Language in this program policy should clarify that while non-family DCW providers are an option, Paid Parent Caregivers are also an equally suitable option. This permanent program option should be about which provider meets the needs of the member in the most efficient and safe way possible. Families across the state, especially those in rural areas and those from minority backgrounds, have experienced discrimination by state employees regarding this flexibility for a variety of reasons. An explicit explanation on how institutional change through training and monitoring of staff by AHCCCS and DDD leadership regarding this permanent program implementation would be very impactful in rebuilding those family, member, and Support Coordinator relationships.
4. Include a provision that allows foster children residing in DDD / CDH homes to receive Attendant Care hours that foster parents can be paid for as DCW providers. These children receive the general Habilitation allotment appropriate to their foster placement to fulfill their personal care needs. However, their individual need levels should be considered in their Habilitation and Attendant Care evaluations so they can receive all appropriate services by a DCW provider regardless if it is a paid foster parent or outside DCW.

Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. Parent caregivers have been the backbone of the Developmental Disability Community for decades. A comprehensive Paid Parent Caregiver program which includes **both** Habilitation and Attendant Care services validates the irreplaceable work that parents provide on a daily basis in their homes and communities.

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Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves DDD and ALTCS members in Arizona.

Thank you!

Angela

---------- Forwarded message ---------
From: monica indovina <[redacted]
Date: Wednesday, June 28, 2023 at 4:38:47 PM UTC-4
Subject: extension of paid caregivers
To: [redacted]

I am writing to you to express my support towards the **extension** of the parents who serve as paid caregivers for minor children. This program has been highly beneficial to my family. It has allowed my disabled child to access care and receive services. I am an at-home teacher who is able to reinforce and teach goals to my child. Thus, greatly impacting her success in her development. I thoroughly appreciate the additional support services that my child can receive through this program. My child has been able to reach her goals as well as set new goals in a timely manner.

It is my opinion that this program continues and remains permanent.

Thank you for your time and consideration.
Monica and Anthony Bond
[redacted]

---------- Forwarded message ---------
From: AutumnFerguson [redacted]
Date: Wednesday, June 28, 2023 at 2:14:47 PM UTC-4
Subject: Paid Parent Caregiver Proposal
To: [redacted]

Dear AHCCCS and 1115 Waiver Team,

I am a parent of a child who receives DDD and ALTCS services. I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility and it has been extremely beneficial to our family and my child who receives these services. Based on my review of the current proposal for a permanent Paid Parent Caregiver program I would like to give you my feedback. Thank you for your time and consideration

I have filled out the application, attended all the trainings, sent in my references, provided all necessary paperwork, passed the background check and submitted my fingerprint clearance card. I took all the steps as needed to be employed by an agency.

I could go work with a client in their home providing HAB/ATC services or/and I could provide HAB services for my child in our home. Still providing the same services to a client who needs the services regardless who they might be. For me my child is more comfortable with me than a stranger coming into our home working with him. I've tried it in the past and it really disrupted the home environment with all my children to have a stranger in our home. I am able to provide his Attendant care/supervision wherever we are. I can provide one of his very important goal on his Habilitation which is community safety. I practice this goal with him everytime we go anywhere in the community or any outing. I'm truly grateful to have the opportunity to work closely with my son's DDD coordinator to set goals that will provide the skills he will need as he grief into adulthood.
the s

Our community of parent caregivers is asking for a permanent program that allows parents of disabled minor children to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies. Under the current program proposal this request is not being fully met. Please consider the following suggestions:

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Remove the 40 hour restriction of Paid Parent Caregivers. Caring for a child who receives DDD and ALTCS is not comparable to the needs and familial roles of a spouse performing personal care needs for an adult who qualifies for personal care services. Parents of adult DDD and ALTCS members can currently perform some or all Attendant Care and Habilitation hours that their adult children qualify for under their PCSP. The new permanent Paid Parent Caregiver program should mirror the current adult DDD and ALTCS member program. AHCCCS limits every DCW provider to 16 hours of provided care in a 24 hour period, Parent Caregivers would like this same option so that the care of the member's evaluated hours can be fully fulfilled dependending on the availability of non-family and family DCW providers. If this restriction is not an option, a provision that outlines an exception clause and process is requested.

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Community for decades. A comprehensive Paid Parent Caregiver program which includes both Habilitation and Attendant Care services validates the irreplaceable work that parents provide on a daily basis in their homes and communities.

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Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves DDD and ALTCS members in Arizona.

Thank you!

Autumn Ferguson

---------- Forwarded message ---------
From: Kelli Gabaldon [redacted]
Date: Wednesday, June 28, 2023 at 1:54:29 PM UTC-4
Subject: 2023 Parent Provider Program
[redacted]

Dear AHCCCS and 1115 Waiver Team,

I am a parent of a child who receives DDD and ALTCS services. These services are vital to my 10-year-old Nonverbal, Autistic, ADHD, globally delayed child who elopes and needs 24 Hr. care. I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility and it has been extremely beneficial to our family and my child who receives these services. She thrives with having a parent providing these services, as it's a Daily routine, comfort, and reliable schedule. Having her parent guide teach and implement procedures when providing personal hygiene, is invaluable to my child. There's something to say when a level of comfort during a delicate time in a child's life such as puberty. Her feeling safe and knowing she will not be that 90% who are sexually assaulted, abused or neglected because her parent DCW is providing her Hab and ATC Services.
The inconsistency and more importantly lack of providers was hindering my child's Progress with Habilitation and Attendant care. We were unable to find or have consistent providers daily and this was causing regression, behaviors, and unfair to a child who needs a routine and strict schedule. The inconsistency and lack of providers was hindering her progression. Having her parent and consistency has been vital in her progression and success with HAB.

Based on my review of the current proposal for a permanent Paid Parent Caregiver program I would like to give you my feedback. Thank you for your time and consideration while reading my real-life experience and suggestions.

Our community of parent caregivers is asking for a permanent program that allows parents of disabled minor children to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies. Under the current program proposal this request is not being fully met. Please consider the following suggestions:
and suggestions.

Our community of parent caregivers is asking for a permanent program that allows parents of disabled minor children to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies. Under the current program proposal this request is not being fully met. Please consider the following suggestions:

- Include Habilitation as a service parent of minor DDD and ALTCS members can perform as a certified DCW provider. Parents of adult DDD and ALTCS members can currently perform both Attendant Care and Habilitation hours for their children and parents of the minor population would like this permanent option to mirror that program allowance.

The DCW workforce shortage applies to Habilitation providers just as much or more as it does to Attendant Care providers. Habilitation services fulfill the member's "personal care" needs by allowing them continual practice with their own personal care and rehabilitation. This is extremely helpful to families like ours who have prepubescent children who thrive with routine and comfort of a parent. The only difference in Attendant Care and Habilitation personal care is that an individual receiving Habilitation can perform their personal care partially and needs assistance mastering these skills. There has been massive improvement to the IDD population in Arizona since parents of minors have been able to provide this service at the correct time and place that is applicable to the member. Parents being paid as Habilitation providers was allowed under the Covid-19 flexibility program and the ARPA program extension as a "personal care" service and we would like to continue to have it as a permanent option.

- Remove the 40 hour restriction of Paid Parent Caregivers. Caring for a child who receives DDD and ALTCS is not comparable to the needs and familial roles of a spouse performing personal care needs for an adult who qualifies for personal care services. Parents of adult DDD and ALTCS members can currently perform some or all Attendant Care and Habilitation hours that their adult children qualify for under their PCSP. The new permanent Paid Parent Caregiver program should mirror the current adult DDD and ALTCS member program. AHCCCS limits every DCW provider to 16 hours of provided care in a 24 hour period, Parent Caregivers would like this same option so that the care of the member's evaluated hours can be fully fulfilled depending on the availability of non-family and family DCW providers. If this restriction is not an option, a provision that outlines an exception clause and process is requested.

- Create a plan to train and maintain supervision of front line DDD and ALTCS staff as they implement this permanent program option for families across the state. Language in this program policy should clarify that while non-family DCW providers are an option, Paid Parent Caregivers are also an equally suitable option. This permanent program option should be about which provider meets the needs of the member in the most efficient and safe way possible. Families across the state, especially those in rural areas and those from minority backgrounds, have experienced discrimination by state employees regarding this flexibility for a variety of reasons. An explicit explanation on how institutional change through training and monitoring of staff by AHCCCS and DDD leadership regarding this permanent program implementation would be very impactful in rebuilding those family, member, and Support Coordinator relationships.

• Include a provision that allows foster children residing in DDD / CDH homes to receive Attendant Care hours that foster parents can be paid for as DCW providers. These children receive the general Habilitation allotment appropriate to their foster placement to fulfill their personal care needs. However, their individual need levels should be considered in their Habilitation and Attendant Care evaluations so they can receive all appropriate services by a DCW provider regardless if it is a paid foster parent or outside DCW.

Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. Parent caregivers have been the backbone of the Developmental Disability Community for decades. A comprehensive Paid Parent Caregiver program which includes both Habilitation and Attendant Care services validates the irreplaceable work that parents provide on a daily basis in their homes and communities.

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Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves DDD and ALTCS members in Arizona.

Thank you!

Kelli Gabaldon
[redacted]

---------- Forwarded message ---------
From: Jennifer Renzulli [redacted]
Date: Wednesday, June 28, 2023 at 1:39:21 PM UTC-4
Subject: Paid Parent Caregiver
To: [redacted]

Dear AHCCCS and 1115 Waiver Team,

My name is Jennifer Castine, I am a parent of a child who receives DDD and ALTCS services. I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility and it has been extremely beneficial to our family and my child who receives these services. Based on my review of the current proposal for a permanent Paid Parent Caregiver program I would like to share our story and give you my feedback. Thank you for your time and consideration while reading my experience and suggestions.

When COVID hit there was a lot of uncertainty. We already were struggling to find providers that actually showed up and put in the effort/cared. We had a lot of no call no shows, people being on their phones, being late/leaving early, the list goes on and on. We wasted SO much time finding a provider and then when they dropped off finding another one and going through the "get to know you" process all over again. The turnover rate of providers is very high. We were on a hamster wheel constantly going in circles. It was heartbreaking not only for me but for my son because transition isn't easy for him. He would get to know a provider and then they would leave and we would have to do it all over again. Many of his habilitation goals are regarding his Personal Care (showering, potty training, dressing, brushing teeth, etc.) which only added to the difficulty of having so many providers leave. His Personal Care goals for Habilitation are very private things and it was always difficult for him to have a stranger see him in such a way, for example on the potty. When parents were approved to become Habilitation providers for their children it changed our life in so many positive ways. Consistency for one, we created a routine so he knew what to expect each day during our Habilitation time. He thrived! Noone knows my son better than I do so it cut out the time wasted on "getting to know you" and he was comfortable with me working on his private Personal Goals. He made more progress with me than he has with any other provider. Not only has he made ginormous strides but this has also helped our family financially. When my son was born, our family had the plan that my husband and I would go back to work full time. Well, life had other things in mind. With the amount of time and care my son needed I wasn't able to go back to work and that did have a financial impact on us. Since being able to do parent Habilitation it has given us that extra income that we put back into our son. During the past few years, we have been able to sign him up for drawing classes, Lego classes, sports and so many other things that allow him to just be a kid outside of school and therapy. I know I am just one voice of many that this program has helped tremendously. Please help me help my son by keeping Paid Parent Habilitation.

Our community of parent caregivers is asking for a permanent program that allows parents of disabled minor children to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies. Under the current program proposal this request is not being fully met. Please consider the following suggestions:

> Include Habilitation as a service parents of minor DDD and ALTCS members can perform as a certified DCW provider. Parents of adult DDD and ALTCS members can currently perform both Attendant Care and Habilitation hours for their children and parents of the minor population would like this permanent option to mirror that program allowance. The DCW workforce shortage applies to Habilitation providers just as much as it does Attendant Care providers. Habilitation services fulfill the member's "personal care" needs by allowing them continual practice with their own personal care and rehabilitation. The only difference in Attendant Care and Habilitation personal care is that an individual receiving Habilitation can perform their personal care partially and needs assistance mastering these skills. There has been massive improvement to the IDD population in Arizona since parents of minors have been able to provide this service at the correct time and place that is applicable to the member. Parents being paid as Habilitation providers was allowed under the Covid-19 flexibility program and the ARPA program extension as a "personal care" service and we would like to continue to have it as a permanent option.
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> Create a plan to train and maintain supervision of front line DDD and ALTCS staff as they implement this permanent program option for families across the state. Language in this program policy should clarify that while non-family DCW providers are an option, Paid Parent Caregivers are also an equally suitable option. This permanent program option should be about which provider meets the needs of the member in the most efficient and safe way possible. Families across the state, especially those in rural areas and those from minority backgrounds, have experienced discrimination by state employees regarding this flexibility for a variety of reasons. An explicit explanation on how institutional change through training and monitoring of staff by AHCCCS and DDD leadership regarding this permanent program implementation would be

very impactful in rebuilding those family, member, and Support Coordinator relationships.

Include a provision that allows foster children residing in DDD / CDH homes to receive Attendant Care hours that foster parents can be paid for as DCW providers. These children receive the general Habilitation allotment appropriate to their foster placement to fulfill their personal care needs. However, their individual need levels should be considered in their Habilitation and Attendant Care evaluations so they can receive all appropriate services by a DCW provider regardless if it is a paid foster parent or outside DCW.

Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. Parent caregivers have been the backbone of the Developmental Disability Community for decades. A comprehensive Paid Parent Caregiver program which includes both Habilitation and Attendant Care services validates the irreplaceable work that parents provide on a daily basis in their homes and communities.

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Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves DDD and ALTCS members in Arizona.

Thank you!

Jennifer Castine

From: Jennifer King [redacted]
Date: Wednesday, June 28, 2023 at 1:15:51 PM UTC-4
Subject:
To: [redacted]

Dear AHCCCS and 1115 Waiver Team,

I am a parent of a child who receives DDD and ALTCS services. I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility and it has been extremely beneficial to our family and my child who receives these services. Based on my review of the current proposal for a permanent Paid Parent Caregiver program I would like to give you my feedback. Thank you for your time and consideration while reading my experience and suggestions.

Our community of parent caregivers is asking for a permanent program that allows parents of disabled minor children to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies. Under the current program proposal this request is not being fully met. My child is allotted habilitation, respite, mental health therapy, and occupational therapy hours. **Due to a severe shortage of providers the only consistent service my child has received over that past several years is habilitation provided by a parent. Prior to the public health emergency we simply went without respite and habilitation because we could not find a provider. Our habilitation goals now include hygiene matters that my child nor I are comfortable having a stranger be part of. One of the greatest discriminations people with disabilities face is the lack of privacy allowed during hygiene tasks. Having a loving parent provide this habilitation rather than someone from outside the family is a step in the right direction of civil rights for persons with disability. Additionally, our mental health therapist and occupational therapist have both left the industry within the last year. Parent providers for habilitation are critical to meeting the needs of those with disabilities.** Please consider the following suggestions:

Include Habilitation as a service parents of minor DDD and ALTCS members can perform as a certified DCW provider. Parents of adult DDD and ALTCS members can currently perform both Attendant Care and Habilitation hours for their children and parents of the minor population would like this permanent option to mirror that program allowance. The DCW workforce shortage applies to Habilitation providers just as much as it does Attendant Care providers. Habilitation services fulfill the member's "personal care" needs by allowing them continual practice with their own personal care and rehabilitation. The only difference in Attendant Care and Habilitation personal care is that an individual receiving Habilitation can perform their personal care partially and needs assistance mastering these skills. There has been massive improvement to the IDD population in Arizona since parents of minors have been able to provide this service at the correct time and place that is applicable to the member. Parents being paid as Habilitation providers was allowed under the Covid-19 flexibility program and the ARPA program extension as a "personal care" service and we would like to continue to have it as a permanent option.
Remove the 40 hour restriction of Paid Parent Caregivers. Caring for a child who receives DDD and ALTCS is not comparable to the needs and familial roles of a spouse performing personal care needs for an adult who qualifies for personal care services. Parents of adult DDD and ALTCS members can currently perform some or all Attendant Care and Habilitation hours that their adult children qualify for under their

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Jennifer King

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Date: Wednesday, June 28, 2023 at 1:15:51 PM UTC-4
Subject:
To: [redacted]

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Thank you!

Jennifer King

From: Jen Zupan [redacted]
Date: Wednesday, June 28, 2023 at 1:09:30 PM UTC-4
Subject: Paid Parent Caregiver Program
To: [redacted]

Dear AHCCCS and 1115 Waiver Team,

I am a parent of a child who receives DDD and ALTCS services. I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility and it has been extremely beneficial to our family and my child who receives these services. Based on my review of the current proposal for a permanent Paid Parent Caregiver program I would like to give you my feedback. Thank you for your time and consideration while reading my experience and suggestions.

From a personal level, my son has only been met with incompetent providers for his needs in the past, prior to Covid regulations. Regardless of my follow-up with them in his cooperation with the goals set for that session, there were always excuse why they were not being attempted. I felt they simply accepted the Habilitation hours for the higher payrate.

Now that I have been providing Habilitation, he has been making gains. I am exhausted but he is my child. I will do what I need to build and maintain his skill base within all of his environments. I want him happy and healthy to whatever level of contribution he has to his self as well as our community as a whole.

In addition, even prior to covid it was difficult to find staffing. Agencies pushed parents to use family and friends as our first choice. Today, it's been impossible even to get respite.

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Thank you!

---------- Forwarded message ---------
From: Kristal Van Boven <[redacted]>
Date: Wednesday, June 28, 2023 at 11:13:16 AM UTC-4
Subject: Paid Parent Caregiver program waiver
To: [redacted]

Dear AHCCCS and 1115 Waiver Team,

I am a parent of a child who receives DDD and ALTCS services. I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility and it has been extremely beneficial to our family and my child who receives these services. Based on my review of the current proposal for a permanent Paid Parent Caregiver program I would like to give you my feedback. Thank you for your time and consideration while reading my experience and suggestions.

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program and the ARPA program extension as a "personal care" service and we would like to continue to have it as a permanent option.
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How is not allowing parents to provide hab services meeting these goals?

- Mitigate DCW shortage and other access to care challenges by allowing payments to parents who serve as paid caregivers for their minor children,
- Increase member satisfaction and promote positive health and well-being. outcomes for the target population.
- Extend an additional support service to restore, enhance, and maintain family functioning to preserve effective care for the member in the home and community, and
- Ensure that members receive high-quality care while increasing timely accessibility to providers.

Will there suddenly be enough hab providers for everyone?

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Thank you!

---------- Forwarded message ---------
From: Meghann Hodge <[redacted]>
Date: Wednesday, June 28, 2023 at 2:49:27 AM UTC-4
Subject: Parent Provider Program
To: [redacted]

Dear AHCCCS and 1115 Waiver Team,

I am a parent of a child who receives DDD and ALTCS services. I am participating in the Paid Parent Caregiver program under the Covid-19 Flexibility and it has been extremely beneficial to our family and my child who receives these services. Based on my review of the current proposal for a permanent Paid Parent Caregiver program I would like to give you my feedback. Thank you for your time and consideration while reading my experience and suggestions.

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2. Remove the 40 hour restriction of Paid Parent Caregivers. Caring for a child who receives DDD and ALTCS is not comparable to the needs and familial roles of a spouse performing personal care needs for an adult who qualifies for personal care services. Parents of adult DDD and ALTCS members can currently perform some or all Attendant Care and Habilitation hours that their adult children qualify for under their PCSP. The new permanent Paid Parent Caregiver program should mirror the current adult DDD and ALTCS member program. AHCCCS limits every DCW provider to

16 hours of provided care in a 24 hour period, Parent Caregivers would like this same option so that the care of the member's evaluated hours can be fully fulfilled dependending on the availability of non-family and family DCW providers. If this restriction is not an option, a provision that outlines an exception clause and process is requested.

3. Create a plan to train and maintain supervision of front line DDD and ALTCS staff as they implement this permanent program option for families across the state. Language in this program policy should clarify that while non-family DCW providers are an option, Paid Parent Caregivers are also an equally suitable option. This permanent program option should be about which provider meets the needs of the member in the most efficient and safe way possible. Families across the state, especially those in rural areas and those from minority backgrounds, have experienced discrimination by state employees regarding this flexibility for a variety of reasons. An explicit explanation on how institutional change through training and monitoring of staff by AHCCCS and DDD leadership regarding this permanent program implementation would be very impactful in rebuilding those family, member, and Support Coordinator relationships.

4. Include a provision that allows foster children residing in DDD / CDH homes to receive Attendant Care hours that foster parents can be paid for as DCW providers. These children receive the general Habilitation allotment appropriate to their foster placement to fulfill their personal care needs. However, their individual need levels should be considered in their Habilitation and Attendant Care evaluations so they can receive all appropriate services by a DCW provider regardless if it is a paid foster parent or outside DCW.

On top of the community requests, that I fully support, I would like to share some of my own personal experiences with being a Parent Provider, specially for Habilitation for my young daughter:

My daughter has gone through waitlist after waitlist waiting for services: Physical Therapy, Occupational Therapy, ABA (behavioral) Therapy, Speech Therapy, etc. After waiting lists of months and months to get in for an evaluation, and waiting for insurance to go through, providers to be found, goals to be made, etc We face the challenges of finding a consistent slot for our children to come in to receive therapy. Every single company I called, every parent I talked to about their experience, every person I brought it up to all say the same thing: there is a shortage of providers for these services. We cannot match the demand. But even if you are lucky enough to get a permanent slot and on-going therapy how long does that last? Availability changes and bumps you out of your slot, providers move, families move, people quit, people get sick or injured or have babies and need long term leave, and then what happens? We are bumped back onto callalkation lists and back to waiting. Therapy is halted, progress is slowed or even stopped and in some cases lost to the point you have to start back from square one.

This vague explanation is exactly what we have experienced with my own family. Here is a piece of our story:

My daughter waited over a year to get in for an Autism Evaluation. Once she got in she was diagnosed right away, we were handed a list of recommended therapies and supports and steps to help her. While we called place after place to get her some help we were met with: fully companies, therapist shortages, companies that could not travel to where we were located, companies that do not accept our insurance, companies that found us a provider then backed out last minute because the provider quit or needed to go to someone else who was already receiving service but their therapist quit or moved or something. While we waited months and months to find places, get evaluations, start services etc. My daughter is harming herself (biting, hitting, scratching, head banging, pulling out her hair etc), Aggressing towards her brother, parents, pets, peers, etc, Melting down, unable to advocate for herself, explain what happened when things go wrong, struggling with self care skills, and so much more. She was evaluated for Speech and Occupational Therapy in August, she received one trial session with a temporary therapist and was placed on a cancellation list to get drop in while waiting for a therapy slot. She received one speech therapy drop in and 0 Occupational drop in within a three month span. In November she received a permanent speech therapy slot. She got a month of service before her therapist took a 2 week vacation for the holidays and it put a halt in her progress and led to a regression. Meanwhile she picked up one more drop in Occupational therapy session in January in which they recommended we get a physical therapy evaluation. She got that evaluation the following week and that same week she started a permanent slot with OT. She was contracted for weekly PT but has yet to have a permanent therapist in 6 months of waiting. While on the callelation list she has been offered 4 drop in sessions in 6 months time. She has also had a lot of therapist changes and cancellations in OT, and last month she lost her speech therapist because she moved away and now she has gone over a month without any speech therapy. She began ABA therapy 3 weeks ago and goes 5 days a week for 4-6 hours a day and we were hopeful for consistency and progress with the level of therapy she is receiving. but we have already had several cancellations and 2 supervisor changes in just 3 weeks.

On top of the inconsistency, lack of staffing, etc. the progress my child has made in these therapies is small because of several issues that being a parent provider solves: These therapy sessions are at a scheduled time. During this time they get a brief picture of my child on her best behavior, "masking" with a stranger. Even once she opens up to them she is still uncomfortable doing many things she struggles to do around them. Even when it is not an issue with how comfortable she is, there is only so much you can do to see the target behaviors and challenges the goals are targeting. So we run into issues getting goals met, and progress seen.

Examples: My daughters Habilitation goals involve undressing/dressing herself. Even if I was comfortable allowing someone to work with her on these things, she is not. They have a goal in OT for "taking off her shirt independently" this is targeted by placing an oversized tee shirt over the top of her shirt she wore that day and having her remove the added tee. Even with remainders that her other shirt is still on my daughter refuses to run this goal. She is uncomfortable undressing around others (even her dad, brother, aunts, grandmothers,etc. in the privacy of her own home) In the months she has had this goal it has been attempted 3 times and she has successful attempted 0 times. No progress has been made. I have been a parent provider for her Habilitation for one week and she has mastered removing and putting on her pants independently, and can take off and put on her shirt is 80% independence at least 8/10 times.

Why has she made such drastic progress in one week of Habilitation, but no progress in 6 months of OT? Because she is comfortable around her mother, because we are able to target this naturally: before bath, when she attempts to use the toilet, when she changes at bedtime, etc. She does not feel like this is a contrived task to test her but instead it is a chance to be independent in a day to day task. And isnt that the goal of Habilitation? for the members to be comfortable and able to naturally target day to day challenges to be more independent?

Other goals she has run us into similar issues:

Washing herself in the bathtub. This is inappropriate for a provider who is a stranger to work on. Playing with her brother with nice hands, sharing, reducing aggression toward him and herself, coping skills when challenges around this happen, coping and expressing what happens when she is injured or terrified or melting down. These are goals that need to be run naturally. A scheduled Habilitation session with an outside provider limits the ability to work on these things in that: you cannot ethically contrive these things. It is unethical for have a child get injured so you can work on how to express what happened and cope with it. It is dangerous to contrive something that will lead to a child aggressing toward another or themselves. And it would be unnatural to contrive these things and make the skills

rehearsed and unlikely to translate and generalize to a natural occurrence of the setting.
By being a parent provider I am with my child at all times, working on skills and goals in their natural setting, when they occur naturally. It allows for more practice on these skills in a way that is effectively teaching her to be independent without feeling forced or tested. We do not have to worry about not being able to target goals because they do not occur at her scheduled time. We do not have to worry about providers cancelling or quitting. We do not have to worry about lost progress due to lack of providers and waiting periods.

Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. Parent caregivers have been the backbone of the Developmental Disability Community for decades. A comprehensive Paid Parent Caregiver program which includes both Habilitation and Attendant Care services validates the irreplaceable work that parents provide on a daily basis in their homes and communities.

Click here to connect with the Arizona parent led grassroot initiative leaders:
www.raisingvoicescoalition.com

Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves DDD and ALTCS members in Arizona.

Thank you!

---------- Forwarded message ---------
From: Nichole Fernandez <[redacted]>
Date: Wednesday, June 28, 2023 at 2:13:30 AM UTC-4
Subject: Parents As Paid Caregivers Program
To: [redacted]

Dear AHCCCS and 1115 Waiver Team,

First, thank you for the opportunity and forum to provide comments and feedback about this program. Our community of parent caregivers is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers.

I am a parent of a child who receives DDD and ALTCS services, specifically habilitation and respite services, both of which we have not had a caregiver provide since March 2020. As we were unaware of the parent provider program until recently, we have not yet participated in the Paid Parent Caregiver program under the Covid-19 Flexibility but are looking forward to receiving these services in the near future.

Based on my review of the current proposal for a permanent Paid Parent Caregiver program I would like to give you my feedback. Thank you for your time and consideration while reading my experience and suggestions.

Our community of parent caregivers is asking for a permanent program that allows parents of disabled minor children to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies. Under the current program proposal this request is not being fully met. Please consider the following suggestions:

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perform their personal care partially and needs assistance mastering these skills. There has been massive improvement to the IDD population in Arizona since parents of minors have been able to provide this service at the correct time and place that is applicable to the member. Parents being paid as Habilitation providers was allowed under the Covid-19 flexibility program and the ARPA program extension as a "personal care" service and we would like to continue to have it as a permanent option.

2. **Remove the 40 hour restriction of Paid Parent Caregivers.** Caring for a child who receives DDD and ALTCS is not comparable to the needs and familial roles of a spouse performing personal care needs for an adult who qualifies for personal care services. Parents of adult DDD and ALTCS members can currently perform some or all Attendant Care and Habilitation hours that their adult children qualify for under their PCSP. The new permanent Paid Parent Caregiver program should mirror the current adult DDD and ALTCS member program. AHCCCS limits every DCW provider to 16 hours of provided care in a 24 hour period, Parent Caregivers would like this same option so that the care of the member's evaluated hours can be fully fulfilled dependending on the availability of non-family and family DCW providers. If this restriction is not an option, a provision that outlines an exception clause and process is requested.

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4. **Include a provision that allows foster children residing in DDD / CDH homes to receive Attendant Care hours that foster parents can be paid for as DCW providers.** These children receive the general Habilitation allotment appropriate to their foster placement to fulfill their personal care needs. However, their individual need levels should be considered in their Habilitation and Attendant Care evaluations so they can receive all appropriate services by a DCW provider regardless if it is a paid foster parent or outside DCW.

Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. Parent caregivers have been the backbone of the Developmental Disability Community for decades. A comprehensive Paid Parent Caregiver program which includes both Habilitation and Attendant Care services validates the irreplaceable work that parents provide on a daily basis in their homes and communities.

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Thank you for your time and consideration! Our community looks forward to our continued collaboration to create a permanent program that best serves DDD and ALTCS members in

Arizona.

Thank you!
~Nichole Fernandez

---------- Forwarded message ---------
From: Jessica Phillips <[redacted]>
Date: Wednesday, June 28, 2023 at 1:46:02 AM UTC-4
Subject: Re: parent provider programs
To: [redacted]

Dear AHCCCS and 1115 Waiver Team,

I am a parent of a child who receives DDD and ALTCS services. I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility and it has been extremely beneficial to our family and my child who receives these services. Based on my review of the current proposal for a permanent Paid Parent Caregiver program I would like to give you my feedback. Thank you for your time and consideration while reading my experience and suggestions.

I really hope habilitation can be added. Without my husband doing habilitation my daughter would have declined rapidly on a physical and cognitive level because of so many OT, PT, and other therapists constantly quitting and causing my daughter to have inconsistencies which then has an effect on her overall attitude and wellbeing. My husband has also sought other trainings to help our daughter improve due to the constant gaps with her therapies which goes on for months. Our daughter has not only a chromosome duplication that has an unknown significance, but she need substantial support at all times because she is a Level 3 autistic child. My husband spends a relentless amount of time planning her daily tasks and ways he can perform different therapeutic tasks to help her improve each and every day while maintaining the consistency that she desperately needs. Each agency provides additional training and help when it comes to wanting to expand on how to best help our child. I truly hope that you will reconsider this decision to take away HAB to ensure not only me as a parent of a special needs child, but other parents as well can provide the most adequate care for our children.

Our community of parent caregivers is asking for a permanent program that allows parents of disabled minor children to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies. Under the current program proposal this request is not being fully met. Please consider the following suggestions:

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ALTCS is not comparable to the needs and familial roles of a spouse performing personal care needs for an adult who qualifies for personal care services. Parents of adult DDD and ALTCS members can currently perform some or all Attendant Care and Habilitation hours that their adult children qualify for under their PCSP. The new permanent Paid Parent Caregiver program should mirror the current adult DDD and ALTCS member program. AHCCCS limits every DCW provider to 16 hours of provided care in a 24 hour period, Parent Caregivers would like this same option so that the care of the member's evaluated hours can be fully fulfilled dependending on the availability of non-family and family DCW providers. If this restriction is not an option, a provision that outlines an exception clause and process is requested.

Create a plan to train and maintain supervision of front line DDD and ALTCS staff as they implement this permanent program option for families across the state. Language in this program policy should clarify that while non-family DCW providers are an option, Paid Parent Caregivers are also an equally suitable option. This permanent program option should be about which provider meets the needs of the member in the most efficient and safe way possible. Families across the state, especially those in rural areas and those from minority backgrounds, have experienced discrimination by state employees regarding this flexibility for a variety of reasons. An explicit explanation on how institutional change through training and monitoring of staff by AHCCCS and DDD leadership regarding this permanent program implementation would be very impactful in rebuilding those family, member, and Support Coordinator relationships.

Include a provision that allows foster children residing in DDD / CDH homes to receive Attendant Care hours that foster parents can be paid for as DCW providers. These children receive the general Habilitation allotment appropriate to their foster placement to fulfill their personal care needs. However, their individual need levels should be considered in their Habilitation and Attendant Care evaluations so they can receive all appropriate services by a DCW provider regardless if it is a paid foster parent or outside DCW.

Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. Parent caregivers have been the backbone of the Developmental Disability Community for decades. A comprehensive Paid Parent Caregiver program which includes both Habilitation and Attendant Care services validates the irreplaceable work that parents provide on a daily basis in their homes and communities.

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Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves DDD and ALTCS members in Arizona.

Thank you!

-Jessica and Jakar Phillips

From: melissa DIGGINS [redacted]
Date: Monday, August 14, 2023 at 3:16:29 PM UTC-4
Subject: Minor Child Parent Provider
To: [redacted]

To whom it may concern,

I took the day off and attended the 8/2 parent forum. How disappointing! We never got called upon to speak and our voices were silenced. What AHCCCS does not understand is the impact this "new proposal" would have on my disabled child. He went years without services as vendor calls came up empty year after year. We have blown through our savings paying for private therapy and had we not done that, our child would still be non verbal autistic. Year after year we are told they are "hiring more providers", but we have yet to ever gain access to one——To this very day. This proposal need to be amended to include parent providers as a permanent option for families like ours. We have our kids best interest at heart, and will be the ones fitting the bill if they don't learn to be independent and care for themselves. Each step is a journey. It takes a long time, but ending this provision means we are out of luck with ever giving our son a chance at a happy and independently life when we leave this earth.

Mrs Diggins
Proud Autism Mom and Current Parent HAB provider.

From: Laura Morgan [redacted]
August 14, 2023 at 8:57:01 Subject: PM UTC-4
To:
[redacted]

The paid parent provider program has literally changed my child's life for the better.
I cannot even imagine the thought of it being taken away from so many children and their needs.
My child receives HAB and attendant care done by myself. Along with their not being any providers willing to do this work nor work around my child's schedule,we would never feel comfortable with a stranger coming in to see my vulnerable, developing daughter change her clothes,using toilet,shower etc. NEVER!
My daughter has blossomed,made great advancements,strides and her confidence is skyrocketing with me being able to help and teach her and focus 100% on her needs.
I recognize that the powers that be do not care about our children's well beings,if it doesn't affect you you don't care. This is so saddening. How can you sleep at night taking away a program that has greatly helped so many disabled children? Maybe you have a child that is healthy and neurotypical but that is not the case for all of us. How would your child like a stranger coming in to your home and seeing them naked,use the restroom,help them dress,see them in their most private states? You wouldn't like it but it doesn't affect you so again you don't care. This situation is cruel and, concerning and quite frankly embarrassing that higher ups want to do this to young children. Shame on you.

---------- Forwarded message ---------
From: Jessi [redacted]
Date: Monday, August 14, 2023 at 10:18:55 PM UTC-4
Subject: Extraordinary Care assessments
To: [redacted]

To Whom it May Concern,

Raising Voices Coalition and parents of minor DDD members across Arizona ask you to join with us to request changes to the AHCCCS Paid Parent Caregiver Proposal in order to provide a permanent solution that will provide equitable care to all minor DDD members.

Extraordinary Care and Ordinary Care are currently being evaluated for minor DDD members by individual Support Coordinators through assessments for Attendant Care and Habilitation hours based on their personal discretion and ideology because the current standardized tool provided for their use by DDD covers cradle to grave development instead of age appropriate developmental standards.

Under the current proposal put forth by AHCCCS for a permanent Paid Parent Caregiver Program in Arizona, there is no framework to define Extraordinary Care and Ordinary Care of minors. The current intention of AHCCCS is to build in safeguards that allow for Ordinary Care. However these safeguards would create unequal access to Extraordinary Care to some DDD and ALTCS members based on their individual needs assessments.

According to CMS which gives the framework for all states to create Medicaid waiver programs that provide appropriate supports for their members, Extraordinary Care is defined 'as care exceeding the range of activities that a Legally Responsible Individual (parent of a minor or spouse) would ordinarily perform in the household on behalf of a person without a disability or chronic illness of the same age, and which are necessary to assure the health and welfare of the participant and avoid institutionalization. If the state allows Legally Responsible Individuals to provide waiver services, it must establish criteria that define extraordinary care.' In addition, Ordinary Care is defined as, 'the typical responsibility of a Legally Responsible Individual ordinarily provided to people, with or without a disability or chronic illness.' (page 121 https://drive.google.com/file/d/1HlsRl2mjlgH9v2DhExHctj8sYKRjynvF/view?usp=sharing)

In public forums regarding the new Paid Parent Caregiver Proposal there has been discussion between AHCCCS leaders and community members around Ordinary Care and the roles of Legally Responsible Individuals. AHCCCS leaders are currently proposing program restrictions (40 hour weekly cap on Attendant Care and removal of Habilitation) for Parents Providers of members under the age of 18. This would limit access to authorized care hours currently performed by the parent providers.

In order for Extraordinary Care to function equitably in Arizona, AHCCCS leaders need to define Extraordinary Care and create new evaluation tools for Support Coordinators to use in the evaluation of Attendant Care and Habilitation for minors. This is necessary for Arizona's permanent program which allows parents of minors to perform paid waiver services because disabled minors have unique Extraordinary Care needs at each stage of development.

We can no longer operate within a system that leaves these determinations up to individual Support Coordinators without the correct framework to support their understanding of Extraordinary Care. Families in Arizona have experienced a wide degree of evaluation inconsistency and discrimination across the minor DDD member population under the current lack of appropriate evaluation tools.

The framework to define and evaluate Extraordinary Care through the individual planning process should be built into the evaluation tools for services instead of the blanket regulation of a permanent Paid Parent Caregiver Program.

The Raising Voices Coalition Requested Changes to the Paid Parent Caregiver Proposal and parent caregivers across Arizona believe that these changes will allow for Extraordinary Care and Ordinary Care of minors to be appropriately evaluated throughout their years of development regardless of who provides the service hours.

If you have any further questions feel free to contact me directly or our grassroots leaders Brandi Coon and Lauryn VanRooy.

Bra...@raisingvoicescoalition.com
Lau...@raisingvoicescoalition.com

Thank you for your consideration as we collaborate to create the most optimal program to serve the needs of our minor members.

Thank you,

Jessica Grace
[redacted]

---------- Forwarded message ---------
From: Jilly Ressler <[redacted]>
Date: Monday, August 14, 2023 at 11:04:40 PM UTC-4
Subject: Parent provider
To: [redacted]

Hello. I am writing to provide input regarding proposed changes to parent providers for AHCCCS and would be so grateful for your attention to how these changes would have a negative impact on our family.

I am a parent of a beautiful and cherished [redacted] with Down syndrome. She is also an AML leukemia survivor after living for 7.5 months at Phoenix Children's Hospital. During her hospitalization, it became apparent that I was no longer able to continue my employment as an MSW, working in medical settings.

The parent provider program that began during covid was a Godsend to me and my husband. I had experienced difficulties in getting providers for my daughter. I had some success in utilizing older daughters or friends of these daughters and they did an excellent job but the position wasn't lasting. The bottom line is despite their affection for [redacted], they could make more money doing other things without all the paperwork and maintenance of being a provider. So the opportunity to be my own daughter's provider was helpful and made sense.

A few of my daughter's habilitation goals are in regards to getting ready in the morning. She processes slowly when she wakes up and we have been utilizing prompts to move her along to increase her independence. I can not fathom how I could get a provider to come to my home at 5:30 am to 7:30 am. I certainly could not find someone I know even though we are surrounded in a beautiful community of friends and support via Scottsdale Bible Church. It just isn't realistic and besides, I really don't want anyone else dealing with my [redacted] naked and completing morning tasks for obvious reasons. She deserves as much privacy as possible.

The parent provider program makes it possible for me to be home with my daughter but also increase her social opportunities. I have heard that there are concerns that this program limits the members' social environment but I would say it is just the opposite. My daughter has a rich social life and opportunities via Young Life, Camelot Horse therapy, Gigi's Fit, Scottsdale Parks and Recreation and activities through both Scottsdale Bible Church and Mountain View Presbyterian. It is my active involvement that makes her big world possible. In fact, a few of her habilitation goals are centered on teaching conversation skills and life skills like taking turns. Our family is very intent on empowering our [redacted] to having poise and as much independence as possible.

Please take careful consideration on the impact that these proposed changes would have on your members and their families. I am aware that many families do not have an extensive social network and these families will be highly unlikely to find individuals to provide habilitation services.Some are not even able to find respite providers that they so obviously desperately need. Please do all that you can to advocate for your members by continuing the paid provider program as it is. Be aware that by cutting off the paid provider program, you would only be increasing the financial stressors involved with raising a child with special needs.

Thank you in advance for your concern and best intentions regarding my daughter.

Sincerely,

Mrs. Jilly Ressler
[redacted]

---------- Forwarded message ---------
From: Devinmarie Zuleski <[redacted]>
Date: Tuesday, August 15, 2023 at 1:48:22 AM UTC-4
Subject: Habilitation
To: [redacted]

To Whom It May Concern,

Id like to introduce myself, my name is Devin Zuleski, mother of a 4.5 year old special needs child, I wanted to say thank you for you time please consider the following!

> AHCCCS has shared a few pieces of data with Raising Voices Coalition regarding their viewpoint and reasons for their program restrictions. Additionally on their Aug. 2nd Public Forum they shared some preliminary data that shows how many parent DCW's are employed and non parent DCW's are employed. Agencies and Raising Voices Coalition are skeptical of the validity of the data collected by AHCCCS and presented on Aug. 2, 2023. You can review these research papers and data and then express to AHCCCS how your experience and your child's experience with parent providers differs from what they have shown and researched.
>
> Vulnerability to Loneliness in People with Intellectual Disability
> Relational Fragility and the Isolational Trajectory in the Latter Stages of Life
> Effects of Social Isolation and Loneliness in Children with Neurodevelopmental Disabilities
> August 2, 2023 Parents as Paid Caregivers Waiver Amendment Proposal Presentation with Data
>
> Caregiver Burnout - Please specify to AHCCCS what items (i.e. Respite, Therapy and/or Cleaning Services) that would better support you with Caregiver Burnout. Also share with AHCCCS how the restrictive provisions they are proposing will not improve Caregiver Burnout, but make it worse. You can also reference the Raising Voices Coalition Data in your reply as it shows true figures regarding caregiver stress levels.
> Social Isolation - Share with AHCCCS how your child has experienced Social Isolation and what aspects contribute to social isolation to your child? Does having a parent as a paid provider contribute or prevent social isolation for your child? How?
> Community Involvement - Share with AHCCCS how your child has experienced Community Involvement with typical providers and what aspects of having a paid parent provider assists your child with disabilities in having a greater amount of community involvement.

Thank you ,

Devin Zuleski

---------- Forwarded message ---------
From: gwendolyn howe <[redacted]>
Date: Tuesday, August 15, 2023 at 11:43:03 AM UTC-4
Subject: Habilitation-Parents
To: [redacted]

I, for one, would like to express how important habilitation is for my son, who is not qualified to do any work programs and needs constant supervision and direction.
He needs guidance and support, academics and life skills. -Everything that habilitation is supposed to represent… things that I do on a regular basis, even past the hours that I am luckily paid for.
I have not been able to return to full-time work in over 10 years because I am home taking care of my son, and now that he is home full-time and not in school- especially so.
I absolutely positively rely on funds that I am given for caring for my son to make ends meet and believe you me - it isn't much. I cannot stress enough how every penny is important and habilitation pays two dollars more an hour than attendant care.
I cannot continue to ensure that he is cared for and growing in the best way, which is something that I can provide- if I can't even pay the bills.

Gwen Howe
[redacted]

From: Markita M <[redacted]>
Date: Tuesday, August 15, 2023 at 12:16:33 PM UTC-4
Subject: Habilitation & Attendant Care from Parents
To:[redacted][redacted]

Habilitation & Attendant Care Is very important to me and my family because my child has experienced abuse in the past when using these provided services. Being able to provide these services in the home have truly been a blessing to our family. It has taken away a lot of stress and anxiety as a whole. It has allowed me to be able to work and still be able to have time with the children and be able to take care of them in full capacity with out being taken away from them. I don't know what I would do without this program. It has been such a blessing to our lives and taking it away would put the stress back into our family. Please consider making this permanent. It would be one less stressful thing we have to deal with.

