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Emerging Respite Care Strategies in Medicaid Home and Community-Based Services Waivers for Older Adults, Adults with Physical Disabilities, and their Family Caregivers

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Introduction

Abundant research — and often our own lived experience — points to the physical, mental, and emotional toll of caregiving. With caregivers increasingly asked to perform more intense and complex care, respite care is integral to giving caregivers a much-needed break. Respite care is a service typically delivered in the home or a facility-based setting that provides short-term relief for caregivers. It is one of the most desired caregiver services, and Medicaid is one policy lever to fund it. Through Medicaid's federal-state partnership and under a variety of home and community-based services (HCBS) coverage authorities, states have the flexibility to design HCBS to meet the long-term care needs of their populations. While states utilize a number of federal programs to provide respite, Medicaid is the largest payer of long-term care services, including respite.

In 2022, NASHP found that 47 states and DC cover respite through Medicaid HCBS waivers serving older adults and adults with physical disabilities. For the 23 states that offer managed care for these populations, all 23 Managed Long-Term Services and Supports (MLTSS) states include respite services in their managed care contracts. No two states' respite policies are identical, and many states have not created new or updated old respite policies in years or decades. Despite Medicaid's role as a major payer of long-term services and supports (LTSS), the amount that states estimated they will spend on respite care is a small portion compared to other waiver services. Although most states offer respite through Medicaid, varied program policies and payment rates among states greatly affect caregivers' access to high-quality respite services. Trials have found that when older adults' caregivers receive supports that include respite, caregiver outcomes improve, older adults' nursing home placement is delayed, and there is a decrease in hospital readmissions and emergency room expenditures.

Respite is a key component of the 2022 National Strategy to Support Family Caregivers. To inform this national strategy, our partners, the University of Massachusetts at Boston and Community Catalyst, conducted listening sessions with family caregivers to identify their challenges and service improvement recommendations. One of the highest priorities that family caregivers identified was respite care and the need for a "break." However, family caregivers expressed concerns and identified desired improvements in delivering the service. For example, many found it difficult to trust unknown providers to provide care (especially in their homes) or, alternatively, to procure and pay for quality providers. They also wished for more flexibility in program policies, such as expanding the types of providers that could provide respite. The interest in respite care from family caregivers inspired our deep dive into this service and our search for innovative policy approaches among states.

In late 2022, NASHP interviewed Medicaid HCBS waiver administrators from seven states: Iowa, Kentucky, Louisiana, Missouri, Texas, Virginia, and Washington. After a comprehensive 50-state review of respite services within Medicaid waivers and managed care programs serving older adults and adults with physical disabilities, we chose these seven states due to their innovative approaches to administering respite care. This paper identifies emerging respite policy strategies and key themes from these interviews. Many of these strategies can be implemented as small policy changes (e.g., waiver amendments and renewals) but can make a large impact and difference for older adults and their caregivers. As Medicaid state officials look toward both small and large-scale waiver redesign — especially as the COVID-19 public health emergency (PHE) unwinds — these findings can be used as a resource to strengthen respite care policies.

Home and Community-Based Services (HCBS) Waiver Basics

- Home and-community based services (HCBS) allows individuals who meet an institutional level of care (e.g., nursing home) to receive long-term care services in their home and community.
- Under an HCBS waiver, State Medicaid agencies administer HCBS through a fee-for-service delivery system, a managed care system, or both.
- States must demonstrate budget neutrality, meaning the total federal costs under the waiver cannot exceed total federal costs absent the waiver.
- The federal Home and Community-Based Services Final Rule requires a person-centered service plan for all individuals receiving Medicaid HCBS, based on an individual assessment to determine the type and appropriate amount of services.
- HCBS can be either provider-managed or participant-directed ("self-direction")
    - If a state allows and a beneficiary requests self-direction of HCBS, the individual has budget and/or employer authority to decide how much and which types of HCBS they need, as long as they stay within their individual budget and adhere to any provider qualifications set forth by the state.

Emerging Strategies

Key themes and emerging strategies drawn from our seven state interviews include the following, with each examined in more detail below:

Education: Recognizing that awareness and outreach are the first steps to access, study states developed strategies to ensure that caregivers and caseworkers understand respite's availability and importance.

Types of Respite: Study states created multiple types of respite care based on the complexity of a member's needs.

Flexibility: To minimize disruptions in caregiving, study states' policies provided flexibility to meet month-to-month changes in individual participant's and family caregiver's respite service needs.

Self-Direction: Study states used self-direction programs to integrate family members and friends into the direct care workforce as respite care providers.

Managed Care: Study states leveraged the flexibilities offered by managed care to streamline and increase access to respite services.

Payment: Respite reimbursement rates can influence providers' willingness to provide respite, which in turn can affect respite access and utilization.

For a detailed description of each study state's Medicaid respite services, please see the appendix at the end of the paper.

Recognizing that awareness and outreach are the first steps to access, study states developed strategies to ensure that caregivers and caseworkers understand respite's availability and importance.

Being a caregiver is a natural and assumed role for many, but caregivers often don't know what services are available to support them. States can integrate culturally aware and targeted initiatives so that education on respite services reaches diverse populations. When study states took extra steps to teach individuals and communities about respite, families better understood how to access the care and support they needed. Washington and Kentucky offer examples of innovative outreach strategies.

Washington: Culturally Aware Training for Respite Providers and Families in the Port Gamble S'Klallam Tribe

Washington Aging and Long-Term Supports Administration, through the ACL Lifespan Respite Grant funding, are piloting a culturally aware training and education program for respite providers and family caregivers with the S'Klallam Tribe.

The state recognizes that caregivers who are members of the tribal communities are more likely to use respite if the person providing respite is also a member of the tribe. Leaving a family member under the care of someone else requires trust, and familiarity among tribal members facilitates such trust, as it implies understanding of one's family and culture. Tribal members are also more likely to find out about a service and use it if they know someone who provides it — and more likely to apply if they hear about it from someone they trust, like a fellow tribal member.

