

TO: Interested Parties

DATE: March 2026

Re: The efficiency and necessity of Medicaid home and community-based services (HCBS)

Every person will at some point in their lives either give, need or receive aging and disability care. Every day, [10,000 Americans turn 65 years old](#), and the number of older adults [over 85-years-old is expected to more than double by 2040](#). More than [1 in 4 people in the U.S. have disabilities](#), and across the country, more than [one in five adults receive ongoing support](#) with everyday activities like bathing, dressing, going to work, and taking medications.

Aging and disability are a fundamental part of the fabric of our daily lives, and caregiving is essential. Without action to protect Medicaid home and community-based services, we will lose the services and caregiving that enable living and aging with dignity for people with disabilities of all ages and for older adults.

Home and community-based services (HCBS) are essential.

Until we, or someone in our family, need help with basic needs of living – ranging from helping us dress or get around to eating, bathing, toileting or helping with supports for work, we may not recognize how important home and community-based services (HCBS) and the people who provide them are. People with disabilities and older adults need support, and direct care workers, like personal care attendants, home health aides, and nursing assistants, along with family caregivers provide it. We count on direct care workers and family caregivers to:

- Help an older parent return to living independently after a hospitalization for a stroke or fall;
- Enable a grandparent with dementia to stay at home while getting support for cooking, taking medication, moving around the home, and transportation for medical appointments;
- Provide daytime or nighttime nursing care to a child with complex medical needs that require continuous monitoring and fast intervention so parents can have relief without worrying about their child’s safety; and
- Support a working-age adult with intellectual and developmental disabilities to get ready for work and maintain their employment.
- Help an adult with significant mental health needs avoid unnecessary hospitalization and maintain stable housing, employment, and meaningful relationships in the community.

Medicaid HCBS enables older adults and people with disabilities who need care to make choices that are best for themselves, their families, and their unique needs.

Today, [8.4 million people rely on Medicaid for the home and community-based services](#) that provide these essential supports, enabling older adults to live in the homes they worked their entire lives for, adults with disabilities to be in their communities instead of nursing facilities, and children with disabilities to grow up at home with their parents and loved ones, instead of in

pediatric nursing institutions. The vast majority of people – [including 94 percent of older adults and 90 percent of people with disabilities](#) – want to live and age in their own homes and communities.

Most people with disabilities and older adults who need care [do not have an alternative insurance option to access HCBS](#), since Medicare has a very limited benefit, most private health insurance options do not cover long-term care, and private long-term care insurance is prohibitively expensive with high denial rates.

HCBS spending increases reflect more people getting the help they need in the community.

HCBS spending has been increasing across the country as a direct result of decades of work by families, people with disabilities, and older adults who want to live, work, and age with dignity in their own homes and communities, alongside [bipartisan federal and state efforts to rebalance funding to HCBS from institutional care](#). Simply put, [more people are enrolled in Medicaid HCBS](#) and fewer people are relying on expensive institutional care.

Yet, demand for HCBS and unmet need are both high.

The US population is [older today than it ever has been](#); the [number of older adults in the US is expected to increase by 30 million people](#) from 2022 (57.8 million) to 2060 (88.8 million). People turning 65 already have a nearly [70 percent chance of needing long-term care](#), and approximately 20 percent will need more than five years of services. Service needs are also by no means limited to older people – [over half of people receiving Medicaid long-term care are under the age of 65](#).

Across the nation, [there are over 600,000 people on Medicaid waiting lists for HCBS](#). Current cuts to Medicaid and [threats of further cuts to services put this system of care and support for so many of us at risk](#). Without HCBS, people with disabilities and older adults lack the supports they need to live in the community, forcing people into nursing facilities or other institutions, increasing pressures on family caregivers, or leaving people to go without care entirely.

HCBS are efficient and cost-effective.

HCBS is significantly less expensive for states and the federal government to provide than nursing home care. Rebalancing by utilizing Medicaid funding to avoid institutionalization can [save considerable money for states](#). Nationally, [Medicaid enrollees who receive institutional services have significantly higher average expenditures](#) (over \$54,000 per user) than average expenditures for people who use Medicaid HCBS (under \$18,000 per user). [Medicaid HCBS users make up 87 percent of Medicaid LTSS users but only 63 percent of LTSS expenditures](#). For people with intellectual and developmental disabilities, the average cost to serve a person in their homes and communities is more than [\\$300,000 less expensive than services in a public institution](#).

