



Make today a breakthrough.

October 30, 2021

President Joseph R. Biden  
The White House  
1600 Pennsylvania Avenue  
Washington, DC 20500

Dear President Biden:

As the leading national organization that represents individuals with a neuromuscular disease known as spinal muscular atrophy (SMA), **Cure SMA strongly supports the provisions included in the Build Back Better Act [framework](#) that expand home and community-based services (HCBS) for individuals with disabilities and invest in the caregiving workforce that deliver these essential services.**

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.** Cure SMA recently released a [major report](#) that highlighted the caregiving needs of individuals with SMA and their families. In addition, 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 Community Survey.

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 with SMA** 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 during summer school given students often return to their hometown rather than remain in the college town during summer months. *"I am constantly*



worried. How will I go to the bathroom? How will I get out of bed the next morning to get to school?" An **older adult with SMA from Massachusetts** utilizes PCAs to transfer out of bed, for food preparation, feeding, and for dressing and bathing. He faces great challenges in finding workers to assist with his independent living needs. A couple of years ago, he received 20 or more applicants for an open PCA position. *"Now, I have received zero applications for jobs I have posted over the past several years."*

**Cure SMA is pleased that the Build Back Better framework would help address the caregiving challenges and needs of individuals with SMA and other disabilities.** The investments proposed in the framework would incentivize states to expand HCBS for older adults and people with disabilities through an increased federal match. In addition, the resources focused on the direct care workforce will greatly assist individuals with SMA and their families in recruiting and retaining reliable and qualified PCAs to assist with their daily living activities. Cure SMA appreciates your support of these important provisions that will help increase independence and community living for individuals with SMA.

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