Advancing Equity for Older Adults without Family Caregivers: Trends in Medicaid Waivers

ADVANCING STATES

Advancing Equity for Older Adults without Family Caregivers: Trends in Medicaid Waivers

FALL 2024

AUTHORS

Jane Lowers, PhD, MPA

Stephanie Herr, MPHc

Emory University

Contents

Background

The number of older adults in the United States who need long-term services and supports (LTSS) is growing rapidly, with unpaid family care accounting for 65 percent of that care.[1] However, one in seven older adults with significant needs for LTSS in 2020 did not have a spouse or children; by 2080, the proportion will be one in four. While some of the care for that population is projected to shift to paid care professionals, adults aging solo often turn to friends, neighbors and other members of their social networks to provide care.[2]

Medicaid provides states with a broad array of opportunities to deliver home and community-based services (HCBS) to help older adults and adults and children with disabilities to live independently in their community using sections 1915(c) and 1115 of the Social Security Act. States must submit documents to CMS in order to obtain approval under these authorities to offer HCBS. For ease of reference throughout this document, we will use the word “waiver" or “waivers” to encompass any authority that a state uses to deliver HCBS.

Many waivers incorporate provisions that recognize the importance of family caregivers in planning and providing those services. However, states vary widely in whether and how they define family in waivers, and those definitions may not reflect the needs and resources of adults aging solo and the friends and neighbors who look after them.

To assist states designing and/or revising HCBS waivers, ADvancing States analyzed how waiver language defines family caregivers and how those definitions relate to older adults without immediate family available as caregivers.

[1] M. Favreault, J. Dey, L. Anderson, H. Lamont and W. Marton. Future Change in Caregiving Networks: How Family Caregivers and Direct Care Workers Support Older Adults Now and in the Future. Office of Behavioral Health, Disability and Aging Policy Aug. 2, 2023 Washington, DC:

[2] J. Lowers et al. Solo But Not Alone: An Examination of Social and Help Networks among Community-Dwelling Older Adults without Close Family. 2022. J App Geron

Use Cases

To illustrate the potential real-world impacts of waiver definitions, we present two use cases of adults without family caregivers and the ramifications of different provisions and variation in waiver language.

Case 1: Trish and Claudette are neighbors in a mobile home park. Both are widowed with limited incomes, and both have children living in distant states. As Claudette begins having health problems, Trish drives her to appointments and begins managing her medication and eventually her health care.

Case 2: Linda joined Main Street Church after moving to a new city upon retirement. Linda's fellow parishioners don't know her well, but they know she was never married and has no children. A judge orders Linda to stop driving after several accidents, and it becomes clear that she has progressive cognitive decline. Members of the pastoral care committee take her to church and shopping.

Methods

ADvancing States reviewed Section 1115 demonstrations and Section 1915(c) waiver applications listed as "approved" on Medicaid's State Waivers List between January 1 – June 30, 2024. The analysis focused on waivers that included adults ages 65 and older. The full text of each waiver was searched for text addressing the following questions:

1. How does the waiver define "family," "caregiver," or "legally responsible individual," if at all?
2. Who can participate in development of a person-centered service plan?
3. What training or support services, if any, are available to family or caregivers?
4. If respite services are covered, for whom are they offered?
5. Who can be paid to provide waiver services?

Waiver text relating to each question was evaluated and categorized for analysis. For example, waiver descriptions of who can participate in care planning were broadly categorized into "consumer and LRI/guardian only" or "consumer and anyone they choose." Waiver applications use various terms for the person receiving services, including client, consumer, individual, member, participant, person, and recipient. For purposes of this report, we use "consumer."

