



# TAKE ACTION TODAY

## Advocacy Toolkit: Medicaid Home and Community- Based Services



NATIONAL ALLIANCE  
FOR CAREGIVING



The National Alliance for Caregiving and the Caregiver Nation Coalition developed this advocacy toolkit to help partners, caregivers, and advocates communicate the value of Medicaid home- and community-based services (HCBS) and take action to preserve and protect them. HCBS provide vital supports that makes caring at home possible, while caregivers balance work, finances, and their own well-being.

Now is a pivotal moment for the future of HCBS. The services that help older adults and people with disabilities remain at home and avoid institutional care are facing increased scrutiny, and they are at significant risk for elimination and cuts. We must ensure HCBS are protected for vulnerable individuals and their caregivers.

This toolkit is designed to move advocacy into action by providing the tools to educate decision-makers, engage your community, and amplify the importance of HCBS, including:

- A snapshot of Medicaid home- and community-based services and the critical role they play in supporting family caregivers.
- Key messages on why HCBS are valuable to family caregivers, local communities, and the broader economy.
- Resources, including fact sheets, infographics, and informational articles.
- Template social media graphics and sample copy.
- Template newsletter and letter to the editor highlighting a call to action.

With 13%, or 8.19 million, of our nation's 63+ million family caregivers covered by Medicaid, it is critical that we elevate their voices. We must clearly demonstrate the value of Medicaid HCBS and the essential role these services play in helping older adults, people with chronic conditions, and people with disabilities live with dignity in their homes and communities across the country.

*If you have any questions, please reach out to Kim Cantor at [kim@caregiving.org](mailto:kim@caregiving.org).*

## I. Snapshot: Medicaid Home and Community-Based Services

**Medicaid home and community-based services (HCBS)** are essential to the long-term care of millions of Americans. These services provide the support people need to remain safely at home and in their communities, rather than moving to an institution. These services directly support the family caregivers who provide essential ongoing care to these individuals every day.

Services can include:

- Home health care, such as in-home nurses, therapists and dieticians
- Self-directed services that allow an individual to choose their care needs
- Caregiver respite that allows breaks both in and out of the home
- Caregiver counseling and training for the primary caregiver
- Adult day programs like adult daycare and senior centers

In 2023, according to the Centers for Medicare and Medicaid (CMS), 8.4 million people were using HCBS.<sup>1</sup> In 2025, more than 600,000 people were on the wait list for HCBS programs across the states.<sup>2</sup> Medicaid HCBS are especially valuable to family caregivers because they help make caregiving more sustainable, both emotionally and practically.

Of these services, respite care and self-directed care services are particularly helpful to family caregivers.

**Respite care** provides a crucial break for family caregivers, either planned or in the event of an emergency. The service allows for a trained professional to provide temporary relief for the caregiver, improving the well-being of the patient and caregiver, maintaining positive familial relationships, and reducing caregiver hardship.

**Self-directed care services** are models of care implemented through Medicaid waivers that allow a Medicaid beneficiary to select, train, and manage those that support them. This gives a beneficiary autonomy in their own care. Under some

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<sup>1</sup> Carpenter, A., Stepanczuk, C., Murray, C., & Wsocki, A. (2025, October 17). Trends in Users and Expenditures for Home and Community-Based Services as a Share of Total Medicaid Long-Term Services and Supports Users and Expenditures, 2023. Mathematica. <https://www.medicaid.gov/medicaid/long-term-services-supports/downloads/ltss-rebalancing-brief-2023.pdf>.

<sup>2</sup> Burns, A., Wolk, A., & O'Malley Watts, M. (2025, November 20). A Look at Waiting Lists for Medicaid Home- and Community-Based Services from 2016 to 2025. KFF. <https://www.medicaid.gov/medicaid/long-term-services-supports/downloads/ltss-rebalancing-brief-2023.pdf>.

waivers, the trained workers can be friends or family members, meaning family caregivers can be paid for the care they provide daily. This payment supports family caregivers and makes it easier for them to continue caring for their care recipients at home.

## II. Key Messages

### Medicaid HCBS and Importance to Family Caregivers

Medicaid HCBS are a lifeline for family caregivers and their care recipients, allowing them to remain in their homes with dignity and stability. HCBS are especially valuable to family caregivers because they make caregiving more sustainable.

