



R A I S I N G V O I C E S

C O A L I T I O N

Parent Perspective

AHCCCS Proposal for a Permanent Paid Parent Caregiver Program



Important Background Information

- 2020 the State of Arizona allowed, on a temporary flexibility during the pandemic, parents of minor children enrolled in DDD and ALTCS to be certified and trained Direct Care Workers (DCW) for their own children. The hours these parents could provide included Attendant Care and Habilitation.
- In 2021 AHCCCS received approval for their ARPA proposal which included an extension to temporary flexibility allowing parents of minors with disabilities to be Paid Providers for Attendant Care and Habilitation services. This ARPA extension was originally set to end (per AHCCCS publications) September 30, 2024.
- AHCCCS published a 1115 waiver amendment proposal in June of 2023 expressing their intent in creating a permanent Paid Parent Caregiver program. This proposal is currently under the public feedback period until August 21, 2023. AHCCCS intends to submit their waiver amendment request to CMS in August after the public feedback period has closed.
- A public forum was held on July 18, 2023 and a second forum will be held via Zoom on August 2, 2023.

What is the Intention of AHCCCS

Under this Demonstration proposal, the agency will seek to:

- Mitigate DCW shortage and other access to care challenges by allowing payments to parents who serve as paid caregivers for their minor children,
- Increase member satisfaction and promote positive health and well-being outcomes for the target population,
- Extend an additional support service to restore, enhance, and maintain family functioning to preserve effective care for the member in the home and community, and
- Ensure that members receive high-quality care while increasing timely accessibility to care providers.

https://www.azahcccs.gov/Resources/Federal/PendingWaivers/ParentCareGivers.html?fbclid=IwAR345QbsL8pz2SYIJ_hya-h7psJG_k-uRXgMbGM4FO5Jq8sQfl-pHwTJD-4

What Will Change?

- If the waiver proposal is approved by CMS as currently written, Habilitation will no longer be a service parents of minor DDD members can provide beyond November 13, 2023.
- Attendant Care Services will be limited to 40 hours per week of care per member. There is no exception to this provision and it limits both parents from providing more than 40 hours a week of paid care regardless on if they reside in the same household or not.

For your information:

- Parents of adults with disabilities can currently provide Habilitation and they are not limited to 40 hours per week of care.
- AHCCCS has stated that they intend to model this program off of the currently operating Adult Paid Spouse program which is limited to 40 hours a week of services. These populations and familial relationships are not comparable with the minor DDD population.

Why does AHCCCS want to exclude Habilitation?

- AHCCCS has expressed their opinion that if parents of minors with disabilities provide Habilitation services the members will face social isolation and less community involvement. They believe a non-family DCW providing Habilitation services will decrease social isolation or decreased community involvement.
 - To date, statistics or research have not been given to support this argument.
 - Generalization of services is a far better approach and correctly utilizes parents as Paid Habilitation providers.
 - The parent caregiver experience has indicated an increase in community involvement and less social isolation for minor members under the current flexibility.
- AHCCCS has claimed that CMS would not allow Habilitation to be a service parents of minors could provide.
 - This has been proven factually inaccurate through my correspondence with CMS.
 - Habilitation does not need a waiver but could be written into our state plan as a service parents of minors can provide. Attendant Care is the only item that needs a federal waiver to allow parents to facilitate.

Why does AHCCCS want to include a 40 hour limit?

- The 40 hour rule for Attendant Care was included as a safeguard example for parent caregiver programs by CMS.
 - This was listed as a safeguard example and is not a requirement.
 - Other states with existing similar programs do not have this provision.
- AHCCCS is concerned with adult transition and caregiver burnout.
 - Regardless of who provides the Attendant Care or Habilitation services parent burnout will be the same if not worse if items like the DCW shortage, these program limitations, and underutilized Respite hours are not evaluated and fixed.
 - The inclusion of an extraordinary circumstances clause would facilitate the members who have unusual situations, cultural preferences or Article 9 requests where care is more appropriately facilitate to a minor member by a parent provider.

Additional Notes

- Provider Agencies do not have a workforce ready to backfill the immediate ending of Habilitation services performed by parents of minors beginning November 2023. Despite their best efforts of these provider agencies, there is not enough interest in DCW positions to facilitate the care for this population at this current time.
- EVV systems and Provider Agencies do not have the ability to implement or regulate these new program rules.
 - Parents (one or both) can be employed by multiple agencies, there is no way for agencies to track or see how many hours parents are billing for each member.
 - A 16 hour per day rule for all DCW providers (regardless of familial status) would be much easier to enforce across the board for all ALTCS members.
- Concerns regarding DDD Support Coordinator discrimination is extremely real and already being felt by families. New policies and evaluations need to be assessed with these changes to help create systematic change that does not discriminate against paid family providers.

What can the DDAC do to help?

- Create and/or sign onto a collective letter asking for the inclusion of Habilitation and the removal or accommodation of more than 40 hours a week of paid care for parents of minor members.
- Reach out to AHCCCS about your concerns regarding the current proposal through their public feedback channels.
- Attend the upcoming August 2nd public forum.
- Utilize the ACTION ITEMS document and sample letters created by Raising Voices Coalition to help create further awareness on this issue.

Thank you!

Relevant and referenced links will be provided in the chat for your reference.

Questions?

Brandi Coon

brandi@raisingvoicescoalition.com

www.raisingvoicescoalition.com