

# Policy Brief: The Role of Medicaid in Supporting Family Caregivers

February 2025



## Introduction

**More than 53 million Americans provide ongoing, complex care for friends or family members with disabilities or health care needs.**

While the federal government offers some assistance through programs like the National Family Caregiver Support Program, the Lifespan Respite Care Program, and Veterans Affairs Caregiver Programs, these fractured initiatives cannot meet the growing needs of millions of family caregivers.

Medicaid has emerged as the nation's primary source of support for these caregivers, making it possible for many Americans to receive care in their homes rather than in costly nursing facilities. As the largest payer for long-term services and supports, Medicaid serves approximately 4.5 million people through home-and-community-based services (HCBS). Unlike Medicare, which typically does not cover these services, Medicaid provides both direct financial support to family caregivers and critical supplemental services such as respite care, training, and counseling - all of which help families avoid or delay institutional care.

## THE BIG PICTURE

**Approximately 53 million Americans provide ongoing, complex care in the U.S.**

**Medicaid supports 4.5 million individuals through home care services.**

**Medicaid accounts for about two-thirds of all home care spending in the U.S.**

The National Strategy to Support Family Caregivers (National Strategy)– established by legislation passed by Congress and signed into law by President Donald Trump - recognizes Medicaid’s central role in supporting family caregivers. The National Strategy identifies Medicaid as a critical program for expanding access to respite care, providing direct payment to family caregivers, and offering essential training and support services. It specifically calls for strengthening Medicaid programs to better serve family caregivers, including recommendations to increase access to self-directed services (also called consumer-direction), expand respite care options, and develop more comprehensive caregiver assessment and support systems within Medicaid programs.

However, these vital supports face an uncertain future. Recent proposals to significantly reduce Medicaid spending could constrain states’ ability to maintain these crucial programs, potentially forcing more families to turn to institutional care and affecting millions who rely on Medicaid to help them care for their loved ones at home.

### CARE STORY

#### MEDICAID: A LIFELINE FOR FAMILY CAREGIVERS

*When Gail became the primary caregiver for her mother who lives with multiple complex conditions including kidney failure and vascular dementia, she faced both career disruption and financial strain. Like many family caregivers, she had to adapt quickly, turning to Medicaid not only for her own healthcare needs but also as resource for providing care for her mother. With support from Medicaid and family, Gail found ways to navigate the healthcare system and develop essential caregiving skills. Her story illustrates how Medicaid serves as a crucial support system, helping family caregivers maintain their own wellbeing while providing vital care to loved ones.*

*Gail, Illinois Family Caregiver, Caring for her 76-year- old mother with dementia\**

## Medicaid Programs Benefiting Family Caregivers

Through home and community-based waiver programs (HCBS) under §1915, states may offer multiple types of support to family caregivers. CMS and healthcare providers notably relied on expanded HCBS waivers during the COVID-19 crisis to meet the overwhelming need for care and ongoing workforce shortages. These programs have demonstrated that family caregivers can provide high-quality care to Medicaid beneficiaries at reduced costs, helping to bridge gaps where there are shortages of paid healthcare workers enabling more people to receive care in the familiar and preferred setting of their own homes and communities.

While Medicaid’s offerings vary from state to state, many states provide vital services that support family caregivers with education, training, and limited financial assistance (see **Figure 1**). For example, these programs can offer:

\*Caregiver Stories, Illinois Family Caregiver Coalition, 2024

## Self-Directed Services / Consumer-Direction

Medicaid enrollees can have greater autonomy over their care through this waiver program, which allows them to select, train, and sometimes compensate family members as caregivers. The self-direction program – also called consumer-direction – provides autonomy to the person who needs care and alleviates pressure on a healthcare system facing severe direct care workforce shortages.<sup>1</sup> According to a 2023 Kaiser Family Foundation survey of Medicaid HCBS programs, most states reported widespread staffing shortages, including among direct support professionals, personal care attendants, nursing staff, and home health aides.<sup>2</sup>

### Key Features of Medicaid Self-Direction

- Nearly all states (47) allow Medicaid enrollees to self-direct their home care, giving them the ability to select, train, and dismiss their caregivers.
- Forty-seven states and the District of Columbia provide financial compensation to family caregivers (under varying circumstances) and offer additional support services, most notably respite care
- Support services for family caregivers are most extensively available in programs serving people with intellectual or developmental disabilities, followed by older adults (age 65+) or who have physical disabilities.
- Family caregivers can typically receive payment for providing personal care services (e.g. bathing, dressing, light housework, money management, meal preparation, and transportation) which Medicaid offers through various home and community-based services (HCBS) programs.
- Most states pay family caregivers an hourly wage similar to other care workers, but ten states (CA, GA, IA, LA, MD, MO, NM, NC, ND, SD) have implemented structured family caregiving programs that provide a daily rate instead.<sup>3</sup>

