

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

Raising Voices Coalition / Arizona Developmental Disabilities Planning Council

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Abstract

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

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

Background

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

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

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

consider the impacts of the temporary Paid Parent Provider program has had on Arizona families of minor children with disabilities from their first hand perspectives.

Objective

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

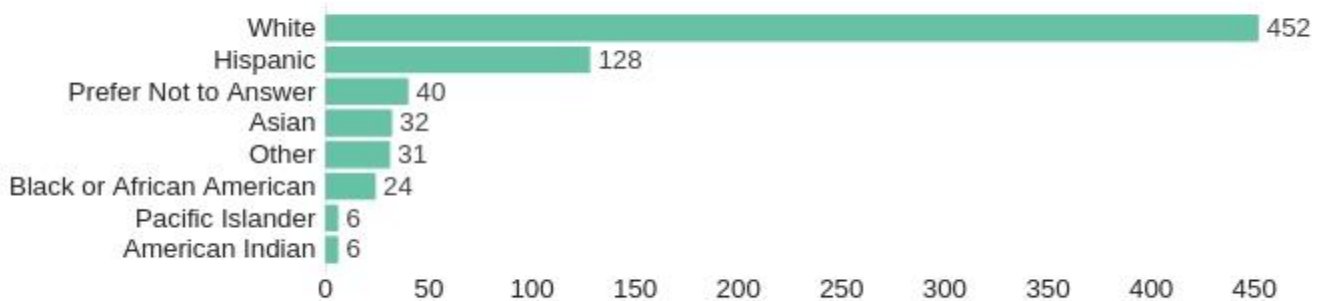
Results and Discussion

Demographic Information

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

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

Ethnicity of Participants



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

Family and Member Impact

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

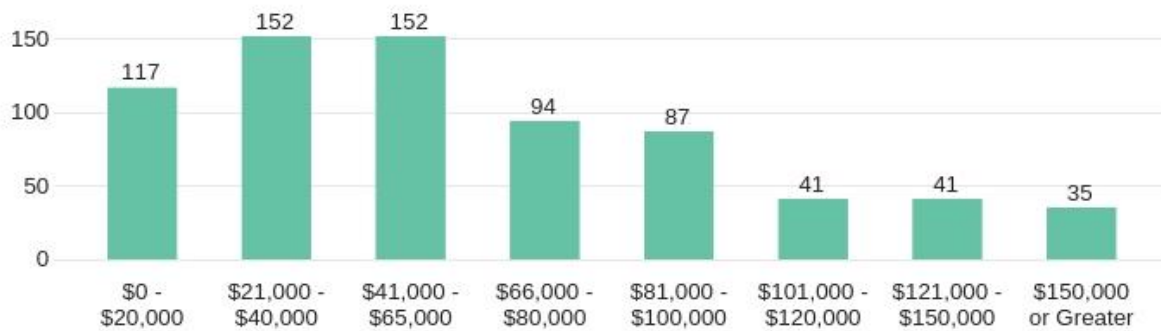
“The Paid Parent Program addresses the social disparities and systematic barriers for families and children who have developmental disabilities and those who are medically fragile. In rural and poverty ridden communities access to quality services is not accessible.

Due to the salary for a Provider there is a high turnover, unethical issues or even more trauma sustained. Parent Provider incorporates families strengths, culture and resiliency.”

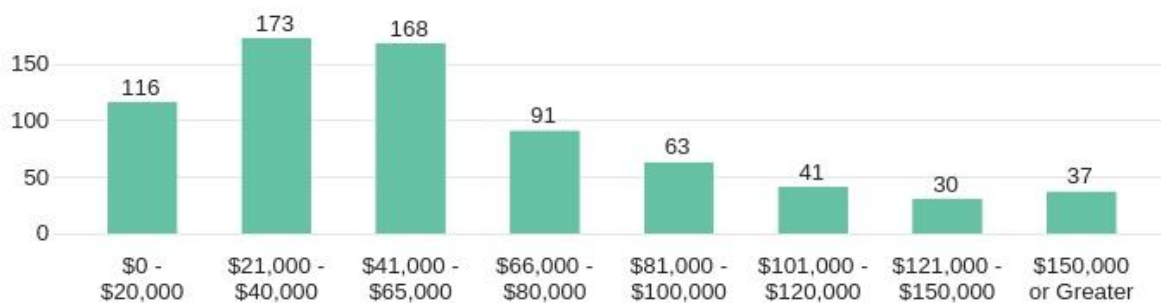
Anonymous Parent Provider

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

Annual Gross Household Income Prior to the Paid Parent Provider Program



Current Annual Household Income



Housing and Financial Stability

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

Fifty percent of households that participated in this survey reported a moderate to high risk of losing their housing prior to 2020. With the temporary program in place, only 9% stated they are at a medium to high risk of losing their housing. If the program were to end, 61% of participants indicated a medium to high risk

of losing their housing. Thirty-two percent of households with minor DDD and/or ALTCS members identified themselves as the sole financial provider of their household.

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

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

Social Service Impact / Impact on Services and Resources

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

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

Abuse and Neglect Prevention

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

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

Provider Agencies

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

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

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

Anonymous Agency Owner

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

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

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

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

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

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

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

Funding

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

Conclusion

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

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

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

Supplemental Research

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

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