Medicaid and HCBS are also lean. Medicaid spent \$146 billion dollars on home and community-based services in 2023, the year with the most recent data. [HCBS grew by](#)

[approximately 4.7% per capita](#), a slower growth rate than per capita spending in [Medicaid generally](#), and slower than [per capita growth generally](#) across all kinds of insurance.

Cutting Medicaid HCBS significantly increases costs to states as people with disabilities and older adults are forced into institutional care and are more likely to go to emergency rooms for needs that could've been prevented. For example, [in California](#), cutting HCBS recipients by 3 percent, [a significantly smaller cut than 2010-2011](#), would cost the state \$57 million in just the first year due to higher cost of nursing facility care for people who lose HCBS access.

Direct care workers, including immigrant care workers, and family caregivers are at the heart of caregiving.

[Nearly 5 million people in the U.S. are direct care workers](#), providing paid care in homes and communities that enable living and aging with dignity. The number of direct care workers is more than double the number in 2000, but [growth in the workforce has not kept pace with the demand for services](#). The vast growth in the direct care workforce is not indicative of program integrity concerns, instead reflecting the needs of a rapidly aging population and increased understanding of the value of HCBS for the independence and freedom of both people with disabilities and older adults.

The majority of care is provided by family caregivers. In the U.S., [130 million people – or 40 percent of all adults – are family caregivers](#) for people with disabilities or older adults. The value of the unpaid care family caregivers provide is estimated to be over [\\$600 billion](#) annually.

We need to invest in the direct care workforce and support family caregivers.

Although [experts project continued growth of close to a million workers by 2032, the total workforce falls far short of the almost 9 million jobs that will need to be filled](#) to meet the needs of all who need care. In short, we are facing a direct care worker crisis [across every state](#).

[Experts attribute that shortage to a variety of factors – especially low wages, limited benefits, and the lack of a career pathway – all making it difficult to attract and retain workers.](#)

Immigrants who are willing to undertake this work are at the heart of providing paid care. Immigrants play a particularly large role in the home care workforce, [making up one in three workers \(32%\) in home care settings](#).

The lack of adequate and robust investment in the direct care workforce leaves massive barriers to community living and aging in place for people with disabilities and older adults. For example, a recent [survey of community providers](#) supporting people with intellectual and developmental disabilities found that due to the workforce shortage, 62% of providers reported turning away new referrals due to inadequate staffing, 59% of providers intended to delay the launch of new programs, and 52% of providers were considering further cuts to programs if recruitment and retention challenges failed to subside.

Family caregivers are often the only option to fill the gap. Family caregivers for older adults and people with disabilities who are being paid through Medicaid are doing real labor that would

otherwise be provided by unrelated individuals. They are filling crucial gaps in the labor market. This work looks different from typical caregiving families members tend to do for each other, or the care a parent gives a typically developing child. Instead, paid family caregiving can involve fully bathing and grooming a grown adult, transferring someone from a bed to a wheelchair, helping with bowel programs, and fully assisting with all aspects of toileting, and even skilled medical care such as monitoring, suctioning, and changing tracheotomies so ensure individuals can breathe.

[Self-directed HCBS programs](#), which allow individuals who need HCBS to decide who to hire as caregivers and afford the opportunity for people to hire their family as caregivers at a very modest rate, provide choice and control over the services they receive, and result in better, more consistent care. This makes caregiving possible and sustainable for family caregivers, as it allows recouping a small portion of lost income while caring for their relative, who may also be living on a fixed income. In Georgia, [one family caregiver](#) earns approximately \$18,000, despite providing 24/7 care to her sister with mental health disabilities. All but three states enable payment for some family caregiving in recognition of the critical, valuable work they provide and to ease the shortage of direct care workers.