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***Kaiser Family Foundation: How do Medicaid Home Care Programs Support Family Caregivers?***

## Caregiver Training and Education

Medicaid-funded caregiver training and education varies by state and target population. Training can be specialized for caregivers of people with specific conditions like Alzheimer's disease or developmental disabilities or focus on helping caregivers assist with functional needs. As of 2020, about half of all states offered education, training, or counseling through Medicaid waivers or state plan amendments for caregivers of older adults and people with functional limitations. Among intellectual and developmental disability waivers, about one-third included family caregiver training, while ten states specifically offered training for caregivers of children with autism.<sup>4</sup>



<sup>1</sup><https://www.kff.org/medicaid/issue-brief/how-do-medicaid-home-care-programs-support-family-caregivers/>

<sup>2</sup><https://www.kff.org/medicaid/issue-brief/payment-rates-for-medicaid-home-and-community-based-services-states-responses-to-workforce-challenges/>

<sup>3</sup><https://www.kff.org/report-section/how-do-medicaid-home-care-programs-support-family-caregivers-appendix/>

<sup>4</sup><https://nashp.org/medicaid-supports-for-family-caregivers/>

## Respite Care for Family Caregivers

Recognizing the value of respite care, some states have begun offering respite programs through Medicaid, allowing the family caregiver time to rest, run errands and attend to their own medical needs. Respite care can take many forms, including formal respite programs, support from a home health aide, adult day services, and homemaker support. These programs can help alleviate the strain and stress related to the caregiver's role in supporting a Medicaid beneficiary. Although several federal programs help fund respite care, Medicaid remains the primary funder of respite and other long-term care services.<sup>5</sup>

Research shows that providing respite and other supports to caregivers of older adults leads to multiple benefits: improved caregiver well-being, delayed nursing home placement, and reduced costs from hospital readmissions and emergency room visits.<sup>6</sup>

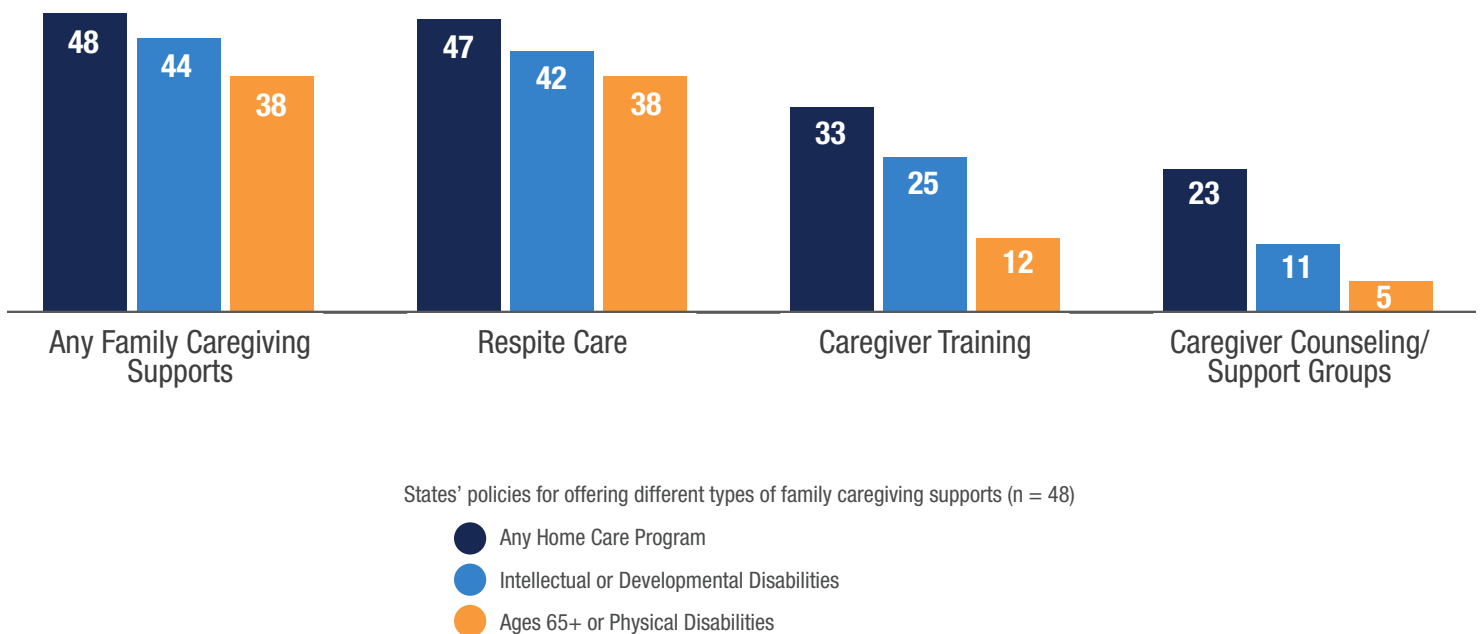
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***National Academy for State Health Policy: Emerging Respite Care Strategies in Medicaid Home and Community-Based Services Waivers for Older Adults, Adults with Physical Disabilities, and their Family Caregivers***

