

EMAIL 1

Johnson, Dara

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**From:** WILLIAM HAWES <hardrockhawes@msn.com>  
**Sent:** Monday, July 20, 2015 10:39 AM  
**To:** Rountree, Virginia  
**Cc:** Johnson, Dara  
**Subject:** The Arizona Training Program aka Randolph House

It has come to my attention that the Arizona Training Program, originally called The Arizona Children's Colony, is imperiled due to Federal laws (HCBS-aka Home and Community-based Setting Requirements) Under this law, the Arizona Training Program is presumed not to meet the compliance standards of this act. A waiver is required to continue operations as had been successfully done for over fifty (50) years. I urge you to apply for this waive.

I am familiar with the good work that the Arizona Training Program (earlier known as the Children's Colony) does. When I first came to Arizona in 1960, a co-worker had his son there and told me of the excellent care given. More recently, I am acquainted with another person who has her younger sister there- again, highly satisfied with the care and compassion shown. To uproot these residents to a new setting, with different, perhaps not caring staff would be detrimental, possibly inhumane.

I urge that action be taken to preserve the status quo of the Arizona Training Program, aka the Randolph House.

William Hawes  
Dewey, Arizona



EMAIL 2

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Monday, July 20, 2015 5:11 PM  
**To:** HCBS  
**Subject:** AHCCCS Community Forum  
**Attachments:** DTP QVs.docx

Dear AHCCCS - I received the flyer related to community input for HCBS. Attached are my comments addressed to Dr. Love (DDD). Thank for your time. [REDACTED]

[REDACTED]

[REDACTED]

Emil Z

July 20, 2015

Dr. Laura Love, Deputy Director  
Division of Developmental Disabilities  
1789 W. Jefferson  
Phoenix, AZ 85007

Subject: Day Treatment & Training/Center Based Employment

Dear Dr. Love:

Congratulations on your appointment. You have always been responsive to parents, guardians, and people with disabilities. This letter is related to the AHCCCS community Forum announcement requesting input.

I feel DDD Day Treatment & Training (DTT) and Center Based Employment (CBE) should be inclusionary and offer the same opportunities for all DDD members. My son [REDACTED] is autistic, MI, deaf, has behavior disorders, and medical issues associated with his facial abnormality. He does not have physical disabilities and is very active. Over the past year I have been researching DTT-CBEs for [REDACTED] since his current DTT lost their work contract. During this search I have learned some DTT-CBEs reject certain DDD members. [REDACTED]

For example, a neighbor with a high functioning DDD son (reads, uses cell phone, works independently, takes the bus, and has 'alone' time) commented how happy they are at a DTT-CBE near our home. I mentioned her comments to another neighbor with a DDD son (autistic) and we separately toured the program since they had openings. This large DTT-CBE has many wonderful opportunities; work, volunteering, community outings, art activities, culinary, exercise programs, and more. [REDACTED] seemed very comfortable at this program, but was rejected because he is a 1:1 and deaf. My neighbor with the autistic son toured the same program and her son was rejected because he is a 1:1 and too autistic. The QV of the program nicely explained the difficulties of staffing 1:1s and our sons did not fit into their culture/flow. [REDACTED]

If AHCCCS-DDD continues to allow some DTT-CBEs of picking and choosing [REDACTED] up with a two tier system; those only accepting the higher functioning DDD members [REDACTED] that accept any member. Unfortunately, the DTT-CBEs offering the best integrated opportunities (social, work, etc) for [REDACTED] do not want him in their 7-8 hour/day programs. AHCCCS-DDD could correct this problem by:

- 1) Insist all DTT-CBEs (over 25 clients) have similar representation of the total DDD population. This would stop the picking/recruiting of the highest functioning/easier members.

- 2) Honor ADA laws – because my son is deaf he will always be a 1:1 for sign language. DTT-CBEs should not be allowed to reject deaf members because ‘they’ are considered a burden since they need a higher skilled provider. At my son’s current DTT he was not allowed entrance until I recruited, tested, and trained a provider they hired. Like the schools, QVs awarded contracts for DTT-CBE need to embrace the ADA laws and provide skilled staff to deaf members when attending their programs. They should not expect a parent-guardian to recruit, test signing skills, and train.
- 3) Create a check and balance program – when a DDD member is rejected from a desired DTT-CBE with openings the QV need to document rationale for rejection. This documentation needs to be assessed by the member’s support coordinator and reported to Contracts. If Contracts feels the member is being discriminated based on their disability/staffing needs then real corrective active is required.

Based on my experience, the only realistic way to change the culture/flow of some DTT-CBEs would be through Contracts. DTT-CBEs refusing to accept all DDD members and not honoring ADA laws should not be awarded a QV contract. DTT-CBE programs are funded with federal (Medicaid) and state dollars – can you imagine a public school or hospital banning a DDD member because they are too autistic or deaf or in a wheelchair due to CP? Yet, it is acceptable for DTT [REDACTED] my son. [REDACTED] has a normal lifespan – does this mean for the next 40-50 years he can NEVER attend a DTT-CBE that offers employment, volunteerism, or social events the higher functioning/easier members are privileged to attend because he is a deaf 1:1?

I’ve kept in contact with [REDACTED]’s special education teachers and we visit them throughout the year. They are disappointed [REDACTED] cannot participate in the work force. These teachers worked hard so [REDACTED] could learn to count, socialize, communicate, complete 5-7 step task, and receive job training. They keep encouraging me to fight for [REDACTED] because they believe he has potential for meaningful work.

In summary I feel all DDD members should have the same opportunities for DTT-CBE. Rejection based on their disabilities should not be accepted. Thank you [REDACTED] for your time.

Sincerely,

[REDACTED]  
[REDACTED]  
[REDACTED]

[REDACTED]

Copies: Ms. Leah Gibbs and [HCBS@azahcccs.gov](mailto:HCBS@azahcccs.gov) (flyer comment webpage)

Email 3

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Wednesday, July 22, 2015 3:10 PM  
**To:** HCBS  
**Cc:** Johnson, Dara  
**Subject:** REQUEST

After reviewing numerous documents available on your website, I still do not see the actual rules stating - Any setting that is located on the grounds of, or immediately adjacent to, a public institution (Arizona Training Program at Coolidge) and Any other setting that has the effect of isolating individuals receiving Medicaid HCBS from the broader community of individuals not receiving Medicaid HCBS.

Please provide a copy of the actual rules or direct me to the specific location on your website where I can read further. Thank you for your time.

[REDACTED]

Sent from my Windows Phone

*[Illegible handwritten text]*

*[Illegible handwritten text]*



Emily

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Monday, July 27, 2015 2:48 PM  
**To:** Sikkema, Timothy, C; Rountree, Virginia; Johnson, Dara; Key, Lori, A; Merritt, Trina  
**Subject:** Waiver request for ATPC  
**Attachments:** Victoria J.pdf

Please see the attached wavier request for our ATPC Group Homes. Let me know when you have scheduled the first official meeting so I may notify Patricia's family in order for them to be there.

Respectfully,

[REDACTED]



Emil 4

July 23, 2015

[REDACTED]

[REDACTED]

RE: Wavier for the new Federal HCBS Regulation

To Whom It May Concern,

I am the court appointed guardian and representative payee for my sister, [REDACTED] who for the past 43 years has resided at the Arizona Training Program, Coolidge, Arizona.

In accordance to the [REDACTED] Federal HCBS regulation, my sister's home of 43 years will be taken away from her and others in the ATPC group home residents. I believe, she will fall under the VOR Olmstead of Illinois.

VOR Olmstead Amicus Brief #98-536

In the Supreme Court of the United States October Term, 1998

I quote in part:

This is an amicus curiae brief on the merits, prepared by Voice of the Retarded ("VOR")(FN), it is adopted by 141 organizations advocating the rights of the disabled. (FN2)

Interest of the VOR Amici

VOR is an advocacy organization incorporated in Illinois, dedicated to insuring that individuals with mental retardation receive the care and support they require in a setting "appropriate to their needs". Depending on the unique condition of each disabled person, that appropriate setting could be community placement, or institutionalization. A spectrum of choices must be available, because not every disability lends itself to community placement.

My sister, [REDACTED], began living at the Arizona Children's Colony in 1972 at the age of 24 years, when it was a full institutional setting. In 1982, [REDACTED] was transferred into a group home located on the same campus where she could receive skilled training and care necessary for her health and welfare geared toward her severity of disability. In 2002, the Arizona Children's Colony was renamed to the "Arizona Training Program, Coolidge. [REDACTED] her mother, spearheaded this effort.

Moving [REDACTED] at this time, to another facility or group home, after 43 years at this location, would be detrimental to her safety, health and wellbeing. [REDACTED] knows and feels comfortable with the staff who take care of her on a daily bases, and feels secure in the only home she knows. I fear, moving her would severely threaten her health and wellbeing, as well as her life.

Here are some of [REDACTED]'s yearly evaluation (ISP) required by the DES/DDD for the State of Arizona [REDACTED]

- [REDACTED] is an aging 67 year old severely disabled elderly woman.
- She has profound cognitive disabilities
- She suffers from seizures and takes medications for control
- Lumbar Spine Osteopenia
- Femoral neck and hip osteoporosis
- Life threatening Pica (ingests foreign objects)
- She does not adjust well to changes
- She has a history of falls and the inability to evacuate a home in an emergency situation

Patricia is not [REDACTED] residing at ATPC:

- Social opportunities and activities are organized by staff and she does attend those that allow her to utilize her wheelchair. She is limited in the distance she can walk. Because of [REDACTED]'s severe Osteoporosis she must wear a gait belt for staff assistance.
- She enjoys watching her Lawrence Welk DVD's
- She enjoys her visits with family every 6 to 8 weeks, and celebrating the holidays at family members homes.
- [REDACTED] has stated she is happy in her home at ATPC group home residence

Recently, March, 2015, [REDACTED] was hospitalized, after a fall, afterwards developing a life threatening pneumonia along with accompanying heart attack. During her stay, [REDACTED] became extremely agitated, over a medical procedure, her doctors were unable to affectively treat her and had to put her into an induced coma for 10 days. When recovering, and out of the induced coma, one of her ATPC staff was brought in at meal times to feed her because she refused to eat for hospital staff.

At 67 years old, [REDACTED]'s health is declining and very fragile. Moving her, I feel, would be catastrophic to her health and life.

65 years ago, our mother [REDACTED], started fighting for disabled children in the state of Illinois. Upon moving to Arizona she became instrumental in the State of Arizona and dedicated herself to Arizona and all disabled children for the Right of the Disabled. She was recognized around the state and across the country as a volunteer organizational leader and a strong influential voice, working to assure dignity and security of the families and affected individuals. She applied sense of meaning and protection to the ATPC residents through her legislative efforts and work in the areas of total quality care, legal rights and status, housing and guardianship service.

Her distinguished career, serving as an advocate for the developmentally disabled [REDACTED] spanned 47 years.

Here are a few of her accomplishments: [REDACTED]

- Founder of the ARC of Arizona and was President of ARC of AZ 1977 - 1981
- Member of the Local and National Board of Directors ARC
- Awarded the Council Award by the Governor's Council on Developmental Disabilities and the AZ Department of Economic Security

- ARC Lifetime Achievement Award in 1990
- Six times awarded the Juanita Sheppard Memorial Award
- The Distinguished Service Award 1995
- Awarded the AZ Department of Economic Security Award 2001 for the life-time "Outstanding Volunteer Service"

[REDACTED]'s, mother fought to make Patricia's life as a Disabled Citizen, as normal as possible. If alive today she would be fighting for the residents of ATPC group home, to receive a Federal HCBS Wavier to keep these adult handicapped people, at the end of their lives, in their home where they are safe, well cared for and most of all, content.

As, [REDACTED]'s, legal guardian and sister, I strongly request a Federal HCBS Wavier be granted to the ATPC Group home residents, to live their remaining life out in dignity, contentment and in the way they have been accustomed to for most of their lives.

To move [REDACTED] at this time would be devastating to her and would compromise her very existence.

Based on the VOR Olmstead Amicus Brief #98-536, [REDACTED], and other residents of ATPC group home, do not conform to placement in a community setting or institutionalization, "not every disability lends itself to community placement". They deserve to live the remainder of their lives as residents of ATPC

I, as [REDACTED]'s guardian, request a HCBS Federal Wavier from being placed in a community group home.

Respectfully,

[REDACTED]  
Guardian to [REDACTED]  
ATPC group home [REDACTED]

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EMails

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Friday, July 31, 2015 4:24 PM  
**To:** Johnson, Dara; HCBS  
**Subject:** GROUP HOMES LOCATED on the CAMPUS of the ARIZONA TRAINING PROGRAM - COOLIDGE (ATPC)  
**Attachments:** jeffries ahcccs reply.docx

Please see the attached letter, noting that the original was mailed via certified mail to Timothy Jeffries, Director, AZ Department of Economic Security with copies to yourself at AHCCCS; Governor Ducey; and my State Congress folks. Your time and consideration to this serious matter are appreciated.

Respectfully,

[REDACTED]





Encls

[REDACTED]

[REDACTED]

July 30, 2105

Timothy Jeffries  
Director, Arizona Department of Economic Security  
1717 W. Jefferson  
Phoenix, AZ 85007

Re: Group Homes Located on the Campus of the Arizona Training Program – Coolidge (ATPC)

Dear Director,

Earlier this month, members of my family attended a meeting in Coolidge that was hosted by AHCCCS and the Division of Developmental Disabilities (the Division). The purpose of the meeting was to inform the guardians and families of a CMS regulation that impacts all of us who have family members living in a Group Home at ATPC. My observation was that the meeting was designed to educate us about the subject regulation with the true intention of requiring and expecting us to conclude and accept that the only option available was to move our family member to a community based home in the private sector. The handout shared with each attendee provided resources to help us locate alternative housing and available supports throughout the transitional period, which on the surface is helpful and positive. My question is, well honestly, I have more than one - It seems this approach is self-serving and short-sighted. It seems the Division and perhaps the Arizona Government, as a whole, buys into what some of the discipline's experts advise – there is no place for institutions in 2015 – period. This theory, in my humble opinion, again, is self-serving and short-sighted. I am grateful for folks in the developmental disability community who are physically able and at a higher level intellectually who can speak for themselves; move around their communities with little or no support; an institution is NOT the place for them. I am not advocating a setting such as ATPC for such a high functioning individual; however, most of the folks who continue to call ATPC their home cannot boast of such capabilities. They have physical AND intellectual limitations too great and that

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Timothy Jeffries

Director, Arizona Department of Economic Security

require special and unique care and [REDACTED] - Arizona Government, in spite of direction/pressures coming from CMS that is a function of the United States Government.

Please allow me to turn the focus onto my sister, [REDACTED], whom we call [REDACTED]. She moved into an ICF on the ATPC Campus on Valentine's Day in 1963, when she was 13 and I was eight. I recall my now deceased parents saying that this was the hardest decision they had ever had to make. The tipping point to making this decision, was an assurance that she would be cared for in the event something should happen to them. They prayed that she would die before them, but because of the excellent quality of care she has received through the years, she will be turning 66 in October, after being told she would never see her 16<sup>th</sup> birthday, and she continues to outlive our parents. In the history of her stay at ATPC, there have been other attempts to close the Campus, all of which have failed to this date. It saddens and angers me to think we're fighting our Government for these special individuals, yet again. Let me return to introducing you to [REDACTED], if I may. She is legally blind, cannot speak, cannot read or write; yet, she joyfully goes to work daily, carrying her beloved lunch bag. She is so disappointed if her schedule changes and she cannot go to work. She can navigate the Campus with little assistance because she knows its layout, has neighbors who know her and where she belongs and are available to assist if it becomes necessary. If [REDACTED]'s Government requires her to move to a community based facility, she starts from Ground Zero. Is she up to it? Mr. Jeffries, you are new to the DES here in Arizona. How much courage did it take you to start at your recent Ground Zero? If you had a fragile loved one who is similarly limited, tell me, would you ask him or her to make the changes you've been required to make when it is absolutely unnecessary, because there are other options available.

With a stroke of a pen; with the courage to simply say, "NO!" – all this foolishness can stop. I'm asking you as a concerned sister and one who sees value in such special folks, please, take some time to think this process through. Wherever these folks move, money is going to be required to recreate their supports. That will be costly. These supports are currently in place at ATPC. Please exercise compassion and common sense and hear the heart of the concerned [REDACTED] family. I fear that some of these folks will not survive the disruption that is being expected of them by our Government.



Page 3

Timothy Jeffries

Director, Arizona Department of Economic Security

I am available to answer any questions you may have or, If you are interested in knowing what my thoughts as far as other options for the Group Homes and the ATPC Campus as a whole, feel free to contact me at your convenience.

Respectfully,

A redacted signature consisting of two lines of black scribbles.

cc: Governor Ducey  
AHCCCS  
Adam Driggs, AZ State Senator  
Kate Brophy McGee, AZ State Representative  
Eric Meyer, AZ State Representative

Email 6 (Duplicate of Email 4)

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Monday, July 27, 2015 2:48 PM  
**To:** Sikkema, Timothy, C; Rountree, Virginia; Johnson, Dara; Key, Lori, A; Merritt, Trina  
**Subject:** Waiver request for ATPC  
**Attachments:** Victoria J.pdf

Please see the attached wavier request for our ATPC Group Homes. Let me know when you have scheduled the first official meeting so I may notify Patricia's family in order for them to be there.

Respectfully,

[REDACTED]



Email

July 23, 2016

[REDACTED]

[REDACTED]

RE: Wavier for the new Federal HCBS Regulation

To Whom It May Concern,

I am the court appointed guardian and representative payee for my sister, [REDACTED], who for the past 43 years has resided at the Arizona Training Program, Coolidge, Arizona.

In accordance to the new Federal HCBS regulation, my sister's home of 43 years will be taken away from her and others in the ATPC group home residents. I believe, she will fall under the VOR Olmstead of Illinois.

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*In the Supreme Court of the United States October Term, 1998*

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*VOR is an advocacy organization incorporated in Illinois, dedicated to insuring that individuals with mental retardation receive the care and support they require in a setting "appropriate to their needs". Depending on the unique condition of each disabled person, that appropriate setting could be community placement, or institutionalization. A spectrum of choices must be available, because not every disability lends itself to community placement.*

My sister, [REDACTED], began living at the Arizona Children's Colony in 1972 at the age of 24 years, when it was a full institutional setting. In 1982, Patricia, was transferred into a group home located on the same campus where she could receive skilled training and care necessary for her health and welfare geared toward her severity of disability. In 2002, the Arizona Children's Colony was renamed to the "Arizona Training Program, Coolidge. [REDACTED], her mother, spearheaded this effort.

Moving [REDACTED], at this time, to another facility or group home, after 43 years at this location, would be detrimental to her safety, health and wellbeing. [REDACTED] knows and feels comfortable with the staff who take care of her on a daily bases, and feels secure in the only home she knows. I fear, moving her would severely threaten her health and wellbeing, as well as her life.

Here are some of [REDACTED]'s yearly evaluation (ISP) required by the DES/DDD for the State of Arizona [REDACTED]

- [REDACTED] is an aging 67 year old severely disabled elderly woman.
- She has profound cognitive disabilities
- She suffers from seizures and takes medications for control
- Lumbar Spine Osteopenia
- Femoral neck and hip osteoporosis
- Life threatening Pica (ingests foreign objects)
- She does not adjust well to changes
- She has a history of falls and the inability to evacuate a home in an emergency situation

Patricia is not lacking in social contact residing at ATPC:

- Social opportunities and activities are organized by staff and she does attend those that allow her to utilize her wheelchair. She is limited in the distance she can walk. Because of [REDACTED]'s severe Osteoporosis she must wear a gait belt for staff assistance.
- She enjoys watching her Lawrence Welk DVD's
- She enjoys her visits with family every 6 to 8 weeks, and celebrating the holidays at family members homes.
- Patricia has stated she is happy in her home at ATPC group home residence

Recently, March, 2015, [REDACTED] was hospitalized, after a fall, afterwards developing a life threatening pneumonia along with accompanying heart attack. During her stay, [REDACTED] became extremely agitated, over a medical procedure, her doctors were unable to affectively treat her and had to put her into an induced coma for 10 days. When recovering, and out of the induced coma, one of her ATPC staff was brought in at meal times to feed her because she refused to eat for hospital staff.

At 67 years old, [REDACTED]'s health is declining and very fragile. Moving her, I feel, would be catastrophic to her health and life.

65 years ago, our mother [REDACTED], started fighting for disabled children in the state of Illinois. Upon moving to Arizona she became instrumental in the State of Arizona and dedicated herself to Arizona and all disabled children for the Right of the Disabled. She was recognized around the state and across the country as a volunteer organizational leader and a strong influential voice, working to assure dignity and security of the families and affected individuals. She applied sense of meaning and protection to the ATPC residents through her legislative efforts and work in the areas of total quality care, legal rights and status, housing and guardianship service.

Her distinguished career, serving as an advocate for the developmentally disabled [REDACTED] spanned 47 years.

Here are a few of her accomplishments:

- Founder of the ARC of Arizona and was President of ARC of AZ 1977 - 1981
- Member of the Local and National Board of Directors ARC
- Awarded the Council Award by the Governor's Council on Developmental Disabilities and the AZ Department of Economic Security



- ARC Lifetime Achievement Award in 1990
- Six times awarded the Juanita Sheppard Memorial Award
- The Distinguished Service Award 1995
- Awarded the AZ Department of Economic Security Award 2001 for the life-time "Outstanding Volunteer Service"

Patricia's, mother fought to make [REDACTED]'s life as a Disabled Citizen, as normal as possible. If alive today she would be fighting for the residents of ATPC group home, to receive a Federal HCBS Wavier to keep these adult handicapped people, at the end of their lives, in their home where they are safe, well cared for and most of all, content.

As, [REDACTED]'s, legal guardian and sister, I strongly request a Federal HCBS Wavier be granted to the ATPC Group home residents, to live their remaining life out in dignity, contentment and in the way they have been accustom to for most of their lives.

To move [REDACTED] at this time would be devastating to her and would compromise her very existence.

Based on the VOR Olmstead Amicus Brief #98-536, [REDACTED], and other residents of ATPC group home, do not conform to placement in a community setting or institutionalization, "not every disability lends itself to community placement". They deserve to live the remainder of their lives as residents of ATPC

I, as [REDACTED]'s guardian, request a HCBS Federal Wavier from being placed in a community group home.

Respectfully,

[REDACTED]

Guardian to [REDACTED]  
ATPC group home [REDACTED]

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Email 7 (Duplicate of Emails 6 + 4)

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Sunday, August 02, 2015 9:42 AM  
**To:** HCBS  
**Subject:** HCBS comment on ATPC  
**Attachments:** Victoria J.pdf

RE: Wavier for the new Federal HCBS Regulation  
To Whom It May Concern,  
Please see attached letter.

I am the court appointed guardian and representative payee for my sister, [REDACTED], who for the past 43 years has resided at the Arizona Training Program, Coolidge, Arizona. In accordance to the new Federal HCBS regulation, my sister's home of 43 years will be taken away from her and others in the ATPC group home residents. I believe, she will fall under the VOR Olmstead of Illinois. Respectfully,

[REDACTED]



EM-17

July 23, 2015

[REDACTED]

[REDACTED]

RE: Wavier for the new Federal HCBS Regulation

To Whom It May Concern,

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At 67 years old, [REDACTED]'s health is declining and very fragile. Moving her, I feel, would be catastrophic to her health and life.

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As, [REDACTED]'s, legal guardian and sister, I strongly request a Federal HCBS Wavier be granted to the ATPC Group home residents, to live their remaining life out in dignity, contentment and in the way they have been accustom to for most of their lives.

To move [REDACTED] at this time would be devastating to her and would compromise her very existence.

Based on the VOR Olmstead Amicus Brief #98-536, [REDACTED], and other residents of ATPC group home, do not conform to placement in a community setting or institutionalization, "not every disability lends itself to community placement". They deserve to live the remainder of their lives as residents of ATPC

I, as [REDACTED]'s guardian, request a HCBS Federal Wavier from being placed in a community group home.

Respectfully,

[REDACTED]

Guardian to [REDACTED]  
ATPC group home [REDACTED]





EM:G

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Monday, August 03, 2015 6:48 PM  
**To:** HCBS  
**Subject:** Comments for CMS - HCBS

Hello, I wrote a previous letter regarding comments for DTT-Community Based Employment and received a response that it was received from this website. Wanted to provide another comment and appreciate the ability to do so. My son receives DDD-AHCCCS services.

Comment: All DDD QVs providing direct care services to a consumer need to honor the ADA laws. This would include HCBS providers, DTT/DTT-CBE, PT, SP, OT, residential programs, and nursing. Example: my son is profoundly deaf and only signs. He also has a tracheostomy and is eligible for nursing, but DDD QV nursing agencies DO NOT provide signing nurses. If a non-signing nurse is managing my son and he needed help or was sick, a nurse would not understand him. Please support the ADA laws.

DDD needs a third unbiased party to assess signing levels of their consumers and this information should be passed on to their QVs to ensure communication is appropriate. For instance, my son also has cognitive impairments and does not sign at the level of a typical deaf person. My son expresses about 250-300 signs and does not require a high level signer (from what I understand there are different levels of ASL signers), but definitely needs a care provider who can appropriately sign.

On a final note, there are some QVs that do a great job with providing sign language for their deaf consumers. Thanks,  
[REDACTED]

Sent from my iPad



EMA19

Johnson, Dara

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**From:** Robin Lopez <robinl@weecarecorp.com>  
**Sent:** Monday, August 10, 2015 3:31 PM  
**To:** HCBS  
**Subject:** Arizona's Systemic Assessment and Transition Plan Comments

Good Afternoon,

I attended the Public Forum on 8/5/15 (1st Session).

Some questions/comments that came to mind are:

How does all of this pertain to children that are receiving DDD services? Parents/guardians make decisions for them.

How does this pertain to child day treatment programs such as DTS and DTT? If the member doesn't want to attend the field trip, how does the center handle this situation when their is ratio billing? If the member stays back who stays when the provider is handling 4:1? Is further reimbursement going to be made to allow for these members to "choose" not to participate?

What is the motivation for providers/caregivers to enter this field? complete training? provide quality care? They are paid so minimally due to reimbursement that most do not want to do this job any longer.

What is the motivation for DDD SC's to stay long term? They are overloaded with cases, paid minimally, etc.

We hear from many families that their SC is not supportive, doesn't assist, that they just calculate how many hours, but don't listen to the need. They appear too restricted and not able to offer guidance, support, explanation of services.

Often we have to request a copy of the ISP multiple times before finally getting a copy. Then they do not offer much information about the member, what their needs are, how best to support them, etc. The ISP mainly highlights the daily schedule in terms of calculating how much time needs to be approved.

For members living in group homes, residential settings, they should be afforded the same rights as others. However, they are living in these settings for a reason. Many members should not have a key to the home, be able to come and go, etc. For safety concerns more than anything. Access to food whenever, does that mean cooking in the middle of the night? What does that mean for the other members at that setting? Guests whenever? Does that mean at 3am if they so choose? What about the other members? Safeguards should be in place to protect them.

Thank you in advance for your time and attention. Have a wonderful week.

--

**Thank you,**

**Robin Lopez**

HCBS Director / Wee Care Corp.

4870 N. Litchfield Rd. #101 / Litchfield Park, AZ 85340

HCBS Dept.: 623-299-9442 / Main Office: 623-935-6040 / Direct: 623-806-1572 / Fax: 623-935-6046  
[robinl@weecarecorp.com](mailto:robinl@weecarecorp.com) / <http://www.weecarecorp.com>

Under Titles VI and VII of the Civil Rights Act of 1964 (respectively "Title VI" and "Title VII") and the Americans with Disabilities Act of 1990 (ADA) Section 504 of the Rehabilitation Act of 1973 and the Age Discrimination Act of 1975, *Wee Care Corporation* prohibits discrimination in admissions, programs, services, activities or employment based on race, color, religion, sex, national origin, age, and disability. *Wee Care Corporation* must make a reasonable accommodation to allow a person with a disability to take part in a program, service, or activity. Auxiliary aids and services are available upon request to individuals with disabilities. For example, this means that if necessary, *Wee Care Corporation* must provide sign language interpreters for people who are deaf, a wheelchair accessible location, or enlarged print materials. It also means that *Wee Care Corporation* will take any other reasonable action that allows you to take part in and understand a program or activity, including making reasonable changes to an activity. If you believe that you will not be able to understand or take part in a program or activity because of your disability, please let us know of your disability needs in advance if at all possible. To request this document in alternative format or for further information about this policy please contact: *Amy Donnel 602-565-1798*. Para obtener este documento en otro formato u obtener información adicional sobre esta política, *Amy Donnel 602-565-1798*.

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EMAIL 10

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Monday, August 10, 2015 4:20 PM  
**To:** Johnson, Dara  
**Cc:** Karen Van Epps; Patricia Thundercloud  
**Subject:** Re: HCBS Rules - Public Comment Period (August 2015)  
**Attachments:** AHCCCS - Public Forum.docx

Hi Dara,

It was very nice to meet you at the ACCESS public forum on August 5, 2015. Thank you for your presentation and allowing the public to participate and comment on the upcoming 5-Year Plan. I know you had limited time to take comment, so I chose to share my thoughts with you via email.