Limitations

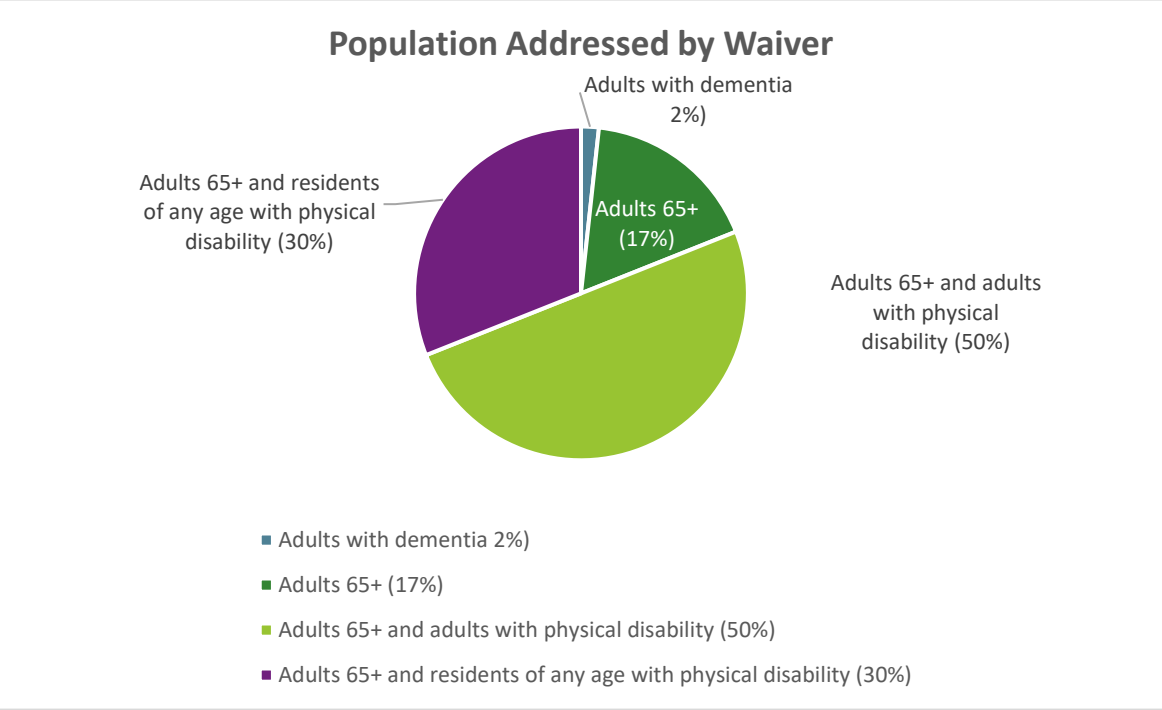
States have discretion in how they define family, caregiver, or legally responsible individual (LRI), and few waivers specifically do so. Within a single waiver, multiple terms (e.g., primary caregiver, unpaid caregiver, natural supports) may be used. We did not look at state statutes or agency regulations for definitions not specified in waivers.

Services not specified in waivers may be nonetheless offered through other state or local mechanisms.

Waivers Overview

We identified 58 waivers in 49 states and the District of Columbia that provide HCBS for adults ages 65 and older (referred to as older adults). These included nine 1115 demonstrations and 49 1915(c) waivers. Six states (Indiana, Massachusetts, Michigan, Mississippi, Missouri, and South Dakota) had more than one waiver serving older adults.

Half of the waivers that were reviewed included both older adults and adults 18+ with physical disabilities in their service population; one third included residents of any age (including minors) with physical disabilities along with older adults; 10 were specific to older adults, and one (Missouri) focused on adults with dementia.



Who is in a Family?

Waivers use terms including "family," "relatives," and "natural supports" to define who may participate in a range of waiver-related activities. These terms may be used to include (as in who can participate in care planning) or exclude (e.g., who can be paid for providing care). Waivers typically distinguish between family members or relatives and legally responsible individuals. Standard text in the 1915(c) waiver application template states, "A legally responsible individual is any person who has a duty under state law to care for another person and typically includes: (a) the parent (biological or adoptive) of a minor child or the guardian of a minor child who must provide care to the child or (b) a spouse of a waiver participant."