The pilot's training aims to increase the number of tribal community members who are qualified and trained to provide respite. The pilot educates tribal families about the benefits of using a trusted, familiar respite provider to give caregivers a break. Through coordination with established agencies that tribal members know to look to first, such as the Elders Program, the pilot further increases awareness of respite and improves outreach efforts. In developing outreach about respite that incorporates understanding of cultural values and traditions among tribal populations, the pilot is an example of intentional outreach that can help diverse populations feel understood and supported. While this program is still a pilot, and results and materials are not yet published, the state hopes to eventually use this model as a template for other tribal community respite programs in Washington.

"Because of what we learned about equity and diversity during the COVID-19 pandemic, we have really ramped up trying to help tribal communities learn about respite and train tribal community members to provide respite because those are the people tribal members trust and would feel more comfortable having in their homes as respite providers."

—Washington State Official

Kentucky: Education through Case Managers and Community Engagement

Waiver administrators in Kentucky's Department for Medicaid Services educate participants about the availability of respite services through their case managers and community organization engagement.

Case managers, who explain what types of services are available to beneficiaries and coordinate the provision of services, are encouraged by waiver administrators to highlight respite specifically as an important part of the array of services a person can receive. When a case manager explains respite and its importance to a waiver participant and their family from the onset of services, a caregiver better knows how to utilize it to take the breaks they need.

Kentucky also engages outside organizations, such as support groups, councils, and coalitions, in their respite outreach. As these groups are trusted sources of information for their members, waiver administrators have found it effective to educate these groups about the benefits of respite for caregivers and in turn have these organizations educate their members.

"We've really been working with our case managers, our support brokers, the people that are leading those [person-centered care planning] meetings to make sure you look at the whole person, suggest [respite], and let them know what it's all about. Encourage them, let them know how important it is that they understand that them being healthy and taken care of makes them a better caretaker."

—Kentucky State Official

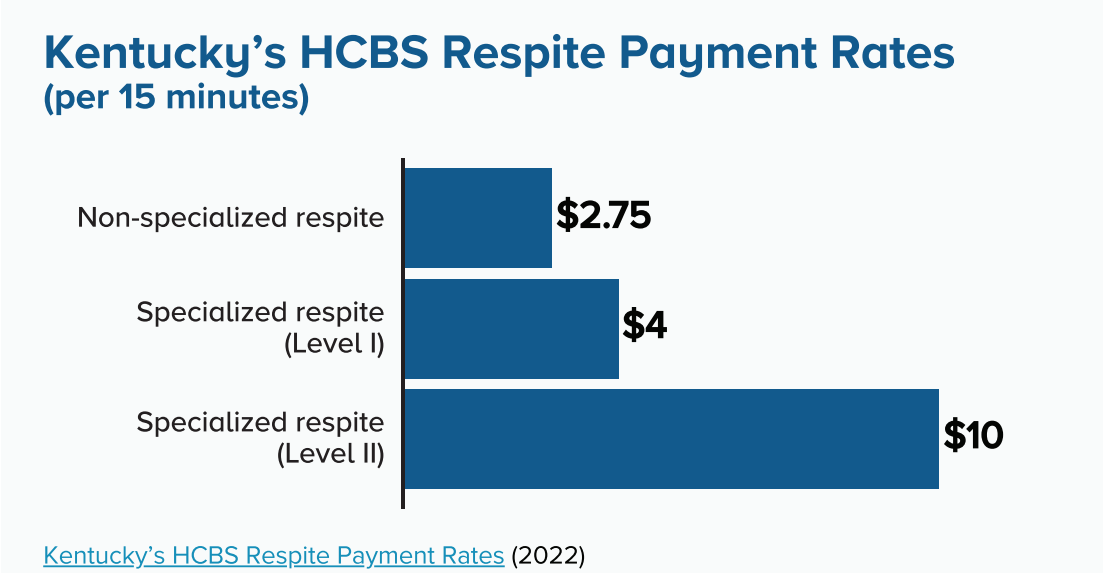
Study states created multiple types of respite care based on the complexity of a member's needs.

In Medicaid waiver applications, most states typically offer respite services as a single service type ("respite") or differentiate by service location ("respite — in-home" or "respite — facility-based"). Three of the study states, however, further differentiate among types of respite services. This approach enables these states to target services more closely to an individual's needs. This differentiation may become particularly important as states increasingly grapple with addressing comorbid conditions and complex care needs among waiver participants.

Among these three states, **Kentucky's** 1915(c) KY Home and Community Based Waiver offers both specialized and non-specialized respite for a non-paid caregiver, with the following distinction:

- Non-specialized respite: This service is only self-directed and addresses individualized self-care, safety, positive social impact and recreational needs, and supervision needs.
- Specialized respite: This service is only provider-managed with the additional requirement that direct care staff must have 24-hour access to a registered nurse (RN) for consultation and emergency situations. There are two levels of the service, depending on the individual's acuity and type of service provider:
    - Level I: Meets the Level I High Intensity criteria established in the Kentucky Home Assessment Tool (K-HAT) and is intended for medically fragile or intensive cases that will not require skilled care during the respite time. However, individuals will have access to an RN for consultation if any needs arise.
    - Level II: Meets the Level II High Intensity criteria established in the Kentucky Home Assessment Tool (K-HAT) and is provided by an RN or licensed practical nurse under the supervision of an RN.

Kentucky is unique in that it broadens the circumstances under which a participant could qualify for specialized respite to also include "the sudden absence or illness of the primary caregiver who normally provides care for the participant." Kentucky recently conducted an HCBS Rate Study, through which officials incorporated community input and analyzed provider waiver costs. As of 2022, Kentucky's HCBS provider reimbursement rates for respite care are:



Kentucky's HCBS Respite Payment Rates (2022)

Among study states, Kentucky is one of the few states to vary respite payment rates based on the complexity of a beneficiary's needs. As states navigate the direct care workforce shortage, waiver rate methodology based on specialized care can be an emerging strategy to incentivize providers.

