



Make today a breakthrough.

September 13, 2021

Dear Representative:

As the leading national organization that represents individuals with a neuromuscular disease known as spinal muscular atrophy (SMA), **Cure SMA supports the provisions included in the Energy and Commerce Committee's [portion](#) of the Build Back Better Act that focus on the caregiving needs of individuals with SMA and their families.** We ask that you support the Subtitle G, Part 2 expansion of Medicaid home and community-based services (HCBS) during the Energy and Commerce Committee markup at no less than the \$190 billion for HCBS included in the committee draft.

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 HCBS, such as home health, 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 dressed 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. An **adult with SMA from Illinois** utilizes PCAs to assist with almost every aspect of her daily life. *"Without PCAs, I would not be able to get out of bed each morning, or shower and get dressed to go earn a living at my full-time job. Unfortunately, it is really difficult to find good PCAs because they can often make more money working in retail than they can taking care of me as a PCA. Please help me continue to live independently with the support of PCAs by expanding access to Medicaid services."* A **West Virginia college student** 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 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, 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 need identified by adults with SMA (45%) and families with children with SMA (29%), according to Cure SMA's Annual SMA Community Survey.

Cure SMA is pleased that the Energy and Commerce Committee portion of the Build Back Better Act would help address the caregiving challenges and needs of individuals with SMA and other disabilities. Under Subtitle G, Part 2, states would receive a 7 percent or more federal match increase (FMAP) for expanding HCBS for individuals with disabilities and older adults and for addressing the direct care workforce shortages in their states. In addition, states could receive planning grants to help them develop strategies for expanding HCBS and strengthening the direct care workforce. **These provisions would help to ensure that individuals with SMA and others can access the HCBS hours and skilled staff they need to maintain their health, independence, and community living.**

As a Member of the Energy and Commerce Committee, Cure SMA respectfully asks that you support the HCBS expansion included in Subtitle G, Part 2 of the Energy and Commerce Committee's Build Back Better Act. These provisions, along with the grants to support the direct care workforce that were included in the Education and Labor Committee portion of the act, would greatly improve the caregiving and community living challenges faced by individuals with SMA.

Thank you for your consideration. Please do not hesitate to contact Cure SMA if you have any questions. Your staff can contact Maynard Friesz, Vice President for Policy and Advocacy at Cure SMA, at 202-871-8004 or maynard.friesz@curesma.org.

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 of Policy