From: Gina Schroeder <[redacted]>
Date: Tuesday, August 15, 2023 at 12:23:43 PM UTC-4
Subject: Parent Habilitation services
[redacted]

I would like to express how being a parent and being able to provide the habilitation servers for my child's has helped so much. I don't have to depend on someone showing up to work with my son everyday. I have been able to work on all his goals at times that work the best for our family. It has truly been life changing and so much progress has been made. Please make parents permanent providers for habilitation.

Thank You,
Gina Schroeder
[redacted]

From: Joyful Noise Entertainment <[redacted]>
Tuesday, August 15, 2023 at 12:36:08 PM UTC-4
Subject: Habilitation/ATC program
To: [redacted]

To whom it may Concern: my name is Portia Foss, I'm the Aunt to a sweet special needs boy named [redacted] who is an Arizona resident. His mother my sister Shawnece Domasin, informed me that the program that became avaliable to families during the pandemic that pays parents to be caregivers for thier special needs children was set to end, I'm reaching out to respectfully ask that this decision be reconsidered, this change will be devastating for my sisters family and many others in similar situations, [redacted] has been through so many struggles in his 7 years on this earth, and he thrives moat where he is comfortable and secure, many daycare facilities just aren't equipped to give him the care he needs, so my sister wouldn't be able to work outside of the home to help provide for her family, Shawnece Is a dedicated and adoring mother, her strength in the midst of seeing [redacted] struggle and at times fearing for his very life and navigating all that comes with raising and caring for a special needs child, time and again She's shown true grit, perseverance, and unbridled love for all her children in the face of unimaginable adversity, so I ask for her, for her family and for all Arizona families with special needs children please don't take this option away, please think about these babies, who's going to care for them the way thier own parents can? Have a blessed day! - Portia Foss.

---------- Forwarded message ---------
From: Stacy Strombeck <[redacted]>
Date: Tuesday, August 15, 2023 at 12:41:56 PM UTC-4
Subject: Continuing Parent Providers for Habilitation
To: [redacted]
Cc: [redacted]

To Whom It May Concern:

Our son [redacted] is receives services through DDD and ALTCS. He is on the autism spectrum. We have not had Habilitation Services for him for 8 years, due to being unable to find a qualified service provider. Since COVID, I have been a Parent Provider, and have been doing [redacted] 16 hours of HAB per week.

[redacted] has flourished. He's been able to return to public school, (was using ESA prior to homeschool.) He is making friends, and we have high hopes that he will be able to find and keep a part-time job. Our primary goal is to keep [redacted] safe, and to keep him in our home with as much independence as possible, rather than having him live in a group home.

I've heard that part of the reason Parent Provider program for HAB for children under 18 will end, is because there is data that Parent Providers cause social isolation. In our family, nothing could be further from the truth. We are out in public at the movies, bowling, restaurants, shopping malls and parks every day. I am always working on [redacted]'s HAB goals, appropriate behavior and social skills during these outings. I would like to see the data that supports the social isolation theory.

If the Parent Provider program were to end in November 2023, we would again be unable to find a qualified HAB provider. I believe the pay scale is too low for a challenging job, in today's job market. By "qualified," I mean someone who is not intoxicated, is willing and able to closely supervise my son, and will actually show up once they are hired.

Please consider continuing the Parent Provider program for Habilitation for children under 18. It has and would continue to produce positive outcomes for our children with disabilities.

Thank you for your time and consideration. Please contact me if you'd like any more information.

Stacy Strombeck-Goodrich
[redacted]

From: Staci Warren [redacted]
Date: Tuesday, August 15, 2023 at 12:42:44 PM UTC-4
Subject: Support for Habilitation Parent provider
To: [redacted]

Hi
I'm sending this email to give parent input in favor of making parent provider for habilitation services with DDD a permanent option for families. I am a parent provider and losing this option would be detrimental to our family. Prior to having parent option we were never able to find an outside provider that was reliable and dependable. The financial assistance has been impactful to our family and allows me to contribute to our household and simultaneously help my child become more independent. Please consider making the parent provider a permanent option for habilitation services with DDD.
Thank you
Staci Warren

[redacted]

From: Jess Dunn [redacted]
Date: Tuesday, August 15, 2023 at 12:46:17 PM UTC-4
Subject: Parent provider
To: [redacted]

Good morning, I am writing to give my input on the parents as a provider for habilitation. In our experience we cannot find someone to do habilitation or respite, we have people start and they only last for a few weeks and quit. The easiest and most consistent way to get it is to have myself provide habilitation to our son, with the new law that has potential to take parent providers for habilitation away would NOT best suit a lot of families, specifically ours. Our son has come so far while receiving habilitation from me as his provider, his last hab provider did not work on his goals and sat on her phone the whole time. We have found that having multiple people working with our son, myself included has been the best for him and has given him the most success. It causes extreme distress when our son loses a provider(he has lost 4), he gets adjusted and used to them and then they leave and he has full regression, thankfully since starting with me working with him he has successfully mastered 2 goals and we continue to do maintenance on them to ensure they are still functional. I ask that you please keep paying parents as habilitation providers, it has been the biggest blessing to our son and our family. Thank you for your time.

Jessica Dunn

---------- Forwarded message ---------
From: Mary Rihani [redacted]
Date: Tuesday, August 15, 2023 at 12:46:57 PM UTC-4
Subject: Comment on ahcccs waiver proposal change
To: [redacted]

I am writing to strongly disagree with AHCCCs proposal to discontinue the ability for parents to provide habilitation for their own minor children. This would be detrimental to my child and many other children. My child would essentially lose his habilitation services as we cannot fit more third party provided services into our family schedule. This proposal is extremely disappointing. I hope you will reconsider this, and think of all the children that would lose out on services required for their highest potential as a result of this bureaucratic nonsense.

Mary Rihani

[redacted]

---------- Forwarded message ---------
From: Zulema Avis <[redacted]>
Date: Tuesday, August 15, 2023 at 10:30:02 AM UTC-4
Subject: Tesimony by Parent who is a paid provider for my two children
To: [redacted]

Two who it may concern:

I am a parent who has been a paid provider for my two boy's. Since this proposal was implemented.

There are many reasons to why this program has worked in my household. I as the boy's mother and their habilitation provider have made such a big impact. They feel more comfortable working with me. I am able to work with them on their goals during work hours and follow through as a parent. The funds helped with doing more social outings that have increased their engagement with peers and making friends.

When we had previous habilitation provider's our boys were frustrated and there were some goals they would do with the provider. Sometimes there would be meltdowns. Other times the provider was not even reliable when I needed her to be at my home. This was when I asked my Mom to come help me with the boy's. However, this could not last forever. It's very difficult to find that perfect fit for your family.

To give you an example on a goal, that our younger son feels more comfortable with me, than he would with a provider. Goal: His restroom goal, urinating in toilet correctly. He is working on many aspects of this goal. Like time management, wiping himself, he has a phobia of sitting on the toilet; he uses wet wipes instead of toilet paper to wipe himself. He has to make sure that the toilet seat is wiped down before sitting down on the toilet. [redacted] suffers from chronic constipation. There is a process with him. This is not an easy goal to work with. He is about to turn [redacted] and to have someone else guide him on this goal is so private.

Another one of his goal is dressing himself. This goal has to be done in the early morning and again at night. With me as his provider this is also beneficial to him. Because, I can guide and assist him while, working with him on this goal any time.

Both my boys are learning life skills daily. I work with them and have been teaching them how to cook, clean up after themselves, do their laundry, make their beds, clean their room, create a grocery list, go shopping, their daily hygiene regime. I think as a parent, our children benefit leaning these skills from us because they are in their own environment and they are not with strangers.

When I attended one of the forums, I was able to hear from other parents. I heard both sides. I heard from the side from some parents that they needed providers and were not able to find any reliable ones or any at all.

Then I also heard from parents who were just burnt out. That they needed more support. I truly believe that every household has their own individualize needs in their home. I believe that each case should be handled in such matter. But that those parents who can care for their children and have options later if they choose to find a habilitation provider that they can. I understand that this is not for all. In this case for me, being a paid parent provider has worked and benefited both my boys.

I also feel that if there are parents who are both working and need this habilitation services or one parent is working that they can utilize this option that works for their family needs. But why take it away when it clearly working for many families such as mine.

As a parent, I really hope that you consider the many families you would be impacting if this is taken away. As for us, I would have to find another provider. My previous Habilitation provider was my mother. She moved back to Idaho. So finding someone to fill her shoes would not be easy. Honestly. I hope you all make the right decision for the children.

The Avis Family,

Zulema Avis

Attached are some pictures of the life skills the boys are learning.

From: Debbie Dunn <[redacted]>
Date: Tuesday, August 15, 2023 at 12:48:08 PM UTC-4
Subject: Parent Providers
To: [redacted]

To whom it may concern.

I strongly oppose the discontinuation of Parent providers being able to complete Habilitation services for their minor children. in my specific case, We have waited over three years to have respite and habilitation services provided for my twin sons. There are not enough providers to fill the need. Once I as a parent was able to provide the Habilitation services then the need was filled. If you take this service away we will be right back where we started from on a wait list!! That is precious time, my children will NEVER get back. We were assured this program would be available until September of 2024 with a possibility of it being renewed if there was still a need.

I feel strongly that a sudden change in November that no longer allows parents to provide Habilitation would be extremely detrimental for my family as well as many other families and the system of care as a whole. There are currently thousands of parents across the state participating in this program, and it is virtually impossible to replace those services with non-parent providers that quickly. Additionally, being a parent provider significantly benefits my children as my husband and I are a consistent adult in their lives. I can not tell you the amount of change in providers that happens for other services. It would be the same with habilitation as well!! Consistency in the key.

I believe that having a mix of services from parents and non-parents can help create a more consistent approach with improved continuity and flexibility to help meet the child's needs through different stages and transition phases. Therefore, **I support the notion of making Habilitation a permanent option for parents in the new AHCCCS waiver,** in addition to Attendant Care. I am asking that you reconsider and add back in the ability for parents to provide Habilitation services for their minor children! In the long run, we will be saving the state money by teaching our children the skills they need to be as independent as possible in life thus reducing the cost of care as adults.

Thank you,
Debbie Dunn

From: Stephanie Czechowski [redacted]
Date: Tuesday, August 15, 2023 at 12:53:57 PM UTC-4
Subject: Parent providers for DDD habilitation services
To: [redacted]

I want to express the importance of this program and allowing parents to be providers. With so few providers available my son was on the waiting list for services for MONTHS before Covid hit and I was allowed to become his provider. By not allowing parents to be providers many children will miss out on this valuable services and therefore will be let down by DDD. The purpose of DDD is to provide services for disabled children in need and by eliminating parent providers it eliminates a large provider pool and leaves so many children unserviced.

[redacted]

1•1•6 --
"For I am not ashamed of the gospel, because it is the power of God that brings salvation to everyone who believes: first to the Jew, then to the Gentile." (Romans 1:16 NIV)

"Do not be anxious about anything, but in every situation, by prayer and petition, with thanksgiving, present your requests to God. And the peace of God, which transcends all understanding, will guard your hearts and your minds in Christ Jesus." (Philippians 4:6, 7 NIV)

Sent from my iPhone

From: Pamela Molyneaux <[redacted]>
Date: Tuesday, August 15, 2023 at 1:23:26 PM UTC-4
Subject: Family Habitation Program Continues (Please)
To: [redacted]

Hello ,I'm a parent who has been Allowed the Great Opportunity to do Habitation for my son here in Az. This has Worked out Really Well for my son, because he's a Guy with a few Difficult Disabilities to Deal with,that really only a parent can Q in on. Where Redirecting must be Applied quickly Before any Escalations of Melt Downs or Behaviors occurs . Having this better Avenue to work with, my son is Definitely making better Life Skill Achievements . He is becoming a more Productive and Stable person. And this further lead's My Son to a more relaxing Comfortable Life Style. Many Families like Ours have been Blessed to have An Opportunity like This One, to Really help Their family member. Honestly my Son has not had a good Outcome with pretty much any of his Therapist. It was Always Very Heartbreaking to See no Improvements . And we Really see Improvements with him in this program with actual hands on working with my son he has had a better Learning Experience. And I Truly would like to see it become a Continuous Stability for his Growth . For our Family We've seen A Huge Impact for my son's Real Growth and Development. I would ask that you Please Consider this part of the Parent Habitation Program Becoming a Continuous program for Those Parents that Truly Want to Help Their Special Person Be The Rock Star They Really Are
Thank You for This Opportunity

Sincerely

Pamela M.

From: Christine McCollum <[redacted]>
Date: Tuesday, August 15, 2023 at 1:46:37 PM UTC-4
Subject:
To: [redacted]

Please don't take HAB away from us, has parents. We benefit so much with helping our children personally through HAB. Having a stranger help never really worked. They would quit or never show up.

Thank you.

From: rahel tsehaye <[redacted]>
Date: Tuesday, August 15, 2023 at 2:17:56 PM UTC-4
Subject: About the new proposal no HAB
To: [redacted]

Hello, I have a son he is [redacted] years old who is diagnosed with Autism, the new proposal not a parent provider HAB will be difficult for him one of the problems is there are no providers out there it’s very difficult to find someone to work with him specially because he is getting older, if there are more qualified people it would be no problem but there are none or they start to work when they get another job opportunity they leave so I hope it makes sense why I am asking why it’s important that this kids have parents helping them.
Thank you for your understanding!

Sent from Yahoo Mail for iPhone

---------- Forwarded message ---------
From: [redacted]
Date: Tuesday, August 15, 2023 at 3:18:31 PM UTC-4
Subject: Who specifically thought to cut Hab Providers? Stop paying that person.. Re: Arizona 1115 Waiver: Keep Paid Parent Hab Providers!
To: [redacted]

Dear AHCCCS and CMS,

Who specifically suggested that AHCCCS stop paying parents to provide habilitation for their minor children?

Please release this person name (or these people's names).

Ending paid-parent hab is the Worst Idea in the History of Medicaid.

It is terrible and offensive.

AHCCCS knows very well that they pay Too Little for anyone else to Want to provide habilitation for our kids.

AHCCCS and CMS, please Defund the people who thought of this harmful idea. Let them work for nothing on this, then find an outside job to pay their bills.

That's what they expect parent providers to do.

Joanna Galuszka

[redacted]

> On Wednesday, August 9, 2023 at 01:06:05 AM MST, <[redacted]> wrote:
>
> Dear Ms. Heredia and officers at CMS,
>
> I noticed that the latest 1115 waiver proposal asks to keep paying parents to provide ATC (attendant care) to their children who qualify, with a cap of 40 hours per week.
>
> That's great! But what about paid parent providers of Habilitation?
>
> Arizona still suffers from a lack of adequate Direct Care Workers.
>
> Why wouldn't you let parents continue to get paid to provide habilitation services?
>
> Please put paid parent habilitation providers back in the proposal.
>
> We parents are the only ones who are willing to do it.
>
> Sincerely,
>
> Joanna Galuszka
>
>> On Saturday, August 5, 2023 at 12:38:13 AM MST, <[redacted]> wrote:
>>
>> Dear Ms. Heredia and CMS officers,
>>
>> Do you remember the months (possibly years) of ALTCS parents filing Quality of Care complaints about not being able to find suitable habilitation or respite providers?
>>
>> I had a provider quit because I asked him to trim his fingernails, because he'd accidentally scratched my kid.
>> This provider said he didn't get paid enough (to cut his nails).
>>
>> Well, the covid pandemic fixed that problem.
>>
>> No longer did we parents have to deal with high provider turnover, if the providers showed up at all. (Someone could get a job at Starbucks for similar pay.)
>>
>> Now, we the parents are paid to provide habilitation for our kids.
>>
>> DO NOT END THIS AMAZING FIX TO THE ONCE-BROKEN HCBS SYSTEM. We parents are the ONLY ones who are willing to do this work for these modest wages.
>>
>> And these difficulty-of-care payments, modest as they are, have lifted many of these families out of desperation.
>>
>> There is no way I could take care of my kid and work outside the home. Now I can help my kid and receive payments so we can survive.
>>
>> The argument that paid parent habilitation might lead to isolation is pure baloney.
>>
>> You know what leads to isolation? Having questionable candidates come and go every few months. Being too poor to take kids anywhere to socialize. Spending precious time filing Quality of Care

> > Complaints when I could be helping my kid.
> >
> > Please! Keep the paid parent habilitation program. Please! Extend it permanently (or at least as long as possible.)
> >
> > It took a literal plague for this positive change to happen. Please--I don't want to have to wait for another pestilence, or boils or frogs or sick livestock, before I can get my kid the help he needs.
> >
> > Sincerely,
> >
> > Joanna Galuszka
> > [redacted]
> >
> > > On Thursday, February 18, 2021 at 09:17:47 AM MST, <[redacted]> wrote:
> > >
> > > Dear Officials at U.S. Department of Health and Human Services,
> > >
> > > The Covid-19 pandemic has led to a hallelujah moment for Arizona parents of children with developmental disabilities.
> > >
> > > Your department enabled Arizona's Medicaid program, AHCCCS, to pay parents to provide habilitation (HCBS) services to their own children.
> > >
> > > Please, for the love of all that is holy and good: Keep This Change, Even After the Pandemic Ceases!
> > >
> > > You have inadvertently Solved the hab-provider crisis. Before the pandemic, it was next to impossible to find a high-quality, long-term habilitation provider. The pay was low and the turnover was high.
> > >
> > > But we parents? We Love our kids and we'll do anything for them. Letting us get paid to provide our kids' habilitation is a Win-Win-Win!
> > >
> > > I am grateful for the pandemic for inspiring this idea. It's the best idea someone ever had.
> > >
> > > Please. Keep the change.
> > >
> > > Thank you,
> > >
> > > Joanna Galuszka
> > > [redacted]
> > >
> > > > [redacted] Forwarded Message -----
> > > > **From:** [redacted]
> > > > [redacted]

Sent: Saturday, December 26, 2020, 10:30:13 PM MST
Subject: Best Change from Covid 19: Please Keep Parents as Habilitation Providers

Mr. Wisehart and Mr. Garcia Ramadan,

The Covid-19 pandemic has led to a hallelujah moment for the Division of Developmental Disabilities: DDD has finally allowed parents to get paid to provide habilitation services for their eligible kids.

Please, for the love of all that is holy and good: Keep This Change, Even After the Pandemic Ceases!

You have inadvertently Solved the hab-provider crisis. Before the pandemic, it was next to impossible to find a high-quality, long-term habilitation provider. The pay was low and the turnover was high.

But we parents? We Love our kids and we'll do anything for them. Letting us get paid to provide our kids' habilitation is a Win-Win-Win!

I am grateful for the pandemic for inspiring this idea. It's the best idea someone ever had.

Please. Keep the change.

Thank you,

Joanna Galuszka
Parent of a Special-Needs Child

From: Valerie Johnson <[redacted]>
Date: Tuesday, August 15, 2023 at 5:02:04 PM UTC-4
Subject: Proposed changes to patwnt providers.
To: [redacted]

Good afternoon ,
I am a parent of a special needs son who receives habitation and attendant care from an agency. I use both myself and another provider to help move my son forward in life. With out the flexibility of having both types of paid providers I feel my son would regress.

Sincerely,
Valerie Johnson

[redacted]

---------- Forwarded message ---------
From: Amy Staren <[redacted]>
Date: Tuesday, August 15, 2023 at 6:03:08 PM UTC-4
Subject: Paid Parent Caregiver Program Feedback
To: [redacted]

Dear AHCCCS and 1115 Waiver Team,

As a parent of a child who receives DDD and ALTCS services I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility, and it has been **extremely** beneficial to our family and my child. I would like to share my personal experiences and feedback based on my review of the current proposal for a permanent Paid Parent Caregiver program.

Under the current proposal, the request of an ongoing program option which allows parents of disabled minors in Arizona to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies is not being met. Please consider updating the proposal based on the following questions, suggested solutions, and personal experiences.

Previously, I had not been able to find any Direct Care Workers for my children's habilitation needs despite numerous calls out and even calling agencies myself. To find someone that I would actually trust with my children as well as be reliable and actually effective in their role for habilitation had been like finding a needle in a haystack. I eventually just stopped trying because it was clear that there were simply not enough Habilitation workers, much less any actual quality Habilitation workers out there to meet the needs. Therefore, when the Paid Parent Caregivers Program came out, I was thrilled to be able to provide additional financial support for my family because of course as a special needs parent, there is no shortage of the never-ending medical bills to contend with. My kids still participated in plenty of school, community and family activities, which ensured there was no reason to worry about isolation or loneliness. The extra funds also eased the burden on my husband as the previous sole provider of the family because with our kids having so many constant issues, appointments, sicknesses, etc. it became clear that to have the best family setup given our children's issues, one of us had to stay home to take care of them, take them to all their therapies, doctor visits and surgeries, be ready to get them whenever they got sick and work with them on their goals, skills and behaviors, etc. Thus, getting paid to do habilitation work with my kids had an entire domino effect because my husband wasn't as stressed about our finances, which in turn, made everyone else in the house less stressed, moody and impatient. It's truly been a blessing for our family and thousands of others, which when you unfortunately have to deal with all the hardships that we do, is a rare thing to say.

Being a parent of 2 special needs children is hard enough so to take away this program and replace it with a program where there is either no available Direct Care Workers or the Direct Care Workers that actually might be available aren't reliable, trustworthy, patient or knowledgable enough to do the work that I have to do anyways simply doesn't make sense - especially when so many other families feel the same way. To also put a 40 hour a week cap on the services doesn't make sense either if you have a child that isn't in school or has a similar situation where they are being taken care of at home the majority of the time. That is why I would like to provide some additional thoughts on my 2 biggest concerns with the latest proposal.

Should Habilitation be included in the Paid Parent Caregiver Program?
We have heard the concerns about member isolation and lack of community involvement if parents continue as Paid Parent Caregivers facilitating their child's Habilitation services. Respectfully the parent caregiver community proposes the following solutions:

1. Examine available research and personal feedback statements from members and their families to evaluate the true potential impacts of social isolation and community involvement when parents of disabled children provide Habilitation services. The parent caregiver community's collective experience is that members who have parents facilitating their Attendant Care and Habilitation services have experienced greater member social engagement and community involvement over the last three years. Parent caregivers now have an increased ability to take their children to sporting team practices, community events, movie theaters, all ability parks, church activities and libraries. This is because parent providers can perform the appropriately trained and qualified supports in the correct time and location that is applicable to each member.

2. Implement precise guidelines to facilitate generalization for all Habilitation providers regardless of the DCW's familial status. Habilitation services are designed to have goals where data is collected to evaluate if those goals need to be changed, have been met, or need to be addressed differently. For a goal to be considered met, a member should be demonstrating that they are able to successfully meet that goal outside of the timeframe with a provider in one setting. This is referred to as generalization. The effective implementation of generalization with the pediatric IDD population would lessen, if not eliminate, any complications with adult transitional services. Under this model a program that includes parents as paid Habilitation providers would actually assist and improve in the success of adult transition. There are times when disabled children work successfully with different types of providers in clinics or schools, but the parents are not carrying the work over at home. This can happen for a variety of reasons. Having parents as Habilitation providers would help ensure the child's goals are congruent and carried over in the home and community setting. This will give the member a better chance of independence as they transition through different life stages. With generalization policies in place, Habilitation services being performed by parent providers will actually help facilitate successful transition into adulthood.

3. We know from provider agency data that "the top 3 issues regarding recruiting and retaining career non-family caregivers are schedules of the client members, interest in the position and finding qualified applicants." Most members have Habilitation goals and ADLs that are most appropriately delivered throughout the natural routine of their day. A parent provider is uniquely available in the morning, after school or in the evenings when each member is motivated and focused on the pertinent task. If a non-family provider is available their schedules typically allow them to work in longer time chunks that are not always the most ideal for the member and creates artificial goal or ADL practice. Continuity of care and greater member outcomes can be associated with consistently provided Habilitation care by parent providers who have the greatest ability to be flexible and available for their member children.

Should parent providers be limited to 40 hours a week of paid care per child?
We have heard the concerns of AHCCCS regarding the potential for a difficult adult transition to non-family supports once parent caregivers are no longer able or willing to help facilitate the disabled member's care. The parent caregiver community would like to propose the following collaborative solution to create a win-win scenario:

1. Create a program provision that outlines an extraordinary circumstances clause and the application process that allows parents to provide over 40 hours of paid care per week of authorized and evaluated services per member. These extraordinary circumstances could include, but are not limited to:
    a. The lack of a non-parent DCW being available in the last 3 months to fill the member's

    assessed hours that exceed 40 hours per week. Ongoing DCW searches should continue to be made by the member's agency to fill the assessed hours beyond 40 hours per week of Attendant Care and Habilitation.

   b. The expressed desire made by a member for a parent caregiver to facilitate their assessed DCW hours so that their Article 9 rights are honored.

   c. The profound disabilities and/or significant behaviors of a member where a non-family provider is not equipped to provide DCW support. This determination can be made through a stakeholder team approach, including but not limited to the member's, DDD Support Coordinator, DDD Nurse, DDD Supervisors, Behavioral Plan Experts, Parents / Guardians, Psychologist, or Medical Doctor.

2. Form equality between all Family Provider Programs by allowing all Direct Care Workers, regardless of familial relationship or member age, to provide up to 16 hours of paid care per day. This will allow for employee equality across the lifespan of the member and limit the potential anti-family provider rhetoric currently present within state policies and DDD Support Coordination culture. All evaluations of hours should be based on member needs regardless of who is providing the services to create uniform implementation of all applicable HCBS services by the DCWs available to fulfill those hours.

3. The Family Support Program currently in this proposal addresses caregiver burnout. It is one of the available solutions to facilitate further community support within the disability and caregiver community that will provide greater access to non-profits facilitating counseling services, support groups and meet up activities.

4. Reevaluate Respite reimbursement rates to also address caregiver burnout. If Respite services are not available to the member or their family, parent burnout will continue to be an issue regardless of parents having the option of providing Attendant Care or Habilitation hours. With a comprehensive Paid Parent Caregiver Program in place non-family DCW providers will have greater flexibility to provide Respite services to these same families.

How should current evaluation protocols, training and practices be updated to facilitate equality for all members when accessing member needs?
AHCCCS has stated their intention to amend applicable policy, further suggested action on this topic includes:

1. Forming a committee of community and department stakeholders to amend and critique current DDD and AHCCCS policies and need assessment forms so that the most effective and efficient implementation of this permanent option is utilized moving forward.

2. Provide appropriately determined training and program implementation to DDD and ALTCS Support Coordinators so that Attendant Care and Habilitation hours are equitably evaluated based on the member's needs and to remove organizational bias of familial providers across the member's lifespan. Specifically investigate and determine appropriate DDD staffing needs and training for the members served in rural areas and those from minority backgrounds.

3. Create the option for private sector Support Coordination. Other states have this option within their Medicaid services, and this could be an additional feature in our DDD portfolio to allow for the member's needs to be best evaluated.

In conclusion, Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. By not allowing parents of minors to provide

Habilitation and Attendant Care services or work over 40 hours a week most of the minor disabled community in Arizona will be underserved. A comprehensive Paid Parent Caregiver program validates the irreplaceable work that parents provide in their homes and communities.

Click here to connect with the Arizona parent led grassroot initiative leaders:
www.raisingvoicescoalition.com

Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves all DDD and ALTCS members in Arizona.

Thank you!

CMS perspective on the above noted requested program adjustments and paying Legally Responsible Individuals:

June 28, 2023 - Email Correspondence between CMS and Raising Voices Coalition:
https://drive.google.com/file/d/10CPccmIY7gEr5vq9C6vIaKmncSQOV7kc/view?usp=share_link

May 23, 2023 - Transcription of National Meeting between CMS Leaders and Parent Advocates:
https://docs.google.com/document/d/1h02v6Yk7frWGADcqKgm1zmd0uquMNfW3Jcd0zjHCxOk/mobilebasic?fbclid=IwAR2QLqbwJMQQRz0nj-XqhYzlFlkQbUV5wnyAyv98hivRVYpCjaYHhLBCzYg

Studies and data that support the changes being requested:

Data results from a 2023 Arizona survey of parents who have children with disabilities:
https://docs.google.com/document/d/16PZOk99caDUitg0XmQKqEv2mxXOBeaRywSD_zmjAnYw/edit?usp=sharing

A report on the current caregiver crisis by the National Association of Homecare and Hospice:
https://www.hcaoa.org/uploads/1/3/3/0/133041104/workforce_report_and_call_to_action_final_03272023.pdf

Higher satisfaction of paid supports for adults and minors with disabilities when care is received from paid family providers:
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1089106/

A comparison of healthcare utilization when children receive paid care by a family member vs non-family provider: .https://www.jpeds.com/article/S0022-3476(23)00106-3/fulltext

Youth with Autism Spectrum Disorder have less ED visits and patient outcomes when patient providers are involved: https://www.reliasmedia.com/articles/148366-autism-spectrum-disorder-in-the-emergency-department
https://www.psychiatrist.com/jcp/mental/child/youth-with-autism-in-the-emergency-department/

An evaluation of parent provider involvement in generalization of children with autism:
https://www.sciencedirect.com/.../abs/pii/S0891422205000958

Impacts of the caregiving relationship: https://academic.oup.com/gerontologist/article/56/6/1102/2952858

State Approaches to Reimbursing Family Caregivers of Children and Youth with Special Health Care Needs through Medicaid - NASHP
https://drive.google.com/file/d/1TSt-Rj95DTn711EV8UTq7YqF0yoo0j8u/view?usp=sharing

From: Grace <[redacted]>
Date: Tuesday, August 15, 2023 at 4:37:09 PM UTC-4
Subject: Upcoming proposal comments and concerns
To: [redacted]

To whom this may concern,

The upcoming proposal for changes to the current parent provider program would be extremely detrimental for many families and the system of care as a whole. Our children and the program has benefit from parents being able to provide habilitation services as we know our children best. The outcomes have shown success and access to services for many children that would not otherwise have Habilitation services. These changes would cause unsurmountable regression for many children in the program that have made great strides. Realistically the state would not be able to employ thousands of qualified habilitation providers to provide services therefor our children would suffer greatly from not having services available with such a drastic change. Parents, agencies, and the public were assured this program would remain intact at least until November 2024, if not making it permanent. The state, agencies,and communities are not adequately prepared for such a drastic change and our children that desperately need ongoing support would ultimately suffer from an irresponsible abrupt change to services.

Please put our children’s health and well being at the forefront of these upcoming decisions. Our children deserve to be seen and heard in every decision regarding services.

Respectfully,
Grace Blaser

From: Julie Hahn <[redacted]>
Date: Tuesday, August 15, 2023 at 6:11:01 PM UTC-4
Subject: Keep paid parent provider
To: [redacted]

The gratefulness our family feels for the advancements our severely Autistic twins have made with me as a paid provider is astonishing. It's in the best interest of the children that parents would continue to be their hab providers as consistently is required. When in the past we had outside providers they wouldn't show up or they would be late or be unprofessional, which causes the goals to become more difficult to achieve, thus causes more issues within the home. If your goal is to help these special needs children then the best option is to continue parent provider programs.
Thank you for your time and consideration,
A concerned Mom

From: Jenny Mullins [redacted]
Date: Tuesday, August 15, 2023 at 8:15:42 PM UTC-4
Subject: Fwd: Important Update for Parent Providers
To: [redacted]

Hello,

I wanted to share this public statement from AZA United in support of parents as paid habilitation providers and the reasons that they support this change to the proposal.

Thank you!

---------- Forwarded message ---------
From: **AZA United** [redacted]
Date: Tue, Aug 15, 2023 at 9:03 AM
Subject: Important Update for Parent Providers
To: [redacted]

Proposed Changes for Parent Providers

As you may have heard, AHCCCS has proposed a significant change to the Parent Provider program. The purpose of this email is to share updated information about that proposal along with resources in case you would like to communicate your suggestions to AHCCCS.

Previously, it was announced that the current program allowing parents of minors to provide Habilitation & Attendant Care services for their own child will continue through September 2024. AZA United has planned accordingly and assumed there would be no changes for about another year. AHCCCS intended to use funding from the American Rescue Plan Act (ARPA) to support the program through that time period.

Recently, AHCCCS announced that its federal waiver (which allows Arizona to receive Medicaid funds for DDD & behavioral health services) needs to be renewed in November of this year. The waiver essentially establishes what services Arizona can include in our state Medicaid program, which funds DDD & AHCCCS services. With a new waiver, there is an opportunity to make the Parent Provider program a permanent part of our state system. However, the proposal that AHCCCS published has some changes from the way the program is today.

The biggest change is that, under this draft proposal, parents would no longer be able to provide Habilitation services for their own minor children. Attendant Care would be allowed, up to a maximum of 40 hours per week for the child. Any additional hours would need to be from a non-parent provider.

It is important to know that this is only a DRAFT proposal. AHCCCS is currently accepting public

comments, which means you can contribute your opinion and suggestions via email or regular mail (see Resources section below). The public comment period ends on August 21, 2023.

Our Position:

AZA United supports continuation of the current Parent Provider program, at least through September 2024 as AHCCCS and DDD had previously assured us. We feel strongly that a sudden change in November that no longer allows parents to provide Habilitation would be extremely detrimental for many families and the system of care as a whole. There are currently thousands of parents across the state participating in this program, and it is virtually impossible to replace those services with non-parent providers that quickly. Additionally, we have collectively observed the significant benefits that this program offers children when parents can participate in services if that is what they feel is best for their child.

We believe that having a mix of services from parents and non-parents can help create a more consistent approach with improved continuity and flexibility to help meet the child's needs through different stages and transition phases. Therefore, we support the notion of making Habilitation a permanent option for parents in the new AHCCCS waiver, in addition to Attendant Care. We hope to participate in any future policy discussions that may determine any limits regarding the amount of service hours that parents can provide, as well as any other new requirements that seek to ensure that these services are as or more impactful as they would be if done by a non-parent provider.

Resources:

This website has all of the information about the draft proposal from AHCCCS:
https://www.azahcccs.gov/Resources/Federal/PendingWaivers/ParentCareGivers.html

You can read the actual waiver amendment proposal here:
https://www.azahcccs.gov/Resources/Downloads/Federal/ParentsAsPaidCaregivers-AZ1115WaiverAmendmentDraft.pdf

To submit your own public comments, send an email to:
[redacted]

[redacted]

---------- Forwarded message ---------
From: Jenny Mullins <[redacted]>
Date: Tuesday, August 15, 2023 at 8:18:58 PM UTC-4
Subject:
To: [redacted]

To Whom It May Concern,

Thank you so much for listening to the perspectives and voices of parents and their children with disabilities.

1. AHCCCS has shared a few pieces of data with Raising Voices Coalition regarding their viewpoint and reasons for their program restrictions. Additionally on their Aug. 2nd Public Forum they shared some preliminary data that shows how many parent DCW's are employed and non parent DCW's are employed. Agencies and Raising Voices Coalition are skeptical of the validity of the data collected by AHCCCS and presented on Aug. 2, 2023. You can review these research papers and data and then express to AHCCCS how your experience and your child's experience with parent providers differs from what they have shown and researched.
    a. Vulnerability to Loneliness in People with Intellectual Disability
    b. Relational Fragility and the Isolational Trajectory in the Latter Stages of Life
    c. Effects of Social Isolation and Loneliness in Children with Neurodevelopmental Disabilities
    d. August 2, 2023 Parents as Paid Caregivers Waiver Amendment Proposal Presentation with Data
2. Caregiver Burnout - Please specify to AHCCCS what items (i.e. Respite, Therapy and/or Cleaning Services) that would better support you with Caregiver Burnout. Also share with AHCCCS how the restrictive provisions they are proposing will not improve Caregiver Burnout, but make it worse.

    You can also reference the Raising Voices Coalition Data in your reply as it shows true figures regarding caregiver stress levels.
3. Social Isolation - Share with AHCCCS how your child has experienced Social Isolation and what aspects contribute to social isolation to your child? Does having a parent as a paid provider contribute or prevent social isolation for your child? How?
4. Community Involvement - Share with AHCCCS how your child has experienced Community Involvement with typical providers and what aspects of having a paid parent provider assists your child with disabilities in having a greater amount of community involvement.

Thanks again!
Jenny Mullins
[redacted]

[redacted]

From: Genoveva Salas [redacted]
Date: Tuesday, August 15, 2023 at 9:18:12 PM UTC-4
Subject:
To: [redacted]

Buenas tardes soy madre de hijos con nesesidades especiales yo estoy asiendo el trabajo de habilitación para mi hijo nos acaban de informar que accces ya no quiere que nosotros los padres lo realicemos les pido que no nos quiten esa oportunidad de trabajar con nuestros propios hijos para mi es muy difícil de encontrar probedores para mi hijo y ya que tengo hijos con incapacidades no puedo salir a trabajar en otro lugar y es por eso que les pido si nos pueden dejar seguir realizando este trabajo con nuestros hijos si ustedes piensan que no lo asemos correctamente nos pueden desir que más podemos aser para mejorar y asi mantener el trabajo por favor no nos quites este trabajo los padres somos quien mejor puede realizar este trabajo porque es para nuestros hijos lo asemos con amor pasencia y mucho cariño mi hijo no quiere que lo yeve ala peluquería a cortarse el pelo y l barba el solo quiere que yo lo aga le gusta mucho cuando le corto sus uñas y muchisimas cosas que nomas quiere que su mama las aga

From: Elana Campbell <[redacted]>
Date: Wednesday, August 16, 2023 at 2:09:01 PM UTC-4
Subject: Comments on new proposal from AHCCCS (PPCG)
To: [redacted]

To whom it may concern,

As a parent of a minor who provides habilitation services to my son with autism, the PPCG program has been an invaluable lifeline to parents who are able to actively engage with their child's development and progress to desired independence and mastery of essential skills. Finding a hab worker is incredibly difficult and I have heard from other parents how rewarding and critical it has been to receive payment as a parent for this program. It has also been highlighted in many articles that trying to hold down employment and take care of a special needs child adds a tremendous amount of stress in comparison to other parents with typical children. Allowing parents to receive payment for caring for their child and more importantly providing habilitation services to help their child develop skills to independence is priceless. My hope is that the program for parents to provide hab care to their own minor children is a permanent program for the State.

Thank you,

Elana

Elana Campbell

From: sgartland11@gmail.com <[redacted]>
Date: Wednesday, August 16, 2023 at 2:54:20 PM UTC-4
Subject: Parent providers
To: [redacted]

To whom it may concern,

I wanted to send an email to contribute to the movement involving keeping parents employed as parent providers for attendant and habilitation care.
Any parent of a significantly impaired child can truly understand how incredibly difficult it is to find good providers that are equipped to help our kids. My child is autistic, but he also has pica. He is an absolute danger to himself if he is ever left unattended for any small increment of time. He was diagnosed when he was 11 months old in August 2020, and since then I have not been able to go back to work, and our family absolutely needs to be a two income household.

Simply assigning us more hours for providers is not sufficient. As it is, the attendant providers are only being paid $21 an hour. That’s comparable with many fast food, companies, which is completely unacceptable. If you are going to eliminate us as providers, then the existing non-parent providers need to be given a significant raise. The current pay being offered is not adequate to attract fully qualified individuals to this field.

One or the other are the only viable options, if the goal is truly to help our special needs children. The current pay scale needs to be significantly raised, or parents need to be kept on as providers to help minimize the financial strain of having a special needs child.

Thank you for your time and consideration

Sarah Gartland

Sent from my iPhone

---------- Forwarded message ---------
From: Angela Johnson <[redacted]>
Date: Wednesday, August 16, 2023 at 3:06:55 PM UTC-4
Subject: 1115 Waiver
To: [redacted]

Dear AHCCCS and 1115 Waiver Team,

I attended the July 18th and August 2nd public forums and am extremely disappointed and concerned to learn that AHCCCS is not planning to include Habilitation in their permanent parent provider program.

Currently, I am the Habilitation provider for my three disabled children. This program has been life changing for them and they've actually made huge strides in their goals (which wasn't happening before these flexibilities even when working with ABA providers or other DCWs). If Habilitation isn't included in the new permanent program, my children will likely go without Habilitation services. Prior to the flexibilities, my children were not able to do Habilitation because we couldn't find providers. I know you've thrown around ideas to recruit more DCWs, but it is just NOT realistic to think you can hire enough DCWs to replace parent providers. The past challenges with hiring providers and the past challenges with turnover of these providers have not gone away…there is a HUGE shortage currently of DCWs even with parents being able to do Habilitation.

I know one of your concerns about including Habilitation was member isolation. My children are anything but isolated. They are out in their community all week long…with school, therapy appointments, park play dates, shopping, etc. My children work with and learn from others all day long. In fact, when they are home, they are maxed out on outsiders and don't like visitors because they've spent their day coping and regulating through all of the interactions they've had. Because of this, having a "stranger" DCW come in to work with them is absolutely going to impact their experiences and gains at school and their stamina for time in the community with our family. They will burn out because they are not comfortable having someone they don't know working with them on self care and other Habilitation goals in our home. When we're spending time in the community, I want it to be beneficial and quality time focused so that they're successful, I do NOT want it to be quantity focused (which is counter-productive and what it sounds like AHCCCS is striving for). Quality time in the community is much more beneficial for the disabled community than quantity of time.

If Habilitation is not included in your permanent parent provider program, it will cause more stress and burnout in our home. I will need to find employment outside of the home (with inflation, we are no longer able to afford for me to stay home) which will make continuing to work on my children's goals extremely difficult. Because of the shortage of DCWs, I will be forced to continue to work on my children's goals as best as I can but with much less time and energy. As with any child with a disability, learning new skills is very hard and time consuming for my children. It takes hours and hours over the course of months to make even small progress on a goal or skill. Because they will have limited time with me, they will regress in their skills that they've been making so much progress on during this flexibility. My goal for my children is for them to learn and grow as much as possible during their childhood so that they will need less help as they get older. Without having a parent provider or because of the horrible DCW turnover/shortage, they will receive less opportunities to learn and grow which will increase their needs as adults.

I urge you to please include Habilitation in your permanent provider program that you are submitting. The minor disabled community in Arizona is relying on you so that they can be successful and be able to utilize the services that they need and qualified for.

Thank you for your time.

Angela

From: **Jennifer Garcia** [redacted]
Date: Wed, Aug 9, 2023 at 1:41 PM
Subject: File a Grievance in regard t Paid Parent Caregivers
To: [redacted]

To Whom it May Concern:

I am the mother of a child who receives DDD and ALTCS services. I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which will go into effect November 2023, my son and many more like them will lose access to their Habilitation services or more than 40 hours a week of care by parent providers of minor members. The reason my son will not have access to their appropriately evaluated services is due to the DCW shortage. My agency has specifically stated that they will not be able to recruit, hire, and train enough providers to fill the gaps in service these new rules will create. The did not have enough providers before the pandemic and we all know that the work force has not and may never recover. By being a paid Parent Caregiver I am able to work through our habilitation with consistency and success. This will all come to a halt if they do not include HAB to continue (as well as ATC)in the proposal that has been drafted. Also I am aware that other states already have these programs in affect and if they can get approval from the federal government and laws that surround this why can't we? My sons quality of services will not be satisfactory with out this and it is my understanding that is one of your goals with this proposal.

Thank you for your time, I would like to request a TICKET NUMBER and a return phone call to address this grievance.
Sincerely,
Jennifer Garcia

From: Arianna Mitchell <[redacted]>
Date: Wednesday, August 9, 2023 at 6:29:52 PM UTC-4
Subject: Consumer Comment.
To: [redacted]

Hello I just want to add as a parent who has provided habilitation since a little after covid happened, if I was not able to work with one of children I would not have known how far behind she was with alot of different aspects especially with learning.

Alot of these companies and school districts are nor honest about our children's progress and need. My child's needs have not been met this entire time of receiving ALTCS and DDD services. If we, as parents, are not able to have the availability to help our children due to life's demands and living expenses, we don't have opportunities for that same amount of time for our children.

