

STUCK INSIDE: A NATIONAL REPORT ON CAREGIVING FOR INDIVIDUALS WITH SPINAL MUSCULAR ATROPHY



ABOUT THIS REPORT

During a recent Cure SMA meeting, an adult with spinal muscular atrophy (SMA) who serves on Cure SMA's Adult Advisory Council shared the story of her friend who was abandoned on her toilet when the caregiver she relied on for independence quit on the spot. Her telling of the story brought up her own fears for her health and independence given the essential nature of caregivers in her life and the difficulty in finding and keeping direct care workers.

Other adults with SMA in the meeting echoed her concerns, describing their own caregiving challenges, including not receiving enough caregiving hours from their states, difficulty in filling the hours they have with caregivers, and how caregiving barriers have restricted their independence and limited their everyday living activities. The caregiving challenges and experiences were eerily similar, regardless of their state and whether they lived in a rural community or urban city. One participant spoke about how she would be “*stuck inside all day*” if it weren't for her access to caregivers.

Stuck Inside: A National Report on Caregiving for Individuals with Spinal Muscular Atrophy documents the caregiving challenges and experiences of individuals with SMA from across the country. The report includes numerous first-person quotes from adults with SMA and family caregivers that were collected from surveys and interviews. The SMA community's goal in sharing their experiences is to educate state and federal policymakers about the caregiving needs and challenges they face and to offer practical steps government leaders could take to reduce the caregiver barriers of people with SMA and other disabilities in the United States.

Sincerely,



Kenneth Hobby
President
Cure SMA



Maynard Friesz
Vice President, Policy & Advocacy
Cure SMA

ABOUT CURE SMA:

Cure SMA is the leading national organization that represents individuals with SMA and their families across the United States. Cure SMA educates and advocates for policies that protect access to care, treatment, and services and legislation that promotes independence and community living for all individuals with SMA. Cure SMA also funds SMA research, promotes healthcare best practices, and supports the SMA community through educational events, independence packages, and equipment pools.

EXECUTIVE SUMMARY

THE PROBLEM

Due to significant muscle weakness and motor function loss caused by spinal muscular atrophy (SMA), a neuromuscular disease, many individuals with SMA require in-home caregivers, whether a paid personal care attendant (PCA) or family caregiver, for assistance with daily living activities. Individuals with SMA report needing, on average, about 1-3 caregivers to cover their 100+ hours of caregiving needs each week. Top caregiving duties include transfers in and out of bed and into their power wheelchair, bathroom support, and household duties, such as laundry, shopping, and light housekeeping.

Individuals with SMA and their families view access to caregiving as being crucial, vital, and fundamental in their ability to maintain their health, independence, community living, and participation in society, including attending school and work. *“Because of my caregiving supports, I am on track to complete my bachelor’s degree, go to law school, and become an advocate for people with disabilities like me,”* said a **Michigan student with SMA**. *“Without caregivers and caregiving hours, I would not be able to live independently, be successfully employed, or enjoy anything fun as I would be stuck at home in bed,”* said an **Illinois woman with SMA**.

Unfortunately, the SMA community faces a multitude of caregiving-related challenges. As outlined in this report, individuals with SMA face confusion over what state programs exist that they may qualify for, receive a fraction of the Medicaid caregiving hours they need, and have difficulty in finding and retaining caregivers. On top of those problems, they also fear that their only backup support, usually an unpaid loved one, can no longer help.



“Without caregivers and caregiving hours, I would not be able to live independently, be successfully employed, or enjoy anything fun as I would be stuck at home in bed.”

These challenges disrupt caregiving services, limit community participation, and cause stress over health and safety concerns. *“Cuts in caregiving hours compromise my safety, potentially leading to injury or emergency when not assisted in daily living tasks,”* said a **Louisiana woman with SMA**.

The inadequacies and gaps in the current U.S. caregiving system have forced individuals with SMA to rely more heavily on their spouses, parents, or other loved ones for their caregiving needs. Family caregivers of individuals with SMA provide, on average, 55 to 100+ caregiving hours each week, mostly all unpaid. Caregiving duties for family caregivers are on top of their work schedules and other daily responsibilities, which can contribute to their own declines in physical and mental health. Many individuals with SMA worry about their own independence if something happens to their family caregivers who may represent their only backup support.

The caregiving crisis in the United States will worsen unless policymakers at the state and federal level tackle the challenge. *“The need for caregiving services will continue to grow as SMA treatments prolong lifespans and as Baby Boomers, such as myself, start to need assistance as we age,”* said a **Florida woman with SMA**. *“It’s just going to be a huge problem, and it’s not getting smaller.”*

EXECUTIVE SUMMARY

THE SOLUTION

This report highlights several state and federal policy recommendations from the SMA community that could help address caregiving challenges experienced by individuals with SMA and other significant disabilities. SMA community recommendations include:

- Improve online information about caregiving options in the state so residents can find searchable, consumer-friendly, plain language information about available in-home caregiving supports through Medicaid and other programs
- Update eligibility requirements for accessing caregivers and other in-home support services by eliminating or significantly increasing the asset and income limits in Medicaid waiver and Medicaid Buy-In for Workers with Disabilities programs
- Ensure fair, independent oversight of the state appeals process within Medicaid
- Incentivize Medicaid waiver best practices around eligibility requirements (i.e., Medicaid Buy-In for Workers with Disabilities programs), service options (i.e., adequate caregiving hours, paid family caregivers), and delivery choices (i.e., agency or self-direction)
- Promote Medicaid coverage portability or fast track eligibility for waiver beneficiaries who relocate to another state
- Strengthen the direct care workforce through increased wages, benefits, training, and career mobility



For questions related to the caregiving challenges or recommendations featured in this report, please reach out to Cure SMA at advocacy@curesma.org.

THE CAREGIVING NEEDS OF THE SMA COMMUNITY

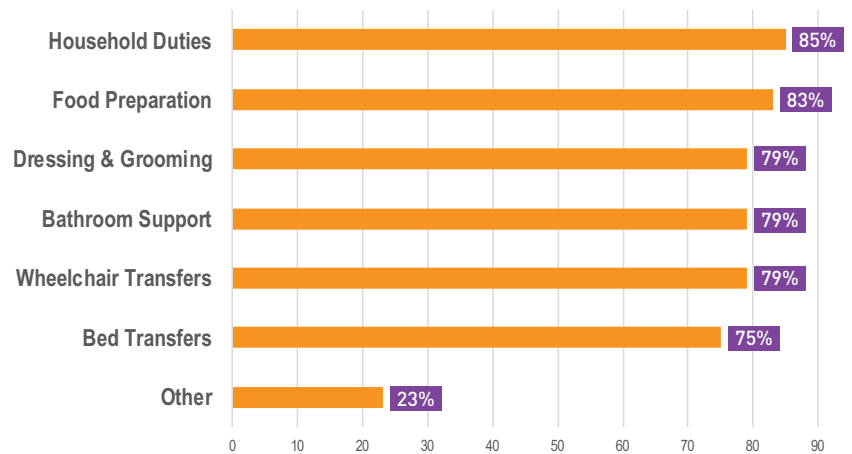
SMA is a progressive neurodegenerative disease that causes severe muscle weakness and motor function loss and impacts a person with SMA's ability to walk, lift their arms, and independently perform key functions of everyday life. Due to the physical effects of SMA, most individuals with SMA rely on personal care attendants (PCAs) or other in-home supports to assist with their daily living activities. *"I am no longer ambulatory. I do not have a lot of 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,"* said a **Florida woman with SMA**.