Missouri defines its two types of respite based on whether a waiver participant's needs may be safely met by someone with specialized training.

- Basic respite is provided to a waiver participant whose needs do not require specialized training.
- Advanced respite is provided to those whose needs do require specialized training.

Waiver participants who may need advanced respite include participants who display disruptive behaviors due to a behavioral health condition, such as Alzheimer's disease, those who are bedfast and need assistance with mechanical transfer equipment, and those who need "special monitoring and assistance … due to swallowing problems." Missouri is the only state to specifically mention those with Alzheimer's disease within their respite definition. For advanced respite, providers are required to complete additional training by an RN based on an individual's needs. While an advanced respite provider does not need to be an RN, the RN needs to observe and document successful service delivery.

Iowa defines the three different types of respite it covers by staff-to-waiver participant ratios and whether, absent the caregiver, a licensed nurse is needed to meet the participant's needs.

- Basic individual respite is provided at a staff-to-participant ratio of one-to-one by a provider who is not a nurse.
- Group respite is respite provided on a ratio of one staff to two or more members receiving respite.
- Specialized respite is provided at a one-to-one ratio by a registered or practical nurse.

While Iowa is one of only a few states to offer group respite, a state official described that utilization for these services varies — with most respite accessed at the individual level. Additionally, Iowa also allows respite services to be provided by a wide variety of providers, including nursing facilities, home health aides, and licensed camps.

To minimize disruptions in caregiving, study states' policies provide flexibility to meet month-to-month changes in individual participant's and family caregiver's respite service needs.

The state officials we interviewed were keen to offer policy flexibilities within their service system to minimize disruptions in caregiving. States understand that an individual's care plan should not be a snapshot in time, but rather malleable to account for unexpected changes in a care recipient's life. These flexibilities fall within two approaches to meet the changes in an individual participant's respite service needs: pooling respite benefits within a state's self-direction program, and packaging respite with personal care. This packaging allows an individual to use the same providers for both respite and personal care, while always giving the beneficiary choice in provider. Allowing the individual to have the same provider can create continuity of care and address unwillingness to have someone unfamiliar or multiple providers in the home. As states look to strengthen support for caregivers within Medicaid, these flexibilities provide a few examples for respite policy design.

Flexibility in Self-Directed Services for Respite

Two of the study states offered approaches for flexibilities with respite within their self-direction programs.

Iowa allows unused respite dollars to be repurposed for future respite purposes. Under Iowa's Consumer Choices Option, individuals have the authority to purchase services through an individualized monthly budget based on a member's assessed needs. Additionally, members may create a "savings plan" to purchase approved goods and services. As promulgated in Iowa's Human Service's regulation 441-78.34(13), the state offers flexibility with an individual's use of respite services within this "savings plan." As stated in the regulation, "Individual funds from unused respite services may be allocated to the savings plan … [for] future respite care." This differs from other HCBS in Iowa, as funds budgeted for other direct services or supports that were not received cannot be saved. This flexibility allows individuals and their caregivers to access respite when they most need it.

Washington permits the pooling of respite units for future use. Similarly, Washington's policy includes the flexibility for individuals to pool their respite care benefit for up to six months if they do not use their full number of allocated hours each month. With caregiving demands a stressful component for families to navigate, this flexibility gives greater choice and preferences to the beneficiary and their caregiver as needs arise.

"We allow [care recipients] to pool their benefit for up to six months. You could use all of your benefit for the next six months and get a weekend in assisted living for your loved one."

—Washington State Official

Packaging Respite and Personal Care Services

To address any service need gaps, study states packaged respite and personal care in a few different ways:

Virginia has the same provider rates for respite and personal care. Virginia state officials reported that within the Cardinal Care (Medicaid) service system, respite and personal care are often interlinked. The rate structure for the Commonwealth Coordinated Care Plus (CCC) Waiver encompasses the same provider rate for both respite and personal care. Additionally, Virginia grants individuals the flexibility to interchange between respite and personal care — if both services are included in an individual's plan of care. A state official noted that they sometimes "see [respite] added on to personal care hours. … It's up to the member or the family." If an individual reaches their respite service limit and a new need arises, Virginia will allow personal care hours to fill in the desired service gap and vice versa. This offers flexibility for both individuals and their families to meet changes

in respite (and personal care) service needs. A Virginia state official noted that the packaging of services makes respite care more known to families.

Kentucky uses personal care if an individual exceeds their respite service limit. To address changes in participant's needs, Kentucky directs its case workers to find other sources of care — including personal care — if an individual's needs exceed the established maximum amount of respite set in the 1915(c) KY Home and Community Based Waiver. As outlined in the waiver, the maximum amount allowed for respite services is "$200 per day alone or in combination with non-specialized respite. Specialized respite alone or in combination with non-specialized respite shall not exceed $4,000 per level of care year." Most paid respite care providers are also personal care attendants or nurses (if skilled care is needed), which makes the interchange between types of care more seamless.

"We really package [respite] with personal care. So, when someone needs personal care, odds are there's a family caregiver or some other unpaid primary caregiver that will need some support when the paid caregiver isn't scheduled to work. I think because we equated the two services, it's often presented as a service package."

—Virginia State Official

Missouri directs individuals to personal care first and uses respite to fill in any care gaps. Similarly to Virginia and Kentucky, Missouri noted that respite and personal care providers are often the same; most participants receiving respite care also receive personal care services. A state official noted that when an individual and their care team develop a care plan, the team will first determine what personal care assistance the individual needs and will then use respite to fill in any remaining care gaps. 1915(c) MO Aged and Disabled Waiver has the following limitations for respite: Participants receiving respite must have a designated caregiver(s) regularly responsible for providing and/or arranging the care of the participant; the per-month cost of respite care in combination with personal care and other waiver services may not exceed 100 percent of the average monthly cost of nursing home care; and an exception to exceed 100 percent of the average nursing home cost can be made by review and approval from the Bureau of Long Term Services and Supports and/or Division of Senior and Disability Services supervisory staff.

