

Spotlight

Medicaid Provides Critical Health Care Coverage to Family Caregivers

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Key Takeaways

- ✓ Close to 1 in 10 (9 percent) family caregivers receive Medicaid coverage for their own health insurance.
- ✓ Family caregivers with Medicaid coverage often provide 40 hours or more of unpaid care each week the equivalent to at least a full-time job.
- ✓ More than half of family caregivers with Medicaid coverage report that they care for family members or friends alone—without other family caregivers and without paid help.
- ✓ If family caregivers with Medicaid coverage were to become uninsured, their care recipients (often older adults) would likely have to pay for care out of pocket, spend down to Medicaid long-term care eligibility, and/or incur more costs to Medicare and Medicaid.

Medicaid plays an important role in supporting family caregivers. Among other supports, it provides essential health care coverage for family caregivers of all ages and helps ensure that family caregivers have access to doctor visits and other important health care services they need as they fulfill their caregiving responsibilities, no matter the other circumstances in their life (e.g., employment, income). More than 4 million family caregivers in the United States report receiving Medicaid coverage for their own health care needs. This figure is consistent regardless of the care recipient's type of health and/or long-term care (LTC) coverage.

This *Spotlight* discusses and provides new data analysis of the AARP and the National Alliance for Caregiving's Caregiving in the United States 2020 survey¹ related to family caregivers who receive Medicaid coverage as their own health insurance. Family caregivers in this analysis all fulfill their caregiver role on an unpaid basis, receiving no payments from Medicaid or private sources.

Profile of family caregivers with Medicaid coverage

Of the 48 million family caregivers of adults in the United States, 9 percent (or about 4.3 million family caregivers) receive Medicaid coverage for their own health care. About one in four (24 percent, or 1.1 million) of these family caregivers are adults ages 50 to 64, whereas most of the remaining are adults under 50 who often take care of a parent or grandparent.

Most Medicaid-enrolled family caregivers are women, and more than half care for older women relatives. In addition, more than half have a high school diploma or less (55 percent) and live with a household income of less than \$30,000 per year (55 percent).

More than one third (35 percent) of the people whom family caregivers covered by Medicaid care for live in a rural area, whereas 15 percent of these caregivers live in a rural area themselves. Rural communities often have less robust provider networks compared

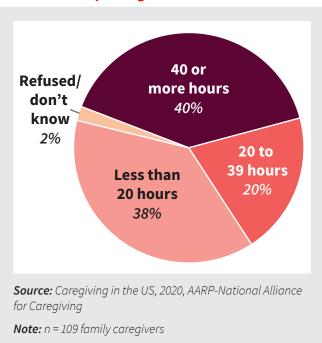
to urban and suburban areas,² making family caregivers, including those with Medicaid coverage, a crucial support for rural care recipients.

Medicaid-enrolled family caregivers spend significant time caregiving

Noteworthy among Medicaid-enrolled family caregivers is the amount of time they devote to caregiving responsibilities. The average family caregiver in this group provides 35 hours per week of unpaid care.

Most (58 percent) report providing 20 hours or more of care per week (the equivalent to a part-time job or more), and close to two in five (38 percent) report devote an amount of time equivalent to a full-time job (40 hours per week) or more of care, including on a constant, around-the-clock basis (figure 1). A much lower share of all family caregivers (37 percent) provides 20 hours or more per week of care.

FIGURE 1
Hours of Unpaid Care per Week among MedicaidCovered Family Caregivers



About one in three family caregivers with Medicaid coverage are employed and balance the dual roles of work and caregiving.

Medicaid-covered family caregivers provide essential care

Family caregivers perform important and often difficult hands-on tasks to support those for whom they care. These include activities of daily living (ADLs), which are basic, fundamental tasks such as eating, bathing, and dressing, and instrumental activities of daily living (IADLs), which are tasks that facilitate independent living such as housework and preparing meals. The support these family caregivers provide often makes the difference in whether their care recipients can get out of bed and go about their day.

Family caregivers covered by Medicaid perform a broad range of caregiving tasks (figure 2) and on average provide help with close to two ADLs and five IADLs. Requiring help with two ADLs is the threshold in many state Medicaid programs for a person to be considered needing a nursing facility level of care

Close to half (43 percent) of these family caregivers help with getting their care recipients in and out of beds and chairs. Similarly, more than one third (38 percent) help with feeding. Like all family caregivers, those with Medicaid coverage often help with several IADLs, and at least 80 percent or more provide help with each of these tasks: housework, grocery and other shopping, preparing meals, and transportation. Often, family caregivers with Medicaid coverage perform tasks at a higher frequency compared to all family caregivers regardless of health insurance status.

More than two in three family caregivers (68 percent) with Medicaid coverage also provide help with medical/nursing tasks, which include wound care and managing medical equipment.

FIGURE 2

Task Performance Frequency among Medicaid-covered Family Caregivers

Category	Task	Frequency
Activities of Daily Living	Getting in and out of beds and chairs	43%
	Feeding	38%
	Getting to and from the toilet	32%
	Getting dressed	27%
	Bathing or showering	26%
	Dealing with incontinence	18%
Instrumental Activities of Daily Living	Housework	89%
	Grocery or other shopping	82%
	Preparing meals	80%
	Transportation	80%
	Giving medicines, pills, or injections	62%
	Managing finances	52%
	Arranging outside services	33%

Source: Caregiving in the US, 2020, AARP and the National Alliance for Caregiving

Note: n = 109 family caregivers

Medicaid-covered family caregivers often provide care alone

Family caregiving can often be a shared experience, in which a few family members or friends will share responsibility for another relative's care. Some family caregivers, however, do this work alone, and Medicaid-covered family caregivers often provide care by themselves.