Many approved waivers have no language defining who can be considered family or a relative. Those that do, however, vary widely from limiting family to blood and marriage ties only to including anyone the consumer identifies as family of choice. The broader definition is consistent with guidance in the Older Americans Act final rule, which specifies that "'an adult family member or other individual' … includes unmarried partners, friends or neighbors."

Table 1: Examples of Definitions of Family Found in Medicaid Waivers
"…family members and relatives shall be defined as all persons related to the client by virtue of **blood, marriage, adoption, or [state] common law"** (Colorado)
A family is defined as any person **immediately related to the participant**, such as: parents/legal guardian, spouse, siblings, adult children; or when the **participant lives with other persons capable of providing the care** as a part of the informal support system. (Kansas)
Relatives, but not legal guardians, are permitted to provide waiver services. **A relative may not be a family member (defined as a spouse or any legally responsible relative) …** (Massachusetts)
For the purposes of this service "family" is defined as the **persons who provide care to a waiver participant and includes a parent or other relative. (**Massachusetts**)**
Family is defined as the individual's family of choice. This may include **persons who live with or provide support to a person**, such as a parent, spouse, significant other, children, relatives, foster family, in-laws, or others **defined as family by the individual receiving services.** (New York)

Use cases:

For both Claudette and Linda, their particular state and waiver program policies would determine whether those providing care would be considered family. The case may be more

straightforward for Claudette, who has a strong relationship with a single care partner, Trish. When the consumer is experiencing cognitive and memory issues, such as Linda, case managers may need to work with several care partners to determine who is most involved and trusted by the consumer.

Policy implications:

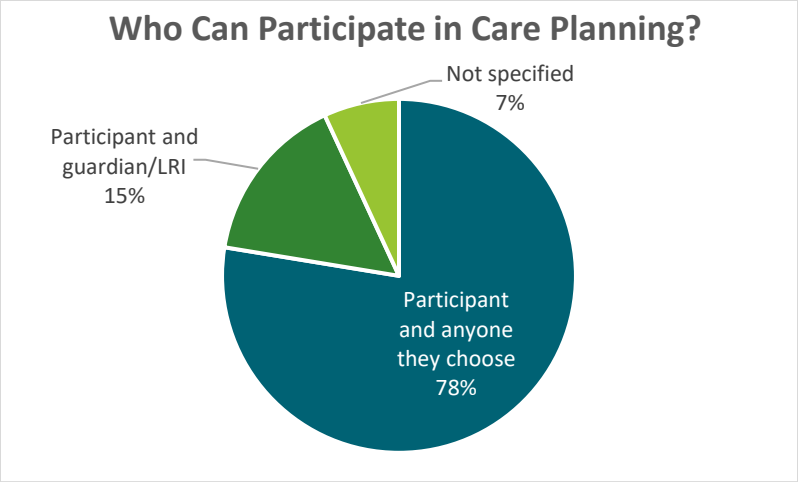
People aging solo often receive help from a variety of distant family members, friends, neighbors and others. Broad and inclusive definitions of family are well-suited to reflect this reality and ensure that those who know the consumer best can be engaged in preserving their independence, if the consumer wishes.

Who Can Participate in Care Planning?

Most waivers specify that the consumer may invite family, friends, or other trusted individuals to participate in the care planning process. Four 1115 waivers did not specify who could participate, and one 1115 and eight 1915(c) waivers limited care planning to the waiver participant and their guardian or LRI. These waivers included one 1115 waiver, three 1915(c) waivers focused on older adults only, and five 1915(c) waivers serving older adults and adults with disabilities.

Use cases:

Under most waivers, Claudette and Linda could invite friends, neighbors and others to join the care planning process regardless of whether they were defined as family. Neither Claudette nor Linda has a guardian or LRI.