- **They help loved ones remain at home.** HCBS provides personal care, homemaker services, adult day programs, transportation, and other supports that allow older adults and people with disabilities to stay in familiar surroundings rather than move into institutional care. This often aligns with what families want most.
- **They reduce caregiver burnout.** Family caregivers often manage care around the clock. Services such as respite care, home health aides, and skilled nursing can give caregivers time to rest, work, or address their own health needs.
- **They extend the caregiver's capacity.** Many family caregivers are not trained clinicians. HCBS can bring professional support into the home, helping with complex medical or daily care tasks that caregivers may not be able to safely handle alone.
- **They ease financial strain.** By covering services that families might otherwise have to pay for out of pocket, HCBS can reduce the economic burden caregivers often face when balancing work and caregiving responsibilities.
- **They improve quality of life for the whole family.** When formal supports are in place, caregivers can spend more time being a spouse, child, or partner, rather than only a care coordinator, strengthening family relationships.
- **They support long-term stability.** Without these services, caregivers may be forced to leave the workforce or may reach a crisis point that leads to nursing home placement.

### What the Data Show

Drawing from [\*Caregiving in the US 2025\*](#), a joint report from the National Alliance for Caregiving and AARP, the data show clearly the need for support for family caregivers in every community across the U.S.

**Family caregivers need support. HCBS including respite care, self-direction, and general in-home care support are helpful and essential. For example, respite care helps alleviate the high emotional stress and demands placed on family caregivers.**

- Caregivers provide an average of 27.3 hours of care per week with nearly 1 in 4 providing 40 hours or more a week.
- 65% of caregivers assist their care recipients with activities of daily living such as bathing, feeding, toileting, and getting dressed.
- 40% of caregivers report providing high-intensity care.
- 55% are performing complex medical or nursing tasks.
- 38% of caregivers report high emotional stress.
- Only 13% of family caregivers are currently using respite care with 39% saying that they want or need access to respite care.

**Family caregivers deserve financial recognition for the care they provide. Medicaid self-directed care services are a proven way of allowing some caregivers to receive a modest stipend that can ease caregiving-related financial strain.**

- 68% of caregivers have asked for a program where they could be paid for at least some of the hours that they provide care.
- 18% of caregivers say they experience high financial strain due to caregiving.
- 11% of caregivers had to start working, work more, or take on a second job due to caregiving.

**People want to live and provide care in the comfort of their own homes. HCBS makes this stability, emotional assurance, and independence possible.**

- 40% of caregivers and care recipients share a household.
- 44% of care recipients remain living in their own home after obtaining a caregiver.
- 94% of older adults and 90% of people with disabilities want to live in their own home as long as possible.<sup>3</sup>
- 4 million caregivers are providing care to their child with a serious condition or illness.
- 29% of caregivers are Sandwich caregivers, meaning they are providing care for an older adult as well as a child under the age of 18.

**Medicaid HCBS Save Money and Acknowledge Economic Value**

Our healthcare system is largely driven by considerations of cost, value, and outcomes. Family caregivers play a critical role within this framework, generating significant cost savings while serving on the frontlines of care—supporting care partners, monitoring

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<sup>3</sup> Caring Across Generations. (2026, March). Medicaid HCBS Memo. [https://caringacross.org/wp-content/uploads/2026/03/Medicaid-HCBS-Memo\\_March-2026.pdf](https://caringacross.org/wp-content/uploads/2026/03/Medicaid-HCBS-Memo_March-2026.pdf).

emotional and physical health, and helping individuals remain safely in the homes and communities they prefer.

### **Supporting family caregivers in caring for a care recipient in their own home costs less annually than it does to support someone in an institution.**

- In 2022, Medicaid spending per person on institutional care was \$48,143 compared to \$16,491 for people receiving HCBS.<sup>4</sup>
- Annual average nursing home cost per person is more than \$108,000 compared to just \$42,000 in Medicaid spending for HCBS recipients.<sup>5</sup>

### **HCBS provides financial relief that costs a fraction of the economic value caregivers provide. Without this support, increased funding and responsibility for those who need care would fall on communities, states, and the federal government.**

- Family caregivers in the U.S. contribute 49.5 billion hours of care annually, valued at \$1.01 trillion per year.<sup>6</sup>
- 47% of caregivers have experienced a negative financial impact due to caregiving, including stopping saving, taking on debt, and either leaving their job or having to work more.
- 70% of caregivers also work while caregiving, but experience negative work impacts such as going in late/leaving early, taking time off, reducing hours or having to give up work all together.

### **Addressing HCBS Concerns**

Medicaid is under attack and facing increased scrutiny from multiple angles. One such approach challenges HCBS citing fraud, waste, and abuse.

- All fraud, waste, and abuse in Medicaid must be addressed to ensure funds reach those who need them most. However, halting funding to HCBS in states where fraud is being investigated harms thousands of caregivers and their care recipients.
- CMS' approach to addressing fraud may exacerbate state financial and administrative challenges as they attempt to reconcile their budgets, possibly

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<sup>4</sup> Carpenter, A., Stepanczuk, C., Murray, C., & Wsocki, A. (2025, October 17). Trends in Users and Expenditures for Home and Community-Based Services as a Share of Total Medicaid Long-Term Services and Supports Users and Expenditures, 2023. Mathematica. <https://www.medicaid.gov/medicaid/long-term-services-supports/downloads/ltss-rebalancing-brief-2023.pdf>.