Freezing Medicaid reimbursement threatens the integrity and stability of state Medicaid programs

Medicaid financing operates within thin margins. Taking actions to freeze, withhold, or defer federal payments for entire service categories, even for services rendered, threatens the integrity and longevity of states' Medicaid programs. States are facing dire financial circumstances as it is. They cannot run a budget deficit and need to keep funds in reserve to address a variety of unexpected costs including natural disaster relief. So any expectations that a state can maintain provider payments and service delivery without a clear timeline for release of federal reimbursement is unrealistic. Withholding reimbursement creates uncertainty, which can be destabilizing for providers, many of whom often operate with small margins. Continued operations under the threat of successive freezes, withholding, and deferments is unsustainable. These actions create a perverse incentive for states to shrink and cut their HCBS programs. These actions will in no uncertain terms hurt people with disabilities and older adults through decreased service availability, longer waiting lists, and increased risk of institutionalization; deepen our reliance on already undersupported family caregivers; and worsen the existing direct care workforce crisis.

States already conduct robust oversight of their HCBS programs

Every state has a Medicaid program integrity unit and a [robust set of tools](#) to ensure accountability for spending. These include data driven audits, oversight of contracts, provider credentialing and oversight, oversight of claims prior and post payment, as well as enforcement mechanisms. These efforts are supported at the federal level by the CMS Center for Program Integrity (CPI) which was established in 2010 to coordinate program integrity efforts and provide data and training to states.

These and other oversight tools, however, are being undermined and even dismantled. For example, this Administration has fired federal Inspectors General and delayed and neglected efforts to improve HCBS data collection, including quality measures that would further strengthen oversight and accountability of expenditures.

Cuts to Medicaid funding from H.R. 1 and from CMS actions will further endanger the availability of care at home and increase the affordability crisis.

Unlike nursing home services, which federal law requires state Medicaid programs to provide, HCBS are optional for states. States cannot cap or limit mandatory services for their Medicaid enrollees, so instead will look to cut optional services such as HCBS to fill existing and growing budget holes. [HCBS makes up more than half of all optional spending.](#)

When federal Medicaid funding is cut, [every single state cuts some of their HCBS services or spending](#), leaving older adults and people with disabilities without access to critical care. Already, [several states have proposed eliminating or reducing funding](#) for some or all home and community-based services.

Across the country, people with disabilities, older adults and their families are testifying to what would happen if HCBS is cut and they lose access: [Idahoans](#) testified that losing access to HCBS means losing caregivers who keep a 9-year-old alive round the clock, speech therapy for a 3-year-old with autism, support with a ventilator and gastric tube for a 53-year-old who is paralyzed from the neck down, and services that enable people with disabilities of all ages to live independently. The stories repeat across the country, as [Nebraskans](#), [Coloradoans](#), and [North Carolinians](#) have all shown.

Without Medicaid HCBS, the egregiously high cost of care makes aging and disability care unaffordable for most families.

There is a growing care affordability crisis, where care is out of reach and doesn't meet the needs of far too many. The median annual cost of care at home in the US is [more than \\$68,000 for 40 hours/week of care from a home health aide and more than \\$228,000 for round-the-clock home health aide, with significant variation across states.](#) These costs far exceed the median annual income for [older adults](#) and [people with disabilities](#). Despite the critical nature of care work, the direct care workers who support older adults and people with disabilities with living where they choose are still underpaid and undervalued. Family caregivers who fill necessary gaps already [spend more than a quarter of their income on caregiving-related needs](#). The only way most families can receive the care they need is through Medicaid.

The bottom line: Our families and our nation need policies that support, not undermine, Medicaid and essential services, the people who need them, and the caregivers and workers who provide them.

Public Opinion:

Support for Aging and Disability Care				
	Total across political parties	Republicans	Independents	Democrats
We should increase funding for HCBS or keep it at current levels (Data for Progress/Caring Across Generations, 2025)	90%	88%	90%	93%
Support among male voters for ensuring affordable long-term care for aging and disabled family members (GSG, 2025)	96%	95%	95%	97%
Likelihood for male voters to vote for a candidate who supports affordable long-term care (GSG, 2025)	79%	73%	75%	88%
Support the use of federal tax dollars to fund programs that help older adults age in their homes rather than in nursing homes (John A. Hartford, 2025)	79%	70%	76%	93%
Support expanding Medicare to include long-term care (DFP, 2024)	88%	86%	81%	94%
Support for expanded services and subsidies for long-term care (Pivotal/BPC Action, 2024)	81%	75%	77%	89%
Congress should take action to improve the availability of quality, affordable home and community care (Hart/Caring Across Generations, 2023)	86%	86%	75%	98%