Individuals with SMA and their families identify household duties, dressing, food preparation, and using the bathroom as the top activities that they need help with from a PCA or other direct care worker. (see chart 1) *"As an adult with SMA, I rely on PCAs for all of my activities of daily living, including bathing, transfers, grooming, cooking, dressing, transportation, and bathroom breaks,"* said **an adult with SMA from Minnesota**. *"As my disease has progressed, I have required increasingly more personal care assistance to get through the day,"* said a **Wisconsin man with SMA**.



"As an adult with SMA, I rely on PCAs for all of my activities of daily living, including bathing, transfers, grooming, cooking, dressing, transportation, and bathroom breaks."

Chart 1 Common Caregiving Activities



THE CAREGIVING NEEDS OF THE SMA COMMUNITY

Individuals with SMA who require in-home support report needing 100+ caregiving hours a week, on average, to assist with their activities of daily living. Most individuals with SMA depend on 1-3 caregivers for this essential caregiving assistance, of which half are paid through Medicaid or other sources and half are uncompensated family caregivers. Medicaid is the nation's largest funder of long-term services and supports, such as caregivers. State Medicaid agencies typically approve fewer caregiving hours for an individual with SMA than what that person requires to maintain their health and independence. *"The 42 hours a week of caregiving hours I receive through the state is not nearly enough for what I need, and it's why I still live at home with my parents,"* said a **North Carolina adult with SMA**. The responsibility to hire and staff caregivers is typically a local caregiving agency or the care recipient themselves if their state offers a consumer- or self-directed option.¹

Individuals with SMA and their families describe their PCAs and other caregivers as "essential," "indispensable," "necessary," and "urgent." Caregivers

are a fundamental part of everyday life for individuals with SMA. Access to caregivers allows them to participate in education, employment, independent living, and community participation.



CAREGIVING NEEDS OF THE SMA COMMUNITY



1-3 Caregivers



100-168 Hours
(Per Week)

CAREGIVERS ARE ESSENTIAL FOR EDUCATION

“Without full-time caregivers, I would not be living independently and getting a quality education at a university. I am currently living in a dorm and working on my master’s degree in clinical psychology,” said a **student with SMA from California**

“Having caregivers made it so I could go to college and live on campus during the week,” said an **individual with SMA from Washington**

“Having caregiver support allowed me to obtain two master’s degrees and work full time, to live independently, and to give back to my community through volunteerism,” said an **individual with SMA from Florida**

“Paid caregivers allowed me to complete a master’s degree at my local university. I have the freedom to work in person, opening up opportunities for socialization that would not be possible were I stuck in the house,” said an **individual with SMA from Massachusetts**

CAREGIVERS ARE CRITICAL FOR EMPLOYMENT

“My caregiver helps me get ready for work and transports me to and from the office with our accessible van,” said an **adult with SMA from Hawaii**

“Our nurses allow me to work part-time and my husband to work full-time,” said a **Maine mother with a child with SMA**

“Caregivers allow me to get up and out of bed each morning and ready to work. Without caregivers I would not be able to live independently or be successfully employed,” said an **adult with SMA from Illinois**

“I work full-time, and without outside support I would not be able to do anything,” said an **adult with SMA from Georgia**

CAREGIVERS ARE CRUCIAL FOR INDEPENDENT LIVING

“I have lived independently with almost 24 hour paid caregiving in an apartment since 2018 thanks to paid caregivers,” said an **adult with SMA from Massachusetts**

“Without caregivers, I am unable to participate in most activities of daily living and definitely cannot have a social life or engage in enrichment activities,” said a **young adult with SMA from Minnesota**

“Without caregivers, I would be confined to a nursing home, unable to be employed, never having attended school, and unable to be a spouse,” said an **adult with SMA from Virginia**

“Having caregiver support allows me to live independently without the fear of facing a fall or other emergency,” said an **adult with SMA from Ohio**

CAREGIVERS ARE VITAL FOR COMMUNITY PARTICIPATION

“Paid caregivers allow me to have higher quality of life and quality medical care/preventative care. I can get outside and go for wheelchair walks around the neighborhood, go shopping, or visit restaurants,” said a **California adult with SMA**

“Access to caregivers has increased and improves quality of life,” said a **Florida adult with SMA**

“Having caregivers has exponentially increased the quality of my life. These individuals have helped me become more independent in every area of my life. With caregivers, I’ve travelled, increased my social life, focused on my mental and physical health, and built lifelong positive relationships,” said an **adult with SMA from North Carolina**

“Having a PCA helps me get out into the community to do something fun or run errands like driving me to doctor’s appointments, shopping, and more,” said an **adult with SMA from Minnesota**

See pages 16-24 for more stories and experiences from the SMA community about the critical role caregivers and in-home supports play in their everyday lives.



THE CAREGIVING CHALLENGES OF THE SMA COMMUNITY

Medicaid is the primary funder of caregivers and in-home services. States can provide home and community-based services (HCBS) through waiver programs that allow individuals with SMA and other disabilities to access their long-term care and supports in their home and community rather than an institution. Unfortunately, individuals with SMA, particularly adults with SMA, face significant challenges in accessing the in-home caregiving services they need to maintain their health and to live independently. These challenges include:

- lack of clear information about caregiving options available in the state,
- eligibility requirements that are restrictive, penalize savings, and limit work,
- state caregiving hours do not meet actual caregiving needs,
- difficulty in recruiting and retaining direct care workers, and
- concern over the health, age, and availability of backup family caregivers.

LACK OF CLEAR INFORMATION ABOUT MEDICAID CAREGIVING OPTIONS

Individuals and families with SMA consistently report great difficulty in accessing useful, consumer-friendly, and plain language information about caregiving options in their state. Federal Medicaid waiver authorities allow states to develop broad or targeted programs that include home and community-based services, such as caregiving, for residents of their state. These programs are not widely known or easily searchable on state government web pages. *“I couldn’t find information directly online about the waiver program that I use. I only found out about it through my counselor at the Division of Rehabilitative Services,”* said an **adult woman with SMA** who receives caregiving services through Medicaid. *“I didn’t even know about Medicaid waivers until I was in my early 20s. No high school counselor or social worker told me about them before. Even when I did find out about them, I applied for the wrong waiver at first because nobody told me which one to apply for,”* said a **Georgia woman with SMA**.

Cure SMA learned that 47 percent of individuals with SMA and their families struggled to find information about paid caregiving options in their state. *“State services are extremely convoluted and difficult to find answers,”* said an **adult with SMA from Virginia** who is not currently connected to a Medicaid waiver program. An **Oklahoma adult with SMA** said, *“I am unable to find specific information about how employment and earning an income would impact my care hours.”* A **young adult with SMA from North**

Carolina said, *“Most of the information I’ve learned has been through other disabled people. I have a great social worker now, but I didn’t know where to find resources when I started this process.”*

Cure SMA, in its own review of state agency web pages, also found that online information about state caregiving services was hard-to-find, confusing, inconsistent, and not consumer-oriented. In some cases, the only available information on state Medicaid waiver programs was the waiver application that the state submitted to the Centers for Medicare and Medicaid Services, which is typically 200 to 300 pages long, very technical, and difficult to navigate. None of the web pages included a searchable portal that allowed consumers to enter their information to learn what waiver and caregiving programs may be available to them. Cure SMA found that the best state web pages included plain language descriptions of the waiver programs, service options, target populations, and eligibility requirements; featured program summary fact sheets and comparison charts; and highlighted consumer-focused videos and application and agency contact information.