<sup>5</sup> Ibid.

<sup>6</sup> Houser, A., Caldera, S., Flinn, B., & Choula, R. (2026). Valuing the Invaluable 2026. <https://doi.org/10.26419/ppi.00402.001>.

leading to a decrease in Medicaid spending and, consequently, less family caregivers and care recipients covered under HCBS.

- Medicaid HCBS currently has a wait list of more than 600,000 across states. A decrease in funding and capacity would increase the number of families in need of these vital services and aggravating caregiver hardship, financial burdens, and caregiver and care recipient health across the country.

Below are several approaches for addressing fraud, waste, and abuse that will not harm caregivers and care recipients, including:

- Target enforcement on intentional wrongdoing – policies distinguishing deliberate fraud from administrative error, proportionate punishment and clear guidance and training on correcting document deficiencies before punitive action is taken.
- Protect continuity of care – establish safeguards to ensure that beneficiaries are not left without access to essential services.
- Use evidence-based, proportionate tools – integrity actions should be rooted in valid evidence of systemic violations, with calibrated analytical methods that keep in mind a genuine need with increase of services.
- Support states as partners, not adversaries – federal oversight should be collaborative and constructive with states, working to strengthen compliance systems, share data and build administrative capacity.

### III. Educational Resources

#### Fact Sheets & Infographics

[Medicaid Home and Community-Based Services \(HCBS\) Fact Sheet](#)

[Medicaid Home and Community-Based Services \(HCBS\) Infographic](#)

[Respite Care Fact Sheet](#)

[Medicaid Home and Community-Based Services \(HCBS\) Self-Directed Care Fact Sheet](#)

[Family Caregivers: America's Essential Economic Engine](#)

#### Additional Resources

[AARP Letter to Energy Committee on Fraud in Medicaid](#)

Barkoff, A., Cohen, M.A., Rosenbaum, S., & Tavares, J. (2026, March 16). [Unfounded Fraud Allegations Threaten Vital Medicaid Home and Community-Based Services](#). HealthAffairs.

Burns, A., Mathers, J. & Rudowitz, R. (2026, March 16). [CMS' New Approach to Federal Medicaid Spending in Cases of Potential Fraud](#). KFF.

AARP and National Alliance for Caregiving. [Caregiving in the US 2025](#). Washington, DC: AARP, July 2025.

[Caregiver Nation Coalition](#)

Caring Across Generations. (2026, March). [Medicaid HCBS Memo](#). Caring Across Generations.

The Disability & Aging Collaborative & Consortium for Constituents with Disabilities. (2026, March 16). [Letter to Congressional Leadership on Critical Role of HCBS](#). Consortium for Constituents with Disabilities.

The Disability & Aging Collaborative & Consortium for Constituents with Disabilities (April 14, 2026). [Letter in support of HCBS](#).

[Kaiser Family Foundation](#)

McCarty, L. (2026, April 13). [Medicaid Cuts Could Force More Kids to Become Caregivers](#). Modern Medical Alliance.

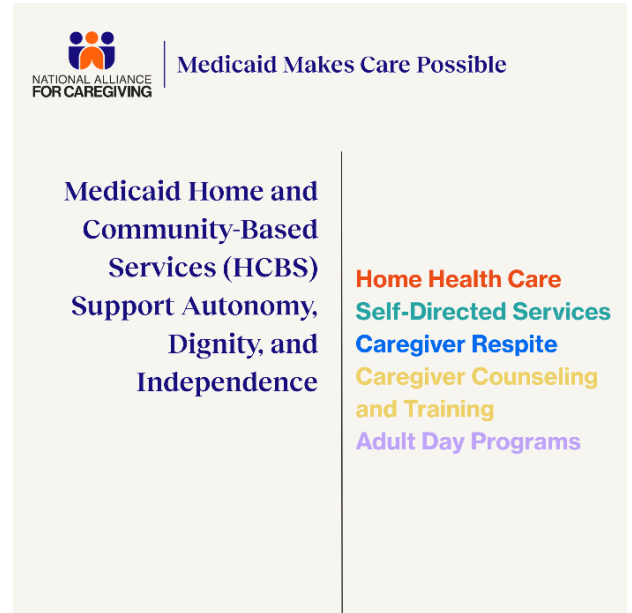
Milken Institute School of Public Health. (2026). [Home and Community Based Services Impacts Tracker Project](#).

National Alliance for Caregiving. (2026, April 22). [Protecting Medicaid Beneficiaries and Their Caregivers, While Ensuring Program Integrity](#).

The Partnership for Medicaid. (2026, March 31). [Partnership for Medicaid HCBS Memo](#). The Partnership for Medicaid.