Supplementing support for parents to work with their children is a very needed service that the state of arizona should not even be suggesting to remove. If the percentage it so small for parents who are providing the services I'm not quiet sure why habilitation is being a service opted to be stopped. While attendant care is still willing to be provided by family members.

The reason in the AHCCCS zoom meeting behind this suggestion was due to a lack of socialization for children with habilitation being provided. While I find that highly improbable and no evidence to make these claims exist, I find that habilitation is done outside of hours that children have to coexist with other children and people in the world. Habilitation hours are very short-term in my childs case. As part time work. 1 to 4 hours max a day is whats allowed to be billed. So I dont understand out of a 24 hours day how habilitation is causing decreased socialization. Especially when services are benefiting a child and being provided by the people who know that child best. Not just doing the service because we were hired to do so and write it on paper as documentation for the state, but because we can afford to provide the service by being paid to do so.

Ahcccs should focus on where and how dollars are being spent through DDD/ALCTS and their vendors first and foremost. DDD has not provided my child with a caseworker who has completed anything in the DDD Ahcccs manual besides vendor calling. DDD never attended a

IEP meeting, never made sure the medications my child was taking was the correct prescription need, never help get the state board of education involved for my child when I was fighting the school system. DDD never did anything with my complaints I submitted to their customer service email, the governor's office, the supervisors of the caseworker, no one ever did anything to have policy enforced by DDD.

When reading the entire 826 pages of the DDD ahcccs policy I was made aware of how under serviced my child really was. If you want to take the dollars away from parent to have a "family support" in place that's optional then you should be mandating the job necessities of the program you are given it to. Taken complaints seriously and listening to the feedback that you are receiving. This program is by far the worst management I've ever seen. And I know this is more off subject of why we should keep habilitation for parents to work with their children, however making the people in charge of ahcccs decisions aware of the issues with the contractors in place, also plays a role in our needed being. Something else should be done with the funding that you are trying to take away from our families. To which have been services us and our children's needs two fold for two plus years now.

I don't understand how taking funds from parents providing any type of service is harming or misusing federal dollars. When in fact the system in place already has caused this issue and made special needs children the last priority in this system being ran by AHCCCS.

Ddd does not help with issues of providers and consistency. None of you can have children within the altcs system or you wouldn't even be suggesting this as a option. And if you do have children under this system having any service provided why are you not standing up and speaking for these disabled children? Why are you not at board meeting raising your voice about the discrimination and despicable caseworker we have for our children?

Whatever ahcccs decides to propose to the federal government only the minimum will only be completed by the states program in Arizona. Which leads me to ask exactly where you all are trying to tie funding to.

Attendant care is a more hourly needed service to which should definitely help families and children. I definitely say if a incapacitated child or adult is in needed of someone to care for them around the clock why not have family or parents do that service. The services are being provided, money is being made to support that service and then the funds are being allowed to help the family in a circle. It's definitely unharmful and not misful. So why would habilitation be?

For instance in my situation I have multiple children with disabilities and only two of which can qualify for DDD altcs services. However that does not stop a parent like me from having multiple appointments for those other children. It doesn't stop me from having to work part time to take care of the responsibilities that the state can't help with. It doesn't stop me from having to attend speciality clinics for those children. And honestly the only benefit that has been a good help is the home therapy session. When they do happen. If you all want to take money from the families that have been using and depending on it then you should be making sure it's going to a place that like the FBI in a sense. A contractor that will over look the services that are not being providing in the appropriate manner for all special needs children and adults. If our child needs speech two times a week and doesn't have it over a month and vendor calls have been placed, then action aganist that program should be happening with those dollars. Services should not be provided the sporadic way they are and tax dollars including being paid by my self, are being used on those half done services.

Honestly that's what I would love to see happen if you take the small percentage of funds away from families for habilitation then place thise funds to a agency not facilitated by this states regimen and provide it to a agency that would not be compromised to enforce the laws and policy in place for these children and their needed services which are not being provided especially in rural areas. In my case buckeye arizona. No one comes this way and if someone does work this way it's not for long term as it is supposed to be.

This system has failed our special children enough and the actions you all are taking at the moment are causing more of that to happen. Funding should be placed in a needed area if it's going to be disbursed in a different manner. That should be the biggest focus of where and how it will be used to create the best outcome for the public who is using the service. Not the state to mis use them and possibly use them for "family support" if they want it as a resource. Put the dollars where they need to be going. To our children and their educational and therapeutic needs.

Dear AHCCCS, 1115 Waiver Team, and anyone else this may concern:

Thank you for this opportunity to provide my input and experience, and thank you for your time and consideration as you read this. The paid parent caregiver program under the COVID-19 flexibility has made a very significant and positive impact on my family and I's life. I am a parent to three children, two of whom have received DDD and ALTCS services since 2017 and 2019. I am asking you to please consider making the parent provider program permanent, including allowing parents of minor children to provide habilitation and attendant care. I am also asking that you remove the 40 hour week limit for parents of minor children. I would also like to request additional training for frontline AHCCCS/DDD employees to prevent discrimination and ensure DDD/ALTCS members are receiving quality services in a timely manner.

As a parent, I loved the description of the habilitation program: A qualified, trained professional to work with my kids one-on-one on specific goals tailored to their needs that help promote communication, safety, and independence. 2017-2021 we kept trying to make this program work for our children and family because doctors, therapists, teachers, and other parents would encourage us to hope for the "right" provider. We were immediately cautioned about the massive provider shortage and strongly encouraged to enlist the help of family and friends to fulfill the role of habilitation and/or respite care. This program pre-COVID was such a major source of stress for my family and I, that if the parent provider program reverts back to what it was originally, we will be forced to have our children cease participation in the habilitation program.

2017-2021 Our experience with habilitation is as follows:

- 2017-2021 we went through more than a dozen habilitation providers. Providers worked anywhere from 4 hours up to 6 months, the majority working only 2-4 weeks.
- Providers were allowed to begin working in my home, with my minor disabled child(ren) without obtaining all of their certifications. We learned that they were given a grace period of 30-90 days to obtain certifications. This is not safe.
- Providers frequently called off, often at the last minute. There were frequent no-call/no-shows, no backup providers, late arrivals, leaving early. Providers would keep inconsistent schedules from week to week and often made schedule changes with little to no regard for my child(ren)'s schedules or needs.
- Majority of the providers were either undertrained or uncomfortable with tasks involving eloping, close supervision, diaper changes, or toileting. This meant that I needed to be available 30-40 hours per week during shifts, at all times, to ensure ALL of my child's needs were being met, including safety needs. Due to this I was unable to obtain employment, utilize my college degree, attend to my healthcare needs, or practice self-care. We turned down countless invitations to gatherings and play dates due to these issues. We did attempt community outings where possible with some

providers, but every provider allowed my child to elope or engage in unsafe activity because they were unable to provide the level of supervision or care my child needed. I also needed to wait until their shift was over to do the most BASIC tasks like running errands, getting gas, or groceries. This was more of a burden to us because there are simply not enough hours in the day to accommodate another person's inconsistent schedule and inability to perform all of their job duties, in addition to daily living tasks.

- Many providers did not know what my child(ren)'s goals were. I never saw data reflecting any progress in goals. Many providers lacked initiative when it came to requesting additional training from supervisors. Providers would ask me to help them come up with activities to do. Many of them genuinely did not understand their job duties. Again, this resulted in my often essentially doing the job for them— while they were paid to do it and I was not. This feels like borderline fraud.
- Some providers crossed major ethical, privacy and safety boundaries by doing things like taking photos of our children and/or home without our knowledge or consent, nitpicking the décor and cleanliness of our home, criticizing my weight and appearance, filing a false DCS report, posting about us on social media, announcing my child's diagnosis in public, and more.
- Providers also had a lot of audacity and lacked tact when they felt it appropriate to criticize and nitpick the cleanliness and décor of my home, my weight, my appearance, my parenting, and more. I constantly felt compelled to clean and organize my home, which took away time from my children that I will never be able to get back. My self-esteem and self-confidence took a huge hit. I was inpatient psych in early 2021 due to depression, anxiety, and feelings of isolation, and burnout. My experience with habilitation in these four years very much contributed to this burnout.
- Prior to my second child's diagnosis, many providers behaved as though my toddler was being nothing more than a nuisance. They would treat my child as if she were a burden in her own home. Out of more than a dozen providers, only one ever thought to encourage my oldest to interact and engage with his sibling while working on goals. This had such a negative impact on my child's self-esteem at such a critical age in early childhood development and I believe that it contributed to my child's anxiety.
- Providers would refer to themselves as my child's friend. Providers lasted anywhere from 4 hours to 6 months, but most averaged 2-4 weeks. How do you explain to a young child that their "friend" disappeared without notice? Or that their "friend" canceled last minute, again?
- One agency supervisor would utilize intimidation tactics and Facebook stalking in order to discourage quality of care complaints being filed. An agency hiring manager failed to conduct background checks on providers and made racist and bigoted comments about providers. When I learned of this egregious behavior, I obviously switched agencies. This is not the norm for agency supervisors and administration, thankfully. However, the

issues with habilitation providers being undertrained, underqualified, and inconsistent was always the same with each company we tried.

One of my favorite advocates with the Autism Society of Greater Phoenix says "children learn best from those who love them." I first heard this years ago and it was so empowering then and still holds true today. I am a trained and qualified parent habilitation provider. I also hold a bachelor's degree in social work. As their parent, I have gone above and beyond for my children from day one, including working to address issues around isolation. As people with disabilities, my children are constantly running into issues—such as separation from their peers, being sent to self contained classrooms, being denied paras, being denied access to least restrictive environments in school, not being allowed to participate in activities because no one will provide accommodations—in a multitude of settings including schools, in public areas, etc. Even a simple trip to the grocery store, restaurant, movie, etc. is almost always met with people staring at them, getting frustrated with them, ignoring them, and it is frustrating to witness this unfold. I find it interesting that stakeholders are only just now concerned about DDD members feeling isolated when this has been a painfully ongoing issue for many years. I would love to see DDD/ALTCS mitigate feelings of isolation by addressing the real systemic issues around what contributes to it, because I can almost guarantee it is not parents providing habilitation services being the cause of this.

This program flexibility saved my life. In the fall of 2021, I became a parent provider and felt a lot more respected and valued as an important member of my kids' team. The agency that hired me has been an invaluable resource and genuinely wants my family and I to be successful with their goals. Their goals have updated multiple times and it is truly incredible to witness my children thriving and reaching their full potential now. My entire family is a lot less stressed and we are not isolated to our home. We are free to come and go as we please, running errands during more convenient times instead of waiting on an inconsistent employee's shift to be over. The progress is there and we can not only prove it with data, but if anyone wants to physically conduct an assessment to see where my kids are making progress—it's glaringly evident that there is an incredible difference now vs. when we were dealing with outside providers.

In addition to the issues we had with providers, there were the occasional issues with support coordinators. I want to preface this by saying that we have been mostly blessed with amazing support coordinators, but occasionally we end up with one that is less than stellar. My family and I had COVID-19 in January of 2022. My family was okay, but I was not. I was hospitalized for five days with double pneumonia and needed oxygen for weeks after I was discharged. The bacteria from pneumonia lingered and caused bacterial meningitis in March of 2022. I was hospitalized for another two weeks and on home health for four more weeks. I had a picc line and needed IV antibiotics 3x per day for a total of 6 weeks (4 at home). During this timeframe, I reached out to our support coordinator for support. The support coordinator told us to put my oldest child in an ABA clinic and utilize that as respite care, had no solutions for his sibling (also a DDD member), and took it upon himself to reduce their habilitation hours with no change in their goals. When he reduced their hours, he did so without my knowledge or my consent. Multiple doctors informed me that I was incredibly lucky to be alive. I could barely function or stay awake for very long, was dealing with incredible fatigue and a lot of health issues. I still have long-term health issues as a result of three major back to back illnesses spanning the course of about 4 months last year. We requested to add attendant care to our oldest child's support plan because he has high support needs that I was now unable to meet. We were declined and cited that it is reserved only for children who are not mobile. The support coordinator's supervisor told me that my health crisis was a personal matter and if my son required that much help, I needed to put him into a group home. They wanted me to put my child in an ABA clinic or a group home when I had a highly contagious, high rate of fatality, serious illness I was recovering from. This example is why we needed more training for frontline DDD employees. There should not be ANY discrimination or shame when parents ask for additional supports for their children, especially not during a crisis. I was able to switch teams and get a new support coordinator, thankfully. However, it was incredibly stressful to worry about an infection in my brain and also stress about job loss and homelessness.

I am truly hoping that my letter is read and thoughtfully considered because it took me so much time to put this together. I've sat down countless times to write this only to stop due to anxiety and panic attacks at the mere thought of having to revert back to the original program. Whatever was going on before was not at all working, it was not helpful, and it was so stressful for my family and I. Since becoming a parent provider, there is a dramatic reduction in stress and I really hope to see this program continue. Regarding the 40 hour week limitation on parents, this should also be lifted because it really does not make any sense. If a DDD member is assessed for services, they need to receive these services in a timely manner and there is still a massive provider shortage. Parents and caregivers are readily trained and available to ensure no break in services.

I do understand the concern about DDD members being isolated or not receiving adequate supports. There are already additional supports outside of parents. My children have their pediatrician, occupational therapist, speech therapists, and a support coordinator checking in every 90 days—to name a few. I am concerned that in this current economic climate anyone would want to take away an income from stressed out parents during inflation and a recession, which WILL cause additional stress. I have yet to see a solution to the provider shortage and when parents now have a loss of income due to the habilitation program being excluded from being permanent, there will then be additional burdens placed on parents. Pre-COVID, we were unable to afford to pay for habilitation providers to participate in community activities and providers really did not want to work because of rising gas prices, low wages, and a lack of benefits.

I feel like making the paid parent program permanent will help many DDD members and their families. It will help parents lessen the impact of caregiver's burnout or avoid burnout all together. I feel like we can also add more to the program to help make it more successful, such as adding free or affordable parenting classes or childhood development classes or disability specific trainings in order to help parents be successful with their children’s goals. Should this program not be made permanent (including habilitation), there will be further burden placed on other state programs such as WIC, SNAP, AHCCCS, and mental health services, as well as hiring enough staff to handle the quality of care complaints and grievances and investigations surrounding providers and the provider shortage.

Sorry this letter was lengthy, but I do appreciate your time and consideration. Thank you.

Ashley Pihlman

From: Angela Johnson <[redacted]>
Date: Wednesday, August 16, 2023 at 3:06:55 PM UTC-4
Subject: 1115 Waiver
To: [redacted]

Dear AHCCCS and 1115 Waiver Team,

I attended the July 18th and August 2nd public forums and am extremely disappointed and concerned to learn that AHCCCS is not planning to include Habilitation in their permanent parent provider program.

Currently, I am the Habilitation provider for my three disabled children. This program has been life changing for them and they've actually made huge strides in their goals (which wasn't happening before these flexibilities even when working with ABA providers or other DCWs). If Habilitation isn't included in the new permanent program, my children will likely go without Habilitation services. Prior to the flexibilities, my children were not able to do Habilitation because we couldn't find providers. I know you've thrown around ideas to recruit more DCWs, but it is just NOT realistic to think you can hire enough DCWs to replace parent providers. The past challenges with hiring providers and the past challenges with turnover of these providers have not gone away…there is a HUGE shortage currently of DCWs even with parents being able to do Habilitation.

I know one of your concerns about including Habilitation was member isolation. My children are anything but isolated. They are out in their community all week long…with school, therapy appointments, park play dates, shopping, etc. My children work with and learn from others all day long. In fact, when they are home, they are maxed out on outsiders and don't like visitors because they've spent their day coping and regulating through all of the interactions they've had. Because of this, having a "stranger" DCW come in to work with them is absolutely going to impact their experiences and gains at school and their stamina for time in the community with our family. They will burn out because they are not comfortable having someone they don't know working with them on self care and other Habilitation goals in our home. When we're spending time in the community, I want it to be beneficial and quality time focused so that they're successful, I do NOT want it to be quantity focused (which is counter-productive and what it sounds like AHCCCS is striving for). Quality time in the community is much more beneficial for the disabled community than quantity of time.

If Habilitation is not included in your permanent parent provider program, it will cause more stress and burnout in our home. I will need to find employment outside of the home (with inflation, we are no longer able to afford for me to stay home) which will make continuing to work on my children's goals extremely difficult. Because of the shortage of DCWs, I will be forced to continue to work on my children's goals as best as I can but with much less time and energy. As with any child with a disability, learning new skills is very hard and time consuming for my children. It takes hours and hours over the course of months to make even small progress on a goal or skill. Because they will have limited time with me, they will regress in their skills that they've been making so much progress on during this flexibility. My goal for my children is for them to learn and grow as much as possible during their childhood so that they will need less help as they get older. Without having a parent provider or because of the horrible DCW turnover/shortage, they will receive less opportunities to learn and grow which will increase their needs as adults.

I urge you to please include Habilitation in your permanent provider program that you are submitting. The minor disabled community in Arizona is relying on you so that they can be successful and be able to utilize the services that they need and qualified for.

Thank you for your time.

Angela

From: Becky S. [redacted]
Date: Friday, August 18, 2023 at 1:42:03 PM UTC-4
Subject: Habilitation Change
To: [redacted]

Hello!

My name is Rebecca Schwartz, I am a mother to a [redacted] who has moderate/severe autism. I have been his hab provider for many years. Within these years and me being able to, he has the stability and understanding of who he is when it comes to his HAB therapy. He is triggered and can become violent to himself when it comes to frustration. I have had many speech therapist not return, along with others such as respite workers, because they are unable to handle what they see when these occurrence's occur. I give my son the comfort and less anxiety of working with someone he knows, along with the consistency he needs in his everyday life.

Please do not take these hours away. It is very important to me and my sons care to continue with these services.

Thank you for your time.

Rebecca Schwartz

From: Christina Medrano [redacted]
Date: Friday, August 18, 2023 at 2:41:32 PM UTC-4
Subject: Continuation for Parent Providers feedback.
To: [redacted]

I am a parent provider for my daughter. I have learned so many quality skills to help my daughter adjust to the ever changing world around her. Most of my useful knowledge came from working with AZA United as a Parent Provider for Habilitation in my home. This helped us keep structure and key skills active for my child through COVID... but then something else amazing happened. With the skills and ability to be a provider for my daughter now... She has developed fabulous self skills. Skills like self-accountability without altering it. Meaning she tells me all the bad stuff she does, how she fixed it and what her real performance was/is. Not just at home with activities or an outburst that I see or experience, but also when I pick her up from school! I get more honest updates from my daughter than I do from the teacher or aides. She has vastly improved working independently on assigned tasks, but this skill was developed with me as her Parent Provider, which she now uses at school and during playtime. My daughter became very attached to me through Covid quarantine and we needed to create gameplans to help her develop skills to complete day to day tasks and activities without me. This has now grown to her completing tasks of all kinds at school without constant supervision as well. I was offered valuable training about Article 9, Green/Yellow/Red levels of care that are allowed or not outside of a child's home environment. I have better communication skills and am better qualified to advocate for my daughter with the Public School System because of the training and provider experience. My daughter reaches and completes goals faster when they are placed in home life with a parent provider. This is the 1st time I have ever experienced a Mother getting paid for providing care that will help their child with a learning disability. This program has the potential to vastly improve the quality and ability to live as a child with a disability and as a mother to a child with a disability. More hours should actually be permitted and wages to continue to grow with the cost of living. Another point to leave you with on MAKING PARENT PROVIDERS PERMANENT... it is an underutilized Employment Pool. There is an employment issue in most of the world. It is hard to find a job that pays appropriately and hard to find qualified employees willing to travel to different homes for this type of care. Parents and Guardians would take more opportunities to resolve that issue for At-Home Providers for Children needing ABA, Habilitation, Respite... ect...if the Parent Providers program was a permanent option that keeps parent/child development at a higher level, a parent is able to work from home, a child is getting quality/trained care and improves the quality and execution of development goals placed with the Healthcare/ABA/BCBA providers with the extended resource of the parent providers. PLEASE MAKE PARENT PROVIDERS A PERMANENT OPTION.

Thank you,
Christina Medrano
Habilitation Parent Provider for 2 years [redacted]

From: April Anderson [redacted]
Date: Friday, August 18, 2023 at 3:10:09 PM UTC-4
Subject: Parent provider program
To: [redacted]

To whom it may concern:
I am a parent provider for my [redacted] son who is diagnosed with Autism Spectrum Disorder. I wanted to take a moment to provide my story and how the paid parent provider program has made a positive impact on my life and the life of my son. In March of 2021, I was forced into quitting my job with the state of Arizona as my son was having significant issues at school that included, but was not limited to aggression. The school was unable to manage my son's behaviors and had to call me to come get him on a continuous basis, even though he had a one-on-one para with him each day. I was stressed and burnt out, especially not knowing how I was going to pay my bills or provide a roof over our heads, as I am a single mother. I attempted, and have been attempting to find services for him, but was not successful due to the lack of providers in my rural town and, of course, COVID. Now that COVID is considered nothing more than the new flu, I have had a vendor call open for respite services for about 9 months now, and still I get nothing. This shows me that there is still a lack of providers available for my son.

Now, please allow me to tell you a little about my son. My son has been verbally and physically abused in every school he has ever attended. Because of this, my son struggles to develop trusting relationships with care providers and tends to respond in a violent manner. Since having me as a paid parent provider, he has made significant progress in his habilitation goals. Some of his habilitation goals include learning how to shower independently and dress himself. My son does not feel comfortable with strangers (or even people he knows) seeing him nude, nor do I feel comfortable with this either.

While I understand the desire to prevent caregiver burnout by limiting hours, and I understand wanting to increase the workforce by removing habilitation as a service that can be provided by a parent, neither goal is realistically achievable. What AHCCCS fails to recognize is that parents do not stop providing for their children just because they are not getting paid, so caregiver burnout is still very much a risk. There are no providers to supplement what the parents provide. There is no respite, and there are no caretakers able to provide childcare for these kids while parents work a job outside of the home to supplement the income that will be lost from having limited hours. The children will regress in their goals because there are no providers, and they are not going to allow some stranger to come and shower them or wipe their butts. As a parent, I would not feel comfortable in allowing someone to perform those tasks either.

The behavioral health field is very short staffed and staff turnover is very high. I know this from not only having several case managers or therapists for my son through the years, but as someone who is in the behavioral health field. These payments that parents receive for providing services to their own child are considered "difficulty of care" for a reason. These children need someone who is going to remain consistent, not abuse them, and not quit on them when the "going gets tough". Adding a limit to the number of hours a parent can bill for, and removing our ability to bill for habilitation will undoubtedly have the opposite effect of what AHCCCS is expecting it to have. It will increase caregiver burnout, jeopardize stable housing for its members, and ultimately cause unavoidable harm to the member and the family as a whole.

With this being said, I humbly ask that AHCCCS reconsider the decision to cease habilitation services as a service parents can provide and I humbly ask that AHCCCS reconsider the limitation of 40 hours per week. The only thing these changes will accomplish are negative to children and to families. It appears at this time, the only thing that AHCCCS is concerned about is saving money for themselves.

I thank you for taking my story and my recommendations into consideration and I am hopeful that it will help in AHCCCS making the right choice about the parents as paid providers program.

Sincerely,
April Anderson

August 18, 2023

Dear AHCCCS and 1115 Waiver Team,

My name is Valerie Rubio, and my son, [redacted], is disabled. My son was born with a rare congenital neurological disorder that has made raising [redacted] extremely challenging on both his family & support team since he was 2 years of age.

I thank God for DES and our enormous support team of educators, therapists, ABA counselors, social justice attorneys, and skilled medical & neurological professionals that have come together over the last 17 years to support my son. If my family did not have this kind of support in place, I honestly don't know if we would have made it as a family or with raising [redacted].

[redacted] started to struggle greatly with his hired caregivers for Attendant Care & HAB services about 14 years of age. [redacted] was growing into a young adolescent and his hormones, coupled with his disabilities, (Autism, partial blindness and a rare neurological condition) made it very hard for the staff to come to our home. [redacted] needed help but not the kind of hired help that had been working for so long. [redacted] was changing and so we needed to change with him. At this time, COVID-19 hit the world. We didn't know what to do. We were not able to have anyone come over anymore, nor were there any trained staff that wanted to at that time. It was a scary time, indeed.

I thank ACCHS-DES for allowing parents to step into this role of caregiver. It has been a blessing to my family. As a parent, I always knew what my child needed because I'm his Mom, but also because I have watched and learned through the years. I knew it was time to help my own child and to help him be a part of the outside world, instead of at times, being confined to his home with trained professionals who told me they were not authorized to go outside the home through their respective agencies. I feel the move to allow parents to work with their own children is very beneficial to the family unit and to the child, so that he can integrate int family life and practice the principles that are needed with the actual people they live with.

A parent caregiver community should do the following to overcome any potential arguments in regards to having parents be paid caregivers:

1. Examine available research and personal feedback statements from members and their families to evaluate the true potential impacts of social isolation and community involvement when parents of disabled children provide Habilitation services. The parent caregiver community's collective experience is that members who have parents facilitating their Attendant Care and Habilitation services have experienced greater member social engagement and community involvement over the last three years. Parent caregivers now have an increased ability to take their children to sporting team practices, community events, movie theaters, all ability parks,

church activities and libraries. This is because parent providers can perform the appropriately trained and qualified supports in the correct time and location that is applicable to each member. 2. Implement precise guidelines to facilitate generalization for all Habilitation providers regardless of the DCW's familial status. Habilitation services are designed to have goals where data is collected to evaluate if those goals need to be changed, have been met, or need to be addressed differently. For a goal to be considered met, a member should be demonstrating that they are able to successfully meet that goal outside of the timeframe with a provider in one setting. This is referred to as generalization. The effective implementation of generalization with the pediatric IDD population would lessen, if not eliminate, any complications with adult transitional services. Under this model a program that includes parents as paid Habilitation providers would actually assist and improve in the success of adult transition. There are times when disabled children work successfully with different types of providers in clinics or schools, but the parents are not carrying the work over at home. This can happen for a variety of reasons. Having parents as Habilitation providers would help ensure the child's goals are congruent and carried over in the home and community setting. This will give the member a better chance of independence as they transition through different life stages. With generalization policies in place, Habilitation services being performed by parent providers will actually help facilitate successful transition into adulthood. 3. We know from provider agency data that "the top 3 issues regarding recruiting and retaining career non-family caregivers are schedules of the client members, interest in the position and finding qualified applicants." Most members have Habilitation goals and ADLs that are most appropriately delivered throughout the natural routine of their day. A parent provider is uniquely available in the morning, after school or in the evenings when each member is motivated and focused on the pertinent task. If a non-family provider is available their schedules typically allow them to work in longer time chunks that are not always the most ideal for the member and creates artificial goal or ADL practice. Continuity of care and greater member outcomes can be associated with consistently provided Habilitation care by parent providers who have the greatest ability to be flexible and available for their member children. Should parent providers be limited to 40 hours a week of paid care per child? We have heard the concerns of AHCCCS regarding the potential for a difficult adult transition to non-family supports once parent caregivers are no longer able or willing to help facilitate the disabled member's care. The parent caregiver community would like to propose the following collaborative solution to create a win-win scenario: 1. Create a program provision that outlines an extraordinary circumstances clause and the application process that allows parents to provide over 40 hours of paid care per week of authorized and evaluated services per member. These extraordinary circumstances could include, but are not limited to: a. The lack of a non-parent DCW being available in the last 3 months to fill the member's assessed hours that exceed 40 hours per week. Ongoing DCW searches should continue to be made by the member's agency to fill the assessed hours beyond 40 hours per week of Attendant Care and Habilitation. b. The expressed desire made by a member for a parent caregiver to facilitate their assessed DCW hours so that their Article 9 rights are honored. c. The profound disabilities and/or significant behaviors of a member where a non-family provider is not equipped to provide DCW support. This determination can be made through a stakeholder team approach, including but not limited to the member's, DDD Support Coordinator, DDD Nurse, DDD Supervisors, Behavioral Plan Experts, Parents / Guardians, Psychologist, or Medical Doctor. 2. Form equality between all

Family Provider Programs by allowing all Direct Care Workers, regardless of familial relationship or member age, to provide up to 16 hours of paid care per day. This will allow for employee equality across the lifespan of the member and limit the potential anti-family provider rhetoric currently present within state policies and DDD Support Coordination culture. All evaluations of hours should be based on member needs regardless of who is providing the services to create uniform implementation of all applicable HCBS services by the DCWs available to fulfill those hours. 3. The Family Support Program currently in this proposal addresses caregiver burnout. It is one of the available solutions to facilitate further community support within the disability and caregiver community that will provide greater access to non-profits facilitating counseling services, support groups and meet up activities. 4. Reevaluate Respite reimbursement rates to also address caregiver burnout. If Respite services are not available to the member or their family, parent burnout will continue to be an issue regardless of parents having the option of providing Attendant Care or Habilitation hours. With a comprehensive Paid Parent Caregiver Program in place non-family DCW providers will have greater flexibility to provide Respite services to these same families. How should current evaluation protocols, training and practices be updated to facilitate equality for all members when accessing member needs? AHCCCS has stated their intention to amend applicable policy, further suggested action on this topic includes: 1. Forming a committee of community and department stakeholders to amend and critique current DDD and AHCCCS policies and need assessment forms so that the most effective and efficient implementation of this permanent option is utilized moving forward. 2. Provide appropriately determined training and program implementation to DDD and ALTCS Support Coordinators so that Attendant Care and Habilitation hours are equitably evaluated based on the member's needs and to remove organizational bias of familial providers across the member's lifespan. Specifically investigate and determine appropriate DDD staffing needs and training for the members served in rural areas and those from minority backgrounds. 3. Create the option for private sector Support Coordination. Other states have this option within their Medicaid services, and this could be an additional feature in our DDD portfolio to allow for the member's needs to be best evaluated. In conclusion, Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS.

By not allowing parents of minors to provide Habilitation and Attendant Care services or work over 40 hours a week most of the minor disabled community in Arizona will be underserved. A comprehensive Paid Parent Caregiver program validates the need to have children like my son, [redacted] integrated into family life, practicing the skills needed with their own family members. I believe this will ensure a higher success rate then with only allowing outside professionals to be caregivers.

Thank you for your time,

Valerie A Rubio & Rubio Family

[redacted]

[redacted]

From: Amanda-Lynn Sanders [redacted]
Date: Friday, August 18, 2023 at 7:22:03 PM UTC-4
Subject: Parent story from Morenci AZ
To: [redacted]

Dear AHCCCS and 1115 Waiver Team,

My name is Amandalynn Sanders,
I am the parent of a child who receives DDD and ALTCS services I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility, and it has been extremely beneficial to my child. I would like to share my personal experiences and feedback based on my review of the current proposal for a permanent Paid Parent Caregiver program.

I have a beautiful [redacted] who is Autistic and hard of hearing. We live in Morenci AZ with very limited resources.

We have been blessed to provide services for her in our home under the covid-19 flexibility for just over a year. As a parent of a child with disabilities it is incredibly difficult to find help in this rural area.

This program as a DCW parent provider has helped the consistency in our home within 1 year i have seen my daughters stress level decrease, an increase in her ambition, she's been able to thrive on routine and consistency. The paid program in turn helps us with gas to many doctors' visits, Alternative communication trainings, some in-person therapies she requires (as telehealth is extremely difficult), occasionally much needed sensory items, etc.

While we haven't begun HAB yet, as we wait for the proposal. I believe my daughter would be greatly impacted If we get the chance to set and meet her individual goals as she gets older. Being so far from available providers had found itself very difficult.

Under the current proposal, the request of an ongoing program option which allows parents of disabled minors in Arizona to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies is not being met. Please consider updating the proposal based on the following questions, suggested solutions, and personal experiences.

Thank you,
-Amandalynn Sanders

From: AZA United [redacted]
Date: Thursday, August 17, 2023 at 4:44:34 PM UTC-4
Subject: Public comment and position statement
To: [redacted]

AZA United supports continuation of the current Parent Provider program, at least through September 2024 as AHCCCS and DDD had previously assured us. We feel strongly that a sudden change in November that no longer allows parents to provide Habilitation would be extremely detrimental for many families and the system of care as a whole. There are currently thousands of parents across the state participating in this program, and it is virtually impossible to replace those services with non-parent providers that quickly. Additionally, we have collectively observed the significant benefits that this program offers children when parents can participate in services if that is what they feel is best for their child.

We believe that having a mix of services from parents and non-parents can help create a more consistent approach with improved continuity and flexibility to help meet the child’s needs through different stages and transition phases. Therefore, we support the notion of making Habilitation a permanent option for parents in the new AHCCCS waiver, in addition to Attendant Care. We hope to participate in any future policy discussions that may determine any limits regarding the amount of service hours that parents can provide, as well as any other new requirements that seek to ensure that these services are as or more impactful as they would be if done by a non-parent provider.

Aaron Blocher-Rubin, PhD, BCBA

President & CEO

Arizona Autism United (AZA United)

AZA United
ARIZONA AUTISM UNITED

From: Kristen Greeley [redacted]
Date: Friday, August 18, 2023 at 7:48:20 PM UTC-4
Subject: Parent habilitation needs
To: [redacted]

Our daughter has a special needs child that she has been working with for the last few years. He is [redacted]. We have seen a big change in his development and learning. She home schools him using these methods and he flourishes. She brings him into many social situations that he has been coming out to use his speaking device much more often making full sentences when he was using one word answers before and crying because he did not understand how to respond before to many social situations. Her son has people for respite care and a steady person coming to work with him in the mornings. If they change people there is a regression as he gets used to new caregiver ways. Please don't let her ability to work with her son be hindered as she can do it better than anyone I have ever seen with him.

Thank you
Kristen Greeley

Sent from my iPhone

---------- Forwarded message ---------
From: Beth Walker <[redacted]>
Date: Friday, August 18, 2023 at 11:19:10 PM UTC-4
Subject: Section 1115 Waiver Renewal
To: [redacted]>

Maybe it's just me, but I don't think parents should be paid to care for their own children AT ALL. If the purpose of this is to allow parents to get payment for OTHER FAMILY MEMBERS to care for their children, that's an entirely different story. But it's an insult to every parent who cares for their children to have a select few get PAID to do their due diligence for a child they CHOSE to bring into the world.

It's bad enough y'all are offering to pay these parents 40hrs/WK. Do NOT pay them a single dime more. That money is supposed to be used to pay OUTSIDE CARETAKERS, and that is how it needs to be spent!

Beth Walker
[redacted]

From: Martin Khanania <[redacted]>
Date: Saturday, August 19, 2023 at 3:16:16 PM UTC-4
Subject: permanent extension of payments to parents who serve as paid care provider.
To: [redacted]>

Hello!

We all seek better life better support for disabled minor children, one way to achieve that is to let parent's care for their disabled minor children and no one will argue the benefits of those children when they have been cared in home setting with trained parents to support them and provide in home care that they need.

We hear stories about disabled children been neglect and abuse in hands of very few stranger care providers. I personally witnessed and seen those children at dentist office suffering when the dentist discussed treatment plan with their care provider and care provider cannot authorized these treatment plan and end up calling the parents of these children and taking long time to locate them this is all not in the children's interest.

Trust, stronger relationships, shared cultures, security, better stress resilience, better health, stronger self-esteem, better brain development all these cannot be provided for these children's unless they been cared by their parents, and as parents we influence child's basic values like religious values, and issues related to their future like educational choices and strong relation with the children's.

We all love our children's specially if they were disabled, we all want them to live normal happy healthy life and state assigned care givers no matter how good they are, rarely can provide half of these good benefits to these children's.

I, as a parent care provider ask the state to approve and allow for the permanent extension of payments to parents who serve as paid caregivers for minor children.

Roda Khanania

Thank you

From: Melissa Blomstrand <[redacted]>
Date: Saturday, August 19, 2023 at 3:47:52 PM UTC-4
Subject: Parent Provider
To: [redacted]>

Hello,

As a parent provider (not by choice) I am writing to express my frustration of the ending of parent providers ability to provide HAB. We have been told for 5 years that “we are looking for a provider”. My autistic son had no access for his most important developmental years as a result, which negatively impacted his progress. Taking away this ability to provide for my son and to be trained properly by an agency to meet his goals, will result in further loss of growth and will in turn make him less functional and need to be on state services for longer. This makes no sense. It actually hurts disabled kids that live in areas outside of public transport lines, making us unable to find a provider despite years of promises and vendor calls. I would also lose the expertise and training of my agency to help me help my child through implementation of best practice. Since I began this process, he has flourished and is making gains in all areas. Please adjust this proposal to include HAB for parents of Minors.

Melissa ([redacted]

Sent from my iPhone

---------- Forwarded message ---------
From: Ashley Hupcik <[redacted]>
Date: Saturday, August 19, 2023 at 3:56:20 PM UTC-4
Subject: Parent Paid providers
To: [redacted]

I have been able to be a paid parent provider of minor children for my [redacted]. Since I have been a paid provider my daughter has progressed from not being able to use a for or a spoon to being able to use it successfully about 70+ percent of the time at meals. He language has progressed. She has learned 20+ new phrases or words. When she had another person working on her goals she wasn't progressing. As parents we work harder because we really want to see our children achieve their goals. I am hopeful that this can become a permanent thing. It really is helping our children as well as us. With the cost of everything rising this income has helped us out as well.

Thank you,

Ashley Hupcik

---------- Forwarded message ---------
From: Melissa <[redacted]>
Date: Saturday, August 19, 2023 at 3:57:13 PM UTC-4
Subject: Parents as paid Caregivers feedback
To: [redacted]>

To whom is may concern,

The paid parent caregiver program has been life changing for our son. We previously have not been successful at finding any consistent, quality help with our son. Since becoming a parent caregiver our son's quality of life has drastically changed.

[redacted] was previously struggling with seizures, nutrition and success at school. With the parent caregiver program [redacted] has reduced his seizures to one or less per month, overall bringing less health issues and hospital visits. In addition, [redacted] has been able to put on weight that his body needed. He is now a healthy weight, has a great appetite and receives nutritious homemade meals daily. [redacted] was previously missing school frequently. Now I am happy to report, he rarely misses a day! He loves school and has been so much happier overall. The biggest change the parent caregiver program has brought is the health of my son. He hasn't had any hospital stays in over 2 years, he rarely even gets sick. He is able to attend school more, misses less therapy sessions and has an improved quality of life. In turn, this has brought much less stress and worry to our entire family.

November 2023 is not enough of a runway for the current proposed change. Please consider the original extension under ARPA funding through September 2024 be maintained to allow paid Parent Providers of Minors to continue for now. We fully support this program becoming permanent.

Thank you,
A Parent Caregiver

From: Tamaretta James <[redacted]>
August 19, 2023 at 4:16:06 Subject: Parent PM UTC-4
provider program
To: [redacted]>

My name is Tamaretta James-Tachine and I am currently and parent receiving this benefit. To my knowledge and actual life experience...this program has really helped us a lot. We were able to use this funding when money was tight in our house hold. We got by with it and we still do depend on it today. Our rent has only gone up and prices of everything isn't getting less. I worry about our future. Why end this now? My son benefited with this also with new sensory toys and outings that he likes to do. I just don't understand. This there another program out there like this?

From: Jessica Alford [redacted]>
Date: Saturday, August 19, 2023 at 5:34:44 PM UTC-4
Subject: Paid Parent caregiver changes for minors
To: [redacted]

Hello,
Recently I became aware that changes were being made in the type of services and amount of hours parents can provide as caregivers that would negatively affect my son. I am an [redacted] who was forced to quit my full time job in the hospital because I was unable to find a third party caregiver for my severely physically and mentally disable [redacted] son. I have tried several different companies and given a very flexible schedule opportunities and still no one. I don't know if it's because the pay is only up to $17/hr with the high cost of living or all the paperwork involved but the availability is severely limited if not nonexistent. I am already unable to work the 50hrs per week my son is alotted because I'm his parent and if my ability to work his habilitation hours is taken away that may put further strain on our finances and living situation. My son doesn't qualify for social security benefits because "I make too much" so this is the only income I currently have to care for him because im unable to find help. I'm sure there are a lot of parents in a similar situation and we're just doing the best we can to provide the care for our kids that it seems no one else is willing to do.

Thank you,
Jessica.

From: Michelle Smith <[redacted]>
Date: Saturday, August 19, 2023 at 6:36:10 PM UTC-4
Subject: Public comment
To: [redacted]>

Hi I'm a parent that has already submitted comments. However I just read a news article that expressed a little differently than what was said in the zoom meeting for ahcccs. It's under the impression that you all are stopping habilitation and only providing attendant care. Thus article states you're proposing habilitation be like a add on service at times if needed. However I'm still a little confused to what is happening within what's being proposed. Are you all trying to change habilitation into attendant care, or does the child have to have attendant care in the plan already. Also are qualifications going to be changing for attendant care? I know every person is different and we can't just state for one person but what if a person should have been getting attendant care instead of habilitation this whole time? Who is monitoring the needs of these cases besides the cade worker with over 40 cases? Who is verifying what these children are getting is what they should be getting. Ahcccs you guys really need to step up the demand of this program for our children. Whether I'm paid for it or not I'm going to be doing what I can and have to for my child. I'm actually a bit torn between if I do get attendant care for my child and I'm having to work and not able to see what's going on with my child would that really be the best method for them. The perversion and undercover nature of people are very disturbing now days. They pretend to be for these children with all these needs but not even related to them, wouldn't hand them a plate of food if they were homeless, wouldn't give their last to them but they are the same people who could trust with our children in private? The day centers especially where I live particular, which there is only one, the man directing the program acting like he was so for all these kids and I seen him first hand touch a disabled kids bottom. The boy couldn't talk, couldn't walk and was stuck in a posture position. And I seen it. And no one did anything about it. So I can speak for people who do thing of this nature for their children are definitely a better option for the children with needs intensively to a daily need. Parents who want to stay with their children should have the options to do so and know that their child is getting the appropriate care and not worrying about bills and providing at the same time. Parents who rather have someone else come in should have the options also. I say to leave the options open instead of constricting them. If habilitation is addressing the bathing, tolieting and other needs in this area I would say if children have this on their plan as habilitation should automatically be switched into attendant care for these needs instead. So parent scan have the option to say who does what for their child. Now don't get me wrong because I'm not saying all parents are the best option for the children either as the news article said. Some people will abuse the program depending on the circumstances. Some parents may not be the best option. I think it just depends on the situation of the family. And all options should be available to all families who are under this long term care program. And when deciding our future for us we should have a say so in what happens as well. So I thank ahcccs for allowing the comments to be presented.

Office of Special Education and Rehabilitative Services

From: Denisse Santoyo <[redacted]
August 19, 2023 at 7:19:10 Subject: PM UTC-4
To:
[redacted]>

Hola buenas tardes nos gustaría quedarnos con el programa ya que es de mucha ayuda para nuestras familias nuestros niños necesitan de toda nuestra atención y ayuda,gracias

From: Cristine Fox <[redacted]>
Date: Saturday, August 19, 2023 at 7:19:51 PM UTC-4
Subject: AHCCCS proposal for a permanent Paid Parent Caregiver program
To: [redacted]>

I am writing to inform you of my support of a permanent Paid Parent Caregiver Program.

With the ending of the Habilitation program for parents. My child will be placed on the vendor list (which he has been on since he was approved for AHCCCS back in Oct 2021). The vendors that reach my area are few and fair between.

I have received a call from 2 people in the 2 years since he was approved.

The first woman was a smoker and our house is an asthma house so that would not work out and the second woman had not moved to [redacted] yet and said she would call back when she would. I have no heard back from her since then.

Every other vendor has told me it's find to employees that live or would commute to my area.

I am my child's only options at this point. Without this program, he has nothing.

The limit on hours is concerning as we are trying to teach our children how to live. Potty training in itself is a 24/7 job. Are we suppose to just stop doing that?

Finding consistent third party care has been impossible. Something has to change in order to find more vendors, get more people involved, excited to be involved if you want the parent program to go away. And once that is in place you need more that a few month notice to pull the program.

Parents need Several MONTHS for transitions and finding third party care otherwise the MEMBER SUFFERS!!!