“State services are extremely convoluted and difficult to find answers.”

ELIGIBILITY REQUIREMENTS THAT ARE RESTRICTIVE, PENALIZE SAVINGS, AND LIMIT WORK

Medicaid eligibility for individuals with disabilities differs by state, but often follow income and asset criteria established through the Supplemental Security Income (SSI) program.² These restrictive thresholds often limit the ability of individuals with SMA, especially those who work or are married, to qualify for traditional waiver programs through Medicaid. “I have been working full time for many years and have worked hard to save money in a 401K. I am afraid this money will make me ineligible to receive any care,” said a **young adult with SMA from Ohio**. “My spouse and my parent are my two primary caregivers. I do not qualify for any government-funded care, and it would be prohibitively difficult to pay out of pocket,” said a **Virginia adult with SMA**. “If you are not on Medicaid, there are not many programs or resources available for married couples,” said a **married Florida man with SMA**.

“I only work part-time to avoid losing caregiving benefits.”

Overall, about 30 percent of adults with SMA said their current earnings or savings made them ineligible for caregiving services through their state. Another 27 percent of adults with SMA said they do not work or work only part-time to maintain their eligibility for caregiving services. “I only work part-time to avoid losing caregiving benefits,” said an **Ohio woman with SMA**. “I constantly worry about increasing income from future promotions and how it may cause future Medicaid denials. I lost it for a month and had to heavily appeal to reverse the denial,” said an **adult with SMA from Hawaii**. An **adult with SMA from North Carolina** said, “I work, but I have to stay on a fixed income to retain Medicaid.” A **young adult with SMA from Minnesota** said, “I would really love to work so I could feel like I’m a part of our community, however, I choose not to work for fear of going over the asset limit for SSI and Medicaid.”

To help alleviate this problem, Congress provided states with new flexibilities in the 1990s to allow individuals with disabilities who work and are above traditional Medicaid income and asset levels to access caregiving and other Medicaid services at no or low cost.³ State programs developed through these authorities are often referred to as Medicaid

Buy-In for Workers with Disabilities programs. These programs have been instrumental in allowing individuals with SMA and other disabilities from across the country to work, earn, and live independently in their communities. An **adult with SMA from Pennsylvania** has worked in corporate business for over two decades while receiving caregiving services through her state’s Medicaid Buy-In for Workers with Disabilities program. “This program allows me to put my higher education and training to use while also receiving assistance with in-home health services.” A **Louisiana adult with SMA** said, “Accessing caregivers through the program is the only way I can remain employed and pay taxes.”

While all states can develop a Medicaid Buy-In for Workers with Disabilities program, not all do, which negatively impacts working individuals with SMA who do not otherwise qualify within traditional Medicaid limits. “I work full-time and have a good income. My insurance does not cover the cost of my personal care workers, and I continue to be in a situation where I cannot afford the care that I need, which has increased as my disease has progressed,” said a **Wisconsin man with SMA**. A **Georgia woman with SMA** said, “I was able to retain Medicaid while working until I got married and now, I can no longer have it because they count my husband’s income.”

“I have moved states every few years, and I am afraid of setting up a caregiver in one state and losing the benefit when moving.”

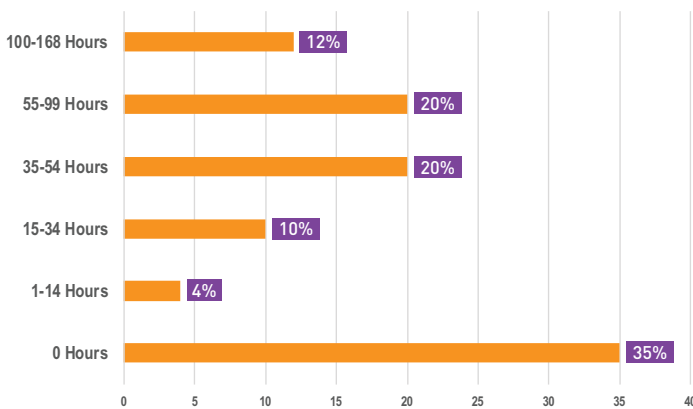
These state disparities create new barriers and limits on individuals with SMA and other disabilities⁴. About 41 percent of adults and families with SMA said they declined a job or school opportunity that was out of state so as not to impact their ability to retain their caregiving services. “I have moved states every few years, and I am afraid of setting up a caregiver in one state and losing the benefit when moving,” said an **adult woman with SMA**. “I worry about losing my PCA services if I am up for a promotion or a raise,” said an **adult man with SMA**. “I have skills that could easily get me a 6-figure job but chose to pursue lower paying work because I am afraid of losing my Medicaid funded caregivers,” said an **adult with SMA**.

STATE CAREGIVING HOURS DO NOT MEET ACTUAL CAREGIVING NEEDS

Caregiving services provided through Medicaid waiver or other state programs impact every facet of life for a person with SMA. *“Having access to caregivers has increased my independent living as well as community participation. When I didn’t have caregivers, I was usually stuck inside the house,”* said an **Arkansas adult with SMA**. *“Caregivers are the only way for us to be a part of society. I’d be in pure isolation otherwise,”* said a **Minnesota adult with SMA**. *“Access to caregivers improves my quality of life,”* said a **Florida adult with SMA**.

Chart 3

Caregiving Hours Received through Medicaid/State (per week)

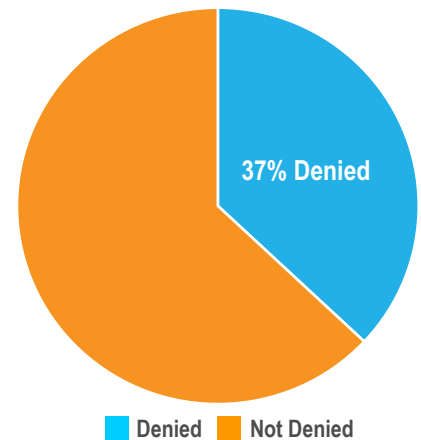


Despite the essential nature of caregiving services, many individuals with SMA (37 percent) receive far fewer caregiving hours from their state than they require to live independently. While most individuals with SMA and their families require 100 or more hours a week of caregiving hours to maintain their health and independence, only 18 percent said they received that level of in-home care through Medicaid. Most reported receiving only 35 to 54 hours a week or 55 to 99 hours a week (see chart 3). *“I only get about 6 hours per day of paid caregiving, which essentially covers a morning caregiver to come and shower me and get me into my wheelchair so I can go to work and then one to come at night to put me into bed. The lack of hours means I am without paid support during the day for toileting and eating,”* said an **Illinois adult with SMA**. *“Caregiving hours provided through Medicaid only cover about two-thirds of coverage time needed,”* said a **Massachusetts adult with SMA**.

