

February 2021

To whom it may concern,

This letter is written in representation of the collective voices of primary caregivers who have children with developmental disabilities in Arizona. Many thanks and appreciation goes to the Arizona Health Care Cost Containment System Administration (AHCCCS) and associated Developmental Disability Department (DDD) for their extensive, robust and timely program adjustments in response to the Covid-19 pandemic. This prompt action anticipated the unique and ever changing needs that our loved ones with disabilities face.

One of the program adjustments stated that primary caregivers of minor children who received DDD hours could become certified Home and Community-Based Service Providers (HCBS) beginning March 13, 2020. Our disability community has experienced how effectively this program has met the needs of DDD members under the age of 18, and because of this, we are advocating for this program to become a permanent choice for families in Arizona who have children with disabilities.

Network Adequacy

We support the existing infrastructure of qualified HCBS agencies and vendors in our state. These agencies work hard to support and advocate for their members to ensure their needs are being met. We believe It takes a village, and we are proud of the systems Arizona has in place to support its special needs individuals.

Given the health and safety concerns with the ongoing pandemic, our experience this last year has shown that it has been difficult for agencies to find non-familial HCBS providers that will stay with DDD placements long-term. This is not an acute issue that has arisen through the duration of this pandemic, but was present prior to and we anticipate it to be an ongoing struggle moving forward. This gives us

great concern around how DDD members' needs are currently structured to be met. While we do not have access to data and cannot speak to vendor and agency employee turnover rates or shortages globally, we can speak from our experience and say that many families in the disability community have experienced frequent loss of their HCBS providers during their years receiving DDD services.

Every individual DDD member's needs are different and because of that HCBS providers are required to certify in a variety of courses. The robust training put into place by DDD for HCBS providers is much appreciated and necessary. Due to the broad nature of the training HCBS providers must also receive extensive in-home training once they are selected to work with an individual DDD member. This in-home training is provided by the primary caregiver, and is often initially extensive requiring multiple full days of instruction. Continual updates to that training must also be given by the primary caregiver so that each provider is well informed and understands the current health and safety needs of the DDD member that they are caring for.

Through the swift action of AHCCCS and DDD, the emergency approval of parent providers during the Covid-19 pandemic DDD members and their families have experienced a solution to the frequent loss of HCBS providers that they previously experienced. Paid parent providers are their child's expert and do not require additional in-home training.

Unique Financial Circumstances

In our collective experience we have found that many families in our disability community struggle financially. Due to the high volume of therapy appointments, care requirements, doctor visits and the unanticipated illnesses of our loved ones with special needs many families only have the ability for one parent or adult to work outside of the home. This becomes especially burdensome for single parent households.

Some DDD families have two adults in the household that can split the workload of financially providing and caring for their disabled child. But depending on the occupation or education opportunities, even families with two adults can struggle financially with just one source of income.

Having paid parent providers has created a unique opportunity not traditionally afforded to special needs families, creating a greater measure of financial safety and stability that many DDD members have been unable to experience previously.

Progress and Precedent

Members of our disability community have seen an improvement in their childrens' habilitation outcomes because of the consistency of parent provider support. This program has created structure and accountability for primary caregivers to dedicate time towards the habilitation of their child with disabilities while providing HCBS agencies consistent documentation on that member's improvement or struggles with their individual goals.

We recognize and understand the balance of being medicaid beneficiaries and also parent providers. This unique situation requires much consideration. Review of the current precedent showing that it can be put into practice permanently should be reviewed and considered. Other states have permanent parent provider programs in place for their members with disabilities under the age of 18. Some of these states include California, Colorado and Minnesota. We believe these programs show that such programs are needed nationally and should be implemented through state managed disability agencies like DDD.

Conclusion

As parents, it is our objective to surround ourselves with a team of friends, family, professionals and providers so that we can give our loved ones with disabilities the best possible support and life that we can offer. We acknowledge that parents cannot do it all, and our

families require help in fulfilling the care requirements for our children with special needs.

The health, safety and risk assessment of each DDD member should be top priority in conjunction with their familial circumstances when making a decision to bring on a new HCBS provider. We are requesting that each DDD member and their family be given the flexibility to choose the provider that best fits their needs whether that be a parent provider, or a non-family provider.

We collectively urge you to extend the parent provider program indefinitely which would provide choice for Arizona's special needs families.

We thank you for your time and consideration.

Sincerely,

Arizona's Special Needs Families