Children should NEVER suffer because of the choices of adults. It's a shame.

Thank you.

Cris Fox
[redacted]

---------- Forwarded message ---------
From: lilian.yslas [redacted]>
Date: Saturday, August 19, 2023 at 8:27:10 PM UTC-4
Subject: Parent of a minor with a Disability
To: [redacted]>

To Whom it May Concern:

Our daughter, [redacted], is a spunky [redacted] with Down Syndrome. She was born with Hypotonia, cognitive delay, and minimal hearing loss. As she's gotten older she's somewhat nonverbal, needs glasses, can't hear certain pitches in one ear, and qualifies for PT, OT, ST, and FT at school and outside of school. She only receives these services for 60 minutes each per week. For school it's only 30-45 mins once per week. [redacted] needs go beyond that once she's at home.

Because of her cognitive delay she's nonverbal when it comes to communicating her needs. She can say words and numbers, but she can't tell us if she's hungry or needs to go to the restroom. Having Habilitation hours helps us constantly practice communication to her specific needs and wants. We are constantly being repetitive, we also use an AAC Device. She's not potty trained so we are also trying to communicate the feeling and ask to use the restroom. She usually grunts or shows frustration rather than words when she needs help. Communication is such a huge goal we work on daily and constantly. It has gotten harder since she is 6 and still in diapers. We have learned what her nonverbal cues are and she's on a consistent schedule where we can time certain toileting needs.

Self care is another goal that we work on for Habilitation. Her fine motor skills are limited. She can grab bigger things, but when it comes to clothing, shoes, toothpaste tubes, toileting, feeding or drinking cups she still needs assistance. She's able to take socks off, but is unable to put them on. Shoes and clothing are hard to put on, so we work on doing that. She struggles with anything to do with her fingers like opening snack bags or zipper type bags So we are working on Occupational type activities. These daily goals are a constant and require the Habilitation time everday. She will not become independent in self care if we aren't constantly practicing these skills.

Habilitation hours allows parents like myself to work with her daily since we aren't financially able to have a therapist working with her on these lifeskill and selfcare needs. As a parent I can comfortably commit my time to [redacted] and all her needs. Without these hours I would have to seek out another individual to help me with her needs. Having move to east Tucson, it has been increasingly difficult to find quality care. I haven't been assigned a Tucson DDD SC and I've been here for 2 months. The lack of employment or urgency to our needs is extremely worrisome.

From a concern parent that uses Habilitation hours,

Lilian Yslas and [redacted]

From: Didiana Herrera <[redacted]>
Date: Saturday, August 19, 2023 at 9:28:41 PM UTC-4
Subject: Didiana Herrera
To: [redacted]>

Soy Mamá de un members , donde realizo diferentes actividades con el .y estoy segura que hay muchas madres cuidadores de sus hijos que si realizan bien sus actividades y todo lo que tiene que ver con que sus hijos aprendan pues lo hee visto y vivido.como trabajadoras con personas con diferentes capacidades y habilidades yo como mama no estoy de acuerdo que quiten seguir atudando a sus hijo se que por obligación hay que hacer porque son nuestros niños pero también les aseguro que como padres muchos encaminamos más que otra persona externas y también tengo evidencia que mi niño ineratua y hace mas cosas con su mamá por la protección que le doy y esta seguro que no lo dejo caer y hace mas repeticiones ya que el mismo espera que su mamá lo haga no imita tanto pero y con su mamá lo hace poco pero lo hace cuando su celebró le dice estoy bien y lo quiero hacer porque lo aprendí. Sigan dándole oportunidades a los padres aunque los tengan que verificar que no hay mejores personas que el apoyo verdadero de unos buenos padres que estan dispuestos ayudar a sus hijos avanzar asi tengan la dificultad que tengan y se que soy un buen apoyo para mi niño y para otros en el futuro. Apoyemos estas decisiones por el bien de ellos

Si lo necesitan.

---------- Forwarded message ---------
From: Lisa Fenwick <[redacted]>
Date: Sunday, August 20, 2023 at 12:34:08 AM UTC-4
Subject: Permanent Paid Parent Program
To: [redacted]

Hello,

I am writing this email to ask for the Permanent Paid Parent Caregiver Program to be approved.

This program benefits my son, [redacted]. Due to the high turn over rate of finding and keeping workers, he has a hard time adjusting to other individuals, lately it has not worked out well for him. Please allow my son, [redacted]the ability to continue working with me, the parent, as this is what he is most comfortable with.

November 2023 is not enough of a runway for this change. Please allow the original extension of September 2024 to be maintained to allow paid Parent Providers of Minors to continue for now.

Thank you,
Lisa Fenwick

---------- Forwarded message ---------
From: S. Engel Grohnke <[redacted]>
Date: Sunday, August 20, 2023 at 2:41:35 AM UTC-4
Subject: PLEASE DON'T ALLOW OUR CHILDREN TO BE WITHOUT
To: [redacted]>

Because that is EXACTLY what is going to happen if we family workers are to cease the precious time and effort we are allowed to teach and care for our members. As DCW we make every sacrifice to make sure our members are very well taken care of and run smoothly for the children. These children (members) will be without any services. Who will answer them as to why? The direct careworker is a very special position and is ridiculously difficult to fill! The minor members have no voice here! This is so unfair to THEM. We need to advocate for them wholeheartedly. We were recruited for a Reason through our world episode, and changed all our lives for the betterment of our community in this case. We should rejoice that these members are so very well cared for. Previously, this particular member had suffered through various workers who said they'd be back- heartbreaking .. then there is the defunct daycares, understaffed, over capacity . Do you know that what that feels like to a child who needs help and can't get it because they're lost in a room of too many and cannot speak? Imagine. These kiddos are Sick all the time, making parents sick, everybody misses work. Then the pollution, the travel time, on and on. My little guy has been subjected to so many obstacles finding "a good fit" a child of 5-year-old should never have to go through, the ill trained, down right mean, uncaring, disappearing Outside DCW. We parents are in fear! Autism is not understood and many can't understand or help him properly. We can't find direct care workers and they feel don't get paid enough, no benefits, sick, retirement & nothing. Not you Ideal job. It's very hard work! To care and do a good job. This decision holds our childrens lives in their hands. These are children (minors) our members are totally dependent. The workers you may find -don't show half the time, leaving us hanging, the travel expenses are not conducive for the trip let alone not to mention with school back on session for most, The hours are split shift. Or you have to set up TWO DCW?! IMPOSSIBLE! TRY IT WE HAVE. No worker wants to come a couple hours in the a.m then split shift back after school?

They would waste in gas any pay thought to be received..... This definitely is taking the child's well-being away from them! The decision is wrong to impead this progress these members are making and for what?? What is a good reason I say? Not one to be had!!!

On top of that, November 2023 is not enough of a runway for this change, and request that the original extension under ARPA funding through September 2024 a least should be maintained to allow paid Parent Providers of Minors to continue for now! We will fight for ours! WE BEG OF YOU TO CONSIDER REALITY IN THIS SITUATION.

Taking HAH away from our children is the worst thing for these kiddos, ask around to those involved DDD, the schools, the doctors,the children themselves

Sincerely

Sydney

---------- Forwarded message ---------
From: Glenda Jones <[redacted]>
Date: Sunday, August 20, 2023 at 2:48:10 AM UTC-4
Subject: Permanent Paid Parent Program
To: [redacted]

To whom it may concern, I writing you to appeal the continuation of the current program. My [redacted] year old daughter has Downs Syndrome and severe Autism. She rarely is able to make it in school and struggles with anxiety and behaviors. DDD has requested all calls for providers for years for us. There has been no response. I am separated from her father and only have the help of her siblings. This program allows me to help/teach my child and keep her at home and not be forced to put her in a facility. The covid period was very difficult on my child and set her back socially and emotionally. She thrives on structure and routine. I have worked at home to provide that. I fear that she will suffer greatly without the parent as a provider program. Please help my daughter and other severely disabled children by making it permanent. Respectfully, Glenda Jones.

Mother of [redacted]

From: Benamer, Kenneth C. <[redacted]>
Date: Sunday, August 20, 2023 at 4:08:32 AM UTC-4
Subject: Urgent Appeal to Preserve the Parent Provider Program
To: [redacted]

Dear AHCCCS program leadership:

I hope this letter finds you well. My name is Ken Benamer, and I am writing to you today as a concerned citizen deeply invested in the future of our community. The proposed changes to the AHCCCS Parent Provider program have prompted me to reach out and share my heartfelt perspective on this matter.

The news of AHCCCS' intentions to alter the Parent Provider program has left many of us feeling uncertain and concerned about the well-being of countless families. As a parent of a special-needs child myself, I understand the vital role that parents play in the lives of their children, especially those who require specialized care. The current program allowing parents to provide Habilitation & Attendant Care services for their own children has provided a lifeline of support for many families.

When it was communicated that this program would continue through September 2024, organizations like AZA United and parents across our state breathed a collective sigh of relief. It seemed as though a sense of stability and security was finally within reach. The reliance on funding from the American Rescue Plan Act to sustain the program was a beacon of hope, promising that the needs of these families would not go unmet.

However, the recent announcement regarding the renewal of AHCCCS' federal waiver has stirred up new anxieties. I understand that this waiver holds the power to shape the services available to Arizona residents through Medicaid funds for DDD & behavioral health services. It presents an opportunity to create a lasting positive impact by integrating the Parent Provider program as a permanent fixture in our state system.

The proposed changes, particularly the reduction of parental involvement in providing Habilitation services, have left me deeply troubled. It is no secret that parents are uniquely equipped to understand and cater to the specific needs of their children. The proposed limitation on Habilitation services could potentially disrupt the well-established bonds of trust and familiarity that parents have nurtured over time.

As someone who has personally witnessed the benefits of the current Parent Provider program, I firmly believe that a sudden shift away from allowing parents to provide Habilitation services would have far-reaching consequences. Families who rely on this program would face immense challenges in adjusting to the new reality. Replacing these specialized services with non-parent providers within such a short timeframe would be an uphill battle, if not an impossible one.

Moreover, the unity of services provided by both parents and non-parent providers has proven to be invaluable in supporting children through various developmental stages and transitions. This diversity of care not only ensures consistent support but also fosters an environment of adaptability that is crucial for the well-being of our children.

I implore you to consider the profound impact that your decisions have on families like mine. The Parent Provider program has been a lifeline, a source of hope, and a testament to the resilience of our community. By advocating for the inclusion of Habilitation as a permanent option for parents within the new AHCCCS waiver, you have the opportunity to stand up for families, to safeguard continuity of care, and to promote a more compassionate and holistic approach to support services.

I kindly ask for your support in upholding the legacy of the Parent Provider program that has enriched countless lives. It is my sincere hope that you will consider my words, along with the voices of many others who share this concern. Please know that I am more than willing to engage in any policy discussions that can contribute to a comprehensive solution that supports the best interests of our children.

Thank you for your time, your dedication, and your consideration of the impact that your decisions hold for our community's most vulnerable members.

With heartfelt gratitude and unwavering hope,

Ken Benamer

From: Stephanie Bonfilio <[redacted]>
Date: Sunday, August 20, 2023 at 5:18:11 AM UTC-4
Subject: Keeping Parent Provider Program
To: [redacted]>

Dear decision makers for AHCCCS,

Warm greetings to you. I hope this letter finds you in good health and high spirits. My name is Stephanie Bonfilio, and I am writing to you with a heart full of concern for our special needs children and their families. As a grandmother who has witnessed firsthand the challenges they face, I am compelled to share my thoughts on the proposed changes to the AHCCCS Parent Provider Program.

My granddaughter, [redacted], has a spirit that is as remarkable as it is fragile, and it is our duty to ensure that she is surrounded by the care and support she needs to flourish. The current Parent Provider Program, which allows her parents to provide Habilitation and Attendant Care services for their own child, has been a blessing for our family, offering a sense of security and understanding that was missing.

When I think about [redacted] journey, I am reminded of the countless times her mother has patiently and lovingly helped her with the most fundamental tasks that we often take for granted. Emma has a deep affinity for painting, and her mother's tender guidance has enabled her to hold a brush and express herself on canvas. It's in these little moments that the Parent Provider Program has made all the difference.

As I read about the impending renewal of AHCCCS' federal waiver, my hope for [redacted] future is tinged with trepidation. The power of this waiver to shape the services that our children receive through Medicaid funds for DDD & behavioral health services is truly remarkable. It presents an opportunity to create a landscape of care that reflects the best of humanity, extending well beyond our own lifetimes. I am writing to beseech you to consider the immense impact this holds for families like ours.

The proposed alterations to the Parent Provider Program, specifically the reduction of parental involvement in providing Habilitation services, troubles me deeply. [redacted] mother, with her unwavering love and understanding, has been [redacted] constant guide. She helps [redacted] practice daily tasks, like buttoning her shirt or feeding herself, with the patience only a parent can offer. The idea that [redacted]s mother may no longer be able to provide Habilitation services weighs heavily on my mind.

I carry the stories of families who have benefitted immensely from the current program. The prospect of families grappling with sudden changes and trying to find non-parent providers to fill the void is deeply concerning. The bond between a parent and child with special needs is irreplaceable, and the care provided is unique in its depth and understanding.

As a grandmother who has seen the impact of this program on families, I urge you to consider the long-lasting implications of your decisions. Our special needs children are deserving of every opportunity to thrive, and it is in your hands to make a difference. By advocating for the continuation of Habilitation as a permanent option for parents within the new AHCCCS waiver, you stand up for the voices of the most vulnerable among us.

I humbly request your support in preserving the essence of the Parent Provider Program that has transformed the lives of countless families. Your commitment to this cause would be a testament to your dedication to the well-being of our special needs children and their families. As a grandmother who cares deeply for their future, I thank you from the bottoms of my heart for your time, consideration, and the compassionate decisions that you make.

With heartfelt warmth and unwavering hope,

Stephanie Bonfilio

---------- Forwarded message ---------
From: melissa DIGGINS <[redacted]
Date: Sunday, August 20, 2023 at 10:34:32 AM UTC-4
Subject: VOID / LOSS of essential care
To: [redacted]>

FACT: They don't have enough employees to offset the parent provides of minors. My child was waiting for years.

FACT: This will create a huge VOID in care, which is discrimination against disabled minors.

Please revise your proposal.

Concerned,

Melissa Diggins

From: shelby taylor <[redacted]>
Date: Sunday, August 20, 2023 at 10:39:56 AM UTC-4
Subject: Parent Provider
To: [redacted]

Hello,

I’m writing in response to the draft/proposal regarding eliminating the parent provider program. My hope is that this service remains a part of my son’s development and care as it has been a life changing opportunity for the both of us. Thank you for keeping this opportunity alive and well for families struggling to provide what is best for their loved ones.

Sincerely,

Shelby Taylor

Sent from Yahoo Mail for iPhone

---------- Forwarded message ---------
From: Elise <[redacted]>
Date: Sunday, August 20, 2023 at 11:07:53 AM UTC-4
Subject: AHCCCS Proposal
To: [redacted]>

To whom it may concern:

It has come to my attention that there is potential for habilitation to be ending as caregiver for my son. This brings some concerns. As new members this year I understand from several people there is significant shortage for habilitation. As we know with children with disabilities any time without care is never great. Also consistent care from same providers as they gain comfort with specific people. This program also allowed us to start habilitation ASAP and has been great benefit to us as we can see track progress and create new goals as needed.

Elise M.Rouen

From: Lloyd Daggett <[redacted]>
Date: Sunday, August 20, 2023 at 11:48:32 AM UTC-4
Subject: Support paying parent caregivers
To: [redacted]>

Although we do not know any children with disabilities, given the care worker shortage and the acute need for care for children with disabilities, we strongly support paying parent caregivers as a compassionate and requisite service

.Lloyd and Margaret Daggett

Freedom is not worth fighting for if it means no more than license for everyone to get as much as he can for himself.
- Dorothy Canfield Fisher

From: Vikas Aligh < [redacted] >
August 20, 2023 at 2:00:14 PM UTC-4
Subject: Parent as paid care givers 1115 waiver request
To: [redacted] >

Hello,

I am writing to request your support in continuing the parent provider habilitation program for minors in Arizona. As a parent of 3 children with 1 on the autism spectrum with significant delays based on several ongoing government recognized assessments, the challenges associated with finding and retaining appropriately trained and trusted providers is real. Below are the reasons I have listed in support of requesting this waiver :

- **Lack of providers in Scottsdale** - Over the last 4 years we have constantly struggled to find trained/certified providers to help with my daughter [redacted] who was diagnosed with Autism at the age of 2. She is 6 now. Despite several vendor calls and multiple reminders, we continue to get the same response about the low number of providers available in the area.

- **Continuity and consistency of the services** - It's a well known fact that kids on the spectrum thrive on routines and consistency. We have experienced very high churn with the few providers that we managed to find after looking for a very long time. Having new providers every few weeks/months does not sit well for [redacted] consistency needs. Being a parent provider allows me to provide uninterrupted services to [redacted] that have shown great results in her overall development. A few major achievements that I have been able to accomplish working with [redacted] include - brushing her teeth , following 1 step and 2 step directions , responding to her name , putting on her shoes, socks and clothes, feeding herself, cleaning up after play and washing hands. Although [redacted] has not mastered all of these skills , she has shown considerable improvement from when these services were provided by an external provider.

- **Addressing her social skills in a community setting** - [redacted] is currently enrolled in [redacted] for 1st grade and has been attending school since she was 3 years old allowing her to get the needed social interaction with other kids and teachers. Additionally, as a parent provider, I am best aware of her interests and take her to local community events based on her likings. We have previously struggled to find a provider that's willing to help [redacted] in a community setting.

- Parent burn-out concerns - While a valid concern, 2 parent households are better positioned to help with the workload associated to working with a special needs kid. My husband has a flexible work schedule that allows him to help me with [redacted] needs and is as invested in her progress as a parent vs us relying on outside help. Parent providers should be allowed to extend services beyond the proposed 40 hour a week cap as long it is 40 hours per person and not for the household. This will allow us to ensure uninterrupted services for [redacted] developmental needs without any dependence on an external 3rd party provider that's tough to find.

Hope all the above reasons are considered for the parent providers of minors requesting continuity of these programs allowing them to support their special needs kids.

Thanks
Payal Aligh
[redacted] Mother

From: Maureen Buhl [redacted]>
Date: Sunday, August 20, 2023 at 2:24:24 PM UTC-4
Subject: Waiver for care givers
To: [redacted]

To the decision makers,

Parents who care for their children with disabilities do so out of love. Their job never ends & it may limit their ability to hold a job that brings in dollars for the necessities of a household. They deserve some reimbursement for the care they provide that otherwise might need to be provided by an outside source.

Maybe if their income was boosted just a bit, these parents could afford some respite care that is essential for all caregivers.

Thank you for your consideration.

Maureen Buhl
nurse & mother

Maureen A Buhl, MSN, PHN,RN
"Look deep into nature, and then you will understand everything better."
~Albert Einstein

From: Raymond Joy <[redacted]>
Date: Sunday, August 20, 2023 at 3:23:22 PM UTC-4
Subject: Devastating Effects of upcoming Parent Provider Changes
To: [redacted]

Hello,

I am the Executive Director of [redacted]. I am writing to ask that AHCCCS does not put these Parent Provider changes into effect. If these changes are put in place, it is going to bring about a state of emergency with Children who need these services the most, not being able to get them. The situation is already basically an emergency situation as we cannot find providers for these families. Since the pandemic we cannot find providers to hire on and help these children. Everywhere you go businesses are looking for help and hiring and cannot find it.

We have well over 100 Parent Providers caring for their children and 1000's of hours per month in habilitation being provided to these vulnerable children that need it most. These kids are going to go without this most needed service if the changes are put in place.

*****We are spending $5600 per month on advertising (for the last 8 months) and we still cannot find providers to hire on. They are not out there, there are no available providers to hire on and take the place of the parents providing habilitation.*****

These changes are going to bring on a STATE of EMERGENCY for these children and families if these changes go into effect.

At the very least, Please put a 2 year moratorium in place until the economy gets back to normal and we can find providers again.

Please do what is right for these children, they are depending on you..

Please feel free to contact me with any questions.

Thank You,

Raymond Joy

Executive Director

[redacted]

---------- Forwarded message ---------
From: Rivko Knox <[redacted]>
Date: Sunday, August 20, 2023 at 3:44:57 PM UTC-4
Subject: Waiver re Paid Parental Health Care
To: [redacted]

My name is Rivko Knox; I have lived in [redacted] and have voted in every election since I was eligible to vote here.

I am quite interested in public policy; follow elections, etc. carefully as well as proposed legislation and very regularly use the Legislature's Request to Speak system to share my views and concerns on various bills. I also regularly contact (phone or email) legislators and other public officials, as I believe in using my voice as well as my vote

I have been very lucky in that neither of my two children or four grandchildren have ever (yet) needed home health care. However, I am aware of many who do; and was so glad to learn that during COVID, the department allowed parents to be paid to provide such care for their children.

Now that the department is considering a waiver to continue this program, to include home health care training, I want to be sure to add my voice in favor of this action. Please do move forward as expeditiously as possible, and of course maintain good records so that hopefully this program will provide its success and then will be made a permanent part of the services provided to children who need home health care.

Sent from Mail for Windows

From: chris grace [redacted]
Date: Sunday, August 20, 2023 at 5:27:05 PM UTC-4
Subject: Paid parent caregiver
To: [redacted]

To whom It May Concern:

My name is Christopher Grace. Raising children isn't easy for anyone but my wife and I were just getting the diagnosis that let us know our children had autism. Things were rough. The school had already misled us for years giving us false confidence that things would get better. Covid hit and we struggled forward constantly looking for hope. Eventually we decided it was better for my wife Jessica to stop working and stay home with the kids to try and salvage a future I did not see but couldn't give up on. I was worried we would be financially destroyed but we did it anyway. What choice did we have? A couple months later our services provider said that we might be able to get compensation for the job we were doing because caregivers just could not be found. I was so thankful, I praised God and hoped it would be something that could help.

Prior to my wife becoming our children's caregiver we had a couple other caregivers. One had a good heart and did the best she could but really had no training or skills. The other one was useless. It took time for these other caregivers to connect with our children, to find out how and what motivates them. As well as for our children to gain trust with these caregivers and feel comfortable with them.This has to happen every time a new caregiver or support is entered into our family and it takes forever, if it even happens at all. As time passed I began to wonder if my children were ever going to make it in this world and if it was my fault. Time just slips away along with your hope and I began to realize that our children most likely would never live independently. This realization was too strong to ignore and it crushed me.

Having my wife as our caregiver changed our lives. This didn't happen overnight as it took time to put the pieces into place. We accepted as much training as possible and moved forward. The children responded better to her because she is their mother. She worked harder and sacrificed more because she is their mother. No time was needed to make a solid connection, gain trust, earn likeability, find out how and what motivated them. Though the transition was hard, it's almost impossible for me to imagine where we would be if this did not happen. I saw progress, I saw hope, I saw love. Sure caregivers want to help and have good hearts but it's nothing compared to what a family member can accomplish and the connection they have. Don't get me wrong, the process can be difficult, challenging, and hectic but it is worth it. I finally am able to see a positive, independent future for my children.

Due to the Paid Parent Caregiving program our children have made better progress. I see a light at the end of the tunnel that makes me think just possibly one or maybe both of them could leave the home one day to live productive independent lives. Possibly (God dare I say it) without help. Without this program myself and my wife would have to make some harsh decisions.We both could go to work and risk seeing our children regress or not have the proper care and service provided or have only one income and have financial destruction. The first option could leave our children for long periods of time without a caregiver and eventually lead to our children needing lifelong care and support.

This would mean group homes, therapies, doctors, etc. all throughout their lives. As we are waiting to find someone to provide these services my wife still won't be able to work, which will cause financial destruction. Either way we are stuck between a rock and a hard place.

This program might not work this well for all children but it sure improves the outcomes of the ones in it. It's a job. Let me repeat that, it's a job. My wife has to clock in and out, file countless paperwork, evaluations, etc. I work outside the home to provide. All parts of this program are important. The attendant care is there to assist with the extraordinary care my children need and the habilitation is there for early intervention and to assist my children with struggles they have to lead an independent life. This early intervention helps my children grow and learn how to conduct themselves in society and with their daily living skills.If you take away Habilitation or any other part of this program my children and others like them will be worse off and regress. That means more money, time, and effort to put it back if possible. This has been the best thing for us, our family, the community, the taxpayer, and the world. They get out more, they are growing better, our lives are greatly improved. Please God don't destroy my family, my children, or our world just after you gave them to us. Please. We have been more cohesive as a family. I see real improvements in our lives. We have been able to go out more to give our children opportunities for adventure, learning and growing than ever before. My life and my family are so much better, words cannot describe. This program saves the lives of children and families that care for them. The impact is unmistakable and real.

Thank you for your time and consideration on this matter. I pray that you do the right thing by allowing parents to continue to provide quality care to their children and include habilitation and no cap on hours.

Respectfully,

Chris Grace

From: shawnece domasin <[redacted]
Date: Saturday, August 19, 2023 at 5:53:55 PM UTC-4
Subject: Good afternoon
To: [redacted]>

https://chng.it/SGQ4N6dLPZ

Attached is 623 signatures for advocacy for parents as paid providers. I would appreciate it if you guys would take a look at it. I have also reached out to 3 state legislators on this issue.

From: Tracy Stewart <[redacted]>
Date: Sunday, August 20, 2023 at 5:59:21 PM UTC-4
Subject: Parent Provider Program
To: [redacted]>

Dear AHCCCS and 1115 Waiver Team –

As an agency that has been contracted with DDD for the past 20 years (since 2005), our organization has observed and participated in the Parent Caregiver program under the Covid-19 Flexibility. I would like to share my company's experience and feedback based on the review of the current proposal for a permanent Paid Parent Caregiver program and our personal observations working very closely with our members and their parents, step parents, primary caregivers (guardians) and family members.

Under the current proposal, while we are excited that AHCCCS is proposing the paid provider program for minor children be permanent, the current proposal does not meet the current needs of the members receiving DDD services.

Habilitation is a critical service. It allows our members a change to gain independent skills by teaching them. These independent skills allows them a change to be functional members of our community and gain skills to have social relationships, job or volunteer opportunities, community involvement, and become more independent in their functional life skills. I respect and can see that AHCCCS has concerns in that there could potentially be parent burn out and/or that parents will restrict members by providing Habilitation Services. As you all know, I am also a parent of an adult and we work closely with our members. Since the parent program began 2 years ago, we have seen an increase in all of the skills I stated above with our members. Even members that are total care, and many thought would not be able to learn skills are. The number one reason I feel this is occurring is because the parents are taking this seriously and providing them opportunities that caregivers have not. Our children believe in us as parents. They trust us to not put them in a situation that is not safe. They want to make us happy and they try harder. With a caregiver, these are strangers that come into their home and not only do parents/primary caregivers have to build a relationship and trust so does the member. With staffing turnover, often times that relationship and trust do not occur as there is a revolving door. Each time a caregiver leaves, we see regression and a significant time that it takes to recoup the skills lost. Also, parents are involved in 90 day meetings and if the Support Coordinators (SC's) are trained correctly they will conduct a meeting to ensure the skills and goals are increasing their independence. If it is not, it should be deemed by the team that Habilitation is not an appropriate service and another service potentially be assessed. Also I would like to address that the number one, most important thing I have seen decrease with the parent provider program is Abuse and Neglect. We have had less reports over the past two years of members being removed by their homes by DCS, parents or legal guardians requesting out of home placement and less investigations for abuse/neglect. That means are members are being cared for with quality caregivers and that is what we all want. I am asking that AHCCCS reconsider allowing parents of minor children to provide Habilitation and Attendant Care services. Rather than following the spouse program (of which they are not), follow the adult program. The age of the member does not matter and the services being provided are the same.

I would also like to address the restriction of 40 hours per week combined between all parents. There are so many concerns surrounding this. The first being, if a member has over 40 hours of services there is an assessed need. It is the responsibility of DDD/AHCCCS and agencies to ensure that the member receives services for what is assessed. Prior to Covid, through the surveys conducted by agencies there was documentation to support a true caregiver shortage. Although we recruit daily, it takes the right person and it is truly looking for that needle in a haystack. Its just not accepting a job. There is extensive training, background checks, fingerprinting, new hire paperwork and that process takes time and is not easy. Providers give up and accept other positions as we are competing with lower end fast food jobs due to our lower salaries. Although we are grateful for the increases we have received, lets face it – caregivers are not compensated for what they should be and that makes recruitment difficult. With a staffing shortage – who is going to provide these critical services? Also with an implementation date of 11/12/23, how are we going to hire enough caregivers to ensure critical services are completed. Then we have the issue with relationship building and trust being built. During this time we will have regression with our members and constant turnover. It is not fair to our members that if a parent or primary caregiver is available to provide consistent services that the member has to suffer with inconsistency and excessive turnover or no services at all.

Additionally, from an agency perspective if implemented how is it going to be controlled. We can tell parents they cannot bill more than 40 hours combined and can control that within our agency but we have no idea what is happening at another agency. They can split hours and we would never know and the support coordinators do not have access to providers and they will not know. Additionally, what constitutes a parent by legal nature. We have always viewed a step parent through marriage as a parent. However, that parent has not legally adopted the member. Are we going to have to request legal documentation that is HIPAA protected in the eyes of the family? How is AHCCCS going to control this and notify agencies on how to implement?

At the end of the day, we all want our members to thrive by having the supports that are assessed implemented. My limiting them to 40 hours and not permitting Habilitation we are going to have a staffing shortage, services not implemented and thus member regression. If it is working than why change it? That is the biggest question.

Medicaid is willing to approve the Parent program as a permanent program. They are also not restricting Habilitation or 40 hours – that is an Arizona policy only. Please consider doing what is right for the member and allowing this program to mirror the parent program for adult children. The age of the member does not matter when you look at each member side by side. The programs are the same.

Thank you for your time and consideration. I can be reached on my cell phone at [redacted]

Tracy Stewart

Executive Director

[redacted]

[redacted]

Remember you're Never Alone with Affinity

From: Chris Ferguson <[redacted]>
Date: Sunday, August 20, 2023 at 6:01:10 PM UTC-4
Subject: Make Parent Provider Provision Permanent
To: [redacted]>

Dear AHCCCS,
My family and I have been fortunate to have access to the parent paid caregivers program. My wife is [redacted] our [redacted] year old daughter is [redacted] nd our [redacted] year old son is [redacted] They both have Autism. Natalie is high functioning and [redacted] is low. The paid program has made it possible for me to not have to work at my current job as much. [redacted] needs a lot of help. He has to get medicine and other supplements at curtain times of the day. He needs a lot of therapies during the week. With having to work as many hours at my other job, and I am now able to help with getting him to and from all of them. It is so hard relying on other people to help with all we need to do on a daily basis. With me getting paid something I can help our family more than any other scenario right now. Thank you so much for all your help and your consideration in extending this option for my family and I.

Dear AHCCCS and 1115 Waiver Team,

As a parent of a child who receives DDD and ALTCS services I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility, and it has been extremely beneficial to our family and my child. I would like to share my personal experiences and feedback based on my review of the current proposal for a permanent Paid Parent Caregiver program.

Under the current proposal, the request of an ongoing program option which allows parents of disabled minors in Arizona to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies is not being met. Please consider updating the proposal based on the following questions, suggested solutions, and personal experiences.

Should Habilitation be included in the Paid Parent Caregiver Program?
We have heard the concerns about member isolation and lack of community involvement if parents continue as Paid Parent Caregivers facilitating their child's Habilitation services. Respectfully the parent caregiver community proposes the following solutions:

1. Examine available research and personal feedback statements from members and their families to

evaluate the true potential impacts of social isolation and community involvement when parents of disabled children provide Habilitation services. The parent caregiver community's collective experience is that members who have parents facilitating their Attendant Care and Habilitation services have experienced greater member social engagement and community involvement over the last three years. Parent caregivers now have an increased ability to take their children to sporting team practices, community events, movie theaters, all ability parks, church activities and libraries. This is because parent providers can perform the appropriately trained and qualified supports in the correct time and location that is applicable to each member.

2. Implement precise guidelines to facilitate generalization for all Habilitation providers regardless of the DCW's familial status. Habilitation services are designed to have goals where data is collected to evaluate if those goals need to be changed, have been met, or need to be addressed differently. For a goal to be considered met, a member should be demonstrating that they are able to successfully meet that goal outside of the timeframe with a provider in one setting. This is referred to as generalization. The effective implementation of generalization with the pediatric IDD population would lessen, if not eliminate, any complications with adult transitional services. Under this model a program that includes parents as paid Habilitation providers would actually assist and improve in the success of adult transition. There are times when disabled children work successfully with different types of providers in clinics or schools, but the parents are not carrying the work over at home. This can happen for a variety of reasons. Having parents as Habilitation providers would help ensure the child's goals are congruent and carried over in the home and community setting. This will give the member a better chance of independence as they transition through different life stages. With generalization policies in place, Habilitation services being performed by parent providers will actually help facilitate successful transition into adulthood.

3. We know from provider agency data that "the top 3 issues regarding recruiting and retaining career non-family caregivers are schedules of the client members, interest in the position and finding qualified applicants." Most members have Habilitation goals and ADLs that are most appropriately delivered throughout the natural routine of their day. A parent provider is uniquely available in the morning, after school or in the evenings when each member is motivated and focused on the pertinent task. If a non-family provider is available their schedules typically allow them to work in longer time chunks that are not always the most ideal for the member and creates artificial goal or ADL practice. Continuity of care and greater member outcomes can be associated with consistently provided Habilitation care by parent providers who have the greatest ability to be flexible and available for their member children.

Should parent providers be limited to 40 hours a week of paid care per child?
We have heard the concerns of AHCCCS regarding the potential for a difficult adult transition to non-family supports once parent caregivers are no longer able or willing to help facilitate the disabled member's care. The parent caregiver community would like to propose the following collaborative solution to create a win-win scenario:

1. Create a program provision that outlines an extraordinary circumstances clause and the application process that allows parents to provide over 40 hours of paid care per week of authorized and evaluated services per member. These extraordinary circumstances could include, but are not limited to:

    a. The lack of a non-parent DCW being available in the last 3 months to fill the member's assessed hours that exceed 40 hours per week. Ongoing DCW searches should continue to be made by the member's agency to fill the assessed hours beyond 40 hours per week of Attendant Care and Habilitation.

    b. The expressed desire made by a member for a parent caregiver to facilitate their assessed

DCW hours so that their Article 9 rights are honored.

c. The profound disabilities and/or significant behaviors of a member where a non-family provider is not equipped to provide DCW support. This determination can be made through a stakeholder team approach, including but not limited to the member's, DDD Support Coordinator, DDD Nurse, DDD Supervisors, Behavioral Plan Experts, Parents / Guardians, Psychologist, or Medical Doctor.

2. Form equality between all Family Provider Programs by allowing all Direct Care Workers, regardless of familial relationship or member age, to provide up to 16 hours of paid care per day. This will allow for employee equality across the lifespan of the member and limit the potential anti-family provider rhetoric currently present within state policies and DDD Support Coordination culture. All evaluations of hours should be based on member needs regardless of who is providing the services to create uniform implementation of all applicable HCBS services by the DCWs available to fulfill those hours.

3. The Family Support Program currently in this proposal addresses caregiver burnout. It is one of the available solutions to facilitate further community support within the disability and caregiver community that will provide greater access to non-profits facilitating counseling services, support groups and meet up activities.

4. Reevaluate Respite reimbursement rates to also address caregiver burnout. If Respite services are not available to the member or their family, parent burnout will continue to be an issue regardless of parents having the option of providing Attendant Care or Habilitation hours. With a comprehensive Paid Parent Caregiver Program in place non-family DCW providers will have greater flexibility to provide Respite services to these same families.

How should current evaluation protocols, training and practices be updated to facilitate equality for all members when accessing member needs?

AHCCCS has stated their intention to amend applicable policy, further suggested action on this topic includes:

1. Forming a committee of community and department stakeholders to amend and critique current DDD and AHCCCS policies and need assessment forms so that the most effective and efficient implementation of this permanent option is utilized moving forward.

2. Provide appropriately determined training and program implementation to DDD and ALTCS Support Coordinators so that Attendant Care and Habilitation hours are equitably evaluated based on the member's needs and to remove organizational bias of familial providers across the member's lifespan. Specifically investigate and determine appropriate DDD staffing needs and training for the members served in rural areas and those from minority backgrounds.

3. Create the option for private sector Support Coordination. Other states have this option within their Medicaid services, and this could be an additional feature in our DDD portfolio to allow for the member's needs to be best evaluated.

In conclusion, Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. By not allowing parents of minors to provide Habilitation and Attendant Care services or work over 40 hours a week most of the minor disabled community in Arizona will be underserved. A comprehensive Paid Parent Caregiver program validates the irreplaceable work that parents provide in their homes and communities.

Click here to connect with the Arizona parent led grassroot initiative leaders:
www.raisingvoicescoalition.com

Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves all DDD and ALTCS members in Arizona.

Thank you!

Thank you again!!

Chris Ferguson
[redacted]

Like Us on Facebook
Follow Us on Twitter

From: Fran Alhadeff <[redacted]>
Date: Sunday, August 20, 2023 at 6:22:36 PM UTC-4
Subject: Parent Providing Habilitation
To: [redacted]>

To whom it may concern,

Please reconsider extending the date for parents getting paid to provide habilitation for their children with autism passed November 2023.

My son has excelled by working with me to get dressed, tie his shoes, and do personal hygiene since I started one and ½ years ago. He worked with at least eight other professionals/organizations, and they could not achieve ONE goal on the list. The people they send have NO experience with children or with ASD. They are not trained and are VERY young. Parents offer unique benefits and advantages that might not be as readily available when hiring a stranger or external habilitation provider.

Here are some reasons why having parents like myself provide habilitation for their autistic children is beneficial:

Intrinsic Understanding: Parents have an inherent understanding of their child that goes beyond what an external caregiver might possess. We are intimately familiar with our child's personality, preferences, triggers, and communication style. This deep understanding helps me more effectively anticipate and address my son's needs.

Strong Bond: A parent-child bond is a foundation of trust and comfort. Children with autism often thrive in environments where they feel safe and secure. Having parents as facilitators provides a sense of security, leading to better cooperation, outcomes, and activity engagement.

Consistency: If you do not know, children with autism often respond positively to routine and predictability. Parents are more likely to provide consistent care and maintain established routines, contributing to a stable and supportive environment for our child's growth and development.

Tailored Approach: As a parent of an ASD son, no one knows my child better than myself. Parents can tailor interventions, create communication strategies and activities to suit a child's specific strengths and challenges. This personalized approach yields a more effective outcome and better progress.

Holistic Perspective: Parents have a comprehensive view of their child's life, including interactions at home, school, and in the community. This holistic perspective allows parents to identify patterns and triggers that impact a child's behavior and well-being, which an inexperienced professional does not have.

Continuous Learning: Parents are often motivated to learn as much as possible about autism and related therapies. We attend workshops, read research, and collaborate with professionals to stay informed. This ongoing learning equips parents with diverse strategies to support their child's development. The people sent to our house have NO training and NO desire to get training. It's just a paycheck.

Emotional Connection: Providing habilitation for our children allows parents to engage in meaningful activities that promote bonding and shared experiences. These positive interactions contribute to my child's emotional well-being and social skills development.

Flexibility and Adaptability: Parents are typically more flexible and adaptable to their child's changing needs. They can seamlessly adjust strategies as the child's skills and behaviors evolve over time, ensuring that interventions remain relevant and effective.

Advocacy: Parents are natural advocates for their child's needs. When we provide habilitation, we can advocate more effectively for our child's individualized requirements, ensuring that interventions align with our child's specific goals.

Promoting Independence: Parents are invested in helping their children achieve greater independence. By providing habilitation themselves, parents can actively support skill development and gradually transition their child to more self-reliant behaviors.

Please let me know if you would like to discuss this further. My number is [redacted]

From: Rene Rebillot <[redacted]>
Date: Sunday, August 20, 2023 at 8:06:00 PM UTC-4
Subject: Parent reimbursement
To: [redacted]>

Yes. It should be permanent. It is hard to find qualified reasonably priced child care

From: Austin Osiecki <[redacted]
Date: Sunday, August 20, 2023 at 8:45:52 PM UTC-4
Subject: Paid Parent Provider Program
To: [redacted]>

Austin Osiecki [redacted]>

Good Evening,

I am writing again as one last ditch effort to provide input from a family that is benefiting from the paid parent provider program. After our meeting on the 2nd, there are a few things that have stuck with me.

1.) If minor members lose access to their habilitation parent provider on 11/11/2023 without having another care worker, the repercussions will go well beyond social isolation:

+ Potential loss of financial security for member and family unit
  ** for our family, we will no longer be able to afford our rent, utilities, food, and basic costs of living
+ Increased stress for the member and their caregiver, in families who are already managing extraordinary levels of stress every day due to medical conditions, schedules packed with therapies and medical appointments, etc.
  ** creating a schedule around my daughter's therapies and classes would be a nightmare, our schedule is very sporadic for 6 hours of therapies per week and 20 hours of schooling
+ If a DCW is available (40 hours/week or more in a lot of cases), this will still mean a complete and sudden change in the member's caregiver. This can lead to potentially disastrous regression in members with autism, Down syndrome, and other developmental disabilities who thrive on routine and consistency.
  ** my daughter is 4 with Down syndrome and autism, she does not accept new people well and will easily become overstimulated with causes meltdowns and rebellion
+ There will not be enough people to fill the DCW openings in November, leading to even more isolation and regressions
  ** I will have to seek other employment outside of the home, taking away any time I had to work on goals with my daughter and having to remove her from several of her therapies
+ If parents have to find other ways to be financially secure and work outside the home, the members are also more likely to not receive care at all, including care outside of Habilitation (Occupational, Physical, Speech, Feeding therapy, etc).
  ** as I stated before, we will need to drop her extra therapies that she is thriving in, in order to accommodate a working mom schedule

2.) If the main concern is socialization, why not simply require that socialization/community goals be a part of every Person Centered Service Plan? These goals are documented, approved and reviewed quarterly with DDD service coordinators and supervised by agencies. As parents, being able to provide habilitation to our children allows us to spend quality time together, be consistent with goals throughout the entire day/night during appointments and typical outings, witness and quantify progress, identify areas of opportunity, play an active role in their development, and strengthen the family unit.
** Four of my daughter's goals require socialization and being out in public, when I was working a typical job, we were unable to participate in aquatic therapy, hippotherapy (horse therapy), visit museums, parks, aquariums, splash pads, etc

3.) Most of our children with special needs are already spending a lot more time than typical children with third-party care providers which greatly increases their risks of becoming sick when most have weakened immune systems, even more so now post-COVID.

** my daughter currently sees 5 therapists on top of friends and family weekly. She ended up sick last week and we have no idea who or what it came from. Adding another person and having them understand that a small cold could easily kill my daughter is not something we are willing to sacrifice.

4.) Finally, in the meeting, AHCCCS participants brought up that we need to think about the long-term impact of this program on members and caregivers, not just the short-term. Allowing parents to continue to provide habilitation to their children would have the following long-term benefits for everyone:

** Improved chance for the members to have independence and self-reliance in the future, thanks to consistent, uninterrupted habilitation services in a natural environment, at the time when the service is the most impactful (toileting, hygiene, safety in and out the house, home care skills, social skills, etc.)

** Improved chance for the parents as they are aging to not have to care for their adult child, therefore reducing burnout

** More DCWs becoming available as trained parent providers will be highly skilled to care for other children/adults

** MORE socialization and additional therapies opportunities creating in a robust learning environment for the member

Again, I appreciate the opportunity to share my thoughts on this program that has greatly benefited my daughter.

Thank you

From: D. Levi Boillot <[redacted]>
Date: Sunday, August 20, 2023 at 11:27:48 PM UTC-4
Subject: Please allow parents of disabled minors become trained and certified
To: [redacted]

Parents of disabled children are desperate. They want help for their child. If there is a shortage of workers, who will help care for those children? Many families don't have two parents in the home. Minor children need caregivers. Especially if they are dependent because of their disabilities.