About 37 percent of individuals with SMA said they sought more caregiving hours from their state but were denied (see chart 4). *“My caregiving hours were decreased by 14 hours a month and we appealed it. I thought we would win the appeal, but we did not,”* said a young adult with **SMA from California**.

Some individuals with SMA ruled out an appeal due to bureaucracy or related reasons. *“I was told I have maxed out on what is allowed unless I went into a nursing home, so I did not appeal,”* said an **Illinois adult with SMA** who identified a lack of caregiving hours as her biggest barrier in life. Another adult with SMA was unaware she could ask the state to reconsider its decision. *“I get re-evaluated every year and it never changes. There isn’t a way to appeal their decision that I’m aware of.”* Even some who appealed and won were unsatisfied with the result. *“In my appeal letter, I pointed out that no human goes to the restroom only morning and night. I was able to get a mid-day shift. Now I can use the restroom a whopping 3 times a day!”* said a **Florida woman with SMA**. *“Every year, I ask for more hours and am denied. I appeal this and then the state and I typically compromise,”* said a **Massachusetts woman with SMA**.

Chart 4 Individuals Denied Caregiving Hours By Their State



“In my appeal letter, I pointed out that no human goes to the restroom only morning and night. I was able to get a mid-day shift. Now I can use the restroom a whopping 3 times a day!”

The loss or lack of adequate caregiving hours adversely affects individuals with SMA and their families. *“It reduced my independence and restricted our schedules,”* said a **Washington woman with SMA**. A **Missouri woman with SMA** said, *“It has delayed my ability to live independently.”* A **Texas woman with SMA** said the lack of caregiving assistance led to *“missing certain things for school, medical appointments, and other activities.”* A **California man with SMA** said the cut in caregiving services caused *“huge disruption to family*

quality of life and freedom to live a normal life, including cancelled trips, inability to visit family/friends, and unhealthy stress levels.”

Many individuals with SMA try to limit the disruption on their daily lives by turning to family members, including parents, partners, children, and siblings, for backup caregiving support. “My mom does everything she is able for me somehow with no pay. It is getting harder and harder for her,” said a **Tennessee woman with SMA**. “I lean on family for unmet needs and uncovered shifts,” said a **Florida woman with SMA**. “I still heavily rely on my parents. I cannot seriously consider moving out knowing that it would leave huge gaps in coverage, and the cost to pay for caregivers out of pocket would make rent or a mortgage untenable,” said a **Massachusetts man with SMA**.

Some individuals with SMA pay out of pocket to fill the gap in caregiving, which can cause significant economic hardship. A **Texas mom of a child with SMA** said, “We pay \$1,000 a week out of pocket for caregiving.” A **California woman with SMA** said, “I pay out of pocket

from savings accrued while I was working.” A **Missouri woman with SMA** said, “I pay my caregivers out of the pocket to work extra hours that I need covered.” A **young adult with SMA from Minnesota** said her family had to pay caregivers out of pocket for the first two years of her college to meet her overnight hour needs. A **Florida man with SMA** said his biggest barriers was “finding additional resources or finances to help with the burden of paying for caregivers.”

Several individuals with SMA pointed to the strain a lack of caregiving hours has placed on their families, both personally and economically. “It has strained my relationship with my mom,” said an **Oklahoma adult with SMA**. “Family has lost their jobs. They have been upset with me over it. Care suffers,” said a **Kentucky adult with SMA**. “It caused a lot of destructive relationships,” said a **Minnesota adult with SMA**. A **California woman with SMA** described the tremendous guilt she feels because her mom, who makes up the caregiving difference, “has had to cancel trips and put her life on hold to always be on call for me and to fill in the gaps.”

DIFFICULTY IN RECRUITING AND RETAINING DIRECT CARE WORKERS FOR CAREGIVING POSITIONS

The caregiving crisis facing our country has threatened the care, safety, and independence of individuals with SMA and their families. The growing U.S. elderly population⁵ and Medicaid’s increasing shift to home and community-based services⁶ have strained a direct care workforce that was already underinvested in and undervalued. “The need for caregiving services will continue to grow as SMA treatments prolong lifespans and as Baby Boomers, such as myself, start to need assistance as we age,” said a **retired adult with SMA**. “It’s just going to be a huge problem, and it’s not getting smaller,” she added.

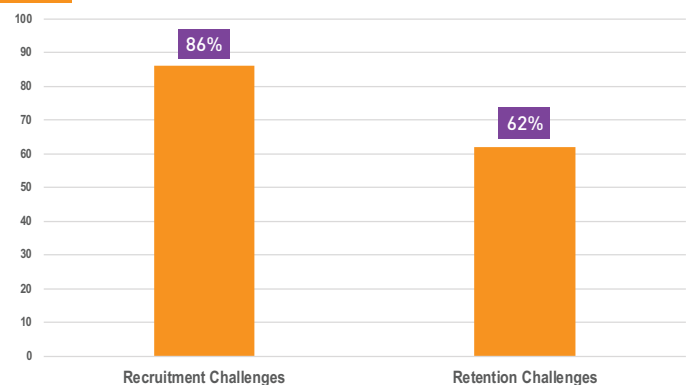
Individuals with SMA, on average, utilize 1-3 caregivers to assist with their daily activities. Unfortunately, most adults and families with SMA reported difficulty in finding (86%) and retaining (62%) workers to cover their caregiving shifts (see chart 5). “It is the ABSOLUTE HARDEST,” said an **adult with SMA from Minnesota**. “And hiring GOOD caregivers is even harder since there seems to be zero training.” An **adult with SMA from Florida** said, “I’ve faced many gaps in caregiving due to the agency not having anyone. It has greatly impacted both my mental and physical health.” A **parent of a child with SMA** said, “Finding someone we trust to provide needed care,

be flexible, keep our son safe but encourage independence is a difficult task.” A **young adult with SMA from Massachusetts** said, “I have not been ‘fully staffed’ in about a year and supplement my needs with assistance from my parents and partner.”



“I have not been ‘fully staffed’ in about a year and supplement my needs with assistance from my parents and partner.”

Chart 5 Difficulties Finding and Retaining Caregivers

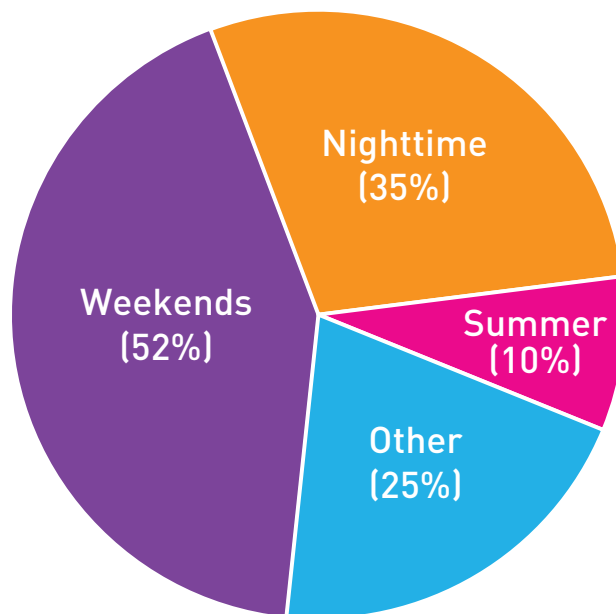


The shortage of direct care workers across the country weighs heavily even on individuals and families with SMA who are fully staffed with caregivers. “I have a great team right now, but that could change at any moment. Caregivers typically don’t receive benefits and the pay is especially low if they’re employed through an agency,” said an **adult with SMA from North Carolina**. A **Massachusetts man with SMA** said, “Caregivers who are interested in health care are usually nursing students who plan to take a higher paying nursing position once they earn their degrees, so they are temporary.”