## Template Social Media

Click [HERE](#) To download graphics.



## X (Twitter)

### Post 1:

Family caregivers hold our care system together providing complex care daily. Yet only 13% get respite support, though many more need it. #Medicaid #HCBS reduces burnout, eases financial strain, and keeps loved ones at home.

Protect Medicaid HCBS. Families cannot do this alone.

### Post 2:

Family caregivers juggle 27 hrs/week of care + work & their own health. Medicaid #HCBS provides respite, in-home support, and services that prevent unnecessary institutional care.

These services are essential for families and must be protected. #FamilyCaregivers #LongTermCare

## **LinkedIn/Facebook/Instagram**

Family caregivers are a critical part of our long-term care system, yet too often public policy overlooks the support they need to continue providing care at home.

Family caregivers in every community provide an average of 27.3 hours of care each week. Nearly 65% assist with daily activities like bathing, dressing, and feeding, and more than 6 in 10 are performing medical or nursing tasks at home once handled only in clinical settings.

And the strain is growing:

- Only 13% of caregivers receive respite care
- 39% say they need respite support
- Nearly 1 in 5 report high financial strain related to caregiving

Medicaid home- and community-based services (HCBS) help fill this gap by providing respite care, in-home assistance, and self-directed options that make caregiving more sustainable while allowing older adults and people with disabilities to remain at home with dignity.

Without HCBS, many families are left with impossible choices: reducing work hours, exhausting savings, delaying their own healthcare, or turning to more costly institutional care.

Protecting Medicaid HCBS is not only good policy for older adults and people with disabilities. It is essential policy for the family caregivers who keep our care system functioning every day.

#FamilyCaregivers #Medicaid #HCBS #LongTermCare

## IV. NEWSLETTER TEMPLATE

### **Family Caregivers Are a Critical Part of the Care System. Medicaid HCBS Help Keep That System Working.**

Our nation's more than 63 million family caregivers are on the front lines of care, providing ongoing and often complex support every day in communities across the country. Medicaid home- and community-based services (HCBS) are a vital lifeline for millions of families because they make caregiving more sustainable both emotionally and financially while helping older adults and people with disabilities remain at home with dignity and stability.

Family caregivers provide an average of 27.3 hours of care each week, with 65% assisting with daily activities such as bathing, dressing, and feeding. Their responsibilities are becoming more complex, with more than 6 in 10 caregivers performing medical or nursing tasks at home. Yet despite the demands, support remains limited. Only 13% of caregivers currently receive respite care, even though 39% say they need it.

These numbers reinforce what families already know: family caregivers are a critical part of the care system, and Medicaid HCBS help keep that system working.

HCBS support families in meaningful ways. They help reduce caregiver burnout by providing respite care, home health aides, and skilled support. They ease financial pressure by covering services families would otherwise have to pay for themselves. They also strengthen families by making it possible for loved ones to remain at home and allowing caregivers to spend more time as spouses, children, and partners—not only as care coordinators.

Without Medicaid HCBS, many families face impossible choices: leaving the workforce, draining savings, delaying their own healthcare, or moving a loved one into institutional care earlier than necessary.

Family caregivers cannot continue to fill growing gaps in long-term care without stronger support. Policymakers must protect Medicaid HCBS from cuts or elimination and ensure these services remain available to the families who rely on them. Medicaid HCBS are not optional. They are essential to sustaining family caregiving, supporting independence, and preventing more costly institutional care.

## V. LETTER TO THE EDITOR TEMPLATE

To the Editor,

**[Start with your personal connection:** *Briefly share your experience as a caregiver, care recipient, or advocate. For example—who you care for, how long you’ve been caregiving, and what that has looked like in your daily life.*]

For families like mine, home and community-based services (HCBS) are not optional; they are essential. These Medicaid-funded services make it possible for people to remain in their homes and communities, rather than being forced into institutional care.

**[Add a specific example:** *How has HCBS such as respite care, home health support, or self-directed care helped you or your loved one? What would be different without it?*]

Across the country, more than 63 million family caregivers provide an average of 27.3 hours of care each week, often assisting with daily activities like bathing, dressing, and feeding. Yet only 13% of caregivers currently receive respite care, even though 39% say they need it.

**[Localize it:** *If possible, include a state-specific stat, waiting list number, or local program impact to ground this in your community.*]

Right now, access to HCBS is at risk. Proposals to restrict or withhold funding would have serious consequences for families who rely on these services every day. While accountability is important, cutting or delaying funding would only shift the burden onto families and increase strain on an already fragile care system.

For caregivers like me, this isn’t a policy debate. It’s about whether we can continue to care for our loved ones safely and with dignity at home.

I urge policymakers to protect and strengthen Medicaid HCBS so that families across **[your state/community]** and the country can continue to access the support they need.

Sincerely,

*[Name / City / Affiliation]*