I am speaking to you both as a parent/guardian of a 20 year adult son who has lived in a DD Residential Group Home since 2007, and as a DD- HRC member. My son [REDACTED], sustained a Traumatic Brain Injury at birth, his condition is permanent, will never change or improve to the extent that he will become independent. While I understand and appreciate that we want to give our members as many rights as most normal individuals, I have come across many members who do not fit into the mold of the 5-Year Plan and should be exceptions to the rules. I was concerned about the following topics that were presented. I did understand from your presentation at the public forum, that there will members who will be exceptions to the rules, based on their medical and functional limitations, but wanted to share my thoughts all the same. I am attaching a word document addressing my comments/concerns.

✓ I am also interested in volunteering for the work-groups that you are planning on putting together, I would be most interested in the Residential Group Home Work-Group, and feel that I would have a lot to offer.

Thank you again for allowing our participation, I look forward to working with you in the future.

[REDACTED]  
**Parent**  
**HRC - District West Vice Chair**

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**From:** "Johnson, Dara" <[Dara.Johnson@azahcccs.gov](mailto:Dara.Johnson@azahcccs.gov)>  
**To:** "Johnson, Dara" <[Dara.Johnson@azahcccs.gov](mailto:Dara.Johnson@azahcccs.gov)>  
**Sent:** Friday, August 7, 2015 10:23 AM  
**Subject:** HCBS Rules - Public Comment Period (August 2015)

Thank you for registering for the AHCCCS community forums on the HCBS Rules. This email is being sent to inform you AHCCCS has posted the PowerPoint Presentation for the community forums to the AHCCCS website ([www.azahcccs.gov/hcbs](http://www.azahcccs.gov/hcbs)) for reference. AHCCCS encourages forum attendees to print and bring their own copy of the presentation.

Additionally, Arizona's Systemic Assessment and Transition Plan has been posted on the website ([www.azahcccs.gov/hcbs](http://www.azahcccs.gov/hcbs)) for public comment. The public comment period will be for the duration of August 2015. You may provide public comment ~~at the following link~~ and/or you may submit public comment via email or mail. Please reference the website for information and instructions on submitting public comment. AHCCCS will review and consider all public comment received.

Dara Johnson  
Program Development Officer

AHCCCS  
701 E. Jefferson St., MD 6100  
Phoenix, AZ 85034  
(602) 417-4362  
(602) 256-6421 (fax)  
[Dara.Johnson@azahcccs.gov](mailto:Dara.Johnson@azahcccs.gov)

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August 5, 2015

1. Seek Employment and Work in Competitive Integrated Settings -

- a. My son in particular, would require a 1:1 staffing at all times as he is highly behavioral, impulsive, and displays physical aggression, verbal aggression, and property destruction. He also has severe sensory impairments and does not tolerate large groups or loud noises.  
My concern here would be from both a safety and liability issue, should my son insult, abuse, injure or cause property damage, who would be responsible?
- b. My son would require a 1:1 due to his Health and Safety issues, he has visual field loss, no depth perception he is unsteady on his feet and is a fall risk. He does not sit for any length of time due to his sensory impairment-vestibular issues.  
My concern here would be his safety. How would we keep him safe, prevent him from falling?
- c. My son would require a 1:1 because he is an AWOL Risk, and has no concern for his safety or the safety of others. He is at risk in the community.  
My concern would be how to keep him safe in the community.
- d. My son would require a 1:1 due to his public displays of affection, invades space and privacy. He is very affectionate and does not understand sex, he is very friendly, and is very affectionate towards both sexes. He like to kiss everyone and tells them that he loves them, which includes strangers he has just met. If he gets rejected he can display behaviors.  
My concern is he would be at risk to be arrested for sexual assault or someone could retaliate and hurt him.

2. Locking Doors with Appropriate Staff Having Keys to the Doors

In my opinion, for members that have a lower cognitive ability or medical issues, this would be a disaster for the following reasons:

- a. No supervision while they are locked in their rooms.
- b. Members can Intentionally lock staff out of their rooms
- c. Staff with use of keys will be blamed for missing/stolen items, sexual abuse, etc...
- d. Increase of incidents of members being punished and locked in their rooms by staff
- e. Medical Emergency – If member has a medical emergency, i.e., seizures, diabetic emergency, etc... Staff would not know, and or would not be able to help member in time.
- f. Injury – Member could fall and injure themselves, intentionally hurt themselves, ingest anything poisonous or toxic
- g. Property damage
- h. AWOL – Member could go AWOL without staff knowing
- i. Does not provide greater privacy than unlocked doors
- j. If theft is an issue, install cameras in common areas

August 5, 2015

3. The individual has Freedom and Support to Control his/her own Schedules and Activities Including Access to Food at Any Time
  - a. If a member lives with other members in a residential group home or ADH, there is usually One car for all members. If the members have conflicting schedules and activities, how would that be Resolved? This would impact their freedom to control his or her Activities or Schedules.
  - b. Staffing – How will this impact staffing?
  - c. Who is making the decision on how/what transportation gets used?
  - d. If one member wants to eat Taco Bell and another Mc Donald's, do you go both places?
  - e. Favoritism
  
4. Access to Food at Anytime

While I am all for access to food at any time, I do feel that there are going to be circumstances that should be considered, such as:

  - a. Eating Disorders – PICA, Overeating, Weight Issues,
  - b. Medical Conditions – Diabetes, GERD, etc....
  - c. Is access to food limited to the home or in the community? If in the community will the member be allowed to go to get food at 3 or 4am? How would this impact the staff ratios of the house
  - d. Is the staff to cook meals at any time the member demands a meal?
  
5. Lease Agreement
  - a. How does this effect the contract they have with DD/Member?
  - b. Will the agency be allowed to terminate the lease with members who do not follow it, or will there be warnings, Etc.?
  - c. Will a member be kicked out of their placement, if they do not comply with the terms of the lease agreement?
  - d. Will there be exemptions for members with cognitive impairments?
  
6. Direct Care Staff Education/Wages:
  - a. Many staff that are hired have little to no experience, and at times do not read or speak clear English. This is very frustrating because the staff must be to follow both an ISP and BTP. In my experience, this has led to more incidents of behaviors, abuse and neglect of our members.
  - b. In my communications with staff they state are underpaid, overworked, (often doing 12-16 hr. shifts) do not get raises for years on end, no benefits, no insurance, and often have no hopes to advance within their company. This leads to a higher staff turnover, staff not being happy, a lack of consistency with the members, and abuse and neglect of the members



August 5, 2015

Direct Care Staff, Cont.

- c. It is my personal opinion that staff that working with highly behavioral members are underpaid and should be provided additional/higher training or education, such as BHT (Behavior Health Technician) or higher. This would increase their knowledge regarding behaviors and how to deal with them, which would reduce incidents and behaviors.
- d. Many staff have told me they would be interested in taking these courses if it would result in increases in pay, advancement for the future.



Email 11

Johnson, Dara

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**From:** John Chacon <JohnC@bethanyranchhome.org>  
**Sent:** Wednesday, August 12, 2015 12:08 PM  
**To:** HCBS  
**Subject:** Volunteer

Good Morning,

Please accept my request to be involved in the work group that is working on the assessment specifically the ADH/CDH standards. My contact information is below.

Thank Yyou,

John Chacon  
Associate Director of Developmental Homes  
Bethany Ranch Home INC.  
6130 N. 16<sup>th</sup> Street  
Phoenix, AZ 85016  
Direct—602-615-9501  
Fax—602-279-3691

Afterhours Emergency Line  
602-708-7001  
M-F 5:00 pm-8:00 am  
Sat. & Sun. All Day



EMAIL 12

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Thursday, August 13, 2015 4:50 PM  
**To:** HCBS  
**Subject:** Center-based work employment

To whom it may concern;

I am sending the email on behalf of my niece, whom is a special needs adult and participates in an all day program and employment program.

These programs are beneficial to my niece the program's gives her a sense of pride, long term skills and builds on her everyday living skills.

The Center-based employment gives her the opportunity to work in a safe environment. In community employment there are concerns about safety and being taken advantage of- she does not recognize danger.

Losing CBE or paid work activities would be a negative impact for my niece. Individuals such as my niece with disabilities are the last to be hired and first to be fired as the economy changes. Employers will not give my niece the same opportunities because of her productivity rate is between 30%-60%.

CBE gives my niece a deep sense of achievement and self- worth a feeling of accomplishment and an increased feelings of normalcy and being part of the community. So please continue with these programs as it will affect many if the opportunities are taken away.

Thank you

[REDACTED]

Sent from my iPhone



EMAIL 13

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Thursday, August 13, 2015 5:46 PM  
**To:** HCBS  
**Subject:** This is about Marc Center

I would really like it if we could stay open because then none of us special needs kids would have jobs or anything so I would really really really love it if you could keep it is this is coming from [REDACTED] at Marc East it would be Amazing if the works shop stayed opened we could have a job





EMail 14

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Friday, August 14, 2015 6:49 AM  
**To:** HCBS  
**Subject:** Fw: All Day Program and Employment Program Participants and Families

On Thursday, August 13, 2015 6:04 PM, [REDACTED] wrote:

To whom it may concern:

My son is Down's Syndrome and has been participating in the Marc Center Based paid work activities for several years. It has been such a blessing for him and we as his family.

Special needs people have very few options in their lives to make them meaningful and complete. As normal people we can look where we want and accomplish anything that we are willing to put our mind to and willing to work for. My son does not have this option nor to any of the many people that work with him. They really only have two choices. One is the work at Marc East or to stay home and watch TV for the rest of his life. No human that wants to have an important, to them, quality of life wants to watch TV all day long. For normal people TV is a couple of hours at night and the a little on the week end. Why would special needs people want to sit in front of the TV day in and day out for the rest of their lives with no hope of change. They many not be normal, but my [REDACTED] can feel the difference of work and off work.

[REDACTED] looks forward to going to the Marc East center everyday to see his friends, to have a reason to get up, get dressed, have something meaningful for him to do at work and the socialization he gets makes his life worth living. He loves being able to work at his tasks and see them completed. He loves to work at the center and it carries over to his personal life at home. They also have activities that they would not ever have in any other way. A reason to go to a dance, a Halloween or Christmas party, Valentine Dance. Who in the normal world would invite my son Jeff or any of those that work with him to their parties and activities. Marc East invites them and they all love it !!

The government wastes money in many areas, but there are no other options for my son and the thousands of others just like him. Arizona needs to stand out in front and continue to help those that have NO OTHER CHOICE!!

Please.

[REDACTED]



EMAIL 15

Johnson, Dara

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**From:** Cherie Vance <Cherie.Vance@marccr.com>  
**Sent:** Friday, August 14, 2015 7:07 AM  
**To:** HCBS  
**Subject:** Work Activities closings

I have worked in this field many years. We realize community employment is a great goal, but there are so many that would be unable to work a community job. They may not work at a competitive pace, they may be vulnerable to strangers or they may have some conditions such as eating disorders, health issues or seizures that need close supervision that most employers would not be willing to do. These individuals may have many good skills that they get to develop in a safe environment such as the workshops. These individuals take great pride in their accomplishments in the workshop no matter how big or small they may be and taking this away from them would take the pride they feel away. The amount of the paycheck means little to most of them, it is receiving a check at all that is important. I have seen many individuals work in the community and very few maintained these jobs for any length of time. Most are let go for a variety of reasons one being they do not work at a competitive rate, or they are unable to multi task or they may do something that is unacceptable for the work place. Some find community employment stressful and this then brings on other issues. It would be very sad for all the individuals who are served in these programs and have grown personally even if they were small accomplishments because of them. One individual has already gone home very upset just hearing that his shop may close. He couldn't understand why they would do this to him. He likes to work and has made many friends there. We are asking that you reconsider the decision on closing workshops and the very negative effects it would have on so many people.

**Cherie Vance Program Coordinator**  
Marc Community Resources  
Employment Related Services/Marc East  
10839 E Apache Trail  
Apache Junction, Arizona 85120  
(480) 354-8212 / Cell (480)694-3721  
Fax (480) 354-8270

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Email 16

Johnson, Dara

From: [REDACTED]  
Sent: Friday, August 14, 2015 8:13 AM  
To: HCBS  
Cc: James Fella; Chrys; [REDACTED]  
Subject: Funding for Work Programs

Dear AHCCCS,

Its my understanding that you are considering eliminating funding for day programs for the handicapped. What a travesty that would be!!

My daughter, [REDACTED], has been at the MARC Center, 924 N. Country Club Drive, Mesa for 25 years. She functions on a 7 year old level, academically, and is not capable of being in the general community for employment. Her judgement is limited and we have encountered 2 serious incidents of "stranger danger". She needs to be in a sheltered setting or a low risk environment, as do so many of the clients at MARC. She makes limited income but it gives her a sense of pride that she is doing something meaningful.

So, I speak not just for [REDACTED] but all the clients who depend on day programs to be productive and part of society. They are different. They need special help. Employers will not hire the handicapped over someone who is "normal". They will get shoved aside for sure.

Please do not cut this funding. They are actually doing important work at the sheltered workshops. Let them continue to feel good about themselves.

Thank you for listening,

[REDACTED]

[REDACTED] les  
[REDACTED] 6  
[REDACTED] 6

[REDACTED] 5  
[REDACTED] 4



EMAIL 17

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Friday, August 14, 2015 1:07 PM  
**To:** HCBS  
**Subject:** Employment Program

I am a 72 year old retired nurse. I was several hurt on the job. When I wrote my nurse's notes it was hand written all the time and wherever I worked. I have been suffering from lower back pain for fifteen years. I moved from New York to Arizona fifteen years ago. Shortly after buying a new house. I was bitten by a tick and caught Lyme disease. My Fiancé left me and I had not family to help me nor friends. I was severely ill with fever and weakness and pain . I sold the house I Surprise and moved to Sun City alone. I was very lonely and thus tried to committe suicide. I live in an independent living complex and feel a strong need to help others who are mentally or physically hurting. I have been offered two full time jobs as a peer support specialist.. My psychiatrist that this is too heavy a load for my age. Nevertheless I want to experience a sense of achievement and self-worth. 2 A feeling of mastery and accomplishment. 3 A sense of inclusion and connectedness.. 4 Increasing feelings of normalcy and being part of the community. I can only do this when I am transported to my classes to learn the necessary skills I need to help others.

Sincerely yours, [REDACTED]





EMAIL 18

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Friday, August 14, 2015 1:11 PM  
**To:** HCBS  
**Subject:** Eliminating my Daughters Work Program

I am writing to tell you how angry I am about even the possibility of the Marc Center's work program being eliminated! This is a place where my daughter can have self worth and get paid a little for doing such marvelous things that we never thought she could do. She doesn't need a restrictive day program she would be so unhappy! Employment elsewhere for her is not possible.

She came home traumatized at just the thought of this happening, if it did I don't know how I would console her. She doesn't miss work and is very upset if she is sick and has to stay home.

In the community these individuals are the last to be hired. It doesn't matter about how much she makes it is that she is working and brings home a paycheck.

She feels a deep sense of accomplishment, and mastery at being able to work at Marc Center East. She is so excited when she sees her items being sold at Target, Walmart, of Costco. It gives me a sense of pride about reducing reliance on and the amount of federal entitlements.

She feels normal and a part of a community where she is like everyone else.

I hope you will not think of money in your decision, but the kids, young adults and adults that love it there and would be totally devastated if it would close!

Sincerely,

[REDACTED]

11/11/11

11/11/11

EMH 19

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Friday, August 14, 2015 1:26 PM  
**To:** HCBS  
**Subject:** The Elimination of Paid Work Activities

To Whom it May Concern:

I am a participant in a paid work activities employment program. I have a SMI diagnosis that left me believing I couldn't work in competitive community job. The reasons being needed medication injections every two weeks and various other appointments and groups etc. During that time I was very grateful to be a participant of center-based employment. It allow me to feel useful, I was able to learn new skills and enhance others.. Also I felt safe and was working with peers with various disabilities. Even though I am currently trying to find competitive community employment I would be devastated if that job did not work out and I could not return to a program like this.. So I hope that it will be heard losing this program would hurt the most vulnerable population in our communities



EMail 20

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Friday, August 14, 2015 7:36 PM  
**To:** HCBS  
**Subject:** Keep AHCCCS

I am writing on behalf of a co-worker and her son.

The Marc Center in Mesa has been a place of work for [REDACTED]. We've seen him grow up and has grown into a nice young man. I would not want the Marc Center close. I don't know if it would be possible for [REDACTED] to secure a job in the community. He has support at the Marc Center and they provide a safe environment. In another setting there would be concern for his safety and being taken advantage of. With an employer he may not receive competitive pay due to productivity. Disabled persons are usually the last to be hired and the first to be fired as the economy changes.

My co-worker is a teacher and as we all know teachers do not get paid what they are worth. With [REDACTED] working he is able to provide for himself. That has to be a big help to the household. [REDACTED]'s job is not only about money, it gives him a sense of achievement and self worth. I can see confidence in him as he helps his dad.

I hope that my email helps in the decision to keep these important programs open for those who can not otherwise act on their own behalf.

[REDACTED]

[REDACTED]

Mesa, Arizona



Email 21

Johnson, Dara

**From:** [REDACTED]  
**Sent:** Saturday, August 15, 2015 8:22 AM  
**To:** HCBS  
**Subject:** Concerning the closure of workshops for the disabled population of Arizona

I was recently advised there is a proposal circulating at AHCCCS to close the protected workshops currently available for the disabled and replace them with required community placement or participation in a day program.

As a parent, I find this both upsetting and pointless. My son, [REDACTED], will be 39 years old in December of this year and has been disabled since he contracted encephalitis at the age of 14 months. Since leaving school, he has participated in these workshops, or enclaves, and considers them "his job." And having a job is more important to him than most people can comprehend.

He does not fall into the category of the disabled that can function successfully in a predominantly unsupervised community-based employment position and the last thing he needs is permission to play all day long in a day program. These workshops have provided him with socialization opportunities but, more importantly, they have provided him with a sense of worth.

His pride at having earned a paycheck never goes away, never gets old and never diminishes for him. It doesn't matter whether the check is for \$10 or for \$40; he's thrilled with every single one -- and there are very few "normal" people who can say that. His job allows him to participate in Mesa Parks and Recreation programs for the disabled that have a cost associated with them, such as his bowling program. In addition, MARC sponsors dances and group activities on a monthly basis that could not easily be replaced.

He effectively kills time after he gets off work with his TV and his video games and movies and these activities don't need to be extended into his "work" day.

I realize there are segments of the population that seem to be easy targets for "cost-cutting" initiatives and that the disabled are rapidly falling into this category after the long decades of slow advancements made on their behalf. This is NOT the time to deny my son and his peers of something that makes them feel good about themselves; that makes them feel as if they belong; that they are just as much a valued segment of society as you or me. I cannot urge you strongly enough to find another method for cutting costs that will involve office supplies, not PEOPLE.

--  
[REDACTED]

"Finish each day and be done with it. You have done what you could. Some blunders and absurdities no doubt crept in; forget them as soon as you can. Tomorrow is a new day; begin it well and serenely and with too high a spirit to be encumbered with your old nonsense."

Ralph Waldo Emerson, (attributed)  
US essayist & poet (1803 - 1882)

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Email 23

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**From:** Kelly Czekanski <kaczekan@cox.net>  
**Sent:** Saturday, August 15, 2015 11:11 AM  
**To:** HCBS  
**Subject:** Sheltered workshops

To whom it may concern,

It is unacceptable. The thought that budget cuts mean taking away from a community that needs support the most. There are so many other ways to save money. To take it out on them is inhumane. Everyday we put out our money to support people who thrive on welfare because it pays more than a typical job and requires very little participation with society. Yet we contribute to their laziness and manipulation of state resources to ignore their responsibility as a United States citizen. Yet that resumes, and the disabled community, the community who is the most appreciative, who doesn't complain about wages or hours, who is happy just to be contributing to being part of a great country continually is the target of budget cutting and the threat of closure.

If you have any compassion for your fellow human beings, you will work hard to not take away the only pride these individuals have and the only way they feel they contribute to our society.

Make it so when YOU go to bed at night you can sleep peacefully and not have the weight of millions of individuals and their lives on your shoulders.

Nothing great every comes easy.

Kelly!



EMA 24

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Saturday, August 15, 2015 9:51 PM  
**To:** HCBS  
**Subject:** Fwd: Elimination of Paid Work Activities through AHCCCS

>  
> To whom it concerns -  
>  
> My brother is developmentally disabled.  
>  
> Years ago, he didn't have a job. He was angry and depressed. I understand why. He felt like he was worthless. It was difficult on our whole family.  
>  
> Much of this turned around when he got a job as a grocery bagger at a local supermarket. Having a job allowed him to feel like a person. His anger abated. He no longer wanted to take his own life. He felt as if he were part of human society.  
>  
> But even so, there were concerns. Sometimes customers would scorn him. Oftentimes, his coworkers would mock him and treat him poorly. He was often taken advantage of by the people he worked with. More than once he was physically threatened. His coworker assailants were teenagers, and had much to learn about the injustices of life. We worried for his security - emotional, financial, and physical.  
>  
> My brother lost his job because he was baited by these cruel coworkers. Unemployed and without purpose, he fell back into his anger and depression. We were as supportive as possible, but without a job, he felt hopelessly rejected from society. Our efforts were useless.  
>  
> My brother then got a job at the MARC center. He was in a supervised environment, able to work and produce. He felt valuable again. He was proud of his work, excited to contribute. It wasn't about the money. It was about being treated like a person. He hadn't felt that in so many years. There are some kinds of support a family can't provide on their own.  
>  
> He has worked at the MARC center for many years, and his relationships and job skills have grown. It's been a long time since he's faced the kind of emotional depths of his unemployed days. However, ACCCHS is now considering cutting his job program. I know exactly what will happen to my brother - and the thousands that are in his position. Rejected again from society, they will fall into despair. They will be unable to contribute economically, they will require additional mental health services, their families will suffer. Some may take their own lives. We were close many times. I fear we may be headed there again.  
>  
> Please consider the value that can be given to these people that are so often shunned from society. It's not about the money that they receive, which is only a few dollars per hour. Their wages could even be cut further. It's about allowing them the basic human decency of working for a living and contributing in some small way. It's all they want, and as Brad's sister, I beg you to please allow my brother to stay employed. It means the world to him. It means the world to all our family.  
>  
> Sincerely,  
>  
> [REDACTED]

11/11/11

11/11/11

EMA 25

Johnson, Dara

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**From:** [REDACTED]@gmail.com>  
**Sent:** Sunday, August 16, 2015 1:34 PM  
**To:** HCBS  
**Subject:** Marc Center

I would be very disappointed with the idea your giving us about closing the workshop, it provides me to make good friends and go bowling with. My name is [REDACTED] and I'm autistic. I have a hard time doing things like normal people would do. I like coming to Marc Center just to do my jobs. I feel proud. The reason why I don't want you to close down the workshop because it provides me and the other people to help us make money and be more like other people who aren't autistic. We would like to continue coming to Marc Center.

Sincerely,

[REDACTED]





EMail 26

Johnson, Dara

From: [REDACTED]  
Sent: Sunday, August 16, 2015 3:16 PM  
To: HCBS@azahcccs.gov.  
Subject: Opposing cbe shut down for our adults

To AHCCS

The shutting down of the employment center is a grave and horrible way to cut cost at the expense of my son [REDACTED]. He has worked there for almost ten years and takes great pride in what he does and the atmosphere is positive and promotes success in the work force. How can you even think about taking these opportunities away from the disability population? We as a state need to encourage our adults to be part of a bigger picture and feel worthy in what we do.. Equality for all and that means with working together in a stable and safe environment. This is what the Marc center provides for our challenged adults. There is not a need for more day programs that do not provide work ethics and makes our kids feel like they are not able to work for money. Day programs have there benefits but working is not one of them. All adults need the chance to have pride in what they do and receive a check for that work well done. What is a society worth if we do not provide them with these opportunities to feel useful? We have tried employment for [REDACTED] outside of the Marc center and it does not work. Employers are not interested in hiring our kids and not only that the support to be successful is just not there. Where as at Marc the support is always there and it is in the least restrictive setting. This has helped [REDACTED] to know that he can and does accomplish work skills. He feels part of the work force and gets the extra help that he needs to succeed at his job. [REDACTED] has many times shown me items at Target and Walmart that he has worked on which has given him a sense of inclusion and connectiveness. This makes him proud of his job. [REDACTED] has a deep sense of achievement and self-worth not previously experienced in the work force.

Let's just be realistic our adults with disabilities are the last to be hired and the first to be fired as the economy changes. This puts them at the bottom of the list to be part of the work force. The Marc Center keeps them employed in the least restrictive way and with support and a pay check. It does not get much better than that believe me I have tried other avenues with [REDACTED] and the Marc Center is top notch and the work program needs to stay in tact. My son [REDACTED] feels normal and part of the community of working adults. Is this to much to ask of an agency to promote success for our adults? I as a parent am outraged that effective and safe employment options may be taken away from not just my son [REDACTED] but from all the other adults with disabilities that work at the Marc Center. CBE is the way of employment for these adults and not community employment. I have tried community employment and it is a

disaster and made my son feel unworthy in the work force. The amount of the paycheck that [REDACTED] gets does not matter it is the pride he has and the work skills that he has mastered that makes the Marc Center priceless. You cannot put a price tag on mastery and achievement in [REDACTED] work day. So as a parent of my son [REDACTED] I strongly oppose the end of the CBE work force at the Marc Center. The program needs to stay in tact for our adults so they can remain part of the bigger picture and feel worthy in our society to go home with a paycheck no matter the amount. Money is not the big picture here self-worth and pride however is. DO NOT TAKE THIS AWAY!!!!!!!!!!!!!!!!!!!!!!

[REDACTED]

Sincerely [REDACTED] son  
[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

Email 27

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Sunday, August 16, 2015 3:21 PM  
**To:** HCBS  
**Subject:** MARC DAY PROGRAMS

To Whom It May Concern:

I am the parent of a 33 year disabled adult who works at the MARC Center in Apache Junction. I recently learned that Arizona state is planning to eliminate the MARC Center employment program.

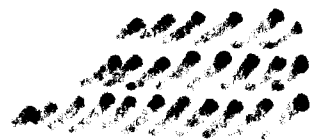
[Elimination of the MARC Center will be devastating for my daughter! She suffers from seizures and is unable to work in any community-type program. At the MARC Center I know that my daughter is in a safe environment with staff that know her and know what to do if and when my daughter has a seizure. There is no place outside of the MARC Center where my daughter could work and have the safety net of staff to be there in the event of a seizure. In addition, I cannot think of any place that would hire her competitively because her employment would be a liability that no business would want to take on.]

[My daughter earns very little at the MARC Center. However, she enjoys the work and is given jobs that she can successfully complete. She is proud of her paychecks, however small they are, and feels a sense of accomplishment that her work has been rewarded.]

Having a child with a disability is difficult enough, but eliminating her work program would impact her life dramatically. I truly hope that the Employment Program can find a way to continue to stay open and functioning. It serves a real need and an important need for the disabled population.

Sincerely,

[REDACTED]



EMail 28

Johnson, Dara

**From:** [REDACTED]  
**Sent:** Sunday, August 16, 2015 10:47 PM  
**To:** HCBS  
**Subject:** Elimination of paid work activities

To Whom this may concern:

My name is [REDACTED] and my Daughter [REDACTED] is in a wonderful work program through the marc center and I would like to express my feelings as to why you shouldn't eliminate this program or any other programs that help our adults with disabilities.

These programs are not only a necessary tool for my Daughter but a feeling of accomplishment for her. You see [REDACTED] cannot work in public places we have tried and she gets very confused and has panic attacks, Trisha has been diagnosed with mental retardation along with OCD, Bi-Polar as well as her panic attacks. [REDACTED] cannot be out in a public setting for long periods of times and has to have someone to be there in case of an attack in some instances [REDACTED] has had seizures due to one of her attacks.

[REDACTED] does not do well in restrictive day programs either as it is to confusing for her and she doesn't like being in an environment that doesn't give her options or she doesn't feel like she is being constructive. That is one of the reasons we thought her getting a job would be good for her but a job in the public was devastating to her.

With CBE [REDACTED] as all of the best worlds, friends that are of her same circumstance, the help of people that understand the needs and are willing to go the distance for these special individuals. [REDACTED] is a part of something awesome, they make a small wage which for [REDACTED] is the neatest thing to go to the bank and cash her check which is usually no more than \$22.00 every two weeks, we then make a big deal out of it and go to Wal-mart and get a hair cut if needed, or a pedicure or just get some learning books.

When [REDACTED] sees, things such as the toys in the plastic cups in the machines she say Mom I did that or when she sees plastic hangers for sale at the stores she says I do that, or the mail she says to me I know how to do that. [REDACTED] gets so excited to tell people she works at the marc center. And her family is so proud of her.

Trisha doesn't work very fast, she doesn't know the concept of fast and because [REDACTED] equilibrium never fully developed she is limited to movements as far as walking, running, stepping, things of that nature. [REDACTED] wouldn't last in any time of community job setting.