Please allow parents to become trained and certified and paid as direct care workers to their children to 1) help alleviate the worker shortages and 2) help alleviate the financial strain that comes with caregiving when one isn't able to fully commit to work outside the home due to caregiving responsibilities.

Sincerely, Levi Boillot & Family

From: Carrie Goettl [redacted]>
Date: Monday, August 21, 2023 at 1:49:10 AM UTC-4
Subject: Parents as Paid Care Givers Waiver Ammendment
To: [redacted]

To Whom it May Concern:
Thank you for your continued patience and attention to this matter.
I wanted to share with you our family's experience with a parent provider in the home. First, it looks like strategically planned, naturally occurring experiences with goal completion. Instead of brushing teeth at three in the afternoon, learning to dress or shower at odd times, or make a meal when it isn't meal time, my child is learning scheduling and planning for these things in a natural timeframe as well. He completes them when it is normal to complete them, as part of his day, setting him up for better success as an adult.

Next, it is finding community in our community. In a paper titled " Vulnerability to Loneliness in People with Intellectual Disability", it was repeatedly stated that many instances of isolation and loneliness were "likely" to happen because of a child's disability. There is truth to some of this. But as a mother of Five, my typical children have experienced it to a greater degree than my son with disabilities. He experiences it because his peers outgrow his abilities. However, my son was more isolated without a HAB provider (we have never had a reliable, nor obtainable one in 12 years) than he is with a parent provider. We have taken trips to the mall with friends, gone to the arcade and laser tag, swimming, and play dates, not to mention online gaming with friends. He experiences service opportunities with friends that build a friendship on something more than socializing. He is becoming familiar with the store staff in our area as we frequent the businesses and introduce him and they get to know him and talk to him. He is developing a community of people who love and support him.

My son has apraxia of speech. Because I know his attempts at words, I can help him formulate what to say on his communication device as he speaks to others. This enables him to be with his peers more as he is learning to communicate and be heard. In order for any other provider to know this, they would have to be with him for years. I have seen many of his providers (therapists and teachers) assume they know what he wants and that makes him feel isolated and sad, that they don't take time to really figure out what he is trying to say. This is a crucial area for him.

I have read the Parents as Paid Caregivers Waiver Amendment. I appreciate the goals for parent providers that have been listed therein. We have experienced all of these goals being met with my son. I cannot imagine having that progress removed from him and returning back to no Habilitation service being available to him. I sincerely hope Ahcccs does understand the importance of these goals and the prime position parents are in to accomplish them. The graph in this document also showed the number of parent providers. It could be viewed a couple of different ways, in my opinion: "There are not many parent providers, so ending it won't affect many children." OR "That is a large number of children whose parents 'likely' took on the job because they were not getting the services they needed and that is too large a number to allow to slip through the cracks. It would be in their best interest to continue to allow their parent to provide services to them."

We appreciate your work for our children and the benefit it is to them. We sincerely ask you to keep the parent Habilitation providers on board in the wake of caregiver shortages.

Thank you for your consideration.
Carrie Goettl
[redacted]

---------- Forwarded message ---------
From: [redacted] <[redacted]>
Date: Monday, August 21, 2023 at 1:53:50 AM UTC-4
Subject: NO !!! on 1115 Waiver .
To: [redacted]
Cc: April Romot [redacted]>

Please do not pass 1115 Waiver as it stands.

Parental ability to provide Habilitation is VITAL to the children in our State.

Both ATC and Habilitation are absolutely critical and getting those services on a regular schedule without a lot of breaks in service means the difference between success and failure for our children.

I'm a grandparent of a child with Down Syndrome. I am also a Provider of Home Care Based Services. . With the shortage of workers, and the competition with fast food wages, it's hard to get and keep services.

In our case, we're my daughter to lose the Habilitation hours for pay, she would be forced to get a 3rd job, and her son would have to be cared for by others and be out of the home that much more.

Parents who truly go through the process of becoming an agency employee, justify the hours worked, and are monitored for total hours should be given that opportunity. No one knows these children like their parent/caregiver.

Waiver 1115 does more damage to what the children truly need, takes away services they qualify for and NEED !! Especially when parents live outside of city centers.

I, my family, my friends, and even my employer (an HCBS company) do NOT support the Waiver and emplore you to NOT pass this.

Thank you for your time and consideration,

Registered Voter, Tax Payer, Grandmother, and HCBS Provider

Julie Klein Gabhart
[redacted]

Sent from AOL on Android

From: Whittney Finkas <[redacted]>
Date: Monday, August 21, 2023 at 2:14:25 AM UTC-4
Subject: AHCCCS program
To: [redacted]

Hey AHCCCS program,

Hope you're doing good! I wanted to shoot you a message about something that's been on my mind. I've been working as a Habilitation Care Provider for families with special needs kids, and I've seen some things that I think you should know about.

So, there's this family I've been helping out—they've got this awesome kid (we'll call him [redacted]. He's got the kind of smile that makes your day, and he's the happiest when he's around familiar faces who really get him. [redacted] parents are like superheroes, doing everything they can to give him the care he needs. But here's the thing: finding good Habilitation care providers is like looking for a unicorn. Seriously, it's tough. Before I started working with [redacted], he had gone through 4 different Habilitation Care providers, in a short period of time. And it took a lot of effort for [redacted] parents to train and start to trust these workers, only for it to not work out, and they had to start from scratch all over again.

Now, the AHCCCS Parent Provider Program is in the spotlight because of some proposed changes. You know, the ones that might put a cap and limit on how much parents can do and get paid for when it comes to providing Habilitation services. And that's got me worried for families like [redacted]. I am part of a Facebook group for families of special needs kids, and the parents talk about what a blessing this program of being a paid Parent Provider has been for them. Taking away the parents' ability to care for their kids, especially in such a personal way, just doesn't sit right.

Here's the kicker—I'm constantly getting texts and calls from friends and "friends-of-friends," asking if I can be a worker for their families too. It's kind of flattering, but I can't stretch myself that thin. There's just too much demand and not enough of me to go around. It's frustrating to see so many families struggling to find the help they need.

So, I'm hoping you can keep all this in mind as you're making decisions about the ahcccs/DDD program. Families like [redacted] need more support, and that often comes best from parents who know them inside and out. Keeping parents involved in providing Habilitation Care as a paid provider makes all the difference in the world.

Thanks for listening to my little rant. I know you've got a lot on your plate, but this stuff really matters to families like the one I work for. Your support in keeping parents in the loop would mean a lot.

Thanks again,

Whitney Porter

---------- Forwarded message ---------
From: [redacted]
Date: Monday, August 21, 2023 at 3:09:51 AM UTC-4
Subject: Input for Paid Parent Caregivers
To: [redacted]

To whom it may concern,
My wife and I have 2 children that have services with DDD & ALTCS. We've had services since 2010, at first, we were able to get decent caregivers for HAB, attendant care & respite. But as the years went on, it was very common for workers to refuse to do basic services for our children. Even though we had a list of duties from DDD for each service, the agencies were very lenient towards the workers, telling us they were short on caregivers. My children were missing out on much needed HAB and attendant care!

Everything changed when we were able to participate in the Paid Parent Caregiver Program. My wife and I are able to provide proper attendant care for our disabled non-verbal and non-ambulatory son which includes: bathing, feeding, diapering, medications, appointments, etc. We also work on HAB goals for both children. Our daughter has improved with her reading skills, money management and we are teaching her basic life skills as a part of HAB.

If we are unable to be paid as our children's Attendant Care & HAB workers, our children will be underserved and will regress. We ask that the program will continue to allow us to be paid 40+ hours for Attendant Care and HAB.
Thank you for your time!

Edward Paul Castanon

From: Dean Cook [redacted]>
Date: Monday, August 21, 2023 at 4:06:05 AM UTC-4
Subject: Paid Parent Caregiver program
To: [redacted]

To whom it may concern,

I am the parent/caregiver for my autistic son [redacted]. Since I have been able to work with him on Hab goals I have seen a great improvement in his ability to follow instructions because his comfort level with me is greater than when we had him working with others. I feel the challenges [redacted] will face with the proposed changes will immediately set him back from the progress made. With [redacted] autism I also feel any changes without time to adjust will be detrimental to his progress. Thank you for listening.

Dean Cook
[redacted]

From: Kristina Castanon <[redacted]>
Date: Monday, August 21, 2023 at 4:09:35 AM UTC-4
Subject: Continue The Paid Parent Program
To: [redacted]>

Dear AHCCCS and 1115 Waiver Team,
I am a parent of 2 disabled children and this program has been a tremendous help for me and my husband. We have two disabled children with different disabilities and diseases. Our youngest son required so much that schools would reject him so I homeschool him. Before this I couldn’t get a part-time or full-time job to help my husband provide for our family of 5. We struggled financially very much before this program became available. This program has helped my family so very much because we could bring in income as well as being able to fully provide habilitation and attendant care services ourselves to our two disabled children. We lean upon each other when the other needs a break or rest & it’s a relief to not have a stranger in our home to provide any of these services for us. Our experience with that was not pleasant at all . It was a nightmare. It brought more stress to our family. Many times these caregivers were not wanting to carry so much of a responsibility as to care for a child they did not know or have feelings for. And soon into being hired they would quit, not lasting more than two weeks. This also brought much unrest to our home as well as to our two disabled children. The sudden changes and the addition of adding a new face wasn’t easy for my children to adjust. Not to mention the stress it caused me to train them in the care of our son. Our son is fully disabled in every way. He’s non-verbal , vision impaired, g-tube fed every hour and 15 mins, he’s non-ambulatory , seizure risk, fall risk, has severe mental retardation. He is fully dependent on us for his complete daily hygiene needs & diapering & bathing etc etc… He’s on a morning medication regimen and a nighttime medication regimen. His care is a 24/7 job most days and nights because he also suffers from insomnia so there’s some nights he doesn’t fall asleep even with medication. So our situation is very continuous and challenging. This paid parent program has relieved some of the stress because it has allowed us to spend more time with our children engaging with them as we teach and train them as well as being able to afford family field trips and outings together, which wasn’t possible to do before this program because our income was much next to nothing. Only being able to afford rent some months. But now we can afford rent and an car payment and insurance as well as spending money to invest in our children.
My oldest daughter has autism and a rare bone disease called multiple hereditary exostosis. In

her early childhood years she had a total of 14 surgeries to help correct some of the problems that this bone disease caused. She'll continue to have deformations throughout her young adult life. She's being monitored every 6 months or yearly by multiple specialists/surgeons. She also has some mild mental disabilities. She learns very slowly and needs lots of help with her schoolwork. She struggles socially and has a hard time interacting with her peers. Although she's not as disabled as her brother she still requires lots of prompting and I constantly have to remind and encourage her in her daily routine. She's not fully independent . I am still very actively involved with her daily. She also has therapy appointments weekly that because of Covid I put off but have recently added some to our weekly routine.

Thank you for taking the time to read this email . My hopes in writing this email is to open up your eyes to our daily challenges with our two disabled children . And also to share with you the benefits that this program has provided for a struggling family of 5. Please don't change anything about this program. I serve my son with his habilitation and attendant care services. My husband serves our daughter with her habilitation services. But we're always parenting and that will never end , especially in our situation. We need this program to stay in place and to continue to pay for one parent to serve habilitation and attendant care for one child. 40 hours per week per service. If you cut this program or only allow for one parent to serve only 40 hours per week for one service and for only one disabled child. This will greatly hinder us and our children. It was difficult to find a caregiver before Covid, and it's twice as difficult now. Please don't alter this program in any way. This program enables parents like us to freely provide well-rounded care to our own disabled children in every aspect of their life financially, emotionally, mentally and academically. This program has relieved us of much stress because it allows us the flexibility and freedom to give our children one on one care every day as well as stability and in the comfort of their own home surroundings . And it frees us parents to do so without worrying about money. Please keep this program going. It's the best thing for families like ours .

Thank you

Sent from my iPhone

From: Mirabel Tambalc [redacted]
Date: Monday, August 21, 2023 at 5:33:09 AM UTC-4
Subject: Continued Habilitation for my Son
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To whom it concerns,

I would like to comment in regard to the proposed change in funding of the Parent Provider Program to Minors for Habilitation. I would like for this program to continue as my son has greatly benefited from these service. We have had great difficulty to get outside providers for Habilitation for my son as it takes some time to find a provider through the interview process, and then once we do the providers to not stay for long and we have to start all over.

The home habilitation program through PPP has been a great benefit for our family and our son. My son has made significant progress toward the goals I have been working on. For example, he can now tie a bow for his shoes which he has struggled with for a long time.

Again, we would like to see the current program of PPP habilitation continue so that we can continue the progress we have made with our son. Please look into a proposal to CMS that would allow for this.

Regards,
Marie

From: jennifer zoltz [redacted]
Sent: Sunday, August 20, 2023 10:09 PM
To: jennifer zoltz [redacted]
Subject:

Dear AHCCCS and 1115 Waiver Team,

As a parent of a child who receives DDD and ALTCS services I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility, and it has been extremely beneficial to our family and my child. I would like to share my personal experiences and feedback based on my review of the current proposal for a permanent Paid Parent Caregiver program.

Under the current proposal, the request of an ongoing program option which allows parents of disabled minors in Arizona to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies is not being met. Please consider updating the proposal based on the following questions, suggested solutions, and personal experiences.

Should Habilitation be included in the Paid Parent Caregiver Program?
We have heard the concerns about member isolation and lack of community involvement if parents continue as Paid Parent Caregivers facilitating their child's Habilitation services. Respectfully the parent caregiver community proposes the following solutions:

1. Examine available research and personal feedback statements from members and their families to evaluate the true potential impacts of social isolation and community involvement when parents of disabled children provide Habilitation services. The parent caregiver community's collective experience is that members who have parents facilitating their Attendant Care and Habilitation services have experienced greater member social engagement and community involvement over the last three years. Parent caregivers now have an increased ability to take their children to sporting team practices, community events, movie theaters, all ability parks, church activities and libraries. This is because parent providers can perform the appropriately trained and qualified supports in the correct time and location that is applicable to each member.

2. Implement precise guidelines to facilitate generalization for all Habilitation providers regardless of the DCW's familial status. Habilitation services are designed to have goals where data is collected to evaluate if those goals need to be changed, have been met, or need to be addressed differently. For a goal to be considered met, a member should be demonstrating that they are able to successfully meet that goal outside of the timeframe with a provider in one setting. This is referred to as generalization. The effective implementation of generalization with the pediatric IDD population would lessen, if not eliminate, any complications with adult transitional services. Under this model a program that includes parents as paid Habilitation providers would actually assist and improve in the success of adult transition. There are times when disabled children work successfully with different types of providers in clinics or schools, but the parents are not carrying the work over at home. This can happen for a variety of reasons. Having parents as Habilitation providers would help ensure the child's goals are congruent and carried over in the home and community setting. This will give the member a better chance of independence as they transition through different life stages. With generalization policies in place, Habilitation services being performed by parent providers will actually help facilitate successful transition into adulthood.
3. We know from provider agency data that "the top 3 issues regarding recruiting and retaining career non-family caregivers are schedules of the client members, interest in the position and finding qualified applicants." Most members have Habilitation goals and ADLs that are most appropriately delivered throughout the natural routine of their day. A parent provider is uniquely available in the morning, after school or in the evenings when each member is motivated and focused on the pertinent task. If a non-family provider is available their schedules typically allow them to work in longer time chunks that are not always the most ideal for the member and creates artificial goal or ADL practice. Continuity of care and greater member outcomes can be associated with consistently provided Habilitation care by parent providers who have the greatest ability to be flexible and available for their member children.

Should parent providers be limited to 40 hours a week of paid care per child?
We have heard the concerns of AHCCCS regarding the potential for a difficult adult transition to non-family supports once parent caregivers are no longer able or willing to help facilitate the disabled member's care. The parent caregiver community would like to propose the following collaborative solution to create a win-win scenario:

1. Create a program provision that outlines an extraordinary circumstances clause and the application process that allows parents to provide over 40 hours of paid care per week of authorized and evaluated services per member. These extraordinary circumstances could include, but are not limited to:
    a. The lack of a non-parent DCW being available in the last 3 months to fill the member's assessed hours that exceed 40 hours per week. Ongoing DCW searches should continue to be made by the member's agency to fill the assessed hours beyond 40 hours per week of Attendant Care and Habilitation.
    b. The expressed desire made by a member for a parent caregiver to facilitate their assessed DCW hours so that their Article 9 rights are honored.
    c. The profound disabilities and/or significant behaviors of a member where a non-family provider is not equipped to provide DCW support. This determination can be made through a stakeholder team approach, including but not limited to the member's, DDD Support Coordinator, DDD Nurse, DDD Supervisors, Behavioral Plan Experts, Parents / Guardians, Psychologist, or Medical Doctor.
2. Form equality between all Family Provider Programs by allowing all Direct Care Workers, regardless of familial relationship or member age, to provide up to 16 hours of paid care per day. This will allow for employee equality across the lifespan of the member and limit the potential anti-family provider rhetoric currently present within state policies and DDD Support Coordination culture. All evaluations of hours should be based on member needs regardless of who is providing the services to create uniform implementation of all applicable HCBS services by the DCWs available to fulfill those hours.
3. The Family Support Program currently in this proposal addresses caregiver burnout. It is one of the available solutions to facilitate further community support within the disability and caregiver

community that will provide greater access to non-profits facilitating counseling services, support groups and meet up activities.
4. Reevaluate Respite reimbursement rates to also address caregiver burnout. If Respite services are not available to the member or their family, parent burnout will continue to be an issue regardless of parents having the option of providing Attendant Care or Habilitation hours. With a comprehensive Paid Parent Caregiver Program in place non-family DCW providers will have greater flexibility to provide Respite services to these same families.

How should current evaluation protocols, training and practices be updated to facilitate equality for all members when accessing member needs?
AHCCCS has stated their intention to amend applicable policy, further suggested action on this topic includes:

1. Forming a committee of community and department stakeholders to amend and critique current DDD and AHCCCS policies and need assessment forms so that the most effective and efficient implementation of this permanent option is utilized moving forward.
2. Provide appropriately determined training and program implementation to DDD and ALTCS Support Coordinators so that Attendant Care and Habilitation hours are equitably evaluated based on the member's needs and to remove organizational bias of familial providers across the member's lifespan. Specifically investigate and determine appropriate DDD staffing needs and training for the members served in rural areas and those from minority backgrounds.
3. Create the option for private sector Support Coordination. Other states have this option within their Medicaid services, and this could be an additional feature in our DDD portfolio to allow for the member's needs to be best evaluated.

In conclusion, Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. By not allowing parents of minors to provide Habilitation and Attendant Care services or work over 40 hours a week most of the minor disabled community in Arizona will be underserved. A comprehensive Paid Parent Caregiver program validates the irreplaceable work that parents provide in their homes and communities.

Click here to connect with the Arizona parent led grassroot initiative leaders:
[redacted]

Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves all DDD and ALTCS members in Arizona.

Thank you!
Jennifer Zoltz

Hello!!
Thank you so much for taking the time to read this. My name is Jennifer Zoltz, my husband Chris and I have a [redacted], who has autism, adhd, a chromosome deletion, and is non-verbal. She is our world, and she is amazing. With [redacted] needs, I am with her basically 24/7, with the exception of her tutoring hours. I gave up a while ago to find a habilitator to work with her. It is extremely difficult to find someone that is qualified, willing, able, that actually shows up, and that is a good match. It is hard to even find someone to do respite, so we can go to dinner or a movie on a very, very rare occasion. I can't seem to talk my family into helping, while knowing they can get paid for it.
Habilitation is a position that is very hard to fill, people like to have solid hours for their schedules, not 2 here and 3 there, driving around town. And with gas prices, forget it. I don't blame them. It's a lot of work to work with people with special needs. If you know someone with a family member with special needs, you should shadow them or do respite for one day. It is A LOT.
So back to square one. We know [redacted] best, we provide consistency, support, a loving positive environment, get some communication from her, have the extra time together to have social time with her friends and have community outings, know how to work with her to help her while trying to teach her and so on. There simply aren't enough people to fill this many spots in AZ. The need is so great, and it is a

tough position to keep filled with good employees at all times across the state.

As far as the financial benefit to our family is concerned, it has been a huge blessing to help carry the burden of the never-ending medical bills. I had to quit working to take care of [redacted] when she was diagnosed. Being an autism mom is seriously a full-time job with all the therapies, doctors, etc.. it's like being a professional manager of a person, not to mention the day-to-day life with autism. I have lost track of how much we spend on her care monthly just for supplements and one of her specialists is well over $2200 a month. We charge everything and pay what we can. It's more than our mortgage! It is insanely expensive to have a child with special needs, the extra income has kept us afloat. Please, think about if your son or daughter was in this position, what would you want for them?

Sincerely grateful,
Jennifer

From: Asraa Abd AL Razaq [redacted]
Date: Monday, August 21, 2023 at 8:35:37 AM UTC-4
Subject: Parents paid as a caregiver
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To whom this may concern,
This is Asraa Abd AL Razaq. I am [redacted] mom. Just so you know: [redacted] is a [redacted] nonverbal autistic child. He was born prematurely, at around 24 weeks, and his knowledge and communication skills have increased significantly. Because of this paid caregiver program, [redacted] went from not being able to communicate that he's hungry, to being able to tell us when he wants to walk outside. Now, he still has a long way to go, as he is still incapable of speaking full sentences and speaks a few words, but it is a start. Before starting habilitation, I worked as a security guard. Woeking as a security guard meant that I was able to take care of [redacted], but not to the same segree that I am now. Since starting habilitation, I've been able to teach [redacted] a lot. I have also been able to incorporate methods I've learned from his ABA therapist. I am emailing you to let you know this, and that I hope that this paid caregiver program becomes permanent.

Thank you,
Asraa Abd AL Razaq
[redacted]

From: Ariel Sansom [redacted]
Date: Monday, August 21, 2023 at 9:08:25 AM UTC-4
Subject: 1115 input
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

On August 1st, [redacted] celebrated 14 years of delivering consistent, compassionate, and quality services to our members and their families. Our providers are the heart of our habilitation, respite, and attendant care services by making intentional and equitable connections to their members and families. Many of our providers and families have been with us since the beginning, and no matter how long you have been with the company, we appreciate you and we are incredibly grateful for you! We are honored to grow into our community with you over the next 14+ years!

However, we know that the past few years have brought about a lot of challenges and company-wide changes while trying to provide home and community-based services through a world-wide pandemic and a growing caregiver shortage. When we entered the great unknown of the Public Health Emergency (PHE), we were excited to open a new chapter of service delivery with the parent provider program for minor children flexibility. Throughout the past three years, parents have played a vital role in their children's attendant care and habilitation services. The benefits of this program prompted AHCCCS to continue this flexibility after the PHE through the American Rescue Plan Act (ARPA) until September 2024.

The advocacy efforts of parents across the state have been the driving force for AHCCCS to now permanently expand this program through the Arizona Section 1115 Demonstration Waiver Amendment. While we support AHCCCS and their efforts to improve and sustain the Arizona systems of care for our state's most vulnerable population by permanently implementing a parent provider program for minor children; we anticipate challenges in service delivery if the waiver is implemented as currently written.

[redacted] supports parent providers in being able to provide both attendant care and habilitation for their minor children.

Our families have expressed deep concerns about their minor children experiencing regressions due to the instability this proposal causes. The caregiver shortage will be magnified under the current proposal, knowing that parents make up at least 15% of the workforce for minor services. At [redacted], 93% of our minor members receive at least a portion of their habilitation hours from a parent provider. Minor members who are only eligible for habilitation services are at risk for gaps in their service delivery (41% of our minor members).

The timeline on the draft waiver amendments is also anticipated to go into immediate effect if approved by November 11th. At this time, unless the timeline is extended, we are unable to guarantee the seamless transition of these members' habilitation services from parental to non-parental providers by this deadline. As described, additional AHCCCS workforce development efforts will not be ready or adequate to assist agencies like ours within this anticipated timeline; nor are they a one-size-fits all solution. It takes more than 4 months to recruit, hire, train and match providers with our minor members; especially when taking into consideration member and family preferences, developing trust within the intimate settings of a caregiver role, and variances in availability for scheduling. Lastly, not all of our families can utilize or rely on extended family members or friends to become their child's provider. The solution to the provider shortage is complex. AHCCCS has identified 130,000 vacancies within the direct care workforce, and by excluding habilitation and alienating 15% of the current workforce for minor children; this causes a larger strain on the service delivery system and does not move the community towards filling those vacancies for universal coverage; especially over the next few months if the proposed November 2023 timeline remains as is.

Parent providers are upheld to the same direct care worker standards as any other provider; and provide the same level of access to peer-to-peer support and community access for their minor children. [redacted] believes that both attendant care and habilitation fall within the category of "extraordinary care" as defined by AHCCCS. While there are standards set forth by the Division of Developmental disabilities for these services through assessment matrices, the differences in training and methodology are currently exclusionary and subjective.

The 1115 Demonstration Waiver as proposed is a multi-pronged approach that attempts to address service and family stability, provider recruitment and retention, and continue to transition the community out of the PHE in alignment with standard practices; however, the limitations of the waiver discussed above by excluding habilitation from the parent provider program needs to be further addressed by AHCCCS. We are hopeful that AHCCCS will continue to respond to public comments and feedback, and we trust that AHCCCS will continue to develop and formulate this waiver so that our minor members will continue to be able to adequately access their habilitation services without gaps in service.

Ariel Sansom
[redacted]

From: Chris Chan <[redacted]>
Date: Monday, August 21, 2023 at 11:25:12 AM UTC-4
Subject: Parent provider habituation
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello,

Please allow parents to continue habituation. This has been extremely helpful to my son as I am able to help him develop independent living skills. I am very grateful for this program and want to continue helping my son develop. Without it, I will have to allocate my time to generating income which will not benefit my son with autism.

Thank you,
Chris Chan
--
[redacted]

From: Brithza Allen [redacted]
Date: Monday, August 21, 2023 at 11:52:20 AM UTC-4
Subject: Paid Parent Providers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To whom it may concern,

I would like to introduce myself. I am a single mother of two kiddos with special needs. My youngest son receives services from DDD for Habilitation and Attending Care from me directly. As a single mother having someone not only that I trust but my child has confidence in meeting their needs is important.

He struggles with strangers and any change can severely harm his progress and the potential to become a successful adult in the future. This kind of disruption to his care causes him to have regressive behavior. We have come such a long way with his behavior and teaching him how to calmly react to small changes so that when big changes occur we can overcome those.

I strongly believe that being his parent and providing these services directly to him not only benefit my child but myself as a parent. We have common goals to be successful and I have learned so much with programs about being a better parent. It is very important to my family for us to keep a consistent person in [redacted] life and limit the amount of change to his daily routine.

Thank you for your time.,

Brithza Allen

From: Brittany <[redacted]>
Date: Monday, August 21, 2023 at 2:24:42 PM UTC-4
Subject: paid parent program
To: [redacted]

Hello, to whom it may concern:

I am writing a public comment on how important it is to keep the paid parent program. DCWs are few and far between when it comes to the quality of care someone you love deserves. I understand capping hours at 40 per week but please do not take this very necessary assistance away from our disabled kids. This has allowed parents of disabled kids to get out much more frequently to work on habilitation goals as well as have consistent loving care. Taking this away will take away the consistency as DCW have an extremely high turnover rate and habilitation companies struggle to find providers year round.
Brittany Powers

From: Odessa C [redacted]
Date: Monday, August 21, 2023 at 2:26:29 PM UTC-4
Subject: Public feedback
To: [redacted]

Good morning,

As a parent of a child who receives DDD and ALTCS services I have participated in the Paid Parent Caregiver program since the being of 2023. It has been extremely beneficial to our family and my child. It is very important to have a provider that my family can count on. My son has other services like respite, occupational therapy and speech therapy.

For respite care last year we had a college student as our respite provider. She was wonderful but due to her busy schedule she had to cancel several times.

For speech and occupational therapy we were on a waitlist for quite a awhile before we were able to get on going appointments because we live in the west valley and there aren't as many companies.

The turnover for therapists hasn't be helpful. We're had several cancelations or changes in therapists. We even had to go back to scheduling appointments because of a therapists leaving and the company not having replacements. My son is suppose to have speech twice a week but because we weren't on on going we had to make appointments for whatever time/day. Sometimes we were lucky to get in once a week but it was more likely to get once every two because there wasn't any available appointments. About 2 months ago we finally got back on on going appointments. During that time we've had quite a few appointments canceled because a therapist wasn't available. And we had to change appointment days because another therapist left the company. Also, we're still on waitlists for feeding and aba therapy.

Not having to have to worry about habilitation or attendant care services has been so wonderful. As a parent provider I've been able to provide these services to my son without interruption. I don't have to worry about someone else's schedule and I'm able to work around my son's schedule. Also, some of the goals my son works on are dealing with him in the bathroom or with him unclothed. I don't know if I as a parent would be comfortable with

another adult seeing my child's private areas.

I completely understand why AHCCCS wants to cap hours at 40 to prevent parent burnout. But to limit the parent provider program to just attendant care and removing habilitation would cause more harm than good. Parents would have to try and find someone who would be willing to work around our schedules since we as parents of minor children would still need to be present while a child is receiving services. Due to covid AZ was able to take a huge step forward with the paid parent provider program and became one of many states that allow paid parent provides. I hope AZ keeps moving forward instead of taking a step back.

Thank you,

Odessa Coryell

From: Randi Hilligas [redacted]
Date: Monday, August 21, 2023 at 2:29:46 PM UTC-4
Subject: regarding parent provider program
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

As a parent of a child who receives DDD and ALTCS services I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility, and it has been extremely beneficial to our family and my child. I would like to share my personal experiences and feedback based on my review of the current proposal for a permanent Paid Parent Caregiver program.

My life has improved dramatically in so many ways since I was able to provide services for my son. As a single mom, it was incredibly draining and difficult to provide care for my son as well as work 40 hours a week to provide for him and the rest of my children and myself. I was constantly exhausted and had a very hard time staying patient, as his needs are great and I am his sole caregiver. When I was able to be paid to take care of him, it took a HUGE burden off of him and I. Our relationship has improved dramatically. His outbursts and "bad days" are becoming fewer and less frequent. He is THRIVING under my care, as he always was, but now that I dont have to work 40 hours a week on top of taking care of him, the quality of my care has increased. I cannot tell you how much of a blessing this has been. I have cried with gratitude on more than one occasion. I am begging you, as a parent to please not take this away from us. Getting outside help was a nightmare. I spent 2 years working with childrens advocacy groups that promised to help me, only to be ignored, my calls not returned, never receiving responses from case workers, switching case workers FIVE times and starting all over and working with habilitation providers that never showed up or called. It was incredibly frustrating to deal with an autistic child with absolutely no routine. This program has saved our lives in many ways.

Under the current proposal, the request of an ongoing program option which allows parents of disabled minors in Arizona to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies is not being met. Please consider updating the proposal based on the following questions, suggested solutions, and personal experiences.

Should Habilitation be included in the Paid Parent Caregiver Program?
We have heard the concerns about member isolation and lack of community involvement if parents continue as Paid Parent Caregivers facilitating their child's Habilitation services. Respectfully the parent caregiver community proposes the following solutions:

1. Examine available research and personal feedback statements from members and their families to evaluate the true potential impacts of social isolation and community involvement when parents of disabled children provide Habilitation services. The parent caregiver community's collective experience is that members who have parents facilitating their Attendant Care and Habilitation services have experienced greater member social engagement and community involvement over the last three years. Parent caregivers now have an increased ability to take their children to sporting team practices, community events, movie theaters, all ability parks, church activities and libraries. This is because parent providers can perform the appropriately trained and qualified supports in the correct time and location that is applicable to each member.

2. Implement precise guidelines to facilitate generalization for all Habilitation providers regardless of the DCW's familial status. Habilitation services are designed to have goals where data is collected to evaluate if those goals need to be changed, have been met, or need to be addressed differently. For a goal to be considered met, a member should be demonstrating that they are able to successfully meet that goal outside of the timeframe with a provider in one setting. This is referred to as generalization. The effective implementation of generalization with the pediatric IDD population would lessen, if not eliminate, any complications with adult transitional services. Under this model a program that includes parents as paid Habilitation providers would actually assist and improve in the success of adult transition.

2. There are times when disabled children work successfully with different types of providers in clinics or schools, but the parents are not carrying the work over at home. This can happen for a variety of reasons. Having parents as Habilitation providers would help ensure the child's goals are congruent and carried over in the home and community setting. This will give the member a better chance of independence as they transition through different life stages. With generalization policies in place, Habilitation services being performed by parent providers will actually help facilitate successful transition into adulthood.
3. We know from provider agency data that “the top 3 issues regarding recruiting and retaining career non-family caregivers are schedules of the client members, interest in the position and finding qualified applicants.” Most members have Habilitation goals and ADLs that are most appropriately delivered throughout the natural routine of their day. A parent provider is uniquely available in the morning, after school or in the evenings when each member is motivated and focused on the pertinent task. If a non-family provider is available their schedules typically allow them to work in longer time chunks that are not always the most ideal for the member and creates artificial goal or ADL practice. Continuity of care and greater member outcomes can be associated with consistently provided Habilitation care by parent providers who have the greatest ability to be flexible and available for their member children.

Should parent providers be limited to 40 hours a week of paid care per child?
We have heard the concerns of AHCCCS regarding the potential for a difficult adult transition to non-family supports once parent caregivers are no longer able or willing to help facilitate the disabled member’s care. The parent caregiver community would like to propose the following collaborative solution to create a win-win scenario:

1. Create a program provision that outlines an extraordinary circumstances clause and the application process that allows parents to provide over 40 hours of paid care per week of authorized and evaluated services per member. These extraordinary circumstances could include, but are not limited to:
    a. The lack of a non-parent DCW being available in the last 3 months to fill the member’s assessed hours that exceed 40 hours per week. Ongoing DCW searches should continue to be made by the member’s agency to fill the assessed hours beyond 40 hours per week of Attendant Care and Habilitation.
    b. The expressed desire made by a member for a parent caregiver to facilitate their assessed DCW hours so that their Article 9 rights are honored.
    c. The profound disabilities and/or significant behaviors of a member where a non-family provider is not equipped to provide DCW support. This determination can be made through a stakeholder team approach, including but not limited to the member’s, DDD Support Coordinator, DDD Nurse, DDD Supervisors, Behavioral Plan Experts, Parents / Guardians, Psychologist, or Medical Doctor.
2. Form equality between all Family Provider Programs by allowing all Direct Care Workers, regardless of familial relationship or member age, to provide up to 16 hours of paid care per day. This will allow for employee equality across the lifespan of the member and limit the potential anti-family provider rhetoric currently present within state policies and DDD Support Coordination culture. All evaluations of hours should be based on member needs regardless of who is providing the services to create uniform implementation of all applicable HCBS services by the DCWs available to fulfill those hours.
3. The Family Support Program currently in this proposal addresses caregiver burnout. It is one of the available solutions to facilitate further community support within the disability and caregiver community that will provide greater access to non-profits facilitating counseling services, support groups and meet up activities.
4. Reevaluate Respite reimbursement rates to also address caregiver burnout. If Respite services are not available to the member or their family, parent burnout will continue to be an issue regardless of parents having the option of providing Attendant Care or Habilitation hours. With a comprehensive Paid Parent Caregiver Program in place non-family DCW providers will have greater flexibility to provide Respite services to these same families.

How should current evaluation protocols, training and practices be updated to facilitate equality for all members when accessing member needs?
AHCCCS has stated their intention to amend applicable policy, further suggested action on this topic includes:

1. Forming a committee of community and department stakeholders to amend and critique current DDD and AHCCCS policies and need assessment forms so that the most effective and efficient implementation of this permanent option is utilized moving forward.
2. Provide appropriately determined training and program implementation to DDD and ALTCS Support Coordinators so that Attendant Care and Habilitation hours are equitably evaluated based on the member's needs and to remove organizational bias of familial providers across the member's lifespan. Specifically investigate and determine appropriate DDD staffing needs and training for the members served in rural areas and those from minority backgrounds.
3. Create the option for private sector Support Coordination. Other states have this option within their Medicaid services, and this could be an additional feature in our DDD portfolio to allow for the member's needs to be best evaluated.

In conclusion, Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. By not allowing parents of minors to provide Habilitation and Attendant Care services or work over 40 hours a week most of the minor disabled community in Arizona will be underserved. A comprehensive Paid Parent Caregiver program validates the irreplaceable work that parents provide in their homes and communities.

Click here to connect with the Arizona parent led grassroot initiative leaders:
www.raisingvoicescoalition.com

Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves all DDD and ALTCS members in Arizona.

Thank you!

Randi Hilligas, mother of [redacted], a child with autism who is THRIVING under this program.

From: nalvarado[redacted] [redacted]
Date: Monday, August 21, 2023 at 2:33:35 PM UTC-4
Subject: I would like to continue providing services for my minor child as there is a shortage of providers in the state of Arizona. Thank you. I can be contacted at [redacted]
To: [redacted]

I would like to continue providing services for my minor child as there is a shortage of providers in the state of Arizona. Thank you. I can be contacted at [redacted]

[redacted]
Respectfully
Nery E Alvarado

From: Ingrid Salvador [redacted]
Date: Monday, August 21, 2023 at 2:39:54 PM UTC-4
Subject: Parent provider - habilitation
To: [redacted]

Hi,

I hope all is well.

I would like to express my sincerest gratitude for allowing parents to provide habilitation services to their kids during the pandemic.

I wish that it could parents would be allowed to keep providing these service in the future. It's hard to find dependable providers to provide these services. As you may know, kids with challenges needs routine. Also, there are some habilitation goals where parents are better suited to provide. My son is 8, we have bath goals that we are working on. I don't feel comfortable other people doing these goals with him.

I think 40+ hours of services per child is excessive for the child and the parent.

Thank you so much!

-Ingrid Salvador

From: Jay Duts [redacted]
Date: Monday, August 21, 2023 at 2:42:22 PM UTC-4
Subject: Do not remove Habilitation
To: [redacted]

To whom it may concern:
I, Jerome Duterte, a parent of a minor is against removing the Habilitation because of the following reasons:

1. my kiddos having retrogression will not help with having different habilitation attendant now and then.. And to think they're just undergraduate as said in the meeting in the ahcccs to work likes ojt to fill up the vacancy is not good idea
2. From our experienced with the therapist they usually have habitual absences without make up within the week.. and how the schedule will work with another attendant/provider if you will remove habilitation to the parents of the minor
3. The agency told us if you will remove the habilitation with parents of the minor hundreds of provider is needed to fill up the vacant slot and the kiddos with disability will suffer
4. Habilitation is needed for our kids so we can learn what are their strengths and weaknesses. If we the parents will not be able to work on to it ..We will not be able to help our own kids someday and learn how to handle them.
5 My kiddo and my family needs privacy too
6 My kiddo is verbal but he doesn't know physically what's going on with his surroundings.. He can't even say if he is in pain or if he is physically or sexually assaulted.. How can we help him if another person will come to our house
7 If there is provider who will come to our house, our presence is still needed because our kid is a minor and there is no difference if we become the parent provider.. our care to our kid is beyond the natural support or extraordinary.. We are stress but still we know we're able to help with our best for his frustration and controlling his behavior .. We're able to protect him from harm in which he cannot do by himself.. Every family wants the best for their kids and only family can understand their feelings

Sincerely yours
Jerome Duterte

From: Cory Gonzales [redacted]
Date: Monday, August 21, 2023 at 2:40:01 PM UTC-4
Subject: Parents as Paid Caregiver
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

As a DDD Support Coordinator I have opinions, observations, anecdotes, coupled with a high level of professional experiences, training and education to complete member assessments.

Prior to Covid 19 PHE parents of minor age children could not be direct care workers (DCW) because they are natural supports and as the parent of a minor age child it is their role to teach, support and nurture their child(ren), unless there are extenuating circumstances. During the Covid PHE parents were able to become HAH & ATC providers to avoid allowing other DCW's in the home and risk infection to the member and family. Since the policy change it has become burdensome to complete the assessments for HCBS services. As SC's we were guided to complete an assessment without considering if the DCW is a parent or other provider. With this in mind every child would be assessed for services because children cannot complete daily living skills, community and home safety skills independently nor can they be home alone safely.

Parents of minor age children started calling to request assessments stating their current agency or even agencies they were unfamiliar with reached out to them to become paid providers. I had one agency contact a family out of the blue, the agency got the family contact info from prior vendor calls, to suggest the guardians become the providers. The agency went to the family home, requested banking info and social security numbers of the guardians so they could become DCW's. Now the guardians needed the help but they are not capable of doing the work, which is why the member was assessed. I have had many parents state they want to be DCW's because they lost their job or had a decrease in hours at work. These are often the same parents who have reported over the years that they are unable to help their child learn and develop the necessary skills to live full independent lives. The other problematic area is the agencies contacting parents telling them to request more hours for ATC & HAH. This morning I am completing an HAH assessment. The first assessment was completed 6/28/23 and the child was assessed 6 hours/week because the parents stated they are unable to help their child cooperate when completing ADL's, being safe in the community or using the toilet. Last week the family contacted me stating their agency reached out to them to tell them to request 20-25 hours of HAH because the agency doesn't have available DCW's and they told the parents, who have asked for outside help, to become DCW's. Another mother of triplets was assessed HCBS services because mom has a severe disability and is unable to fully care for her children without proper support. The agency contacted mom, told her to become the DCW and request more hours so mom requested a reassessment. During the reassessment with the agency in attendance, mom said she wasn't disabled, didn't have a job , wants to be the DCW then requested additional HCBS hours to financially support her and the family. In a recent initial ALTCS review the mom came to the review knowing the agency she wanted and the amount of hours she wanted for HCBS services. During the assessment and discussion of parents as natural supports she said she has an autistic child and shouldn't have to be expected to care for him without state financial support because she cannot be employed outside of the home due to meeting his needs. On the flip side, I have one parent who has made a change in parenting as a result of hearing/listening to our conversation about her role as DCW and parent. She has taken extra classes, including positive behavioral supports, within the agency she works with and has searched out other support for her child such as sensory needs, ABA and Cubby sensory beds. This parent does not ask for hours outside of the assessment and we have developed a trusting relationship to help her and the family meet the needs of the member while building a stronger family foundation.

The new policy goes against everything we have been taught to observe and assess for our members and families. It has caused rifts between families and the Support Coordinators because I have had too many meetings where the guardian and agency staff have become aggressive toward me- raising their voices, telling me I don't care about them, I don't understand, I am not capable of knowing my job, etc. It was bad enough we tolerated this while we were virtual but now going into the family homes it is untolerable and there have been times I ended the meeting because of the high level of disrespect toward me. Now, as an SC I have to assess a child member's needs (which are plentiful by the nature of being a child), not consider the role of the natural support and authorize HAH &/or ATC hours without being given a proper guideline by AHCCCS or DDD as to what an appropriate amount of hours are. I am not in favor of this policy at this time without clear AHCCCS and DDD guidelines to differentiate between a natural support and direct care worker role.

Thank you for taking the time to read this email and offering the opportunity to provide my input.

Cory Gonzales
[redacted]

From: Josie Encinas [redacted]
Date: Monday, August 21, 2023 at 3:06:30 PM UTC-4
Subject: Changes to ATC and HAH for parent providers
To: [redacted]

Good afternoon,

I'd like to take the time to introduce myself and my family to you all so you might understand why cutting the hours and services that parents provide might not be a great idea. My name is Josie. My husband Joseph currently provides ATC and HAH to one of our children who receive support services through DDD funded by AHCCCS and ALTCS. Joseph and I have 5 children total and both work outside of the home as well. Our oldest son is disabled and unable to live in our home because of the inability to find providers available and willing to work with him due to the nature of his disability. My husband would gladly work with him, full time, if hours were not cut, and we could also find a provider willing to work with our 11 year old, who is also disabled but very much more manageable for an outside person to work with. Unfortunately, not many agencies have workers, or have people who even want to work. We don't have family available or friends, as most of our close knit community/family work outside of the home. Our 11 year old is visually impaired and has cerebral palsy. Our 12 year old is autistic, ADHD, and bipolar. We also have a 6 year old, 5 year old, and soon to be 4 year old. Most providers that come into our home are overwhelmed with all that we have going on. The ones that have stuck around, have not provided the support or level of care required for my sons. I've had to place cameras in the home to view what is going on when I'm not there. I've caught providers not feeding my son, and denying it with in on camera. I've have so many no shows, it's insane. Since 2020, when the pandemic hit, I believe our family has had 20+ providers. This is not appropriate for children with the needs mine have. It would be crushing to lose the service hours, as no provider sticks around for long term. Please reconsider the reduction in hours and reduction in services parents are able to provide. Also, just because an outside person is performing the service hours, does not mean the client will get socialized more. In fact, I find it to be less, as most providers do not want to transport children into the community at all. Should you allow parents to provide services with no cap in hours, as well as, allowing them to provide skills training(which we do anyways) , it would give families not only the consistency they need, but some sort of financial freedom to not worry about losing a job over a provider no showing. It gives the ability for the family to go and do life enrichment activities. It's gives the client a sense of community. Please think of the whole picture.

