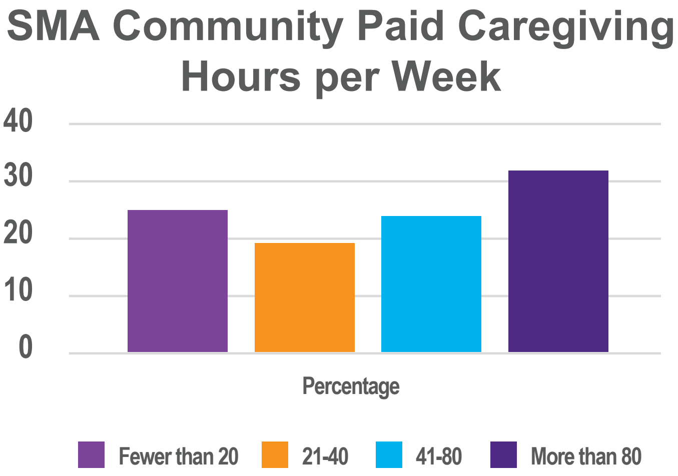
PROTECT MEDICAID HOME CARE FOR PEOPLE WITH SPINAL MUSCULAR ATROPHY

Self-Directed Care and Paid Family Caregiving are Essential to Independence, Health, and Work

Individuals with spinal muscular atrophy (SMA), a rare neuromuscular disease, rely on Medicaid-funded home care to maintain their health, independence, and ability to live in and contribute to their communities. Bipartisan policies expanding Medicaid home and community-based services (HCBS) have improved health outcomes, reduced institutionalization, and enabled participation in school and work. Federal and state proposals that reduce access to or limit eligibility for Medicaid home care, including self-directed care and paid family caregiving, would have serious consequences for individuals with SMA and their families.

SPINAL MUSCULAR ATROPHY AND THE SMA COMMUNITY'S CAREGIVING NEEDS

SMA is a neurodegenerative disease that causes severe muscle weakness and loss of motor function. As a result, most individuals with SMA rely on one or more caregivers to assist with nearly all activities of daily living, including eating, bathing, dressing, mobility, and respiratory care. Many individuals utilize paid caregivers, such as private duty nurses (PDNs) or personal care attendants (PCAs), to meet these needs, including 56% who receive more than 41 hours of paid care each week[1]. One **adult with SMA** shared, "I am no longer ambulatory. I have limited upper body strength. I need assistance with many activities, basically any part of my day that requires me to do something using the major muscles of my body." Another **adult with SMA** said, "Paid caregivers allowed me the freedom to work in person, opening up opportunities for socialization that would not be possible were I stuck in the house[2]."



MEDICAID HOME CARE: NECESSARY, ACCOUNTABLE, AND ESSENTIAL

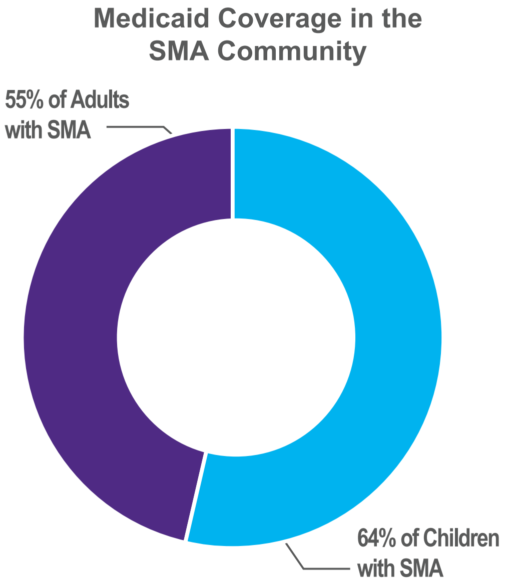
> "Home care allows me to work and be a taxpaying citizen.
>
> -adult with SMA

Medicaid-funded home care allows individuals with SMA to maintain their health, attend school, work, and live independently. Without access to home care services such as self-directed care and paid family caregiving, individuals with SMA face increased health risks, financial hardship, and, as one **adult with SMA** shared, "being forced to go to a nursing facility," a setting that is often more costly than home care and community participation[3].

Medicaid home care for people with SMA is necessary, accountable, and essential. Policies that limit access to these services—or that inappropriately group essential home care with broader discussions of waste, fraud, and abuse—threaten independence, health, and economic stability for individuals with SMA and their families. **Congress and states should protect and strengthen Medicaid HCBS, preserve self-direction, and maintain flexibility to allow paid family caregiving.**

