



COMMONWEALTH of VIRGINIA

Department of Medical Assistance Services

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January 3, 2025

MEMORANDUM

TO: The Honorable Ghazala F. Hashmi
Chair, Senate Education and Health Committee

The Honorable Mark D. Sickles
Chair, House Health and Human Services Committee

FROM: Cheryl Roberts
Director, Virginia Department of Medical Assistance Services

SUBJECT: Report on the Possibility of Allowing for Respite Services for Paid Legally Responsible Individuals

This report is submitted in compliance with Chapters 646 and 679 of the 2024 Acts of Assembly, which state:

That the Department of Medical Assistance Services (DMAS) shall analyze the possibility of allowing for respite services under the Community Living Waiver, Family and Individual Support Waiver, and Commonwealth Coordinated Care Plus Waiver when the legally responsible individual is an unpaid caregiver all or part of the time and when there are multiple adult caregivers providing any portion of unpaid care for the waiver-receiving child. DMAS shall develop recommendations on allowing for respite services under such circumstances and shall estimate the cost of providing such respite services. DMAS shall submit its recommendations, cost estimate, and methodology used for obtaining the cost estimate to the Chairmen of the House Committee on Health and Human Services and the Senate Committee on Education and Health no later than November 1, 2024.

Should you have any questions or need additional information, please feel free to contact me at 804-664-2660.

CR/wf
Enclosure

Pc: The Honorable Secretary Janet V. Kelly, Secretary of Health and Human Resources

Report: The Possibility of Allowing for Respite Services for Legally Responsible Individuals

November 2024

Report Mandate:

Chapters 646 and 679 of the 2024 Acts of Assembly state: That the Department of Medical Assistance Services (DMAS) shall analyze the possibility of allowing for respite services under the Community Living Waiver, Family and Individual Support Waiver, and Commonwealth Coordinated Care Plus Waiver when the legally responsible individual is an unpaid caregiver all or part of the time and when there are multiple adult caregivers providing any portion of unpaid care for the waiver-receiving child. DMAS shall develop recommendations on allowing for respite services under such circumstances and shall estimate the cost of providing such respite services. DMAS shall submit its recommendations, cost estimate, and methodology used for obtaining the cost estimate to the Chairmen of the House Committee on Health and Human Services and the Senate Committee on Education and Health no later than November 1, 2024.

Background

Respite is a service available in three of Virginia's four 1915(c) Home and Community-Based Services (HCBS) waivers: the Community Living (CL) waiver, Family and Individual Support (FIS) waiver and Commonwealth Coordinated Care Plus (CCC+) waiver. Per section 12VAC30-120-900 of the Administrative Code of Virginia, respite is a waiver service "furnished on a short-term basis because of the absence of or need for the relief of the unpaid primary caregiver who normally provides the care". Respite provides the member with up to 480 hours of support per year. According to the DMAS

dashboard for waiver service utilization (<https://dmas.virginia.gov/data/waiver-services/>), in State Fiscal Year (SFY) 2023, 40,673 individuals across the three applicable waivers used respite, totaling \$223.7 million in expenditures.

When an individual is approved for a waiver, the individual (or family) is required to identify a primary caregiver who will provide personal care services and document whether the primary caregiver is paid or unpaid. Personal care is hands-on, active care to the individual in providing support to complete the member's Activities of Daily Living (ADLs). ADLs include bathing, dressing, toileting, transferring, feeding/assistance with eating, and ambulation.

Prior to the COVID-19 pandemic, Legally Responsible Individuals (LRIs), defined as parents of minors under the age of 18 and spouses of waiver individuals, were not permitted to be paid providers of any Medicaid waiver services. Most often, the LRI would be an unpaid primary caregiver and qualify to receive up to 480 hours of respite per year. In situations in which the primary caregiver is also the paid attendant, respite benefits are not available for the member.

As part of the Commonwealth's response to the COVID-19 pandemic, DMAS requested and received approval for an allowance from the Centers of Medicare and Medicaid Services (CMS) to permit LRIs to receive reimbursement

for providing personal care services. Additionally, Chapters 646 and 679 of the 2024 Acts of Assembly direct DMAS to modify the program rules for the CL Waiver, FIS Waiver and CCC+ Waiver as follows:

- (i) Modify the 40-hour-per-week work limit to allow LRIs with more than one waiver-receiving child to receive reimbursement for 40 hours of work per week per child receiving a waiver;
- (ii) Eliminate the requirement that, in order for a LRI to receive reimbursement for personal care services, no one else be available to provide services to the member; and
- (iii) When a member under the age of 18 receives personal care through consumer direction, as defined in 12VAC30-122-20, modify the program rules to allow a LRI or stepparent to be the employer of record.

Consumer Direction Service Delivery Model

The LRI who provides personal care services can act as the paid attendant by working through a licensed personal care agency or as an employee through the consumer-direction (CD) model. Consumer-direction is a service delivery model that empowers the Medicaid member or their designee to choose and employ an attendant. The member or their designee is the employer of the attendant and is responsible for managing the attendant, including approving timesheets for payment. For cases where an LRI is a caregiver, it is common for the employer to be the other LRI (parent).

There are 1,700 LRIs employed as caregivers for their children or spouses under the CD model. While it is possible (and recommended by DMAS) to use a licensed personal care agency to hire the LRI, DMAS does not have exact figures on how many LRIs are employed by these agencies. Based on stakeholder feedback and townhalls with members and families, LRIs most often are reimbursed through the consumer directed model.