Adults and families with SMA said their most difficult caregiving shifts to cover were nights and weekends (see chart 6). “I do not know how long my husband and I can sustain doing our care by ourselves on the weekends. We simply need more help but we’re not getting it,” said a **Pennsylvania woman with SMA** who has struggled for two years to find weekend caregivers. A **Florida woman with SMA** said, “I’m also alone overnight though I should not be as I cannot move and am supposed to use a trilogy for breathing. It’s the chance I take to be able to live independently.” “I’ve been shorthanded for months as I’ve been unable to fill all my caregiving shifts,” said a **Mississippi adult with SMA**.

Low pay and limited or a lack of benefits contribute to the caregiving crisis in the United States.⁷ “PCA pay is often less than what caregivers can get from regular babysitting positions,” said a **Massachusetts man with SMA**. “My PCAs do not get paid enough or receive enough hours to be competitive with other employers. The only reason they stick around is because they truly do care about me,” said an **adult with SMA from a rural community**. Caregiver pay and benefits are also common problems in urban areas. “The reimbursement rate for a caregiver through my state’s waiver program is less than wages paid to fast food workers. It’s absolutely tragic,” said an **adult with SMA from a major metropolitan area**. “The rate of pay is simply too low for caregivers to stay. Many make more money working retail or fast food. There is no one to fill shifts,” said an **adult woman with SMA from Florida**.

Chart 6 Caregiving Shifts Difficult to Fill



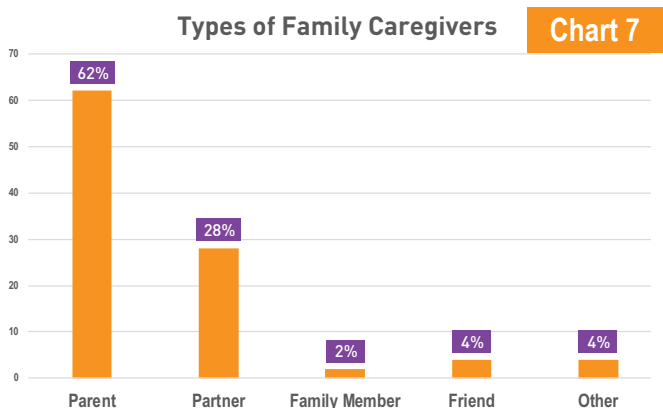
“The rate of pay is simply too low for caregivers to stay. Many make more money working retail or fast food. There is no one to fill shifts.”

Among the available pool of caregiver candidates, many lack training or knowledge of the position. “Prospects often aren’t fully comfortable and/or aware of the unique needs and challenges of the disabled community. There is a lot of training and education that the care recipient must perform to get the care they vitally need,” said an **adult with SMA from Pennsylvania**. An **adult with SMA from Minnesota** agreed, “I’ve had many caregivers not know how to take care of someone. It is really frustrating how care agencies usually provide zero training for their employees.” An **individual with SMA from Missouri** said, “I only have two people I can rely on. The others are not dependable and do not show up when I need them.”

CONCERN OVER THE HEALTH, AGE, AND AVAILABILITY OF FAMILY CAREGIVERS

When individuals with SMA struggle to find and retain direct care workers or they receive only a fraction of the caregiving hours they need, they turn to family caregivers to pick up the difference. About 79 percent of all individuals with SMA reported having at least one unpaid family caregiver, which can include parents, grandparents, partners, siblings, and other relatives (see chart 7). “I receive caregiving hours through various caregiving agencies. For the rest, I rely on family to help me with everything,” said an **adult with SMA from Washington**. “My wife is my caregiver

and has been for our nearly 18 years of marriage,” said an **adult with SMA from California**. “I still rely a lot on my parents,” said an **adult with SMA from North Carolina**. “Parents and siblings help but unfortunately it means missing out on things as it keeps us more homebound,” said an **Iowa parent of a child with SMA**. “My grandparents primarily take care of me when I don’t have a caregiver and they’re in their 70-80’s,” said a **Minnesota woman with SMA**.



Many family caregivers play a primary role in their loved one’s lives, providing daily and weekend help with everything from transferring in and out of bed and wheelchairs to assistance with dressing, grooming, meal preparation, and bathroom support. Family caregivers of individuals with SMA provide, on average, about 45 hours per week in unpaid caregiving services, according to Cure SMA’s Understanding the Caregiver Experience report, which is significantly higher than the 23.7 hours per week of all caregivers.⁸ A **Texas woman with SMA** said, “My parents help me day and night.” An **adult with SMA from Florida** said, “I couldn’t do it without the help I get from my spouse.”

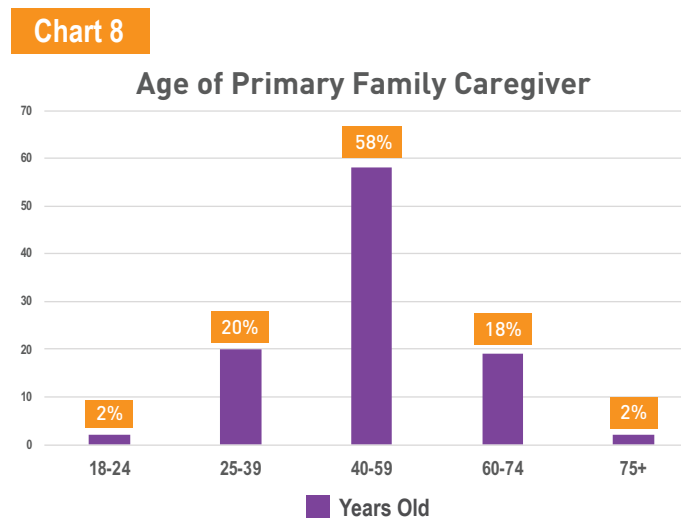
Family members that do not play a primary caregiving role are often the only backup for an individual with SMA. “Because of the worker shortage, my parents often have to cover when my caregiver calls in sick or during planned days off,” said a **California man with SMA**. “Family members, primarily my mom and dad, assist during these time periods,” an **individual with SMA from Pennsylvania** said about gaps in caregiving. “I rely on my parents. However, there have been times when I have had to miss something because my parents are unavailable,” said a **Texas woman with SMA**.

Many individuals with SMA worry about what will happen to them if their family caregiver becomes unavailable due to health, injury, or other reasons.

Several studies have chronicled the detrimental health effects of family caregiving, which can include stress, depression, physical ailments, poor diets, and missing their own healthcare appointments.⁹ “My parents are getting older and the physical and mental aspects of caregiving is getting more challenging for them,” said an **adult with SMA from Hawaii**. “His back is slowly going,” an **individual with SMA from Kentucky** said in describing her family caregiver. “He’s 28. When he’s 58 he won’t be able to provide my care. This is unsustainable.” A **Louisiana woman with SMA** said, “My father is having some issues with his back and his neck.”