Policy implications:

Waivers that open the care planning process to the consumer's full base of support may give case managers the best opportunity to fully assess the needs and resources of individuals aging solo. Importantly, the federal HCBS settings rule requires that care planning be led by the consumer as much as possible, including centering their priorities for what services and supports to receive and from whom. The Administration on Community Living offers guidance on developing person-centered systems. In 1915(c) waivers, the individual service plan development process is detailed in Appendix D.

Few adults aging solo have guardians or legally responsible individuals. States drafting or renewing waivers that include older adults should review care planning language to ensure that provisions relevant to minors or adults with I/DD are not unintentionally limiting care planning for older adults with different social supports.

Caregiver Training

Half of the waivers (28) offer some form of training or support for either paid or unpaid family caregivers. Caregiver skills (such as disease management, self-care, or health system navigation) or coaching are the most common benefits, found in 14 waivers. These services range from training for the consumer and their caregiver on disease management to specific caregiver coaching programs to help reduce burnout and health risks for both the consumer and caregiver. Some services, such as Structured Family Caregiving (SFC) offered in South Dakota's waiver program (see Table 2, below) or Missouri's dementia-specific SFC program, offer caregiver training provided by a Medicaid enrolled provider agency. In other cases, such as Minnesota's caregiver training and counseling, services may be provided by individual consultants, care organizations, or community or education institutions.

Table 2: Sample Caregiver Training Provisions

State/Authority	Sample Language
AZ (1115) Arizona Medicaid Section 1115 Demonstration	**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. Family Support includes assisting the family to learn skills related to: (a) adjustment to the beneficiary's disability or aging process or significant life events or transitions, (b) enhancing and improving the health and well-being of the beneficiary and family unit, (c) navigating the health care system, self-advocacy, (d) development of natural supports and community support systems, (e) participating in the PCSP development, and implementation of individual and family goals and (f) long-term life planning. (Attachment L: ALTCS Service Definitions)
FL (1915(c)) FL.0962.R02.00	**Caregiver Training:** Training and counseling services for individuals who provide unpaid support, training, companionship

Florida Long-Term Care Waiver	or supervision to recipients. For purposes of this service, individual is defined as any person, family member, neighbor, friend, companion, or co-worker who provides uncompensated care, training, guidance, companionship or support to a person served on the waiver. This service may not be provided in order to train paid caregivers. Training includes instruction about treatment regimens and other services included in the plan of care, use of equipment specified in the plan of care, and includes updates as necessary to safely maintain the enrollee at home. Counseling must be aimed at assisting the unpaid caregiver in meeting the needs of the enrollee. All training for individuals who provide unpaid support to the enrollee must be included in the enrollee's plan of care. (Appendix C)
IN (1915(c)) **IN.0210.R07.00** **Indiana Health & Wellness Waiver**	The purpose of **Caregiver Coaching and Behavior Management** is to enable the stabilization and continued community tenure of a Waiver participant by equipping the participant's lay caregiver(s) with the necessary skills to manage the participant's chronic medical conditions and associated behavioral health needs related to a cognitive impairment and/or dementia. This is not a service provided directly to the waiver participant, but to their lay caregiver(s). This service allows family caregivers who are not eligible to participate in Structured Family Caregiving (i.e.) to access support. (Appendix C)
MN (1915(c)) **MN.0025.R09.00** **Minnesota Elderly Waiver**	**Caregiver Support:** Training and Education is a service that provides caregivers with instruction to improve knowledge and performance of specific skills relating to their caregiving roles and responsibilities and builds caregiver capacity to provide, manage and cope with the caregiving role. It covers training and education on topics, including: • activities related to health, nutrition, and financial management • providing personal care • disease management • managing risk factors • mental health

