



Make today a breakthrough.

April 21, 2021

The Honorable Sherrod Brown
The Honorable Bob Casey
The Honorable Maggie Hassan
United States Senate
Washington DC 20510

The Honorable Debbie Dingell
United States House of Representatives
Washington DC 20515

Dear Senators Brown, Casey, and Hassan and Representative Dingell,

As the leading national organization that supports and advocates for individuals with spinal muscular atrophy (SMA), **Cure SMA thanks you for focusing on the community living needs of individuals with disabilities.** We are pleased to share our views on the discussion draft of your Home and Community-Based Access Act (HAA), which seeks to make home and community-based services a mandatory offering within Medicaid and sets minimum, standardized requirements for all state programs.

SMA is a degenerative disease that robs individuals of physical strength, greatly impacting their ability to walk, talk, and perform other essential functions of everyday life. People with SMA benefit from Medicaid-funded home and community-based services, such as personal attendant services, respite care, or transportation, to promote independence and assist with activities of daily living. **A 27-year-old with SMA Type 2** lives independently in her community with the help of Medicaid home and community-based services. She qualifies for 90 hours a week of personal care services to assist at points throughout the day and week. Through her state's consumer-directed care Medicaid program, she hires direct care workers and creates a schedule to assist with her morning and evening needs and to get her to work and medical appointments. In addition, she pays out-of-pocket for an additional 15 hours for extra overnight coverage because her Medicaid-supported personal care benefit does not meet her actual need. It is a problem that many individuals with SMA face across the country. *"Your quality of life as a person with a disability is dependent on the state you reside in,"* she said in pointing to states with limited services or long waiting lists. *"Many of my friends with SMA from other states are unable to live independently because they do not receive enough personal care services through their state. There are enormous discrepancies in healthcare and services for independence."*

Cure SMA fully supports the overarching goals behind the legislation. HAA recognizes that home and community-based services are an essential support that must be mandated and standardized within Medicaid. The legislative draft would establish minimum levels of services that all states must meet or exceed and recognizes the importance of a trained and robust direct care workforce to provide quality services and care. Cure SMA is pleased to share the following comments related to the HAA discussion draft. In addition, we support the themes and recommendations included in the response from the Consortium for Citizens with Disabilities.

STANDARDIZE AND EXPAND MEDICAID ACCESS FOR WORKERS WITH DISABILITIES:

The current Medicaid framework does not meet the needs of working-aged adults with SMA who must navigate complicated state systems that often force unnecessary choices between career or earnings advancement and maintaining the personal care services they need to live independently. The federal government provided states greater flexibility to offer Medicaid coverage to higher income workers with disabilities who otherwise qualify for Medicaid based on their disability status. However, not every state offers a buy-in option for workers with disabilities and for states that do, the eligibility requirements vary, sometimes creating unintended career advancement disincentives.ⁱ A **young woman with SMA Type 2** recently moved cross country for her first full-time job following law school. In accepting the attorney position on the West Coast, she had to give up the personal assistance benefit she received in her home state that allowed her to live independently. While the state she moved to has a buy-in option, the income thresholds for the program are unreasonably low. Her attorney's salary makes her ineligible for the program. To qualify for caregiving support through Medicaid, she would need to quit her job or profession. She currently pays out of pocket for her caregiver support, which she estimates costs more than \$100,000 per year based on her 20 to 24 hours per day caregiving needs. *"The financial strain is enormous and not sustainable,"* she said. *"The current system disregards the value of people with disabilities and their ability to earn, contribute, and make a meaningful difference."* A 2021 bipartisan report highlighted the shortsightedness of the policy when it found that promoting employment for workers with disabilities through a robust buy-in program represents a cost-effective policy for state Medicaid agencies.ⁱⁱ

- **Cure SMA Comment & Recommendation:** HAA should promote employment opportunities for working-age adults with SMA and other disabilities by standardizing the Medicaid Buy-In (MBI) programs that some states operate through existing authority. HAA should remove asset and income caps and establish a universal sliding scale option that allows qualified workers with significant disabilities, such as SMA, to buy into Medicaid regardless of income. Medicaid should not limit potential and meaningful careers through arbitrary limits that hurt people with disabilities and minimizes their potential. A standardized benefit is consistent with the goals of your legislation in fulfilling the intent of the Americans with Disabilities Act and in streamlining, standardizing, and delivering quality access to home and community-based services for people with disabilities. In addition, HAA should emphasize benefits counseling education to ensure that individuals with disabilities understand the interconnection between employment and their community supports. An **adult with SMA** described the need for more education around benefits counseling noting that, *"There are many restrictions and rules to be aware of and there is never a clear roadmap to figure it out."*

ENSURE APPROPRIATE TYPES AND LEVELS OF SERVICES

Individuals with SMA may face restrictions in the types and levels of services available through their Medicaid waiver or buy-in program. The number of caregiving hours an individual with SMA

requires to go to school or work and to live independently rarely matches the approved hours provided through Medicaid. Some individuals with SMA pay out-of-pocket to make up the difference, but that is not feasible for most, which jeopardizes their ability to live independently. Accessing the appropriate type and level of home and community-based services are especially challenging during the transition to adulthood in states with different programs for children and adults with disabilities. A **young man with SMA** noted that he received more caregiving hours when he was enrolled in his state's home and community-based Medicaid program for youth with disabilities under age 21 than when he transitioned to the adult program. *"Once I turned 21, they drastically cut my hours by more than half,"* he said. *"Their rationale was that I was older and more independent and needed less care. The opposite was true. To continue working, attending school, and being independent we need help getting up in the morning, assistance during various parts of the day, and help at bedtime, and so hours should be increased, not reduced as an adult."* Because he was denied overnight caregiving hours, the young man had no option but to remain living at home with his parents, who provide overnight and weekend support. A 2021 study found that dependence and the lack of independence were the biggest difficulties identified by adolescents and young adults with SMA. One respondent wrote, *"The fact that you always have to rely on someone that starts to become overwhelming."*ⁱⁱⁱ