I have had [REDACTED] in Day programs before and she has regressed by that I mean she went backwards as far as her learning skills, speaking and would become agitated easily.

You know something else, people look at the disabled and feel sorry for them, well I don't want anyone feeling sorry for my Daughter because she is a person that can succeed if given the chance and if AHCCCS takes these services away then their taking there lively hoods away and how else are they supposed to live? My husband and I cannot take care of her, we already pay her medical, dental and optical along with what ever else she needs that SSI doesn't help with, cloths, bedding supplies, therapies etc.

Why AHCCCS is so willing to take away services that help the community is beyond me, people with Disabilities are people too! they are just as important to the work force as anyone, they are paid very little and it saves the big business from having to pay minimum wage for such jobs as what the CBE is able to have these special individuals to do.

Why not focus more on the individuals that are getting food stamps, health care and emergency money when they really don't need it. Look I can tell you of a few families that are getting these services and in no way do they need it, and they brag about it!

I also know of families that need help and can not get the help they need, these are families that wouldn't ordinarily ask for it because they want to do it on there own but can't at this time not because there not trying because believe me they are!

I beg you to please really think about what your planning to do and know that you will be hurting people that really need these jobs, not for the money but for the opportunities it gives them, the respect it gives them and the happiness.

Thank you,



Emil 29

Johnson, Dara

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**From:** Sherry Howard-Wilhelmi <hgoosebumps@cox.net>  
**Sent:** Sunday, August 16, 2015 11:25 PM  
**To:** Johnson, Dara  
**Cc:** hgoosebumps@cox.net  
**Subject:** PCP workgroup request

Hi Dara:

Please add me to the workgroup for the PCP facilitators. As you know, I am one of the original sixty and would love to be part of it.

Thanks so much,

Sherry Howard Wilhelmi  
602-628-3904





EMA 30

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Monday, August 17, 2015 10:08 AM  
**To:** HCBS  
**Subject:** Center-Based Paid Work Activities

Dear Folks:

Our son, age 40, has Down's Syndrome. He is currently participating in a center-based work activity program at MARC East.

He takes great pride in the fact that he's able to earn a paycheck and the work that he does. He has learned to work independently and as part of a team accomplishing various tasks. He is not able to perform community based employment that would allow him to participate for the amount of hours per week that he spends at the MARC East center.

Any reduction or elimination of center-based employment would deprive him of his sense of achievement and self-worth.

We feel your contemplated actions are very detrimental to his well-being as well as the well-being of all those affected by your projected decision. Any such action is deplorable and unjust.

Please reconsider your thinking and do the right thing.

[REDACTED]



EMail 31

Johnson, Dara

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**From:** Marion <v1f@cox.net>  
**Sent:** Monday, August 17, 2015 11:41 AM  
**To:** HCBS@azahccs.gov  
**Subject:** Marc Center Programs

It's very important that the day programs and employment programs (CBE) be continued as is. The Marc center provides a much needed service to their client's and families. Everyone needs to have a purpose and meaning in their daily life. This program truly is a lifeline for many people.

Thank you for your support!

Marion DiMiceli

Sent from my iPhone



EMM 32

Johnson, Dara

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**From:** ██████████  
**Sent:** Monday, August 17, 2015 1:51 PM  
**To:** HCBS  
**Subject:** Marc Center

To Whom It May Concern:

My son came home from the Marc Center last Friday with a paper he was anxious to show me. It said that AHCCCS is considering eliminating CBE programs such as the Marc Center where my son works. He has already written an email to you, and is reminding me daily to get this one done. Obviously this is important to him, and as such, it is important to me - so here is what I have to say:

My son ██████ is autistic - diagnosed at age 3. He didn't choose to be this way, and while we are fortunate that he has been able to achieve many things and have some level of independence, he will never live the "normal" life you and I take for granted. He will never drive, be able to work in the community without supervision, get married, have children, or live on his own. When I am gone, I don't know what his life will be like. The Marc center has been a Godsend. He loves going there and doing all the different jobs. Every day he tells me what they worked on. If it weren't for the Marc Center he would probably have very limited social interaction. Now he looks forward to the monthly social activities and is participating in Bowling with many of his co-workers. Even though he earns less than \$40.00 monthly, he is so proud of his paychecks, and fills out his bank deposit slip so we can put it in the bank.

He is too functional to just sit at home or at an adult day care program. ██████ wants to have a regular job and live on his own. While I know this is not an option for him at his level of functioning, I love that he wants that. The Marc Center program gives him the hope that maybe one day he will be able to achieve what he wants. Vocational Rehabilitation Services have already determined that independent employment is not a viable option for him, so the Marc Center has given him the opportunity to have a job. It is the best thing that has happened for him and I do not want to see him lose that.

Please consider how important CBE programs are for people like my son who, through no fault of their own, are unable to live "normal" lives. If our goal as a society is to encourage and motivate ALL people to achieve to their highest ability, then it would be unconscionable to eliminate the very programs that provide that.

Respectfully submitted,

████████

Sent from Windows Mail



Email 33

Johnson, Dara

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**From:** Jillian Glasser <jillianannie@gmail.com>  
**Sent:** Monday, August 17, 2015 3:07 PM  
**To:** HCBS  
**Subject:** Elimination of Paid Work Activities

To Whom It May Concern:

Closing the employment program is an awful idea.

We need to keep the MARC Center open!

Sincerely,

Jillian Annie Glasser





EM:34

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Monday, August 17, 2015 3:24 PM  
**To:** HCBS  
**Cc:** swinterton@swlaw.com; John Alig  
**Subject:** Proposed elimination of onsite employment activities for those with severe mental or developmental challenges

August 17, 2015

AHCCC  
c/o Office of Intergovernmental Relations  
801 E. Jefferson Street, Mail Drop 4200  
Phoenix, AZ 85034

To Whom It May Concern

[ It has come to my attention that the State of Arizona is considering the elimination of onsite employment activities for those with severe mental or developmental challenges. I'm writing because I strongly disagree with this elimination.

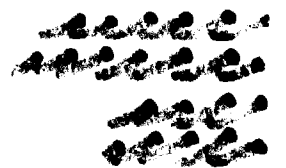
My child has been in group homes for over 15-years and was born with serious mental and developmental problems. He is currently working at the Marc Center in their sheltered workshop. After he turned 18, the State of Arizona assisted in finding him work at a local grocery store as a 'bagger'. In the beginning this job worked well; however, over time the store management continued to increase the required hours and the stress of the job became more than he could handle. At the same time his mental illness became much worse, leading to him losing this job.

The work provided by the Marc Center fits his abilities and provides him with a level of socialization not available in the for-profit world. He calls daily telling me of the work he is doing and how happy he is. It would be disastrous if he was to lose this work. The for-profit business is all about productivity. The job he has needs to meet production goals be is much more focused on the individuals being employed.]

If the workshop is eliminated, the only alternatives for us would be the for-profit world (already discussed) or the day program. The latter would not allow him to exercise his desire to work, but rather simply sit with those who function at a much lower level than he. Please allow for the continuation of the on-site employment options for this population.

Sincerely

[REDACTED]  
[REDACTED]  
[REDACTED]  
[REDACTED]



Em: 135

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Monday, August 17, 2015 7:23 PM  
**To:** HCBS  
**Subject:** Restricting or Cutting CenterBased Activities For the Disabled

To whom this may concern I am appalled that you would even consider taking away support for a program that is providing a safe functional work place for many of our state's mentally and physically disabled to participate. By taking these funds many folks would be put out of work that keeps them going and progressing in mental growth and esteem. These disabled folks would not be able to exist in a typical workplace environment especially in this state with it's easy fire (right to work) policy. In actuality it would cost more to pay for all of the unemployment for the large amount of these individuals being regularly out of work. Not including the dangers these folks would face in a regular workplace environment. Of course as many other government agencies some of you might view them as nothing more than animals. They are people and are productive. My daughter has adopted the Marc Center as her place to go and make things happen 5 days a week. That's more than I can say for a bunch of people who are collecting welfare so they can sit around and drink by the liquor store down on Brown and Mesa Drive. Or for the tons of Illegal Aliens you are allowing to have a free ride at our expense! [These disabled folks go to work and enjoy the peace of a safe environment with nice dedicated managers who encourage them to do well and they do. These folks don't need to be ganged up in day programs where they will do nothing but digress.] My daughter has been working at the Marc Center for three years now and is contributing more to this society than a large amount of people walking or riding bicycles down on Brown Rd. and Main Street! [I have never heard her complain of how much she is getting paid. Though it is not much. CBE allows our daughter to work so we are also freed up to work at the same time allowing us to remain sound in this lousy economy. Taking CBE away would not only do harm to our daughter but would leave one of us to have to no longer work. Our daughter requires 24 hour supervision so someone will have to do it.] She is just one more person who will not be depending on federal entitlements. Aren't there enough leaches out there without disabilities? Restricting or cutting CBE would be trying to fix a machine that is already running while it is running. That is just plain foolishness! Please do not take away the one thing that is making our daughters day in this cold, sick and unappreciative working society.

Sincerely Yours [REDACTED] : Concerned father



EMAIL 36

Johnson, Dara

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**From:** [REDACTED] <[REDACTED]>  
**Sent:** Monday, August 17, 2015 10:00 PM  
**To:** HCBS  
**Subject:** Funding of CBE

I am concerned about funding being taken away from center-based employment. You want individuals involved in these programs to be involved in the community. These employment centers are the only place where these individuals can be safely employed in their community. Regular jobs are not an option because they need more supervision than these jobs provide. Besides they do not understand the concept of danger or that there could be those that are predators and others that would take advantage of them. There are not enough jobs for this population out there. Where do you propose that they all work? There are still many others looking for jobs as well.

My daughter, who is mildly autistic, needs the outlet that her work program provides. She would be stuck at home because there is nowhere else for her to go. This would place a financial burden on our family because I would have to quit my job and stay home with her. Where is the community in that?

Some programs may need to be cut in the state, but do not cut programs that are so vital to so many. This will have so many damaging affects on the people of Arizona for a long time.

[REDACTED]



Em137

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Tuesday, August 18, 2015 9:38 AM  
**To:** HCBS  
**Subject:** future of paid work training programs

My name is [REDACTED]. I am a former client and now a staff member at a Vocational Rehab. Facility that has 2 paid training workshops. I believe eliminating these programs would be a terrible idea. It's hard for me to find the words to express how much I know these programs work to significantly help individuals. I have a physical disability that makes my days difficult sometimes and it's harder for me to maintain a schedule due to having a lot of bad days when I don't feel good at all and this center has helped me immensely with their patience and caring. It has taken me a few years to be able to hold a 3 day a week schedule. I know no other type of employer or work, besides self employment, that would allow for someone to make up days missed due to illness as this facility has. I believe people in my position would be able to find employment, but would not be able to hold employment for long at any one place when they never know how you are going to feel day to day!! They would be let go time after time. I KNOW these programs help the majority of individuals that participate in them and with the effort put forth by staff members that are there to help them. I've seen it first hand!! And that's not even taking into consideration of the freedom, boost of confidence, financial and emotional strength it gives the individuals!! It lets them have a sense of self worth!! Again that's not even taking into consideration the help and relief it may provide for the care takers and/or parents that need to work themselves, especially single parents or care givers!! I'd hate to see the community lose this!! Thank you for your time and consideration.





Email 38

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Tuesday, August 18, 2015 7:44 PM  
**To:** HCBS  
**Subject:** Day Program

To whom It may concern, We are writing to you regarding the possible upcoming cuts to funding of the day programs in Az. through AHCCS. We are the parents of a 43 year old daughter with cerebral palsy and developmental disabilities. Our daughter, [REDACTED] has been attending the MARC center workshop since arriving in Arizona 5 years ago. Working at the MARC Center has made such a difference in her life.....gives her life meaning . She now feels like a real part of society. Our daughter would not be able to work outside in the community due to her disabilities. If this program is cut she would be devastated, as would we. She was so very upset when this news was announced - her exact words were "what will I do if I don't have my job?"

Please look to other sources to save money. Our disabled children work each day not for the money, but the self worth and accomplishment they feel. Perhaps it would behoove you to visit the MARC Centers and see the comradery these people have with each other as a team. Please, we ask you, in good consciousness do not cut this program and hurt our most vulnerable citizens who trust and depend on us.

Sincerely,

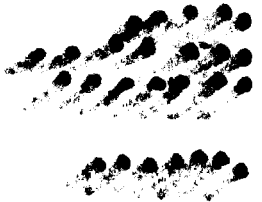
[REDACTED] Barbara Carpenter



Enail 39

Johnson, Dara

From: [REDACTED]  
Sent: Tuesday, August 18, 2015 8:47 PM  
To: HCBS  
Subject: Elimination of CBE



August 18, 2015

AHCCC  
c/o Office of Intergovernmental Relations  
801 E. Jefferson Street, Mail Drop 4200  
Phoenix, AZ 85034

To Whom It May Concern

It has come to my attention that the State of Arizona is considering the elimination of onsite employment activities for those with severe mental or developmental challenges. I'm writing because I strongly disagree with this elimination.

Every day, [REDACTED] gets up and goes to work at his job in the sheltered workshop at MARC center. Every day he is happy to get up, cheerfully get dressed, and practically run into his job from excitement. I am passionate about my job as a hospice nurse, but most mornings I wish my alarm clock would just die. My brother [REDACTED] is 41 years old and has fragile X syndrome. He is wonderful, loving, kind, charitable and willing to help anyone who asks. He is also willing to get in their car and ride off with them. Although [REDACTED] is 6 foot 2 and 200 pounds, he has poor muscle tone and very poor motor planning, he cannot do the physical things that a typical person of his stature can do, but because he looks "normal" people expect him to. When he falls short, anger erupts, and he does not know how to deal with it. [REDACTED]'s naiveté has almost resulted in other adults attempting to punch him. He has no safety awareness. He cannot read, drive, understand how to use the bus, shop, fix food, or complete all of his personal care by himself. He can tell you everything you want to know about Abraham Lincoln. The last is exactly why the day program is unsuitable for him.

Matt also has some medical conditions as a result of his syndrome. He can be incontinent. So when he's working in this competitive employment opportunity you all have planned, and fills his pants with stool, how is that going to increase his chances of long term employment?

I cannot even begin to explain how much self-worth this innocent kind man derives from his job putting band aids into nuddybuddies (medibuddies pronounced in [REDACTED]). The containers for these first aid kits say that they are assembled by the disabled community and then sold in drug stores and Walmart. We even found one in a drug store in Italy last year. [REDACTED] personally takes credit for that one. This is his whole world, he derives great self-worth from his job. If he lost it, he would be devastated -as would our whole family.

[REDACTED] is so proud of his 30 dollar pay check! He often wants to take out whole family to dinner with it, not realizing that it cannot buy dinner for all 5 of us.

Please imagine these disenfranchised adults who sometimes drool, or have seizures, or are incontinent in a competitive work environment. They will be "competed" into glorified day care. Day programs are great if that

is the least restrictive environment, but for [REDACTED] it would be mind-numbingly boring. Places like MARC and other sheltered programs offer something that we just cannot get anywhere else- a living. Imagine having no real reason to get up in the morning. Please do not take jobs away from those that cannot speak for themselves! ]

[REDACTED]

[REDACTED] RN, BSN, M.Ed, CHPN

[REDACTED]

[REDACTED] 5

Sent from my iPhone

Email 40

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Wednesday, August 19, 2015 2:14 AM  
**To:** HCBS  
**Subject:** ELIMINATION OF PAID WORK ACTIVITIES

My name is [REDACTED] and I am the stepfather to [REDACTED], a client and employee of the MARC CENTER at Signal Butte and Main in Mesa. It is a very important part of my sons life that he enjoys the opportunity to be a productive member of our work force. It also allows him to see his friends and coworkers each week which without the MARC CENTER he would not. You see Shannon is blind and disabled. His entire social experience revolves around his interaction at the CENTER. His ability to enter events at the Arizona Special Olympics, the bowling league at East Mesa Bowl, the acceptance by his peers create an atmosphere of self worth he would doubtless not enjoy. His self esteem and self worth are all gauged by his interaction with those who share the disabled life and accept him. The very act of applying for and getting hired outside the MARC CENTER workshop would not happen. The joy he shows when he receives his check is indescribable. Though the pay is considerably less than a sighted person his feeling of being a part of the whole is evident. HE is a contributor in our society. The majority of employers would not even consider hiring Shannon yet he fills a niche and feels the weight of responsibility for his job. Less than fifty years ago the accepted response to bringing a child into the world who was disabled was to send them away, institutionalize them and forget they existed. Thank God times are changing. They feel a sense of pride when they don't share the same reliance on federal entitlements as others in their same situation. They are excited when they see the fruits of their labor in a product they worked on being sold at Target or Costco. The general sense is they are members of the community workforce and the community at large. The paid work activities play an important part in the social wellbeing and growth of these people. They strengthen our lives with their positive outlook and genuine love of our entire race. There are things in our society that could be done without however this is not one of them. Let these valuable members of our society perform their jobs. Let them enjoy being contributors in the workplace and providers of joy.



Em: 141

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Wednesday, August 19, 2015 8:33 AM  
**To:** HCBS  
**Subject:** Paid work activities

To whom it may concern:

I can't believe you would even consider shutting down the Marc Center! It's such a valuable program!! What little she makes, is her play money. It creates self worth for her.

She doesn't want to miss going to the Marc Center East, because she knows she is getting a little bit of money to put in her bank account and she gets to see her friends. SSI deducts the money that she does make at Marc Center East, so it is not creating an extra expense.

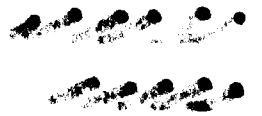
She can not go out in the work force because of her anxiety and disabilities. She is around people she feels comfortable with. She is reviewed quarterly and is setting goals for herself.

This program keeps her active, provides social skills and she has the opportunity to learn new skills. It gives her responsibilities and keeps her active.

**Please** reconsider this program change.

Sincerely,

[REDACTED]  
Guardian  
[REDACTED]





Emily 42

Johnson, Dara

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**From:** Felice and Jack Cohen-Joppa <nukeresister@igc.org>  
**Sent:** Wednesday, August 19, 2015 9:54 AM  
**To:** HCBS  
**Subject:** Tucson forum

Hi,

I am wondering why you picked a place for the Tucson forum so far from the center of town (University area or downtown). This could really be a problem for some individuals with disabilities and their families. Hopefully the bus strike in Tucson will at least be over by then (2 weeks so far).

Felice Cohen-Joppa



EMAIL 43

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Wednesday, August 19, 2015 2:02 PM  
**To:** HCBS  
**Subject:** All Day Programs and Employment Programs at Marc Center

To Whom It May Concern,

I do respite for a 25 year old young man who works at the Marc's Center and it would be devastating if this center was closed down. He loves his job and he needs to socialization that it gives him. He is non-verbal and very much depends on people to watch him. Although he is very smart in his own right he still needs supervision in a working setting. He will always give 100% at the Marc Center but for his own growth he needs the social atmosphere where it makes him feel liked and accomplished, plus the little bit of money he makes helps him to buy things he loves like headphones and such and it gives him good practice with money when we do go to the store, it is one of his goals. There is no way he could ever work out in a public setting. Because he is non verbal and needs to be directed on what he needs to be doing. The customers would never be able to communicate with him and therefore it would be frustrating for both him and the customer. His parents also have little means of transportation and for them to have to drive him around to various jobs would cause a huge hardship on his family. Please don't close down the Marc Center these special kids need to have a place to go where they are accepted and loved and feel very accomplished and proud of themselves.

Thank You,

[REDACTED]



EMH 44

Johnson, Dara

**From:** [REDACTED] <[REDACTED]@gmail.com>  
**Sent:** Wednesday, August 19, 2015 7:48 PM  
**To:** HCBS  
**Subject:** RE: Center-based paid work activities

To Whom it May Concern:

As a parent of a disabled adult, a sister of a disabled adult, and a teacher of special education, i am deeply concerned about the possible cut (or elimination) to center-based work activities. *This was NOT the intent of Employment First. This would be socially and emotionally devastating to my son, my sister, and thousands of other families and individuals for whom center-based employment is vital.*

Those who work through these centers certainly do NOT need more restrictive day programs!! If that was all they could handle, that's where they'd be going already! They also can NOT handle regular competitive employment, or again, don't you think they would be doing so? Believe me, we would love for them to be in the competitive workplace if they could. Indeed, both my son and my sister tried working in the competitive environment, but my son had to quit ( the job WE found for him) after two weeks because it was too stressful and overwhelming, and he didn't get the support and repetitive training he needs. My sister was brought under DDD center-based employment due to struggles with social skills (very common in those with cognitive disabilities or autism). She needed someone to coach her, as MARC center did, on when she could talk, when she shouldn't, and how to handle conflict. A regular employer would have just fired her. We come to these centers because that is where our loved ones fit best, and in fact it's the only place they fit!! ]

In addition, Voc Rehab is not set up to help those with even mild to moderate disabilities. Our son is fairly high-functioning, yet for 9 months after his high-school graduation, they did next to nothing for him except provide some bus training, and help him fill out a few job applications (for jobs that were way too challenging for him). If a person has a physical disability only, they might be helpful; for those with even mild to moderate cognitive disabilities, or moderate autism, they are no help at all.

Here is another reason center-based employment should not be cut or eliminated: employers will NOT want to hire disabled adults and pay them minimum wage, when they can get non-disabled adults who will be more productive and have less issues with social skills.

[And finally, the best reason: I have rad the law. It is NOT intended to be a means for budget cutting by state agencies, but only a way to get more individuals with disabilities out in the community, IF they have the skills. Many if not most, don't. Just like schools are required to offer a full spectrum of educational settings and services for students with disabilities, so the state should do the same. Cutting these center based programs means many, many individuals with disabilities would be stuck at home, unable to work at all, too high-functioning for a day program. It would be devastating and cruel.]

Please, please, do not cut these programs. This was not the intent of Employment First!!!

[REDACTED]  
Parent, Sister, Teacher of Disabled Individuals



Page 45

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Thursday, August 20, 2015 8:34 AM  
**To:** HCBS  
**Subject:** My son, [REDACTED]

My son, [REDACTED] has autism. For several years, he's worked at Gompers Vocational Center. It is a safe, structured environment that he enjoys going to. [REDACTED] due to his autism requires a routine setting. Putting him out in the community would NOT be the best placement for him. Please, oh please, keep [REDACTED] in mind before YOU decide to turn his happy, structured life UP SIDE DOWN. Think!!! Would you like someone who has NEVER walked in your shoes decide (even if they mean well) to mess with YOUR job, mess with YOUR location, mess with your LIFE. Instead, poll the individual and/or their families. Disrupt ONLY those ASKING for this change, NEEDING this change, WANTING this change.

Sincerely,

[REDACTED]  
[REDACTED]'s Concerned Mother

Sent from my Samsung Galaxy Express™, an AT&T LTE smartphone

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Email 46

Johnson, Dara

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**From:** [REDACTED]@net>  
**Sent:** Thursday, August 20, 2015 10:50 AM  
**To:** HCBS  
**Subject:** Center Bases Employment Programs  
**Attachments:** CBE program.docx  
**Importance:** High

We are quite concerned with information that we have received that AHCCCS might be considering eliminating or restricting the CBE programs throughout the state. Please accept the attached as our comments and concerns regarding this topic and the affect it might have on our son [REDACTED] and others like him.

Sincerely  
[REDACTED]



EM 416

To whom it may concern:

We were informed a couple days ago of a proposal by AHCCCS to eliminate or restrict the CBE (center based employment) and only offer a competitive community employment throughout the state. This was either due to a new Federal Law or re-interpretation of an existing law. I can't fathom why anyone that has knowledge of people with developmental disabilities would even consider this to be a just and fair decision for all of these individuals.

Our son is 48 years old and has been in the CBE program for 20 plus years. At one point he was in the community with a competitive job and it did not work out for him. He needs the shelter and structure of a CBE program. He had no stranger/danger skills and even though self-sufficient in some areas needs constant supervision and to be monitored/directed. The CBE job Marc Center provides him is meaningful and gives purpose to his life. He understands that he is being paid based on what he can achieve and sometimes he is really good at striving for these goals and then there are those other times. When he is paid, he is totally proud of the paycheck he receives even though the amount would be minimal to you or I, such as an average \$35.00 a month. He can identify with others in his family because they work and get paid just as he does. Why anyone would think that businesses that are so competitive today would hire people that cannot maintain a specific level of productivity is beyond us. Marc Center does an excellent job of providing piece work for these individuals that they can be successful at doing and at the same time motivate them to try even harder. On top of this Marc Center provides other social after work activities such as Oasis, dances, craft night, etc. At some point we realize that he will need to retire from the CBE workshop and then a day type program would be beneficial where he can go and be social but not have to work.

In the state of Arizona in the past 48 years a lot of positive changes have taken place for people like our son. It is evident to consider a change such as this to vulnerable people our state would be taking massive steps backwards. Marc Center must constantly contend with budget cuts that limit their ability to

[REDACTED]

[REDACTED]

function while other welfare type programs where people can work and hold down competitive type jobs are less affected.

[ So then our next questions to you are: what happens to these people that cannot function in the competitive employment? What other LTC benefits are being looked at to be eliminated? Where can we go to find out more information such as what Federal Law? Why as parents and legal guardians are we just being notified of this at this late date – you have our names and addresses? ]

We would appreciate any information that you can provide and ask you to please not eliminate the CBE programs for these individuals.

Sincerely,

[REDACTED] Jenkins

[REDACTED] Cir

[REDACTED]

[REDACTED] et

[REDACTED]

Emil 47

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Thursday, August 20, 2015 2:03 PM  
**To:** HCBS  
**Subject:** Employment program

I'm writing in response to the changes being proposed by new Federal Laws.

My [REDACTED] is 41 years old, has Fragile X, and IBS. He has worked in the community, Box Smart, Insight, and Basha's. He has always enjoyed his work, and looks forward to going each day. He always has something to tell when he gets home.

He really prefers working in the workshop. The jobs vary, and he can socialize with his peers, and the staff. Working in the community is not for everyone. The key word, is working, having a job, and getting paid. Not everyone is able to work in the community, they can work, but with behavior and medical issues and yes drooling, it is not in their best interest.

My concern is, if the workshop has to close or only can accept certain individuals, where will all the people?

My husband and I are planning on attending the Gilbert Forum. We tried calling, but it would not, but we get sound no person or computer!!!!



# Email 48

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Thursday, August 20, 2015 3:59 PM  
**To:** HCBS  
**Subject:** marc center

HELLO!

My husband and I would like to introduce you to our two sons, [REDACTED] and [REDACTED], who is four years younger. Both are mentally retarded but the doctors do not know why.

We came to Arizona from California in 1978 more than a little frightened because we did not know what kind of services were available for the boys. [REDACTED] had been working at Goodwill and wanted to find work and earn a salary.

We were directed to the MARC Center and found it quite capable of making [REDACTED] happy and providing him with work and work skills training.

He did several things but pulling copper wire is one job we won't forget. DIRTY!! I laid his jeans on the patio floor and hosed them off to get them ready for the washing machine. But, [REDACTED] was just happy to be there. [REDACTED] He grew in his skills and one day MARC decided he was ready to try working in the cafeteria at Tempe High School four hours a day. He was so excited. He was a contracted employee, had a paycheck, a bank account and some pocket money. [REDACTED] When he got a raise, he quietly whispered to me, "Do I make more than dad?" I told him almost, but of course he didn't.

[REDACTED] Twice his supervisors changed causing a problem for [REDACTED] so the MARC Center sent someone over to teach the supervisors and Rob how to communicate and work together. Well, he's worked at Tempe High (Go Buffalos!) for thirty years, is in the State Retirement System and while he has BEEN paid HE ALSO HAS BEEN PAYING for his apartment, food, clothing, medical bills and INCOME TAX! All this thanks to the MARC Center staff!

I am sending you a copy of this so you can see he can barely spell and write his name and his speech is very hard to understand as he talks quietly and runs his words together much of the time.

FOUR YEARS AFTER ROB STARTED..... [REDACTED] graduated from Getz School and we felt very comfortable taking him to the MARC Center as we were confident they could develop his abilities without making him feel inferior or unimportant. This is a crucial factor when you are teaching someone.

Fortunately, [REDACTED] likes to keep busy! He even cleans his apartment just to keep busy. However, then he was not much of a talker. A psychologist found out Mike talked at home and had an unusual vocabulary for his disability.

He used words like illusion etc., appropriately at home. So he said he wasn't going to help [REDACTED] any more and [REDACTED] we would have to talk for himself! This is a difficult problem and it took a long time but Mike talks to people more and initiates conversation some times.

[REDACTED] He had many jobs. One day we went to the Home Depot Hardware department and [REDACTED] walked over and checked out the boxes of screws. The labels were not on straight! He said, "These were NOT made at the [REDACTED] MARC Center! We do them right."

[REDACTED] The MARC Center is a place where everyone can feel comfortable. The staff understands them and cares about them. [REDACTED] Once, he had pneumonia and stayed home a week. When he got better he said he was ready to go back to the MARC Center. He said, "I belong there."