MEDICAID HOME CARE HISTORY & SMA COMMUNITY USE

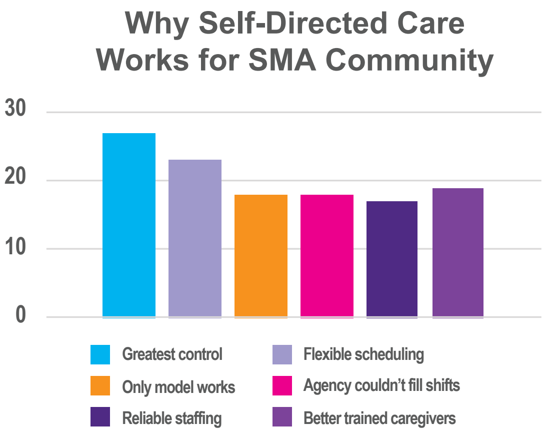
Medicaid is the primary funder of long-term services and supports (LTSS) for individuals with significant disabilities and chronic conditions, including SMA[4]. Prior to 1981, Medicaid primarily covered care in institutional settings such as nursing facilities. In 1981, Congress created HCBS waivers to allow states to provide care in homes and community-based settings[5]. Because institutional care is significantly more expensive, this shift to HCBS improved outcomes, reduced costs, and increased consumer satisfaction[6].


Medicaid Coverage in the SMA Community

Since then, bipartisan policy changes and the Supreme Court's *Olmstead* decision have accelerated the shift toward community-based care. Today, more than 60% of Medicaid LTSS spending supports care in the home and community[7]. Many individuals with SMA rely on Medicaid for some or all of their caregiving services. **One adult with SMA** explained, "I need caregiving support to perform all activities of daily living. I need at least 16 hours of caregiving support per day, which I get through Medicaid." Another **person with SMA** shared, "Medicaid home care allows me to work and be a taxpaying citizen. It is also cheaper and improves quality of life."

SELF-DIRECTED CARE: A MODEL THAT WORKS FOR INDIVIDUALS WITH SMA

Historically, home care services were managed by the state agencies or contracted providers. Over time, federal policy expanded to allow self-directed care (also known as consumer-or participant-directed care), enabling individuals with disabilities to better meet their own needs and preferences[8]. Under this model, participants or their representatives hire, train, and supervise caregivers within approved service levels[9].


Why Self-Directed Care Works for SMA Community

For individuals with SMA, self-directed care provides critical flexibility, control, and reliability. A **young adult with SMA** said, "Through consumer-directed services, I was able to attend college, make friends, and live a very enriched and happy life." Individuals consistently cite greater control over who enters their home as a key benefit. An **SMA parent** said, "It helps knowing who is with my child." Another **SMA community member** said, "It allows us to have people we know and trust in our home."

Self-directed care also better accommodates complex and time-sensitive needs. An **adult with SMA** said, "I need specific care including needing a stronger person, which many agencies cannot do. I also need care at specific times of the day like when I wake up and go to bed." Another **adult with SMA** shared how self-directed care allows her to better meet her specific needs throughout the day: "Most agencies require a minimum of two-hour shifts, but I only have one shift a week that is that long."

Cure SMA survey data reflects this experience, with 78% of respondents reporting self-directed care works better than agency-based care. However, not every individual or family with SMA can access self-direction through their state[10]. An **adult with SMA** said, "I would love to try self-direction. It would be amazing to arrange a caregiver that has the flexibility to care for me at the hours that I want."

PAID FAMILY CAREGIVING: AN ESSENTIAL OPTION FOR INDIVIDUALS WITH SMA

Home care for individuals with SMA and other disabilities is often provided by personal care attendants, private duty nurses, or other direct care workers. Medicaid also allows states to compensate certain family members for providing Medicaid-approved care under existing authorities[11]. Many states use this flexibility to support person-centered care, reduce service gaps, and address workforce shortages. An **adult with SMA** said, “I would probably have to move to an assisted living facility without my family caregiver.” A **father of a child with SMA** said, “The nursing shortage has been the single most important pain point in managing SMA and our daughter’s care. It’s super frustrating.”

For individuals with SMA, paid family caregiving is often essential. Family members provide the most consistent and knowledgeable care, which is especially important given the complex and unpredictable nature of SMA. This level of expertise is difficult to replicate or find through agency staff. A **man with SMA** said, “My mother being my caregiver has saved my life more times than I could count due to staffing issues for my PDN care.” A **woman with SMA** shared, “Family caregivers can recognize something is medically wrong from just a facial expression or a noise. That’s hard to teach.” She added, “Keeping someone healthy and stable at home also saves Medicaid money with fewer hospital admissions.”

> “There is a shortage of nurses and a lack of education about SMA patients.
>
> -parent of a child with SMA

This model also supports family financial stability[12]. One **adult with SMA** said, “If Medicaid is willing to pay someone else to cover 40 hours so a parent can leave the house to work a full-time job, then why not just let the more knowledgeable parent work those hours. It makes no sense to add a less qualified middleman to do the same task a parent could do better and for the same cost.” Another **individual with SMA** shared, “Without Medicaid funded family caregiving… we would be homeless.”

