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Written Statement for the Record

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U.S. Senate Special Committee on Aging Hearing on

Importance of Medicaid Home and Community-Based Services

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

Thank you for holding a hearing on Aging in Place and the impact of Medicaid home and community-based services (HCBS) and other public programs that promote independence and community living for older adults and people with disabilities. Cure SMA, which represents children and adults with a neuromuscular disease known as spinal muscular atrophy (SMA), will focus its comments on Medicaid-funded caregiving services given their importance to individuals with SMA and their families during the holidays and throughout the year. In short, Medicaid caregiving is indispensable to people with SMA. Policy changes or funding cuts that limit access to caregiving services or reduce available hours will lead directly to isolation, increased health risks, and unnecessary institutionalization.

SMA Community Depends on Medicaid Caregiving Services

Most individuals with SMA rely on daily support from Medicaid-funded caregivers to maintain their health, independence, and ability to live in the community.[i] Due to muscle weakness and motor function loss caused by SMA, individuals with SMA often require assistance with wheelchair transfers, grooming, bathroom use, and meal preparation and feeding.[ii] One **adult with SMA** said, *"I am 100% dependent. Without home caregivers I would have to leave my home to live at a nursing facility.* Another **individual with SMA** said, *"Medicaid empowers me to be a contributing member of the community, and without it I would surely be in an institutional setting."*

Access to Medicaid-funded caregiving enables individuals with SMA to attend school, go to work, and engage fully in community life. As another **adult with SMA** shared, *"My caregivers are my lifeline. Without them, I wouldn't be able to be a part of the community or be independent in any capacity."* A **SMA community member** added, *"I am fortunate to have found a reliable, long-term caregiver. Although I am physically dependent, I am cognitively able and fully participate in town and church activities."*

SMA Community Concern About Caregiving Cuts and Changes

Individuals and families affected by SMA frequently struggle to obtain the caregiving hours they require. Many receive far fewer hours than they need, delaying independent living plans or restricting community participation. A **young adult with SMA** noted, *"I receive 48 hours of Medicaid caregiving a week. I need almost 24/7 care to live independently. As a result, I live with my parents who provide many unpaid caregiving hours."*

Limited hours also force individuals to forgo meaningful activities. One **adult with SMA** shared, *"There are lots of things in the community that I would like to participate in, but I can't* *because I just don't have enough hours, and I cannot do them alone due to my SMA."*

Individuals and families with SMA are deeply concerned about how Medicaid changes or funding cuts could affect their daily lives. A **mother of two children with SMA** said, *"I worry they'll lose the hours they have, which is barely enough to get them out of bed each day, in bed each night, showered a few times each week, and cover the basic g-tube feeding times."* A **woman with SMA** who works full-time said, *"I worry I will lose caregiving coverage, which could jeopardize my employment if I am unable to get up and ready to go to work each day."* Another **young adult with SMA** added, *"I worry that potential cuts to Medicaid will impact my health and ability to live independently."*

Some individuals with SMA are already experiencing proposed cuts. One **adult with SMA** described how her state plans to reduce her caregiving hours, including the specialized support she needs for safe transfers in and out of her wheelchair. *"If this goes through, the cut would leave me isolated at home and could endanger my health, as I would be forced to limit my food and liquid intake to unhealthy levels due to bathroom limitations,"* she said. *"This ordeal has been overwhelming. It makes me want to scream or cry."* Another **SMA community member** echoed that sentiment by saying, *"The uncertainty to my lifeline is anxiety-inducing."*

SMA Community Priorities for Strengthening Medicaid Caregiving

Cure SMA recently documented caregiving challenges in our *Stuck Inside* national caregiving report.[iii] In addition to limited and threatened caregiving hours, the SMA community identified:

- Difficulty in finding caregivers, driven largely by low wages,
- Restrictive income and asset limits that penalize those pursuing work or financial stability, and
- Lack of Medicaid portability for individuals who move across state lines.

On the caregiver shortage, a **father of a child with SMA** said less than half of his daughter's approved private duty nursing hours are filled in any given week. The family has been *"effectively trapped at home,"* missing family gatherings, vacations, and local events due to nursing support gaps. *"We can't find qualified nurses willing to staff the shifts. The nursing shortage has been the single most important pain point in managing SMA and our daughter's care. It's super frustrating."*

Conclusion

Medicaid-funded caregivers and caregiving services are essential for education, critical for employment, crucial for independent living, and vital for community participation of people with SMA.[iv] Yet individuals with SMA and their families face significant barriers to accessing these services during the holidays and throughout the year.

One **adult with SMA** shared, *"My life-threatening medical condition is actually not the worst thing I have to face. The thing that has most inhibited my quality of life is the constant fight I have to go through daily, just to be able to live in the community like everyone else. With constant threats to Medicaid funding, and the amount of work and advocacy it takes to obtain Medicaid services, it feels like I am constantly being punished for my disability. I am exhausted."* Another **individual with SMA** added, *"Caregiving is not a luxury. It gives people* *the opportunity like me to pursue the same goals as anyone else. The importance of caregiving cannot be understated.”*

Cure SMA urges Congress to use its oversight and authorizing authority to strengthen Medicaid and ensure that individuals with SMA, and others with complex disabilities, can access the Medicaid-funded caregiving services they need to remain healthy, live independently, and contribute to their communities. Thank you for considering the perspective of Cure SMA and SMA community.

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[i] Cure SMA 2024 State of SMA Report, https://www.curesma.org/wp-content/uploads/2025/04/State-of-SMA-Report2024_vWeb.pdf#page=32

[ii] Cure SMA 2024 National Caregiving Report, https://www.curesma.org/wp-content/uploads/2024/01/Advocacy_Report_Stuck_Inside_vFnl_Web.pdf

[iii] Cure SMA 2024 National Caregiving Report, https://www.curesma.org/wp-content/uploads/2024/01/Advocacy_Report_Stuck_Inside_vFnl_Web.pdf#page=14

[iv] Cure SMA 2024 National Caregiving Report, https://www.curesma.org/wp-content/uploads/2024/01/Advocacy_Report_Stuck_Inside_vFnl_Web.pdf#page=7