FIGURE 1.

### State Supports for Family Caregivers Through Medicaid Home Care



Note: Home care is also known as "home- and community-based services" or HCBS. All states except Florida, Indiana, and Utah responded.

Source: KFF Medicaid HCBS Program Survey 2024

<sup>5</sup><https://nashp.org/emerging-respite-care-strategies-in-medicaid-home-and-community-based-services-waivers-for-older-adults-adults-with-physical-disabilities-and-their-family-caregivers/>

<sup>6</sup><https://nap.nationalacademies.org/catalog/23606/families-caring-for-an-aging-america>

## Medicaid Work Requirements and Family Caregivers

Family caregivers who qualify for Medicaid often face a challenging situation when balancing their caregiving responsibilities with work requirements. Data from 2023 shows that while approximately two-thirds of Medicaid enrollees between ages 19-64 maintained employment, nearly 30% were unable to work due to various reasons that traditionally qualified for exemptions under previous policies—including caregiving duties (12%), personal illness or disability, and school attendance (see **Figure 2**).

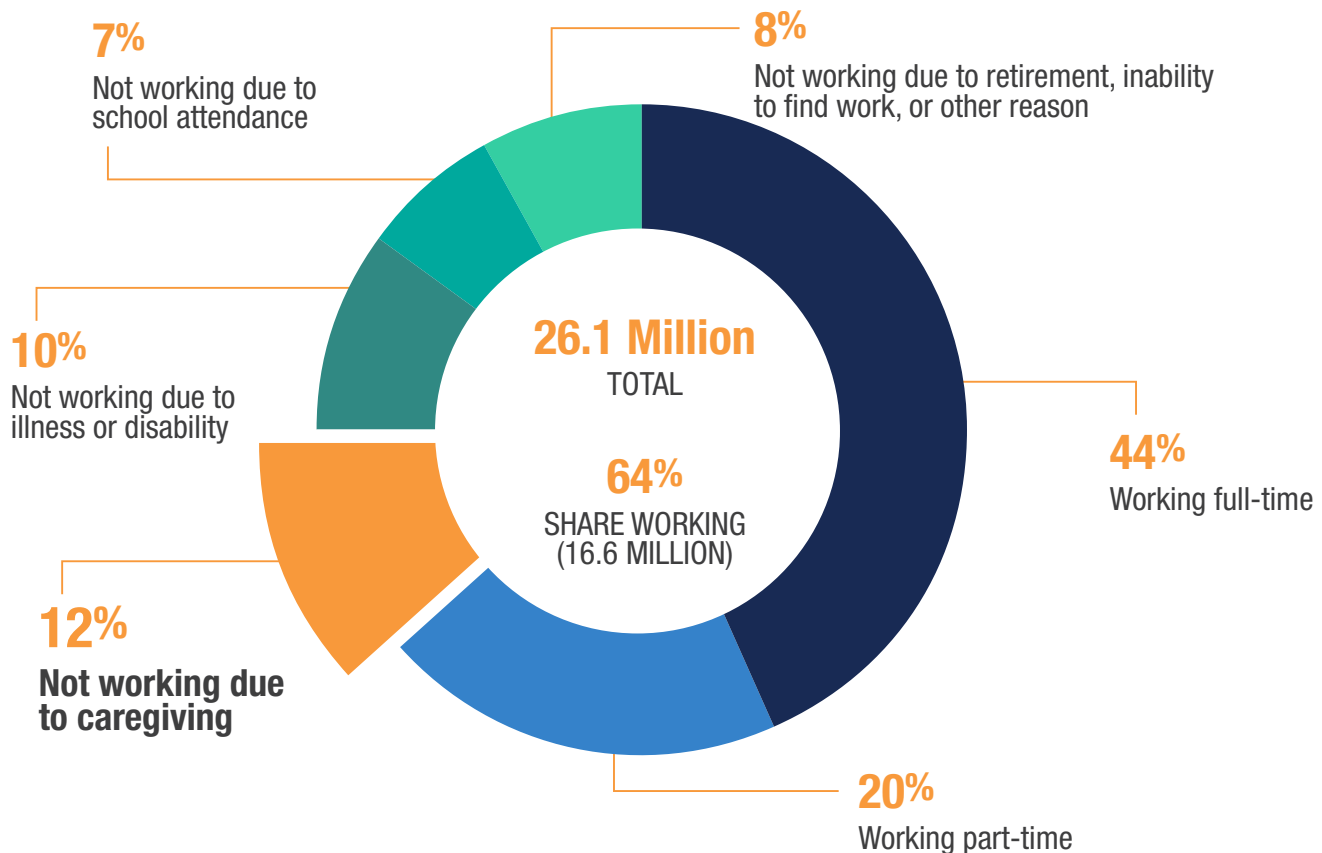
Implementing work requirements for Medicaid eligibility can pose significant challenges for family caregivers enrolled in the program. Many caregivers reduce their work hours or leave employment to provide necessary care, making it challenging to comply with work requirements. This situation can jeopardize their access to health coverage, essential for maintaining their well-being and ability to provide care.