Benefits for Eligible LRI Caregivers

While respite services are not available for members who have an LRI as a paid attendant, sick leave is available under the consumer-direction model for attendants who work an average of at least 30 hours per week. The sick leave benefit is available for up to 40 hours per year. When the sick leave benefit is used, a backup attendant, who can also be a paid attendant, is expected to provide personal care services.

LRI caregivers also qualify for a “Difficulty of Care” exemption. This exemption under Section 131(c) of the Code of Federal Regulations exempts income earned by caring for a person living in the same home from being included as gross income for federal income tax purposes. This exemption is extended for all live-in caregivers providing services through a Medicaid waiver.

Options

To address the provision of respite when the LRI is an unpaid caregiver all or part of the time and when there are multiple adult caregivers providing any portion of unpaid care for the waiver-receiving child, DMAS can:

1. Keep the current definition of respite and only allow it for caregivers who are not receiving any payment for their caregiving; or,
2. Change the definition of respite to make it available to parents who are paid LRIs when multiple adults are providing any portion of unpaid care to the child. Changing the definition would have a significant fiscal impact.

Keep the current regulations in place by only allowing respite for unpaid caregivers.

This option needs no further analysis. This is the option that allows for consistent application of respite services to the entire waiver population. Leaving the definition as it is keeps the access to respite care strictly for those who are not paid caregivers.

Allow respite when a waiver individual has an LRI as a paid attendant and multiple adults providing any portion of unpaid care to a waiver member who is a minor

This option would extend the definition of respite to include unpaid primary caregivers and parents who are paid attendants if another adult provides some portion of unpaid care to the waiver member. This, in essence, would make a pathway for all paid LRIs of minors to receive respite services. As it is written, any adult who provides support to the member, including natural supports, would support the LRI in receiving respite. This could include another parent, grandparent, aunts, uncles, or friends. Waiver services do not generally provide paid 24-hour care; unpaid natural supports often deliver some care.

This option only includes LRIs who are parents, as the language reflects care for children and does not mention spouses who can also be paid LRIs. While supporting children in the community is a fundamental aspect of home and community-based waiver services, so is supporting adults who are medically fragile or those living with a disability. This change would be one-sided and unfairly favor caregiving for children over adults who all meet the institutional level of care.

Such a change would cause an imbalance in Long-Term Services and Supports in the Commonwealth. Under this option, once a child reaches 18, respite would no longer be an allowable service if the parent continued to be documented as the primary caregiver and a paid attendant. LRIs do not include parents of adult children, nor does it include paid caregivers who provide both paid and unpaid supports for adult members. A couple of examples of these paid caregivers include adult children caring for aging parents with dementia and primary caregivers who provide support for individuals who have physical disabilities. It is important to note that these caregivers are not legally obligated to provide this care. Parents of minors and spouses are legally required to care for their children and meet their needs.

For calculating the fiscal impact related to this option, DMAS considered the 1,700 CD LRI attendants and an expected utilization adoption of 95%, for a total of 1,615 new individuals being authorized and using the respite service. Based on actual utilization numbers and costs from Fiscal Year 2023, DMAS determined the average cost per month per user for respite is \$5,749.89 annually. When multiplying the projected number of CD LRI attendants by the average cost per

user, DMAS determines the additional costs for respite under this option to total \$9,711,678 for Fiscal Year 2026 (\$4,474,112 general funds and \$5,237,566 non-general funds). This estimate excludes any costs for LRIs under the agency-directed model as we do not have data on these individuals.

If the General Assembly decides to allow respite to all primary caregivers, including those serving adults, allowing for consistent application across waivers, the cost would be significant. Based on actual utilization from Fiscal year 2023, DMAS determined that 6,657 individuals, covering both agency-directed and consumer-directed, did not utilize any respite on the three waivers. DMAS assumes that the reason is due to having a paid primary caregiver, thus making them ineligible for the service. Assuming the same 95% adoption rate as option 2 (for a total of 6,324 new users) and \$5,749.89 as the annual cost for the service, DMAS projects the fiscal impact of allowing respite to all primary caregivers would be is \$38,028,888, (\$17,519,680 general funds and \$20,509,208 non-general funds) in Fiscal Year 2026.

Recommendation

To satisfy the report mandate, DMAS recommends keeping the definition as it is now and continue to allow respite only for caregivers who are not paid. This would not result in significant Medicaid spending increases and allows for the most consistent approach for all waiver members and their caregivers.

About DMAS and Medicaid

The mission of the Virginia Medicaid agency is to improve the health and well-being of Virginians through access to high-quality healthcare coverage. The Department of Medical Assistance Services (DMAS) administers Virginia's Medicaid and CHIP programs for approximately two million Virginians. Members have access to primary and specialty health services, inpatient care, dental, behavioral health as well as addiction and recovery treatment services. In addition, Medicaid long-term services and supports enable thousands of Virginians to remain in their homes or to access residential and nursing home care.

Medicaid members historically have included children, pregnant women, parents and caretakers, older adults, and individuals with disabilities. In 2019, Virginia expanded the Medicaid eligibility rules to make health care coverage available to more than 600,000 newly eligible, low-income adults.

Medicaid and CHIP (known in Virginia as Family Access to Medical Insurance Security, or FAMIS) are jointly funded by Virginia and the federal government under Title XIX and Title XXI of the Social Security Act. Virginia generally receives an approximate dollar-for-dollar federal spending match in the Medicaid program. Medicaid expansion qualifies the Commonwealth for a federal funding match of no less than 90% for newly eligible adults, generating cost savings that benefit the overall state budget.