	• navigating long-term care systems • communicating with health care providers and other family members • family dynamics • self-care skills • dealing with difficult behaviors, and other areas as specified in the support plan • the use of equipment and technology to maintain the health and safety of the participant Caregiver Counseling is an individualized person-centered service designed to support caregivers by assisting them in in their decision-making and problem solving. Caregiver Counseling is provided by enrolled Caregiver Consultant providers who will conduct an assessment of the caregiver's needs and strengths. Providers will develop a support plan based on the caregiver's identified needs and provide ongoing support to reach established goals. Ongoing support may include, but is not limited to: • facilitation of a person-centered learning and discovery process • development of a service description and plan to reach established goals • family counseling, family meetings • implementing tools and strategies for coping with changes in personality and behavior, • problem solving and conflict resolution, • finding resources. (Appendix C)
SD (1915(c)) **SD.0189.R07.00** **South Dakota Home and Community-Based Options and Person Centered Excellence (HOPE) Waiver**	**Structured Family Caregiving**: Educational resources, coaching and support are designed to provide each caregiver with the competencies necessary to provide daily care to a participant and help the caregiver identify health status changes and other signs that could lead to unplanned hospitalizations or preventable events. (Appendix C)

Other waivers incorporate training for caregivers on use of assistive devices needed by the consumer, or on continuing specific therapies (e.g., occupational, speech) prescribed to the consumer.

Use cases:

Friends and neighbors like Trish often begin offering assistance casually, but the scale and complexity of care can increase dramatically. Waivers that train caregivers to recognize and respond to disease-specific needs, engage with waiver-provided services, or engage in self-care have potential to expand the capacity and longevity of informal care systems.

Policy implications:

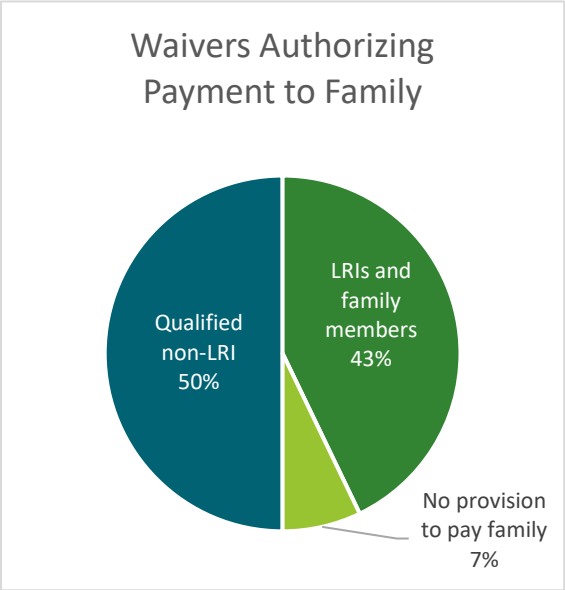
Caregiver training can support all caregivers, whether family or not, to reduce the need for paid services. States delivering caregiver supports in waivers should consider adapting language similar to that from Florida (See Table 2, above), which clarifies that caregivers need not be related to the consumer to receive caregiver support and training.

Several states have implemented Structured Family Caregiving options in their waiver applications. SFC incorporates payment, training, caregiver coaching and other supports for a primary caregiver, generally via a licensed entity such as a home health agency.

Payment for Providing Care

Among 58 waivers serving older adults, 54 included some provision to pay family or friends. These waivers included structured family caregiving models, self-directed care in which consumers could hire and manage caregivers directly, and models allowing eligible caregivers to be hired, paid, trained, and supported through home care agencies.

Waivers that serve older adults often limit payments to spouses, as they frequently fall within the definition of legally responsible individual (LRI). State definitions of LRI typically include parents or guardians of a minor child or the spouse of a waiver participant.



