

The Invisible Workforce: How Medicaid Work Requirements Overlook the Labor of Family Caregiving

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Introduction

According to the National Alliance for Caregiving and AARP, more than 53 million American adults serve as family caregivers, providing ongoing support for loved ones with aging-related needs, disabilities, or serious health conditions.

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.

"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

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 1**).

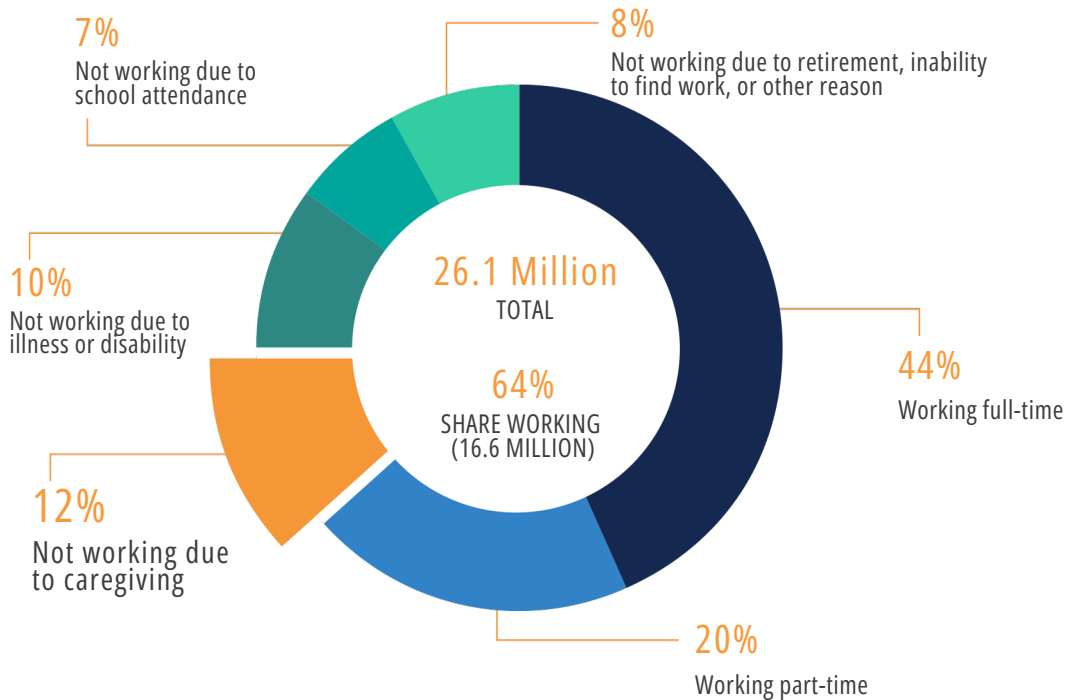
Implementing work requirements for Medicaid eligibility can pose significant challenges for family caregivers enrolled in the program. Many caregivers reduce their work hours or leave employment to provide necessary care, making it challenging to comply with work requirements. This situation can jeopardize 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 home and community-based services. 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 1.

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

Key Considerations: Family Caregiver Coverage at Risk

- **Balancing Caregiving and Work:** 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 (1).
- **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 (2).
- **Varying Exemption Policies:** Caregiver exemption approaches to previous Medicaid work requirements have varied significantly by state. While Arkansas broadly exempted all adults living with children under 18, New Hampshire restricted exemptions to primary caregivers of children under age 6. Research suggests narrower exemption definitions—whether limited to single caregivers per household or only for young children—would significantly increase Medicaid coverage losses among those providing essential family care. Further, exemptions rarely account for family caregivers of older adults and people with serious illnesses and disabilities (3).



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. 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.

(1) Justice in Aging, 2018. <https://www.justiceinaging.org/wp-content/uploads/2018/11/JusticeInAging-Medicaid-IssueBrief-November19-11am-2018.pdf>

(2) CDC, 2024. <https://www.cdc.gov/mmwr/volumes/73/wr/mm7334a2.htm>

(3) Buettgens & Green, 2022. <https://www.urban.org/research/publication/assessing-potential-coverage-losses-among-medicaid-expansion-enrollees-under>