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Written Testimony for the Record

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**U.S. Senate Special Committee on Aging
March 23, 2022 Hearing on**

An Economy That Cares: The Importance of Home-Based Services

Chairman Casey, Ranking Member Scott, and Members of the Committee,

Thank you for holding a hearing to examine the importance of home-based services that allow people with spinal muscular atrophy (SMA) and others to maintain their health and independence. As the leading national organization that advocates for children and adults with SMA, a rare degenerative neuromuscular disease that robs individuals of physical strength, Cure SMA is pleased to share the perspective of individuals with SMA and their families on the critical nature of home-based services and their ongoing challenges in finding personal care attendants (PCAs) and other paid caregivers.

Many individuals with SMA require assistance with daily activities, such as personal hygiene, getting dressed, eating, and transferring out of bed and into a motorized wheelchair. These Medicaid-funded caregiving services are essential for individuals with SMA, of all ages, to attend school, go to work, live on their own, and contribute to their communities. A **3rd grade teacher with SMA from Texas** receives essential assistance from PCAs at three intervals during the day, in the morning to help her get dressed and transport her to work, in the middle of the day, for restroom breaks, errands and medical appointments, and in the evening, to assist with end-of-day tasks, such as showering and getting ready for bed. Without this assistance, she would not be able to live independently or earn a living. A **Maryland family with a son with SMA** relies on licensed registered nurses (RNs) or licensed practical nurses (LPNs) for in-home care and services, such as g-tube feeding and airway clearance, and to support their son as he attends school. *“Professional caregivers are so vital for all people and a healthy community, society and world,”* **an adult with SMA** said about access to Medicaid home and community-based services, a key priority in Cure SMA’s *Greater Independence* legislative agenda.

Regardless of the state they live in, individuals with SMA and their families face regular challenges in finding and retaining caregivers and in accessing the caregiver hours they need to remain independent.

CHALLENGES IN FINDING AND RETAINING CAREGIVERS

Individuals with SMA, on average, utilize 2.5 caregivers to assist with their daily activities, according to Cure SMA’s 2021 Community Survey. However, finding paid caregivers, such as PCAs, nurses, and home health aides, is increasingly difficult for adults with SMA (45%

of whom identified it as a top unmet need) and for families of children with SMA (29% said it was a top unmet need). A **Massachusetts man with SMA** who requires paid caregivers for his independence has been unable to fill open caregiving jobs. *“Not long ago, 1 part-time opening drew about 20 applicants. Now, I have received 0 applicants for jobs over the past couple of years.”* Finding caregivers is a problem in urban and rural areas across the country. A **woman with SMA who lives in one of the 50 largest U.S. cities** said, *“finding and retaining a solid crew of caregivers that are reliable, understand the job, and are compatible with me”* was her biggest challenge in maintaining her independence. A **woman with SMA from Maine** worries what will happen if her current caregivers leave for other jobs. *“I live in a rural place and can’t even get caregiving services here even though I need them.”* Low pay and a lack of benefits, training, and career mobility contribute to challenges in finding and retaining caregivers. *“It has been an incredibly difficult journey to find anyone who is willing to work due to the level of assistance required to help me get through an average day,”* said a **woman with SMA from Ohio**.

CHALLENGES IN RECEIVING ADEQUATE CAREGIVING HOURS

Nearly half (47%) of all adults with SMA and families of children with SMA that utilize home care services require 40 or more caregiving hours a week, including 19% who need 100 hours or more of weekly caregiving support. However, many individuals with SMA report a significant gap in the caregiving services they need and the caregiving hours they are approved for through their Medicaid agency. A **28-year-old North Carolina working adult with SMA** lives with his parents because he lacks the caregiving hours to live on his own. *“My caregiving need is at least 50-60 hours a week, but Medicaid only pays for 40 hours, which is not a lot when you need SMA level of care.”* He noted that his caregiving hours were cut when he turned 21. *“They think you are more independent and need less care. The opposite is true. I am more independent, and I need more hours to keep my independence and to continue to work.”* A **Florida woman with SMA** also faces a lack of approved caregiving hours. *“I’m well under the hours I need to have all my necessary shifts filled.”* Given the nature of the disease, caregiving needs may increase for a person with SMA as they age. A **52-year-old working adult with SMA from Wisconsin** said the changes in his SMA has required increasingly more personal care assistance to stay employed and get through the day. *“It has progressed to the point where I need assistance with all daily living activities, such as dressing, bathing, eating and toileting. 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.”*

CHALLENGES FOR FAMILY CAREGIVERS

Due to the lack of caregiving support through Medicaid, many individuals with SMA must turn to unpaid family caregivers to assist with unmet needs. Cure SMA’s 2021 *Understanding the Caregiver Experience* survey found that family caregivers of children and/or adults with SMA provide, on average, 45 hours per week in unpaid caregiving services, which is significantly higher than the 23.7 hours per week of all caregivers, reported in the 2020 [Caregiving in the U.S. report](#). Family caregivers of individuals with SMA reported financial strain, work limitations, and poorer health due to their caregiving responsibilities. Many adults with SMA who rely on a parent or spouse when they lack

Medicaid caregiving hours face an additional threat to their independence due to the age of their caregiver. About 65% of family caregivers of adults with SMA are 50 years old or older, according to Cure SMA's caregiving survey. *"My mother helps me when I don't have a PCA but as she is in her sixties, I worry about the toll it takes on her health."* said a **Mississippi adult with SMA**. An **Indiana woman with SMA** fears her independence if something happened to her family caregiver. *"If I didn't have my mom, I would no longer be able to be independent and potentially would have to move into a long-term nursing facility."*

CONCLUSION

Cure SMA and the SMA community wholeheartedly agree that home-based services, which we highlighted in our recent [Caregiving Needs of the SMA Community: In Their Own Words](#) report, are important and essential and deserve our country's attention and investment. We appreciated that Congress increased the federal funding match that states receive for Medicaid home and community-based services in the American Rescue Plan (ARP). The extra ARP funds have helped states begin to address the caregiving shortage in their states. For example, a **Tennessee woman with SMA** was able to recruit for a caregiver position at a higher wage through her consumer-directed program because of the ARP funding increase. However, this federal funding match was temporary. The caregiver challenges are ongoing.

Cure SMA asks Congress to act on the information and testimony from this Special Committee on Aging hearing to increase caregiving hours and to address the workforce shortages that exist across the care economy. Thank you for considering the views and experiences of individuals with SMA and their families.