"We generally will build a care plan with first [asking] what kind of personal care assistance do they need … and then we look at filling the gaps with the respite."

—Missouri State Official

Louisiana allows the same providers for respite and personal care to address workforce shortages. As with the other identified study states, in-home personal care attendant providers are the same as respite ("caregiver temporary support service") providers. As stated in the Community Choices Waiver Provider Manual, a personal care attendant provider can also deliver respite as long as they have a valid provider license and have enrolled in Medicaid to provide

respite services. As with other states, Louisiana experiences direct care workforce shortages. However, a state official noted that Louisiana does not experience workforce shortages specific to respite because both services have the same providers. Louisiana identified that enrollees within the waiver do not often request respite specifically; rather, most individuals request personal care instead to meet their needs. As with Missouri, the state views respite care as an extension of personal care. If the individual needs respite for longer, they may use in-home personal care instead, based on the member's needs and preferences.

Study states used self-direction programs to integrate family members and friends into the direct care workforce as respite care providers.

Self-direction programs allow the care recipient to become an employer with discretion to hire a professional aide, or even a family member or friend, to be a paid respite provider while their primary caregiver takes a break. Respite delivered through self-direction programs can integrate family members or friends into the formal caregiving system and provides comfort to families as they take a break because someone they know is providing care for their loved one. Given the significant shortage of direct-care workers, self-direction programs are an emerging workforce strategy to supplement the lack of agency-hired respite providers with family or friends of waiver participants. States often deliver respite care through self-direction programs because of the flexibility and comfort they provide to care recipients and their families.

Under self-direction programs, the care recipient may pay a family member to be their primary caregiver. Paying primary family caregivers reduces the financial strain of caregiving on families but may unintentionally reduce their access to respite services. In most states, a waiver participant qualifies for respite only when their primary caregiver is unpaid, meaning that if a self-direction program participant chooses to pay their primary family caregiver then the participant may not also pay someone else to provide respite care. This restriction limits the primary caregiver's ability to take a break from their caregiving duties. There is undoubted benefit when family caregivers are paid, but states may want to consider the paid caregiver's inability to access respite as caregiver supports are developed.

"Having family members be workers does help cover a gap given the workforce issues, but then who is proving respite to that family member? … It definitely covers a gap, but there is a quality of life for that caregiver that may become important and affect the participant."

—Louisiana State Official

During the COVID-19 PHE, 29 states implemented temporary flexibilities to allow family members and/or additional types of relatives (such as legally responsible adults) to be paid primary caregivers or providers for services such as respite. States will have to decide whether to make these temporary changes permanent as the PHE ends in May 2023, and access to respite will be affected by these decisions, as most states only allow unpaid primary caregivers access to respite. In states where the flexibilities continue post-PHE, most paid primary caregivers will not be able to access respite and others might choose not to, as they are reliant on the income received from caregiving.

Examples of Self-Direction Programs in Iowa, Kentucky, and Virginia

Iowa offers self-direction through its Consumer Choices Option under the state's HCBS waivers. When a waiver participant elects the Consumer Choices Option, they have discretion as the employer to set their own training, experience, or qualification requirements for their employees, including respite providers. This flexibility facilitates a simple hiring process for family members and friends to receive payment for providing respite. The participant maintains access to specialized and group respite outside their monthly self-direction budget. The state official explained that due in part to the flexibility and comfort provided through self-direction under the Consumer Choices Option, respite is one of the highest utilized services in Iowa's HCBS waivers.

"Under the Consumer Choices Option, the member has that employer authority and the member determines the training, the credentials, the requirements for their employees. The state does not set those specific requirements; they just have to be qualified by training and/or experience to deliver the services, and the member gets to decide what that is."

—Iowa State Official

Kentucky's Participant Directed Services (PDS) program similarly allows 1915(c) HCBS Medicaid waiver enrollees to hire their own providers for non-medical waiver services, including non-specialized respite. Each participant in PDS has a support broker to help them develop a person-centered care plan, hire and supervise employees, and coordinate services. As the direct support professional shortage makes it difficult to find enough agency-hired respite providers to meet the need for respite, the waiver administrator explained that hiring family and friends is a solution to fill that gap and keep caregivers and care recipients comfortable with the person providing respite care.

"We've had a direct-support professional shortage across the board. A lot of people went to participant-direction, so that's where we've seen the growth. … Where self-direction will not work [due to an individual not having family or friends to employ], it is sometimes very difficult to find the providers."

—Kentucky State Official

Virginia allows self-direction under Consumer-Directed (CD) Services. If a family member wants to provide respite so an unpaid primary caregiver can take a break, they most often use the CD program rather than being hired through an agency. Compared to more complex and lengthy training requirements for agency-hired respite providers, training and responsibilities are set by the waiver participant and typically are less extensive for a family member hired for respite through CD.

Study states leveraged the flexibilities offered by managed care to streamline and increase access to respite services.

A few of the study states — Iowa, Texas, and Virginia — allow managed care organizations (MCOs) flexibilities to expand and enhance respite service access and utilization. Texas used contractual language with MCOs to extend respite as a value-added service for populations not typically eligible for a state's Medicaid waiver program. A value-added service allows a managed care organization authorization to voluntarily cover additional services under the state plan for certain enrollees. Additionally, study states gave MCOs the flexibility to increase respite care service limits to exceed those found in the states' Medicaid waivers. Often deployed to incentivize enrollment in a specific MCO, these respite policy flexibilities are an emerging strategy within states' MLTSS systems.

