



Arizona Section 1115 Waiver Amendment Request: Parents as Paid Caregivers

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I. SUMMARY

The Arizona Health Care Cost Containment System (AHCCCS) is requesting an amendment to the State's current Demonstration project, "Arizona Medicaid Section 1115 Demonstration" under section 1115 of the Social Security Act (Project Number 11-W-00275/9). In response to the COVID-19 Public Health Emergency (PHE), AHCCCS submitted and received approval for an Appendix K waiver amendment to allow for certain flexibilities to their program, including payments to parents who serve as paid caregivers for minor children. The goal of this proposal is to better address the direct care worker (DCW) shortage by permanently extending payments to parents who serve as paid caregivers for minor children while also further developing the Arizona Long Term Care System (ALTCS) to include extended family supports to preserve a supportive home environment and mitigate access to care challenges.

Since 1982, AHCCCS has been delivering high-quality, cost-effective health care services to Arizonans via a managed care delivery system authorized through an 1115 waiver. In 1988, AHCCCS' original 1115 Demonstration was substantially amended to allow Arizona to implement ALTCS for individuals who are elderly and/or have physical disabilities and individuals with intellectual/developmental disabilities. Since that time, the ALTCS program has evolved by creating an array of home and community based settings and services to support members to live in the least restrictive setting while still receiving the appropriate care. The program has continued to grow to over 65,000 members in July of 2023 with approximately 89 percent of members receiving HCBS. The ALTCS program includes a flexible service delivery model whereby spouses and family members (including parents of adult children) can provide paid authorized services within the member's own home. Prior to COVID-19, parents of minor children had never been paid for the care they provided to their minor child.

The COVID-19 Public Health Emergency (PHE) necessitated new innovations and service delivery models to ensure members continued to receive services if the family decided not to allow DCWs into their homes or if DCWs decided not to continue working in the home setting to mitigate the risk of exposure. As a result, AHCCCS submitted and received approval for a temporary Appendix K PHE flexibility to allow parents to be reimbursed for the provision of the "extraordinary care" that was required of them throughout the course of the pandemic. The agency received an extension of this flexibility for six months after the end of the PHE on March 22, 2023, extending the program until November 11, 2023, under the same Appendix K authority. As defined in AHCCCS' 1115 Waiver, "extraordinary care," is defined as "care that exceeds the range of activities that a [parent] would ordinarily perform in the household on behalf of the recipient [member], if he/she did not have a disability or chronic illness, and which are necessary to assure the health and welfare of the enrollee, and avoid institutionalization." The State is seeking to ensure the continuation of allowing for parents to be reimbursed for the provision of this "extraordinary" attendant care and habilitation services to their minor children past the current expiration date of November 11, 2023, through a section 1115 Demonstration amendment.

Under this Demonstration proposal, the agency will seek to:

- Mitigate DCW shortage and other access to care challenges by allowing payments to parents who serve as paid caregivers for their minor children,
- Increase member satisfaction and promote positive health and well-being outcomes for the target population,
- Extend an additional support service to restore, enhance, and maintain family functioning to preserve effective care for the member in the home and community, and

- Ensure that members receive high-quality care while increasing timely accessibility to care providers.

II. OVERVIEW

Background

On March 13, 2020, the President of the United States declared the 2019 novel coronavirus (COVID-19) a nationwide emergency pursuant to Section 501(b) of the Robert T. Stafford Disaster Relief and Emergency Assistance Act, 42 U.S.C. 5121-5207 (the “Stafford” Act). The President’s declaration provided authority for the Secretary of the U.S. Department of Health and Human Services to enhance States’ ability to respond to the COVID-19 outbreak, including the power to temporarily waive or modify Medicaid and CHIP requirements under Section 1135 of the Social Security Act. Temporary flexibilities were granted through policy changes or various legal authorities.

To minimize disruption in care for AHCCCS members requiring home and community-based services (HCBS) during the course of the PHE, Arizona requested and received approval via an Appendix K amendment which allowed parents of minor children to receive payment for attendant care and habilitation services. Most recently, Arizona obtained an extension of this Appendix K amendment currently set to expire six months after the end of the public health emergency on November 11, 2023. Upon careful review of this authority with Agency staff and external stakeholders, AHCCCS has determined the need to make payments to parents of minor caregivers an on-going flexibility within the State’s Section 1115 Research and Demonstration Waiver.