Whether through self-directed payments or agency-run models, non-kin caregivers appear to have fewer obstacles than family for receiving payment for delivering waiver services in most cases. Some structured family caregiving models limit participation to specific family roles. Georgia's SFC provision requires that the waiver participant and primary caregiver be related biologically or by marriage, but the primary caregiver cannot be the participant's spouse. Missouri's SFC program for dementia includes family, non-family, and legal guardians as caregivers. South Dakota's waiver includes both relatives and fictive (or chosen) kin, defined as "an individual who is not related by birth, adoption, or marriage but who has an emotionally significant relationship with the participant" and who, for purposes of the waiver, lives with the waiver participant.

Use cases:

Waivers serving older adults pose relatively few barriers for non-kin caregivers – Claudette and Linda's support networks would likely be eligible. It is unclear whether "family" or "relative" have the same meaning throughout individual waivers; even if Claudette identified Trish as family of choice for care planning purposes, it is unclear whether that would preclude Trish, who is related by neither blood nor marriage, from becoming a paid caregiver for Claudette.

Policy implications:

Provisions to pay caregivers who are part of the consumer's support network but not part of the professional personal care workforce are important for helping older adults secure assistance to live independently from trusted sources, and many waivers now include such provisions. Fewer waivers, however, have provisions to train these same caregivers to perform the tasks they can now be paid for. Efforts to increase the engagement of family, friends, and others in waiver-supported care may require not only payment but ongoing training.

Access to Respite Care

Forty-eight waivers serving older adults included some provision for respite care. Five (10%) of these waivers specify they cover respite only in the home, four (8%) only provide respite in formal settings such as assisted living or long-term care facilities, while 37 (77%) allow for respite in either setting. The 1115 waivers in New Jersey and Rhode Island included provisions for respite care but did not specify where services could be provided. While most of the waivers (27) pay for respite care either from a caregiver or a respite professional, there is wide variation across the other waivers in terms of who can provide respite care. For example, some waivers only cover respite delivered by licensed professionals, regardless of whether the care is provided in the home or an institutional setting and other waivers specify that relatives can be hired by agencies as respite providers.

Waivers vary considerably in how they determine eligibility for respite but typically describe respite as a short-term service provided in the absence of or need for relief of a person providing care for the consumer. Most waivers (29) define that person as the "primary caregiver" but another 12 specify an unpaid caregiver, and five specify a caregiver who lives with the consumer. Three waivers take a broad definition: the consumer's "natural supports."

Use cases:

Friends and neighbors who take on caregiving would be unlikely to qualify for respite in states that require a caregiver to live with the consumer, but Trish would likely qualify as Claudette's primary caregiver or unpaid caregiver. Linda's case could be more complex: case managers would need to determine who qualified as the primary/unpaid caregiver to satisfy most waivers.

Policy implications:

Waivers that limit respite to situations in which a caregiver resides with the consumer exclude caregivers, related or unrelated, who may provide substantial support while living separately. In addition, when eligibility for respite services is limited to circumstances where there are only "unpaid" caregivers this may conflict with other waiver provisions that allow for payment to family, friends and LRI. States need to consider whether they want to exclude respite care when a primary caregiver receives some compensation for providing waiver-based care. A family or friend caregiver's paid status should not necessarily preclude respite care.

Summary

Older adults without immediate or nearby family are a rapidly growing portion of the population, and many will need help from non-family sources to live independently. State waivers serving older adults vary widely in the ways they define family and caregivers, and in the caregiver supports they offer.

States can improve equitable access to caregiver support for people without immediate family in their HCBS waivers in a number of ways:

- Apply a broad definition of "family" to include whoever is important to the consumer.
- Ensure thorough care planning to identify the full range of friends, neighbors, and others who may be willing to help the consumer.
- Offer training, respite, payment, and other supports for caregivers defined broadly (e.g., not limiting respite to consumers who have a caregiver residing with them)

Leadership, innovation, collaboration
for state Aging and Disability agencies.

241 18th Street S, Suite 403
Arlington, VA 22202
Phone: 202-898-2578
www.advancingstates.org
www.hcbs.org