



Make today a breakthrough.

June 25, 2021

The Honorable Bob Casey  
The Honorable Chuck Schumer  
The Honorable Ron Wyden  
The Honorable Patty Murray  
The Honorable Maggie Hassan  
The Honorable Sherrod Brown  
United States Senate  
Washington DC 20510

The Honorable Debbie Dingell  
The Honorable Frank Pallone  
The Honorable Jan Schakowsky  
The Honorable Doris Matsui  
United States House of Representatives  
Washington DC 20515

Dear Senators and Representatives,

As the leading national organization that supports and advocates for individuals with spinal muscular atrophy (SMA), **Cure SMA supports the investment in and focus on independence and community living for individuals with SMA and other disabilities in your Better Care Better Jobs Act (S. 2210, H.R. 4131).**

SMA is a degenerative disease that robs individuals of physical strength, greatly impacting their ability to walk, move and lift their arms, and perform other essential functions of everyday life. People with SMA benefit from Medicaid-funded home and community-based services (HCBS), such as personal attendant services, respite care, and rehabilitative services, to promote independence and assist with activities of daily living. For example, a personal care attendant (PCA) may assist an individual with SMA in getting out of bed and dressing in the morning so they can get to work or attend school.

**However, individuals with SMA face significant and ongoing challenges in accessing adequate HCBS coverage hours and in recruiting and retaining direct care workers who provide these important services.**

A **young adult with SMA from North Carolina** requires at least 50 to 60 hours a week of caregiving needs to help him in the morning, during the day while he works, and at night. However, his state has only approved 40 hours of PCA services. Unable to cover the remainder of his caregiving needs from his own pocket, he must live at home, where his parents can assist, rather than live independently, in his own apartment, like others his age. A **West Virginia college student** who attends a school out-of-state has been unable to find enough employees to cover his care needs. His current PCAs are mostly college students. He worries whether there will be enough workers over the summer, for his college internship, given students often return to their hometown rather than remain in the college town. *"I am constantly worried. How will I go to the bathroom? How will I get out of bed the next morning?"* An **older adult with SMA from Massachusetts** utilizes PCAs to transfer out of bed, for food preparation, shopping, and feeding, and for dressing and bathing. It is challenging to fill his caregiving needs. A couple of years ago, he would receive 20 or more applicants for an open PCA position. *"Now, due to lack of affordable housing in my community, I have received zero applications for jobs I have posted over the past 2 ½ years."*



**These examples are not unique.** Caregiving support was one of the most significant *ongoing* unmet needs identified by adults with SMA (45%) and families with children with SMA (29%), according to Cure SMA's Annual SMA Community Survey. Caregiving challenges were especially difficult during the COVID-19 pandemic. **Maryland parents of a child with SMA** themselves covered non-stop caregiving shifts, 24/7, for over six months without any additional home nursing support. *"With appropriate care, my son can grow, thrive, attend school, and participate in many daily activities,"* the Maryland father said. *"Without the care he needs, he will languish...not from his disease, but from lack of support."* Similarly, the caregiving struggles of a **New York family with a child with SMA** were recently highlighted in a [New York Times](#) article.

**Cure SMA is pleased that your legislation, H.R. 4131 & S. 2210, would help address the caregiving challenges and needs of individuals with SMA and other disabilities by investing in Medicaid HCBS and developing strategies to expand and strengthen the direct care workforce.** Cure SMA and our supporters are especially supportive of the following provisions included in your legislation:

- Requiring coverage of personal care services (*page 25*);
- Incentivizing the use of self-directed care of Medicaid HCBS (*pages 21-22*);
- Adopting, expanding eligibility for, or improving coverage provided under Medicaid buy-in programs for workers with disabilities (*pages 25-26*);
- Supporting family caregivers, including through respite care and paid family caregiving (*Page 25*);
- Expanding financial eligibility criteria for HCBS services up to current Federal limits (*Page 25*); and
- Providing presumptive eligibility and including individuals on Medicaid HCBS wait lists (*pages 3 & 25*).

**Approving these and other important provisions in your legislation would significantly meet the independent living needs of individuals with SMA and ensure that they can access a qualified workforce of direct care workers to provide these essential services.** Thank you for your leadership in helping to address the caregiving needs and challenges faced by the SMA community. For more information, your staff can contact Maynard Friesz, Vice President for Policy at Cure SMA, at [maynard.friesz@curesma.org](mailto:maynard.friesz@curesma.org) or 202-871-8004.

Sincerely,

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