Thank you,
Josie Encinas

From: Elizabeth Pratt [redacted]
Date: Monday, August 21, 2023 at 3:41:52 PM UTC-4
Subject: Feedback about paid parent caregivers
To: [redacted]

Dear AHCCCS and 1115 Waiver Team,

As a parent of a child who receives DDD and ALTCS services I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility, and it has been extremely beneficial to our family and my child. I would like to share my personal experiences and feedback based on my review of the current proposal for a permanent Paid Parent Caregiver program.

I am a parent to four kids, two of which are autistic and receive services through DDD/ALTCS. They were both diagnosed during covid and this is the only hab services we've known. They are comfortable with me as a parent being able to help them. Most of our goals are related to hygiene and self care. If they were to take away this program, my kids would refuse to work with anyone else (nor would I as a parent be comfortable having someone else doing these goals). We have made so much progress and it would be a huge step back for us.

I hope you will consider the damage it would do to our vulnerable community members to end this invaluable program.

Sincerely,
Elizabeth Pratt

From: Bob Goodrich [redacted]
Date: Monday, August 21, 2023 at 3:47:29 PM UTC-4
Subject: Parent provider program
To: [redacted]

I am the parent of a teenage son with developmental disabilities. My wife began working with my son during COVID because there were no providers available then. She has been working with my son since then. My son has been doing really well and we have noticed a big improvement in his behavior and overall and positive outcomes from the parent provider program.

If the parent provider program is discontinued it will be extremely hard to find a provider who is available to work with my son and is capable and experienced enough to be as effective as my wife has been with my son. I think the Parent Provider Program has been positive for the participating families and should be continued.

Sincerely,

BobGoodrich
[redacted]

From: Gabrielle Hampton [redacted]
Date: Monday, August 21, 2023 at 3:55:49 PM UTC-4
Subject: Please keep paid parents of minors
To: [redacted]

Hello, i am a parent of a minor and provide habilitation services for my son. My son was diagnosed with level 2 autism and since then, our entire world has changed. We had a loss in the family so we processed the loss plus the change in our family. I'm a college alumni and a mother, I don't have any family out here of my own other than my kids, and honest feedback on this would be that it changed my sons life and my entire family's life with this ability to help my son reach his goals and show him the world. I do have a respite provider to help as needed and it has been just a huge blessing to be able to help my son gain confidence in the world, as his mother I know what's best for him, what are triggers and what we can do to prevent meltdowns. I really want to say thank you for giving me as his mother the opportunity to be his parent provider, to show him the way he knows best, to guide him and nourish him around the clock. I pray and hope this program stays permanently as it changed and help my son progress and also the agency we have been with has provided so much help and encouragement with this process. By obtaining the level 1 clearance, exams, trainings, article 9, when I'm on the clock I work, and I work with a heart full of love, patience, and reliability. All while making sure my son is well taken care of, and there's never one day I won't show up or call out. I do this around the clock to support him and his needs, registered through the state, I have obtained additional trainings to help me as a habilitation provider and I have exceeded all expectations and have reliability with my son and his goals.

Again, thank you so much and I pray this program to provide habilitation to minor children STAYS as it has shown a huge increase in dependence, reliability, progress, happiness and dedication.

Thank you for everything and everything you guys continue to do for our families.

-Gabby Hampton

From: Amanda Wyble [redacted]
Date: Monday, August 21, 2023 at 4:01:26 PM UTC-4
Subject: Parent Provider Feedback
To: [redacted]

Good afternoon,

I think the parent provider program should remain in place without a 40 hour restriction and habilitation should be included.

My twins have both benefited from parent provider program. In the past, I was unable to secure providers for my kids. Our support coordinator would put out vendor calls and I would be contacted by various companies but none ever came through with a provider. Vendors and our support coordinators would always suggest finding friends or family willing to become providers. That simply isn't an option for so many families, including ours.

Additionally, minor children are in school for a large portion of the day (plus outside therapies and medical appointments) leaving only early mornings, evenings, and weekends open for services. This makes it even harder to find providers.

Placing a 40 hour restriction in parent providers is unreasonable, especially in cases where there are two parents that are restricted to 40 hours between them. I heard in one of the hearings that this is to prevent worker burnout. If that was the case, there would be a cap of 40 hours per week per provider regardless of whether they were of any relation to the member.

Parents should be able to provide habilitation to their children. In one of the hearings, I heard that this allows the member to be around non-family members and learn to work with others. Most of our children have to interact with numerous other people throughout the day. They are with teachers, bus drivers, aids/paras, therapists, doctors, nurses, and other direct care workers. Some days, it can be overwhelming how many workers they have to accept into their lives.

One of my twins is in diapers. Being a parent provider has allowed my son the opportunity to work on toileting goals with someone he feels safe with. I think it is also important to note that regardless of the amount of training or preemployment background checks, the more people we involve in our children's basic toileting and hygiene needs, the more vulnerable they become.

I urge you to include habilitation in the parent provider program and to eliminate the proposed 40 hour cap.

Thank you,

Amanda Wyble

From: Justine Riley [redacted]
Date: Monday, August 21, 2023 at 4:03:27 PM UTC-4
Subject: Paid Parent Providers
To: [redacted]

Hello,

I am writing this email to give my input into the decisions going on regarding the paid parent provider program. Looking for consistent qualified providers for my child has been nearly impossible since the covid disaster. I have not had luck with finding and keeping a provider for any service for long. I struggle to obtain respite, habilitation, and attendant care providers. When I learned that I could certify and complete these needs on my own, I was nervous, but happy. Now that I have been my child's provider for a year, the growth he has shown is amazing. I know that our routine and the consistency of what we have built matters and has contributed to his growth, steady growth. Thinking about scrambling to find providers for his needs and then have to go through the process countless times with no light at the end of the tunnel makes me nervous because of the effect it will have on my child. If you discontinue the paid parent providers program I believe many children with regress and it will have a tremendous effect on families. Please consider my input in your decisions regarding this amazing program that has assisted special needs children in reaching their goals.

Thank you,

Justine Riley

From: Jennifer Lalone [redacted]
Date: Monday, August 21, 2023 at 4:26:29 PM UTC-4
Subject: Parent paid Habilitation provider
To: [redacted]

I am writing you to please consider keeping the parent paid hab services. Being a paid provider for my son has been beneficial for my son. My son doesn't like strangers coming into the home and it takes him a long time to warm up to them. Finding a steady consitant provider willing to service the city of Maricopa is also hard to find. The extra income has helped our family go on more outings to work on my sons safety goals in the community.

Sincerely

Jennifer Lalone

From: April Enriquez [redacted]
Date: Monday, August 21, 2023 at 4:34:59 PM UTC-4
Subject: Parent provider program
To: [redacted]

Hello, My names is April Enriquez, I am a parent paid provider for my [redacted] daughter [redacted]. [redacted] has Autism and a fear of people and places like most children. Therapies alone with the same providers are incredibly difficult on certain days due to [redacted] diagnosis. Being able to be her provider has dramatically changed her life as well as mine. Since I am in fact, her parents she's obviously comfortable with me. Being able to work on her goals for daily needs and have the financial compensation has been such a blessing. Since starting this journey her speech, safety awareness, daily hygiene needs have increased dramatically. She is now able to start conversation, use the bathroom and do basic care actions with assistance. Things that we take granted for on the daily are always a struggle for her. Since being able to be home and have this extra time she has grown in ways I could never imagine. If I had to go back to working a regular job, my daughter would struggle in every way. AHCCCS and DDD are programs to help the people. The are designed to support the needs of people like my daughter. In taking away the parent provider program you would be doing a disservice to not only my daughter, but every child under DDD. I am begging you to listen to the parents! The way our kids will struggle if you take this program will cause distress. Phoenix already has a lack of provides and therapists. My daughter has been on a waiting list for occupational therapy for three years!!! The west valley in which I live in is so underfunded financially, as well as with providers. I hope in sharing my story you better understand the way this program has impacted the lives of Autistic children and their parents. Please do not take this blessing from us.
Thank you for your time,
April Enriquez

From: Lisa Lamb [redacted]
Date: Monday, August 21, 2023 at 4:38:36 PM UTC-4
Subject: HAB parent program
To: [redacted]

Hello,

I wanted to reach out to tell you how important having HAB for our daughter, done by me, her go to person and caregiver has been life changing.

By not having "new people" in the home all the time and having to explain her Syndrome and goals, how to work with her appropriately has give us the time to really focus on her areas of difficulty. There is no adjustment period, no anxiety, no judgments, and the best part, I get to work her goals into our everyday life- and she has no clue we're even doing it.

She has gotten stronger, trying harder things and not giving up because she doesn't want to let me down.

Please do not take this program away from us. This is changing our children's lives and our family all for the positive.

Thank you-

Lisa Lamb
[redacted]

From: Marisa Hernandez [redacted]
Date: Monday, August 21, 2023 at 4:44:11 PM UTC-4
Subject: Paid Parent Caregiver program
To: [redacted]

Dear AHCCCS and 1115 Waiver Team,

My name is Marisa Hernandez. I live in Ajo, Arizona with my two children. My son, [redacted], is a [redacted] member of the Tohono O'odham tribe. [redacted] is autistic with speech and language impairment and receives DDD and ALTCS services. I am currently participating in the Paid Parent Caregiver program under the Covid-19 Flexibility. This program has been very beneficial for my son and our family. It has allowed my son to receive the services to which he is entitled. I am very grateful for this. I would like to share my experiences and feedback based on my review of the current proposal for a permanent Paid Parent Caregiver program.

Our community is small, rural, and historically underserved. The employment pool is small. As a result, [redacted] did not receive the Home and Community Based services for which he is qualified until I became a certified Direct Care Worker. As his provider, I am currently providing attendant care and habilitation services for [redacted]. My attempts to find a respite care provider have proven unsuccessful. I have had people start the process but none have followed through to become certified. As a result, [redacted] has never received respite care, though he has qualified for this service for years. The vendor call his support coordinator has put out has gone unanswered.

I attended the community forum about the Paid Parent Caregiver program on August 2, 2023. While I appreciate the movement toward making the Paid Parent Caregiver program permanent, I have concern over the removal of habilitation as a service I can provide to my son. Because of the lack of DCWs, I fear he will never again receive habilitation services if I am not allowed to provide it for him. I heard some ideas that are being put in motion to potentially increase the pool of DCWs. My concern is I did not hear anything that will address the shortage in rural areas such as Ajo. I also did not hear a plan of action to ensure my son does not lose his services. This is very worrisome as my son is routinely overlooked and unconsidered, programs and services are not created and implemented with my son and our family in mind.

There was some discussion during the forum about the risk of member isolation if parents are providing habilitation services. For my son, I hold the opposite concern. [redacted] finds it difficult to cope with people outside of our immediate family in his home for extended periods of time. He currently attends school 5 days a week for 4 hours a day. He has an abbreviated schedule because he cannot cope with an average school day, at this time. His team and I are working to increase his time at school, as his stamina builds. I know that having an outsider working on habilitation goals with him before and after school will likely cause regression in his educational progress and decrease his time with his peers. He has a limit to how long he can be “on” and meet expectations placed on him by outsiders. I have spent years building trust with my son and honoring his needs. I do not wish to break this by insisting he work with someone unfamiliar with him after a long day at school. I also do not want to tax his stamina for attending events with family and in the community. This time is important for him and to our family.

Thank you for taking the time to learn more about my son and our family's experience. I appreciate your work and your consideration.

From: Kimberly [redacted]
Date: Monday, August 21, 2023 at 4:48:00 PM UTC-4
Subject: Continue parent provided program
To: [redacted]

Hi-
Please consider continuing the parent provider program. It has been greatly beneficial for our family.

Sincerely,
Kimberly Barua
[redacted]

From: Anthony Meyer [redacted]
Date: Monday, August 21, 2023 at 4:52:08 PM UTC-4
Subject: Paid Parent Caregivers in Arizona
To: [redacted]

Dear AHCCCS and 1115 Waiver Team,

As a parent of a child who receives DDD and ALTCS services I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility, and it has been extremely beneficial to our family and my child. I would like to share my personal experiences and feedback based on my review of the current proposal for a permanent Paid Parent Caregiver program.

We relocated to AZ last year from CO due to limited school options for my son with Autism Level 2. Previous to this year, my son was lacking on the right support at school from teachers to paras and curriculum tailored for kids in the spectrum. My son continued to get more and more behind, and we made the tough choice of leaving CO away from our family to come to AZ where we have more options available. With that we made sacrifices and really appreciated the option to be paid as caregivers due to the limited staffing options available. It is very hard to do all regular activities with my son. We also understand the limitations with recruiting and retaining career non-family caregivers.

The parent caregiver community's collective experience is that members who have parents facilitating their Attendant Care and Habilitation services have experienced greater member social engagement and community involvement over the last three years. Parent caregivers now have an increased ability to take their children to sporting team practices, community events, movie theaters, all ability parks, church activities and libraries. This is because parent providers can perform the appropriately trained and qualified supports in the correct time and location that is applicable to each member.

My son is eleven years old but developmentally he is more like a 5 year old. He needs constant attention to do simple tasks and has speech, gross, and fine motor delays. We understand his needs better than anyone else. Being able to assist with both attendant care and habilitation support will help our son to continue to master goals and be out in the community doing activities that will expand his cognitive and motor skills.

Thank you for listening and do not hesitate to reach out for any questions.

Studies and data that support the changes being requested:

Data results from a 2023 Arizona survey of parents who have children with disabilities:
https://docs.google.com/document/d/16PZOk99caDUitg0XmQKqEv2mxXOBeaRywSD_zmjAnYw/edit?usp=sharing

A report on the current caregiver crisis by the National Association of Homecare and Hospice:
https://www.hcaoa.org/uploads/1/3/3/0/133041104/workforce_report_and_call_to_action_final_03272023.pdf

Higher satisfaction of paid supports for adults and minors with disabilities when care is received from paid family providers:
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1089106/

A comparison of healthcare utilization when children receive paid care by a family member vs non-family provider: .https://www.jpeds.com/article/S0022-3476(23)00106-3/fulltext

Youth with Autism Spectrum Disorder have less ED visits and patient outcomes when patient providers are involved: https://www.reliasmedia.com/articles/148366-autism-spectrum-disorder-in-the-emergency- department

https://www.psychiatrist.com/jcp/mental/child/youth-with-autism-in-the-emergency-department/

An evaluation of parent provider involvement in generalization of children with autism:
https://www.sciencedirect.com/.../abs/pii/S0891422205000958

Impacts of the caregiving relationship: https://academic.oup.com/gerontologist/article/56/6/1102/2952858

State Approaches to Reimbursing Family Caregivers of Children and Youth with Special Health Care Needs
through Medicaid - NASHP
https://drive.google.com/file/d/1TSt-Rj95DTn711EV8UTq7YqF0yoo0j8u/view?usp=sharing

Thank you,
Laura Meyer

From: M. Dentremont [redacted]
Date: Monday, August 21, 2023 at 4:59:53 PM UTC-4
Subject:
To: [redacted]

I am sending thimerosal in regards to Parent Providers. I think it is a travesty to consider this to be cancelled as many including myself have kids with special needs. Many kids do not take to outside strangers abd it is difficult to find Providers. Parent providers really helps the needs of the kids. It would be unfair to remove the program for many parents. Kids are fragile and need the parents.

Please keep the providers in AHCCCS thank you

From: Natalie Jasso [redacted]
Date: Monday, August 21, 2023 at 5:52:30 PM UTC-4
Subject: HAB for minor children
To: [redacted]

To whom it may concern,

I'm writing on behalf of myself, my husband and our minor child who is a DDD member.

We are deeply concerned with the proposal to take away the ability for parents to provide HAB for our minor children.

There are many benefits for us as a family to help support out child, and having safeguards in place when providing HAB goals for our children with sensitivity natured goals (ie-learning how to dress, bathe, potty training). These are goals of ours that I would never let any other provider provide with my child.

Parents of minor children are not burned out from caring for our children in this matter. We are burned out from having to keep advocating for our children.

We do not know what we will do if HAB is taken away from us as parents, but we do know that waiting lists for services are long at every agency in our state. Where will these providers come from November 12? There are not enough in our state for immediate support.

Please reconsider your proposal and please keep parent providers for minor children for HAB. This issue impacts many parents in the state of Arizona, and the affects of it being taken away will be vast.

Regards,
Natalie Jasso

From: Chris Chan [redacted]
Date: Monday, August 21, 2023 at 6:07:23 PM UTC-4
Subject: Parent provider habituation
To: [redacted]

Also to add to my last email.

It has been almost impossible for me to find someone to care for my son with autism. There are no providers who are willing to care for a special needs child.

From: Maria Eugenia Wilson <[redacted]>
Date: Monday, August 21, 2023 at 6:15:26 PM UTC-4
Subject:
To: [redacted]

Dear AHCCCS and 1115 Waiver Team,

As a parent of two children who receive DDD and ALTCS services I have participated in the Paid Parent Caregiver
program under the Covid-19 Flexibility, and it has been extremely beneficial to our family and my children.
The program has allowed us to work intentionally writing goals and has enabled us to see our children progress in amazing ways. We had otherwise waited for services and providers and did not have any habilitation or respite providers. The shortage in our state is abysmal and our children need early intervention now, time is of the essence. We have also been able to receive financial support, as a parent of two children with ASD, it is really difficult to have a full time job. Our days include occupational therapy, speech therapy, appointments with specialists and some extra curricular activities to expose the kids to typical developing model peers.

Thank you for considering us. We are asking for the Paid Parent Caregiver program to continue.

Thank you,

Maria Eugenia Wilson

From: ShenanaGrims - <[redacted]>
Date: Monday, August 21, 2023 at 6:19:55 PM UTC-4
Subject: Parent Provider Feedback
To: [redacted]

To Whom It May Concern,

Good afternoon and thank you for taking time to receive public feedback on the proposed changes to the waiver regarding parent providers and elimination of habilitation services by parent providers.

First thank you for all the efforts that were made to propose making parent providers a permanent choice for your clients our disabled children.

I am writing to give you our families concerns regarding eliminating the parent's ability to provide habilitation. Our children are non-verbal and communicate through physical expression. We had to pull my daughter out of school and begin to homeschool her because she became aggressive all of the sudden with other people trying to change her pull up and toilet her. We believe this is because she was molested at school. She is communicating clearly that she does not want anyone else personally caring for her this way and teaching her potty training skills and personal care activities (all hab goals) she is only peaceful when I myself or my husband helps her with these goals. Why are our Children's preferences not being considered in this decision? Why should we rob them from the choice of care providers?Just because they are non verbal does not mean that they cannot communicate who they feel safe with caring and supporting them in their goals. If HAB is taken away we certainly cannot put our children (especially those who have been thru the trauma of sexual molestation) into a strangers care who they don't trust.

Are you aware that in Arizona the statistics of nonverbal females who are sexually molested by their unrelated care providers is above 90% and for non- verbal males it is nearly 75% and that in both cases they are molested at least ten times before they found out?

In conclusion by robbing our children who need such personal care goals the option to decide who the trust in helping them with these goals is absolutely detrimental to their safety and goes against their rights as human beings. Please do not rob our children of this choice.

Thank you for considering my words and plea in advocating for our precious children.

Sincerely,

Megan Grim
Parent Provider
Of CJ Grim and Jackson Grim

From: Betsy Norris <[redacted]>
Date: Monday, August 21, 2023 at 6:38:05 PM UTC-4
Subject: Parent Provider Habilitation
To: [redacted]

Dear AHCCCS and 1115 Waiver Team,

I hope this letter finds you well. As parents of three boys, two of whom are beneficiaries of DDD services, we wish to address the vital question of including Habilitation services in the Paid Parent Caregiver Program. Our personal experience with this program has been transformative, leading us to advocate for its continuation and expansion.

Our younger son, diagnosed with autism, is an active participant in public school and extracurricular activities alongside his typical peers. The flexibility offered by parent-provided services allows us to seamlessly integrate his habilitation goals into his daily routines, ensuring he receives the necessary support while maintaining his commitments. Our older son, who is dual-qualified under epilepsy and autism, faces more complex challenges. His unique combination of medical needs and behavioral complexities has made it challenging to find suitable educational and therapeutic environments. He requires attentive supervision to prevent wandering and elopement, and his busy schedule involves in-clinic therapy and adaptive activities. As his habilitation provider, we are empowered to ensure he practices essential life skills during moments when he's most receptive or incorporate them into our family outings.

While we understand concerns about caregiver burnout and community engagement, we'd like to share that the flexibility provided by this program, coupled with the support from the agency employing us as parent providers, has enabled us to address our older son's needs within the comfort of our home while adhering to his therapy schedule. This initiative simultaneously enables our younger son to flourish more typically at school while receiving essential support at home.

Our personal experiences demonstrate the profound impact of the Paid Parent Caregiver program on our family's life. The ability to tailor habilitation and attendant care services to our sons' unique needs has facilitated their growth, development, and community engagement in ways that would have otherwise been incredibly challenging.

We urge you to carefully consider the remarkable positive implications that the Paid Parent Caregiver habilitation program can have for families like ours. This program recognizes the invaluable role parents play in supporting their children's growth and development and contributes to their overall well-being and potential while acknowledging the extraordinary care we must provide.

Thank you for your dedication to this crucial initiative and for prioritizing the well-being and potential of children like ours. Your commitment to making a difference in their lives is sincerely appreciated.

Sincerely,
Betsy Norris
[redacted]

From: Tyler Grim <[redacted]>
Date: Monday, August 21, 2023 at 6:33:52 PM UTC-4
Subject: AHCCCS Parents as Paid Caregivers (PPCG) Proposal
To: [redacted]

To Whom It May Concern,

Good afternoon and thank you for taking time to receive public feedback on the proposed changes to the waiver regarding parent providers and elimination of habilitation services by parent providers.

First thank you for all the efforts that were made to propose making parent providers a permanent choice for your clients our disabled children.

I am writing to give you our families concerns regarding eliminating the parent's ability to provide habilitation. Our children are non-verbal and communicate through physical expression. We had to pull my daughter out of school and begin to homeschool her because she became aggressive all of the sudden with other people trying to change her pull up and toilet her. We believe this is because she was molested at school. She is communicating clearly that she does not want anyone else personally caring for her this way and teaching her potty training skills and personal care activities (all hab goals) she is only peaceful when I myself or my wife helps her with these goals. Why are our Children's preferences not being considered in this decision? Why should we rob them from the choice of care providers? Just because they are non verbal does not mean that they cannot communicate who they feel safe with caring and supporting them in their goals. If HAB is taken away we certainly cannot put our children (especially those who have been thru the trauma of sexual molestation) into a strangers care who they don't trust.

Are you aware that in Arizona the statistics of nonverbal females who are sexually molested by their unrelated care providers is above 90% and for non- verbal males it is nearly 75% and that in both cases they are molested at least ten times before they found out?

In conclusion by robbing our children who need such personal care goals the option to decide who the trust in helping them with these goals is absolutely detrimental to their safety and goes against their rights as human beings. Please do not rob our children of this choice.

Thank you for considering my words and plea in advocating for our precious children.

Sincerely,
Tyler Grim
Parent Provider
[redacted]

From: Allison Bourget [redacted]
Date: Monday, August 21, 2023 at 6:58:01 PM UTC-4
Subject: Inclusion of Parent-Provided Habilitation in the Paid Parent Caregiver Program: A Pivotal Step Forward
To: [redacted]

To whom this concerns,

I trust this message finds you in good health. I am writing to passionately advocate for the inclusion of parent-provided habilitation services within the scope of the Paid Parent Caregiver Program. This addition has the potential to create a transformative impact on the lives of both caregivers and care recipients. I am eager to outline several compelling reasons for this inclusion using bullet points:

Empowerment of Parent Caregivers: Inclusion of parent-provided habilitation acknowledges the significant role parents play in the developmental journey of their children with special needs. It empowers parents to actively engage in skill-building activities that foster their child's independence, while also offering them the financial support they rightfully deserve.

Holistic Approach to Care: Parent-provided habilitation services encompass a holistic approach to care that emphasizes not only physical well-being but also cognitive, emotional, and social development. This approach recognizes that parents possess unique insights into their child's needs, enabling them to tailor interventions to best suit their child's progress.

Enhanced Care Consistency: By allowing parents to provide habilitation services, the care recipient benefits from a consistent caregiving approach. Parent caregivers are intimately familiar with their child's routines, preferences, and challenges, ensuring a seamless transition between different care activities.

Cultivation of Trust and Comfort: Care recipients often feel most at ease in the presence of their parents. Inclusion of parent-provided habilitation services facilitates an environment of trust and comfort, enhancing the care recipient's willingness to engage in therapeutic activities and skill-building exercises.

Personalized and Tailored Interventions: Parents possess an innate understanding of their child's strengths, weaknesses, and developmental goals. Inclusion of parent-provided habilitation allows for interventions that are uniquely suited to the individual needs and aspirations of each care recipient.

Strengthening the Parent-Child Bond: Parent-provided habilitation deepens the bond between parent and child. Engaging in purposeful activities together fosters a sense of shared accomplishment, nurturing emotional connection and boosting the care recipient's self-esteem.

Cost-Effective Solution: Parent-provided habilitation can be a cost-effective solution for families, as it utilizes existing resources within the family unit. This approach can result in more efficient allocation of resources, benefiting both caregivers and the broader healthcare system.

Diverse Skill Development: Parent-provided habilitation enables parents to work on a diverse range of skills with their child, such as communication, social interaction, motor skills, and self-care. This comprehensive approach contributes to the overall growth and development of the care recipient.

Continuity of Care Philosophy: The inclusion of parent-provided habilitation aligns with the continuity of care philosophy, wherein parents seamlessly transition from providing daily care to actively participating in therapeutic activities, resulting in a well-rounded approach to caregiving.

Parental Advocacy and Empowerment: Involvement in habilitation services empowers parents to become effective advocates for their child's needs, leading to more informed decision-making and a greater sense of control over their child's developmental journey.

Validation of Caregiving Role: Including parent-provided habilitation in the program recognizes the invaluable caregiving role that parents play in the lives of their children with special needs. It reaffirms their dedication and contributions within the caregiving ecosystem.

The inclusion of parent-provided habilitation services within the Paid Parent Caregiver Program represents a significant step towards fostering a more inclusive, supportive, and empowering caregiving environment. This progressive approach not only strengthens the parent-child bond but also acknowledges the crucial role parents play in shaping the development and future of their children with special needs.

Thank you for considering this important proposal. I am confident that by embracing this recommendation, we can collectively contribute to a brighter future for parent caregivers and their care recipients. If you require further information or would like to discuss this proposal in more detail, please do not hesitate to reach out.

Warm regards,

Allison Bourget

[redacted]

From: [redacted]
Date: Monday, August 21, 2023 at 7:06:40 PM UTC-4
Subject: Keep Paid Parent HABILITATION providers!
To: [redacted]

Dear AHCCCS,

Don't you do it.

Don't you dare toss out paid habilitation to parents.

You would just send us back to the sh*thole Direct Care Worker wasteland, where the few candidates who do apply end up not showing up or not cutting their nails, or they look like they were picked out of a police lineup.

Do not go back to the "way things were" with hab before Covid.

Keep Paid Parent habilitation.

Joanna Galuszka

On Tuesday, August 15, 2023 at 12:18:25 PM MST, [redacted] wrote:

Dear AHCCCS and CMS,

Who specifically suggested that AHCCCS stop paying parents to provide habilitation for their minor children?

Please release this person name (or these people's names).

Ending paid-parent hab is the Worst Idea in the History of Medicaid.

It is terrible and offensive.

AHCCCS knows very well that they pay Too Little for anyone else to Want to provide habilitation for our kids.

AHCCCS and CMS, please Defund the people who thought of this harmful idea. Let them work for nothing on this, then find an outside job to pay their bills.

That's what they expect parent providers to do.

Joanna Galuszka

On Wednesday, August 9, 2023 at 01:06:05 AM MST, <jgal...@yahoo.com> wrote:

Dear Ms. Heredia and officers at CMS,

I noticed that the latest 1115 waiver proposal asks to keep paying parents to provide ATC (attendant care) to their children who qualify, with a cap of 40 hours per week.

That's great! But what about paid parent providers of Habilitation?

Arizona still suffers from a lack of adequate Direct Care Workers.

Why wouldn't you let parents continue to get paid to provide habilitation services?

Please put paid parent habilitation providers back in the proposal.

We parents are the only ones who are willing to do it.

Sincerely,

Joanna Galuszka

On Saturday, August 5, 2023 at 12:38:13 AM MST, [redacted] wrote:

Dear Ms. Heredia and CMS officers,

Do you remember the months (possibly years) of ALTCS parents filing Quality of Care complaints about not being able to find suitable habilitation or respite providers?

I had a provider quit because I asked him to trim his fingernails, because he'd accidentally scratched my kid.
This provider said he didn't get paid enough (to cut his nails).

Well, the covid pandemic fixed that problem.

No longer did we parents have to deal with high provider turnover, if the providers showed up at all.(Someone could get a job at Starbucks for similar pay.)

Now, we the parents are paid to provide habilitation for our kids.

DO NOT END THIS AMAZING FIX TO THE ONCE-BROKEN HCBS SYSTEM. We parents are the ONLY ones who are willing to do this work for these modest wages.

And these difficulty-of-care payments, modest as they are, have lifted many of these families out of desperation.

There is no way I could take care of my kid and work outside the home. Now I can help my kid and receive payments so we can survive.

The argument that paid parent habilitation might lead to isolation is pure baloney.
You know what leads to isolation? Having questionable candidates come and go every few months. Being too poor to take kids anywhere to socialize. Spending precious time filing Quality of Care Complaints when I could be helping my kid.
Please! Keep the paid parent habilitation program. Please! Extend it permanently (or at least as long as possible.)
It took a literal plague for this positive change to happen. Please--I don't want to have to wait for another pestilence, or boils or frogs or sick livestock, before I can get my kid the help he needs.
Sincerely,
Joanna Galuszka
Phoenix, AZ

On Thursday, February 18, 2021 at 09:17:47 AM MST, [redacted] wrote:

Dear Officials at U.S. Department of Health and Human Services,

The Covid-19 pandemic has led to a hallelujah moment for Arizona parents of children with developmental disabilities.

Your department enabled Arizona's Medicaid program, AHCCCS, to pay parents to provide habilitation (HCBS) services to their own children.

Please, for the love of all that is holy and good: Keep This Change, Even After the Pandemic Ceases!

You have inadvertently Solved the hab-provider crisis. Before the pandemic, it was next to impossible to find a high-quality, long-term habilitation provider. The pay was low and the turnover was high.

But we parents? We Love our kids and we'll do anything for them. Letting us get paid to provide our kids' habilitation is a Win-Win-Win!

I am grateful for the pandemic for inspiring this idea. It's the best idea someone ever had. Please.

Keep the change.

----- Forwarded Message -----
From: [redacted]
To: [redacted]
Cc: [redacted]
Sent: Saturday, December 26, 2020, 10:30:13 PM MST
Subject: Best Change from Covid 19: Please Keep Parents as Habilitation Providers

Mr. Wisehart and Mr. Garcia Ramadan,

The Covid-19 pandemic has led to a hallelujah moment for the Division of Developmental Disabilities: DDD has finally allowed parents to get paid to provide habilitation services for their eligible kids.

Please, for the love of all that is holy and good: Keep This Change, Even After the Pandemic Ceases!

You have inadvertently Solved the hab-provider crisis. Before the pandemic, it was next to impossible to find a high-quality, long-term habilitation provider. The pay was low and the turnover was high.

But we parents? We Love our kids and we'll do anything for them. Letting us get paid to provide our kids' habilitation is a Win-Win-Win!

I am grateful for the pandemic for inspiring this idea. It's the best idea someone ever had.

Please. Keep the change.

Thank you,

Joanna Galuszka
Parent of a Special-Needs Child

From: Angela Plicht [redacted]
Date: Monday, August 21, 2023 at 7:07:41 PM UTC-4
Subject: Please extend Parents as Paid Providers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>
Cc: angelaplicht@gmail.com <angelaplicht@gmail.com>

To Whom It May Concern:

Habilitation is essentially a list of very specific goals set by the parents and Division of Developmental Disabilities (DDD) that will help the individual (whether a child or adult member) become more independent. The idea is that this helps the individual reach their developmental milestones, many of which they could be years behind. DDD determines an appropriate number of hours per week for the individual to have a provider work with them to reach these very specific goals. Sometimes it's a handful of hours, sometimes it's a full-time job-worth.

During COVID, DDD temporarily approved parents to become paid habilitation providers of their children with special needs. From what I would imagine, it was due to a couple things:

1. Providers were uncomfortable going into other homes in fear of catching/spreading COVID. This resulted in a deficit of providers:member ratio leaving many members without habilitation services.
2. Many children/individuals with special needs tend to be immune-compromised and simply put, we were quarantining. We could not have additional people come into our home during that time.

As a result, members were not receiving the services seemed necessary by DDD.

To assist the members, DDD allowed parents to become paid habilitation providers. By allowing this, DDD became our hero, and at the same time an inadvertent and fantastic domino-effect was created. Members were back to receiving habilitation, and by the parents. This, in turn, created an environment where the parents have now become more involved and invested in the habilitation, creating a much better continuity of care. Arising from more invested and involved parents are stronger relationships and habilitation goals being practiced more frequently throughout the typical day, leading to the possibility of these goals being mastered more quickly. And as an even bigger bonus, families are now able to provide focused habilitation at the most beneficial times for the member. Habilitation can now be worked into the day more naturally, allowing the member to get the most out of it.

As we have learned to live with COVID and made it more manageable, we have been very much open to having a habilitation provider work with our member. Unfortunately what we have found is that providers seem to be few and far between. Especially in searching for someone to work with our four year old whose challenges include Autism, Down syndrome, he is non-verbal, and he is also potty-training. We have asked multiple agencies about providers but I've only received ONE call back with someone open to assisting, and they turned out to be too far from our area and not interested in the commute. We have messages posted in various Mom and Family Facebook groups, but every one of us is struggling to find providers. There are so many concerned parents right now, worried that our kids are going to fall further behind because there aren't enough providers available to support the members needs. We just do not have anywhere near enough people willing and able to provide these habilitation hours to our kids.

Has DDD done any analysis comparing the total designated weekly hours/member vs the total weekly hours/provider availability?

Have you had to hire someone in the past 18 months? Maybe you haven't had to hire, but you have most likely experienced the pains of being short-staffed. We know this is not limited to habilitation providers. The staffing shortage we are experiencing is across the board. Where have all the workers gone?

By removing the option for parents to be paid providers it's going to be nearly impossible for members to receive their designated benefits.

With this paid parent provider option ending, the MAJORITY of members with special needs will not be able to have the Habilitation assistance DDD has agreed they truly need. In addition to having trouble finding someone to provide habilitation for our kids, it's also going to create additional financial burdens on many families. Instead of some of these parents being able to supplement with a part time job while they're paid to provide the Habilitation, they'll now have to get a full time job and will no longer be available as often to provide habilitation to the Member. I foresee this leading to less parental involvement, habilitation hours left unfulfilled, members not receiving the benefits deemed necessary, and ultimately an entourage of unmet milestones.

PLEASE keep the parents as paid providers an option. It is a crucial piece to the puzzle we have to create as parents of children with special needs. Taking this away will only be hurting our children, your members, and the future of the individual.

Thank you!
Angela Plicht

From: Rebekah C. [redacted]
Date: Monday, August 21, 2023 at 7:31:05 PM UTC-4
Subject: Thank You for Supporting Parent Caregivers! A personal message from a parent...
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To whom it may concern, please read the message below that I also submitted to Arizona Legislators and take these comments into consideration as you evaluate the proposed changes regarding Attendant Care and Habilitation services that are currently provided by parents.
Thank you,
Rebekah C.

Dear Arizona Democratic Legislators,

On behalf of Raising Voices Coalition and parent caregivers of disabled minors in Arizona I want to personally reach out and thank you for your participation in the collective letter signed by House and Senate Democrats supporting parents of disabled minors as Habilitation and Attendant Care providers.

For your information, the parent caregiver community is asking AHCCCS to include a clause in their waiver proposal that allows parents of minors to work over 40 hours per week only under extraordinary circumstances. We do understand the perspective of democratic leaders in holding HCBS agencies accountable for building and providing a strong and reliable non-family DCW workforce. **Please see my personal message below explaining my perspective...**

> I would like to ask you to support parents ability to work more than 40 hours a week to provide services for their children which is under threat as well. While it sounds good on paper to limit the number of hours that can

be worked for parent providers to prevent burnout, the reality is that parents will continue to do the services but just won't be compensated for them if this limit is put into place.

If you would like to help prevent burnout for parents who are providing services for their children with special needs, the most impactful thing you can do is to insure access to quilty and reliable Respite providers.

In the 5 plus years since my son became eligible for 600 hours of respite annually, we have had very inconsistent providers and long seasons without any repsite at all. The provider we have had for the past year and a half has limited availability, so two days a week I get an hour of time to myself before it's time to pick up my other children from school. While it is less stressful not taking my son who has special needs with me for the hour trip to pick them up, it's not exactly "respite".

Our provider has made some big mistakes, like forgetting to feed my son lunch on a couple of occasions, but she is better than not having anyone (which sounds really pathetic.) Although she is not ideal, it has been a huge blessing to have her provide repsite one night a week so that my husband and I can have a date night, but if she leaves it could be months before we find someone to replace her. Did you know that "Surveys show that the rate of divorce in families with a child with disabilities may be as high as 87%."? According to this article on Psychology today.

https://www.psychologytoday.com/intl/blog/a-better-divorce/202302/divorce-and-special-needs-children

Our son’s respite provider is not reliable and in fact gave only a few days notice that she would be not be here the following Friday or Monday. The very next Thursday I received another text from her saying that starting the next day she would not be able to provide respite for my son for the following month, for 2 out of 3 days that we have been scheduled per week. I injured my elbow in April and was finally planning to go to physical therapy but may not be able to do that if I can’t come up with someone else to care for my son during those appointments. I am unable to schedule anything without the possibility that she will cancel last minute. It is demeaning to be at the mercy of someone else's whim's. Thankfully my husband has stepped in on many occasions when she has flaked out on her commitment, but that doesn't come without a price. It's stressful for him to miss work.

> I would love to be able to hire someone who is responsible and reliable, which I could potentially afford to do if I were able to continue to provide services for my son, but if that ability goes away or is limited to 40 hours a week, I am at greater risk of burnout than I was previously.
>
> One possible solution would be instead of paying providers a low wage to do more hours than a family would likely be able to find someone to do (600 every year), the families received the funds that would be paid for respite and allow them to hire their own provider and determine the pay rate that would ensure their child is receiving the best care possible, care that parents could feel confident about instead of leaving their child with someone that they are uncertain will take good care of their child.
>
> Please take a moment to put yourself in my shoes and think about what sort of person you would want to provide care for your child. Would you leave your child with my son's repsite provider?

We are very thankful for the time and energy it took to compose and collect support for this letter to AHCCCS. The families that this program impacts are feeling hope and so much gratitude for your representations and involvement on our behalf!

We will continue to keep you updated with any additional or relevant information shared by AHCCCS regarding this proposal, its relevant data and future developments. If you would like more information about how important supporting parent providers is, please visit https://www.raisingvoicescoalition.com. You can also go directly to a survey that was conducted this year titled… Effectiveness and Evaluation of Paid Parent Providers of Disabled Minors as a Permanent

Option for Families in Arizona
https://raisingvoicescoalition.com/downloads/2023SurveySummary.pdf

Thank you!

Rebekah C.

[redacted]

From: Velia Aguirre [redacted]
Date: Monday, August 21, 2023 at 7:34:38 PM UTC-4
Subject: Parent HAB provider
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello,

I am writing to express the great need for parents to remain paid habilitation providers for my son. When our [redacted] was diagnosed with autism and had severe self-injurious behavior I needed to leave my job. There is a serious employment shortage for HAB and respite providers and I waited years to find a HAB provider it was not until 2022 that I decided I could not wait any longer for a HAB provider. We waited from 2019-2022 to find one. Our son requires exceptional care, and the state is unable to provide the employees for these dependent persons.

Thank you,
Velia Aguirre

---------- Forwarded message ---------
From: [redacted]
Date: Monday, August 21, 2023 at 7:46:39 PM UTC-4
Subject: Paid parent provider program
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

This would be such an injustice to end. Our child has absolutely blossomed receiving HAB and attendant care through the paid parent provider program. It has enabled our family to do so much to help and assist our little girl. Please consider making this permanent and not capping hours at 40 . We have children that need care much more than 40 hours. Thank you.

---------- Forwarded message ---------
From: jacque taylor ferguson [redacted]
Date: Monday, August 21, 2023 at 7:59:12 PM UTC-4
Subject:
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

As a parent of a child who receives DDD and ALTCS services I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility, and it has been extremely beneficial to our family and my child. I would like to share my personal experiences and feedback based on my review of the current proposal for a permanent Paid Parent Caregiver program.

Under the current proposal, the request of an ongoing program option which allows parents of disabled minors in Arizona to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies is not being met. Please consider updating the proposal based on the following questions, suggested solutions, and personal experiences.

Should Habilitation be included in the Paid Parent Caregiver Program?

We have heard the concerns about member isolation and lack of community involvement if parents continue as Paid Parent Caregivers facilitating their child's Habilitation services. Respectfully the parent caregiver community proposes the following solutions:

Examine available research and personal feedback statements from members and their families to evaluate the true potential impacts of social isolation and community involvement when parents of disabled children provide Habilitation services. The parent caregiver community's collective experience is that members who have parents facilitating their Attendant Care and Habilitation services have experienced greater member social engagement and community involvement over the last three years. Parent caregivers now have an increased ability to take their children to sporting team practices, community events, movie theaters, all ability parks, church activities and libraries. This is because parent providers can perform the appropriately trained and qualified supports in the correct time and location that is applicable to each member.
Implement precise guidelines to facilitate generalization for all Habilitation providers regardless of the DCW's familial status. Habilitation services are designed to have goals where data is collected to evaluate if those goals need to be changed, have been met, or need to be addressed differently. For a goal to be considered met, a member should be demonstrating that they are able to successfully meet that goal outside of the timeframe with a provider in one setting. This is referred to as generalization. The effective implementation of generalization with the pediatric IDD population would lessen, if not eliminate, any complications with adult

transitional services. Under this model a program that includes parents as paid Habilitation providers would actually assist and improve in the success of adult transition. There are times when disabled children work successfully with different types of providers in clinics or schools, but the parents are not carrying the work over at home. This can happen for a variety of reasons. Having parents as Habilitation providers would help ensure the child's goals are congruent and carried over in the home and community setting. This will give the member a better chance of independence as they transition through different life stages. With generalization policies in place, Habilitation services being performed by parent providers will actually help facilitate successful transition into adulthood.

We know from provider agency data that “the top 3 issues regarding recruiting and retaining career non-family caregivers are schedules of the client members, interest in the position and finding qualified applicants.” Most members have Habilitation goals and ADLs that are most appropriately delivered throughout the natural routine of their day. A parent provider is uniquely available in the morning, after school or in the evenings when each member is motivated and focused on the pertinent task. If a non-family provider is available their schedules typically allow them to work in longer time chunks that are not always the most ideal for the member and creates artificial goal or ADL practice. Continuity of care and greater member outcomes can be associated with consistently provided Habilitation care by parent providers who have the greatest ability to be flexible and available for their member children.

