



RAISING VOICES

COALITION

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

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

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

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

This goal can be reached 1 of 2 ways:

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

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

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

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

Contact Information:

Brandi Coon

brandi@raisingvoicescoalition.com

www.raisingvoicescoalition.com

951.807.1672

Lauryn Van Rooy

lauryn@raisingvoicescoalition.com

www.raisingvoicescoalition.com

480.464.4817

Supporting Documentation:

2023 Arizona Data Report - Paid Parent Providers

https://docs.google.com/document/d/16PZOk99caDUitg0XmQKqEv2mxXOBeaRywSD_zmjAnYw/edit?usp=sharing

CMS PowerPoint - Leveraging Family Caregivers for Personal Care Services

<https://www.medicaid.gov/medicaid/home-community-based-services/downloads/leveraging-family-care.pdf>

NASHP - State Approaches to Reimbursing Family Caregivers of Children and Youth with Special Health Care Needs through Medicaid

<https://drive.google.com/file/d/1TSt-Rj95DTn711EV8UTq7YqF0yoo0i8u/view?usp=sharing>

Disability Organizations that Support this Initiative:



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