

August 4, 2026

The Honorable Ben Ray Luján
United States Senate
498 Russell Senate Office Building
Washington DC 20510

The Honorable Tim Kaine
United States Senate
231 Russell Senate Office Building
Washington DC 20510

Dear Senators Luján and Kaine,

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

SMA is a rare, neurodegenerative disease that causes significant muscle weakness, often leading to full paralysis and affecting a person's ability to breathe, swallow, cough, and move. Due to these symptoms, most individuals with SMA rely on caregivers for daily tasks such as dressing, grooming, and bathing, as well as more complex needs such as respiratory support, nutrition assistance, and safe patient transfers. As **one adult with SMA shared**, *"without caregiving services, 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."*

Many individuals with SMA who require daily assistance seek caregiving support through Medicaid, the primary funder of caregiving and other long-term services and supports for individuals with SMA and others with significant disabilities or chronic conditions.ⁱ Despite demonstrated need, most in the SMA community struggle to access the care they need to maintain their health, live independently, and work and contribute to their community.ⁱⁱ Individuals with SMA also struggle to find and retain caregivers, especially for nights and weekends, even though the need for care does not end during these hours.ⁱⁱⁱ As **one adult with SMA shared**, caregiving challenges have *"reduced my independence and restricted our schedules."* Another **person with SMA** said a lack of Medicaid caregiving hours *"has delayed my ability to live independently"* compared to peers without disabilities.

The HCBS Access Act recognizes the important role of Medicaid home care in promoting the health, independence, and community participation of people with SMA and other disabilities, and helps address the caregiving challenges our community faces through meaningful provisions, including:

- Making HCBS a mandatory Medicaid benefit rather than the optional, waiver-based benefit it is under current law;
- Increasing federal funding to states to enhance, expand, or strengthen HCBS services;
- Standardizing HCBS benefit categories such as personal assistance, caregiver and family support, respite care, transportation, supported employment, and housing and wraparound services; and
- Funding grants to help address direct care workforce shortages.



Cure SMA and the SMA community we represent also appreciate the bill's attention to self-directed care, which many individuals with SMA depend on to hire and manage caregivers — including, in many states, family members who understand their specific care needs. The legislation's investments and improvements would help individuals with SMA and others access the care and in-home support they need to live independently and thrive in their communities.

Cure SMA thanks you for your leadership on this critical legislation and looks forward to working with you to advance the HCBS Access Act. Please do not hesitate to contact Maynard Friesz, Vice President for Policy and Advocacy at Cure SMA, at maynard.friesz@curesma.org or 202-871-8004 with any questions or if we can be of assistance.

Sincerely,

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

Kenneth Hobby
President

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

Maynard Friesz
Vice President, Policy

ⁱ Centers for Medicare and Medicaid Services: <https://www.medicaid.gov/medicaid/long-term-services-supports>

ⁱⁱ Cure SMA Stuck Insite Caregiving Report: https://www.curesma.org/wp-content/uploads/2024/02/2024_Advocacy_StuckInside_FactSheet_V2.pdf

ⁱⁱⁱ Cure SMA Stuck Insite Caregiving Report: https://www.curesma.org/wp-content/uploads/2024/02/2024_Advocacy_StuckInside_FactSheet_V2.pdf