“I have had to rely on my aging parents who are increasingly unable to provide my care.”

The situation is even more precarious for individuals with SMA with older family caregivers (see chart 8). “My parents are slowly aging and will eventually have more difficulty doing caregiving tasks. They have more aches and pains than they used to,” said a **Maryland woman with SMA**. A **Tennessee woman with SMA** said, “My mom has poor health, and she has lots of pain in her joints.” “My mother helps me when I don’t have a PCA, but I worry about the toll it takes on her health given she is in her 60s,” said an **adult with SMA from Mississippi**. “I do worry about the level of care my parents can provide as they get older,” said a **North Carolina man with SMA**. “My parents are getting too old to pick up the slack”, said a **Missouri woman with SMA**.



See pages 16-24 for more stories and experiences from the SMA community about the caregiving challenges they face.

SOLUTIONS TO IMPROVE CAREGIVING FOR SMA COMMUNITY

SMA COMMUNITY RECOMMENDATIONS TO IMPROVE CAREGIVING

Based on the feedback and experiences of individuals with SMA and their families, Cure SMA recommends the following state and federal actions to break down barriers to caregiving services and to promote independent living for people with SMA and other disabilities.

Improve Online Information About Caregiving Options in the State

Many individuals with SMA and their families struggle to find or understand what their caregiving options are in their state. *“Each program is confusing, and it is difficult to know where to start,”* said an **Ohio woman with SMA**. A Cure SMA review found online information about state Medicaid waiver programs and caregiving services hard-to-find, confusing, inconsistent, lacking, and not consumer-oriented.

Cure SMA Recommendation: States should make online information about their Medicaid waiver program and related caregiving services available in an interactive, consumer-friendly, plain language online web page or portal to ensure individuals with SMA and other disabilities can easily learn about their caregiving and healthcare options.

Update Eligibility Requirements and Income Limits to Qualify for Caregiving Services

Many states continue to use outdated earnings and asset limit requirements when determining eligibility for caregiving services under Medicaid. Even the increased asset and earning levels included in state Medicaid Buy-In for Workers with Disabilities programs limit the ability of some individuals with SMA and other disabilities to reach their full earnings potential to stay within allowable limits.

Cure SMA Recommendation: Asset and income limits used to determine eligibility for Medicaid and other federal programs (i.e., SSI) should be eliminated or significantly increased to allow all individuals with disabilities who rely on caregiving services to access these essential supports without impacting their ability to marry, work, and save for their futures.

Incentivize Medicaid Waiver Best Practices around Eligibility, Service Options, and Delivery Choices in State Medicaid Waiver Programs

States have used existing federal authorities to develop best practices in Medicaid waiver programs around eligibility requirements (Medicaid Buy-In for Workers with Disabilities programs), service options (adequate caregiving hours, paid family caregivers), and delivery choices (agency and self-direction). However, not all states offer these best practices to their residents.

Cure SMA Recommendation: States should be incentivized through an increased federal match for implementing Medicaid waiver best practices to better serve individuals with disabilities.



Promote Medicaid Coverage Portability or Fast Track Eligibility for Waiver Beneficiaries who Relocate to Another State

Medicaid waiver programs and caregiving coverage varies widely among states. In addition, some states have waiting lists to access home and community-based services.¹⁰ Individuals with SMA and other disabilities who relocate to another state due to a family move, job relocation, or emergency are at risk of losing their caregiving. *“Your quality of life as a person with a disability is dependent on the state you reside in,”* said a **Massachusetts adult with SMA**. *“There are enormous discrepancies, especially with PCA services, which is a big frustration and limits.”*

Cure SMA Recommendation: A new Medicaid authority should be established to allow program portability across state lines or a fast-tracked eligibility process to ensure individuals with disabilities can retain caregiving services if they relocate to another state.

Strengthen the Direct Care Workforce through Increased Wages, Benefits, Training, and Career Mobility

Individuals and families with SMA in all 50 states reported challenge in recruiting (86%) or retaining (62%) direct care workers to cover their caregiving shifts. *“I can’t tell you how upsetting it is to constantly be in the process of recruiting, hiring, and training new folks to assist me with my life, only to lose them a few months later to a job opportunity that pays more,”* said a **Minnesota woman with SMA**. In addition, caregivers often lack skills and knowledge about how to properly care for an individual with SMA, placing the training burden on the care recipient themselves.

Cure SMA Recommendation: State and federal investments and strategies are needed to strengthen the direct care workforce through increased pay and benefits, credentialed training, career mobility opportunities to other health professions, and other incentives.



Ensure Fair, Independent Oversight of State Appeals Process within Medicaid

Individuals with SMA regularly report receiving far fewer caregiving hours through their state Medicaid program than what they need to live independently. *“No human goes to the restroom only morning and night, yet I was only initially approved for caregiving hours during those times,”* said an **adult with SMA** who questioned whether state officials who determine caregiving hours understand what it is like to live with a disability like SMA. Many appeal the state’s decision, which can be lengthy and time consuming (*“it took me a month and a half to prove I needed the services”*), and with varying results. *“We appealed because the hours were decreased by 14 hours a month. I thought we would win the appeal, but we did not,”* said a **California adult with SMA**.

Cure SMA Recommendation: States should utilize an independent board that includes healthcare and disability experts for Medicaid appeals related to adequate caregiving hours for individuals with disabilities.

CONCLUSION

HELP ME LIVE INDEPENDENTLY AND CONTRIBUTE TO SOCIETY

Individuals with SMA want to live independently, participate in their communities, and contribute to society like everyone else. However, due to debilitating muscle weakness caused by SMA, many require the assistance of others to get out of bed, transfer into their wheelchairs, and perform other regular daily activities. *“I am entirely dependent on caregivers. I can’t survive if I don’t have someone taking care of me,”* said a **25-year-old woman with SMA**.

While SMA limits her physical abilities, her biggest barrier to life is her ability to access caregiving in her state. *“I would love to move out and be on my own, just like any other 25-year-old wants to be. However, because I can’t get enough care hours, I do not see a future where I would be able to be independent and live on my own,”* she added.

Her experience is the norm, not the exception.

Caregiving challenges, including a lack of caregiving hours and difficulty in finding paid caregivers, are pervasive, across all 50 states and all communities. The solution to the caregiving problem in the United States does not require a medical miracle or scientific breakthrough. Our country’s caregiving challenge can be fixed through smart public policy and strategic investments.

“The point of government disability benefits should be to support disabled people in staying healthy, doing work that is the most lucrative and matches their skills and education.”

Individuals with SMA and their families shared their experiences and recommendations for this report to inform policymakers and other key stakeholders about the chronic caregiving challenges they face and possible solutions to help. Now, it is up to them, our state and federal leaders, to take up this urgent cause and to ensure individuals with SMA and other disabilities have the in-home support they need to contribute to society and reach their highest potential. *“Disabled people will remain poor and at the mercy of government benefits until the rules are dramatically changed,”* said a **Pennsylvania woman with SMA**. *“The point of government disability benefits should be to support disabled people in staying healthy, doing work that is the most lucrative and matches their skills and education.”*

Cure SMA and the SMA community urges state and federal leaders to help take up this cause and to make it easier for people with SMA and other disabilities to maintain their health, independence, and quality of life.