Addressing Arizona’s Workforce Shortage Through Temporary Flexibilities

Prior to the PHE, Arizona experienced overall workforce shortages in the state. These shortages were further exacerbated by the PHE and are particularly pronounced for DCWs delivering services in HCBS settings.¹ Further complicating matters, there is a nationwide shortage of in-home caregivers due to rising demand for services related to the aging population². In Arizona, this translates to potentially 41,000 new and available jobs for direct-care workers over the next seven years to help meet demand.³ A workforce survey of DCWs conducted by the Paraprofessional Healthcare Institute (PHI) in 2021 estimated that Arizona providers will need to fill nearly 130,000 job openings from 2016.⁴

As the PHE continued, the DCW workforce challenges were exacerbated and the system became more reliant on parents providing authorized paid care, while parents became increasingly accustomed to the care being delivered in this way. As a result, when ARP Section 9817 funding became available AHCCCS decided to continue this PPCG flexibility through September 30, 2024 using the Section 9817 funds to provide an additional runway for parents, case managers, and the provider agencies representing the DCW workforce to prepare for this flexibility to end and make plans for this transition to mitigate any

¹ Watts, M., Musumeci, M., Ammula, M. 2021. *State Medicaid Home & Community-Based Services (HCBS) Programs Respond to COVID-19: Early Findings from a 50-State Survey*. Kaiser Family Foundation. <https://www.kff.org/report-section/state-medicare-home-community-based-services-hcbs-programs-respond-to-covid-19-early-findings-from-a-50-state-survey-issue-brief/>

² MACPAC. 2022, March. *State Efforts to Address Medicaid Home-and Community-Based Services Workforce Shortages*. https://www.azahcccs.gov/shared/Downloads/News/2022/220322_MACPAC-brief-on-HCBS-workforce.pdf

³ Duarte, C., 2019, February 10. *Shortage of Home-Care Workers in US, Arizona called a ‘Growing Crisis’*. Arizona Daily Star. https://tucson.com/news/local/shortage-of-home-care-workers-in-us-arizona-called-a/article_f3acc21a-f915-593d-b0fa-d207080a3680.html

⁴ Campbell, Stephen. *Insights From the Frontline: Results of a Statewide Survey of Paid Caregivers in Arizona*. Paraprofessional Healthcare Institute (PHI), 2021.

potential access to care risks. Outside of extending PPCG, AHCCCS prioritized the use of the ARP funding to develop a multi-pronged approach to address recruitment and retention of DCWs to bolster the workforce to assume the provision of care after the conclusion of the flexibility. These strategies were informed by the HCBS stakeholder community as well as the 2021 PHI survey findings suggesting opportunities to support paid caregivers through additional compensation, training, supervision, and opportunities for advancement and support. The multi-pronged approach includes the following activities:

- Time limited directed provider payments to support recruitment and retention efforts,
- Develop new or additional trainings, including specialized trainings as a way to promote workforce retention,
- Support the career pathway of a DCW by promoting transparency on how to begin a career as a DCW and provide administrative resources to encourage recruitment,
- Promote investments in the development of new tools and technologies, such as a workforce database that helps the agency monitor workforces across the state, including DCWs, and
- Expand existing processes and technologies in the state, such as home-grown training programs.

Seeking Payment to Parents as Paid Caregivers Permanently

Addressing workforce shortages needs to focus simultaneously on filling the current gaps as well as preparing for future membership growth to mitigate compounded shortages in the future. In recognition of these challenges, the Agency proposed numerous interventions and investments described above aimed at attracting and retaining the DCW workforce through its [Section 9817 ARPA Spending Plan](#), including payments to parents of minor children. However, over the course of implementing the aforementioned initiatives, based on stakeholder feedback and available data it became apparent to the State that the PPCG program continues to be a critical lifeline for children with complex needs (and their families) that AHCCCS serves. The anticipated workforce needs and projected increase in our ALTCS population, combined with the anticipated number of DCWs entering the workforce, creates a scenario where augmenting the DCW workforce in Arizona through this PPCG program is essential to ensuring members are able to receive the care they need.