Texas allows Medicaid managed care organizations to provide in-home respite as a value-added benefit for those not enrolled in one of the state's Medicaid waiver programs. Texas is one of two states that allows its MCOs to add respite as a value-added benefit for enrollees within its managed care program. A state official described that this benefit is geared toward individuals enrolled via the state plan who do not qualify for the STAR+PLUS HCBS waiver. While the value-added service is not required, MCOs and Medicare-Medicaid Plans (MMPs) contracted to provide STAR+PLUS services offer respite as a value-added service. Texas also offers another respite policy flexibility: the option for MCOs to increase respite care service limits to exceed those found in the states' Medicaid waiver. Within the STAR+PLUS HCBS program's 1115 waiver, the respite service limit is 30 days per individual service plan year. After individuals are initially evaluated for HCBS through a medical necessity level of care assessment, MCOs work with individuals and their family members to develop and authorize services within a person-centered individual service plan. Texas allows MCOs and MMPs the discretion to exceed the respite service limit, if needed, for situations such as when primary caregivers become ill or there is a breakdown in family support.

Iowa uses contractional language with MCOs to increase respite service limits. As outlined in the Iowa Health Link managed care contract between Iowa Department of Human Services and its MCOs, "MCOs will provide additional hours of respite care for caregivers of eligible members." This flexibility is done to ensure caregivers are provided necessary breaks; as long as the state maintains budget neutrality, individuals and their families can receive the amount of care needed.

"Say if somebody on the health and disability waiver [meets] their [respite service] cap, and the family really is having a rough time — they need more respite in there — [then] the MCO can agree to pay for additional respite services above that cap based on the individual need."

—Iowa State Official

Virginia's MCO policies and procedures streamline respite service access. State officials within Virginia's Commonwealth Coordinated Care Plus (CCC Plus) waiver program described how the state works with MCOs to streamline the authorization process to remove barriers to access respite care, and create exceptions for members who do not meet all requirements. Per agreement between Virginia and the MCOs, respite is typically authorized in bulk by the year — with a max of 480 hours per state fiscal year — to allow individuals access to respite care how they best see fit. A state official noted this is done to "remove barriers" and "make it easy" for individuals to access respite. Additionally, Virginia gives MCOs the discretion to authorize long-term services and supports (LTSS) "more broadly in terms of criteria, amount, duration, and scope, if the individual care plan determines that such authorization would provide diffident value to the member's care" to give enrollees increased service access, if needed.

Respite reimbursement rates can influence providers' willingness to provide respite, which in turn can affect respite access and utilization.

With workforce shortages among every type of direct care, some study states expressed that it can be especially difficult to find respite providers, as they are often reimbursed at a lower rate and for fewer hours than other services. Rate increases that target respite specifically can incentivize providers to deliver respite to unpaid primary caregivers when they need it. Overall rate increases for the HCBS workforce can also aid in advancing respite service access, as they are a strategy to recruit and retain the larger direct care workforce.

Washington: Additional Administrative Rate to Increase Reimbursement

Washington increased its respite rate to incentivize provider participation. Interviewees expressed that providers in Washington can be hesitant to provide respite because fewer hours of respite are provided per month as compared to other services. To make up for the administrative burden of providing hours on a low-hour beneficiary care plan, the state now adds an administrative rate on top of the respite rate. This additional rate increases the overall level of reimbursement for respite providers and helps offset the administrative cost, thus increasing the number of respite providers willing to provide care. More willing respite providers increases access to respite for beneficiaries and their families.

"Folks that only have 20 hours a month [of respite], in some ways it is harder to staff than someone who has 180 hours or 200 hours a month because as an agency you have all the admin with not as many hours to recoup the hours to staff a case. So, we also have provided an admin rate on top of that rate. If they serve even one unit of service in a month, they get to claim $25 for that month to help defray their admin costs to staff a low-hour plan."

—Washington State Official

American Rescue Plan Act Rate Increases

Forty-nine states modified payment rates and/or allowed retainer payments for HCBS providers, including respite providers, using money from the American Rescue Plan Act (ARPA) during the PHE. While these rate increases were not specific to respite, they attempted to stabilize and support the larger HCBS workforce, and state decisions to end the rate increases or make them permanent could affect access to respite providers.

Multiple study states expressed that they have already made the HCBS rate changes from the ARPA permanent or are working to make them permanent in upcoming budgets and regulations as the COVID-19 PHE comes to an end. Virginia's PHE-induced rate increases were made permanent by its state legislature and integrated into the budget for years to come. Iowa increased its 2022 provider rates by 4.25 percent using ARPA funds, and Iowa Department of Health and Human Services leadership is working the with Iowa General Assembly to commit to funding these increase after the ARPA funding expires. Kentucky leaders also explained that they are conducting a thorough rate study and they hope that permanent rate increases from the rate study results will coincide with the end of the PHE's ARPA-supported rate increases.

Summary

The information from these seven case study state interviews gleans key insights on how states currently deliver respite care and offers emerging strategies that other states can replicate. States looking to improve access to respite for HCBS waiver participants and their family caregivers can turn to education and outreach; varied types of respite and rates for each type; flexibilities through packaging respite and personal care and allowing respite hours to pool; self-direction programs; creative approaches through MCOs; and reimbursement rate increases. Many of these emerging strategies are relatively minor improvements to current respite policies but can significantly ease access to Medicaid-funded respite services.

States understand the value of family caregivers, and respite provides key support to family caregivers upon which health systems depend. Our case studies revealed with certainty that respite provision varies widely by state. Despite this variation, there is general interest in improving access to respite and great opportunity to do so. The COVID-19 PHE allowed states to make temporary changes to HCBS delivery that affected respite, including flexibilities to allow family members to be paid providers and temporary rate increases and/or retainer payments. The future of respite care will be affected by states' decisions to make these policies permanent or end them as the PHE ends in May 2023, making now an opportune time for states to consider updates and improvements to respite policies. The emerging strategies identified in this paper highlight policy changes for states to improve respite care to better support family caregivers and delay more costly and oftentimes unwanted institutional care.