WHY ACCESS TO CAREGIVING MATTERS FOR PEOPLE WITH SMA

ARKANSAS

“Having access to caregivers has really increased my chances of independent living as well as community participation. When I didn’t have caregivers I was usually stuck inside the house.”



CALIFORNIA

“I use a paid PCA for my morning routine: transfers out of bed into wheelchair, showering, toileting, dressing, making coffee, light housework and pet care. I also have a once-a-month housekeeping team for a full cleaning (not expressly disability-related).”

“My wife is my caregiver. She helps me with all of my activities of daily living, including getting out of bed, showering and getting dressed for the day. She helps with all of the physical work that I cannot do.”

“Access to caregivers is essential to keep me alive, I am completely dependent on caregivers.”

“Paid caregivers allow me to have a higher quality of life and quality medical preventative care. I am able to get outside & go for wheelchair walks around the neighborhood, go shopping or visit restaurants and events.”

“I used to tutor kids and would not have been able to drive to them and work with them if I did not have a caregiver with me full time.”

“Having caregivers helps me go to my doctors’ appointments, get fed, and do all activities of daily living.”



COLORADO

“My caregiving needs are through my parents. Education and community participation are what my parents have helped make possible.”



FLORIDA

“Paid caregivers helped me to successfully work part time until disease progression forced me to retire. I am able to live independently because of paid caregivers.”

“My caregiver helps with all of my daily needs such as but not limited to, getting out of bed, transferring to my wheelchair, getting dressed, bathing, toileting, preparing meals, getting drinks, switching positions during sleep, grabbing things etc.”

“Access to caregivers has impacted all areas in my personal life. Access to caregivers has increased and improved my quality of life.”

“I am the spouse (wife) of a type 3 SMA (husband) and sole caregiver. Only payment is love. My husband (SMA type 3) relies on me for all support.”



GEORGIA

“Having caregiver support allowed me to obtain 2 master’s degrees and work full time, to live independently, and to give back to my community through volunteerism. Without caregiver support I would not be able to do any of these things!”

“I need caregiving support to perform all activities of daily living. I need at least 16 hours of caregiving support per day. I receive this care through Medicaid.”



HAWAII

“A lack of caregiving has delayed my ability to live independently. I would have to pay out of pocket for additional help, so I rely on my parents and boyfriend. to make up the difference.”



IOWA

“My child is 24/7 ventilator dependent and requires around-the-clock care. She relies on caregiver for everything.”



ILLINOIS

“I rely on caregivers to be able to complete all activities of daily living including showering, dressing, eating, transferring into my wheelchair, and to put me into bed at night.”

“Caregivers allow me to get up and out of bed each morning and get ready to work or have fun that day. Without caregivers I would not be able to live independently, be successfully employed or enjoy anything fun as I would be stuck in bed.”

“My caregiver allows me the freedom to participate in work and social activities that otherwise would be inaccessible to me.”

“I depend on caregiving for almost all activities of daily living. Without caregivers, I cannot get out of bed or go to bed. I depend on them to use the bathroom. Caregivers help me with dressing, bathing, positioning, shopping, filling my medicine, eating, paperwork and filing bills, help at medical appointments, etc.”

“Caregivers have allowed me to meet my everyday needs and function well enough to work part-time from home. They help me to get up, get ready, and dressed to work at my computer and also position things within my reach.”



INDIANA

“I live at home, and my mother provides all my care beyond the home nursing hours I have and any time a nurse is not available to work those hours.”



KENTUCKY

“Caregiving has provided us with some freedom from solely focusing on our daughter’s care and the anxiety/worry that come along with it.”



LOUISIANA

“As far as my SMA goes, my strength is not strong. I need help getting in and out of the vehicle and into my power chair. I can move around pretty good. I have to have somebody bring me to the doctor.”



MAINE

“Our nurses attend school with our son. He needs one-on-one nursing to be there. Our nurses allow me (mother) to work part-time and father to work full-time.”



MARYLAND

“Currently my parents provide all of my caregiving needs. My parents’ care allows me to live with them in our own home and be prepared for any activities I have the energy to participate in, whether at home or in the community. I rely on my parents.”



MASSACHUSETTS

“I rely on my husband for food shopping, meal prep and all household duties.... all unpaid while he is working a full-time job.”



“I was able to live on campus at college because of my staff of 12-15 caregivers. I work full-time in a hybrid setting for a healthcare organization because I have caregivers coming to help me use the bathroom throughout the day.”

“My caregivers allow me to volunteer my time on local boards by supporting my everyday needs.”

“Paid caregivers allowed me to complete a master’s degree at my local university. I have the freedom to work in person, opening up opportunities for socialization that would not be possible were I stuck in the house.”

“Paid caregivers also give freedom to natural caregivers, like my parents, to have their own careers, take trips with their friends, or just enjoy a night out.”

MINNESOTA

“Without a caregiver, I’d actually have zero place in society. I wouldn’t be able to attend classes every day, live independently, or be able to be a functioning human in society. I’d be in pure isolation. Caregivers are the only way for us to actually be a part of society.”



“Having a PCA helps me do every daily task that I can’t do independently, and it helps me get out into the community to do something fun or run errands; like driving me to Dr appointments or shopping.”

“I am unable to participate in most activities of daily living and definitely cannot have a social life or engage in enrichment activities. I rely on my parents for everything and cannot live independently even though i would like to.”

MISSOURI

“A lack of caregiving has delayed my ability to live independently.”



NORTH CAROLINA

“Having caregivers has exponentially increased the quality of my life. These individuals have helped me become more independent in every area of my life.”

“With caregivers, I’ve traveled, increased my social life, focused on my mental and physical health, and built lifelong positive relationships.”

“Finding a preschool teacher that is willing to provide extra support our son needs is life changing for him, for all of us.”



NEW HAMPSHIRE

“If I had caregivers, my husband would finally get a break, and not have to worry about me.”



OHIO

“I require 70+ hours of care weekly (personal care, light housekeeping, errands, transferring to and from wheelchair, and occasional travel accompanying).”

“Access to caregivers impacts every facet of my life.”

“My ability to remain in my own home and out of a nursing facility is 100% dependent on this.”



OKLAHOMA

“Having my private duty nursing has allowed me to attend college and receive a bachelor’s degree.”

“I can’t survive if I don’t have someone taking care of me, and I don’t have anyone in my life who can sit with me and take care of me without getting paid.”



PENNSYLVANIA

“It’s as simple as this: without caregivers I would not be able to work and participate in society whatsoever.”

“Without nursing, she would be unable to attend school in-person in a mainstream environment, where she is currently thriving. One of her parents would have to quit their job to care for her full-time, which would have a detrimental impact on the family. Travel for medical appointments would be difficult if not impossible in some circumstances.”



SOUTH CAROLINA

“My parents and significant other take care of all if my caregiving needs, but as my parents are aging they will not be able to help me as much (physically) anymore.”

“I would not be able to participate in any of the above activities if it were not for the help of caregivers.”



TENNESSEE

“Having family or friends’ support allows me to live independently without the fear of facing a fall or other emergency. When I am tired and unable to care for myself, I depend on them.”