Under this proposal, parents who do provide these services must meet all requirements as established by AHCCCS policy including being employed/contracted by an AHCCCS Registered Direct Care Service Agency, demonstrating competency to provide care including passing specific competency tests, and complying with Electronic Visit Verification (EVV) per the 21st Century Cures Act (Cures Act). The services and number of authorized hours will be assessed and determined through the Person-Centered Service Planning (PCSP) process including a determination of what services/hours will be provided by informal (uncompensated) supports. Additionally, the provision of informal supports must be voluntary on the part of the caregiver. AHCCCS will update the Home and Community Based Services (HCBS) Needs Tool (HNT) to define the services and tasks that may be assessed for and qualify as “extraordinary care.”

Agencies employing or contracting with parents providing these services must maintain agency supervisory visits as further detailed in AMPM 1240-A. As part of the quarterly supervisory visits, a succession and workforce plan for the member/family shall be established that gets evaluated, updated, and implemented. The individual workforce development plan should include at a minimum, planning for respite workers and contingencies should the parent be unable to provide care or fulfill their responsibilities as the caregiver. The member specific plans shall inform the agency’s broader workforce planning efforts to ensure they are responsive to member needs and preferences. Supervisory visits

should also include an assessment of the well-being of the family member(s) and offer support/services/resources for any identified need.

In accordance with AHCCCS Medical Policy Manual (AMPM) Section 1620, case managers will review with a member/family members/Health Care Decision Makers (and other members of the service planning team) various service delivery models and utilize a decision tree to make an informed decision regarding the model that will best meet the member's needs, including decisions about the individuals who will serve as caregivers such as DCWs recruited by the agency and/or member/family, non-parental family members, and/or parents as a last resort when other options have been exhausted and when the parent is willing and able to provide the paid care.

Consistent with AHCCCS' ALTCS guiding principles, the person centered planning process should maximize member-direction and support the member to make an informed decision and lead/participate in the process to the fullest extent possible. Specifically, Members will have an informed choice of providers and shall have the final say in who provides their care, including whether a parent or non-parent DCW serves as a paid caregiver. Case managers will document any selection of a member-directed service model option in the PCSP, including the option for parents of minor children to provide paid care. Unless medically contraindicated, the PCSP shall also include an individualized habilitation goal based upon the member's needs and preferences that affords the member interaction with peers in community settings.

Parents who provide these services must also maintain quarterly in-person case management visits as further detailed in AMPM 1620-E. Parents would be limited to 40 hours of paid care, per child, in a given week where paid care by a parent caregiver cannot exceed more than 16 hours in a single day. If two children are receiving direct care services (habilitation, attendant care, personal care, or homemaker services), the parent(s) may provide up to a combined 80 hours of paid care per week (40 hours for each child). The exact number of hours (up to 40 per child) approved for payment will be determined through the person-centered planning process and must meet medical necessity requirements. Although these hourly limitations are in place, members can still receive more than 40 hours of authorized paid care in a given week through the use of an alternate caregiver.

Currently, in Arizona, there are 277 members receiving over 40 hours of paid care from their parent providers out of the total 3,454 members with parent DCWs. In order to allow adequate time for families and provider agencies to prepare for the 40 hour limit, the state proposes to implement a phased-in approach for families already enrolled in the program and currently providing care over the 40 hour limit. The phased-in approach will be implemented as follows:

1. From the time of approval until January 31, 2024: There will be no hourly limitations in place.
2. From February 1, 2024, until May 31, 2024: There will be an 80 hour per week limitation.
3. From June 1, 2024, to September 30th, 2024: The hourly limitation will drop to 60 hours a week.
4. Beginning October 1, 2024, and thereafter: The 40 hour per week limitation will be in effect.

Providers will ensure they have active and implementable workforce plans that are reflective of their entire current membership needs irrespective of whether or not members are served by a parent DCW. Parents of minor children should only be considered for paid care as an alternative when all other options have been exhausted. This workforce plan will be considerate of recruiting and retaining an

adequately trained and competent workforce that can meet their membership's unique healthcare and acuity needs and preferences.