Should parent providers be limited to 40 hours a week of paid care per child?

We have heard the concerns of AHCCCS regarding the potential for a difficult adult transition to non-family supports once parent caregivers are no longer able or willing to help facilitate the disabled member’s care. The parent caregiver community would like to propose the following collaborative solution to create a win-win scenario:

Create a program provision that outlines an extraordinary circumstances clause and the application process that allows parents to provide over 40 hours of paid care per week of authorized and evaluated services per member. These extraordinary circumstances could include, but are not limited to:

The lack of a non-parent DCW being available in the last 3 months to fill the member’s assessed hours that exceed 40 hours per week. Ongoing DCW searches should continue to be made by the member’s agency to fill the assessed hours beyond 40 hours per week of Attendant Care and Habilitation.

The expressed desire made by a member for a parent caregiver to facilitate their assessed DCW hours so that their Article 9 rights are honored.

The profound disabilities and/or significant behaviors of a member where a non-family provider is not equipped to provide DCW support. This determination can be made through a stakeholder team approach, including but not limited to the member’s, DDD Support Coordinator, DDD Nurse, DDD Supervisors, Behavioral Plan Experts, Parents / Guardians, Psychologist, or Medical Doctor.

Form equality between all Family Provider Programs by allowing all Direct Care Workers, regardless of familial relationship or member age, to provide up to 16 hours of paid care per day. This will allow for employee equality across the lifespan of the member and limit the potential anti-family provider rhetoric currently present within state policies and DDD Support Coordination culture. All evaluations of hours should be based on member needs regardless of who is providing the services to create uniform implementation of all applicable HCBS services by the DCWs available to fulfill those hours.

The Family Support Program currently in this proposal addresses caregiver burnout. It is one of the available solutions to facilitate further community support within the disability and caregiver community that will provide greater access to non-profits facilitating counseling services, support groups and meet up activities.

Reevaluate Respite reimbursement rates to also address caregiver burnout. If Respite services are not available to the member or their family, parent burnout will continue to be an issue regardless of parents having the option of providing Attendant Care or Habilitation hours. With a comprehensive Paid Parent Caregiver Program in place non-family DCW providers will have greater flexibility to provide Respite services to these same families.

How should current evaluation protocols, training and practices be updated to facilitate equality for all members when accessing member needs?

AHCCCS has stated their intention to amend applicable policy, further suggested action on this topic includes:

Forming a committee of community and department stakeholders to amend and critique current DDD and AHCCCS policies and need assessment forms so that the most effective and efficient implementation of this permanent option is utilized moving forward.
Provide appropriately determined training and program implementation to DDD and ALTCS Support Coordinators so that Attendant Care and Habilitation hours are equitably evaluated based on the member's needs and to remove organizational bias of familial providers across the member's lifespan. Specifically investigate and determine appropriate DDD staffing needs and training for the members served in rural areas and those from minority backgrounds.
Create the option for private sector Support Coordination. Other states have this option within their Medicaid services, and this could be an additional feature in our DDD portfolio to allow for the member's needs to be best evaluated.

In conclusion, Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. By not allowing parents of minors to provide Habilitation and Attendant Care services or work over 40 hours a week most of the minor disabled community in Arizona will be underserved. A comprehensive Paid Parent Caregiver program validates the irreplaceable work that parents provide in their homes and communities.

Click here to connect with the Arizona parent led grassroot initiative leaders: www raisingvoicescoalition.com

Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves all DDD and ALTCS members in Arizona.

Thank you!

Being able to be my child's habilitation provider has been life changing. She has progressed leaps and bounds because because im truly invested in her getting these goals accomplished. And being able to get paid allows me to be able to be the caretaker of my daughter instead of trying to find someone to take of her and go to work just to provide for her. No one cares more about her accomplishing these goals than me and finding reliable people who actually put in a real effort is so hard to find. Please let us keep providing hab for our children!
Sincerely,
Jacque Ferguson

From: Randy Morgan [redacted]
Date: Monday, August 21, 2023 at 8:09:04 PM UTC-4
Subject:
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To whom it may concern: Our family is participating in the paid parent provider program, for our child. Please consider keeping both HAV and ATC permanent, and not capped at 40 hours.

This would be a devastating loss for disabled children in Arizona.

Sent from Mail for Windows

From: Lee Rodgers [redacted]
Date: Monday, August 21, 2023 at 8:15:48 PM UTC-4
Subject:
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To whom it may concern,
Please consider making the paid parent provider program permanent. Please include HAB and ATC and do not cap the hours. This has tremendously helped our child grow and develop so much. We are a family of providers for our child. It would be a devastating loss to take this away. Thank you!
Parent of disabled child

Sent from my iPhone

From: jalen grayson [redacted]
Date: Monday, August 21, 2023 at 8:27:49 PM UTC-4
Subject: Concerns
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To whom it may concern,
Please consider making the paid parent provider program permanent. Please include HAB and ATC and do not cap the hours. This has tremendously helped our child grow and develop so much. We are a family of providers for our child. It would be a devastating loss to take this away. Thank you!
Parent of disabled child

Sent from my iPhone

From: Tia Russell [redacted]
Date: Monday, August 21, 2023 at 8:55:55 PM UTC-4
Subject: Parent hab program
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

I want to start by saying thank you for the opportunity to be apart of this program. I want to share my experience and thoughts about being able to provide services for my child. My daughter [redacted] was diagnosed with being on the autism spectrum back in 2020. Since the pandemic started a few months after, [redacted] did not receive any services. With this unfortunate situation, she has fell so far behind on her progress. It has been a challenge working 12 hours at the hospital and trying to be apart of [redacted] development. With her strict schedule, it's not easy to find employment that accommodates. So with this program I was allowed to be hands on with her to make sure we're working aggressively to get her to a point where she is accomplishing the small things we take for granted. I don't want to depend on someone else to come and work with her that has a family vacation coming up or they want off because of their birthday. This is my daughters daily living that depends on these skills. I hope this email reach you and will be taken under consideration. Thank you!

Sent from Yahoo Mail for iPhone

From: Cherry M [redacted]
Date: Monday, August 21, 2023 at 8:59:37 PM UTC-4
Subject: Habilitation is important for Parent provider of a minor
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To whom it may concern:

As a parent provider of a minor, I May say Habilitation is important in the daily lives of our young children with disabilities whether it's autism, medically related, Down syndrome and intellectual disability.. As a witness how my son slowly learning basic needs for his activities of daily living.
I am thankful for AHCCCS,CMS,ALTCS AND DDD for allowing parents of minor to be their provider.. We learn a lot from our daily battle in life together with our children.. We are not only parents who support(natural support for some) our children but we became a CPR certified, article 9 certified, fingerprint level 1 holder, even Direct care worker certified.. We are continue learning like anyone else.. Habilitation is essential to our children and I hope you will not take away this as proposed by your office.. If new provider of habilitation will come and go to our home I don't know how my child who was immuno compromised can handle it, he has a lot of absences in school.. I cannot see him sick all the time because he doesn't take medicine, he doesn't know if he's in pain or not, he's scared of clinic and doctors office. And covid is still around the corner. This pandemic give us a lot of fear in the future.. A lot of challenges to get new habilitation provider with few in our area and some are not align with the schedule. The agency I'm with also voice out concern if we the parents will be remove as parent provider our child will have a problem getting a new one coz they need to hire a hundreds of provider , and I believe some also has this problem coming. There is a lot beneficial factor for the child/children with disabilities if the parent will provide the minor their habilitation, think about it.. We doubled our effort to keep our kiddo healthy, stress free, give more learnings, to be independent and support all through out their daily lives.. We as a family love them and nurture them..I hope you'll keep the habilitation for parent provider with a minor..

Cherry Anne Duterte

From: Melissa Gordon [redacted]
Date: Monday, August 21, 2023 at 9:08:46 PM UTC-4
Subject:
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To whom it may concern,

I want to share my comments on the proposal for the Paid Parent Provider program to become permanent. I would like to start by telling you how much my son has improved since I have been able to stay home and provide him his HAB and ATC hours. He has progressed significantly in all areas of need. I attribute this to the consistency, predictability and schedule I have been able to provide him by being able to stay home and offer him the support services he needs. His need for high amounts of hours (both HAB and ATC) is slowly diminishing as a result of this. My son is autistic and has very high anxiety, a need for structure, predictability and solid relationships. Rotating providers does not provide a solid relationship and contributes to his high anxiety. He has learned to distrust providers coming into the home due to the constant changing of provider staff, their inconsistent attendance and that's if a provider can be found. Each new provider increases his anxiety and makes it harder for the next provider because he learned quickly he can not count on the providers to stay and work with him. When they leave or rotate out he asks what he did to make them leave and takes their leaving personally. Part of his Autism is he struggles with perspective taking so he does not understand nor believe us when we explain it was not his fault they did not stay. As I mentioned his needs for hours are going down since I have been able to stay home with home. However they are still higher than the 40 hours a week which I would be limited to if the change to parent provider ATC hours is to be implemented. In addition, if I am no longer allowed to bill his HAB hours we will be stuck again with trying to find a provider who can work with his behaviors, be consistent and who he would be willing to trust. The paid parent provider program was the best thing that ever happened to my child. It allowed for one person, whom he already trusts and will remain consistent to be able to stay home with him and work on his goals and objectives. I feel going back to counting on agencies (sometimes multiple agencies with a lack of qualified employees) will have the predictable effect of either causing him to regress or at the very least, halt any forward progress towards his goals. This may then result in a need for more ATC/HAB hours not less. Thank you for being willing to consider the parent perspective on this matter. We truly are the experts on our children and it is nice to see that someone is listening to us.

Respectfully,
Melissa Gordon

From: Ivie Manalo [redacted]
Date: Monday, August 21, 2023 at 9:19:02 PM UTC-4
Subject: Parent provider habilitation
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello,

Please allow parents to continue habilitation. This has been extremely helpful to our son as my husband and I are able to help him develop independent living skills. There are no available providers to provide these services. Since the pandemic it has been extremely difficult finding providers (it has been very difficult for our service agency to hire providers). I am very grateful for this program and want to continue helping our son develop. Without it, I will have to allocate my time to generating income which will not benefit my son with autism.

Thank you,
Ivie & Chris Chan
--
[redacted]

From: Brittany Heironimus [redacted]
Date: Monday, August 21, 2023 at 9:44:49 PM UTC-4
Subject: Public comment
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

Please reconsider adding habilitation to the the proposal. This program has saved our family from homelessness and my son is now thriving and actually making progress! Before the program, my partner was working 7 days a week, and doubles on the weekends just to barely pay the bills. I am now crying thinking back to how burnt out and exhausted we were. Now my partner is able to spend more time with my son and give me breaks as I am the 24/7 caregiver. I am now able to focus on my son instead of stressing over poverty and finding someone else to not only care for him but to help him learn functional skills. I have now had the time to work with him one on one consistently and educate myself on how to help him. I am now in school for applied behavior analysis and special education. I am the best person for my son. He is very hard to care for as he is completely non verbal and very particular and has severe self injurious behaviors. My family can finally breath and with my consistent one on one habilitation he is making so much progress and I believe he will turn into a functional adult if I am able to keep providing services for him.

If the proposal goes through without the habilitation, we are going to have a huge lapse in service. I doubt we are going to be able to find a provider and my son is going to regress terribly. I am not going to be able to keep a job because my son is not going to have a consistent provider. Even in ABA, I have had to pick him up almost daily because he screams until he vomits and gets sent home. We are probably going to have to move across the country to go live with my parents. Please consider adding habilitation to the proposal. Special needs families need this you don't understand the kind of war we go through everyday because our children don't fit into this society that they are forced to adapt too.

Sincerely,
An autism mom who wants to change her child's life for the better.

---------- Forwarded message ---------
From: Jessica [redacted]
Date: Monday, August 21, 2023 at 9:51:37 PM UTC-4
Subject: Parent letter
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To whom it may concern,

I have a child that is [redacted] with autism and intellectual disability. I'm a parent but [redacted] an educator.

It was difficult prior to family members to provide care for my son due to schedule conflicts, the time needed to work on goals and the lack of care to put into the goals. As well as he struggles with new people.

The flexibility I now have being a parent provider is amazing and I know the goals are being worked on and he is getting the care he needs on his time.

I just ask that you continue to allow parents to be providers as we know what is best for our own children.

Thank you for listening,

Jessica

From: Sherri Biringer [redacted]
Date: Monday, August 21, 2023 at 9:55:58 PM UTC-4
Subject: Habilitation for parents
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

I completely believe parents need to keep getting paid for habilitation work with their special child or children in some cases. In this horrible economy we live in and low income families can barely get by with all of the extra expenses of having a special child. My grandsons mama is the best thing for him . She has her hands full daily with an autistic non verbal [redacted]. She doesn’t have the ability to have family help her and dad has to work low paying jobs so they can barely get by. Her getting paid is so helpful and very benefits to their son. Keep habilitation for parents. A very concerned and grateful grandparent . Sherri Biringer
Sent from my iPhone

From: Leslie McFall [redacted]
Date: Monday, August 21, 2023 at 10:08:35 PM UTC-4
Subject: Parent Provider Habilitation Services
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To Whom It May Concern,

Good afternoon and thank you for taking time to receive public feedback on the proposed changes to the waiver regarding parent providers and elimination of habilitation services by parent providers.

First thank you for all the efforts that were made to propose making parent providers a permanent choice for your clients our disabled children.

I am writing to give you our families concerns regarding eliminating the parent's ability to provide habilitation. Our niece and nephew are non-verbal and communicate through physical expression. Our niece was pulled from school and is beginning to homeschool because of trauma. She became aggressive all of the sudden with other people trying to change her pull up and toilet her. We believe this is because she was molested at school. She is communicating clearly that she does not want anyone else personally caring for her this way and teaching her potty training skills and personal care activities (all hab goals) she is only peaceful when I my sister in law, her mother or my brother in law her father helps her with these goals. Why are our Children's preferences not being considered in this decision? Why should we rob them from the choice of care providers? Just because they are non verbal does not mean that they cannot communicate who they feel safe with caring and supporting them in their goals. If HAB is taken away we certainly cannot put our children (especially those who have been thru the trauma of sexual molestation) into a strangers care who they don't trust.

Are you aware that in Arizona the statistics of nonverbal females who are sexually molested by their unrelated care providers is above 90% and for non- verbal males it is nearly 75% and that in both cases they are molested at least ten times before they found out?

In conclusion by robbing our children who need such personal care goals the option to decide who the trust in helping them with these goals is absolutely detrimental to their safety and goes against their rights as human beings. Please do not rob our children of this choice.

Thank you for considering my words and plea in advocating for our precious children.

Sincerely,
Patrick and Leslie McFall
Thank you for considering my words and plea in advocating for our precious children.

From: Amanda Marquez [redacted]
Date: Monday, August 21, 2023 at 10:53:53 PM UTC-4
Subject: Permanent Paid Provider Program
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hi Director Heredia and Staff,

I appreciate all you are doing to implement the permanent Parent Provider Program but I feel it necessary to share my families experiences to help you understand just how important it is to include parent provided Habilitation in this program and to hopefully remove the 40 hour restriction.

My Autistic child has had services since he was [redacted] [redacted] he just turned [redacted] this year. We have been through about 4 Habilitation providers since that time because it is very hard to keep someone on for longer than 3 months and the rest of the time my son ends up on a waiting list without a provider at all due to the very real provider shortage. The providers that were sent to my home were subpar, inconsistent and for the most part unable to attend to my child's needs. Even when my child had a provider it was mandatory that I stay in the home with them and pretty much supervise them while they were supposed to be working with him. The providers were not able to work on his potty training goals or his bathing goals as my Autistic child would not allow them to get close to him during those private moments for weeks and would have a meltdown insisting for my help instead of theirs. So even on the rare occasion that a Habilitation provider was available to my child, I still had to do the work (unpaid) and that and the inconsistency of providers showing up and the inability to retain a provider for an extended period of time resulted in my inability to hold a steady job and provide for the family. By the time my child became comfortable enough with a provider to let them around his body they would quit within a month after that trust had been built.

The other issue I found is that when we were offered a Habilitation provider they were not a well suited match for my child's needs. My son is very active and is a runner as well, he needs to be watched 24/7 for safety purposes but some of the providers he was paired with were elderly, walking with a cane for support and unable to attend to his needs. One provider screamed at my son for jumping on the bed and almost falling into a dresser because she was unable to physically stand up from her chair to prevent him from hurting himself. Her screaming at him caused immediate trauma and he ran to me and clung to me until she left the house. I could not get him to stop crying for hours after she left. Another, Habilitation provider would call out sick multiple times a week and my son would have a meltdown everytime she didn't show up because he is aware of his Habilitation schedule and that lack of consistency was to much for him. She also would have mental health breakdowns in my home while providing services. She would randomly start crying in front of my child and he did not understand. He would think that she hated him but she would insist she just needed a mental health break. She only lasted a few weeks and of course I had to monitor her with my child because of her mental health breakdowns and I therefore could not work. Another Habilitation provider would come to the house and take multiple breaks (breaks are fine), but she would come back inside to work with my [redacted] child smelling like cigarettes and marijuana. I had to let her go and once again could not work. The next provider sent our way 3 years later (we were on a waiting list with vendor calls going out after each DDD meeting without any help or supports) was the same elderly woman who screamed at my child and could not assist him years prior so we of course had to turn her away for our child's safety. We remained on a waiting list for a Habilitation provider after that and never received one. I was uninformed regarding the Covid Parental Paid Provider Program and did not start utilizing that service until about 2 months ago.My child was still on a waiting list up until that time and since I have become his paid provider I have been able to dedicate my time to his Habilitation goals and we have made progress. It is my hope that we can continue making that progress without unneeded interruption. Without Habilitation in the Permanent Parent Paid Provider Program my son will once again regress as I have to scramble to take care of his needs while simultaneously working from home. This does not lessen parental burnout, removing Habilitation increases burnout in everyway. I will have to try to work from home while simultaneously caring for my child and hoping he doesn't have a meltdown while I'm on the phone with clients, my time is directed away from him so that I may financially provide for his needs and I cannot rely on an external Habilitation worker to show up consistently or even be able to handle my child or successfully work on his goals.

Another point I would like to bring up is that my child's Habilitation goals are not focused on social skills, they are solely focused on life function goals such as independent dressing, bathing, feeding and toileting goals. These goals are imperative as he needs to be able to achieve them to function in society which will one day increase his opportunities to socialize independently as an adult without relying on a provider. My child tries to understand what we have taught him in regards to stranger danger and appropriate touching. We have taught him that only Mommy or Daddy need be present when he is working on goals that render him vulnerable as a child. We have taught him this because we did not have a consistent provider and we have been working on these goals as a family all along. So now he has the mindset that no strangers are allowed to help him in the bathroom, the bath or with dressing. This is actually an amazing thing for him to know as it prevents him from being hurt by a stranger in any situation that would allow for that. Having an external provider come in would confuse his understanding of stranger danger and once again increase his vulnerability as a Special Needs Child. Not only that but it is very unlikely that he will allow a stranger to help him in these moments after having learned about Stranger Danger because his mind and thinking is very rigid and he does not understand that an external Habilitation provider is an exception to that rule. He is very keen on his privacy and as I stated before will only allow a parent to help him in these moments and I honestly as a parent can't argue that with him as it's his body and should most definitely be his choice. Please do not remove Parental Provided Habilitation for this reason.

I know one of the main reasons you are wanting to exclude Habilitation is that you are concerned about socialization but if we can not work on these lifeskill Habilitation goals first it well severely limit the amount of socialization he gets to experience in the present and in the future. There are many activities/schools etc that require a child to be fully potty trained or they cannot participate. Please understand that even the Habilitation goals that may not seem oriented towards social skills in this moment will help our children to achieve them in the future.

The hardship that removing Habilitation will place on parents and families such as mine is simple to understand in that our children will reject outside supports for personal care, hygiene and toileting goals and the progress the children have made and will continue to make with their parents will be diminished as parents have to scramble to find "consistent", "trustworthy" and "reliable" outside supports. Parents will have to focus their attentions on finding a source of income to replace the income they were receiving as providers and outside jobs require time away from the children who need their supports the most. Please don't do this to our kids. They will regress and parents will be burdened with not only burnout but extreme amounts of stress. Even if "external" Habilitation providers are brought in the parents will have to monitor them unpaid and it doesn't make sense.

If a child's Habilitation goals are focused on independence in self care your argument for socializing is not relevant as these goals are not meant to be achieved in a social situation and should be as private as possible for the mental health of both the children and the parents. These goals are just as important, if not as important as socialization goals and it feels as though you are completely disregarding the vulnerable children who have these specific self care goals for Habilitation. Parents are the best candidates to work on these goals with their Autistic children to ensure an understanding of body autonomy and stranger danger to prevent these kids from becoming familiar with the presence of a strange adult in the room with them, touching them in their most private areas. In a sense allowing strangers to assist our kids in these moments is a form of grooming that gets them comfortable with any adult who may claim that they are trustworthy or have permission to "touch" or kids. We are basically telling our kids that it is okay in special circumstances to allow strangers to touch them and that is something most of us as parents are not willing to allow in order to keep our children safe from predators. Please understand this and add Habilitation to this proposal to further ensure and protect the safety of our most vulnerable population.

I want to tell you of a real life scenario that occurred after my son had an "external" Habilitation provider. We decided to take him to the [redacted] and he had become accustomed/comfortable with going to the bathroom around "strangers" so he pulled his pants down in front of everyone at the theme park as he prepared himself to go to the bathroom. He didn't think twice about it because he was used to doing this with his provider and also stand in providers. He did not understand the difference and he cried profusely when we tried to explain it to him because on one hand he was being taught it was okay with "HAB" providers but he didn't realize that it wasn't okay with just anyone. This is an example of how not allowing these children privacy sets them up for future issues and even problems down the line with the law (indecent exposure). All he wanted to do was go to the bathroom and he had been shown that it was okay around strangers. It is not okay for this very reason.

I want to tell you a real life story that has to do with the impact of inconsistent "external" Habilitation providers. My son had a provider when he was [redacted] that he had grown to love over the course of a few months. She could not handle the stress of the job and my child's meltdowns and so she decided to quit one day without notice and without a goodbye. My son waited for her to come to the home at the scheduled time for weeks and everytime she didn't arrive he would cry. I had to lie to him and tell him that she moved away to Montana to be with her family. He still cries over her 6 years later and asks me to book a flight to Montana to go visit her. He does not have the comprehension skills to understand this situation and so it still causes meltdowns 6 years later. Consistency is so important and choosing to offer incentives to college students to become HAB providers only makes this problem worse. It ensures that the providers will be temporary, that our special needs kiddos will develop a bond with them and then be let down over and over again. This is not a solution for the Autistic population that requires consistency to ensure that there is no regression. In fact this option all but ensures consistent trauma for Autistic children and the parents will be the ones who have to help them recover from trauma time and time again. This does not reduce parent burnout it increases it ten fold and many parents may forgo services all together to prevent repeatedly traumatizing their children. Parents being forced to choose between traumatizing their kids or electing for services should not be the proposed solution. Please hear the voices of parents with Autistic children as we have walked these difficult roads and know what is best for our kids. There is no provider more consistent, more loving and more motivated to see a child succeed than a Parent Provider.

I also wanted to touch base on the imposed 40 hour restriction. I will start with the assessment for needs performed by the Support Coordinator. In our situation over the years and with multiple Support Coordinators our child's assessment had never been based solely on need but instead reframed by the amount of hours the Support Coordinator usually can get approved by a Supervisor. I will use our last meeting as an example. My child was assessed with needs that were over 50 hours but as the Support Coordinator put it she needed to shave some of those hours off or they would most likely not be approved. With ATC she asked if I would like to remove one of the mealtimes and reduce laundering hours for my child who has accidents multiple times a day. She asked me to remove several important Habilitation goals to keep the hours under 25. She said this was common practice to make sure hours would be approved. I didn't think to argue it as this had been my experience with all Support Coordinators prior. So to be clear in no way were the actual needs of my child taken into consideration, rather, the hours that would be typically approved were granted. I just want to reiterate that if this process were based on my child's needs he would have many more hours and much more opportunity for success. I feel this assessment process needs to be looked at so the needs of each child are accommodated appropriately.

Even with the above mentioned process and the "shaving" of hours my child was assessed at above 40 hours of combined ATC and HAB services. It is important to note that even with the "shaving" of hours I will be accommodating my child's needs albeit unpaid which again causes unnecessary burden and stress upon myself as a parent and increases burnout because I have to simultaneously run a business because I need that income if I can not be paid as a provider for my time. As, I said I am still going to give my child that time as he very much needs it and trusts me and relies on me to provide what he needs. At this point he will not allow a stranger to assist with anything that crosses his privacy boundaries which in my opinion is a good thing and a wonderful step towards future independence. So making it mandatory to seek an outside provider would not work in our situation or in the situation of many families like ours. So the burnout for the parent will increase despite your "best efforts" to prevent it by taking away HAB in this proposal. So many children have become accustomed to their parents as providers and now this proposal seeks to destroy that consistency, that trust that has been developed between parent and child and it will disrupt not only the childrens worlds but the parents as well creating stress for the children(clients) and the parents. If this proposal goes through as is, this is guaranteed to happen as parents seek to keep up the consistency with their children and also seek external employment to maintain the household. For many of us changing up what is already working isn't an option as we know better than anyone how that will affect our children and will simultaneously cause trauma and regression. The Autistic population requires consistency and the only thing I have seen over the years are consistent changes in providers and the lack of them and that is not what my child needs to thrive and become a successful adult. My goal as a parent is not to have my child depend on others his whole life it is to teach him to be as independent as possible. Taking away Parental Habilitation and limiting the hours our children need is not a solution that will work. Habilitation teaches our children skills and Independence where Attendant Care allows us to do things for them. We need Habilitation for those kids who are capable of achieving independence.

In regards to socialization. Socialization should not be the focus of Habilitation for all kids. All kids do not currently have socialization goals and their needs for socialization are met in other ways. Music therapy, Outschool Socialization classes with kids across the country, classes with peers without disabilities, social outings, the park, swimming, family outings, playdates etc... Parents strive to ensure their kids needs are met in all areas including socialization so it is not necessary to imply that Habilitation be the key to our childrens socialization goals when many times our kids Habilitation goals focus on life skills and self care goals which cannot be worked on in a social environment and must require privacy. Habilitation goals are not the same for all children across the board, their individual are needs are assessed. If you are wanting to bridge socialization gaps for Special Needs kiddos please have more events and meetups for our children throughout the Valley. Swimming meetups, bowling, Minecraft, gaming, sports, holiday events, dance parties all of these would be amazing to help the minor Special Needs population and it's not easy to find events like these for kids under 18. Please add more of these and I'm sure many families will take part with their kiddos and new relationships between children will foster social growth. Every Special Needs event for kids under 18 is packed and many times they sell out. Add more events for our kids and this will remedy the socialization worries that you may have but please don't use HAB, our childrens needed services to attempt to satisfy socialization goals when many of our children's Habilitation goals are privacy/body based.

I ask you to consider what I have written as I know so many families who have the same issues as mine. Please consider our stories and understand the needs of our children by adjusting the proposal to include Parent Provided Habilitation and by allowing parents to work the hours allotted to our children. I promise you we love our kids and will work with them with or without pay but with pay you are guaranteed to relieve burnout as we won't also have to juggle side jobs simultaneously (that is burnout, I assure you but for my child I will keep going).

I hope that to ensure that parents don't experience "caregiver burnout" free counseling services could be put in place. Self Care workshops for caregivers can be implemented and external providers could still be provided by agencies on an as needed basis. The one thing that I find really helps caregiver burnout is already in place and that is respite. Please try to find more respite providers as we haven't been able to find one a reliable one in over 2 years.

Thank you and Blessings to you and all the families and kiddos,
Amanda Marquez

From: Angelica Chavarria [redacted]
Date: Monday, August 21, 2023 at 10:23:27 PM UTC-4
Subject: Thank you for hearing us out.
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

As a parent of a child who receives DDD and ALTCS services I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility, and it has been extremely beneficial to our family and my child. I would like to share my personal experiences and feedback based on my review of the current proposal for a permanent Paid Parent Caregiver program.

We have never had a respite or HAB provider that wasn't related to us. It has always been on my husband or myself to look (and beg) for people to go through all of the hoops necessary to be our HAB or Respite provider. Family members who agreed to do it, never finished the thorough vetting and onboarding process.

The only ones that have helped are our daughter's older sisters. My oldest daughter did it during COVID when campus closed and she was forced to move back home and take college classes online. My second oldest daughter gave us Respite for 2 months before she too left for college.

The paying for college incentive you all are debating may not be very helpful to actually help us fill these roles. My daughters worked their butts off to have an opportunity for free college through their grades. I am afraid that all the fearless hard working young adults that would help us, are already busy pursuing their futures.

Caregiver burnout happens regardless. When my Dad watches our daughter once every 3 months I tell him "Even if we had a weekly date night, we'd be too tired to do anything." What helps is being able to have less stress and to minimize avoidable stressful situations. Before our amazing Support Coordinator [redacted], we went through a lot of support Coordinators. I don't believe our support coordinator is even in favor of the parent provider program, but she has been reliable, and always helps to solve problems. She truly cares about my daughter, and for that I am beyond thankful.

Not having somebody who quits once we go through the exhausting and tumultuous path of my daughter getting comfortable with a new person has been a huge stress relief! Not having to worry if this person will show up, and if so for how long, again and again, has been a huge stress relief.

The extra income this provides helps us by letting me be home to work on goals vs outside of the home working a part time job as I once did working evenings, nights, and weekends at [redacted]. I have a college degree, however, due to the demands of having a special needs child, I work in a postion that pays less, but gives me the ability to be available for my daughter at any time. Meltdowns at school, numerous specialist visits, all the extra sick days because our children touch and try to lick everything.

We all want the best for our children. Reliable, safe, caring support has never been a dependable benefit of DDD / ALTCS. Never. We can't even utilize the ABA benefit due to staff turnarounds. It was more traumatic of an experience for my daughter rather than a benefit.

We are in the community. We have our support circle. While everyone works and is unable to be our HAB or Respite provider, we are able to meet up for cookouts, activities, and playdates. Please consider the fact that children are actually more involved due to parents being able to be with their children more and not at various jobs outside of the home.

Thank you for the gift of your time.

Angelica Chavarria

Should Habilitation be included in the Paid Parent Caregiver Program?
We have heard the concerns about member isolation and lack of community involvement if parents continue as Paid Parent Caregivers facilitating their child's Habilitation services. Respectfully the parent caregiver community proposes the following solutions:

> Examine available research and personal feedback statements from members and their families to evaluate the true potential impacts of social isolation and community involvement when parents of disabled children provide Habilitation services. The parent caregiver community's collective experience is that members who have parents facilitating their Attendant Care and Habilitation services have experienced greater member social engagement and community involvement over the last three years. Parent caregivers now have an increased ability to take their children to sporting team practices, community events, movie theaters, all ability parks, church activities and libraries. This is because parent providers can perform the appropriately trained and qualified supports in the correct time and location that is applicable to each member.
>
> Implement precise guidelines to facilitate generalization for all Habilitation providers regardless of the DCW's familial status. Habilitation services are designed to have goals where data is collected to evaluate if those goals need to be changed, have been met, or need to be addressed differently. For a goal to be considered met, a member should be demonstrating that they are able to successfully meet that goal outside of the timeframe with a provider in one setting. This is referred to as generalization. The effective implementation of generalization with the pediatric IDD population would lessen, if not eliminate, any complications with adult transitional services. Under this model a program that includes parents as paid Habilitation providers would actually assist and improve in the success of adult transition. There are times when disabled children work successfully with different types of providers in clinics or schools, but the parents are not carrying the work over at home. This can happen for a variety of reasons. Having parents as Habilitation providers would help ensure the child's goals are congruent and carried over in the home and community setting. This will give the member a better chance of independence as they transition through different life stages. With generalization policies in place, Habilitation services being performed by parent providers will actually help facilitate successful transition into adulthood.
>
> We know from provider agency data that "the top 3 issues regarding recruiting and retaining career non-family caregivers are schedules of the client members, interest in the position and finding qualified applicants." Most members have Habilitation goals and ADLs that are most appropriately delivered throughout the natural routine of their day. A parent provider is uniquely available in the morning, after school or in the evenings when each member is motivated and focused on the pertinent task. If a non-family provider is available their schedules typically allow them to work in longer time chunks that are not always the most ideal for the member and creates artificial goal or ADL practice. Continuity of care and greater member outcomes can be associated with consistently provided Habilitation care by parent providers who have the greatest ability to be flexible and available for their member children.

Should parent providers be limited to 40 hours a week of paid care per child?
We have heard the concerns of AHCCCS regarding the potential for a difficult adult transition to non-family supports once parent caregivers are no longer able or willing to help facilitate the disabled member's care. The parent caregiver community would like to propose the following collaborative solution to create a win-win scenario:

> Create a program provision that outlines an extraordinary circumstances clause and the application process that allows parents to provide over 40 hours of paid care per week of authorized and evaluated services per member. These extraordinary circumstances could include, but are not limited to:
>
> > The lack of a non-parent DCW being available in the last 3 months to fill the member's assessed hours that exceed 40 hours per week. Ongoing DCW searches should continue to be made by the

member's agency to fill the assessed hours beyond 40 hours per week of Attendant Care and Habilitation.

The expressed desire made by a member for a parent caregiver to facilitate their assessed DCW hours so that their Article 9 rights are honored.

The profound disabilities and/or significant behaviors of a member where a non-family provider is not equipped to provide DCW support. This determination can be made through a stakeholder team approach, including but not limited to the member's, DDD Support Coordinator, DDD Nurse, DDD Supervisors, Behavioral Plan Experts, Parents / Guardians, Psychologist, or Medical Doctor.

Form equality between all Family Provider Programs by allowing all Direct Care Workers, regardless of familial relationship or member age, to provide up to 16 hours of paid care per day. This will allow for employee equality across the lifespan of the member and limit the potential anti-family provider rhetoric currently present within state policies and DDD Support Coordination culture. All evaluations of hours should be based on member needs regardless of who is providing the services to create uniform implementation of all applicable HCBS services by the DCWs available to fulfill those hours.

The Family Support Program currently in this proposal addresses caregiver burnout. It is one of the available solutions to facilitate further community support within the disability and caregiver community that will provide greater access to non-profits facilitating counseling services, support groups and meet up activities.

Reevaluate Respite reimbursement rates to also address caregiver burnout. If Respite services are not available to the member or their family, parent burnout will continue to be an issue regardless of parents having the option of providing Attendant Care or Habilitation hours. With a comprehensive Paid Parent Caregiver Program in place non-family DCW providers will have greater flexibility to provide Respite services to these same families.

How should current evaluation protocols, training and practices be updated to facilitate equality for all members when accessing member needs?

AHCCCS has stated their intention to amend applicable policy, further suggested action on this topic includes:

Forming a committee of community and department stakeholders to amend and critique current DDD and AHCCCS policies and need assessment forms so that the most effective and efficient implementation of this permanent option is utilized moving forward.

Provide appropriately determined training and program implementation to DDD and ALTCS Support Coordinators so that Attendant Care and Habilitation hours are equitably evaluated based on the member's needs and to remove organizational bias of familial providers across the member's lifespan. Specifically investigate and determine appropriate DDD staffing needs and training for the members served in rural areas and those from minority backgrounds.

Create the option for private sector Support Coordination. Other states have this option within their Medicaid services, and this could be an additional feature in our DDD portfolio to allow for the member's needs to be best evaluated.

In conclusion, Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. By not allowing parents of minors to provide Habilitation and Attendant Care services or work over 40 hours a week most of the minor disabled community in Arizona will be underserved. A comprehensive Paid Parent Caregiver program validates the irreplaceable work that parents provide in their homes and communities.

Click here to connect with the Arizona parent led grassroot initiative leaders: www raisingvoicescoalition.com

Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves all DDD and ALTCS members in Arizona.

Thank you!

From: CHRISTOPHER ZOLTZ <[redacted]
Date: Monday, August 21, 2023 at 10:22:58 PM UTC-4
Subject: Concerned parent
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

AHCCCS,

I am a father of a child that receives paid parent caregiver funds. This has made such a positive impact to our family as my wife is unable to work a normal job outside of our home due to our daughters need for full time care.
Please take into consideration what this lose would mean to a lot of families across this state, including ours.

Sincerely
Chris, Zoltz

---------- Forwarded message ---------
From: Adan Mendoza [redacted]
Date: Tuesday, August 22, 2023 at 12:14:16 AM UTC-4
Subject: DDD Family Habilitation services
To: [redacted]

Hello,

My name is Heather Mendoza, my son has Autism and currently receives DDD services.
I am also a DCW for [redacted] through an agency and provide Habilitation services. It has come to my attention that the habilitation service through family members may be coming to an end in November 2023. I think the services should be allowed to continue through the family.

My son was non-verbal when he was diagnosed. He would have melt downs every single day multiple times a day, could not dress himself, wipe himself etc.
After working with my son for many years, we have a seen a dramatic change! He stopped wearing diapers at the age of 7. [redacted] can now also talk (sometimes hard to understand) and [redacted] does not have as many meltdowns. Habilitation services provided by the family has been the best thing for my son especially since it is very hard on him to have new people come in and out of the home. He does not respond well to new people, especially when they do not know [redacted] and his routine. Since a family member has been providing his habilitation he has come so far and I want him to continue to grow! [redacted] never used to be able to take off his shorts, socks or shirt without complete assistance. Now [redacted] can take off most of his shirt by himself and can take off his shorts and socks! This is just a small list of things he can now do or has shown us he is learning to do and some tasks require little assistance compared to before. There are still tasks he can not do without assistance and we continue to work on that.
I plead and beg you to please not make the change to habilitation services provided by family members this November. This has helped our son so much and we do not want want to see him regress and stop moving forward.

Thank you so much,
Heather Mendoza
[redacted]

From: Monique Peterson [redacted]
Date: Tuesday, August 22, 2023 at 12:39:55 AM UTC-4
Subject: Feedback for atc and habilitation for providers vs agency
To: [redacted]

To Whom It May Concern:

I want to first thank you for allowing us parents to be a part of feedback towards this change in policy on services provided through DDD. My household is also very appreciative for this program and us being able to provide these services by the family.

I attended one of the feedback meetings and they stated we can provide feedback and email over. They also mentioned that only the Adult Tenant Care Services are being considered to continue allowing family members to provide. Habilitation they are asking to have that service go back to companies to provide. I am asking that both ATC and Habilitation considered to be provided by family and this is our families feedback on why.

It was mentioned that they worry about family burn out. I want to personally state I do not feel that would ever be the case at least for my household as both my husband and I share the responsibility and partner in making sure these services are completed. We have a good routine and honestly before these services were offered, we had already been doing everything to ensure he can lead the best quality of life within his limitations. He did not get into DDD services until he was 7.5/8 years old. Also, to have to have someone in our home this much puts more weight on us as a household. It means more cleaning and sanitizing to ensure germs are kept minimal, to follow up and ensure the provider is coming and now we would be limited if we choose to do services later or earlier to be able to have family events that come up. This also requires them to train us on how they are reaching the goal. Why not cut out the middle person and just keep it with the family. Having an agency provide services also leaves us feeling stuck and with no flexibility if an outside person has to come. I am more exhausted having to clean my house daily vs as needed since the provider would have traveled to other families' homes as well as the risk of brining in colds or Covid are now higher. I also have another child who has her routine interrupted when we have to have someone come and provide services, so to keep this to a minimum it would be better if parents had the choice if they want someone to do the services or do themselves.

We know that there is a huge shortage with personnel to be able to provide these services and although you are working on resolving this the amount that is going to be needed at such a quick pace is going to leave many of us with gaps in service. This is highly affected if your parents have children that need these services that are school age. If you have majority of families that need habilitation and since life skills it's going to have to be done before, after school and weekends. I know and have experienced even with just our DDD coordinator alone the shortage in this field has. We have not had DDD services for a year yet and have already been through 4 providers and still don't have a permanent one assigned. Every time we turn around, we are getting notice we have a new coordinator and sometimes we have been waiting for an assigned one as the one we just got assigned is no longer there. We sometimes don't even get notice and I have had our 3 month set up, had the house ready and no one came at our appointment time. I then had to call DDD only to find out our provider was no longer there and we will have to set up a new appointment and do all the preparations all over again. We have had this with a lot of our services through the last year and we would rather have the choice to be the main ones to provide the service to help prevent gaps and unnecessary routine disturbances.

For our son he has made it clear that he does not want any other people coming to the house and even tried to have us cancel his ABA appointments as well as his behaviors escalate on days he just don't want to be bothered. Currently he receives ABA and that takes up 3 evenings of his week after school. If we have to have someone come to house to complete these tasks it is only going to escalate behaviors as he is already exhausted from school and ABA. When we provide his habilitation or ATC services, he is not made aware and just thinks its part of his daily routine which is how it should be. We make sure he feels that he is just getting ready for the day or going to bed as that is what his goals are mainly set for at this time. By allowing parents to provide both of these services it makes it discreet for the child and not to feel different or that they are not capable of doing tasks that their siblings can do. This also allows us to see what we need to do to help him reach the goal. When someone else is providing they may be able to do the tasks for them but when we take over I notice it can go backwards compared to when we are already on board with providing. This also makes it frustrating for the child as a habilitation provider may help them one way and then when its an off day for that provider and we have to do we might not do it exactly the same. This is going to increase aggressive behaviors and a lot of push back. Which then makes it harder on us parents.

This brings me to my next thought and where Article 9 training comes in. Article 9 helps to advocate for the child to be apart of society, not to be excluded. When we are having to have someone come to our house to have our child do basic skills they are made to stand out and be separated especially if there are other children in the house that do not need services. The other children don't have someone come to help brush their teeth or wash their hands. By allowing parents to provide these services at the house it makes it more natural. We also think about the fact that some of our goals lean towards personal care in the shower or using the restroom. Disabled children are at higher risk for being sexually and/or physically abused and my household personally does not want an outside person assisting with these tasks. This then also teaches our children that it is ok for people to see their personal areas especially since many care givers do not stay long. When multiple people are allowed to see our children undressed especially ones who can't comprehend the difference, we are setting our child up to be a possible victim by telling them it is ok for a stranger to see their private areas.

They also brought out during the meeting that they worry about our children not being socialized if all services are provided by the parents. This is not the case for our household as well as we put events together or go to events just to ensure our child is included and properly socialized. For the habilitation at least in our circumstances they are daily living skills and not social skills. If I may make a suggestion that if you feel that is the case with some families, could you set up events around Arizona and require parents to attend so many annually in order to receive DDD unless circumstances don't permit/with some exceptions or for us to submit events we have done with our child receiving services. Also, my son goes to a charter school and receives social skills during the day. So I am not sure how the agency feels that the kids may be isolated.

There is so much more I could add on why its beneficial for parents/guardians to have the choice if they want to be the provider or to use an agency. I appreciate my husbands and our feedback being considered and I hope this will help advocate for DDD to permanently change the policy to give parents the option to provide services or for an agency. Our family is for providing the services ourselves as that is going to benefit our child in the long run.

I am hoping that many have provided their feedback as each family's needs are different and that's why I am hoping it will be an option/choice for us to decide which route fits our households needs for services. As each of us know our child/ren and which way is more beneficial for them as we work with them daily and usually have a better understanding of their needs than some stranger on the outside.

Sincerely,

Monique Peterson & Peter Moore

---------- Forwarded message ---------
From: Leila Woodard [redacted]
Date: Tuesday, August 22, 2023 at 12:43:28 AM UTC-4
Subject: Urgent Request to Extend the Parent Provider Program
To: [redacted]

Dear AHCCCS, DDD, Arizona legislators, and Governor Hobbs,

I am writing to you as a concerned parent of a disabled child who heavily relies on the parent provider program. I have recently learned that this program is set to end in November 2023, and I am deeply worried about the consequences this will have on my son's well-being and the well-being of many other families in similar situations.