The handicapped WANT to learn and grow. They WANT to have friends. They WANT to have jobs and get a paycheck even if it is small. They WANT to contribute to the community and to do that, they need places like the MARC Center! The staff understands, loves, cares and teaches.



You don't find that in the outside world!

Sincerely,



P.S. Do we have problems? Oh yes, [redacted] got a call this morning and [redacted] had totally lost it which is highly unusual.

He is very upset thinking the MARC might close, but he was upset that someone had a T shirt with Marie Osmond's picture on it!! (I know, you've had that happen at work too!!) Since Marie was on TV she has been his make-believe girl friend. It would be a fantasy for us but it is real for him. Janey Durham and I together figured out what had happened and she suggested we pick him up to calm down. When Bob brought him home, he was totally calm and I had a chance to tell him how God forgives and FORGETS. He got the picture and I am hoping he says "I'm sorry to the boy with the T shirt..." How was your day?.....

P.P.S. What if there was no MARC Center?The boys would have sat home and I would be in a sanitarium.





Emal 49

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Thursday, August 20, 2015 4:21 PM  
**To:** HCBS  
**Subject:** Day Programs and Employment Programs

This letter is in regard to the changes being considered by AHCCCS in regards to the above mentioned programs.

I am a parent/guardian of a 33 year old special needs young lady. She is actively working in the MARC Center work program. My daughter is thriving from this work environment. Since she has been part of this program for the last 6 years or so, her self esteem has grown in leaps and bounds. What a sense of pride to walk down the aisle at Target and see the medical first aid kits she has helped put together actually for sale to the public.

Some of my issues with the upcoming changes being considered are:

She would loose the job that she loves so much, not to mention the fact that she would be unemployable. What would she do all day? This job has helped my daughter overcome some self mutilating tendencies that she had with idle time and boredom.

My daughter had a job in the community and it was a negative experience for her. She feels safe in the work center at the MARC Center.

I fear if she lost her work program she would revert back to her negative behaviors.

Please take the time to consider these individuals that need this and other programs like this to survive, not only financially but emotionally.

I appreciate your compassionate and thoughtful consideration in this very important matter.

Sincerely,  
[REDACTED]



Email 50

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Monday, September 21, 2015 9:02 AM  
**To:** HCBS  
**Subject:** DEFUNDING OF HANDICAPED PERSONS

It is a sad indictment of a society that funds multimillion dollar vacations for government officials and families and refuse to care for those who cannot care for themselves. We have two mentally challenged sons who have some sense of self worth due in part to the MARC Center program. Most if not all of the participants at MARC CENTER would be unable to enjoy any quality of life with out the additional social and work involvement provided by this type of service.. You might consider Challenging PUBLICLY a FED Law that disfranchizes a minority population.

Sincerely  
[REDACTED]



EMAIL 51

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Friday, August 21, 2015 12:06 PM  
**To:** HCBS  
**Subject:** STATE CONSIDERING THE ELIMINATION OF PAID WORK ACTIVITIES

To Whom it may concern:

My son has attended the Marc Community Resources Inc., since July 2006. Due to his head injury, his disability he has not been able to hold employment in a public setting. The Marc Center has provided continual building of his self-confidence in all areas of his life along with giving him the sense that his life is worth something. He has the confidence that he can finish something that he starts, which gives him a deep sense of achievement and self- worth.

He feels he is contributing to the productivity needed in the economy and his community. His hope is that someday he will acquire the experience needed to hold permanent employment.

He has come a very long way in so many ways and could have not done it without the center offering this experience for a better tomorrow, as he continues to build work experience, instructions on how to complete an application and friendships and using his time in an enjoyable and productive way.

It would be a disaster the clients to have their life taken from them, as well as what it will do to their families. Our request is that this all day program will not be eliminated.

It would be most appreciated for AHCCCS to continue this center based paid work activities for my son as well as others who participate in this program. This is their life outside the their home.

Thank you for what you have provided and what our hope is that you will continue.

Sincerely,

[REDACTED]



Emil 52

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Friday, August 21, 2015 1:38 PM  
**To:** HCBS  
**Subject:** Program Funding

To Whom It May Concern,

I'm writing this e-mail to express my concern about a notice that I received regarding the possible elimination of funding for CBE programs.

My son, [REDACTED], works at Marc Center in Mesa. He is an adult with developmental disabilities and some medical issues. [REDACTED] does well working in a supervised setting and flourishes in that work environment. [REDACTED] doesn't require the restrictive setting of a day program.

My son does not however, recognize some major safety issues...i.e., stranger danger and the like, and would not do well working in the community as a result. I feel that my son would possibly be taken advantage of in a situation that was not supervised like the setting he presently work in.

[REDACTED] feels a great sense of accomplishment at his job. He tells me about the different projects that he's working on and he feels a great sense of self worth as a result of performing these tasks. Regardless of the money that is earned, [REDACTED] loves working at Marc Center and takes pride in what he does.

To see this program dissolved as a result of funding would be a travesty. There is a large population of people like my son that are being so well served by this program. I can only speak for my son, but I can assure you that this program has provided [REDACTED] with a sense of normalcy and it also provides the opportunity for interaction with his peers.

**PLEASE** continue to fund this program so that [REDACTED] and thousands of others can lead a productive and contented life.

Thanks in advance for your consideration in this important matter.

Sincerely,

[REDACTED]





EMAIL 53

Johnson, Dara

From: [REDACTED]  
Sent: Saturday, August 22, 2015 10:12 AM  
To: HCBS  
Cc: ginaf@azafh.com; Scott Hess  
Subject: Center-Based Employment cuts

To Whom It May Concern:

It has come to our attention that the Center-Based Employment program that serves adults with developmental disabilities is on the chopping block in Arizona. Our son, [REDACTED] currently works in a CBE environment and brings home about \$35.00 every two weeks. That's \$70.00 a month. He gets up every morning to tell us he has to go to work for the day. Because he's grown up in a household that values hard work, he knows he's making us proud. And, he is proud of himself for having a job. His CBE is a huge contributing factor.

Sadly, when he was finishing up his last year at Metro-Tech and working at Goodwill, he experienced a change in teachers from one who was supportive and empowering to one who was old-school who thought adults with developmental disabilities were not capable of working there. Not only did this teacher ruin his chances of working at Goodwill ~ he still talks about it with a very sad affect ~ she also was a major factor in the demise of the cooperative program between Metro-Tech and Goodwill.

You see, adults with developmental disabilities are at the bottom of the totem pole in terms of employment opportunities in the community. And so many of them WANT to work. They WANT to contribute. They just need some extra support to make that happen.

While [REDACTED] is a hard worker, he is also very trusting. He does not carry his own debit card in his wallet. He's had money, sunglasses, and other personal items stolen when out in the community with minimal support. When he's calm and unstressed, he can give his home address and phone numbers for my husband and myself. Not so when he's distressed. The extra support he receives from the CBE program provides him a safe, low-risk environment that allows him to explore different job options without the worry of being taken advantage of.

When his sunglasses were stolen, he felt like it was his fault. After he left Metro-Tech and before he was accepted into the CBE program, he was very sad. His brother went to school everyday. I went to work everyday. He was sitting at home watching TV. He didn't understand why HE wasn't going to work everyday, too. The change in his attitude after his first week at CBE was incredible, and when he brought his first paycheck home, he was smiling from ear to ear!

Given current labor law related to minimum wage, the state of unemployment, and the overwhelming numbers of low-skilled workers in the workforce, it's not prudent or realistic to expect an employer to hire an adult with developmental disabilities at competitive wages. They need extra supports at work. Estimates show that their productivity is less than that of a typical employee, though in some situations, I'd beg to differ ~ if you deduct



BMA 154

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Saturday, August 22, 2015 11:33 AM  
**To:** HCBS  
**Subject:** Center-Based Programming Concerns

To: AHCCCS

From: [REDACTED]  
[REDACTED]  
[REDACTED]

To Those in Charge of Decision Making,

It is my understanding that you are meeting about budgetary concerns. It seems that once again you are targeting those who are unable to defend or speak for themselves. I find it very disgusting that you are even considering cutting services to center-based paid work activities. My son is 40 years old and has Down Syndrome. He has worked part-time in the competitive market as a courtesy clerk for minimum wage for 20 years. During that time he NEVER had a friend or social situations he was invited to. When not at the grocery store he attended a center-based program, where he had friends, a feeling of accomplishment in a work environment that matched his needs.

Things are even worse in this current economy, where things are so technology oriented, that employers would never hire someone that can only work at 20-25% rate. They also have to make a profit and there are a lot of people without special needs looking for positions. Those companies that send work to the centers are not doing it to save money as much as helping individuals have a feeling of self-worth and accomplishment. I myself was a job developer for students with special needs in the school systems and getting students jobs became impossible. Even the thought of volunteering became a farce, they were being used to replace a paid position.

Also, in this current society stranger/danger issues are a big concern with these individuals. They are not able to discriminate and that is why the center-based programs are a safe haven for them and their families. All one needs to do is listen or watch the news to see where individuals unable to discriminate have been victims or perpetrators of society.

I wonder why you would even consider eliminating individuals with documented IQ's of 30-50, other behavior and health issues, and unable to discriminate to where they have nothing. Those individuals in the center-based work centers are there because it provides them with a safe environment where they are productive citizens, self-worth is increased, and a definite feeling of accomplishing a job. Wages may be an issue, but these individuals are paid by a time study system that has worked for well over 40 years. These individuals do not need day programing because their abilities and needs would not be met, because they need work to feel accomplishment.


I wonder how many of you making such decisions have actually been to a center-based program, especially the MARC Centers where you would see individuals working and accomplishing what we all need and desire. The amount of the paycheck is not the issue, if you would talk to any parent, caregiver or consumer. The issue is being proud and productive in a world that values those attributes.

Please consider the consumers as individual persons and not the value of their vocational abilities. Just think how you would feel when and if the same has happened to you. The difference is you could find something else, where they can't.

If you do away with the programs, then I assume they could collect unemployment, which would cost you a lot more.

Anyway, thanks for reading this and hope that you will allow your conscience and heart to override budgetary issues.

Thank you,

 Parent of someone attending MARC Center

EMAILS

Johnson, Dara

**From:** [REDACTED]  
**Sent:** Sunday, August 23, 2015 1:04 PM  
**To:** HCBS  
**Subject:** Possible Defunding :

My son special needs son recently received a letter in the mail that the state of Arizona is considering defunding of programs such as Marc Community Resources Inc.

In 1979 the US NAVY transferred me to the great state of ARIZONA for duty. Our SON WAS 5 YRS. OLD AT THAT TIME.

WE had already noticed his late development of speech, reading and social interaction . WE had him involved early treatment in SAN DIEGO with US NAVY. When transferred to ARIZONA THE NAVY ENSURED THAT I WAS STATIONED NEAR ASU because of their reputation for speech therapy . WE took our son to ASU as suggested and continued therapy and onto elementary school in CHANDLER, ARIZONA. There would be extra after school tutors virtually through to the 6 TH grade.

Then into JR. HIGH AND HIGH SCHOOL in the SAME SCHOOL DISTRICT resulting in the awarding of a diploma in 1984.

There was NO SUGGESTION OR GUIDANCE from ANYONE to test our child for SPECIAL NEEDS throughout his entire 12 YRS. of school plus the exposure in SAN DIEGO.

MY GUESS IS THAT THE MALFUNCTIONS of THE BRAIN were hard to diagnose and TEACHER'S COLLEGES had not caught up with any possible advancements of knowledge in that SPECTRUM. CONSEQUENTLY no diagnosis of DEVELOPMENTAL DISABILITIES soon enough to have enough SUPPORT MECHANISMS in PLACE for EARLY INTERVENTION !!!!!!!!

OUR SON WAS finally diagnosed in his 30's with AUTISM SPECTRUM DISORDERS and SCHIZOPHRENIA DISORDER.

FINALLY AFTER NEARLY 4 YRS. In the BEHAVIOR HEALTH SYSTEMS ( MARC CENTER FINALLY ENTER the PICTURE after a visit to a (( US CONGRESSMAN office )) this is unsatisfactory.

MARC CENTER has been a blessing for our son, IT would be nice if could be in a MORE COMPETITIVE ENVIRONMENT but TIME PHASED BEHAVIOR EMPLOYMENT may cause UNINTENDED CONSEQUENCES for not only our son but others.

IT is this parents opinion that the STATE of ARIZONA has not caught up with it's support mechanisms for those DIAGNOSED with DEVELOPMENTAL DISABILITIES after the age of 18. . MEDICAL KNOWLEDGE AND BEHAVIOR is ADVANCING all of the time.

MY son and others that were in VARIOUS ARIZONA SCHOOL SYSTEMS in 80 – 90's resulting in the late diagnoses of various DEVELOPMENTAL DISABILITIES are in the middle of a corn maze . Thank GOD for MARC CENTER and OTHERS who have a direct involvement with physically and mentally challenged individuals.

TEAM MEMBERS,

[REDACTED]  
AGE 70

MAY GOD take a GUIDING HAND

Sent from [Mail](#) for Windows 10



EM: 156

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Sunday, August 23, 2015 1:44 PM  
**To:** Gina Felker  
**Cc:** HCBS  
**Subject:** COMMENT ON AHCCCS  
**Attachments:** AHCCCS 1.jpg; AHCCCS 2.jpg

Hi Gina,

THANK YOU FOR SENDING US LETTER FOR: Urgent Action Required

We attached our comments, which we sent via e-mail to [HCBS@AHCCCS.GOV](mailto:HCBS@AHCCCS.GOV)  
Also, YOU CAN USE OUR COMMENT TO PRESENT OUR OPINION TO ANY RELATED AGENCY.

BEST REGARDS,

[REDACTED]





EMA 156

Phoenix, 08.23.2015

OUR COMMENT ON:

**AHCCCS IS CONSIDERED THE ELIMINATION PAID WORK ACTIVITIES FOR  
DISABLE PEOPLE for Day Program and Employment Program at AFH**

Instead, the lawmakers to make law for people needs, THIS FEDERAL LAW IS TARGETED AGAINST THE PEOPLE!

What is poorer in this law is DIRECT NEGATIVE IMPACT ON THE DISABLE PERSONS THEY NEED OUR ATTENTION, HELP and CARE AND MENTALLY STABILITY.

Sometimes, I am asking myself: ARE WE DISABLE COMMUNITY WITH OUR COVETOUSLY, THINKING "IN ONE WAY-FOR OURSELFS, ONLY?"

My disable daughter and other in "PERRY Foundation" are related to Day and Employment Programs, got motivation FOR WORK AND LIFE, GIVEN WITH BIG EFFORT MADE FROM STAFF AND TEACHERS.

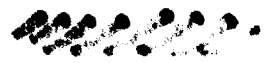
On the beginning we were skeptical about her attention to do something, but later she SHOWN THAT SHE CAN DO MANY THINGS AND BECAME BETTER CONCENTRATION AND ACHJVEMENT.

Her work in group, contact with teachers and colleagues giving her more fun and support to go ahead and her filling that she doing useful job make her happy!

Our support to her and weekly contact and control with "PERRY FOUNDATION STAFF" encourage her to REACH higher level of work activities. THIS EFFORT IS IMMESURABLE.

In the group she is safety and motivated to do more and more, and is laughing when the job is finished. Also, she is working by hands and IMPROVING HER FINE MOVEMENT, WHAT IS VERY IMPORTANT FOR HER AND US. THESE BOTH PROGRAMS IN "PERRY FOUNDATION" ARE GOOD ORGANIZED ACCORDING THE CLIENTS POSSIBILITIES TO DO ACTIVITIES.





OUR CONCERN ABOUT LOSS OF LONG -TERM CARE SERVICES FOR OUR DAUGHTER AND OTHER, TARGETED DISABLE PEOPLE, IS BIG AND WOULD HAVE HUGE NEGATIVE EFFECT AND DISASTER FOR US AS PARENTS, AND ON THEIR LIFE AND MENTALLY STABILITY.

We think that CBE HAS NOT DEEP SENSE AND ENOUGH EXPERIENCE ABOUT DAYLI WORK OF "PERY FOUNDATION", ABOUT POSITIVE IMPACT ON DISABLE PEOPLE AND STAFFS EFFORT AND ACHIVEMENT.

We, parents are seeing their happiness, when they after two weeks of their work come home, and show CHECK AND SAY:"I EARNED MY MONEY FOR PIZZA!"

I HAVE LAST MY DAUGHTERS CHECK of \$18.99, for work of 22 hours, with pay rate \$0.95/hour, and deduction TAXES for MED=\$ 0.30 and SS=\$1.28.


THIS AMOUNT, WHEN SHE GOT, MADE SHE "HAPPY TO THE SKY", BECAUSE HER THINKS THAT HER WORK IS VALUED, AND SHE IS PART OF COMMUNITY!!!

Also, TARGET, WALMART and COSTCO giving 5% of their profit for Community supporting disable people!!!


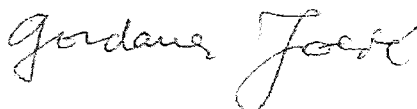
**OUR OPPINION IS THAT AHCCCS NEEDS TO STOP ANY CONSIDERATION WHICH CAN LEAD TO DISTURB WORK AND LIFE OF DISABLE PEOPLE, and to work on their improvement to FIND THEIR PLACE UNDER THE GOD AND SUN!**

Thank you!

PARE NTS:

, father 

Master in Civil Engineering, Professional Civil/Structural Engineer

, mother 

Professional Civil Engineer

Email 57

Johnson, Dara

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**From:** Integrated Accounting Services <iascpa@msn.com>  
**Sent:** Sunday, August 23, 2015 4:38 PM  
**To:** Rountree, Virginia; Johnson, Dara  
**Subject:** ATP Waiver

Myself and many of the people in my congregation in east Phoenix have provided service at the ATP located in the town of Randolph. We would like to request a waiver so they can remain open and serving the patients that have lived there for many years.

Sincerely,  
Mike Warren



EMM | SB

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Sunday, August 23, 2015 7:55 PM  
**To:** HCBS  
**Subject:** Elimination of paid work activities  
**Attachments:** AHCCCS letter 8-23-15.doc

Please consider the attached letter.





Emil 58

August 23, 2015

AHCCCS  
To All Those Concerned

We need you to please continue funding the CBE programs for the disabled population, which includes our son.

This program is the only place that our son could have meaningful employment. He does not need a more restrictive day program or a program that only offers entertainment choices.

The potential loss of long term care services for him and the rest of the disabled population would be a disservice to them.

If left to those types of programs, my son would sit by himself all day and rock and flap with little or no interaction with other people.

My son has no comprehension skills in regards to time, danger/and or stranger-danger, the value of money and its worth and what it can do. He cannot be left alone by himself, and only understands 2-3 directions at the most and needs much supervision to stay on task and complete the job. He needs people who have been trained to help and care for people such as our son.

He would not be able to be hired out in community employment and be able to hold down a job.

The work he does at CBE are things that he can understand and do with consistent supervision as simple as they may be. He has a sense of accomplishment and pride that he can go to work each day and participate in this environment.

We sincerely ask you to keep in place the CBE and long term care services that are already in effect. It would be an extreme hardship for our family if these services were not offered.

Thank you.

A redacted signature consisting of several thick, black, horizontal strokes.







Emil 60

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Monday, August 24, 2015 3:00 PM  
**To:** HCBS  
**Subject:** Proposed elimination of Center-based employment

To Whom it May Concern:

We are writing in regards to proposed changes to restrict or eliminate center-based employment. We are the parents of a 50 year old developmentally disabled son who currently participates in work activities at MARC. Our son attempted community employment in the past and was fired. He is almost completely deaf, has limited verbal skills, is mentally handicapped and has behavioral issues. Center based employment is his only option.

Working in the community without adequate supervision poses a number of safety issues for these individuals who are not high functioning and do not recognize danger, or when someone is trying to take advantage of them. Companies cannot and will not provide that type of supervision. Additionally, few companies can afford to hire an employee whose productivity is marginal. At MARC we don't have to worry about his safety and we can rely on the continuity of employment.

Our son is very proud of the work he does and the paychecks he receives, no matter the amount. Our son enjoys the interaction with his co-worker friends and workshop staff. Outside of work our son socializes with the other residents of his group home and attends various activities such as movies and sporting events. Additionally, we frequently have him home on weekends to attend family functions such as soccer games for our grandchildren and family dinners.

We are retired and my husband is 80 years old. We worry about our son's future and what will happen when we are gone. Please do not eliminate the only job he has available in a safe and caring environment.

Sincerely,

[REDACTED]

██████████

██████████

Enal 61

Johnson, Dara

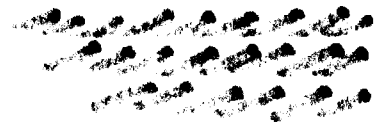
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**From:** [REDACTED]  
**Sent:** Monday, August 24, 2015 5:12 PM  
**To:** HCBS  
**Subject:** Center Based Employment

In our estimation, it would be most ill-advised to eliminate Center Based Employment. Our daughter has been a client at the MARC Center in Mesa for 15 years. She has a permanent impairment (since birth) that limits her mental (not physical) abilities. She reads at only a 2<sup>nd</sup> grade level and is 36 years of age. At MARC she has the opportunity to engage in productive employment, including 2 days per week working at Basha's grocery stores under the supervision of MARC work coaches/supervisors. Her disability would make it impossible for her to compete for employment in the job marketplace in our community. Elimination of her Center Based Employment option would deprive her of the ability to be productive and perform meaningful work in the economic community. Hundreds, possibly thousands, of people in her situation, would be relegated to "warehousing" situations where they are essentially in "baby sitting" environments. We don't see how this can be justified by any standard, whether moral, ethical, or economic.

Elimination of the funding for CBE's would fit the classic definition of "penny-wise and pound foolish."

[REDACTED]  
[REDACTED]  
[REDACTED]





EMAIL 62

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Monday, August 24, 2015 7:56 PM  
**To:** HCBS  
**Subject:** Termination of CBE

To Whom It May Concern,

I was recently made aware that changes in the Federal Law may cause the Arizona Government to cancel the AHCCCS funded CBE programs. As a parent of a participant in this program I am furious that the Legislators of this great state would consider this act. I am a Native of this state since 1961 and I say that with great pride when someone asks me how long have you lived here "I'm a native". My Daughter has several Mental Illnesses that have prevented her from getting or holding a job since high school. Prior to her introduction to the Marc Center she felt like her life was a failure and had no sense of self-worth. She would cry alone in her room on a regular basis, with no friends and was in a state of depression. She spent her days in her room with the curtains closed and just shut the world out. She has become a completely different person since she was introduced to the Marc Center. She now feels like she has a real job with friends that she can communicate with on a daily basis. She is very proud of what she has accomplished and the fact that she is able earn and income is very rewarding to her. My daughter has been traumatize over the years as she has been hired for entry level positions, mainly in the food service industry, just to be let go in the first several days of employment. The reason is the same every time," I just don't think it's going to work out" She just can't adjust to the demands of working in a community job and the fast pace that is required. This may be the only meager source of income that my Daughter will ever know. I ask as a parent of and adult child that has been physically and mentally transformed by this program and the leaders that run it, please look deep into your souls and ask yourselves. If this was my child or family member in this program what could or would I do to preserve the self-worth of these tender souls. Do the right thing and lets not take another positive program away from these individuals that have almost nothing in life to live for except this program. I ask you as a Proud Citizen of the State Of Arizona, preserve the CBE Program at the Marc Center that is funded through AHCCCS.

Sincerely,

[REDACTED]

Father of and Adult Child in Need!

11/11/11

11/11/11

Kamil 63

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Tuesday, August 25, 2015 8:56 AM  
**To:** HCBS  
**Subject:** Center Based Employment

Good Morning,

My name is [REDACTED] and I am the parent of a developmentally delayed and mentally challenged adult, [REDACTED], aged 45.

Dawn has been a client at the MARC Center since 1991, after she graduated from high school.

I was shocked and disappointed to hear that employment options are being taken away from my daughter and other individuals with disabilities.

Competitive Community Employment has never been a successful option for [REDACTED]. She needs formal support in a safe environment to feel a sense of accomplishment. The MARC Center provides this important and meaningful opportunity for [REDACTED]. Her last community employment left her feeling isolated and frustrated. She was let go because of low productivity and too many illnesses. This experience was very disheartening for her and frustrating for us, as her parents, as well. Additionally, there are very few opportunities in the community for mentally challenged adults.

Center Based Employment gives [REDACTED] a sense of self worth, achievement and pride as she has never experienced in any community employment. She is so proud of her daily accomplishments and it is reflected in the brief summary she gets from her job coach.

Please preserve this program. It is a low risk environment for these individuals with much a needed support system for their success.

Thank you for your attention and considerations.

Sincerely,

[REDACTED]  
[REDACTED]  
[REDACTED]  
[REDACTED]



Email 64

Johnson, Dara

**From:** [REDACTED]@net>  
**Sent:** Tuesday, August 25, 2015 9:09 AM  
**To:** HCBS  
**Cc:** Johnson, Dara  
**Subject:** AHCCCS Assessment and Transition Plan for Group Home and CBE

>>  
>>  
>>

>> Sent from my iPad

>> I had previously sent an email outlining our concerns after receiving a handout from Marc Center of proposed changes and potential elimination of the CBE program. We were advised that this information was not accurate. I was directed to the AHCCCS website to read the HCBS assessment and Transition proposal and now I am even more upset and concerned for our son's well being.

>> To present ourselves: we are the parents and co-legal guardians of [REDACTED] who lives in a Marc Center Group Home and attends the Marc Center East ER program (CBE). Our son is 48 years old and has been in this setting/environment for 20+ years. He has previous experience with an apartment type housing and community competitive job when he was much younger. Both of which did not work out as he has no stranger/danger skills, and needs the structure and support offered by the current Marc Center CBE program.

>> We have reviewed the AHCCCS Assessment and Transition plan in an attempt to determine its potential affect on our son [REDACTED], if any. After this review we do not have any major concerns with the Group Home Assessment and Transition Plans as they seem to be pretty straight forward and understandable. On the other hand in regards to the Center Based Employment we have strong comments and are deeply troubled by the direction that is being proposed. It does not seem like any consideration is being given for them as individuals other than the need to push them into a setting that may not be in their best interest. As stated our son is 48 years and does not adapt or accept change. As his Mother I cannot see these changes happening for him and I see a very unhappy individual because the workshop as he knows it is no longer there.

>> The description for Center Based Employment states: Provides controlled and protected work environment, additional supervision and other supports for individuals engaged in remunerative work either in a sheltered workshop or in the community. Marc Center currently provides both of these environments. Concerns and comments follow:

>> 1) No where in the assessment/ transition does it mention keeping or supporting the current CBE program or sheltered workshop which provides a controlled and protected environment. [REDACTED] has no stranger/danger skills and every person he encounters he considers a friend!

>> 2). Not sure what "transition the CBE to a "facility based pre-employment" and into a pre-vocational service focusing on developing non-job-task strengths/skills with goal of integrated employment. Where does this leave those clients unable to achieve or maintain these goals that look good on paper?]

>> 3). The entire proposal appears to be geared towards getting the clients into an environment that may not be safe and a tragic upset to their life styles! The rules also seem to apply to a person with just a disability as apposed to people with intellectual disabilities and behavioral problems like our son and others like him.

>> 4). Outside of the CBE work environment most of the clients already have full social calendars/activities, i.e. Programs by the city parks and recreation TGIF, Marc Center craft nights/dances/social Oasis club, Mesa/chandler fund raiser style show that clients participate in, Special Olympics, etc. They move comfortably in the community eating out, going to movies, shopping, church and weekend time with their families. "Doug is currently on a 11 Day vacation and Cruise to Hawaii"!

>> 5). The whole proposal reminds me of the minimum wage fiasco a few years back that the Arizona voters passed. When I contacted the Governors Council on Disabilities to express our concerns and stated Doug was happy with the pay he received from his remunerative work and I would not know what to do with more money. The response I received

was that " I could buy him nicer things" ! It was obvious that the person advocating for a 48 year old Downs Syndrome that cannot read or write, had a limited understanding of his needs.

> 6) The proposal states that businesses are required to hire these individuals! The reality in today's work environment with people out of work is that the business ~~is not required to hire the individual to their expectations at a competitive rate.~~

> 7) In the prior email I stated that our son loves the current CBE program. He is proud of his paycheck, loves the work that challenges him to do better to make more money. It gives him a feeling of self worth and achievement. The rest of his family goes to work so this is a normal process for him. But it is a program that he can work within and achieve high satisfaction!

> 8). Briefly mentioned in the proposal is the "Affordable Care Act ". Does this program have a direct reflection on the compliance issues?

> 9). I don't know where the money will come from or the staffing to run a program of this magnitude! There is already a need for staffing as people can make more at a fast food restaurant.

> 10). A great concern and worry is that Doug might loose some of his LTC benefits.

>>  
>> Since ~~he~~ was born 48 years ago so many positive strides have been made for these individuals and he was at the forefront of these changes. He has benefitted greatly from these changes. No longer are they placed in a place like the Coolidge facility and they currently have places like Group Homes and the CBE program where he is happy, challenged and content.

>>  
>> We appreciate and thank you for your attention to our comments/concerns in regards to our son and others like him. I cannot attach previous email as our main computer broke during these emails.