Extend Family Support/Home Care Maintenance:

As an auxiliary support to the PPCG proposal detailed above, the Agency is proposing to establish a home care training family support (family support) service as part of the HCBS benefit package detailed in "Attachment L" of the State's approved STC document (Project Number 11-W-00275/9) for the long-term care population on the basis of the institutional level of care criteria (age or disability) that qualifies them for long term services and supports. Family support is directed toward restoration, enhancement, or maintenance of the family functioning to increase the family's ability to effectively interact and care for the member in the home and community. This service provides critical supports to members and their caregivers for the purpose of learning about, navigating, and planning for implementation of their Person-Centered Service Plans (PCSP) and help to address the needs of the family member(s), who are providing compensated and uncompensated care, including challenges they face when coping with the member's health care condition(s) and related stress and isolation that accompanies continuous and daily care of the member. Currently, a comparable service is available to AHCCCS members with a behavioral health need under the rehabilitation benefit in the agency's State Plan. By extending this benefit to the long-term care population and expanding beyond just those with a behavioral health need, AHCCCS will be better positioned to preserve the supportive environment and sustain the likelihood of members remaining in their home, thereby mitigating access to care challenges and risks of the member's utilization of higher levels of care in order to have their needs met.

AHCCCS is seeking authority to provide family support to primary caregivers (providing compensated and uncompensated care) of children and adults enrolled in the Arizona Long Term Care System (ALTCS) program. The service will be provided by family members who have lived experience in supporting a family member enrolled in the ALTCS program and demonstrate competencies required to provide the service. Family support may involve activities such as assisting the family to learn skills related to adjustment to the member's disability or aging process or significant life events or transitions, enhancing and improving the health and well-being of the member and family unit, navigating the health care system, self-advocacy, development of natural supports and community support systems, participating in the PCSP development, and implementation of individual and family goals and long-term life planning.

Family support would be limited to ALTCS members who are residing at home and will not supplant case management services. Primary family caregivers are eligible for the service and that includes families created through birth, foster care, adoption, marriage, or a self-created family unit. The service will be authorized by the case manager with limits on the amount, frequency and/or duration specified in PCSP and based on assessed needs. The PCSP will include a specific assessment of the family members' physical and mental well-being and outline targeted goals for both the family member and the member specific to the family support service. Family support may be provided individually or in a group setting. Additionally, more than one provider agency may bill for family support provided to a member at the same time if indicated by the member's assessed needs as identified through their PCSP.

III. WAIVER AMENDMENT PROPOSAL DETAILS

A. Proposed Cost Sharing Requirements under the Demonstration as Amended:

This Demonstration does not change the Medicaid benefit package design; there is no new cost-sharing, copayments, or coinsurance for any benefit provided under the waiver. State Plan benefits will continue

to be applied in accordance with the State Plan and all eligibility groups will continue to receive all State Plan benefits.

B. Proposed Changes to the Delivery System under the Demonstration as Amended:

The delivery system for persons impacted by this proposed 1115 Waiver amendment will not vary from AHCCCS' current program features as described in the current State Plan and Demonstration.

C. Proposed Changes to Benefit Coverage under the Demonstration as Amended:

Through the Extended Family Support and Home Care Maintenance Demonstration, AHCCCS is seeking to add an additional benefit to the existing HCBS benefit package detailed in "Attachment L" of the State's approved STC document (Project Number 11-W-00275/9). The proposed service provides critical support to members and their caregivers to assist with the education, navigation, and implementation of their PCSPs to address the needs of the family members serving with the goal of restoring, enhancing, and maintaining family functioning.

D. Proposed Changes to Eligibility Requirements.

The Demonstration does not change the Medicaid benefit package design; there are no new eligibility requirements outside of those established as an eligible minor within ALTCS enrolled within Arizona's 1115 Demonstration Project.

IV. REQUESTED WAIVER & EXPENDITURE AUTHORITIES

REQUESTED WAIVER & EXPENDITURE AUTHORITIES

Comparability; Amount, Duration, Scope of Services

**1902(a)(10)(B); 1902(a)(17)
(42 CFR 440.240)
(42 CFR 440.230)**

To the extent necessary to enable the State to offer different or additional services to some categorically eligible individuals, than to other eligible individuals, based on differing care arrangements for eligible minor ALTCS members in the Parents as Paid Caregivers Program.

