



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

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To the Oregon Senate Human Services Committee,

My name is Brandi Coon and I am a parent of a child with developmental disabilities in Arizona. I am also a Co-Founder of Raising Voices Coalition which is a grassroots organization that educates family caregivers on advocacy tools, champions local and national movements to improve the quality of life for those with disabilities, and builds bridges between families and government managed departments to empower innovative inclusive solutions. In 2020 Arizona incorporated paid parent providers to their DCW workforce for minor members that qualify for long term care and developmental disability services.

In the Spring of 2020 the Arizona Medicaid Department (AHCCCS) and the Division of Developmental Disabilities (DDD) published a broad range of program flexibilities to accommodate the ever changing conditions of the Covid-19 pandemic. One of these program flexibilities gave parents of minor DDD and Arizona Long Term Care System (ALTCs) members the ability to provide Attendant Care (personal care and housekeeping) and Habilitation (goals based) hours for their own children. Both of these hour types are not categorized as a 1:1 service in Arizona. Previously paid parent providers were restricted, although parents of adult members could provide these hours to their member children after they reached the age of 18. Monetary support required to fund these Covid-19 flexibilities came from the Public Health Emergency allocations.

Parents of minor members who utilize this flexibility are required to complete the same training and certifications as a non live-in DCW (direct care worker) prior to working with their own child. The hourly pay rate for parent providers of minor members is the same as non live-in providers. There continues to be flexibility for parents to choose who provides their child's authorized hours. If an additional qualified DCW is available, hours can be split in any way the family deems appropriate. There is no wait list requirement for paid parent providers of minor or adult members. This provides

immediate access to authorized service hours that were previously being provided for free by parent caregivers on a daily basis.

All parent providers in Arizona are under the same EVV (Electronic Visit Verification) requirements as non live-in providers. Beyond the restrictions and policies in place for all DCWs in Arizona, parent providers have not had any additional restrictions on locations or activities that can be provided during the service hours. Because AHCCCS decided not to place any additional requirements or policy regulations on parent providers of minors, it gave the provider agencies the ability to seamlessly add this program into their DCW workforce portfolio.

In 2021 AHCCCS requested additional funding and program authorization for parent providers of minor members beyond the Federal Public Health Emergency through the use of ARPA (American Rescue Plan Act). The Arizona State Legislature matched their funding requirement which, I believe, was 20% of the program cost. Through ARPA parents of minor members are authorized to be paid parent providers through September 30, 2024. Ongoing advocacy efforts are being made in Arizona by multiple state disability organizations and parent providers to continue this program permanently beyond the ARPA program.

By interviewing hundreds of parent providers in Arizona we have seen many common benefits to this program for our member children. These include, but are not limited to:

- Continuity of care,
- Less provider turnover,
- Decreased hospitalization,
- Increased member medical, behavioral and physical safety,
- Higher fulfillment of services,
- Household financial stability,
- Increased cultural sensitivity for personal care preferences,
- Greater access to care for those who live in rural areas,
- Consistent goal and care incorporation throughout the member's day,
- Decreased parental stress,
- Personal care being given by someone the child feels safe with and
- Greater agency and state oversight for services received by the member vs having the services go unprovided for any length of time.

Extended explanation of each of these program benefits could be explained but suffice it to say, parent providers fill a gap in the caregiver workforce that is being felt all around the country. Timely deliverance of service hours appropriately evaluated for and given by the state through utilizing parent providers have shown improvement to the overall wellbeing of each member and their family.

In the process of receiving approval from CMS (Centers of Medicare and Medicaid Services) for the parent provider Covid-19 flexibility and program extension under the ARPA program, Arizona did not face any pushback. CMS was in full support of these programs. On January 4, 2023 CMS published a letter to all State Medicaid Directors expanding the scope of in lieu of a service or setting (ILOS) programs. A quote from that letter states, "ILOSs (in lieu of a service or settings) provide states with an opportunity to address many health disparities and unmet physical, behavioral, developmental, long-term care, and HRSNs (health-related service needs) of Medicaid managed care enrollees."

There are many options available to states to create or expand their current provider policies and funding options to include paid parent providers for minor and adult members. These include but are not limited to:

- New state law and appropriate funding support
- Alternative reimbursement rates for agencies regarding Paid Parent Providers
- Parent nursing program similar to the Arizona LHA or Colorado Parent CNA Programs
- ARPA program and funding as a short term solution to funding concerns
- Amendment of the current state plan or new Medicaid waiver(s) without new legislation
- In lieu of service or setting program approved adjustments

The easiest and least restrictive way for states to incorporate these programs is to extend the current DCW programs in place in your state with minimal policy adjustments or restrictions.

In conclusion, I have collaborated with and continue to advocate for parent providers across this country. The benefits to members and their families far outweigh the tradition of historic DCW programs. 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.

Sincerely,

Brandi Coon

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Attachments:

1. [Arizona ARPA Proposal](#)
2. [1/4/2023 CMS Letter to State Medicaid Directors](#)
3. [Member Qualifications for Arizona Long Term Care System \(ALTCS\)](#)
4. [PAS Assessment 0-5 \(used for ALTCS application\)](#)
5. [PAS Assessment 6-11 \(used for ALTCS application\)](#)
6. [PAS Assessment Over 12 \(used for ALTCS application\)](#)
7. [Attendant Care or Housekeeper Evaluation](#)
8. [Attendant Care Supervision Evaluation](#)
9. [Habilitation Care Evaluation](#)
10. [DCW Provider hiring and training requirements. Chapter 1200. Section 1240-A](#)