Appendix

This appendix serves as a fact sheet for each state's Medicaid waiver respite services, including the basic components of the service and the emerging strategies employed.

Iowa

Iowa's Department of Health and Human Services (HHS) Iowa Medicaid Division oversees two waivers that offer respite services for older adults and adults with physical disabilities: 1915(c) Health and Disability (HD) Waiver and 1915(c) Elderly Waiver. A third waiver, 1915(c) Physical Disability Waiver, also serves these populations but does not offer respite. For enrollees in the HD and Elderly waivers, an interdisciplinary care team identifies the types of respite care needed based on a member's acuity:

- Basic individual respite is provided on a staff-to-member ratio of one-to-one to members without specialized needs requiring the care of a licensed registered nurse or licensed practical nurse.
- Group respite is respite provided on a ratio of one staff to two or more members receiving respite.
- Specialized respite is provided on a staff-to-member ratio of one-to-one to members with specialized medical needs requiring the care, monitoring, or supervision of a licensed registered nurse or licensed practical nurse.

Both of Iowa's service delivery methods fee-for-service and managed care — offer numerous respite emerging strategies. Specifically, Iowa was selected as a case study state due to offering numerous respite service types, allowing multiple types of caregivers to provide respite through self-direction, pooling of respite benefits, and managed care incentives. As codified in Iowa's Human Service's regulation 441-78.34(13), its consumer choices (self-direction) option allows unused monthly respite dollars to go toward savings for future respite purposes. While some states set training and credential standards for providers even within self-direction, Iowa allows the beneficiary complete employer authority by determining these qualifications. This includes the allowance of all three family caregiver provider types to deliver respite services: a relative, legally responsible person, and a legal guardian. However, Iowa does note in its regulations that "respite cannot be provided to a member whose usual caregiver is a consumer-directed attendant care provider for the member." Iowa also offers numerous respite service types based on an individual's acuity: basic individual respite, group respite, and specialized respite. Iowa's payment methodology includes a direct-care workforce incentive that details the payment for respite connected to the staff-to-member ratio. Lastly, Iowa's managed care delivery system, Iowa Health Link, allows for the approval of additional hours of respite based on an individual's need.

Iowa: Key Medicaid Respite Service Elements	
Federal Authority	Concurrent 1915(b)/1915(c) • 1915(c) Health and Disability (HD) Waiver • 1915(c) Elderly Waiver
MLTSS State	☑ Yes • Iowa Health Link ☐ No
Respite Service Types	• Basic individual respite • Group respite • Specialized respite
Respite Service Limits/ Payment Methodology	• Payment for respite connected to the staff-to-member ratio
Allowable Respite Service Setting	☑ Facility-based ☑ In-home
Self-Direction of Respite Services	☑ Yes ☑ No
Types of Caregivers Allowed as Respite Providers	☑ Legally responsible person ☑ Relative ☑ Legal guardian

Kentucky

The Kentucky Department for Medicaid Services administers the 1915(c) KY Home and Community Based Waiver serving older adults and adults with physical disabilities. Kentucky offers two respite service types:

- "Specialized respite services are defined as short-term care [that] is provided to a waiver participant due to the need for relief of the primary non-paid caregiver or the sudden absence or illness of the primary caregiver who normally provides care for the participant. Specialized respite direct-care staff must have 24-hour access to an RN for consultation and emergency situations. Services must be provided at a level to appropriately and safely meet the support needs of the waiver participant and that the specialized respite provider has the appropriate training and qualifications. Specialized respite care services shall be required to be of a skill level beyond normal … [companionship services]. Specialized respite can be provided in conjunction with participant-directed respite but not at the same time. Specialized respite services shall only be provided by licensed home health agencies or adult day health care agencies and can be provided in the following locations: (a) the home of the participant, (b) an adult day health care center licensed by the state of Kentucky, or (c) a combination of home and adult day health care center. Specialized respite services must be prior authorized.
- Non-specialized respite is short-term care due to an absence or need for relief of the primary non-paid caregiver and be utilized for participants who are unable to independently manage or execute self-care. … Non-specialized respite care must address individualized self-care, safety, positive social impact and recreational needs, and supervision needs…. Non-specialized respite may be provided in the participant's residence, in the community or at an adult day health care center."

Kentucky was selected as a case study state due to offering and adjusting provider payment rates accordingly for both specialized and non-specialized respite services, self-direction of respite services, packaging respite and personal care, a unique budgetary cap, awareness and outreach of respite services, and streamlining family caregiver provider applications. Along with allowing self-direction for respite services (non-specialized only), Kentucky also allows the flexibility of all three family caregiver provider types to deliver the service: a relative, legally responsible person, and a legal guardian. To streamline access to services, Kentucky engages providers and case managers to certify family caregivers as a part of its waiver application process and advocate for the value of respite care. Another respite emerging strategy Kentucky provides is an alternative service cap/payment methodology: the allowance for $200 per day/$4,000 per level of care year for respite services.

Kentucky: Key Medicaid Respite Service Elements	
Federal Authority	1915(c) • KY Home and Community Based Waiver
MLTSS State	☐ Yes ☑ No
Respite Service Types	• Specialized respite • Non-specialized respite
Respite Service Limits/ Payment Methodology	• For primary non-paid caregivers • $200 per day alone or in combination with non-specialized respite. Specialized respite alone or in combination with non-specialized respite cannot exceed $4,000 per level of care year.
Allowable Respite Service Setting	☐ Facility-based ☑ In-home
Self-Direction of Respite Services	☑ Yes *(only for non-specialized respite)* ☐ No
Types of Caregivers Allowed as Respite Providers	*Only for non-specialized respite:* ☑ Legally responsible person ☑ Relative ☑ Legal guardian

Louisiana

Louisiana's Office of Aging and Adult Services (OAAS) operates the 1915(c) Community Choices (CC) Waiver serving older adults and adults with physical disabilities. For enrollees in the CC Waiver, "Caregiver Temporary Support Services are furnished on a short-term basis because of the absence or need for relief of caregivers during the time they are normally providing unpaid care for the participant. … The intent of Caregiver Temporary Support Services is to provide relief to unpaid caregivers to maintain the informal support system. … Caregiver Temporary Support Services may be provided for the relief of the principal caregiver for participants who receive Monitored In-Home Caregiving services."

