



July 17, 2023

AHCCCS
c/o Division of Community Advocacy and Intergovernmental Relations
801 E. Jefferson Street, MD 4200
Phoenix, AZ 85034

RE: Public Comment – Arizona Section 1115 Waiver Amendment Request: Parents as Paid Caregivers

Director Carmen Heredia,

Thank you for the opportunity to provide comment on the AHCCCS *Arizona Section 1115 Waiver Amendment Request: Parents as Paid Caregivers* proposal dated June 16, 2023.

As a statewide provider of family support for parents and family members raising an infant, toddler, child, youth, or young adult with disabilities Raising Special Kids (RSK) appreciates Arizona's Medicaid program for its support of family caregivers.

In our role as a statewide advocate for Arizona families of children with disabilities, we support the efforts by AHCCCS to seek a well-balanced approach as we transition from the Public Health Emergency toward more standard practices. If the waiver amendment is approved by CMS, we hope to see:

- Pressure on families relieved by compensating parents for caregiving services, with appropriate safeguards that meet the definition of extraordinary care and prevent institutionalization.
- The inclusion of Family Support as a covered service to assist families of children receiving HCBS.
- Continued attention to and monitoring of managed care organizations and provider agencies to recruit, train, and maintain a professional workforce of sufficient capacity to provide Home and Community Based Services.

RSK reviewed the proposed Arizona section 1115 waiver request, consulted and engaged with stakeholders, and considered diverse viewpoints regarding the waiver request. RSK generally supports the proposed waiver request in its entirety and believes it finds the appropriate balance between the CMS standards for "extraordinary" care to prevent institutionalization while also meeting the needs of parents caring for children with high support needs. The waiver request correctly addresses policy issues related to ensuring individuals receiving HCBS have full access to the benefits of community living and that family caregivers meet the necessary qualifications and other criteria for providers of care.

Details on specific support for the request, the need for further information, and our concerns for possible unintended consequences are as follows:

1. Role of Family

Families play a critical role in the health, education, and development of children with disabilities and RSK supports allowing 40 hours maximum per week of paid caregiving services. This establishes a needed balance to preserve and support the role of the family in Arizona's Medicaid system. RSK

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expresses its reservations concerning provisions that would allow families (as they have under PHE flexibilities) to become paid providers of *habilitative services* for their child. This service expansion would change their roles to become *both caregiver and primary paid service provider*. The effects of this could increase caregiver burnout, and lead to greater social isolation of both the child and family. Achieving optimal outcomes for children requires parents and professionals to consult and collaborate on the provision of care and support needed within home and community-based settings.

2. Network Capacity

As a family-serving organization, RSK acknowledges the persistent need for and ongoing shortage of Arizona's direct care workforce and HCBS service providers. RSK supports the restraint used in this request to stop short of making all PHE flexibilities permanent policy. We support AHCCCS in its thoughtful approach to maintain needed investment and preserve incentives for recruiting and training a viable and professional workforce. We believe a shift to a system where families were incentivized to provide habilitative HCBS could lead to complacency among Arizona's provider network about the necessity to develop and maintain sufficient capacity which may ultimately degrade Arizona's system of care for supporting individuals with disabilities and their families. The unintended consequences may lead to provider agencies heavily recruiting parents and family members, leading to an even greater shortage of trained and qualified direct care workers.

3. Extended Family Support

Years of data show that Family and Peer Support services have a high social impact, resulting in improved outcomes for children, youth, and young adults with disabilities and their families by increasing resiliency and decreasing the need for crisis services. As the PHE flexibility benefits end, the need for peer-based parent support will increase. AHCCCS has appropriately reflected in the waiver request the need for and importance of this uniquely effective form of family support. Parents who have lived experience in supporting a family member receiving HCBS will increasingly be a necessary and important connection and link for families to sources of information, training, and support. We have questions surrounding how this will be defined and implemented among families of individuals receiving HCBS. We encourage AHCCCS to work with stakeholders and community-based organizations like Raising Special Kids to ensure peer support services will be provided and maintained at a high level of quality and offered in ways that meet the diverse needs of families.

Summary

Arizona families struggled prior to the pandemic to secure adequate caregiver and habilitative services for their child(ren), primarily due to an insufficient network and provider shortages. During the pandemic, those struggles increased dramatically and the flexibility of allowing families to become paid caregivers for their minor children was a much-needed solution. As Arizona transitions out of the PHE, families continue to face significant challenges as they strive to fill the gaps. RSK offers its strong support for the waiver request and, as this important work continues, is committed to supporting AHCCCS in its efforts to improve and sustain our system of care for Arizona's most vulnerable populations.

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About Raising Special Kids

Raising Special Kids (RSK) is an Arizona nonprofit organization founded in 1979 with a mission of strengthening families and systems of care to improve the lives of children with disabilities. RSK is Arizona's federally designated [Family-to-Family Health Information Center](#) funded by the US Department of Health and Human Services Health Resources and Services Administration (HHS/HRSA), and a founding member of [Parent-to-Parent USA](#) providing evidence-based peer-to-peer support to Arizona's parents and family members raising children with the full range of disabilities. As the Arizona chapter of [Family Voices](#), RSK promotes partnerships with families to improve healthcare services and policies for children. In addition to serving and supporting individual families, RSK exists to assist providers, state and federal agencies, legislators, and other stakeholders to better understand and serve children and youth with disabilities and special health care needs.

Christopher Tiffany
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