Most Medicaid-covered family caregivers (59 percent) report that nobody else provided unpaid care for the person for whom they care in the past year. They also frequently report that their care recipient did not receive any paid help (73 percent) in the past year.

Despite often being a caregiver by themselves, family caregivers with Medicaid often say they felt they had a choice whether to be a caregiver (55 percent) and that they found purpose in their caregiving role (66 percent). Despite often being the sole family caregiver, they did not report a higher rate of *feeling* alone as a result of their caregiving responsibilities.

Family caregivers with Medicaid coverage contribute tangible economic value

The estimated economic value of all unpaid care from family caregivers was approximately \$600 billion in 2021 alone.³ This figure exceeds that of all out-of-pocket health care spending (\$433 billion) and spending on long-term and post-acute care from all sources (\$531 billion).⁴

Family caregivers with Medicaid coverage provide an important contribution to the overall economic value of unpaid family caregiving. Although subgroup analysis of the \$600 billion estimated economic value is not available, it is likely that the frequency of higher-hour (e.g., 20 hours per week or more) caregiving from Medicaid-enrolled family caregivers likely drives the economic value they provide higher than their share (9 percent) of the general family caregiving population.

Loss of Medicaid coverage could jeopardize future caregiving availability and add costs to Medicare and Medicaid

The security and stability that Medicaid coverage provides underpins the ability of family caregivers with Medicaid coverage to continue fulfilling their caregiving role. If Medicaid-enrolled family caregivers were to lose their health coverage, there could be serious implications both for themselves and their care recipients, and it would likely lead to higher costs to public programs that pay for care that family caregivers often perform on an unpaid basis.

Implications for the family caregiver

Losing Medicaid would leave caregivers uninsured or force them to seek employment to gain private insurance. More than one-third (36%) of Medicaid caregivers report fair or poor health. Losing Medicaid coverage could mean they lose access to the health care and medications they need, jeopardizing their own health as well as their ability to provide family care. If they were to find employment with private health insurance, they'd likely have less time to provide their care recipient with the same level of support they provide now.

Implications for the care recipient

The support Medicaid-covered family caregivers currently provide would have to come from somewhere else if they were to lose coverage and be less available to provide care. Medicare does not pay for most long-term care (e.g., home care aides, long nursing home stays), so even though most care recipients are ages 65 or older and have this coverage, they would likely not be able to turn to Medicare to cover most paid services that would fill in for what their family caregiver provided.

Most care recipients would instead have to pay out-of-pocket for services to meet their care needs. The median annual cost of most long-term care (LTC) services exceeds the median household income of older adults (about \$54,000 in 2022) and would quickly consume their median household assets (\$50,200) as well.⁵ The high cost of care could be financially devastating for these care recipients, leading them to seek public coverage.

Implications for Medicare and Medicare

Once a care recipient exhausts their financial resources paying for LTC, or if they do not have much to begin with financially, they could start to receive Medicaid LTC services. Even if the person had Medicaid LTC coverage already, losing the support of a family caregiver could lead a person to consume more and/or higher intensity LTC services (e.g., 30 hours of home care per week instead of 10, moving to a nursing home). This would increase costs to Medicaid, which in 2022 spent on average \$45,800 per adult 65-plus in nursing homes and \$25,900 per adult 65-plus for care in the home and community.

A care recipient could also go without any support in the absence of a family caregiver. This, however, increases the risk of hospitalizations and the need for other health care services for which Medicare would often then need to pay.⁶

Medicaid coverage for family caregivers helps to contain costs

Family caregivers with Medicaid coverage likely help to limit costs to Medicare and Medicaid. With the security of their own health insurance coverage, they can devote what often equates to full-time equivalent-level amounts of unpaid family caregiving. This allows those for whom they care to remain in their homes and communities and likely at less expense to Medicare and Medicaid than they would often require in the absence of their family caregiver.

- 1 "Caregiving in the United States 2020," AARP and the National Alliance for Caregiving, May 14, 2020, https://www.aarp.org/pri/topics/ltss/family-caregiving-in-the-united-states/.
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- 3 Susan C. Reinhard et al., "Valuing the Invaluable 2023 Update: Strengthening Supports for Family Caregivers," AARP, March 8, 2023, https://www.aarp.org/pri/topics/ltss/family-caregiving/valuing-the-invaluable-2015-update/.
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- 5 Ari Houser, "Most Americans Will Need Long-Term Services and Supports in Their Lifetimes; Many Will Face Economic Hardship as a Result," AARP, May 28, 2024, https://ltsschoices.aarp.org/blog/americans-need-ltss-will-face-hardships.
- 6 Caroline Carlin and Guy David, "Reduced Health Care Utilization among Elderly Patients with Informal Caregivers," *The Permanente Journal* 23, no. 3 (2019), https://pmc.ncbi.nlm.nih.gov/articles/PMC6636532/.

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