If work requirements are applied to family caregivers who receive Medicaid, they may become unavailable to support family members who use HCBS. This could jeopardize the quality of care they deliver or eliminate their ability to provide care altogether, potentially leading to higher costs as states may need to replace unpaid care with expensive paid services such as costly institutional care.

FIGURE 2.

### Work Status & Barriers to Work Among Medicaid Adults, 2023

*Includes Medicaid covered adults (age 19-64 who do not receive benefits from Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) and are not also covered by Medicare.*



*Note: Total may not sum to 100% due to rounding. Working Full-Time is based on total number of hours worked per week (at least 35 hours). Full-time workers may be simultaneously working more than one job.*

*Source: KFF analysis of the March 2024 Current Population Survey ASEC Supplement*

## Work Requirements and Family Caregivers: Navigating Policy Challenges

- **Balancing Caregiving and Living Expenses:** Many caregivers reduce work hours or leave jobs to provide necessary care, making it challenging to meet Medicaid work requirements. While the Medicaid program does not systematically record whether its beneficiaries are unpaid caregivers, at least 17 states have considered exempting family caregivers from proposed work requirements with only five states implementing changes as of 2018.<sup>7</sup>
- **Unrecognized Labor and Costs:** Caregiving is unpaid labor, yet it saves the healthcare system billions by preventing costly institutional care by offering ongoing support for those with complex needs. Medicaid work requirements that fail to recognize the work of caregiving force caregivers into untenable choices between employment and providing critical care for their loved ones. Pushing people back to work may place new financial burdens on individual states as more people need alternative support for their medical and care expenses.
- **Increased Administrative Burdens:** Mandating caregiving hour documentation for Medicaid coverage creates an undue administrative burden that disproportionately affects those caring for family members with complex medical needs (e.g., cancer, dementia, rare disease, transplant care). These caregivers, who already dedicate significant time and energy to providing intensive care, must now navigate additional paperwork requirements to maintain their essential healthcare coverage. More local and small businesses will need additional staff time to help employees track and report hours related to work requirements. States may need to spend additional dollars on staff and software systems to manage, monitor, and review work-hour reporting.
- **Risk to Caregiver Health:** Without Medicaid coverage, family caregivers will have greater difficulty maintaining their health, thus compromising their ability to provide care to others. According to the CDC, family caregivers showed significantly poorer health across multiple measures compared to non-caregivers in 2021, with worse outcomes related to depression and chronic conditions.<sup>8</sup>

## How Medicaid Cuts Could Impact Medicare

- **Cuts in Optional Services:** Medicaid cuts would create a devastating ripple effect that extends beyond direct care services. As states face funding shortfalls, they will likely eliminate optional coverage that currently helps millions of low-income seniors afford their Medicare premiums and cost-sharing. This would force more family caregivers to shoulder not only hands-on care responsibilities, but also the substantial financial burden of their loved ones' Medicare expenses - an impossible situation for many families already stretched thin. The result would be a crisis of access as seniors struggle to afford basic medical care, even with Medicare coverage.



