



Make today a breakthrough.

March 13, 2023

The Honorable Bob Casey
United States Senate
393 Russell Senate Office Building
Washington DC 20510-3804

Dear Senator Casey,

As the national organization that represents children and adults with a rare neuromuscular disease known as spinal muscular atrophy (SMA), **Cure SMA is pleased to support your Home and Community Based Services (HCBS) Access Act.** Your legislation would promote access to personal care attendants (PCAs) and other in-home services that many individuals with SMA rely on to maintain their health, independence, and community participation and living.

SMA is a degenerative disease that robs individuals of their physical strength, greatly impacting their muscles used for everyday activities such as breathing, eating, crawling, and walking. 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. Medicaid-funded caregiving services, such as access to PCAs, are essential for individuals with SMA, of all ages. *“Almost every aspect of my daily routine would not happen without PCAs,”* said an **adult with SMA**. *“Without them, I would not be able to get out of bed each morning, shower, and get dressed to go earn a living at my full-time job.”*

Unfortunately, individuals with SMA face significant and ongoing challenges in receiving adequate caregiving hours and in recruiting and retaining PCAs who provide these critical services. The COVID-19 pandemic exacerbated the caregiving challenges faced by individuals and families with SMA. However, the direct care workforce shortage preceded the pandemic, as highlighted in Cure SMA’s report on the caregiving needs of the SMA community.ⁱ *“Not long ago, a part-time PCA opening drew about 20 applicants. Now, I don’t receive any applicants,”* said an **adult with SMA** who ended his comment with a plea to Congress: *“Please help.”* The National Council on Disability (NCD) also urged Congress to act to meet the needs of individuals with disabilities, describing the workforce shortage as being at an *“emergency level.”* In its 2022 “Strengthening the HCBS Ecosystem” report, the independent federal agency recommended that Congress should increase funding to states and make HCBS a mandatory benefit under Medicaid.ⁱⁱ

The HCBS Access Act recognizes the important role of PCAs and other in-home services in promoting the health and independence of people with SMA and other disabilities. The legislation also understands the challenges individuals with SMA and others face in accessing the caregiving hours and direct care workers they need to work, learn, and live in their communities. Your HCBS Access Act would help address these caregiving struggles by:



- Making HCBS a mandatory benefit rather than the optional (waiver) benefit it is considered under current law;
- Increasing federal funding to states to enhance, expand, or strengthen HCBS services;
- Setting an minimum level of services that each state must meet to receive the increased federal match, which would include: personal assistance, caregiver and family support, respite care, transportation, supported employment, and housing support and wraparound services;
- Helping states address the direct care workforce shortage through specialized technical assistance and infrastructure planning grants; and
- Ensuring quality and standardization of HCBS, regardless of which state a person with disabilities resides, through core quality measures.

New investments, improvements, and flexibility in our nation’s caregiving system are desperately needed to meet the unmet caregiving need and to promote independence and community living of the SMA community. *“The current system disregards the value of people with disabilities and their ability to earn, contribute, and make a meaningful difference,”* said an **adult with SMA**. The HCBS Access Act would help individuals with SMA and others to access the care and in-home support they need to live independently and thrive in their communities.

Cure SMA and individuals and families with SMA applaud your leadership on this important issue. We support efforts to help advance the HCBS Access Act during the 118th Congress. 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,

Kenneth Hobby
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Cure SMA

Maynard Friesz
Vice President of Policy & Advocacy
Cure SMA

ⁱ “In Their Own Words: Report on the Caregiving Needs of the SMA Community,” Cure SMA, 2021, <https://www.curesma.org/wp-content/uploads/2021/10/IN-THEIR-OWN-WORDS-Caregiving-Needs-of-the-SMA-Community.pdf>

ⁱⁱ “Strengthening the HCBS Ecosystem – Responding to Dangers of Congregate Settings during COVID-19,” National Council on Disability, 2022, https://ncd.gov/sites/default/files/NCD_Strengthening-HCBS-Ecosystem_508.pdf