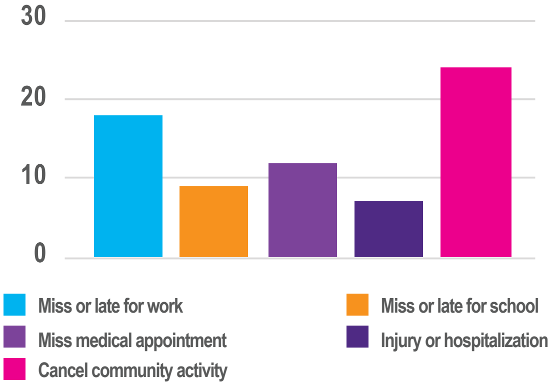
> “I need the assistance that my body cannot do. But I want all of the other things that come with living a full life.
>
> -adult with SMA

WHEN CARE FALLS SHORT: THE REALITY TODAY

Even with Medicaid support, many individuals with SMA do not receive enough caregiving hours to meet their needs. Nearly 40% report receiving far fewer caregiving hours from their state than required to live independently[13]. As a result, individuals and families with SMA often miss work or school, delay medical care, and experience health complications or injuries.

A **woman with SMA** described the impact of insufficient care: “Because no one is available to assist me with restroom activities at night, I often sit in my own mess for numerous hours which can affect my skin and cause pressure ulcers. Even with all that, I would not consider moving into an institution.” These gaps demonstrate that current Medicaid home care services already fall short, and that further reductions would have serious consequences.

The Cost of Medicaid Home Care Gaps



ADDRESSING MISCONCEPTIONS: HOME CARE IS NOT WASTE

Individuals with SMA qualify for Medicaid home care due to significant, medically documented needs. Medicaid waiver programs include strict eligibility requirements, documentation, and oversight, such as electronic visit verification systems, to ensure appropriate use of services[14]. One **adult with SMA** explained, "The amount of checks I go through to prove I need this care is overwhelming. I have a legit disability and need home care to survive." These processes are key to preserving the quality and effectiveness of Medicaid home care, including self-direction and paid family caregiving.

Proposals that characterize the essential home care that people with SMA and others rely on to survive as "waste" reflects a lack of understanding of the daily realities and challenges these individuals face. A **woman with SMA** said, "The notion that home care is considered wasteful is dangerous and creates even more difficulty living a life that is already hard as a result of a serious diagnosis like SMA." In reality, home care enables individuals with SMA and other significant disabilities to live safely in their communities and helps avoid more costly institutional care. A **relative of an individual with SMA** stated, "This is essential care, not unnecessary spending." Another **SMA community member** added, "Spend a day with these families and say that it is waste."

Cure SMA is the leading national organization that represents individuals with SMA and their families across the United States. For more information about the caregiving needs of individuals with SMA and their families, contact Cure SMA at advocacy@curema.org.

1. **Cure SMA State of SMA Report:** https://www.curesma.org/wp-content/uploads/2025/04/State-of-SMA-Report2024_vWeb.pdf
2. **Cure SMA:** https://www.curesma.org/wp-content/uploads/2024/01/Advocacy_Report_Stuck_Inside_vFnl_Web.pdf#page=7
3. **U.S. Department of Health and Human Services:** https://aspe.hhs.gov/sites/default/files/rivate/pdf/73916/costeff.pdf
4. **Centers for Medicare and Medicaid Services:** https://www.medicaid.gov/medicaid/long-term-services-supports
5. **Medicaid and CHIP Payment and Access Commission:** https://www.macpac.gov/reference-materials/federal-legislative-milestones-in-medicaid-and-chip/
6. **AARP:** https://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2013/state-studies-find-hcbs-cost-effective-spotlight-AARP-ppi-ltc.pdf
7. **Centers for Medicare and Medicaid Services:** https://www.medicaid.gov/medicaid/home-community-based-services#:~:text=Home%20and%20community%20based%20services,institutions%20or%20other%20isolated%20settings.
8. **Center for Medicare and Medicaid Services:** https://www.medicaid.gov/medicaid/long-term-services-supports/downloads/hcbs-origins-and-benifits.pdf
9. **Center for Medicare and Medicaid Services:** https://www.medicaid.gov/medicaid/long-term-services-supports/self-directed-services
10. **Medicaid and CHIP Payment and Access Commission:** https://www.macpac.gov/wp-content/uploads/2024/12/05_December-Slides_Self-Direction-for-Home-and-Community-Based-Services.pdf
11. **Center for Medicaid and Medicare Services:** https://www.medicaid.gov/medicaid/home-community-based-services/downloads/leveraging-family-care.pdf
12. **KFF Health:** https://www.kff.org/medicaid/medicaids-home-care-support-for-family-caregivers-in-2025/
13. **Cure SMA:** https://www.curesma.org/wp-content/uploads/2024/01/Advocacy_Report_Stuck_Inside_vFnl_Web.pdf
14. **National Academy for State Health Policy:** https://www.nashp.org/wp-content/uploads/2021/04/paying-family-caregivers-April2021.pdf