My son has six different disabilities and exhibits extreme behaviors, making it incredibly challenging to find hab/attendant care providers who are willing to work with him. Due to his high needs, he requires 65 hours of care per week. However, when seeking providers, I have been repeatedly told that they would rather work in easier jobs such as fast food or retail for the same pay. This has made it extremely difficult to find and retain qualified providers.

Moreover, the extensive training required for these providers is unpaid, which has resulted in many potential caregivers starting the training but never completing it. The burden of caregiver burnout is immense, and the lack of community support and social isolation faced by disabled children and their families is taking a toll on their mental health. It is disheartening to witness the number of special needs parents who have resorted to suicide or contemplated it due to these overwhelming challenges.

As parents, we are forced to prioritize our disabled children above our work, social lives, and personal lives. The latent provider program has been a lifeline for us, allowing us to access the care and support our children desperately need. However, with the negative changes occurring in the special needs sector, such as the elimination of remote therapies and increasing out-of-pocket expenses, it has become financially unfeasible for many families, including mine, to continue providing the necessary care for our children.

I implore you to consider the immense impact that ending the latent provider program will have on existing families who rely on it. I kindly request that you vote against ending this program and instead explore ways to improve and expand it. Our disabled children deserve the opportunity to thrive, and it is our duty as a society to provide them with the necessary support and resources.

Thank you for your attention to this urgent matter. I hope you will take our concerns into serious consideration and work towards a solution that ensures the well-being and future of our disabled children.

Sincerely,
Thank you,
[redacted]

From: K B <[redacted]>
Date: Tuesday, August 22, 2023 at 1:06:57 AM UTC-4
Subject: Parent-Led Habilitation Care
To: [redacted]

Dear AHCCS Representatives,

I hope this letter finds you well. I am writing to discuss a concern that many parents, including myself, share regarding the provision of Habilitation care for our children with developmental disabilities or special needs. Specifically, I ask that AHCCS consider allowing parents to provide Habilitation care for their child permanently, should they choose and demonstrate competence.

I understand the importance of ensuring that those providing Habilitation services are trained and qualified and that our children receive the best possible care. However, I believe there are compelling reasons to support parents as caregivers:

✓ Unparalleled Bond and Understanding: No one understands the unique needs, strengths, weaknesses, likes, and dislikes of a child better than their parents. This intimate knowledge can often lead to more tailored and effective care.

✓ Consistency in Care: Frequent caregiver changes can be challenging and even traumatic for children with developmental disabilities. A consistent caregiver, especially during external crises like pandemics, ensures fewer interruptions in the care routine, leading to more predictable progress and reduced administrative challenges. Allowing parents to provide permanent care guarantees consistency, helping the child to thrive in a stable environment.

✓ Safety and Comfort: Children can feel more secure and comfortable in the safety of their homes and with their parents or guardians. This can lead to a better quality of life and more effective skill acquisition. Also, by limiting external interactions, especially during health crises, AHCCS reduces the potential liabilities and complications related to contagion risks.

✓ Financial Considerations: AHCCS could save resources in the long run by training and certifying parents to provide care. Instead of financing external caregivers, the system would invest in the child's immediate support system.

✓ Compatibility and Reduced Turnover: The challenge of matching caregivers with families can be resource-intensive. Empowering parents alleviate the constant process of vetting, matching, and potential conflicts, translating to fewer resource drains and complaints.

✓ Flexibility and Swift Response: Parents can adapt faster to dynamic situations, leading to less bureaucratic delay and ensuring that children receive timely care. Parents can adapt to their child's schedule and need in real-time without the constraints that external agencies or caregivers might impose.

✓ Emotional Well-being: A child's emotional well-being can significantly benefit from the consistent presence of loving parents who provide care. The assurance that their parents are always there for them can provide an unparalleled sense of security.

Of course, it's crucial to ensure that parents who opt to provide Habilitation care are adequately trained and certified. Periodic evaluations and continued training can be incorporated to ensure the child's needs are met effectively and safely.

In conclusion, while I understand that there might be concerns about implementing such a change, with the proper checks and balances in place, it could benefit both the child and the system. I kindly urge AHCCS to consider this request, considering the numerous potential benefits and the enhanced quality of life it can bring to children under Habilitation care.

Thank you for your time and consideration. I look forward to your positive response.

Warm Regards,

Lakeitha Bolton

From: Sarah Flick <[redacted]>
Date: Tuesday, August 22, 2023 at 1:07:14 AM UTC-4
Subject: Please leave Hab under parent provider
To: [redacted]

To Whom It May Concern:

Habilitation is essentially a list of very specific goals set by the parents and Division of Developmental Disabilities (DDD) that will help the individual (whether a child or adult member) become more independent. The idea is that this helps the individual reach their developmental milestones, many of which they could be years behind. DDD determines an appropriate number of hours per week for the individual to have a provider work with them to reach these very specific goals. Sometimes it's a handful of hours, sometimes it's a full-time job-worth.

During COVID, DDD temporarily approved parents to become paid habilitation providers of their children with special needs. From what I would imagine, it was due to a couple things:

1. Providers were uncomfortable going into other homes in fear of catching/spreading COVID. This resulted in a deficit of providers:member ratio leaving many members without habilitation services.

2. Many children/individuals with special needs tend to be immune-compromised and simply put, we were quarantining. We could not have additional people come into our home during that time.

As a result, members were not receiving the services deemed necessary by DDD.

To assist the members, DDD allowed parents to become paid habilitation providers. By allowing this, DDD became our hero, and at the same time an inadvertent and fantastic domino-effect was created. Members were back to receiving habilitation, and by the parents. This, in turn, created an environment where the parents have now become more involved and invested in the habilitation, creating a much better continuity of care. Arising from more invested and involved parents are stronger relationships and habilitation goals being practiced more frequently throughout the typical day, leading to the possibility of these goals being mastered more quickly. And as an even bigger bonus, families are now able to provide focused habilitation at the most beneficial times for the member. Habilitation can now be worked into the day more naturally, allowing the member to get the most out of it.

As we have learned to live with COVID and made it more manageable, we have been very much open to having a habilitation provider work with our member. Our [redacted] year old whose challenges include non Mobil, non verbal, who has low muscle tone due to his gentic syndrome called coffin lawyer (missing x chromosome) which put him at risk for heart issue along with seizures. He on a seizure block med due to the fact he had 2 febrile seizures last year and at risk for getting more. He sent a month in the NICU after he was born. Then he been back to hospital twice since due to high fever and illness. He see many specialist ent, Gentics, physical medicine, surgical doctor, neuro (seizure specialist), othero spine, orthopedic hip (he also dysplas), gi (he had g-tube), cardiologist, he seen so many that I might actually be forgetting one right now. He also has physical therapy twice a week each session is 1 hour. Plus Ot which also twice a week 1 hour each session. He also goes to private special education school we he also gets pt x2 30mins each, Ot the same speech the same. The school therapist are for educational purposes only. Feeding Therapy we still currently on the hunt for dd has tried many vendor call. They still trying. We looked day care which by the way very few day cares will take kidos like him because of medical complexity. Which why he a the school he at has more of medical staff Also see speech therapy one hour once week. Based off this information it would and is making this more of medial life for him, by me doing hab for him it give him for a normal life I would have worry about a another phone or text that says “sorry i am running be there soon” one less thing to worry about when we already have so much going on for him. I will have worry about have to hear about the progress report from DCW because I will already know and will get see him actually do first hand not only will I get my son to where he should me with goals but it something that I want do for him so that he have some what of a normal life with no DCW issue. Plus I do everything like them do I lock just they would. I was tried just like them. Only difference is and this big one that i believe with all my heart about any parent will know children better then then DCW ever will they could try we can’t try to explain to them as better possible but here the things since we know them Breyer we also know why they do what do. We also know a better way of handling it and will come from place the child knows and will respond better to then a Dcw who might last what maybe a week maybe 2months or if very lucky to even find one who knows. I personally don’t feel comfortable with dCw to work with my child we have enough them doing everything else for child. Let this be are thing. We have messages posted in various Mom and Family Facebook groups, but every one of us is struggling to find providers. There are so many concerned parents right now, worried that our kids are going to fall further behind because there aren’t enough providers available to support the members we need. We just do not have anywhere near enough people willing and able to provide these habilitation hours to our kids.

Has DDD done any analysis comparing the total designated weekly hours/member vs the total weekly hours/provider availability?

Have you had to hire someone in the past 18 months? Maybe you haven’t had to hire, but you have most likely experienced the pains of being short-staffed. We know this is not limited to habilitation providers. The staffing shortage we are experiencing is across the board. Where have all the workers gone?

By removing the option for parents to be paid providers it’s going to be nearly impossible for members to receive their designated benefits.

With this paid parent provider option ending, the MAJORITY of members with special needs will not be able to have the Habilitation assistance DDD has agreed they truly need. In addition to having trouble finding someone to provide habilitation for our kids, it’s also going to create additional financial burdens on many families. Instead of some of these parents being able to supplement with a part time job while they’re paid to provide the Habilitation, they’ll now have to get a full time job and will no longer be available as often to provide habilitation to the Member. I foresee this leading to less parental involvement, habilitation hours left unfulfilled, members not receiving the benefits deemed necessary, and ultimately an entourage of unmet milestones.

PLEASE keep the parents as paid providers an option. It is a crucial piece to the puzzle we have to create as parents of children with special needs. Taking this away will only be hurting our children, your members, and the future of the individual.

Thank you!
Sarah Flick

From: Todd Bigelow [redacted]
Date: Tuesday, August 22, 2023 at 1:16:03 AM UTC-4
Subject: keeping the paid Parent Provider Program for Habilitation care
To: [redacted]

Good Evening,

I am writing to express my sincere gratitude for the incredible support and progress that our son, [redacted], has experienced through the Parent Provider Program. As parents, my wife Jill and I have always sought the best opportunities for [redacted]'s development, and this program has proven to be an invaluable resource in fostering his growth.

[redacted] mother, Jill, who is a Parent Provider for the Habilitation services, has been diligently working on various developmental goals with him. It's truly heartwarming to witness the progress [redacted] has made under her guidance. From mastering the art of opening doorknobs and confidently navigating up and down stairs to independently turning on the water faucet and washing his hands with soap and water, [redacted] achievements have been both impressive and inspiring.

One of the most rewarding milestones has been [redacted] increasing ability to feed himself with a fork or spoon. Jill's patient and nurturing approach has allowed [redacted] to develop the necessary motor skills and coordination, fostering independence and self-confidence.

What sets the Parent Provider Program apart is the flexibility it offers to our family. We greatly appreciate the convenience of working on goals with [redacted] at times that seamlessly integrate into our family's schedule. This flexibility would not be achievable if we were to engage an outside-hired worker to come into our home. As [redacted] parents, we understand the importance of maintaining a consistent routine to accommodate his medical appointments, therapy sessions, and recurring ear infections that have occasionally led to school absences. The ability to customize our schedule ensures that [redacted] development remains a priority without compromising his education.

In light of the ongoing health concerns, particularly in relation to infections like colds, flus, and COVID-19, we are particularly cautious about having outside workers enter our home [redacted] health has always been a top priority for us, and we firmly believe that the paid Parent

Provider Program for Habilitation minimizes the risk of exposure while still offering [redacted] the support he needs to thrive.

The current proposal raises some concerns and areas for improvement, which I believe could significantly enhance the program's benefits to families and individuals with disabilities. I kindly ask that you consider the following points for the betterment of the Paid Parent Caregiver program:

Inclusion of Habilitation Services:
The proposal's exclusion of Habilitation services for parents of disabled minors is a point of concern. I urge the AHCCCS and the 1115 Waiver team to reconsider this aspect. My experiences and those of fellow parent caregivers suggest that members who have parents facilitating both Attendant Care and Habilitation services experience greater social engagement and community involvement. A deeper evaluation of research and personal feedback could provide valuable insights into the actual impact of social isolation versus community involvement for members whose parents provide theses services.

Facilitating Generalization for All Providers:
Implementing clear guidelines for generalization in Habilitation services, irrespective of the provider's familial status, can be pivotal. Generalization ensures that goals met under a provider's guidance extend to real-life settings. This approach promotes consistency and prepares individuals for their transition into adulthood.

Flexible Care and Member Outcomes:
Parent providers, due to their flexibility, can better match their schedules with the needs of their child's goals. This flexibility results in continuity of care, fostering better member outcomes. These providers are uniquely available during times when members are most motivated and engaged, such as mornings, after school, and evenings.

Exceeding 40 Hours of Care:
I understand the concerns about transitioning to non-family supports once parent caregivers are no longer able or willing to provide care. However, I propose the creation of an "extraordinary circumstances clause" to allow parents to provide over 40 hours of paid care per week under certain conditions. These conditions could include the absence of non-parent Direct Care workers, member requests for parental care, or profound disabilities that necessitate specialized care.

Equal Treatment for Family Providers:
To create equality among all Family Provider Programs, consider allowing all Direct Care Workers, regardless of familial relationship or member age, to provide up to 16 hours of paid care per day. This would ensure that evaluations of hours are solely based on member needs, ensuring uniform implementation of applicable HCBS services.

Improving Evaluation Protocols and Training:
Establishing a committee of stakeholders to amend and critique current DDD and AHCCCS policies and assessment forms could help ensure unbiased evaluations. Further training for Support Coordinators could promote equitable evaluation and eliminate organizational bias. The option for private sector Support Coordination should also be explored.

In conclusion, I strongly believe that Habilitation and Attendant Care services should be accessible in a timely manner to all who qualify for DDD and ALTCS in Arizona. The proposed Paid Parent Caregiver program holds immense potential to support families like mine, offering a comprehensive and validated solution. I am deeply appreciative of AHCCCS's efforts in creating a permanent program for Paid Parent Caregivers, and I look forward to a continued collaboration to make this program even more effective and inclusive. This program has had such a positive impact on [redacted] development. My wife Jill's dedication and expertise, coupled with the program's flexibility, have transformed [redacted] journey into one marked by growth, independence, and achievement. As parents, we couldn't ask for a better opportunity for our son.

For those seeking to connect with the Arizona parent-led grassroots initiative leaders, please visit
www.raisingvoicescoalition.com

Thank you for your time and consideration. I eagerly anticipate the positive impact this program will have on the lives of DDD and ALTCS members in Arizona.

Sincerely,

Todd Bigelow
parent of a special-needs, disabled child

From: Jeff Day [redacted]
Date: Tuesday, August 22, 2023 at 1:26:36 AM UTC-4
Subject: Paid Parent Caregiver Program
To: [redacted]

Dear AHCCCS and 1115 Waiver Team,

As parents of three boys, two of whom are beneficiaries of DDD services, we are writing to address the critical matter of including Habilitation services in the Paid Parent Caregiver Program. Our direct experience with this program has led us to advocate for its continuation and advocate for its expansion.

My role as a programmer, has allowed me to work from home, and given me the opportunity to witness the positive changes that have come about as a result of my wife's involvement as a parent provider. Her dedicated care and the flexibility of this program have significantly impacted our family's dynamic, facilitating our sons' growth, development, and integration within the community.

Our younger son, diagnosed with autism, actively participates in public school activities and extracurricular engagements alongside his peers. The flexibility inherent in parent-provided services has allowed us to seamlessly blend his habilitation goals into his everyday routines, ensuring he receives the necessary assistance without compromising his commitments.

Our older son, who holds dual qualifications under epilepsy and autism, faces intricate challenges. His distinct combination of medical necessities and behavioral intricacies has posed difficulties in finding suitable educational and therapeutic settings. Requiring vigilant supervision to prevent wandering and elopement, his jam-packed schedule involves in-clinic therapy and adaptive activities. As my wife serves as his habilitation provider, I've observed firsthand how this role empowers her to guide him in honing essential life skills during moments of peak receptivity or to incorporate these into our family outings.

While we appreciate concerns surrounding caregiver burnout and community involvement, we would like to highlight that the adaptability offered by this program, in conjunction with the support from the agency employing my wife as a parent provider, has allowed us to tend to our older son's needs within the familiar confines of our home while meticulously adhering to his therapy regimen. This initiative concurrently empowers our younger son to excel more typically at school while also benefiting from crucial support at home.

We earnestly implore you to thoughtfully consider the exceptionally positive implications that the Paid Parent Caregiver habilitation program can extend to families similar to ours. This initiative recognizes the invaluable role parents play in bolstering their children's personal development and progress, while acknowledging the care and dedication my wife provides.

We extend our heartfelt gratitude for your unwavering commitment to this vital initiative and for consistently prioritizing the well-being and potential of children like ours. Your dedication to fostering positive change in their lives resonates deeply with us and is wholeheartedly appreciated.

Thank you for your time,

Jeff

From: patrick [redacted]
Date: Tuesday, August 22, 2023 at 1:44:30 AM UTC-4
Subject: Paid Parent Providership Public Comments
To: [redacted]

My name is Aimee Griffith Johnson. I am a mom to two boys with autism, a daughter who's medically fragile, and a foster mom to another son with autism. We are very grateful for AHCCCS' willingness to make parts of the paid parent provider-ship permanent; however, the missing component to this proposal to CMS is Habilitation. Many of us feel that omitting HAB from the proposal waiver to CMS would be a grave mistake. We have a nationwide shortage of providers, and to completely withdraw paid parental support would be creating an even greater dilemma. Members would be completely without HAB services and parent's would still be doing a "paid provider's job", without pay, which would and can put a tremendous strain on a family financially.

Some parent's have to quit their jobs, so that they can provide these much needed services for their children. Without the "mom's and dad's" going through the arduous process of certifications to become a "paid profession-provider", their children would have been without specifically, Habilitations Services.

Many parents and supporters share the same perspective as I do; Adding Habilitation to the waiver 1115 proposal resolution will continue to bridge the GAP as we continue to find resolution to this ongoing nationwide provider shortage and continue to keep family's from going into financial peril.

Thank you for you time.

---------- Forwarded message ---------
From: Nicole Beltran [redacted]
Date: Tuesday, August 22, 2023 at 1:58:18 AM UTC-4
Subject: Parent Provider Program
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

As a parent of a child who receives DDD and ALTCS services I have participated in the Paid Parent Caregiver program under the Covid-19 Flexibility, and it has been extremely beneficial to our family and my child. I would like to share my personal experiences and feedback based on my review of the current proposal for a permanent Paid Parent Caregiver program.

Under the current proposal, the request of an ongoing program option which allows parents of disabled minors in Arizona to provide Habilitation and Attendant Care services as certified and trained Direct Care Workers (DCW) through authorized provider agencies is not being met. Please consider updating the proposal based on the following questions, suggested solutions, and personal experiences.

Should Habilitation be included in the Paid Parent Caregiver Program?
We have heard the concerns about member isolation and lack of community involvement if parents continue as Paid Parent Caregivers facilitating their child's Habilitation services. Respectfully the parent caregiver community proposes the following solutions:

Examine available research and personal feedback statements from members and their families to evaluate the true potential impacts of social isolation and community involvement when parents of disabled children provide Habilitation services. The parent caregiver community's collective experience is that members who have parents facilitating their Attendant Care and Habilitation services have experienced greater member social engagement and community involvement over the last three years. Parent caregivers now have an increased ability to take their children to sporting team practices, community events, movie theaters, all ability parks, church activities and libraries. This is because parent providers can perform the appropriately trained and qualified supports in the correct time and location that is applicable to each member.

Implement precise guidelines to facilitate generalization for all Habilitation providers regardless of the DCW's familial status. Habilitation services are designed to have goals where data is collected to evaluate if those goals need to be changed, have been met, or need to be addressed differently. For a goal to be considered met, a member should be demonstrating that they are able to successfully meet that goal outside of the timeframe with a provider in one setting. This is referred to as generalization. The effective implementation of generalization with the pediatric IDD population would lessen, if not eliminate, any complications with adult transitional services. Under this model a program that includes parents as paid Habilitation providers would actually assist and improve in the success of adult transition. There are times when disabled children work successfully with different types of providers in clinics or schools, but the parents are not carrying the work over at home. This can happen for a variety of reasons. Having parents as Habilitation providers would help ensure the child's goals are congruent and carried over in the home and community setting. This will give the member a better chance of independence as they transition through different life stages. With generalization policies in place, Habilitation services being performed by parent providers will actually help facilitate successful transition into adulthood.

We know from provider agency data that "the top 3 issues regarding recruiting and retaining career non-family caregivers are schedules of the client members, interest in the position and finding qualified applicants." Most members have Habilitation goals and ADLs that are most appropriately delivered throughout the natural routine of their day. A parent provider is uniquely available in the morning, after school or in the evenings when each member is motivated and focused on the pertinent task. If a non-family provider is available their schedules typically allow them to work in longer time chunks that are not always the most ideal for the member and creates artificial goal or ADL practice. Continuity of care and greater member outcomes can be associated with consistently provided Habilitation care by parent providers who have the greatest ability to be flexible and available for their member children.

Should parent providers be limited to 40 hours a week of paid care per child?

We have heard the concerns of AHCCCS regarding the potential for a difficult adult transition to non-family supports once parent caregivers are no longer able or willing to help facilitate the disabled member's care. The parent caregiver community would like to propose the following collaborative solution to create a win-win scenario:

Create a program provision that outlines an extraordinary circumstances clause and the application process that allows parents to provide over 40 hours of paid care per week of authorized and evaluated services per member. These extraordinary circumstances could include, but are not limited to:

The lack of a non-parent DCW being available in the last 3 months to fill the member's assessed hours that exceed 40 hours per week. Ongoing DCW searches should continue to be made by the member's agency to fill the assessed hours beyond 40 hours per week of Attendant Care and Habilitation.

The expressed desire made by a member for a parent caregiver to facilitate their assessed DCW hours so that their Article 9 rights are honored.

The profound disabilities and/or significant behaviors of a member where a non-family provider is not equipped to provide DCW support. This determination can be made through a stakeholder team approach, including but not limited to the member's, DDD Support Coordinator, DDD Nurse, DDD Supervisors, Behavioral Plan Experts, Parents / Guardians, Psychologist, or Medical Doctor.

Form equality between all Family Provider Programs by allowing all Direct Care Workers, regardless of familial relationship or member age, to provide up to 16 hours of paid care per day. This will allow for employee equality across the lifespan of the member and limit the potential anti-family provider rhetoric currently present within state policies and DDD Support Coordination culture. All evaluations of hours should be based on member needs regardless of who is providing the services to create uniform implementation of all applicable HCBS services by the DCWs available to fulfill those hours.

The Family Support Program currently in this proposal addresses caregiver burnout. It is one of the available solutions to facilitate further community support within the disability and caregiver community that will provide greater access to non-profits facilitating counseling services, support groups and meet up activities.

Reevaluate Respite reimbursement rates to also address caregiver burnout. If Respite services are not available to the member or their family, parent burnout will continue to be an issue regardless of parents having the option of providing Attendant Care or Habilitation hours. With a comprehensive Paid Parent Caregiver Program in place non-family DCW providers will have greater flexibility to provide Respite services to these same families.

How should current evaluation protocols, training and practices be updated to facilitate equality for all members when accessing member needs?

AHCCCS has stated their intention to amend applicable policy, further suggested action on this topic includes:

Forming a committee of community and department stakeholders to amend and critique current DDD and AHCCCS policies and need assessment forms so that the most effective and efficient implementation of this permanent option is utilized moving forward.

Provide appropriately determined training and program implementation to DDD and ALTCS Support Coordinators so that Attendant Care and Habilitation hours are equitably evaluated based on the member's needs and to remove organizational bias of familial providers across the member's lifespan. Specifically investigate and determine appropriate DDD staffing needs and training for the members served in rural areas and those from minority backgrounds.

Create the option for private sector Support Coordination. Other states have this option within their Medicaid services, and this could be an additional feature in our DDD portfolio to allow for the member's needs to be best evaluated.

In conclusion, Habilitation and Attendant Care services should be delivered and received in a timely manner by those in Arizona who qualify for DDD and ALTCS. By not allowing parents of minors to provide Habilitation and Attendant Care services or work over 40 hours a week most of the minor disabled community in Arizona will be underserved. A comprehensive Paid Parent Caregiver program validates the irreplaceable work that parents provide in their homes and communities.

Click here to connect with the Arizona parent led grassroot initiative leaders: www raisingvoicescoalition.com

Thank you for your time and consideration! Our community is extremely grateful for the initiative of AHCCCS in creating a permanent program for Paid Parent Caregivers. We look forward to our continued collaboration to create a permanent program that best serves all DDD and ALTCS members in Arizona.

Thank you!

I have provided our personal experience below:

We are grateful for the opportunity you have given us to provide feedback regarding the proposal for the Parent Provider Program and to be the voice for our children.

I have been my son's Habilitation Provider now since May of 2022 and since that time we have seen so many positive benefits of this program. Since he was about 9 months old we have had therapists work with him to help him develop certain skills. Now at 9 years old, he continues to have 4 different therapists work with him one on one on a weekly basis. While we are grateful for their support, needless to say we have had many different therapists coming in and out of our lives. It takes time for him to adjust to someone new and to find the therapist that works best with him. As with any child they need consistency and routine in their lives to allow expectations to be set and provide them with a sense of safety. Inconsistencies can lead to feelings of frustration, disappointment and self-doubt which can have a negative affect on their over all well-being. Our children with disabilities already face daily challenges and adversities, the constant turn over of providers adds to these inconsistencies in their routine.

Since I have gone through the training to be a Habilitation Provider I have a better understanding of how to continue to best support him. With 4 different therapists coming weekly and offering suggestions and ways to support him, I always felt overwhelmed and defeated not knowing where to start or how to apply this information to his day-to-day routine. Before becomimg a Habilitation provider I felt that I was not doing enough to support him and his needs. Now I have a sense of comfort and ease being able to be more involved in his care. It has been so rewarding to work more one on one with him to help him gain confidence in himself and make progress toward his goals. He is also making great progress in school. Working with him step by step each day and tracking his progress has helped me collaborate better with his teacher and team at his school, as well as with his therapists at home.

I understand there is the worry about social isolation with having family members being the provider for their children. My child already faces isolation at home having other providers in the home so much working with him one on one. We feel that it takes away from him being more involved in our daily activities. One of our goals is community safety, so we have been going out into the community more and have been able to go to the zoo, movie outings, the library and other children's activities. I have been able to utilize respite care for any short term relief as needed, when a provider has been available. We had issues with one respite provider consistently canceling last minute.

To meet the need of the member, present the option during the assessment and let the family choose. Services do need to be individualized to that member and family. Let them choose if the family member or an outside provider will provide services for the member. Also offering respite services and counseling resources to prepare the caregiver for burnout could be beneficial. Also providing families with more information on social events for others with disabilities would allow the member to get out more and socialize.

I appreciate this opportunity and the support we receive as a community from ACCCHS.

Sincerely,

Nicole Beltran

[redacted]

---------- Forwarded message ---------
From: S Maq [redacted]
Date: Tuesday, August 22, 2023 at 2:14:48 AM UTC-4
Subject: Parent providers
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

To Whom It May Concern:

Quoting another parent as she said it well (I just changed a little:
"Habilitation is essentially a list of very specific goals set by the parents and Division of Developmental Disabilities (DDD) that will help the individual (whether a child or adult member) become more independent. The idea is that this helps the individual reach their developmental milestones, many of which they could be years behind. DDD determines an appropriate number of hours per week for the individual to have a provider work with them to reach these very specific goals. Sometimes it's a handful of hours, sometimes it's a full-time job-worth.

During COVID, DDD temporarily approved parents to become paid habilitation providers of their children with special needs.

Parents and providers were uncomfortable going into others/having someone come into their homes in fear of catching/spreading COVID. This resulted in a deficit of providers:member ratio leaving many members without habilitation services.
And I found it hard to find a consistent person that would sta opy in the home, even before COVID."

"As a result, members were not receiving the services deemed necessary by DDD.

"To assist the members, DDD allowed parents to become paid habilitation providers. By allowing this, DDD became our hero, and at the same time an inadvertent and fantastic domino-effect was created. Members were back to receiving habilitation, and by the parents. This, in turn, created an environment where the parents have now become more involved and invested in the habilitation, creating a much better continuity of care. Arising from more invested and involved parents are stronger relationships and habilitation goals being practiced more frequently throughout the typical day, leading to the possibility of these goals being mastered more quickly. And as an even bigger bonus, families are now able to provide focused habilitation at the most beneficial times for the member. Habilitation can now be worked into the day more naturally, allowing the member to get the most out of it."

My son is autistic, ADHD, OCD, high generalized anxiety, sensory sensitivities, and trauma. Plus he has a PDA profile, which means demands cause massive anxiety. He would have panic attacks before school and after school he would meltdown.
The parent provider program has helped us so much. For many reasons.

Another parent stated, and said it very well
"By removing the option for parents to be paid providers it’s going to be nearly impossible for members to receive their designated benefits.

"With this paid parent provider option ending, the MAJORITY of members with special needs will not be able to have the Habilitation assistance DDD has agreed they truly need. In addition to having trouble finding someone to provide habilitation for our kids, it’s also going to create additional financial burdens on many families. Instead of some of these parents being able to supplement with a part time job while they’re paid to provide the Habilitation, they’ll now have to get a full time job and will no longer be available as often to provide habilitation to the Member. I foresee this leading to less parental involvement, habilitation hours left unfulfilled, members not receiving the benefits deemed necessary, and ultimately an entourage of unmet milestones."

PLEASE keep the parents as paid providers an option. It is a crucial piece to the puzzle we have to create as parents of children with special needs. Taking this away will only be hurting our children, your members, and the future of the individual."

My son has such high anxiety it would just cause him more to have to work with someone new until we find the right fit, or if they just left because they moved or had to find another job. He feels abandoned each time. He feels like they left because he upset them.

Please don't take away this program, it has helped my child and our family so much .

Thank you!
Shelley Maqueda

From: Bethany Platt [redacted]
Date: Tuesday, August 22, 2023 at 2:54:13 AM UTC-4
Subject: Feedback
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Dear AHCCCS and 1115 Waiver Team,

First of all thank you for seeing the need for this waiver to take place. As a parent of a minor child who receives DDD and ALTCS services, I began participating in the temporary paid parent caregiver program in late 2020. I would like to share how this program has specifically had impacted my child and our family. She began receiving habilitation services after her

trach was removed (may 2020). She was assessed for hours and with no providers available at the time, I began to work the hours allotted to her in November 2020. Ever since then, her hours have increased and I have continued to work habilitation and attendant Care hours as they were added. I have also tried to find providers, but was only successful with one close family member (her aunt) who comes a maximum of 4 hours per week. My [redacted], has done very well with me working with her. I have the flexibility to help her as needed when her schedule varies so much from day to day. Not only that, but [redacted] care is quite complicated in regards to her respiratory status and orthopedic needs. Her right hip has come out of socket (under the care of a previous PT) so it is extremely difficult to find a provider who understands how to carry for [redacted] without causing her body harm. It takes a great deal of time to teach someone how to carry for her properly, and unfortunately provider turnover rates are quite high. I myself was a respite and habilitation provider to a boy with autism when I was in college and I know how quickly providers leave as the family I worked for had a difficult time keeping good people.

I say all of this to emphasize how removing habilitation hours for parent providers could very well negatively impact DDD and ALTCS members. I understand that one reasoning is perhaps the member will be isolated from the community but this could not be further from the truth for most families including mine. [redacted] participates in group tutoring, church activities, in clinic therapy, interacts with her family and friends, and enjoys family outings in the community such as going to the library and going on walks. She also has an in home nurse that we love and are grateful for who comes to work with her three times a week. Penelope is not isolated at all, but instead sees a variety of people in a variety of settings.

Working these hours has also allowed me to help contribute to our families finances, which helps us to take even better care of [redacted]. When [redacted] was born during my senior year of college, I was thankfully able to finish my degree in music therapy and graduate, but I have not been able to enter the workforce as I was suddenly responsible to care for a medically fragile child. I love her and am honored to care for her, so having the blessing of being able to be paid to be her caregiver has been very helpful to our family, and allows us to have my husband not have to pick up as much over time so he can also be home with our family.

While I do not currently work over 40 hours per week, I do think limiting parents to this rule might not also be in the best interest of DDD members and their families. Each parent I have spoken to would be happy to allot hours to a provider, if only they could find a could trustworthy fit. Caring for an individual with disabilities is no simple task, I speak from previous experience from before even having my child. I have heard the reasoning behind the 40 hour limit is to help prevent caregiver burnout, but I myself work much more than 40 hours per week, whether paid or not, care is still required. Perhaps there is another solution to preventing caregiver burnout.

Thank you for your time and for all the hard work that has been done and will hopefully continue to be done. This program has been a huge blessing to my family and the special needs community in general. While there is always work to be done, I am so grateful for the opportunity to submit my feedback.

Warm regards,
Bethany Platt

From: JAQUITA FISHER [redacted]
Date: Tuesday, August 22, 2023 at 2:59:28 AM UTC-4
Subject: Parent provider feedback
To: waiverpublicinput@azahcccs.gov <waiverpublicinput@azahcccs.gov>

Hello, I am Jaquita Fisher a parent provider to my son with autism. I am so thankful for this paid parent provider program. It has provided financial and emotional stability to my family. Money stress is the worse and still having to work jobs knowing the demands of your child are so great is a huge weight off my shoulders having this program. I want to address habilitation and how my son has improved so much on his life skills bathing, teet brushing and toileting. I just don't think that taking this away from the parents helps the child or the family life in any way. A stranger performing these tasks involve more risk and they will never care as much as the parent.

Thank you,
Jaquita Fisher

From: **Jennifer Renzulli** [redacted]
Date: Mon, Jul 24, 2023 at 10:08 AM
Subject: Grievance
To: DDDCustomerServiceCenter@azdes.gov <DDDCustomerServiceCenter@azdes.gov>

Good Morning,

I am a parent of a child who receives DDD and ALTCS services. I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which would go into place in November 2023, my child and many more like them will lose access to their Habilitation services or more than 40 hours a week of care by parent providers of minor members. The reason my child will not have access to their appropriately evaluated services is due to the DCW shortage. My agency has specifically stated that they will not be able to recruit, hire and train enough providers to fill the gaps in service these new rules will create.

Thank you for your time, I would like to request a TICKET NUMBER.

Jennifer Castine
[redacted]

From: **Carrie Goettl** [redacted]
Date: Sun, Aug 20, 2023 at 9:47 PM
Subject: Grievance over paid parent provider possible changes
To: <DDDCustomerServiceCenter@azdes.gov>

To whom it may concern:
I am a grateful parent of a child who received DDD and ALTCS services. I would like to file a grievance against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which would go into place in November 2023, my child and many more like him will lose access to their Habilitation services. The reason my child will not have access to their appropriately evaluated services is due to the DCW shortage. I have tried for many years to get a reliable habilitation provider for my son, with no success. In fact, I just recently requested a respite care provider and was told there were none in my area. While I have been his provider, he has gone out into public, is nearly ready to pass off some personal care goals, is learning to find food in the grocery store, make easy meals, understands stranger danger, and can identify safe people in a store should he need assistance. Being able to be a provider for him has made this possible.

I am grateful for your time and would like to request a ticket number.

Sincerely,
Carrie Goettl
[redacted]

From: **Rudy Marquez** [redacted]
Date: Tue, Jul 25, 2023 at 7:12 PM
Subject: Grievance
To: DDDCustomerServiceCenter@azdes.gov <DDDCustomerServiceCenter@azdes.gov>

Hello,

I am a bonus parent of a child who receives DDD and ALTCS services. **I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal.** Under this proposal, which would go into place in November 2023, my child and many more like them will lose access to their Habilitation services or

more than 40 hours a week of care by parent providers of minor members. The reason my child will not have access to their appropriately evaluated services is due to the DCW shortage. The agency that provides services for my child has specifically stated that they will not be able to recruit, hire and train enough providers to fill the gaps in service these new rules will create.

Please note, this grievance is not a target or unfavorable matter against any single personnel, rather a systemic grievance against a pressing matter that is before the decision makers.

Thank you for your time. Rudy Marquez

From: **aquah.braden@yahoo.com** [redacted]
Date: Mon, Jul 24, 2023 at 10:14 AM
Subject: GRIEVANCE regarding the current Paid Parent Caregiver proposal
To: DDDCustomerServiceCenter@azdes.gov <DDDCustomerServiceCenter@azdes.gov>

Hello,

I am a parent of two children who receives DDD and ALTCS services. **I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal.** Under this proposal, which would go into place in November 2023, my children and many more like them will lose access to their Habilitation services or more than 40 hours a week of care by parent providers of minor members. The reason my children will not have access to their appropriately evaluated services is due to the DCW shortage. My agency has specifically stated that they will not be able to recruit, hire and train enough providers to fill the gaps in service these new rules will create.

Thank you for your time, I would like to request a **TICKET NUMBER** for my records. I can be reached at (602) 427-7975.

Sincerely,
Nefertiti Aquah-Braden

From: **Jessica Nolte** [redacted]
Date: Tue, Jul 25, 2023 at 1:42 PM
Subject: File a Grievance - HAH Parent Provider
To: <DDDCustomerServiceCenter@azdes.gov>

Good afternoon,

My name is Jessica Nolte a parent provider for my two autistic kids. They are currently 7yo and 5yo and both receive DDD and ALTCS services. I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. I strongly disagree with the unsubstantiated decision to exclude Habilitation services from the proposal.

Excluding Habilitation with direct affect kids ability to receive services. There is a work crisis for state related services, it's nearly impossible to find anyone willing to do the hard work of working with disable individuals for the pay the state has currently. I don't blame them, it's hard work, but we can't let those individuals without services that they require. Having a parent provider gives the child the best chance to achieve their independence since parents are the most motivated people to make it happen.

Habilitation has been a blessing in my kids lives, taking away that service will severely impact their ability to successfully achieve their goals. I know the state wants the best for the children and their parents and I'm here as a witness that the best outcome is for parents to be able to provide HAH services for their children.

I hope you will have an open mind to see there is no good reason to prevent HAH to be part of this waiver and do the right thing by our most vulnerable children.

Thank you for your time, I would like to request a TICKET NUMBER.

Thanks!

Jessica Nolte

From: **Barba Family** [redacted]
Date: Sun, Jul 23, 2023 at 10:01 PM
Subject: Grievance against DDD and AHCCCS
To: DDDCustomerServiceCenter@azdes.gov <DDDCustomerServiceCenter@azdes.gov>

Hello,

I am a parent of three children who receive DDD and ALTCS services. **I would like to file a GRIEVANCE against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal.** Under this proposal, which would go into place in November 2023, my children and many more like them will lose access to their Habilitation services. The reason my children will not have access to their appropriately evaluated services is due to the DCW shortage. My agency has specifically stated that they will not be able to recruit, hire and train enough providers to fill the gaps in service that these new rules will create.

I would like to request a ticket number as well. Thank you for your time.

Angela Barba
[redacted]

From: **Ashley Pihlman**[redacted]
Date: Mon, Jul 24, 2023 at 12:07 PM
Subject: Re: Grievance
To: <dddcustomerservicecenter@azdes.gov>

7/27/2023

Re: habilitation services

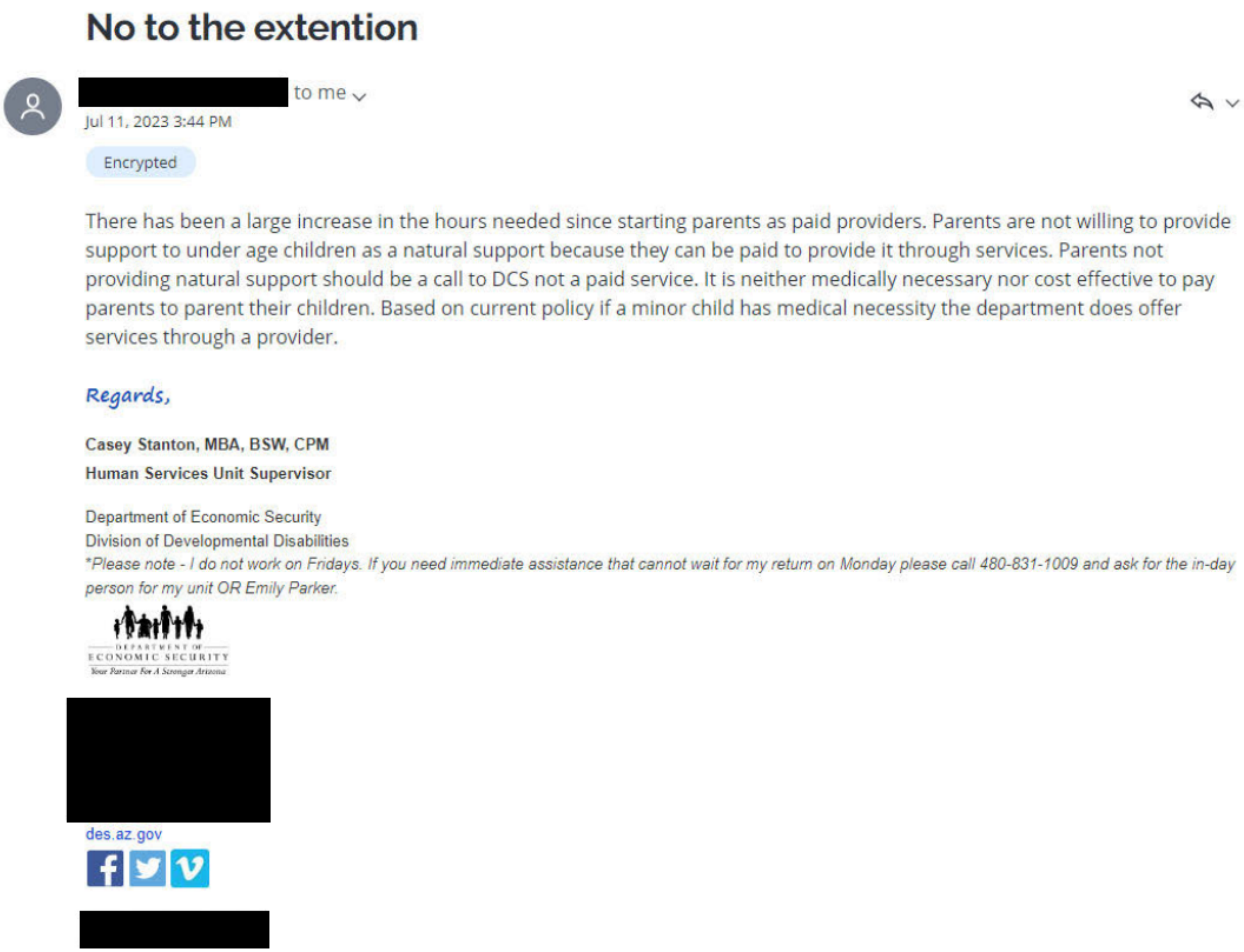
[redacted]Pihlman
[redacted]

[redacted] Pihlman
[redacted]

I am a parent to two children who receive DDD and ALTCS services. I would like to file a grievance against DDD and AHCCCS regarding the current Paid Parent Caregiver proposal. Under this proposal, which would go into place in November 2023, my children will lose access to their Habilitation services. Many other DDD children will also be negatively impacted by this, including losing services if they require more than 40 hours per week of care. The reason my children will not have access to their appropriately evaluated services is due to the direct care worker shortage. My agency has specifically stated that they will not be able to recruit, hire, and train enough providers to fill the gaps in service these new rules will create. Thank you for your time. I would like to request a ticket number assigned to this case.

Thank you,

Ashley Pihlman
[redacted]



No to the extention

[redacted] to me

Jul 11, 2023 3:44 PM

Encrypted

There has been a large increase in the hours needed since starting parents as paid providers. Parents are not willing to provide support to under age children as a natural support because they can be paid to provide it through services. Parents not providing natural support should be a call to DCS not a paid service. It is neither medically necessary nor cost effective to pay parents to parent their children. Based on current policy if a minor child has medical necessity the department does offer services through a provider.

Regards,

Casey Stanton, MBA, BSW, CPM
Human Services Unit Supervisor

Department of Economic Security
Division of Developmental Disabilities
**Please note - I do not work on Fridays. If you need immediate assistance that cannot wait for my return on Monday please call 480-831-1009 and ask for the in-day person for my unit OR Emily Parker.*

DEPARTMENT OF
ECONOMIC SECURITY
Your Partner For A Stronger Arizona

[redacted]

des.az.gov

[redacted]