- **Cure SMA Comment & Recommendation:** HAA represents an enormous step forward by making Medicaid home and community-based service a mandatory benefit rather than an optional benefit and by identifying a comprehensive list of specified services, including personal assistance (i.e., personal care attendants and home health aides), respite services, non-emergency, non-medical transportation, and caregiver and family support services. In addition, HAA establishes a strong individualized assessment process to determine the necessary level of services and supports and, importantly, sets forth a presumption of services. Cure SMA recommends that vehicle modification be added to the list of specified services. In addition, HAA should provide education for enrollees on the individualized assessment process, including ways to appeal the decision related to types and levels of services. Finally, the HAA definition of an eligible individual should be clarified to mean that an individual fulfills eligibility when they meet any combination of functional impairment related to activities of daily living (ADL) or instrumental activities of daily living (IADL).

EMPHASIZE CONSUMER-DIRECTED CARE

Many individuals with SMA utilize the consumer/self-directed care option available through state programs. Consumer-directed care allows an individual with SMA to manage and make certain decisions about the services they receive, such as hiring and training caregivers and establishing daily and weekly schedules.

- **Cure SMA Comment & Recommendation:** Cure SMA appreciates that person-centered planning and self-direction are among the specified services outlined in HAA. In addition, HAA requires that the individualized assessment be conducted with the presumption that

services may be self-directed at the option of the individual. An affirmative statement should be added to the Purpose section of the legislation to emphasize the importance of consumer/self-directed care.

MAKE CLEAR THAT STATES CAN EXCEED MINIMUM STANDARDS

Some current state Medicaid waiver programs include promising, best-practice aspects, such as no income or asset limits or caps that are high enough to incentivize work and career advancement. HAA establishes a strong minimum set of standards and establishes a process (advisory panel) to ensure that the minimum requirements and services meet the ongoing needs of individuals with disabilities. However, more should be done to encourage states to go above the minimum standards to provide greater access to home and community-based services.

- **Cure SMA Comment & Recommendation:** HAA should include financial incentives or other language to encourage states to exceed the minimum requirements set forth in HAA.

INVEST IN DIRECT CARE WORKFORCE

HAA recognizes the challenge many individuals with disabilities and their families face in finding and retaining reliable and qualified caregivers. Direct care workers, such as in-home aides and personal care attendants (PCAs), are essential for individuals with SMA and their ability to live independently, go to school and work, and to fully participate in and contribute to their communities. However, direct care workers often receive low pay and no or limited benefits. A **young adult woman with SMA Type 2** from the Midwest relies daily on personal care attendants. The Medicaid pay structure in her state devalues the contributions of direct care workers, making it harder for her to fulfil her caregiving needs. *“I struggle to find and keep PCAs due to the low pay they are given,”* she said. *“My PCAs work hard and are fantastic but cannot live and pay bills at such a low wage.”* Our country’s caregiver shortage places enormous pressure on the entire family. *“Family members often have to significantly reduce hours or leave jobs and careers to serve as a backup when there is a gap in caregiving services,”* her mom said. *“Professional caregivers are so vital for all people and a healthy community, society and world. Family members are not a sustainable option for ongoing care of a family member.”* Another advocate described how she supplements the low wages Medicaid provides to personal care attendants by adding additional cash per hour to keep good caregivers. *“When my caregiver doesn’t show up, I can’t get out of bed or make it to work. They are essential. They should be compensated with increased pay and benefits to reflect their important role to society.”*

- **Cure SMA Comment & Recommendation:** HAA should invest in the hiring and retention of direct care workers to help address the caregiving crisis that exists in this country.

Finally, we ask that HAA consider addressing the issue of electronic visit verification, which continues to be a concern in the SMA and disability community. Thank you for the opportunity to



provide comment on the Home and Community-Based Services Access Act. For more information, your staff can contact Maynard Friesz, Vice President for Policy and Advocacy at Cure SMA, at maynard.friesz@curesma.org or 202-871-8004.

Sincerely,

A handwritten signature in black ink that reads "K. A. Hobby".

Kenneth Hobby
President
Cure SMA

A handwritten signature in black ink that reads "Maynard Friesz".

Maynard Friesz
Vice President of Policy & Advocacy
Cure SMA

ⁱ Medicaid Eligibility through Buy-In Programs for Working People with Disabilities, KFF, 2021, <https://www.kff.org/other/state-indicator/medicaid-eligibility-through-buy-in-programs-for-working-people-with-disabilities/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D>

ⁱⁱ Improving Opportunities for Working People With Disabilities, Bipartisan Policy Center, 2021, <https://bipartisanpolicy.org/report/improving-medicaid/>

ⁱⁱⁱ A qualitative snapshot into the challenges, successes, and quality of life of adolescents and young adults with SMA, Orphanet Journal of Rare Diseases, February 2021, <https://ojrd.biomedcentral.com/articles/10.1186/s13023-021-01701-y>