Louisiana was selected as a case study state due to its packaging of respite and personal care services to minimize disruptions in an individual's plan of care. Because in-home personal care providers and respite providers work for the same agencies, individuals do not have to search for a different provider.

Louisiana also has a specific 1915(c) Adult Day Health Care (ADHC) waiver that can give caregivers of older adults and adults with physical disabilities a break by providing two types of adult day services through both a medical and social adult day model.

Louisiana: Key Medicaid Respite Service Elements	
Federal Authority	1915(c) • Community Choices (CC) Waiver
MLTSS State	☐ Yes ☑ No
Respite Service Types	• Called "Caregiver Temporary Support Services"
Respite Service Limits/ Payment Methodology	• 30 calendar days or 29 overnight stays per Plan of Care (POC) year for no more than 14 consecutive calendar days or 13 consecutive overnight stays. • The service limit may be increased based on documented need and prior approval by OAAS. • Caregiver temporary support services provided by nursing facilities, assisted living facilities, and respite centers must include an overnight stay.
Allowable Respite Service Setting	☑ Facility-based ☑ In-home
Self-Direction of Respite Services	☐ Yes ☑ No
Types of Caregivers Allowed as Respite Providers	☐ Legally responsible person ☑ Relative ☐ Legal guardian

Missouri

Missouri's Department of Health and Senior Services Division of Senior and Disability Services administers the Aged and Disabled Waiver, a 1915(c) HCBS waiver through Missouri Department of Social Services, MO HealthNet Division, and provides respite under this waiver. Enrollees in the Aged and Disabled Waiver have access to the following types of respite services:

- "Basic respite care services are maintenance and supervisory services provided to a participant with nonskilled needs in that individual's home because of the absence or need for relief of those persons who normally provide care for the participant. This service encompasses all the needs of a participant that might come up during the service provision that fall under supervision, companionship, and direct participant assistance, all the services that are required to maintain the participant in his/her home."
- "Advanced respite care services are defined as maintenance and supervisory services provided to a participant with nonskilled needs that require specialized training in that individual's home because of the absence or need for relief of those persons who normally provide care for the participant. This service encompasses all the needs of a participant that might come up during the service provision that fall under supervision, companionship, and direct participant assistance, all the services that are required to maintain the participant in his/her home. … Participants appropriate for advanced respite care include, but are not limited to: (1) participants who are essentially bedfast and require specialized care involving turning and position, including assistance with mechanical transfer equipment and/or assistance with elimination, including the use of a urinal, bed pan, catheter and/or ostomy; (2) participants who have behavior disorders resulting in disruptive behavior especially due to Alzheimer's disease, which requires close monitoring; (3) participants who have health problems requiring manual assistance with oral medications; and (4) participants who have special monitoring and assistance needs due to swallowing problems."

We chose Missouri as a study state because of some unique respite policies and procedures, including that respite in Missouri is not capped by a dollar figure nor number of hours allowed by the state, advanced respite is available to those who need it, and the same providers do both personal and respite care. An enrollee in the Aged and Disabled Waiver is eligible for as much respite as they need, given that they demonstrate need during the person-centered planning process. With no cap on respite, the state can fully fund the respite in the enrollee's care plan. In addition, the availability of advanced respite enables respite to be provided to enrollees with more complex care conditions, thus giving their caretakers the breaks they need to continue

to provide care. The same providers often do both respite and personal care in Missouri, so respite can be used to fill in gaps in care when personal services are not available.

The state also administers an Adult Day Care Waiver for participants ages 18 to 63 who meet the nursing facility level of care. Adult day care services for participants who are ages 63 and older are covered in the Aged and Disabled Waiver. This type of care is not the same as respite, but it accomplishes a similar goal by helping Medicaid enrollees and their caregivers, especially those who are juggling care responsibilities while working outside the home.

Missouri: Key Medicaid Respite Service Elements	
Federal Authority	1915(c) • MO Aged and Disabled Waiver
MLTSS State	☐ Yes ☑ No
Respite Service Types	• Basic respite (in-home) • Advanced respite (in-home)
Respite Service Limits/ Payment Methodology	• Respite is uncapped, given that a recipient demonstrates sufficient need
Allowable Respite Service Setting	☐ Facility-based ☑ In-home
Self-Direction of Respite Services	☐ Yes ☑ No
Types of Caregivers Allowed as Respite Providers	☐ Legally responsible person ☐ Relative ☐ Legal guardian

Texas

Texas's Health and Human Services Commission offers respite for older adults and adults with physical disabilities through seven LTSS waiver programs, two of which are provided through managed care: (1) the 1915(c) Medically Dependent Children Program (MDCP) waiver (serving individuals up to age 20), and 2) the STAR+PLUS Home and Community-Based Services (HCBS) Program under Texas' 1115 Texas HealthCare Transformation and Quality Improvement Program waiver. Respite is also a STAR+PLUS HCBS service in the CMS Financial Alignment Initiative Medicare-Medicaid Dual Demonstration, which has been extended through at least December 2023. Texas defines STAR+PLUS HCBS respite care services as providing "emergency or short-term relief to unpaid primary caregivers of members who are unable to care for themselves and reside in community settings other than adult foster care (AFC) homes or assisted living facilities (ALF)." Respite services can be provided in and out of the home and are limited to 30 days per year. MCOs and MMPs determine respite service amounts based on the needs of the primary caregiver and document the member's respite care services needs on their individual service plan. MCOs and MMPs have the flexibility to increase the 30-day annual respite service limit based on need and under certain circumstances.