>>  
>> Sincerely,  
>> ~~Mr. [Name]~~  
>> ~~[Address]~~  
>> ~~[City, State, Zip]~~  
>>  
>> ~~[Phone Number]~~  
>> ~~[Email Address]~~  
>> ~~[Address]~~

~~[Redacted]~~

~~[Redacted]~~

Email 65

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Tuesday, August 25, 2015 11:06 AM  
**To:** HCBS  
**Subject:** Discontinuance of center-based employment  
**Attachments:** Reasons for center-based employment.docx

Thank you for your consideration of my concerns.

[REDACTED]





Emil 65

August 24, 2015

To Whom It May Concern:

RE: Discontinuance of Center-Based Employment

I could not believe the notice I received telling me that AHCCCS was considering changes to restrict or eliminate center-based employment. I immediately began to cry knowing what this decision would mean to my son. He is multiply handicapped and would never be employed with competitive community employment. Center-based employment has changed his life in the following ways:

1. In DTT he never used most of the skills he had worked on for 18 years of schooling. In center-based employment he is using those skills and gaining more.
2. He is in a safe, caring environment where no one will take advantage of him. He does not know that anyone is a stranger or dangerous and would go with anyone.
3. He has a job and feels such pride knowing that he is working and bringing home a paycheck. He tells everyone he sees where he works and that he gets paid to do his job.
4. Everyone who possibly can needs to have some kind of work to do. My son does not want to be entertained with activities and outings. Those things are fun on occasion, but not on a daily basis. He does not want to go someplace where he feels like someone is simply babysitting him. He wants to have a job.
5. He is happy to wake up in the morning and get ready to go to work. He talks about going to work over the weekend and it gives him a great deal of joy.
6. He is so happy to share with us what jobs he did during the day and let us know how many units he produced.
7. He is so much more independent. He is blind, has CP, and mental retardation, but has learned to use Dial-A-Ride (which he never would have done without center-based employment). He can independently do everything in his work environment. He can get out of the taxi and walk with his walker to the correct door, wait in the appropriate area until work begins, do his individual job, find the restroom at breaks, go to lunch, and go to the taxi after work to return home.
8. Center-based employment helps him feel normal and more like his other peers and family members.
9. Earning money helps him learn to budget and become more aware of the value of a dollar. He has also learned to save his money for something he would really like to buy.

10. We were thinking of moving to a new house and my son's only concern was that he would no longer be able to go to work. We did not move to make it easier for him to continue working.

11. MY SON IS A DIFFERENT PERSON BECAUSE OF CENTER-BASED EMPLOYMENT.

I do not know which new federal law would curtail center-based employment, but it would be doing a gigantic disservice to those disabled persons who cannot find employment in other places and are benefitting in so many ways from this life-changing program.

Please do not discontinue this type of program. There are so many who benefit from center-based employment. It has changed so many lives.

Sincerely,

A series of blacked-out marks, likely a signature, consisting of several horizontal strokes.

Emil Uo

Johnson, Dara

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From: [REDACTED]  
Sent: Tuesday, August 25, 2015 11:16 AM  
To: HCBS  
Subject: CENTER BASED EMPLOYMENT

Dear Sir/Madam:

I was recently informed that you are considering not continuing to have paid Center Based Employment. My son [REDACTED] is 37 yrs. old and has Autism. He has been attending MARC Center in Mesa. He is doing extremely well there.

I like that he has a safe, clean and secure place to work in. And he is very happy to receive a pay check. It makes him feel that he can accomplish something for doing his work at the Center.

As far as working in the community -- most companies will not hire a person with a disability. Unfortunately. People with Autism and other disabilities need a special environment to work in and be safe. They are not aware of "*stranger danger*" at all. My son once was approached after leaving a bank to cash his check and the guy just put his hand in my son's pocket and took the little bit of money he had. Then gave him back \$5.00 so he could at home. I do not want to see this repeated.

I have had to go to numerous hearings and to court to have my son to be able to attend this program and to have him approved both in New York and Arizona. You would think when a person has a disability that the state would be more then willing to help them. Instead of giving them more grief to go through with.

I sincerely hope and pray that you continue with the Center Based Employment for everyone's sake. They have enough challenges to deal with, they certainly don't need any more to have to contend with.

Thank you.

Regards,

[REDACTED]  
[REDACTED]

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Email 67

Johnson, Dara

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**From:** [REDACTED] <[REDACTED]>  
**Sent:** Tuesday, August 25, 2015 1:34 PM  
**To:** HCBS  
**Subject:** action response for paid work activities

Hello, my name is [REDACTED] i'm very satisfied hear doing training assembly work here at the Marc Center of Country Club in Mesa, Arizona i've been hear going on 3 years i would like to keep it open. Thankyou signed [REDACTED]  
[REDACTED]



Email 68

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Tuesday, August 25, 2015 1:34 PM  
**To:** HCBS  
**Subject:** Funding at Marc and other agencies

To whom it may concern,

I am writing this email because I am outraged that effective employment options are being taken away from the Marc center. My brother in law is an employee at this agency and I am very upset to here that his job may be taken away. The center-based employment offered at the Marc center is the perfect job for my brother in law. His name is [REDACTED] and he takes pride in his job. You should see the sense of accomplishment and pride on his face when he shows off the paychecks that he earns from the Marc center. He is able to work with people who understand his needs. He is able to work with other people who are disabled and doesn't feel so isolated or alone for being different. It is a safe environment that he shows progress in and the thought of it being taken away is very concerning.

The program offers the perfect schedule for [REDACTED] and are very flexible. They are very understanding of all his needs. I honestly don't there is any other place that would be willing to be so patient. I want him to keep working because it really helps him feel accomplished and important. The Marc center has created the perfect environment, there is no other place that can offer the same support [REDACTED] gets here. They never take advantage of [REDACTED] and always treat him with respect. I am concerned that he will not be able to find this at other facilities.

Not only am I concerned that he wont be able to get the same treatment at another job, I am concerned that he will even be able to find one. People with disabilities are the last to be hired and the first to be fired as the economy changes. He needs a job in order to feel a sense of inclusion and to feel connected to the community. Please consider all the lives that you are negatively effecting when making these decisions.

Thank you,

[REDACTED]





Emil 69

Johnson, Dara

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**From:** [REDACTED] <[REDACTED]@marcouncil.com>  
**Sent:** Tuesday, August 25, 2015 1:39 PM  
**To:** HCBS  
**Subject:** CBE

My name is [REDACTED]. I finished serving a prison sentence in 2005 and was diagnosed with PSD shortly after. I was not working, living in a half-way house and not receiving much assistance or encouragement. A friend of mine came and told me about Marc Community Resources. This organization and the services they provide have been very beneficial for me. Over the past 3.5 years, I have participated in their living skills workshops, job development and education programs.

These programs helped me to get back into the community and become a productive citizen. Overall, I learned how to cope with my challenges and daily responsibilities. I have a 12 grade education but due to my Dyslexia I had a very hard time reading. The Marc Community Resources education program has greatly helped me improve my much needed reading and communications skills. The workshops helped me understand and develop good work-based skills including dependability, time-management, teamwork and other coping skills. I was able to progress to the job development programs which included working a regular schedule supervising other clients to complete daily assigned tasks and managing quality control. This helped me obtain a current part-time job in the community at Arizona State University.

The CBE program Marc Community Resources provides has been invaluable to me. I don't know what I would be doing if my friend had not told me about Marc. Not only have I been able to become a productive employee, I have much more confidence and have become self-sufficient. I am now living independently in my own trailer, own my own car, and pay my own bills. This is all because of how Marc programs have and are still helping me.

It is critical that people such as me have CBE opportunities available to increase independence in a safe and structured environment. AHCCCS needs to continue to support agencies in offering these programs.



Emil 70

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Tuesday, August 25, 2015 2:15 PM  
**To:** HCBS  
**Subject:** Elimination of paid work activities  
**Attachments:** ahccs.pdf



Email 70

AHCCCS  
OFFICE OF INTERGOVERNMENTAL RELATIONS  
801 E JAFFERSON ST. MAIL DROP 4200  
PHOENIX AZ 85034

As the mother of a daughter with disabilities I would like to address you considering changes that will restrict or eliminate center-based employment or CBE.

If the CBE were stopped [REDACTED] would have to stay home all the time. She would spend her time sitting in her room watching TV. That is not good for anyone.

[REDACTED] has worked at the Marc Center since 1987. This is where her friends are and her whole life. While attending the Marc they have tried to have her work outside the center. This has not been successful. While working at a Basha's store she had a very nasty employee of the store that said some very bad things to her. After that she refused to go back to a store. She also can not go out in parking lot to gather shopping baskets as she does not watch the car traffic. She did not work well in the grocery store and would need a job coach if she did that full time. I believe Marc had many complaints about her work.

All of her supervisors at the Marc tell me she is very hard worker and does a good job on the work she is assigned to do. There are some jobs she can not do because of eye sight and another job will be found that she can do.

[REDACTED] is not working for a specific amount of wages, she is just thrilled to get a pay check that she can take to the bank and then have her own money to spend.

[REDACTED] can not take a bus or public transportation as she has no idea where to get on or off. She must have a Discount Cab service that picks her up at her front door and delivers her to her work place.

Please take [REDACTED] and all other like her into consideration as you make your decisions on this matter. You will change her whole life, and not in a good way.

Thanks you for your consideration

Sincerely,

[REDACTED]



EMail 71

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Tuesday, August 25, 2015 2:20 PM  
**To:** HCBS  
**Cc:** Johnson, Dara  
**Subject:** Comments on AHCCCS Transition Plan from Paul & Susan Czekanski 8/25/15

August 25, 2015

To Whom It May Concern:

It is my understanding in order to meet new Federal regulations, AHCCCS would restrict or eliminate what is called a Center-Based Employment (also known to some as Sheltered Workshops).

Our daughter, who is in her late thirties and is intellectually-challenged, attends one of these CBE's five days a week. Her intellectual and physical capabilities limit her to very repetitive work assignments where direction, instruction, and monitoring is present or close-at-hand. In most cases visual aides are provided to assist her in the performance of the task and to insure accuracy of the final product. She has worked in a community job for several years prior to the CBE. She worked a couple of hours for several days a week. Over time her time was reduced where her earnings didn't cover the cost of Dial-A-Ride transportation.

She anxiously looks forward to going to work at the CBE each day. Missing a day is sheer misery for her. She is proud of the work she does and has a great sense of achievement. Each payday she proudly shows us her paycheck. The amount of check doesn't matter – it's a check and she earned it. It also places her in an environment where she is with friends (individuals in similar situations) and also in the community with people in general.

If not for the CBE she and many of the others would be condemned to isolation and regress in the social skills needed to survive in our society. Haven't people and organizations in the past worked diligently to help the Challenged out of isolation imposed on them by the ignorance of society? Haven't people and organizations in the past worked diligently to help them be accepted and understood by the community and society in general? Why send them back to those "darker" days.

Competitive community employment with an employer of intellectually and physically challenged individuals is not an option for our daughter. This is true for the majority of other individuals at the CBE. I have noticed that many of the employers who have hired these individuals in the past no longer do so. The number of willing employers seems to have declined and the number of jobs. Competitive community employment requires independent thinking, multitasking, prioritizing tasks, performing tasks in timely and efficient manner, and performing task with little or no supervision. Our daughter and many of the others at the CBE require considerable direction, instruction, supervision and a repetitive work assignment; thus cannot meet the needs of a community employer.

In conclusion CBE's provide a necessary and important service to the intellectually and physically challenged individuals of our community and to the community in general.

[REDACTED]





Email 72

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Tuesday, August 25, 2015 4:28 PM  
**To:** HCBS  
**Subject:** RE Possible Elimination of CBE Programs

Hello. My name is [REDACTED], and I represent my sister, [REDACTED] who lives with a developmental disability, as well as our family, who are her guardians.

[REDACTED] is currently employed by AFH, a Center-Based Employment provider for special needs adults. It has come to my family's attention that based on a new federal law, CBE programs like AFH may become eliminated or restricted in some way. I am sending this email, along with what I'm sure are a fair few people, to protest this interpretation of the law. My sister has benefited so much from these programs – in the short time she's been working with AFH, her social skills and sense of responsibility have increased dramatically, and she's starting to have a better outlook on life. She's learned to communicate more, and she has a lot of fun; it helps her build her self-worth.

Without programs like these, [REDACTED] would either be forced to stay at home (where we do our best, but are not medical/psychological professionals) or to go to another, less viable option like community-based options where specialized support isn't always an option. These CBE centers offer low-risk employment and empowerment opportunities for these guys, who often don't recognize the unfortunate dangers of other options (such as being taken advantage of).

I sincerely hope you take into consideration these thoughts and others from families like mine. These opportunities are rare for Sonia, and I would have to see her lose them. Thank you for your consideration.

[REDACTED]  
On Behalf of the [REDACTED] family and [REDACTED]



Emil 73

Johnson, Dara

**From:** [REDACTED]  
**Sent:** Wednesday, August 26, 2015 8:32 AM  
**To:** HCBS  
**Subject:** Fwd: CBE Funding

Sent from my iPad

Begin forwarded message:

**From:** [REDACTED]  
**Date:** August 24, 2015 at 6:31:34 PM MST  
**To:** <cewbbr@aol.com>  
**Subject:** FW: CBE Funding

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**From:** [REDACTED]  
**To:** [hcbs@azahccs.gov](mailto:hcbs@azahccs.gov)  
**Subject:** FW: CBE Funding  
**Date:** Mon, 24 Aug 2015 16:44:21 -0600

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**From:** [REDACTED]  
**To:** [hcbs@azahccs.gov](mailto:hcbs@azahccs.gov)  
**Subject:** CBE Funding  
**Date:** Mon, 24 Aug 2015 12:10:28 -0600

I am writing to express my extreme concern over the possible change in funding for CBE programs in AZ. If funding is to be eliminated or reduced, it would take away the only viable option for those currently using the programs. All of these clients have either academic, social, and/or or behavioral challenges that make accessing jobs in a the community virtually an impossibility for them. Without the structured environment of a CBE, they would not have any other work option, and a day program is considered to be a more "restrictive" placement as their needs are very different from those clients typically placed in day programs. They deserve the right to have what they consider to be gainful employment, not a recreational type of program. I am the legal guardian and "foster" parent for a young woman who has autism, OCD and is mentally handicapped. She was my student when I was a special education teacher, and has lived with me for sixteen years. [REDACTED] has worked in a CBE setting for the past six years. When she graduated from high school, I observed a variety of programs to find one that would best meet her needs. I know the CBE program is the only employment option for her due to significant behavioral and academic challenges. They provide the structure, guidance, and trained staff needed for her to be successful. [REDACTED] is very proud of her job, and feels a sense of accomplishment every day. She is so eager to share her daily production totals the staff writes on her calendar, that she doesn't even greet me

until she has shown me what she has done. She loves getting her paycheck, regardless of the amount, as she knows it is a reflection of all of her hard work.

A typical job in the community would not be able to meet Patsy's needs for a variety of reasons. They would not have coworkers trained to deal with her severe outbursts, understand her communication limitations, know how to arrange the environment to reduce her anxiety, or be even be able to guarantee her safety as she has no understanding of "stranger danger". She is very gullible, and could be talked into any number of situations that would not be positive for her. I would not be willing to put her at that type of risk.

I can also guarantee that she would be fired the first time she had one of her "tantrums" which can involve aggression towards herself or others. No typical employer is equipped to deal with that. Without the CBE program, I would have to quit my own job to be home with her as I would never feel comfortable having her at any other job setting.

In addition, I do not consider the CBE program to be a non-community based job, for those who work there are a community. The clients have often gone to school together, know each other from Special Olympics or other recreational programs. It is her peer group, and one she is very happy to be a part of every day. For her, it is where she works, and she does not care that it is not a "typical" job. She loves going to work, and misses it when she is not there.

If not having a job in the regular community is a concern for AHCCCS and the new federal guidelines, rest assured that [REDACTED] has many opportunities to interact with the general public, as she travels, shops, goes to movies, dines out, etc., with me. She is not lacking in her exposure to people in the community.

I am hopeful that funding does not change for the CBE programs, for it would have a huge impact on both clients and their families. Please feel free to contact me if you need any additional information. Thank you.

Emil 74

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Wednesday, August 26, 2015 10:14 AM  
**To:** HCBS  
**Subject:** Public Comment HCBS-August 2015  
**Attachments:** Public Comment HCBS-August 2015.docx

Public Comment



Emal 74

To Whom It May Concern:

I strongly oppose this change in policy regarding HBCS waivers. It appears that rural group homes and/or farmstead settings, along with some other provider settings are going to be impacted in a most negative way. It is also quite apparent that the people who put this plan together have little or no first hand personal knowledge of the level of care necessary for the most severely developmentally disabled.

This purports to "provide choices" and "protect the rights of the disabled". Incentivizing the states to reduce the cost of Medicaid sounds great. However, if the price of doing those reductions is to affect the quality of life of the DDD population, particularly those at the lower end of the autism spectrum and/or those who have extremely difficult behaviors, that is a price too high.

Funding has continued to erode over the past few years, making it already more and more difficult for these rural community Providers to remain viable. There are ever increasing administrative, regulatory and policy demands being foisted upon them with no apparent understanding by the powers that be of the costs associated with compliance. This is going to increase substantially (requiring more administrative staff, at an increased cost) if Providers are called upon to document and submit supporting paperwork frequently to prove that a member can stay in their current placement because they haven't met or cannot meet the necessary objective to achieve the next level toward independence. (Please understand that some of these folks will never be independent, and it should be ok to acknowledge that, my brother among them).

There is already pressure on Providers to supply more and more items that previously have been allowed to be paid for by the member, with no accompanying increase in funds. This policy change needs to take into account transportation costs, if the Provider is going to be required to get the member to and from employment or other activities outside the community in which they live. Staffing ratios will need to be changed to 1:1 so that staff can accompany each member in whatever direction they choose to go, at whatever time of day or night.

There is mention made of "volunteer monitors". That causes me great concern. I would question how consistent and how qualified **volunteer** monitors might be in making assessments which could greatly impact how DDD might evaluate a Provider's compliance. It's already highly subjective, depending upon which monitor does an audit. My brother doesn't do well with ever changing staff, and that's true for many in the autism community.

There are all kinds of health and safety issues/concerns that come to mind when I consider the absurdity of my brother trying to lock or unlock his door, cook his own meals, go anywhere he wants at any time he wants. And, if he "chooses" not to work toward his objectives, and thus makes limited or no progress toward whatever arbitrary person, agency or rule stipulates as appropriate for him, then what? In his current rural residential environment, he is treated with dignity and respect. He prospers when he has a predictable, structured routine, though when he is not feeling up to it, he is given the opportunity to abstain from an activity.

I applaud those individuals (and their very supportive parents) with ASD who can function autonomously, have achieved graduate degrees, and who have the ability to self-advocate. And, of course a higher functioning individual on the spectrum should have every opportunity to be a part of the community of their choice. However, for government to insist that those on the lowest portion of the spectrum should go to college, be forced or manipulated into living in a high-risk urban or suburban setting, in the name of having choices – **limits choices**, rather than provides more choices. In a rural community setting there is less traffic, more room to run and roam, less noise and unwanted external stimulus for those who are

hyper sensitive or who cannot detect danger. Opportunities for swimming, gardening, and participating in a rural lifestyle is and should be just as much a choice as an apartment in the city. Additionally, those folks can walk around without danger, develop relationships with fellow housemates, each who has his own room, and function in much the same way a family would function.


Unfortunately, my 57 year old brother has essentially no language, does not know to watch for traffic before crossing a road. He cannot prepare a meal for himself, does not know the value of money, and cannot take his own medications. He wouldn't know if someone was trying to rob him and if he did, he couldn't make himself understood to tell anyone. In reference to the recent CMS suggested rule change which claims that rural group home (sometimes called farmsteads) communities, having scheduled mealtimes and bedtimes is somehow "institutional" is WRONG. I and all my siblings benefitted from this very kind of structure. Four of us are neurotypical, and we turned out just fine.

One size does not fit all. That is the very reason that parents have established these rural community programs. They had children, profoundly disabled with autism and sometimes other challenges as well, for which there was no help when they became adults. A few have been in place for many years, with demonstrable success for the members. Turnover is low because when the members come, they stay because it's home. In fact, some don't want to leave to visit family. It's where they want to be. They feel safe and protected. For them, it is their least restrictive alternative. Most of these programs have long waiting lists, and continually receive calls from frustrated and frightened parents who, after years of waiting and searching, want to find out how to start something like it for their child or children because there is nothing else available.

These CMS-targeted rural programs are incredibly important to a segment of the ASD spectrum. Even with scheduled meal times, activities and shared living spaces, they are not institutions by design, by intent or by any other measure. Forcing choices on some members, while refusing to place new ones in rural community settings, when it's applicable, has the potential to close these Providers down for lack of financial resources. That then, would actually reduce the choices available and *take away the rights* of those who would benefit from those programs. Thus, exactly the opposite of the desired outcome would be the result.

People on the Spectrum should have MORE choices, not fewer. And, those programs that provide for the very most vulnerable among us should be funded at a level that is consistent with what it costs to care for them. I hope Washington D. C. and Arizona are listening.

Sincerely,

  
Sister/Guardian of an adult man with Autism



Email 75

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Wednesday, August 26, 2015 2:58 PM  
**To:** HCBS  
**Subject:** POSSIBLE CHANGES TO CBE

To whom it may concern:

This e-mail is in reference to the news of AHCCCS considering changes that will restrict or eliminate center-based paid work activities.

We are the parents of a son who has Down's Syndrome. He has worked at Marc Center since graduating from high school.

Although he is capable of performing many different tasks such as the ones required in contracted jobs that the Marc Center receives, when he was given an opportunity to try working out in the community, he was unable to meet the expectations of the job.

*Center-based paid work:*

*provides a way for people, including our son, to contribute and have some independence*

*provides a safe work environment where they can function at their various levels of ability*

*-there is not a fear of being taken advantage of (our son would not recognize danger)*

*-community employment is not a viable alternative for many of these citizens who desire to work*

**-those working in CBE are not in need of a more restrictive day program; they have the ability to perform many different tasks very well!**



Email #6

Johnson, Dara

**From:** [REDACTED]@gmail.com  
**Sent:** Wednesday, August 26, 2015 3:06 PM  
**To:** HCBS  
**Subject:** Comments

To Whom It May Concern

We are the parents of a daughter that works at Marc Center. She works 2 days a week at Basha's and we are very concerned about any changes made thru this program.

Our daughters involvement with Marc Center has been nothing but GREAT, EXCITING. and WORTHWHILE.

With the guidance from Marc Center at the onsite at Bashas with supervision while she is working in the community is far superior to anything we've been involved within the past 41 years of her life,

The IQ for children like her is low. She and others like her need to be told and reminded frequently of the old saying of stranger danger. They are trusting of the people around them. We've experienced this situation.

Her self-worth and achievement built on employment has given her self confidence and the meaning of a dollar earned. She now has a bank account with money she has earned and is very proud of it. Just recently she was out to dinner with friends and they offered to pay for her meal. She said "no" I have a job and I have my own money. What a shout out for her and with the job she has earned some independence.

Our daughters growth has been nothing but positive. Her self-worth and achievement which makes her hard work worth while. She has learned to be a hard worker. Young people like her need to be valued and challenged in what they do.

Without this program - center based employed - this would not be possible. They can't compete for wages without that support. Makes them feel more normal and part of the community. Please consider all these pluses for this type of program.

It is so important that they have this type of workplace to live their life to the fullest. They deserve this opportunity.

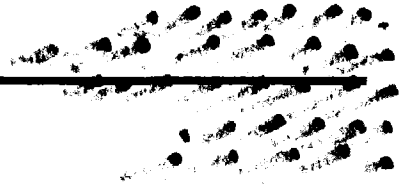
[REDACTED]

Parents of 41 year old [REDACTED]

a very capable and caring individual in our community.



Email 77



**From:** [REDACTED]  
**Sent:** Wednesday, August 26, 2015 8:05 PM  
**To:** HCBS  
**Cc:** sidh55@cox.net; 'Dianne'  
**Subject:** Attn: To the c/o Office of Intergovernmental Relations, AHCCCS

**Importance:** High

To the c/o Office of Intergovernmental Relations,

My name is, [REDACTED] and I'm outraged by the very the very notion that the state of Arizona and AHCCCS is considering eliminating paid work activities as evidenced by the letter I received in the mail Monday.

We can agree that the Arnold v. Sarn lawsuit dragged on for more than two decades and each time it was heard by the court it cost in excess of more than \$100,000.00 once you figure in maintenance and lawyer fees. Nowadays a prisoner in Arizona penal system costs our state a cool \$25,000.00. So we're talking \$125,000.00 easy for and individual, let's say. This is for one individual in a lawsuit. Imagine what it would cost the state for just 60 individuals. 125 individuals, 250, 500, 1,000, 2,000, 4,000, 8,000, 16,000, 32,000, 64,000 individuals should the state of Arizona and AHCCCS decide to consider eliminate paid work activities for these people and they are forced to search for work in the public job sector and they can find nothing due to their situation because what is happening in the news, local and national, right now and they go they go through the judicial and correctional processes. Can you imagine the nightmare the state would be causing these people should they go through the judicial and correctional process because they can find no work and they are forced into a desperate situation; 1, 60, 125, 250, 500, 1,000, 2,000, 4,000, 8,000, 16,000, 32,000, 64,000 individuals, potentially? Center-based employment was designed to keep people who are trying to recover out of prison at the same time be just a bit more productive members of society.

I'm going to tell you a story about me, now. I haven't had a employment within the public sector job since 2001. I went on SSDI right around that time. I heard the whispers that people tell others that I should get a job, this and that. Right now it's pretty interesting with my situation. I have both seizures (not declared) and bipolar disorder. My medications per month from my dentist, psychiatrist, and neurologist alone are, at least, roughly \$2,000.00 per month. This is with both AHCCCS and Medicare under the Quality Medicare Benefit, I have UnitedHealthcare Community Plan HMO SNP. I would need medical, dental, and behavioral health benefits up front, no questions asked, from any perspective employer. Since this will never happen, I'm sharing the rent with my parents with my SSDI as I would need to be making roughly anywhere between \$100,000.00 - \$120,000.00 to be living on my own with ObamaCare, all things considered.

How many others in the public mental health care system are in my situation just like me I wonder. I heard anyone past six months looking for a job, shouldn't bother. And the state is considering eliminating paid work activities for those persons who would be in dire straits if you eliminate paid work activities. These people, such as myself, need paid work activities to get themselves into a better position to at least have a chance to find paid work in this current public job market as it updates their current work resume.

Now the job I had at the Marc Center working the snack bar at Partners in Recovery, East Valley Clinic as cashier, it was a good experience for me (I never reported it to you or DES because my income was under \$100.00). That's the entire point. And that's where the outrage comes in if Arizona decides to eliminate paid work activities. Arizona is going to do, potentially, more harm than what is good for the state and its citizens.

Thank you for your time in reading my email. Stay strong.

Sincerely,



Email 78

Johnson, Dara

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**From:** JAMES E HAMANT <hamant2@msn.com>  
**Sent:** Wednesday, August 26, 2015 8:36 PM  
**To:** HCBS  
**Subject:** comments on transition plan  
**Attachments:** comments on transtion plan.doc

I did not put my name on the comments.  
but add with my e-mail

Eva Hamant





Emil 78

[ On P. 4, AHCCCS said they sought to promote the values of choice, independence, dignity, self-determination, and individuality for its membership. While they tried, since 2013, I do not see evidence of that. In fact I doubt if the 86% who receive HCBS services knows what self-determination is. They had something about member-directed options, but my case managers never knew what that was, even though someone sent me a letter about it. Case managers, supervisors, district manager can't tell the difference from their ISP's and a PCP which is why on P. 55-57 in the transition plan that AHCCCS talks about individual service plans. I and many other parents of HCBS understand the difference and want PCP's. Could it be the self-determination, member directed planning ideas?? Besides now at the 90 day or 60 day review, the case manager has only a 30 minute window which is used to ask about the individual's health, medications, and how the services are going. I have my daughter's writing with an AAC device saved and put into people, places, likes, health if she mentions, and some HCBS goals. Case manager may comment and may even talk to my daughter other than saying hello and good-bye to her.]

[ On P. 5 it shows that 68% of those receiving HCBS live in own homes. It did not mention the percentage of that 68% who attend non residential like day treatment and training programs, center-based employment programs or group-supported employment programs. By excluding those 68% from the transition plan, without a PCP, how can they access residential or non-residential services? Maybe in Arizona there will an opportunity for true supported employment, since those services have had name changes of sheltered workshops to center-based employment, and now under the final rule, AHCCCS wants to call them training programs.

At the DES/DDD Central district HRC meeting, the district manager could not verify the numbers on P. 11 as accurate since they have more group homes and DTA than listed there.]