To the extent necessary to permit the State to offer coverage through MCOs that provide additional or different benefits to enrollees, than those otherwise available to other eligible individuals.

Parents as Paid Caregivers

1905(a)(24); (42 CFR 440.167)

To the extent necessary to enable the State to allow parents to perform demonstration caregiver services, including personal care and habilitation services, for eligible minor ALTCS members notwithstanding the requirements of 42 CFR 440.167.

Comparability; Amount, Duration, Scope of Services

1902(a)(10)(B); 1902(a)(17)

(42 CFR 440.240)

(42 CFR 440.230)

To the extent necessary to enable the State to offer the family support demonstration service to some categorically eligible individuals, and not to other eligible individuals, based on differing care arrangements for eligible ALTCS members living at home.

To the extent necessary to permit the State to offer coverage through MCOs that provide additional or different benefits to enrollees, than those otherwise available to other eligible individuals.

Parents as Paid Caregivers

Expenditures for demonstration caregiver services, including habilitation and personal care, provided by parents of eligible minor ALTCS members that are inconsistent with the requirements of 42 CFR 440.167.

Family Support

Expenditures for the family support demonstration service provided to eligible ALTCS members living at home.

V. EVALUATION DESIGN

Arizona’s 1115 Waiver Evaluation design will be modified to incorporate the AHCCCS Parents as Paid Caregivers demonstration proposal. The table below outlines the proposed hypotheses for this 1115 Waiver amendment and potential performance measures that would allow AHCCCS to effectively test each of the specific hypotheses.

Parents as Paid Caregivers Objectives, Hypothesis, and Approaches

Objectives	Proposed Hypothesis	Potential Approaches
The AHCCCS Parents as Paid Caregivers demonstration and Extended Family Support Demonstration will increase member satisfaction, ensure delivery of medically appropriate services in the community, and promote positive health and well-being outcomes for the target population.	Both the AHCCCS Parents as Paid Caregivers demonstration and Extended Family Support demonstration will maintain or increase the rate of children in the ALTCS program being served in the home.	Data will be drawn from a variety of sources including, but not limited to: <ul style="list-style-type: none"> ● Member surveys, ● State eligibility and enrollment data, ● Claims/encounter data, ● Administrative program data (PMMIS), ● T-MSIS, and ● National/regional benchmarks.
	Both the AHCCCS Parents as Paid Caregivers demonstration and Extended Family Support demonstration yield improved member satisfaction with care.	
	The AHCCCS Parents as Paid Caregivers demonstration will mitigate the DCW shortage by increasing timely	

	accessibility to care providers.	
	The AHCCCS Parents as Paid Caregiver demonstration will improve ongoing care stability for the target population.	
	The AHCCCS Parents as Paid caregivers demonstration will yield cost-effective care for AHCCCS members.	
	The AHCCCS Extended Family Support demonstration will increase member and family unit stability through decreased stress and burnout.	

Arizona will develop and submit to CMS a summative evaluation report within 18 months of the end of the current Demonstration period. Included in this summative evaluation report will be a discussion on the impacts resulting from payment to parents of minor children as paid caregivers and extended family support services.

VI. PUBLIC NOTICE PROCESS

Pursuant to the terms and conditions that govern Arizona’s Demonstration, Arizona must provide documentation of its compliance with the Demonstration of Public Notice process (42 CFR 431.408), the tribal consultation requirements pursuant to Section 1902(a)(73) of the Act as amended by Section 5006(e) of the American Recovery and Reinvestment Act of 2009, and the tribal consultation requirements outlined in STC 13.

Public Website

The AHCCCS Parents as Paid Caregivers amendment proposal was posted on the AHCCCS website at <https://www.azahcccs.gov/Resources/Federal/PendingWaivers/ParentCareGivers.html> on June 16, 2023, for public comment. The web page includes a summary of the waiver amendment request, the schedule (dates and times) of public forums across the state, and this draft Waiver amendment proposal. In addition to the website posting, AHCCCS uses social media accounts and electronic mail to notify interested parties about Arizona’s Waiver amendment proposal.

