



Make today a breakthrough.

October 12, 2023

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

Dear Senator Casey,

As the leading national organization that represents individuals with a neuromuscular disease known as spinal muscular atrophy (SMA), **Cure SMA is pleased to support the introduction of the Home and Community-Based Services (HCBS) Relief Act.** The legislation would help address the in-home caregiving needs and challenges of individuals with SMA and other disabilities.

SMA is a progressive neurodegenerative disease that robs individuals of physical strength and impacts their ability to walk, eat independently, and perform other essential functions. Many individuals with SMA utilize personal care attendants (PCAs) or other in-home support to assist with their activities of daily living, such as getting out of bed, toileting, grooming, and transferring to their power wheelchair so they can get to work, attend school, or participate in community activities.

Medicaid is the primary funder of these critical in-home services. States can provide home and community-based services through waiver programs that allows individuals with disabilities to access their long-term care and supports in their home and community rather than an institution ([CMS 2023](#)). **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.**

Cure SMA's Adult Advisory Council identified caregiving as being among their top priorities during an October 2023 meeting in Washington, DC. Adults with SMA face three chronic challenges related to caregiving: 1) difficulty recruiting and retaining PCAs and other in-home aides, 2) not receiving enough caregiving hours through their state Medicaid program, and 3) fear that their back-up caregivers (often an aging parent or spouse) will be unable to assist due to illness or death. *"Thanks to PCAs provided through my state, I have sustained my independence for years,"* said **an adult with SMA.** *"However, I now fear institutional care because I am unable to find candidates for my open caregiving positions."*

Your HCBS Relief Act would help to meet the needs of individuals with SMA and their families by providing states with temporary, dedicated Medicaid funding to stabilize their HCBS service delivery networks, including strengthening the direct care workforce in their state. Under your proposal, states would receive a 10-percent increase in their federal Medicaid match for two consecutive fiscal years to fund things such as increasing



pay and benefits for direct care workers, paying family caregivers, boosting caregiving hours, and eliminating state Medicaid HCBS waiting lists. *“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 **an older adult with SMA**.

Cure SMA and the entire SMA community appreciate your leadership and efforts to ensure individuals with SMA and other disabilities can access the in-home caregiving supports they need to thrive in their communities. Please let us know how we can help assist in growing support for this legislation, which would address one of the top priorities of the SMA community. Your staff can contact Maynard Friesz, Vice President for Policy and Advocacy at Cure SMA, at 202-871-8004 or maynard.friesz@curesma.org if they have questions or need additional information.

Sincerely,

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

Kenneth Hobby
President
Cure SMA

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

Maynard Friesz
Vice President of Policy
Cure SMA