PCP  
[ On p. 19, AHCCCS does not address the PCP. How can any of the changes listed be implemented without a PCP? PCPs have been in Arizona since at least 1998 and still members who get HCBS can not have one or it is difficult to obtain one. AHCCCS thinks they are a 3 day affair and central district manager can't figure out how to do a 90 day or 6 month review along the lines of a PCP. Actually, a PCP at the 90 day or 6 month review could be a monitor tool for looking at the people in the individual's life-paid vs non paid people, where did they go-inclusive settings, did they like or did not like what they did.

My concerned as a HRC member is that without a real PCP, having rights limited will be a joke on documentation of getting those rights back. I also sit on Program Review Committee (PRC) and review behavior treatment plans. Rights are restricted under the guise of risk assessment in the ISP. The standard remedy is a BTP.

On page 20, AHCCCS will establish competency-based PCP training case managers. The rule mentions that anyone not providing services to the individual can facilitate the PCP. I fear that AHCCCS will put in barriers so that parents or people trained in the past 18 years by Michael Smull or Sonora UCEDD will not be able to facilitate PCP's.

On p 64 I don't believe staff members regularly ask individuals about their needs, preferences and support them in exercising autonomy and informed decision making. On p 65 members are supported to be self-determined. They are required to develop habilitation-related outcomes to support the member's vision. My views are by reading BTP and the individuals ISP, where individuals have no access or limited amount of money, HAH goals of a BTP or some hygiene goal. Case manager rarely show up and sometimes not available on the phone. If they don't have time for this, how will they be about to answer questions or make sure the group home staff are working on informed decision making.

On p. 134 it mentions what a DTA services looks like. District Central HRC members who take turns sitting on PRC have issues because the DTA rarely provide BTP data for the annual review at PRC. (This issue was added to our 2014 annual report.)

I was surprised that District Central HRC did not provide comments. I asked one member since her son lives at home but attends a DTA. She has advocated for her son with the DTA since he tends to eat out of the trash can and sleeps most of the day. I asked her about not commenting since the CMS rule wants inclusive activities. She said several years ago, the DTA did inclusive activities: they drove the individuals around all day in the van and had lunch in a park which had a restroom.

Emil 79

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Wednesday, August 26, 2015 8:44 PM  
**To:** HCBS  
**Subject:** Comment on Arizona Plan for New HCBS Rules

Gentlepersons,

I attended a public forum on the proposed Rules changes, and have downloaded the proposal and rules changes. I want to comment on the Employment Services changes primarily.

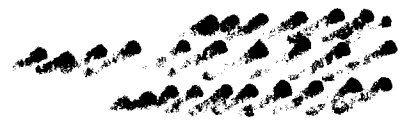
I have a mentally retarded 54 year old daughter, who has provided me with some insights and experience that most people are not privileged to have. She cannot read, cannot count well or deal with money correctly, and she is too small to do labor. There is no magic program that will make it possible for her to transition into the workplace or into volunteer work that requires use of logic. She works very well in a sheltered workshop, assembling rivets for commercial use, and is very proud of her work and her ability to go to work. She is not the only one; some percentage of the population is similarly positioned.

With (dis)abilities, as with most human traits, there is a distribution of talents or abilities which peak somewhere, and decline on either side of that peak. We call the peak of the talent distribution 'normal'; those people having talents near the peak are called normal. Mainstreaming works well with persons near normal; the further one gets from normal, the less well mainstreaming works. When you are as far out as my daughter, you often get laughed at and ridiculed. This happens to her even now when she goes to the mall or to movies.

Your plan appears to limit the number of such people who cannot be mainstreamed that employment services can help. I don't know how that matches with the fraction of the population so positioned; your words seem to indicate that essentially everybody can and should be mainstreamed. To do that, you would have to educate the entire community on compassion and kindness to others. That might prove to be much more expensive.,

It is this problem that is not well addressed in your plan to 'mainstream' employment services for disabled populations

[REDACTED]



EMAIL GO

Johnson, Dara

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**From:** Brandy Petrone <brandy@goodmanschwartz.com>  
**Sent:** Thursday, August 27, 2015 5:59 AM  
**To:** HCBS  
**Cc:** Brandy Petrone  
**Subject:** AAPPD's Comments to Assessment and Transition Plan  
**Attachments:** AAPPD Comments on Plan.pdf

Hello,

Please find the Arizona Association of Providers for People with Disabilities' comments on Arizona's Systemic Assessment and Transition Plan relating to HCB services.

If there are any questions regarding AAPPD's comments, please contact me at the information below.

Thank you,

Brandy

*Brandy Petrone*  
Goodman Schwartz Public Affairs

Office: 602-277-0911  
Cell: 602-821-8318  
Fax: 602-277-3506

300 West Clarendon, Suite 245  
Phoenix, AZ 85013  
[brandy@goodmanschwartz.com](mailto:brandy@goodmanschwartz.com)



Email 80



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August 27, 2015

SUBMITTED VIA EMAIL

Director Tom Betlach  
AHCCCS  
801 E. Jefferson Street, Mail Drop 4200  
Phoenix, Arizona 85034

**RE: Arizona's Systemic Assessment And Transition Plan**

Dear Director Betlach,

Thank you for allowing the Arizona Association of Providers for People with Disabilities (AAPPD) to comment on the agency's Systemic Assessment and Transition Plan related to home and community based services.

AAPPD represents over 80 providers of services to the developmentally disabled across Arizona. Our members represent both rural and urban services and also represent all of the services impacted by the Assessment and Transition Plan relating to developmental disabilities.

AAPPD members have taken significant time to review the Plan. Attached, please find our comments relating to: person centered planning; group homes; adult developmental and child developmental homes; day treatment and training programs; center based employment; and, group supported employment.

AAPPD would like to thank the AHCCCS staff and workgroup members for their time and efforts over these last several months. AAPPD appreciates the open communication the staff has provided as well as the inclusiveness the agency has shown throughout this process. AAPPD also appreciates being included as one of the stakeholders looking at the redesign of employment services that is suggested in the Plan.

If AHCCCS has any questions regarding AAPPD's comments, please contact Brandy Petrone with Goodman Schwartz Public Affairs at [brandy@goodmanschwartz.com](mailto:brandy@goodmanschwartz.com) or 602-277-0911.

Thank you, again, for your agency's work on this Plan and for allowing AAPPD to comment. We look forward to working with you and your staff on this plan as it moves forward.

Sincerely,

A handwritten signature in black ink that reads "Carol A. Carr". The signature is written in a cursive style.

Carol A. Carr  
Chairman, AAPPD



**Arizona Association of Providers for People with Disabilities'  
Comments on Arizona's Systemic Assessment and Transition Plan:**

**Person Centered Planning  
Group Homes  
ADH/CDH  
DTA  
CBE  
GSE**

**Submitted August 27, 2015**



## **AAPPD Comments on Person Centered Planning Assessment and Transition Plan**

AAPPD supports the use of person centered planning (PCP) and feels that it is, in essence, already in-use by providers of services in the DES/DDD system through the use of individual support plans (ISP)/individualized family service plans.

AAPPD raises the following concerns regarding the PCP assessment and transition plan:

### *PCP vs. ISP*

- AAPPD is opposed to remediation strategy #1 and would prefer, instead, to recommend modification of current policies and forms, as necessary.

AAPPD believes that DES/DDD's current ISP and behavior treatment plan meet the requirements to serve as a person-centered plan as described in the rule. The ISP does function as a member directed plan and fulfills the intent of the PCP concept. The member and his or her legal representative are active participants in the development of their service plans as well as active in considering any changes to those plans. AAPPD requests consideration for allowing current processes, like the ISP process in the DES/DDD system, to be used as the basis for any changes that need to be made and that it not be replaced with a new tool altogether.

AAPPD acknowledges that in public forums AHCCCS staff has indicated that the ISP is the PCP; however, the assessment and transition plan do not acknowledge this. Clarification to this point would be helpful.

Listed as one of the weaknesses of the current PCP requirements and practices, is that MCOs utilize different strategies to implement the process and different methods to document the information (#2 and #3). Standardization of the PCP process may not lead to a positive outcome. The needs between the EPD and DDD populations vary greatly. Since the PCP is the vehicle to limit access to rights, this process may need to look different in the DD setting. As the policies and forms are created, great care needs to be taken in recognizing the unique needs in the DD community. It is likely that AHCCCS and DES/DDD can save time and money and avoid implementation issues by modifying the current structure, forms and processes that exist for an ISP rather than recreating a whole new system.

To that end, AAPPD would be willing to bring together a panel of volunteers to work with AHCCCS and DES/DDD on the revisions and upgrades needed to bring the current ISP process into full compliance with the PCP requirements. Individuals within AAPPD's membership have gone through previous PCP training and would be willing to work on these revisions and upgrades.

### *Time Constraints and Funding*

- AAPPD is concerned about the length of time it will take to perform the steps outlined in the rule for the PCP. Compared to the regular ISP, the length of time to perform the plan would dramatically increase. Support Coordinators will have less time available to do other aspects of their jobs. Also, as AHCCCS may be aware, support coordination turnover is very high already. In order for the planning meeting to commence, there must be assurances that the staff has been appropriately trained before the meeting can

begin. If the staff has not been trained, there must be allowances made to reschedule planning meetings until such staff is available.

- As AHCCCS may be aware, under the current system, ISP meetings may be held in which ever setting the family chooses. In many cases, providers are not included at ISP meetings that are not held at the provider's location (for example, the meeting is held at the individual's home not at the DTA). In order to ensure that the new ISP/PCP process works well and is implemented uniformly (remediation strategy #1), the uniform policies that are adopted must include a way to ensure that all members of the individual's team of care takers are included in these meetings, including providers.
- AAPPD is concerned about funding issues. The PCP process seems to take additional time for everyone – the individual, family, provider, support coordinator, etc. Modification of the current ISP process would help alleviate some of this additional time; however, there will still be additional time needed. Funding for staff (both providers and DES/DDD) must be available to cover these increased costs.

#### *Use of Volunteers*

- AAPPD requests clarification and additional information from AHCCCS regarding the use of volunteer PCP facilitators as recommended in remediation strategy #2. Who does AHCCCS anticipate the volunteers will be? Will there be requirements for their background? Are they different from support coordinators? Will individuals be able to facilitate their own ISP/PCP meetings?

Has AHCCCS looked at training provider staff? AAPPD suggests that the remediation strategies should include training for providers and members.

For remediation strategy #6, are the certified PCP facilitators the same as the volunteers? Is AHCCCS contemplating that the volunteers become certified later on? This process is unclear and confusing.

AAPPD suggests looking at the option to train support coordinators before volunteers are trained. Support coordinators are the logical people who should have this responsibility in the DES/DDD system.

- AAPPD disagrees with the timing suggested for remediation strategy #1 and #2. It does not seem possible to develop uniform policy and forms at the same time the system is developing the infrastructure and procedures for volunteer facilitators. In order to create the infrastructure and procedures for volunteers, shouldn't the policies and forms be created first? How can we create procedures for volunteers if the policies they need to learn about are not yet created?

## AAPPD Comments on Group Homes – Assessment

### ✓ Rule 1a; Remediation Strategy #1 (page 49)

- Can AHCCCS provide clarification on what “demonstrates work-related skills” means exactly. What would be considered “work-related skills”?

In addition, AAPPD suggests that this type of referral should be part of the DES/DDD support coordinator’s responsibilities, and not made a responsibility of the Group Home.

The remediation strategy seems to imply that a special meeting may be needed to document this particular referral, as it can take a very long time to get an individual’s ISP/person centered planning team together outside of the regular ISP meetings. AAPPD would also like to note that getting an individual job-ready takes a considerable amount of time. Therefore, it seems more appropriate to make this referral to employment services part of the existing process of regular ISP meetings rather than requiring a special meeting.

Also, where should this referral be documented?

### ✓ Rule 2b; Remediation Strategy #3 (page 59)

- AAPPD disagrees with the compliance level recommended and believes it should be listed as “Compliant”. AAPPD believes that group homes are currently compliant on this issue, and that this requirement already exists in the current contract scope of work. Overall, AAPPD feels that Remediation Strategy #3 does not need to be included.

However, as it is written currently, the phrase “person of their choice” is problematic. AAPPD is supportive of language that would prevent assigned roommates, however, the current language should then be worded differently. AAPPD suggests “...both an option for a private and shared room with individuals in the service of the home.”

There are several questions that come to mind when presented with the “person of their choice” language. Does this mean that individuals not in the service of the home will be allowed to live in the home? Are individuals without a developmental disability allowed to be roommates with individuals with a developmental disability? How would the funding for that type of situation work out? Currently, there is no funding model that would support that type of scenario. In addition, if an individual without a developmental disability is allowed to live in the home, how does that affect issues of confidentiality? Would that individual need to go through all of the safety measures staff must go through, like a background check, Article 9 training, etc.? Finally, how would considerations be made in this case for other members of the group home?

### ✓ Rule 4; Remediation Strategy #4 (page 59)

- What is envisioned in the requirement to “post” the rights and resources? Because the Group Home setting is fundamentally different and is meant to be a family home setting, the “posting” of flyers, posters, etc. would not fit; such flyers would not be posted in a regular family home. In addition, this does not take into account individuals who cannot read and/or understand the material. This should be changed to “provide” the rights and

resources to the member and also to their guardian, as appropriate. The rights and resources could be provided at each ISP evaluation in addition to giving them to the member when they move into the home.

*Rule 5; Remediation Strategy #5 (page 62)*

- While AAPPD does not disagree with the overall remediation strategy, this strategy is not implementable unless the staffing ratio and funding are considered in advance of the requirements being put in place. In some cases, this remediation strategy will increase the schedules and options available to members. In other cases, the remediation strategy may cause additional 1:1 ratios to be considered for individuals choosing to participate in something different.

Individuals certainly should have and do have the right to make their own choices on what they want to do and how they want to do it; however, Group Homes try to teach individuals how to make those choices in the constructs of a “normal” family life. For example, if the individuals in the home want to go to the park, they can do that; however, the park is only open during certain times during the day. If they need to take transportation to get there, like a bus, they need to choose the bus route and the time of that coincides with the times the park is open.

AAPPD suggests that the language in the remediation strategy note that the ISP and health and safety need to also guide the choice made. Today, there are individuals that are served by AAPPD members that would choose to eat pizza and play video games every day if they were given the “...individual initiative, autonomy and independence..” to make their own choices. The individual initiative and autonomy needs to be balanced with their health and safety needs and must be dictated by the ISP/person centered plan.

The ISP and health and safety factors must also dictate the ability to have access to entrances and exits, the ability to have access to food at any time, and the ability to choose with whom to interact. In addition, there are locations in a facility that even all staff are not able to access – members should not have the ability to have access to these areas either.

Informed choice must be a concept that is also recognized in the remediation strategy.

*Rule 6; Remediation Strategy #6 (page 63)*

- AAPPD would like to point out that in the case of the Group Home service, a vendor and the vendor’s staff is involved in the process. What would the standard be for measuring and gauging that satisfaction? Would incorporating member and family input during an annual staff review meet this requirement?

AAPPD suggests that it might be prudent for DES/DDD to include this stipulation in the General Contract Scope of Work rather than include it in the individual service specifications. It generally already exists in 5.8.2.3 as indicated in the Evidence section. A small adjustment could then be made to the general contract, which would require providers to engage customer satisfaction on a regular basis. Monitoring takes place every 90 days, which would provide an opportunity for discourse. In addition, a standard survey could be implemented by providers so that the responses could be measured.

*Rule 7/7a; Remediation Strategies #7-8 (page 66-67)*

- AAPPD would like clarification as to whether the “residency agreement” referenced in Remediation Strategies #7 and #8 is meant to reflect a true lease agreement, as is the language used in the federal rule. If so, a resident agreement and a lease are legally different and should not be used interchangeably. Lease agreements indicate that the Arizona State Landlord Tenant Act now comes into play which creates additional burdens on lessors, vendors and members that is likely not contemplated or necessary. In addition, a lease agreement takes on requirements that the individual signing the lease agreement may not understand. Would a lease agreement stand in a court of law for an individual who was not deemed competent?

There is some concern as to whether or not a lease agreement would encourage the highest level of care. For example, if an individual chooses a provider based on superficial “lease” requirements – like paint color they are allowed to use in their room – would that be the best placement for them to choose?

AAPPD is opposed to the language in Remediation Strategy #7 that would require DES/DDD to develop a residency agreement for members served. AAPPD suggests the language be reworded to require DES/DDD to develop the information that must be included in a residency agreement. Flexibility should be allowed for Group Home vendors to create residency agreements that work for their particular home and family life, but that meets the requirements of what must be included.

AAPPD has concerns over a lease or binding agreement that would prohibit movement. For example, a member might be required to give a standard 30 days notice to get out of a lease. If that member was expected to leave the home after that time, but another placement had not been found, it could create unnecessary complications. Under the current system, providers/vendors/homeowners cannot make an individual leave if those 30 days are up unless there is a place for that individual to go.

AAPPD suggests AHCCCS look at whether incorporating the residency agreement into the existing service plan would make more sense for the system. This would reduce paperwork and potential for confusion for providers, members and families, as they are all currently used to addressing the needs of the individual through the service plan.

In addition, currently, Group Homes have 30 days to correct any problems or issues that are reported by the member. That time is often sufficient to fix any problems that do arise. Would a residency agreement still take this into account? If the residency agreement is really more like a formal lease agreement, then this process may not be allowed under the current State Landlord Tenant Act.

*Rule 7b; Remediation Strategies #9-10 (page 67)*

- AAPPD supports that an individual should be afforded autonomy, however, AAPPD does not think that the personal safety of the individual or other members of the group home should be comprised in an effort to provide independence. The language of the remediation strategy should be clarified to state that age, the ISP/person centered plan, and health and safety of the individual guide these requirements.

In the case of the Group Home service, an individual is placed in a home that is meant to function like a shared roommate home. Each home/group of people sets rules that are part of the construct of normal every day life, and each individual must follow those rules to maintain a positive environment. These rules help teach the individual social and environmental norms. In an effort to create more independence, more confusion would likely be created instead. For example, if an individual were allowed to come and go whenever they pleased, and no boundaries were allowed to be set, this would upset the teaching process of this service type.

In addition, AAPPD would like clarification on what staff members are considered "appropriate staff", as referenced in rule 7b. Does "appropriate staff" mean a supervisor? If so, what if the supervisor was not home with a key to an individual's room when the key was needed or during an emergency?

AAPPD would support independence based on an individual's ISP/person centered plan. As such, AAPPD asks that access to certain things like front door keys, swimming pools, and rooms that contain hazardous materials be evaluated on a case by case basis, taking into account the health and safety of the individual and others in the home.

*Rule 7c; Remediation Strategy #11 (page 69)*

- Group Home settings generally function as a unit. The unit creates a schedule and plans meal times together. The remediation strategy language seems to then allow residents to not abide by those agreements the residents have all agreed to. Could the residency agreements include the schedules and rules the members of that group home have agreed to live by?
- AAPPD questions whether or not items like "food access" should be lumped in with a resident agreement or lease. Overall, it is felt that these types of items should not be grouped together.

*Rule 7d; Remediation Strategy #12 (page 69)*

- AAPPD is generally supportive of this type of information being included in a residency agreement; however, AAPPD would also like to point out that the residency agreement should qualify certain things related to visitors based on the Group Home setting.

Because the Group Home functions as a unit, there are schedules and accommodations agreed to by the residents that should also be taken into account. The residency agreement should reflect this and not undo what the residents have agreed to. For example, if you have a high school student paired with an individual who would party all night if no boundaries were able to stand in place, then the capacity to pair a diverse group of people together would be limited.

Overall, any individual who has total freedom to bring visitors into the home at any time, regardless of the house rules, would disrupt the other residents of the home.

AAPPD supports that an individual should be afforded autonomy, however, AAPPD does not think that the personal safety of the individual or other members of the home should be comprised in an effort to provide independence. The language of the remediation

## AAPPD Comments on Adult Developmental Homes and Child Developmental Homes (ADH/CDH) – Assessment

### *Rule 1a; Remediation Strategy #1 (page 80)*

- AAPPD would like to call specific attention to the fact that a group home and a developmental home are two fundamentally different residential settings. AAPPD suggests that the words “Group Home” be replaced with “Developmental Homes”, in order to encompass both the ADH and CDH services.

### *Rule 2a; Remediation Strategy #2 (page 89)*

- Overall, AAPPD has no concerns with this remediation strategy, as it is standard procedure. However, DES/DDD should be included in the agencies involved, as DD case managers will need to incorporate this process into their routine duties, which cannot be done without the participation of DES/DDD.

In addition, if access to transportation is required and the case manager is responsible for ensuring that access, AAPPD would like clarification on who is expected to provide transportation? Also, who would then be required to pay for the transportation?

### *Rule 4; Consideration Bullet Point #4 (page 92)*

- The consideration lists that “individuals have private communication access either through personal devices or equipment provided by the setting”, AAPPD does not disagree that an individual should have the ability to communicate using modern technology, however, safety should be taken into account in these cases. For example, financial fraud and identity theft are common crimes in today’s age - how are providers to put protections in place to ensure all individuals are not making themselves open to Internet crimes? In addition, if the individual is using application platforms such as chat rooms or social media, how is a provider to balance personal freedom with the safety of that individual and the other individuals in the home? Personal information, such as a home address or social security number can be easily shared online.

### *Rule 4; Remediation Strategy #3 (page 92)*

- What is envisioned in the requirement to “post” the rights and resources? Because the ADH/CDH setting is fundamentally different and is meant to be a family home setting, the “posting” of flyers, posters, etc. would not fit; such flyers would not be posted in a regular family home. In addition, this does not take into account individuals who cannot read and/or understand the material. This should be changed to “provide” the rights and resources to the member and also to their guardian, as appropriate. The rights and resources could be provided at each ISP evaluation in addition to giving them to the member when they move into the home.

### *Rule 5; Remediation Strategy #4 (page 95)*

- The remediation strategy states that an individual should have full access to the “home environment” at all times. Because a CDH/ADH is a home, AAPPD would like clarification on what the “home environment” means. Does home environment refer to typical shared living spaces? Does home environment mean that the member should

strategy should be clarified to state that age, the ISP/person centered plan, and health and safety of the individual guide these requirements.

**AAPPD Comments on Group Homes – Transition Plan**

(No comments)



language be reworded to require DES/DDD to develop the information that must be included in a residency agreement. Flexibility should be allowed for Developmental Homes and vendors to create residency agreements that work for their particular home and family life, but that also meet the requirements of what must be included.

- AAPPD has concerns over a lease or binding agreement that would prohibit movement. For example, a member might be required to give a standard 30 days notice to get out of a lease. If that member was expected to leave the home after that time, but another placement had not been found, it could create unnecessary complications. Under the current system, providers/vendors/homeowners cannot make an individual leave once the 30 days is up unless there is a place for that individual to go.

AAPPD suggests AHCCCS look at whether incorporating the residency agreement into the existing service plan would make more sense for the system. This would reduce paperwork and the potential for confusion for providers, members and families, as they are all currently used to addressing the needs of the individual through the service plan.

In addition, currently, ADH/CDH homes have 30 days to correct any problems or issues that are reported by a member. That time is often sufficient to fix any problems that do arise. Would a residency agreement still take this into account? If the residency agreement is really more like a formal lease agreement, this process may not be allowed under the current State Landlord Tenant Act.

*Rule 7b; Remediation Strategies #8 (page 101)*

- AAPPD supports that an individual should be afforded autonomy, however, AAPPD does not think that the personal safety of the individual or other members of the home should be compromised in an effort to provide independence. The language of the remediation strategy should be clarified to state that age, the ISP/Person Centered Plan, and health and safety of the individual guide these requirements.

In the case of the ADH/CDH service, an individual is placed with a family that is opening their family home for the individual to become part of that family. Each family has rules that are part of the construct of normal everyday life, and each individual must follow those rules to maintain the family environment. These rules do their part to help teach the individual social and environmental norms. The ADH/CDH service is fundamentally different than other residential services because of this, and in an effort to create more independence, more confusion would likely be created instead. For example, if an individual were allowed to come and go whenever they pleased, and a family unit had no authority to set rules and boundaries, this could upset the family dynamic of this service type. In addition, 24-hour access to the facility and for visitors is not practical for CDH homes that host minors. Can a 14-year-old have visitors at any time, for example? Would that be allowed in a home considered culturally normative?

AAPPD would support independence based on an individual's ISP/person centered plan. As such, AAPPD asks that access to certain things like keys, swimming pools, and rooms that contain hazardous materials be evaluated on a case by case basis and taking into account the health and safety of the individual and others in the home.

have full access to the entire home, including the bedrooms of other individuals in the home at any time? AAPPD recommends that this language be rewritten to reflect the language used in bullet point three of the Considerations section on pg. 95, which reflects practices already in place (kitchen, dining area, laundry, and seating in shared areas).

In addition, AAPPD would like to request that health and safety considerations be made for areas of the home that contain hazards, and that the language includes considerations for the ISP/person centered plan. For example, in some homes the laundry room is locked because cleaning supplies and other hazardous substances are contained in that area. The individual initiative and autonomy needs to be balanced with their health and safety needs and must be dictated by the ISP/person centered plan.

✓ *Rule 6; Remediation Strategy #5 (page 97)*

- AAPPD would like to point out that in the case of the ADH/CDH service, a Developmental Home (homeowner) and a vendor are involved in the process. Can AHCCCS clarify whether it would be the vendor or the homeowner that would be responsible for engaging customer satisfaction? If it were required of each Developmental Home, what would the standard be for measuring and gauging that satisfaction? Would each homeowner be responsible for creating a separate survey? If the vendor was involved and responsible for engaging customer satisfaction, could they provide each of their Developmental Homes with a standard survey to administer?

AAPPD would like to suggest that it might be prudent for DES/DDD to include this stipulation in the General Contract Scope of Work rather than include it in the individual service specifications. It generally already exists in 5.8.2.3 as indicated in the Evidence Section. A small adjustment could then be made to the general contract, which would require providers to engage in customer satisfaction on a regular basis. Monitoring takes place every 90 days, which would provide an opportunity for discourse. In addition, a standard survey could be implemented so that the responses could be measured.

✓ *Rule 7A; Remediation Strategies #6 -7 (page 100)*

- AAPPD would like clarification as to whether the “resident agreement” referenced in Remediation Strategies #6 and #7 is meant to reflect a true lease agreement, as is the language used in the federal law. If so, a resident agreement and a lease are legally different and should not be used interchangeably. Lease agreements indicates that the Arizona State Landlord Tenant Act now comes into play which creates additional burdens on homeowners, vendors and members that is likely not contemplated or necessary. In addition, a lease agreement takes on requirements that the individual signing the lease agreement may not understand. Would a lease agreement stand in a court of law for an individual who was not deemed competent?

Finally, there is some concern as to whether or not a lease agreement would encourage the highest level of care. For example, if an individual chooses a provider based on superficial “lease” requirements – like paint color they are allowed to use in their room – would the best placement for them be chosen?

- AAPPD is opposed to the language in Remediation Strategy #6 that would require DES/DDD to develop a residency agreement for members served. AAPPD suggests the

*Rule 7b and 7c; Remediation Strategies #9 - 10 (page 102)*

- Because ADH and CDH services are different than other residential settings and are set in family homes that teach an individual to live in a family environment, the use of the word "facility" is not appropriate. AAPPD suggests changing this language to "family homes".
- Creating a standard for family behavior is problematic, as each family unit functions differently. As mentioned above for remediation strategy #8, families should be allowed to set their own rules and policies that coincide with the health and safety as well as the ISP/person centered plan for the individuals. How can a family teach the individual living with them about eating family dinners if they are allowed to eat at the time of their choosing? How can a family teach a 16-year-old about curfew if they are allowed to "come and go...at any time"?

*Rule 7e; Remediation Considerations Bullet Point #3, Remediation Strategy #12 (page 103)*

- AAPPD supports the concept of providing access to environmental accommodations; however, AAPPD asks that these accommodations be required on a case-by-case basis, so that the needs of each individual are met without requiring unnecessary updates to the family home. Who will be responsible for paying for necessary updates like grab bars in a shower – the homeowner, agency/vendor, or DDD?

In addition, placement in a home should not be considered if an agency is not willing to provide the necessary updates.

**AAPPD Comments on Adult Developmental Homes and Child Developmental Homes (ADH/CDH) – Transition Plan**

*#6 and #7 related to Residency agreements*

As indicated above, AAPPD has concerns about DES/DDD developing residency agreements or leases if the language for the agreement or lease is standard and does not provide flexibility for the family situations that ADH/CDH settings require. AAPPD would prefer that DES/DDD create the requirements for what needs to be in a residency agreement. Even a general form would generate complications and confusion. In the case of ADH and CDH services, DDD writing an agreement for a provider's developmental home, which is a family home, is a major concern. Also as stated above, AAPPD is concerned that a more formal lease agreement is being looked at which brings in additional state laws. AAPPD requests that whatever is created, that it not bring in additional requirements from the Landlord Tenant Act.

In addition, AAPPD would like clarification on whether or not items like "food access" would be lumped in with a residency agreement or lease. Overall, it is felt that these types of items should not be grouped together.

## AAPPD Comments on Day Treatment and Training Programs (DTA) – Assessment

### *Rule 1; Remediation Strategy #2 (page 136)*

- AAPPD supports interaction with the general community. What are the requirements for the people we are bringing into a DTA to foster this interaction? Regarding safety, will there be an expectation that background checks are performed on people being brought into a DTA setting?