### CASE STUDY

### LESSONS FROM GEORGIA'S PATHWAYS TO COVERAGE

*Georgia's Pathways to Coverage program, launched as an alternative to Medicaid expansion, requires low-income adults to report 80 monthly hours of work or volunteer activities to receive coverage. Unlike similar programs in other states, Georgia's policy does not include systematic exemptions for groups such as people with disabilities or those caring for family members, including young children. After one year of implementation, 5,500 of an estimated 240,000 eligible residents enrolled.<sup>9</sup> Implementation challenges included application processing times, documentation requirements, and technology system updates. The program has spent over \$26 million since its rollout, with 90 percent allocated to administrative costs rather than medical services. Administrative processes such as application verification and work hours reporting have affected enrollment rates among eligible individuals.<sup>10</sup>*

<sup>7</sup><https://www.justiceinaging.org/wp-content/uploads/2018/11/JusticeInAging-Medicaid-IssueBrief-November19-11am-2018.pdf>

<sup>8</sup><https://www.cdc.gov/mmwr/volumes/73/wr/mm7334a2.htm>

<sup>9</sup><https://www.cbpp.org/blog/georgias-medicaid-experiment-is-the-latest-to-show-work-requirements-restrict-health-care>

<sup>10</sup><https://www.commonwealthfund.org/publications/explainer/2025/jan/work-requirements-for-medicaid-enrollees>

*“While raising my two children with multiple severe disabilities, Medicaid provided the essential services and supplies necessary to meet their needs. We could not have done it without Medicaid.”*

– Amy, Family Caregiver, Texas



## Policy Considerations

A more flexible Medicaid framework that acknowledges the contributions of caregivers would prevent unnecessary coverage losses and strengthen support for the individuals who keep millions of older adults and people with disabilities in their homes, potentially reducing long-term costs for the Medicaid and Medicare programs.<sup>11</sup>

- **Protect and Preserve Self-Directed Pathways:** Ensure Medicaid beneficiaries can choose family caregivers to support complex in-home care, which helps alleviate the nationwide shortage of professional care workers while reducing the need for costly institutional care.
- **Implement Realistic Exemption Policies:** Create exemptions that recognize two key groups: beneficiaries with severe health conditions who cannot work, and family caregivers who provide their essential care. These exemptions should specifically protect caregivers who must reduce or leave their employment to provide full-time support for family members.
- **Standardize Exemptions:** Establish consistent, clearly defined standards for family caregiver exemptions across all state Medicaid work requirements to prevent coverage losses, minimize administrative burdens for state and federal systems, and ensure clarity for supporters.
- **Recognize Caregiving as Essential Work:** Both in policy and Medicaid eligibility criteria, caregiving should be recognized as vital labor that keeps our current healthcare system running. Treating caregiving as work, such as allowing caregiving activities to meet eligibility work requirements, would ensure that caregivers maintain access to the healthcare services they and those in their care need in order to continue providing care.

## Medicaid Policy Recommendations from the 2022 National Strategy to Support Family Caregivers

- Encourage Medicaid programs, programs offered by the VA, and Medicare Advantage programs to expand community-based long-term care options, including expanding self-directed opportunities to allow for the hiring of family caregivers, while also funding LTC services at rates that attract and retain a skilled direct care workforce.
- Redesign the Medicaid eligibility process so that the care recipient does not have to deplete most of their assets to qualify for services and support.

<sup>11</sup><https://www.aarp.org/content/dam/aarp/ppi/2023/3/valuing-the-invaluable-2023-update.doi.10.26419-2Fppi.00082.006.pdf>

## Conclusion

Family caregivers are essential partners in delivering complex care, helping millions of Americans remain in their homes and communities while reducing costs for the healthcare system. As policymakers consider changes to the Medicaid programs, including work requirements and other eligibility restrictions, it is crucial to understand how these policies affect family caregivers' ability to maintain their own health and continue providing care for the people in their lives. Supporting family caregivers through Medicaid not only helps American families but it also strengthens our broader healthcare infrastructure by preventing costly institutional care, reducing emergency room visits, and addressing workforce shortages in long-term care. Protecting and expanding Medicaid's support for family caregivers represents a strategic investment in the sustainability of our nation's healthcare system.

## Acknowledgements

The Act on RAISE campaign – powered by the National Alliance for Caregiving – is focused on driving implementation of the actions outlined in the National Strategy to Support Family Caregivers. The campaign brings together stakeholders across aging, patient advocacy, disability, and caregiving to strengthen our nation's first-ever National Strategy to support America's 53 million family caregivers providing complex care. The Act on RAISE campaign is supported by a cornerstone investment from The John A. Hartford Foundation.



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*Thank you to The John A. Hartford Foundation for supporting Act on RAISE and making this work possible.*