Publication of Public Notice in the Arizona Administrative Register

On July 07, 2023, public notice of the AHCCCS Parents as Paid Caregivers amendment proposal was published in the Arizona Administrative Register. The notice included a summary description of the 1115 Waiver amendment request, the locations, dates and times of the public hearings, instructions on how to submit comments, and a link to where copies of Arizona’s Waiver amendment proposal are available for public review and comments.

Stakeholder Meetings:

AHCCCS presented the details of Arizona’s Parents as Paid Caregivers amendment proposal at two virtual public forum meetings on July 18, 2023, and August 2, 2023, and at Tribal Consultation held on June 22,

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2023. In addition, the demonstration proposal was presented at the State Medicaid Advisory Committee (SMAC) meeting on July 12, 2023. Stakeholders were able to submit comments and questions on the proposed 1115 Waiver amendment request during any of the forums, by email to: waiverpublicinput@azahcccs.gov, or by mail to: AHCCCS, c/o Division of Community Advocacy and Intergovernmental Relations (DCAIR); 801 E. Jefferson Street, MD 4200, Phoenix, AZ 85034. All comments must have been received by August 21, 2023.

AHCCCS will be presenting the changes to the Parents as Paid Caregivers amendment proposal informed by the public comment period at an additional Public Forum held on September 6, 2023. Details regarding the additional public forum can be found below.

Public Forum Meeting	Meeting Dates & Times	Meeting Web Link & Call-in Information
<p>Post Public Comment Public Forum</p>	<p>September 6, 2023, 1 p.m. - 2 p.m. AZ Time</p>	<p>Register in advance for this webinar: https://ahcccs.zoom.us/webinar/register/WN_KjJweFG1Rw-fUQYYQei_6A</p> <p>Or join by phone:</p> <p>Dial(for higher quality, dial a number based on your current location): US: +1 408 638 0968 or +1 669 444 9171 or +1 669 900 6833 or +1 719 359 4580 or +1 253 205 0468 or +1 253 215 8782 or +1 346 248 7799 or +1 312 626 6799 or +1 360 209 5623 or +1 386 347 5053 or +1 507 473 4847 or +1 564 217 2000 or +1 646 876 9923 or +1 646 931 3860 or +1 689 278 1000 or +1 301 715 8592 or +1 305 224 1968 or +1 309 205 3325 or 888 475 4499 (Toll Free) or 833 548 0276 (Toll Free) or 833 548 0282 (Toll Free) or</p>

		877 853 5257 (Toll Free) Webinar ID: 820 9183 2369 Passcode: 392302918
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More information about the proposed 1115 Waiver amendment, including the proposed 1115 Waiver application and the full public notice and public input process, can be found at <https://www.azahcccs.gov/Resources/Federal/PendingWaivers/ParentCareGivers.html>.

VII. PUBLIC COMMENT SUMMARY

As part of Arizona’s Parents as Paid Caregivers Waiver Amendment, AHCCCS acknowledged, reviewed, and considered all comments received throughout the public input process. In total, AHCCCS directly engaged more than 1700 stakeholders across the state through community forums and other regularly held meetings. AHCCCS received over 2,500 pieces of written and verbal input throughout the duration of the public input process. These responses were obtained from a variety of different stakeholders including, but not limited to, providers, public health organizations, legal advocates, tribal organizations, hospitals, and consumer advocacy groups.

AHCCCS is in the process of compiling and summarizing key themes of all received comments for publication within this proposal. AHCCCS has considered and utilized all comments received to inform the changes of the proposal to create this present version. Publication of all comments along with responses to the most common themes will be included in this updated proposal in the coming week.

VIII. BUDGET NEUTRALITY

This Parents as Paid Caregivers Amendment Proposal is not changing or adding any existing service that will have a material impact on the existing Budget Neutrality Workbook that exists for the State’s current 1115 Demonstration number 11-W-00275/9. Due to the authority regarding parents as paid caregivers already existing through a temporary COVID-19 Appendix K flexibility at the time the full budget neutrality model was created, the State does not anticipate a change within the existing member month rates or capitation rates. Rather, this proposal is requesting a permanent extension of an already existing temporary flexibility through an 1115 Demonstration Waiver.

IX. APPENDIX

Include all supplemental information needed for the application. This can include Budget neutrality reports, public notice documentation, or any other information deemed necessary for the approval of the application.