As providers are expected to provide more choice in activities and classes, AAPPD members expect that community classes will be utilized more often than they are today. How will age differences in community classes be addressed? What will be the expectation of providers? For example, will individuals be able to take an aerobics class where there are participants below and above the age of 15?

AAPPD supports the evidence cited by AHCCCS in the DES/DDD Policy 302. It is important to note that this policy recognizes that the ability for someone to interact with the greater community depends on their abilities. It will be important that the ISP/person centered plan recognize and address this factor.

### *Rule 1; Remediation Strategy #3 (page 136)*

- Can AHCCCS provide clarification on the requirement to stipulate in the service specifications that settings must be located in the community among other buildings or businesses to facilitate integration? AAPPD does not disagree with the concept we think is trying to be portrayed, but is unclear on what it really means. AAPPD is also concerned about the implication for rural Arizona. In some cases, services could be provided in a remote location that may not be “among other buildings...businesses”, etc.

In addition, there has been a push in the greater community to have a better work/life balance which can mean that a nondisabled person can walk to work or have a short commute to work. This includes mixed-used spaces where businesses and apartments/condominiums are in the same building. In writing this service specification, those options should not be taken away from a person with a disability.

What if the location is on a church campus? Is that considered a community setting?

### *Rule 1a; Remediation Strategy #4 (page 137)*

- AAPPD realizes that AHCCCS is comparing each rule with each service; however, in this case, this rule does not fit into a DTA setting. Why are the concepts of employment being assessed within a DTA? The considerations speak to job placement and training, not to a DTA.

That being said, AAPPD appreciates the “partial compliance” recommendation and supports including opportunities to learn about volunteer work in the community to the service specifications.

AHCCCS should also recognize that there is a significant population of people with developmental disabilities that are in retirement status. As long as there is not a

requirement to volunteer or prepare for volunteer work, these individuals should then be able to choose to participate or not participate.

*Rule 1d; Remediation Strategy (page 143)*

- AAPPD is very confused by the comments listed for this rule under the remediation strategies section. First, we are not sure what services are being talked about. The considerations listed do not generally apply to a DTA setting, as work is not generally a part of this setting. Do the services need to be better defined to truly make an accurate assessment?

In addition, the evidence provided seems to suggest at least “partial compliance”. DTA providers today work very hard to ensure individuals receive services in the community. The service specifications already require that the most integrated settings be chosen for the individual (for example, a summer school program should be considered for a school age individual). AAPPD acknowledges that providers can do better, but AAPPD disagrees that the service is not compliant. AAPPD also notes that the setting is listed as partially compliant under rule 2a, which also deals with non-disability specific settings/services.

AAPPD does not fully agree that there are no comparable settings for non-HCB services. What about senior centers, YMCAs, and preschools? If AHCCCS disagrees with comparing these settings, then how can AHCCCS state that DTA is noncompliant when there is no benchmark to compare to?

AAPPD also questions how this rule and the evidence work with the ADA?

Extensive rules already apply to accessibility. If you look at compliance with the ADA, then the setting is likely to be at least partially compliant with this rule.

*Rule 4; Remediation Strategy #7 (page 148)*

- What is envisioned in the requirement to “post” the rights and resources? Because the member is engaged in various activities throughout the day, there does not seem to be one location to “post” the rights and resources that would ensure the individuals see them and have access to the posting. In addition, this does not take into account individuals who cannot read and/or understand the material. This should be changed to “provide” the rights and resources to the member and also to their guardian, as appropriate. The rights and resources could be provided at each ISP evaluation in addition to giving them to the member the first time.

*Rule 5; Remediation Strategy #8 (pages 149-150)*

- While AAPPD does not disagree with the overall remediation strategy, this strategy is not implementable unless the staffing ratio and funding are considered in advance of the requirements being put in place. In some cases, this remediation strategy will increase the schedules and options available to members. In other cases, the remediation strategy may cause additional 1:1 ratios to be considered for individuals choosing to participate in something different.

For example, AAPPD has one DTA provider member with 47 non-ambulatory individuals. None of their non-ambulatory individuals who require assistance with

mobility (pushing their wheelchairs) are at a 1:1 ratio. In order to do large-scale (or small-scale) outings, the provider would have to bring in extra staff to help these individuals. Again, AAPPD does not disagree with the overall goal, but the fundamentals of staffing and costs need to be addressed in order to make these opportunities safe for the individual and cost-effective for the provider.

In addition, individuals certainly should have and do have the right to make their own choices on what they want to do and how they want to do it; however, DTAs try to teach individuals how to make those choices in the constructs of “normal” life, which should also be taken into consideration. For example, if an individual wants to see the latest blockbuster movie that came out – they can do that, but the movie is only available at certain times at the movie theater. If they need to take transportation to get there, like a bus, they need to choose the bus route and the movie time that coincides.

AAPPD suggests that the language in the remediation strategy note that the ISP and health and safety need to also guide the choices made. Today, there are individuals that are served by AAPPD members that would choose to eat pizza and watch a movie every day if they were given the “...individual initiative, autonomy and independence...” to make their own choices. The individual initiative and autonomy needs to be balanced with their health and safety needs and must be dictated by the ISP/person centered plan.

The ISP and health and safety factors must also dictate the ability to have access to entrances and exits, the ability to have access to food at any time, and the ability to choose with whom to interact. In addition there are locations in a facility that even all staff are not able to access – members should not have the ability to have access to these areas either. Will this be taken into account?

Informed choice must be a concept that is also recognized in the remediation strategy.

### **AAPPD Comments on Day Treatment and Training Programs (DTA) – Transition Plan**

As mentioned above in comments on the assessment, there are several remediation strategies that will only be successful if the funding is available to expand the service. To that end, AAPPD is concerned with some of the timeframes suggested. Many of the changes to service specifications and the AHCCCS Medical Policy Manual are to be completed by September of 2018. This date does not match the state fiscal year calendar in which funding is set for the DES/DDD program. Consideration needs to be made for ensuring that the funding for changes are on-line at the same time the new requirements and changes to programs take place.

## **AAPPD General Comments on Group Supported Employment (GSE) and Center Based Employment (CBE) – Assessment and Transition Plan**

As stated in Arizona's Olmstead Plan, under the U.S. Supreme Court's decision, States are required to provide community based services for persons with disabilities who would otherwise be entitled to institutional services when: (a) The State's treatment professionals reasonably determine that such placement is appropriate; (b) The affected person is in agreement with the decision; and (c) The placement can be reasonably recommended, taking into account the resources available to the State and the needs of others who are receiving State-supported disability services.

These tenants of making sure the placement is appropriate, the affected person has made the decision to be there and is reasonably recommended for their needs, should be at the heart of the employment services provided in Arizona.

To that end, AAPPD appreciates being a part of the dialogue to evaluate and possibly redesign our current employment services to better provide the appropriate services to individuals with developmental disabilities that are person-centered and provide individual choice.

### **Philosophical Concerns for the Members We Serve**

AAPPD is generally concerned that there will be only one vocational service left for individuals with severe developmental disabilities – community based employment (group or individual supported employment). Having a goal of community-based employment is what AAPPD provider members have for the individuals we serve today. However, factors such as individual choice, guardian choice, severeness of disability, severeness of behaviors all factor in to whether that individual is successful in community based employment.

Language in the assessment and transition plan seem to indicate that center-based employment should become a pre-vocational setting. First, this conclusion should not be made until a full assessment towards the redesign is completed. Second, removing choice and options in the system is counter to the goals stated in the HCBS rules.

If an individual chooses to not participate in community based employment, but still wants to work – what happens to them? Is their only option going to be a day treatment program?

For individuals who choose not to enter a community based setting or have a hard time learning the skills necessary to be successful in a community based setting (based on their person-centered plan), what will their options be for earning a paycheck? Individuals have the right to earn a paycheck – volunteering cannot be seen as an acceptable replacement for earning a paycheck.

Lastly, pre-vocational services have their place and can help certain individuals gain the skills necessary to be successful in a community based employment setting. However, some individuals need on-the-job training to learn these skills (just like non-disabled individuals). If center-based employment is transitioned to only pre-vocational services, where will these individuals learn on-the-job training? Such training for individuals with developmental disabilities is not available for many jobs. Many center-based employment programs bring the work in-house to help teach individuals what they need to know in order to then take that same job to a community-based setting. As AAPPD reads the assessment today, this option does not seem to still be available.

## **Funding Concerns**

AAPPD is concerned that there will likely be increased costs to the system for the changes recommended in the assessment and transition plan for both GSE and CBE.

As AHCCCS is likely aware, providers of services to people with developmental disabilities have struggled to balance the rates being paid for services with quality care for members, quality pay for direct care staff and the ability to grow as the population grows. Beginning in 2008, providers of services to the developmentally disabled were cut due to bad economic times for the state. Provider rates were cut by 15% in total over several years; only 7% of the cuts were restored to date.

The population of individuals with developmental disabilities continues to grow. By 2019, the state will be serving more individuals with a developmental disability at every age than it did in 2014. Providers will be unable to deal with additional requirements at the same time they are dealing with additional growth in members if the funding is not provided to cover the additional services. There are no "extras" left to cut.

To that end, AAPPD is concerned with the overall timeline suggested. Many of the changes to Service Specification and the AHCCCS Medical Policy Manual are to be completed by September of 2018. This date does not match the state fiscal year calendar in which funding is set for the DES/DDD program. Consideration needs to be made for ensuring the funding for changes are on-line at the same time the new requirements and changes to programs take place.

Especially for employment services, if the funding is not available to create the new programs/services that are potentially needed, the services will fail to materialize, as providers will not be able to afford to bring them on-line.



## AAPPD Comments on Group Supported Employment (GSE) - Assessment

### *Rule 1a; Remediation Strategy #1 (page 191)*

- The remediation strategy seeks to expand the scope of GSE to include “work incentive consultation” and “career advancement services”. Can AHCCCS clarify what is meant by these two services? Providers are unclear what these two would entail and therefore cannot comment properly. Does *career advancement services*, for example, include lateral changes where the individual may simply want to do a different job that may not be considered “advancement”? What incentives are being discussed – what does this include? Do the two services take into account choice by the member?
- The two new services seem to require additional staffing and therefore require additional funds to cover these costs. To the point raised above, can AHCCCS clarify what these two services are in order to determine staffing need requirements and to be able to fully comment?
- How are the families and guardians advised on these two services?
- If the provider has attempted to provide these services and the individual does not wish to “advance further” in their career, will the provider’s efforts still meet these requirements?

### *Rule 1a; Remediation Strategy #2 (page 191)*

- What is considered “other activities”? If a member wants to work and does not want to volunteer, for example, will they be allowed to make that choice? Members value the paycheck they receive no matter the amount. If the member cannot move further in their employment status for whatever reason (as dictated in their ISP), they should still have the choice to work and earn a paycheck. In addition, for some individuals, they are working full time; there is no room for other activities on the job.

### *Rule 4; Remediation Strategy #3 (page 204)*

- What is envisioned in the requirement to “post” the rights and resources? Because the member is engaged in various activities throughout the day, there does not seem to be one location to “post” the rights and resources that would ensure the individuals see them and have access to the posting. In addition, this does not take into account individuals who cannot read and/or understand the material. This should be changed to “provide” the rights and resources to the member and also to their guardian, as appropriate. The rights and resources could be provided at each ISP evaluation in addition to giving them to the member the first time

## AAPPD Comments on Group Supported Employment (GSE) – Transition Plan

### *Transition Plan Recommendation #2 regarding evaluation and re-design of the continuum of employment supports and services*

- AAPPD appreciates being included as an organization participating in this effort. However, we are concerned about the timing of the transition plan. Can AHCCCS clarify the process it hopes to have accomplished by September 2017? By September 2017, is the goal to have the continuum evaluated *and* redesigned? Does redesign include the AHCCCS policy and DDD rules and service specification changes that need to occur? AAPPD suggests that the target date may be too ambitious depending on the goals AHCCCS wants to accomplish. AAPPD believes that the evaluation and general creation could be completed by September 2017, but the changes in policy, services specifications, manuals, etc., at AHCCCS and DDD will likely take longer to accomplish and may likely bleed over to 2018.
- Philosophically, AAPPD is very concerned that the federal rules, the assessment and transition plan take the state in a direction where an individual with a significant disability is essentially relegated to volunteer work and is not given the option to work and earn a paycheck. The goal of the redesign has to allow for choice for all levels of disability and provide those members that want to work, the ability to do so. If they want to earn a paycheck, they should have the opportunity to do so.

As stated in the CMS Informational Bulletin from September 16, 2011, “Consistent with the *Olmstead* decision and with person centered planning principles, an individual’s plan of care regarding employment services should be constructed in a manner that reflects individual choice and goals relating to employment and ensures provision of services in the most integrated setting appropriate.” (emphasis added)

- As the state undertakes this process, the groups involved will have to determine common definitions for employment services that will be used throughout the system. For example, what definition will be used for “competitive integrated employment”. A definition also exists in the federal WIOA rules that the Department of Economic Security/DDD will need to contend with.
- Changes in employment supports and services will also require changes in the funding structure and, most likely, additional funding. How will this be incorporated into the discussion? It takes additional funds to create new supports and services in order to bring them online. Providers will need additional assistance to make any potential changes to supports and services. In addition, AHCCCS should consider the cost for programs, overall, may increase. The funding structure and amount must be addressed in order to make any redesign successful in Arizona.

The description of pre-employment services sounds like a new service that has been created in Arizona, Transition to Employment (TTE). The stakeholders involved need to determine the role TTE plays in this discussion as well.

If AHCCCS does not want to delete the remediation strategy as suggested, the language should be adjusted to state that during the redesign, the idea of transitioning CBE to a facility-based pre-employment service should be considered.

*Rule 1a; Remediation Strategy #5 (page 162)*

- What is considered “other activities”? If a member wants to work and does not want to volunteer, for example, will they be allowed to make that choice? Members value the paycheck they receive no matter the amount. If the member cannot move further in their employment status for whatever reason (as dictated in their ISP), they should still have the choice to work and earn a paycheck.

The current service specifications require that participants be engaged in paid work at least 75% of the time. This will have to be amended to meet the “other activities” requirement. In addition, what are providers supposed to tell customers when individuals need to be pulled off of a job in order to do these other activities? What if there is a job deadline to meet?

*Rule 1a; Remediation Strategy #6 (page 162)*

- AAPPD does not disagree with this remediation strategy; however, AAPPD would like to ensure that choice is maintained in the service specification. A member has a right to learn about all options available to them, including volunteering, but should not be forced to volunteer because their employment option is essentially deleted. The choice to work and earn a paycheck must remain a part of the system.

AAPPD is also concerned that volunteering may turn into community service and will not be a way for an individual to learn important skills towards employment. This concern arises out of other federal requirements. For example, under the Department of Labor, an individual who was gainfully employed cannot be moved to a volunteer position to do the exact same job and not get paid. The Department of Labor also prevents a volunteer from doing the same job as the person next to them that is collecting a paycheck on a regular basis.

Under the *Fair Labor Standards Act*, employees may not volunteer services to for-profit private sector employers. Individuals can volunteer services to public sector employers. For members, their choices would then be limited to only certain types of volunteering that may or may not help with employment goals. In addition, people are allowed to volunteer their services to public agencies and their community with but one exception - public sector employers may not allow their employees to volunteer, without compensation, additional time to do the same work for which they are employed. There is no prohibition on anyone employed in the private sector from volunteering in any capacity or line of work in the public sector.

The Department of Labor also states that just like other individuals, workers with disabilities may volunteer to perform certain tasks without creating an employment

## AAPPD Comments on Center Based Employment (CBE) – Assessment

### *Rule 1; Compliance Level (page 160)*

- AAPPD disagrees with the compliance level chosen. The Assessment lists CBE as not compliant for Rule #1; however, the parts of the rule do not indicate this recommendation. For Rule 1a and 1b, CBE is listed as partially compliant. For Rule 1c, CBE is listed as compliant. Only Rule 1d is listed as not compliant. The average, if you will, of these is that CBE should be listed as partially compliant for Rule #1. AAPPD agrees with the evidence provided for the different parts of the rule as well and believes this indicates the system is partially compliant.

### *Rule 1; Remediation Strategy #2 (pages 160-161)*

- AAPPD does not disagree with the concept of incorporating peers without disabilities in the work environment. Currently, however, staff in facilities are required to be background checked. Will a requirement be put in place for peers to be fingerprinted/background checked? Not all jobs require a background check of workers; it will be unfair if peers are required to be background check when members do not need to be based on their job. Also, the EEOC has been targeting employers who require background checks when not applied consistently within the job. Also, will a ratio be put in place – will incorporation have a level of expectation?

### *Rule 1; Remediation Strategy #3 (page 161)*

- Can AHCCCS provide clarification on the requirement to stipulate in the services specifications that settings must be located in the community among other buildings or businesses to facilitate integration? AAPPD does not disagree with the concept we think is trying to be portrayed but is unclear on what it really means. AAPPD is also concerned about the implication for rural Arizona. In some cases, services could be provided in a remote location that may not be “among other buildings...businesses”, etc.

In addition, there has been a push in the greater community to have a better work/life balance which can mean that a nondisabled person can walk to work or have a short commute to work. This includes mixed-used spaces where businesses and apartments/condominiums are in the same building. In writing this service specification, those options should not be taken away from a person with a disability.

- What if the location is on a church campus? Is that considered a community setting? Is it included in the “etc.” of the examples listed?

### *X Rule 1a; Remediation Strategy #4 (page 162)*

- AAPPD recommends deleting this remediation strategy. In the Transition Plan and in Remediation Strategy #5, AHCCCS recommends a process to evaluate and redesign the current continuum of employment supports. Making the recommendation to “transition the center-based employment service to a facility-based pre-employment service” seems premature to the discussion that needs to take place. Does this mean that employment cannot be provided at a CBE at all? Can the pre-employment services be added?

relationship under the Fair Labor Standards Act (FLSA). But in order to ensure that an employment relationship does not exist and to protect such workers from exploitation, the following criteria must be met:

1. The worker must be legally competent to freely volunteer, or when appropriate the worker's parent or guardian must approve the volunteer activity.
- 2. The volunteer work performed must be substantially different from the work that he or she performs during duty hours.**
3. The work must be performed outside normal duty hours.
4. The work must be of the type that would be normally classified as "volunteer" work. For example, a worker with a disability may volunteer to wheel another individual around in a wheel chair or participate in a community "clean up" program hosted by a work center.

If the Department of Labor already recognizes that an individual with a disability must be doing something different from the work he or she performs in order for it to be volunteering, why are we allowing individuals with disabilities to potentially volunteer for jobs they could be getting paid for?

*Rule 1b; Remediation Strategy #7 (page 165)*

AAPPD does not disagree with the remediation strategy; however, a new requirement in the service specifications has to be partnered with changes in rates to accommodate additional services being provided.

As AHCCCS is likely aware, providers of services to people with development disabilities have struggled to balance the rates being paid for services with quality care for members, quality pay for direct care staff and the ability to grow as the population grows. Beginning in 2008, providers of services to the developmentally disabled were cut due to bad economic times. Provider rates were cut by 15% in total over several years; only 7% of the cuts were restored.

The population of individuals with developmental disabilities continues to grow. By 2019, the state will be serving more individuals with a developmental disability at every age than it did in 2014. Providers will be unable to deal with additional requirements at the same time they are dealing with additional growth in members if the funding is not provided to cover the additional services, including adequately paying for direct care staffing needs.

*Rule 1d; Remediation Strategy #8 (page 169)*

AAPPD disagrees with the remediation strategy listed as it assumes that no employment will be provided by a CBE. Employment opportunities must still be considered as part of a CBE in order consider a redesign of the system as suggested in remediation strategy #5.

*Rule 2a; Remediation Strategy #9 (page 170)*

AAPPD disagrees with the term "pre-vocational" as it is used in this remediation strategy. CBE is not pre-vocational; until such time as the recommendation are made to redesign the program the assumption should not be made that it is only "pre-vocational".

As mentioned above, remediation strategy #5 suggests a redesign of the system. The manual should not be adjusted until such decisions are made.

AAPPD suggests changing the language to "...a requirement for Case Managers to ensure members have access to transportation and support for the purpose of visiting programs with a pre-vocational training program component prior to making a decision on where to receive services." (NOTE: See language in Assessment on remediation strategy #12 (page 175); the language requires providers to exercise strategies for providing pre-vocational services and supports; this language in #12 does not remove options as the language in #9 does.)

*Rule 3; Remediation Strategy #10 (page 172)*

AAPPD agrees that an annual readiness assessment must be conducted for employment in general, not just for community-based employment.

AAPPD suggests that the very first assessment that is completed be a very comprehensive look at the abilities and desires of the individual to work. AAPPD agrees that the member must have an integrated employment goal. The assessment must determine how the provider and member will get them to their goal. The assessment should not assume a starting point for any one member. Because of this, employment options along the spectrum must be left in place to allow individuals to work on the skills needed to move themselves to integrated employment.

This first assessment must include support coordinators, guardians, vocational rehabilitation (where appropriate), and others to determine the individual's desire for employment and ability to be employed. The comprehension level of the individual must be taken into account as the needs and desires of the individual are assessed.

This first assessment should be revisited at every ISP to identify changes in ability and the desires of the individual. This must be done in consultation with guardians, as appropriate.

*Rule 5; Remediation Strategy #12 (page 175)*

AAPPD is concerned about the examples cited to meet this strategy. The examples provided, including facilitating alternate schedules for members and ensuring access to meals and snacks at the time of their choosing, can, in some cases, cause the need for changes in staffing ratios and ultimately funding. The current funding structure does not fund providers to allow for true autonomy. AAPPD is concerned that this will not be taken into account and become a requirement prior to the funding structure being changed to accommodate such a change in service.

In addition, from a philosophical perspective, AAPPD is very concerned about the message being provided to individuals who are seeking employment and/or employment related services. If the goal of the member for any employment or employment related service must be integrated employment as stated in remediation strategy #10, then shouldn't the employment or the employment services being provided emulate and teach about a "typical integrated employment" setting?

For example, in many employment situations, the hours of the employee are set by the employer. The employee may be able to choose from different options in their schedule, but once the schedule has been chosen, there is little latitude for changing the schedule on a daily basis. If my chosen schedule is 9:00 am to 3:00 pm, Mondays and Tuesdays, there are usually consequences for coming in at 10:00 sometimes or leaving at 2:00 when I would like.

In addition, many jobs schedule break time in order to ensure all employees get a break that is not disruptive to the overall work schedule. Will individuals be allowed to take breaks "at the time of their choosing" for snacks and meals when they are in an employment or employment related services. How do you teach this type of culture so the individual can work in that type of integrated work setting when they will be allowed to break the rules, so to speak?

In addition, what if the guardian is dictating the member's schedule?

AAPPD suggests that the Service Specification include that the requirement should be based off of the ISP and health and safety concerns in order to facilitate some of these concerns.

#### **AAPPD Comments on Center Based Employment (CBE) – Transition Plan**

*Transition Plan Recommendation #5 regarding evaluation and re-design of the continuum of employment supports and services.*

*-Ted M  
-cont.*

- AAPPD appreciates being included as an organization participating in this effort. However, we are concerned about the timing of the transition plan. Can AHCCCS clarify the process it hopes to have accomplished by September 2017? By September 2017, is the goal to have the continuum evaluated *and* redesigned? Does redesign include the AHCCCS policy and DDD rules and service specification changes that need to occur? AAPPD suggests that the target date may be too ambitious depending on the goals AHCCCS wants to accomplish. AAPPD believes that the evaluation and general creation could be completed by September 2017, but the changes in policy, services specifications, manuals, etc., at AHCCCS and DDD will likely take longer to accomplish and may likely bleed over to 2018.
- Philosophically, AAPPD is very concerned that the federal rules, the assessment and transition plan take the state in a direction where an individual with a significant disability is essentially relegated to volunteer work and is not given the option to work and earn a paycheck. The goal of the redesign has to allow for choice for all levels of disability and provide those members that want to work, the ability to do so. If they want to earn a paycheck, they should have the opportunity to do so.

As stated in the CMS Informational Bulletin from September 16, 2011, "Consistent with the *Olmstead* decision and with person centered planning principles, an individual's plan of care regarding employment services should be constructed in a manner that reflects individual choice and goals relating to employment and ensures provision of services in the most integrated setting appropriate." (emphasis added)

- As the state undertakes this process, the groups involved will have to determine common definitions for employment services that will be used throughout the system. For example, what definition will be used for “competitive integrated employment”. A definition also exists in the federal WIOA rules that the Department of Economic Security/DDD will need to contend with.
- Changes in employment supports and services will also require changes in the funding structure and, most likely, additional funding. How will this be incorporated into the discussion? It takes additional funds to create new supports and services in order to bring them online. Providers will need additional assistance to make any potential changes to supports and services. In addition, AHCCCS should consider the cost for programs, overall, may increase. The funding structure and amount must be addressed in order to make any redesign successful in Arizona.



Emil 81

Johnson, Dara

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**From:** Tim Kinney <tk@kinneyconstruction.net>  
**Sent:** Thursday, August 27, 2015 8:07 AM  
**To:** HCBS  
**Cc:** Monica Attridge  
**Subject:** HCBS Assessment and Transition Plan Comments for Group Homes, Day Programs and Employment Programs

To Whom It May Concern:

I have served on the Board of Directors of the Hozhoni Foundation for 8 years and am in my third term as President of the Board. I am very proud to be associated with this highly regarded provider that has been supporting individuals with developmental disabilities in Northern Arizona for 45 years.

As a nonprofit Board of Directors, we are very concerned with some of the details of the Assessment and Transition Plan. We take our responsibility for the welfare of clients very seriously, as well as our fiduciary responsibility to the organization. It is from these perspectives that our comments are made.

In the group homes, we are concerned about compromising the health and safety of clients if they or their roommates are able to come and go as they please, have visitors at any time or eat whenever they want. Also, many of our clients may not have the cognitive capability to know that giving a house key to someone else may not be a good decision. Determinations about whether an individual has the capability to come and go as they please need to be related to their health and safety.

Staffing ratios may need to be increased to allow for the integration that is described for day programs. The ratios will need to be increased as needed for individual choice of activities, to ensure safety of the clients. Also, we will need additional clarification of the background checks required for outside individuals who come into the day program to assist, read, teach, etc., as well as for visitors to group homes.

The Board adamantly opposes elimination of center-based employment. It is a necessary component in the continuum of employment services. There is already a time-limited pre-vocational service, Transition to Employment. We understand that policymakers are concerned about the number of individuals working in segregated settings, but eliminating a choice that may actually be the only realistic opportunity a client has for earning paycheck is not the correct solution. The planning process should be assessing the appropriateness of the employment services setting and changing the authorized service if needed. Please fix this process rather than create a hole in the spectrum that will relegate clients to day programs or volunteer work (which many consider work without pay).

We hope that AHCCCS will consider flexibility in these new requirements for individuals with intellectual and developmental disabilities; full autonomy is not always the safest decision for individuals. We also encourage AHCCCS to develop a process that does not require evidence and documentation of failure in the capability to handle rights responsibly every year, unless it is fully funded

There will be significant costs or loss of revenue with these new rules. With a rate system that is currently only funded at 78% of actuarially determined benchmark reimbursement rates, we can ill afford to take on more responsibility without a corresponding increase in funding. Please do not implement any of these rules without this additional funding.

Thank you for allowing me to comment on behalf of our Board of Directors. If you have any questions for me, I may be reached at [tk@kinneyconstruction.net](mailto:tk@kinneyconstruction.net) or 928-779-2820.

Sincerely,

Tim Kinney  
Board President



HOZHONI  
FOUNDATION, INC

Erin 6/2

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Thursday, August 27, 2015 10:24 AM  
**To:** HCBS  
**Subject:** AHCCCS CBE  
**Attachments:** Erin Horan letter to AHCCCS.pdf

To Whom It May Concern:

Please see my attached letter concerning restricting or eliminating center-based paid work activities (CBE).

[REDACTED]







Email 43

Johnson, Dara

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**From:** Genny Jones <gmjjmj@msn.com>  
**Sent:** Thursday, August 27, 2015 1:21 PM  
**To:** HCBS  
**Subject:** CBE-Center Based Employment  
**Attachments:** AHCCS Letter.docx

August 27, 2015

AHCCCS  
C/O Office of Intergovernmental Relations  
801 E. Jefferson Street, Mail Drop 4200  
Phoenix, AZ 85034

**Subject: CBE – Center Based Employment**

**To Whom It May Concern:**

I understand that a new federal law is considering changes that will restrict or eliminate CBE (Center Based Employment) throughout the state of Arizona.

I have been aware of the MARC Community Resources, and how much they have done for the less fortunate in our community for many years – probably for over 30 years.

The CBE needs to be kept funded so people like my niece can contribute to society. This is one program that should stay, and I hope you will see how much good is contributed to our society because of the good that comes out of this program.

The program gives people who cannot work in the corporate world, a chance to contribute to society. It also gives the people who are participating in the program a sense of self-worth. It gives them the opportunity to know that there is work for them to do, and they can happily perform and contribute to society.