Texas was selected for our study because all of the STAR+PLUS MCOs with a Texas Medicaid contract include respite coverage as a value-added benefit for STAR+PLUS members who are not enrolled in STAR+PLUS HCBS program. Additionally, MMPs also offer respite as a value-added benefit.

Texas: Key Medicaid Respite Service Elements	
Federal Authority	1115 • Texas HealthCare Transformation and Quality Improvement Program CMS Financial Alignment Initiative • Medicare-Medicaid Dual Demonstration between CMS, Texas's Health and Human Services Commission, and the STAR+PLUS MMPs
MLTSS State	☑ Yes ☐ No
Respite Service Types	• In-home respite • Out-of-home respite
Respite Service Limits/ Payment Methodology	STAR+PLUS HCBS respite care services (in the STAR+PLUS HCBS and Dual Demonstration programs) are limited to 30 days per individual service plan year. There is a process to grant exceptions to the annual limit. The managed care organization reviews all requests for exceptions and consults with the service coordinator, providers, and other resources as appropriate to make a professional judgment to approve or deny the request on a case-by-case basis. Members residing in adult foster care homes and assisted living facilities are not eligible to receive respite services. Personal assistance services may be provided on the same day as respite services, but the two services cannot be provided at the exact same time.
Allowable Respite Service Setting	☑ Facility-based ☑ In-home
Self-Direction of Respite Services	☑ Yes *(in-home respite services only)* ☐ No
Types of Caregivers Allowed as Respite Providers	Relatives can be a paid respite provider with the exception of a relative who is a spouse, legally authorized representative, primary unpaid caregiver, or who lives with the member.

Virginia

Virginia Medicaid's Department of Medical Assistance Services oversees the 1915(c) Commonwealth Coordinated Care Plus Waiver, which provides services, including respite, to adults age 65 and over, individuals with physical and other disabilities, and people who are technology dependent. "Respite care services are provided to individuals unable to care for themselves and are furnished on a short-term basis because of the absence or need for relief of those primary unpaid caregivers who normally provide care. Respite care services may be provided in the individual's home or place of residence or children's residential respite facility. Respite service may include skilled nursing care."

Virginia was selected as a study state due to emerging respite strategies, including a strong consumer-direction program, packaging of personal care and respite care, permanent rate increases post-PHE, and approaches from MCOs to promote respite service access. Relatives and legal guardians can be respite care providers and give other caretakers a break as needed. Virginia also packages respite care with personal care. Because families are often aware of and receiving personal care, bundling respite care with it makes these families more likely to be cognizant of and use available respite care. After temporary HCBS rate increases from ARPA, Virginia implemented permanent rate increases for HCBS providers. MCOs in Virginia engage in a streamlined respite authorization process to facilitate simple access to respite hours and make exceptions to hour limits when individuals and their families need more respite hours than typically allowed.

Virginia: Key Medicaid Respite Service Elements	
Federal Authority	Concurrent 1915(b)/1915(c) • VA Commonwealth Coordinated Care Plus
MLTSS State	☑ Yes • Commonwealth Coordinated Care Plus ☐ No
Respite Service Types	• In-home respite • Out-of-home respite
Respite Service Limits/ Payment Methodology	• Respite is capped at 480 hours per recipient per fiscal year, as directed by the state's General Assembly. • The rate of payment for respite care is the same as the rate for personal care.
Allowable Respite Service Setting	☑ Facility-based ☑ In-home
Self-Direction of Respite Services	☑ Yes (not available for individuals receiving skilled respite services) ☐ No
Types of Caregivers Allowed as Respite Providers	☐ Legally responsible person ☑ Relative ☑ Legal guardian

Washington

The Washington State Aging and Long-Term Support Administration (ALTSA) administers respite care services through its 1115 Washington Medicaid Transformation Project Demonstration, specifically the Medicaid Alternative Care and Tailored Supports for Older Adults (TSOA) programs. Through these programs, enrollees can receive caregiver assistance services, defined as "services that take the place of those typically performed by the unpaid caregiver in support of unmet needs the care receiver has for assistance with activities of daily living (ADL) and instrumental ADL." Caregiver assistance services include both in-home and out-of-home respite, along with adult day health. 1915(c) waivers, including the WA Residential Support Waiver, the WA COPES Waiver, and the WA New Freedom Waiver, serve similar aging populations and those with disabilities, but they do not offer respite services to waiver participants.

In addition, Washington provides respite under a unique 1115 waiver that has strong family caregiver components. Many emerging solutions are found in Washington's delivery of respite care. The state added an additional administrative rate to the respite service to encourage providers to provide respite care. Individuals also can pool their respite care benefit for up to six months if they do not use their full number of allocated hours. Washington is also piloting a culturally aware training and outreach program for tribal communities.

Washington: Key Medicaid Respite Service Elements	
Federal Authority	1115 • Washington Medicaid Transformation Project Demonstration
MLTSS State	☐ Yes ☑ No
Respite Service Types	As a part of Caregiver Assistance Services: • In-home respite • Out-of-home respite
Respite Service Limits/ Payment Methodology	Administrative rate is added to respite rate to encourage providers to participate in respite care
Allowable Respite Service Setting	☑ Facility-based ☑ In-home
Self-Direction of Respite Services	☑ Yes ☐ No (ALTSA is working to add the ability to hire family/friends for the 1115 Demonstration Waiver program within six months.)
Types of Caregivers Allowed as Respite Providers	☐ Legally responsible person ☑ Relative ☑ Legal guardian (ALTSA is working to add the ability to hire family/friends for the 1115 Demonstration Waiver program within six months.)

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