VIEWPOINT

Medicaid Cuts Could Especially Harm Persons Needing Home-Based Supports

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As congressional Republicans eye federally funded programs for spending cuts, the behemoth Medicaid—with $880 billion total spending in fiscal year 2023[1]—is a prominent target. Since 1965, this complex joint federal-state program has covered acute and long-term care costs for specified categories of individuals with low incomes across all ages, including one-third of children and adults with disabilities (15 million people).[2] Many advocacy groups are fighting against Medicaid cuts, as analysts assess how spending reduction strategies would affect program enrollees and federal and state budgets.[3] One proposed strategy for cutting Medicaid is setting per capita (per person) caps on federal Medicaid funding, shifting growing costs to states. Another approach is switching from Medicaid's current entitlement method (federal funds pay roughly 69% of Medicaid costs, while states cover 31%; states with lower per capita incomes have higher federal matching rates) to block grants (giving states fixed federal dollars, without adjustments for changing enrollment).[1] These cuts would immediately eliminate Medicaid coverage for millions of current enrollees. Drastically reduced spending could especially harm the growing population of older adults who depend on Medicaid for home and community-based services (HCBS), which already have long waiting lists and workforce shortages in many states.[4] Evidence indicates that the vast majority of older adults who can no longer care for themselves prefer HCBS supports to live in their homes and communities rather than entering nursing homes.

In 2020, 56 million people (17%) of the US population were 65 years or older; these numbers will rise substantially over time.[4] Disability incidence rates increase with age (**Table**).[5] In 2022, almost 6% of persons 65 years or older had a self-care disability, such as difficulty bathing or dressing, and likely needed daily in-home supports from paid or unpaid caregivers. At some time, more than half of individuals 65 years or older will likely need assistance with at least 2 activities of daily living.[4] Personal assistance services are expensive. In a 2022 survey, 37% and 46% of respondents, respectively, reported it would be "impossible" or "very difficult" to pay $60 000 for 1 year of in-home or assisted living care.[6] In 2023, median costs for a full-time home health aide were $68 640, far exceeding the $36 000 median income of persons 65 years or older.[4] Given other demographic trends, notably lower birth rates and rising rates of living alone that reduce numbers of potential unpaid caregivers, more older peoples turn to Medicaid as their only option for obtaining in-home personal care. Contrary to the assumptions of many US residents, Medicare covers in-home personal assistance only in limited circumstances.

States can offer various HCBS benefits through different Medicaid mechanisms. All states must cover home health care; under Medicaid waivers, they have options to cover other services, such as personal care and expanded benefits for targeted populations.[7] States' choices about caring for people needing personal supports vary dramatically, with some states prioritizing HCBS and others institutional care. In 2021, 94% of Medicaid participants in Wisconsin needing long-term services and supports have obtained HCBS only, whereas 4% were institutionalized.[7] By contrast, in Florida just 48% of long-term services and supports recipients have obtained HCBS only, whereas 51% were institutionalized. In 9 states, more than 40% of people using Medicaid long-term services and supports are institutionalized. Nevertheless, state Medicaid programs cannot serve all enrollees needing HCBS, leaving 700 000 on waiting lists.[4] Most people on waiting lists have intellectual or developmental disabilities, and 25% are elderly individuals or adults with physical disabilities.[4] Importantly, the COVID-19 pandemic exacerbated shortages of HCBS workers, and 23 states reported permanent closures of HCBS providers in the prior year.[4] A 2022 survey of US citizens who had recently sought in-home personal assistance services found that 12% and 39%, respectively, reported it was "very difficult" and "somewhat difficult" to find care.[6] On May 10, 2024, the Centers for Medicare & Medicaid Services (CMS) issued a final rule requiring that state HCBS payment rates be high enough to ensure an adequate workforce, but whether this rule will be enforced is uncertain.[4]

Per capita caps lock in current spending patterns and likely will hamper efforts to decrease HCBS waiting lists, especially in regions with higher wages that make it harder to attract new HCBS workers. In addition, some individuals, especially those with multiple disabilities, are high-cost HCBS users. In 2023, the median annual costs for round-the-clock home health aide services were $288 288, far more than even private-room nursing home costs ($116 800; Medicaid typically pays only for semi-private nursing home rooms).[4] Even if small, this population of high-cost HCBS users may have outsized effects on Medicaid costs. States with tight Medicaid budgets may decide that institutionalizing Medicaid enrollees who need extensive home-based supports is cheaper than paying HCBS costs.

Thus, drastic Medicaid cuts threaten retrenchment from 2 decades of supporting community-based living toward institutionalizing persons who need substantial HCBS to remain in their homes. However, curtailing HCBS goes beyond mere fiscal considerations, raising major safety concerns. Shockingly high nursing home death rates during the COVID-19 pandemic cast this risk in stark relief.[8] Low staffing was only one of many factors that contributed to lethal outcomes for nursing home residents. The May 10, 2024, CMS regulations aimed to bolster nursing home staff,[4] but whether these new rules will be followed likewise is unclear.

Beyond these safety concerns, Medicaid cuts that substantially reduce HCBS supports would endanger the autonomy and

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Table. US Disability Rates by Age and Type in 2022[a]

	Disability type, age-adjusted prevalence, % (95% CI)		
Age, y	Any	Self-care	Independent living
18-44	23.6 (23.1-24.0)	1.9 (1.7-2.0)	6.5 (6.3-6.8)
45-64	29.1 (28.6-29.6)	5.2 (5.0-5.5)	8.0 (7.8-8.4)
≥65	43.9 (43.3-44.5)	5.9 (5.6-6.1)	10.7 (10.3-11.1)

[a] Data come from the Behavioral Risk Factor Surveillance System (BRFSS) survey, which asks respondents 6 disability questions. Respondents are classified as having any disability if they answer "yes" to any of the 6 questions. BRFSS asks respondents, "Do you have difficulty dressing or bathing?" Respondents who answer "yes" are classified as having a self-care disability. BRFSS asks respondents, "Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor or shopping?" Respondents who answer "yes" are classified as having an independent living disability (https://www.cdc.gov/dhds/data-guides/status-and-types.html).[5]

dignity of individuals with disabilities, including the growing population of older people. For more than 25 years, the Supreme Court's decision in *Olmstead v L.C.*[9] has enshrined the principle that all people with disabilities have the right to live independently in their communities, with state-funded supports and health services—the so-called *Olmstead* integration mandate. Yet the Court itself recognized that honoring this mandate hinges on the government's continued commitment to providing the funds and resources necessary to sustain community-based services. By slashing Medicaid, Congress threatens not only essential HCBS programs but also could eviscerate the *Olmstead* integration mandate—risking reversal of decades of hard-won progress on disability rights and dignified living.

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