Please take into consideration the good that comes out of the above mentioned program and keep it.

Sincerely,

Genny Jones  
Concerned Voter





Email 43 (Duplicate of Email Content)

August 27, 2015

AHCCCS  
C/O Office of Intergovernmental Relations  
801 E. Jefferson Street, Mail Drop 4200  
Phoenix, AZ 85034

Subject: CBE – Center Based Employment

To Whom It May Concern:

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The CBE needs to be kept funded so people like my niece can contribute to society. This is one program that should stay, and I hope you will see how much good is contributed to our society because of the good that comes out of this program.

The program gives people who cannot work in the corporate world, a chance to contribute to society. It also gives the people who are participating in the program a sense of self-worth. It gives them the opportunity to know that there is work for them to do, and they can happily perform and contribute to society.

Please take into consideration the good that comes out of the above mentioned program and keep it.

Sincerely,

Genny Jones  
Concerned Voter



Emil 84

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Thursday, August 27, 2015 2:11 PM  
**To:** HCBS  
**Subject:** HCBS Assessment and Transition Plan - Employment Services

RE: HCBS Assessment and Transition Plan – Employment Services

To Whom it May Concern:

My name is [REDACTED] and my 20-year-old son has a developmental disabilities.

As a parent, I am very concerned with the assessment and transition plan as it relates to possible changes to employment services for my son. I have heard through other parents that attended one of the public meetings, that no choices are going to go away. However, when I read the plan and talk to folks, the plan talks about transitioning “center based employment service to a facility-based pre-employment service”. Does this mean that there will be no employment services at center-based facilities? What will happen to Weston and will he lose his paycheck that he works so hard to obtain?

Also, several families have talked about the option of volunteering. While I am not opposed to volunteer opportunities, Weston has learned how to earn a paycheck. Volunteering and not earning a paycheck will be the opposite of what we have been working with him to achieve.

I hope that AHCCCS will consider ensuring all options are still available to individuals. Thank you for allowing me to comment. If you have any questions for me, I may be reached at [dcolville@msn.com](mailto:dcolville@msn.com).

Sincerely,

[REDACTED]



This email has been checked for viruses by Avast antivirus software.  
[www.avast.com](http://www.avast.com)



Email 85

Johnson, Dara

**From:** [REDACTED]  
**Sent:** Thursday, August 27, 2015 3:12 PM  
**To:** HCBS  
**Subject:** HCBS Assessment & Transition Plan - Employment Services

To Whom It May Concern

My name is [REDACTED] and my 31 year old son is mild to moderately developmentally delayed. He is also ADHD and has a hard time focusing at times. He is currently attending STARS, and has for 4 years and is in the Work Center. He loves it there and has learned a lot. He not only goes there 5 days a week, he goes to the City of Scottsdale and sorts checks for them one day a week. He loves to help other people whenever he can but he is not quite ready to go out into the work force yet.

STARS has done such an excellent job with him, he has learned a lot, it would be very sad to see him lose this.

I am worried with this plan and how it will affect him attending STARS. Now he will eventually be able to go out and get a job with the help of STARS, however he is not quite ready yet. I know [REDACTED] would love to volunteer at STARS if need be, but he would be upset about losing his paycheck. He has learned that the harder he works and the more he accomplishes he earns more and that is really good for his self-esteem. He is so proud when I tell him on payday Fridays how much his check is.

I hope all options will be explored. Thank you for allowing to voice my opinion. My email is [REDACTED] if you need to reach me or [REDACTED] if you need to call me. Sorry if this letter is vague, I am trying to understand all this information.

[REDACTED]  
[REDACTED]  
[REDACTED]

Email Reference ID:  
Contact Us: 1 800 295 3753  
Hours: Monday to Saturday from 7:00 AM to 11:00 PM EST and Sunday 9:00 AM to 7:00PM EST



Email 86

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Thursday, August 27, 2015 3:22 PM  
**To:** HCBS  
**Subject:** CBE - All Day Program and Employment Program

I have a disabled grandson that loves to go to work every day at Marc Center. He is appreciated for the work that he accomplishes daily. They have programs not found in community employment.

Out in the regular community, disabled people are not hired in the jobs that they are able to do, nor are they appreciated and accepted as much as they are in the paid work program. My grandson feel a great and deep sense of self-work and achievement going to work each day now. Please do not take that away from him.

I am asking that you do not consider the elimination of the paid work activities.

Thank you for your consideration in this matter.

[REDACTED]





EMAIL 87

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Thursday, August 27, 2015 3:34 PM  
**To:** HCBS  
**Subject:** STATE CONSIDERING ELIMINATION OF PAID WORK ACTIVITIES

To whom it may concern,

August 27, 2015

My sister, [REDACTED] has been working at BHS Workshop at Marc Community Resource Center on Country Club in Mesa since February 2012.

To eliminate this work program would adversely affect her life. Not only would she experience financial difficulty which helps her to live independently, but also in her sense of self-worth. She works well in an environment that is low risk for discrimination. She has experienced prior traumatizing events while working in community jobs that had no formal support such as MARC offers.

I have concerns about her safety and being taken advantage of. I understand that the majority of those served in CBE do not recognize danger. If the position is eliminated, I'm concerned over the potential loss of long term care services that she needs such as Medicaid, Job Coaching and staff counseling. Losing this opportunity would deprive her of the sense of mastery and accomplishment she enjoys so much as well as a sense of inclusion and connectedness. She feels like she's normal and part of her community thru this work program. Please don't eliminate this benefit from her life and so many others'.

Thank you for your consideration,

[REDACTED]



Emil 80

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Thursday, August 27, 2015 5:10 PM  
**To:** HCBS  
**Cc:** cchavez@starsaz.org  
**Subject:** HCBS Assessment and Transition Plan - Employment Services

My name is [REDACTED]. I am the sister and co-guardian (along with my mother [REDACTED]) of my brother [REDACTED]. I am writing to you about the possible upcoming changes with AHCCCC and Center Based Employment. Thomas is currently employed by STARS. Through his ISP's it has been determined that he is not capable of working in the community.

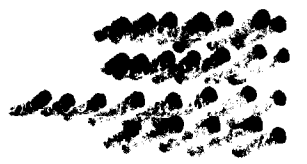
[REDACTED], 60 years of age, has been in an educational or work program his entire adult life. We are totally supportive of his progress and his enthusiasm to go to work every day.

Because of his brain injury at birth, [REDACTED] needs 24 hour supervision. His acceptance into a work center has boosted his morale by receiving a small paycheck every two weeks. The praise and applause he receives from the dedicated staff at STARS is invaluable. We view this staff as his "lifeline" and are eternally grateful. A small paycheck, through piecework, does wonders for his development and good habits. The paycheck is his reward.

[REDACTED] is very happy and has a tremendous will to work, desire to feel achievement, to be appreciated and loved. We are grateful for the gentle, mature man he has become and the staff that is full of encouragement. We are asking you to please leave options available for us in the future. If a DTA were our only option, [REDACTED] would digress. Center Based Employment is perfect for [REDACTED] as I'm sure it is for thousand of others.

Thank you for your consideration.

[REDACTED] (Mother/co-guardian)  
[REDACTED] (Sister/co-guardian)  
[REDACTED] et



Emil 89

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Thursday, August 27, 2015 6:13 PM  
**To:** HCBS  
**Subject:** ELIMINATION OF CENTER-BASED PAID WORK ACTIVITIES/CBE

Good evening.

I am a concerned Mother of a 34 yr. old female with Down Syndrome. I understand funding may be eliminated for her center-based paid work activity at Marc East. [REDACTED] loves her job, waking herself each morning after she has laid her clothes out the night before. She has a speech disability, which makes most people not understand her. [REDACTED] trusts everyone, which makes her ineligible for a job in the community. She would easily be taken advantage of. [REDACTED] is right where she needs to be in terms of employment. The staff are extremely trustworthy at the Marc Center, where [REDACTED] has been employed since her graduation from Highland High in Gilbert, Az. The work [REDACTED] pursues at Marc East gives her a HUGE sense of accomplishment. She sings when she comes home from work. Work is extremely important for [REDACTED]. She will complain when we need to go to a Dr. appt. for her. She slowly will become agitated if she thinks she is being away from work for too long because of a dr. appt./fasting labs. [REDACTED] will not be hired for community employment if Marc Center is eliminated. She is not understandable/safety risk. Jessica has no idea she is not a fully functioning worker in the community where she lives. We congratulate her \$20.00 paycheck every 2 weeks as if it were \$600.00. She tells her Brother Zach and myself to use her money to buy ice cream from McDonalds. [REDACTED] loves her job at Marc East as much as we do. Marc East keeps her emotionally balanced. We don't know what we'll do if there is no Marc East. Thank you for your time and understanding. I am shocked the State of Arizona would even consider eliminating paid work activities at Marc East.

Sincerely,

[REDACTED]



Email 90

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Friday, August 28, 2015 8:16 AM  
**To:** HCBS  
**Subject:** CBE

Dear Sir or Madam,

It came to our attention recently that some wish to discontinue Centered Based Employment.  
We find it TOTALLY RIDICULOUS AND REPREHENSIBLE!!

How could individuals feel the need to do away with something that means so much to people in the Special needs community?

Jobs means a lot to us and WE WANT OUR VOICES HEARD!!!!!!

DON'T LET'S US DOWN!!!!!!!!!!!!!! If CBE is taken away from us the happiness of so many will be on your head.....Don't be another Veterans administration !!!!!!!!!!!

Thank-You for your time  
[REDACTED] &  
[REDACTED]  
former CBE employees





Emil 91

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Friday, August 28, 2015 10:04 AM  
**To:** HCBS  
**Subject:** Center Based Employment

To whom it may  
concern,

8-28-15

We are the proud parents of a 26 year old son with Autism, mental disabilities, and OCD. He is unable to cross the street safely by himself, he does not recognize danger of any kind, he has tantrums, and he gets distracted very easy. Due to his disabilities, he is unable to find work within the "normal community" workplace. When we found out that he could work at the MARC Center, we were delighted that he could find joy, appreciation, and satisfaction in the workplace.

This is the perfect place for him. It allows him to work and receive a little bit of "his" money. When he is working at the MARC Center, he is in a safe environment, and we don't have to worry about him doing something dangerous or injurious to him. He gets SO excited when he gets his paycheck. It is usually in the \$5-10.00 range, and all he realizes is that he earned this money and he just beams with excitement.

A few days ago while shopping, our son was extremely excited to see some of the first aid kits that he assembles on the shelf of the store.

We are FURIOUS that you are even considering stopping such a wonderful program. This is the only program where these special needs adults can get out of the house (instead of watching TV all day or playing video games) and make something of their lives. There isn't any other employment option available to them as they are not employable by "normal" standards. They don't need a more restrictive day program, they need this work program **so that they can feel that they are a productive member of society, and for their own personal achievements.** Those with special needs have feelings and needs, too, and they are NO less important than yours or mine.

As an additional bonus, even though they usually don't make a lot of money, they still contribute to society by paying their taxes and Social Security. Yes, we realize this is a small pittance compared to others, but it is still additional funds.

If there was no work program for our son to go to during the week, he would either be home watching TV, playing his Nintendo, or getting into trouble in some other way. This would require one of us as his parents to either quit work to watch him, hire someone to watch him (we don't get enough respite hours to cover the time needed) or go to a day program where again he doesn't do anything productive. He would feel devastated and punished. Since his disabilities don't allow him to deal with change very well, it would take months if not years to help him feel better. As mentioned above, it would also have a huge impact on the family's finances. It would also increase the costs the state has to pay out for each individual.

In closing, we implore you to not cut the funding for this wonderful work program that so many special needs adults rely upon on a daily basis.

Sincerely,

A signature that has been completely redacted with a thick black marker.

EM192

Johnson, Dara

**From:** Claudia Chavez <CChavez@starsaz.org>  
**Sent:** Friday, August 28, 2015 1:25 PM  
**To:** HCBS  
**Cc:** Richard Homad  
**Subject:** HCBS Assessment and Transition Plan - Employment Services



Please find message from parent below

Thank you,

**Claudia Chavez** | Vocational Program Manager  
**STARS (Scottsdale Training & Rehabilitation Services)**  
7507 E. Osborn Rd. | Scottsdale, AZ 85251 | [www.starsaz.org](http://www.starsaz.org)  
☎: 480.322.1182 | 📞: 480.994.0491 | ✉: [cchavez@starsaz.org](mailto:cchavez@starsaz.org)

Join the conversation!



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----- Hi,

My 25 year old daughter with Down Syndrome has been receiving employment services for about 4 years now. She attends STARS and also did a stint at the Perry Center. At STARS, she cleans remotes, cleans cords, folds towels at the Fire Station one day every two weeks, and is also a part of the Kiwani's Action Club where they do volunteer services.

I see that the Assessment and Transition Plan talks about transitioning from a Center Based Employment to a Facility-Based pre-employment Center. What is the difference?? I am concerned because although my daughter is a great worker, she is vulnerable, and employers do not want to be a baby sitter. With CBE and GSE there is someone there that watches out for her. She is very limited verbally and needs that extra supervision should issues arise.

The plan talks about transitioning from CBE to a Facility Based Pre-employment Service, does this mean there will be no STARS? I have found STARS to be invaluable in teaching employment skills.

There are references to volunteering, although that can be part of keeping active and contributing to the community, I am not sure that there is enough work to go around.

I want to keep my daughter as active in working as possible because it gives her a way to contribute and affects her self esteem. She has somewhere to go in the morning just like everyone else. So, I feel as many options out there for those with disabilities, and all their skill levels is a good thing. I would hate to see things taken away, because it may be the best fit for some of our community.

I like the goal of having GSE for all individuals, they should all strive to attain that. But in reality that may not happen for some of our community. I believe we have come a long way, and People with Disabilities have come a long way. I feel the community really receives my daughter well, however, in the highly competitive job market, employers really look at the bottom line, and also don't want to worry about being sued if something were to happen to one of their employee on the job, so they won't even go there. That is a real fear, so I believe we need to keep as many options open for our community.

One more concern I have, in the move to a Community Based Employment, is it required that participants receive minimum wage? Although that might sound great, it could have the unintended effect of employers just not hiring them as they typically cannot compete with a nondisabled person. Most receive SSI, and the employment is not intended to be a living wage (that holds true for us). We just want her out in the community doing something. Although as a country we have made great strides in attitudes toward people with differences, this group is at a distinct disadvantage in the work force, they just don't have the same capacity.

Emil 93

Johnson, Dara

**From:** [REDACTED]  
**Sent:** Friday, August 28, 2015 1:59 PM  
**To:** HCBS  
**Subject:** HCBS Assessment and Transition Plan - Employment Services

To Whom It May Concern:

My name is [REDACTED], my son, [REDACTED] attends STARS Workshop. [REDACTED] has a developmental disability, which precludes him from holding a full time position in the "real world". He has been in the workshop for 18 years, since his graduation from a high school transition program. This program has provided him with a paycheck for his work there, and he is very proud of this check. STARS is also an important part of his social network.

I have read a good portion of the draft and am very concerned with the assessment and transition plan. What exactly is the facility-based pre-employment service? I believe that my son is receiving an employment service at the center-based facility (STARS). There is no time frame indicated for the transition. Will my son be forced to transition out of STARS to an undefined facility, will he lose his paycheck and his social network? How will AHCCCS encourage companies to hire individuals like my son or will they be passed out of the facility-based pre-employment service with no job, only to sit at home?

Another portion of the draft deals with volunteering in the community. This would be a great option, but only as an extra optional experience. My son already volunteers with his peers at STARS and enjoys this part of his work day, but would not be happy to lose his actual work and paycheck.

In going forward with the work on this plan, I sincerely hope that AHCCCS will look at all options and ensure that they remain open and available. Thank you for allowing me to comment on these important service changes. If you have any questions, please feel free to contact me at [REDACTED] or thru my email - [REDACTED].

Sincerely,

[REDACTED]

Sent from my iPad



EM 194

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Friday, August 28, 2015 2:02 PM  
**To:** HCBS  
**Subject:** Proposed changes for center-based employment

August 28, 2015

Arizona Health Care Cost Containment System  
c/o Office of Intergovernmental Relations  
801 E. Jefferson Street, Mail Drop 4200  
Phoenix, Arizona 85034

[REDACTED]

To Whom it May Concern:

I am writing in regards to proposed changes to restrict or eliminate center-based employment. My brother currently participates in a center-based employment program with MARC. He is 50 years old and is developmentally disabled. He is almost completely deaf, has limited verbal skills, is mentally handicapped and has behavioral issues. He attempted community employment in the past, but was fired. Center based employment is the only option for him.

Working in the community is not a viable option as he requires supervision and direction in his duties. Working in the community poses safety issues as he is trusting and won't understand or recognize if someone is trying to take advantage of him or is a threat. At MARC he has supervisors trained in dealing with individuals with disabilities and who look after his well-being. At MARC I don't have to worry about his safety and I can rely on the continuity of employment.

My brother enjoys going to work and is proud of the work he does and the paychecks he receives, no matter the amount. He likes the interaction with his co-worker friends and workshop staff. Outside of work my brother socializes with other residents of his group home and attends various activities such as movies and sporting events. Additionally, I frequently see him on weekends for family functions such as soccer games for my children and family dinners.

My parents are retired and my dad is 80 years old. After they are gone, my brother will be my responsibility. I want to do whatever I can to ensure that he is happy, healthy, cared for and it able to live his life to the fullest extent possible. Please do not eliminate the only job he has available in a safe and caring environment.

Sincerely,

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EMail 95

Johnson, Dara

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**From:** [REDACTED]  
**Sent:** Friday, August 28, 2015 2:22 PM  
**To:** HCBS  
**Subject:** Arizona's Systemic Assessment and Transition Plan

Thank you for the opportunity to make comments regarding the Plan that is being developed.

g. Our daughter [REDACTED] has lived in group homes since the inception of the group homes program in Arizona. Currently [REDACTED] is under the care of the Hozhoni Foundation in Flagstaff, Az., where she attends the DTA program and resides in a group home with four other ladies of similar levels of disabilities. [REDACTED] is profoundly mentally and physically challenged due to CP and multiple disabilities. She is in a wheelchair most of the day, she is totally defenseless and dependent on others for her care. [REDACTED] can not speak for herself, feed herself, dress herself or help herself in any way. She is 57 years old.

As parents we are very concerned that some of the issues proposed in the new plan. As we understand in trying to read the plan; it involves more integration into the community and clients rights of choice. Our daughter has no ability to make choices for herself. While we know the plan is well intended, it appears that it will be more costly but extremely difficult to implement.

Our first and foremost concern is for [REDACTED]'s safety and care. One persons choices should not impose on another persons rights to a safe and secure living environment. We hope that the new plan will consider our concerns about [REDACTED]'s safety while complying with issues of civil rights. We believe the Hozhoni Foundation is now providing Sherri and a safe and secure environment. In her present setting we have no issues as far as her rights to choose and make choices as these things are addressed in her ISP.

We feel that Hozhoni Foundation is providing [REDACTED] with a wonderful home setting and a day program that fits her needs.



Email 96 (Duplicate of Email 95)

Johnson, Dara

**From:** [REDACTED] >  
**Sent:** Friday, August 28, 2015 3:06 PM  
**To:** HCBS  
**Subject:** Arizona Systemic Assessment and Transition Plan

Thank you for the opportunity to make comments regarding the plan that is being developed.

Our daughter [REDACTED] has lived in group homes since the inception of the group home program in Arizona. Currently [REDACTED] is under the care of the Hozhoni Foundation in Flagstaff, Az, where she attends the DTA program and resides in a group home with 4 other ladies of similar levels of disabilities. [REDACTED] is profoundly mentally and physically challenged due to CP and multiple disabilities. She is in a wheelchair most of the day, she is totally defenseless and depends of others for her total care. Sheri cannot speak for herself, feed herself, or help herself in any way. She is 57 years old.

As parents we are very concerned with some of the issues proposed in the new plan. We understand in trying to read the plan; it involves more integration into the community and clients rights of choice. Our daughter has no ability to make choices for herself. While we know the plan is well intended, it appears it will be more costly and extremely difficult to implement because it will require additional staff to monitor and oversee the more individualized services.

Our first and foremost concern is for [REDACTED]'s safety and care. Further, one persons choices should not impose on another persons rights for a safe and secure living environment. We hope the new program will consider our concerns about our daughter's safety while complying with issues of civil rights.

We believe the Hozhoni Foundation is now providing [REDACTED] with a safe and secure environment. In her present setting we have no issues with her rights to choose as these things are addressed in her ISP.

We feel that Hozhoni Foundation is providing [REDACTED] with a wonderful home setting and day program that fits her needs.

Thanks again for the opportunity to make comments. Please feel free to contact us if you have any questions.

[REDACTED]  
[REDACTED]  
[REDACTED]  
[REDACTED]  
[REDACTED]

Corrected copy.

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Emil 97

Johnson, Dara

**From:** Sylvia Balistreri <sylviab@azhca.org>  
**Sent:** Friday, August 28, 2015 3:17 PM  
**To:** HCBS  
**Subject:** Public Comments on HCBS Rules State Action Plan

**Subject:** Public Comments on HCBS Rules State Action Plan

To AHCCCS Leadership:

Thank you for the opportunity to comment on Arizona's Plan to address the CMS final rules for home and community based services. Having worked in the long term care arena for more than 30 years in the provider community and as a state regulator, I believe I have a unique advantage of viewing care and services to our elders from many different perspectives.

Assessment

My comments center on the state plan review of settings, which includes assisted living facilities, but does not specifically address a segment of assisted living; "directed care" which is defined in statute at ARS §36.401.A.14, and addressed in rule at R9-10-815. Directed Care services according to ARS §36.401.A.14 "means programs and services, including supervisory and personal care services, that are provided to persons who are incapable of recognizing danger, summoning assistance, expressing need or making basic care decisions." The residents in directed care/memory care facilities are almost always in the mid to late stages of Alzheimer's disease or other types of dementia and the overall goals of their care at this level is not to integrate them back into the community but to provide them a safe environment where they can live at their highest potential. These residents will not, and cannot be rehabilitated. They have progressive diseases that will eventually end their lives.

I believe it is important for AHCCCS to address directed care and specifically directed care that is provided to residents with dementia (often referred to as "memory care") because by rule, these facilities must have secured perimeters and most have delayed egress. These elements have been an issue that CMS has viewed as potentially having the effect of isolating individuals receiving Medicaid HCBS from the broader community of individuals not receiving Medicaid HCBS. I believe the following points describe the care provided in these assisted living communities.

1. Arizona facilities have been successfully managing this level of care in these secure settings for many years.
2. These settings provide a cost-effective quality alternative to otherwise more restrictive skilled nursing settings.
3. In most cases community activities, services and resources are brought to the assisted living community to enhance the individualized care provided.
4. In most cases residents live and interact within a secure environment because it provides needed structure and safety to enhance their independence.
5. These memory care facilities have outside areas for walking, socializing, often gardening, having picnics or other outdoor activities.
6. These memory care facilities seek to preserve life skills by providing activities that help residents feel a sense of purpose such as helping distribute mail, sort clothes, fold laundry, water plants, and care for pets.
7. Residents achieve their highest well-being and individualized care in assisted living memory care settings through programs that are smaller and have predictable and structured schedules.
8. Some residents are able to attend outside events with family such as family outings, restaurant meals or church services, but this is the exception rather than the norm as most residents with this level of dementia become overwhelmed and agitated in the community at large.
9. Resident service plans are individualized and have goals to help each resident function at his/her highest level of well-being.

Thank you for the opportunity to make these comments.

Sincerely,

Sylvia Balistreri, RN, BSN  
Director of Quality & Regulatory Services  
Arizona Health Care Association

Sylvia Balistreri, RN, BSN  
Director of Quality & Regulatory services  
Arizona Health Care Association  
1440 E. Missouri Ave. Suite C-102  
Phoenix, AZ 85014  
[sylviab@azhca.org](mailto:sylviab@azhca.org)  
Ph: 602-265-5331  
Cell: 480-747-7549

EMAIL 98

Johnson, Dara

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**From:** Morgan Edward Hagel <morganh31@cox.net>  
**Sent:** Friday, August 28, 2015 4:06 PM  
**To:** Johnson, Dara  
**Cc:** 'Dianne'  
**Subject:** RE: Attn: To the c/o Office of Intergovernmental Relations, AHCCCS  
  
**Importance:** High

*general info*

Ms. Johnson,

It looks like you have just about everything covered. My question is how do you propose utilizing Arizona first responders in regards to persons with behavioral health challenges, overall, when other States are struggling to find solutions to the growing epidemic of homelessness going into center-based employment? An article from the New York Times about what is happening in San Francisco, a sister city, for your reading pleasure:

<http://www.msn.com/en-us/news/us/san-francisco-firefighters-an-unintended-safety-net-for-the-homeless/ar-BBm8oUs?ocid=spartandhp>

Again, thank you for taking time out of your busy schedule to read my email. I look forward to reading your response.

Sincerely,  
Morgan Edward Hagel

-----Original Message-----

**From:** Johnson, Dara [mailto:Dara.Johnson@azahcccs.gov]  
**Sent:** Thursday, August 27, 2015 1:12 PM  
**To:** Morgan Edward Hagel <morganh31@cox.net>  
**Cc:** 'Dianne' <levisfriend12@cox.net>  
**Subject:** RE: Attn: To the c/o Office of Intergovernmental Relations, AHCCCS

Great! We look forward to seeing you tomorrow.

Dara Johnson  
Program Development Officer

AHCCCS  
701 E. Jefferson St., MD 6100  
Phoenix, AZ 85034  
(602) 417-4362  
(602) 256-6421 (fax)  
Dara.Johnson@azahcccs.gov <mailto:Dara.Johnson@azahcccs.gov>

From: Morgan Edward Hagel [mailto:morganh31@cox.net]  
Sent: Thursday, August 27, 2015 12:57 PM  
To: Johnson, Dara  
Cc: 'Dianne'  
Subject: RE: Attn: To the c/o Office of Intergovernmental Relations, AHCCCS

Ms. Dara Johnson,

No problem. My mother and I will be at the Gilbert location tomorrow, August 28th, 2015. Thank you.

Sincerely,

Morgan Edward Hagel

From: Johnson, Dara [mailto:Dara.Johnson@azahcccs.gov]  
Sent: Thursday, August 27, 2015 7:57 AM  
To: Morgan Edward Hagel <morganh31@cox.net <mailto:morganh31@cox.net> >  
Subject: RE: Attn: To the c/o Office of Intergovernmental Relations, AHCCCS

Thank you for your interest in the Centers for Medicare and Medicaid Services (CMS), Home and Community-Based Setting (HCBS) Rules and your public comment submission. AHCCCS will review and consider all public comment received.

Please note: AHCCCS has added a community forum on August 28, 2015, to focus specifically on how the HCBS Rules may impact center-based and group-supported employment services. Attached is the flyer for the forum and information on how to RSVP.

The AHCCCS website ([www.azahcccs.gov/hcbs](http://www.azahcccs.gov/hcbs) <<http://www.azahcccs.gov/hcbs>> ) provides detailed information on the draft assessment of the state's current compliance and a draft transition plan for meeting compliance standards of all residential and non-residential settings, including settings that provide employment services.

The draft transition plan does not include plans to eliminate center-based employment services. We understand that some people from the MARC Center received a handout regarding this issue. Unfortunately, this handout contained incorrect information. We encourage you to visit our website for information and hope to see you at the forum on August 28, 2015.



Email 99

Johnson, Dara

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**From:** Danie McCallum <jndmcc@gmail.com>  
**Sent:** Friday, August 28, 2015 4:10 PM  
**To:** HCBS  
**Subject:** Videoconference for HCBS Employment Programs

*general*

We attended the videoconference in Tucson today regarding potential changes in the HCBS center-based employment programs. While we appreciate the opportunity to review and comment on potential changes in the programs, several things about the videoconference detracted from its effectiveness.

First, almost half of the allotted time for the conference was used to discuss changes to the residential programs. If these programs were mentioned at all, they should only have been mentioned in passing, so the time could be focused on the employment programs.

Second, no one from the conference facility was present to operate the video equipment. The microphones in the conference room had apparently not been turned on, so attendees who wanted to make a comment or ask a question were unable to participate.

Finally, there was no sign-in roster available, and no one was present to collect any of our written comments. The comment sheets were left in the conference room, and hopefully will get to you soon.

As we mentioned, we appreciate the chance to learn and comment on any proposed changes; please keep us informed.

Jim and Danie McCallum



Email 100

Johnson, Dara

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**From:** Evelyn Stansbarger <evestansbarger@gmail.com>  
**Sent:** Friday, August 28, 2015 8:04 PM  
**To:** HCBS; Alho Arizona  
**Subject:** Residents Rate

AK

**My biggest complaint is that when a resident comes in on a private pay and eventually qualifies for ALTCS.**

A resident who pays a private rate and then qualifies for ATLCS. The problem is the drastic rate change. I would want to keep the resident if the family is willing to pay the difference. However, ALTCS does not allow the group homes to collect any more than what ALTCS pay.

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***Evelyn Stansbarger, Owner/Manager  
Golden Year Care Home, LLC***