“I have a paid aid that helps daily with stretching, bathing, bathroom duties, and hygiene. My mom is always doing some type of deep cleaning and making sure that I have everything I need.”



TEXAS

“Having a nurse with me has helped me to be more independent.”



VIRGINIA

“Without caregivers, I would be confined to a nursing home, unable to be employed, never having attended school, and unable to be a spouse.”



“I have to rely on family for all my caregiving needs.”

WASHINGTON

“Having caregivers made it so I could go to college and live on campus during the week.”



CAREGIVING BARRIERS AND CHALLENGES FOR PEOPLE WITH SMA

ARKANSAS

“It is difficult finding a caregiver who wants to work weekend hours.”

“We’ve fought for years to get me 24 hours caregiving services and it is just now being fully funded and implemented. Since it’s just now being approved, it delayed my ability to live as independently as possible.”



CALIFORNIA

“As my disease progresses, more of my financial resources will go toward caregiving.”

“My biggest barrier is private duty nursing shortage due to poor state compensation rates.”

“My biggest barrier is keeping consistent 24/7 care with no gaps.”



FLORIDA

“The rate of pay is simply too low for caregivers to stay. Many make more money working retail or fast food. There is no one to fill shifts.”

“I’ve struggled to maintain night care (to be put into bed) as the agency cannot always staff it. I’ve paid out of pocket but it’s difficult as Medicaid will not allow any kind of savings.”

“Finding additional resources or finances to help with the burden of paying for caregivers represents a barrier to caregiving.”



GEORGIA

“Risk of losing Medicaid funded caregivers if I make too much money at work.”

“I have had to rely on my aging parents who are increasingly unable to provide my care.”



HAWAII

“Being able to afford caregiving services for hours beyond that provided by Medicaid.”

“A lack of caregiving services has delayed my ability to live independently.”



IOWA

“Finding weekend/night help to attend activities of other children.”



ILLINOIS

“Need for transportation, physical support for transfers, assistance with daily routine activities.”

“One of my parents stays with me sacrificing their time and opportunities.”

“The number of caregiving hours I receive is currently my biggest barrier. I pay out of pocket in addition to relying on family members and friends to help with my care at no charge.”

“I feel like I’m preventing my spouse from being able to do some of the things she wants to do because she is my primary caregiver. For example, she would like to return to work, but the reality is that I wouldn’t be able to continue working as I would need someone to care for me.”

“It is difficult for me to find caregiving to help me during holidays.”

“I do not receive enough hours for nighttime. I have to rely on family members, but I worry what will happen when my elderly parents are not able to live with me.”

“I cannot stay alone in bed at night due to emergencies with my BiPAP, etc., but my Medicaid waiver will not pay for 24 hour care, so I do not have enough hours to have someone stay with me overnight. I am desperately worried about this in the future.”



INDIANA

“I live at home, and my mother provides all my care beyond the home nursing hours I have and any time a nurse is not available to work those hours.”



KENTUCKY

“Not enough hours are provided by my state’s HCBS waiver program.”

“I have paid out of pocket to the best of my ability, but unfortunately my boyfriend has to do the vast majority of it. This impacts our relationship negatively in many ways and is absolutely unavoidable.”



MAINE

“There is a lack of nurses in Maine.”



MARYLAND

“The onerous process of hiring through Medicaid - lack of information, many repetitive interviews, and long wait times.”



MASSACHUSETTS

“It is difficult to find someone appropriate for what I need. Since my husband now works full time, my independent living has decreased.”

“An inability to find caregiving has delayed living independently.”

“Recruiting and retaining caregivers has been especially difficult post-pandemic. I still heavily rely on my parents. I cannot seriously consider moving out knowing that it would leave huge gaps in coverage, and the cost to pay for caregivers out of pocket would make rent or a mortgage untenable.”



MICHIGAN

“No one wants to work since Covid. Wages are not the best.”



MINNESOTA

“Finding and maintaining caregivers is the ABSOLUTE HARDEST and hiring GOOD caretakers since there seems to be zero trainings.”

“The biggest barrier I feel like I face with my family caregiver is sometimes we argue, but that is normal with family, it’s just hard when they’re the ones that provide all of your care.”

“I qualify for only 70hrs a week even though I need 24/7 care. I can’t afford to pay out of pocket for the hours that aren’t paid.”

“Finding caregivers in my area is difficult. I rely on my parents for everything and cannot live independently even though I would like to.”



MISSOURI

“Dependability of caregivers has been a problem.”

“A lack of caregiving has delayed my ability to live independently.”



NORTH CAROLINA

“My biggest barriers to caregiving are getting enough hours and finding enough people. I still rely a lot on my parents.”

“I get 42 hours a week from the state. This is not nearly enough for what I need, and it’s why I still live at home with my parents.”



NEW HAMPSHIRE

“I don’t have any assistance from Medicare because I work, own my home, and vehicles.”



OHIO

“I require 70+ hours of care weekly (personal care, light housekeeping, errands, transferring to and from wheelchair, and occasional travel accompanying).”

“Access to caregivers impacts every facet of my life.”

“My ability to remain in my own home and out of a nursing facility is 100% dependent on this.”



OKLAHOMA

“Having my private duty nursing has allowed me to attend college and receive a bachelor’s degree.”

“I can’t survive if I don’t have someone taking care of me, and I don’t have anyone in my life who can sit with me and take care of me without getting paid.”



PENNSYLVANIA

“My challenges are finding and retaining qualified, reliable, and open-minded caregiver employees.”

“Medicaid provides an appropriate amount of hours, but the nursing agencies have been unable to consistently staff.”



SOUTH CAROLINA

“I do not receive any Medicaid caregiving. I rely on my parents and significant other.”

“My parents are aging and may not be able to help me as much (physically) anymore.”



TENNESSEE

“It is difficult to know what programs I am eligible for.”

“I have also been working full time for many years and have worked hard to save money in a 401K, I am afraid this money will make me ineligible to receive any care.”

“I am forced to rely of family and friends as I am not enrolled in any programs that would help me to hire a caregiver.”

“I need two caregivers all the time for my personal care and one for my independent living goals.”



TEXAS

“It is challenging to find quality and reliable nurses.”

“There have been times when we don’t have a nurse, that I have had to miss something because there is no one to care for me while my mom or dad are away.”

“It is very hard to always have to rely on unreliable people to do typical things.”



VIRGINIA

“I do not qualify for any government-funded care and it would be prohibitively difficult to pay out of pocket.”



WASHINGTON

“Not having enough hours, or quality of caregivers.”





END NOTES

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¹⁰ A Look at Waiting Lists for Home and Community-Based Services from 2016 to 2021, KFF, 2022, <https://www.kff.org/medicaid/issue-brief/a-look-at-waiting-lists-for-home-and-community-based-services-from-2016-to-2021/>

ADVOCATE FOR INDIVIDUALS WITH SPINAL MUSCULAR ATROPHY AND THEIR FAMILIES



Cure SMA Advocacy | 800-886-1762 | advocacy@cureSMA.org | cureSMA.org

Cure SMA is a national organization that advocates for individuals with spinal muscular atrophy, a progressive neurodegenerative disease that robs people of physical strength, taking away their ability to walk, swallow, and breathe.