



Make today a breakthrough.

September 9, 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 Education and Labor 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 these direct care workforce provisions during the Education and Labor Committee markup.

Because SMA takes away physical strength and impacts a person's ability to walk and eat, many individuals with SMA utilize a personal care attendant (PCA) or other direct care worker to assist with their activities of daily living. For example, **a 44-year-old school teacher with SMA Type 2** has PCAs assist her at three different times during her workday: in the morning, to help her get dressed, transfer her into a power wheelchair, and to drive her to work; during the middle of the day, for a restroom break and to take her to the doctor and other appointments; and at night, to assist with end-of-day tasks, including showering and preparing for bed. **A 34-year-old individual with SMA Type 3** relies on PCAs to live independently and to work full-time. *"Almost every aspect of my daily routine would not happen without PCAs. Without them, I would not be able to get out of bed each morning, or shower and get dressed to go earn a living,"* she said.

**Direct care workers, such as PCAs, play a critical role in the lives of individuals with SMA. However, many people with SMA have a difficult time recruiting and retaining PCAs and other essential direct care workers.** One **individual with SMA Type 3** described how PCA openings a few years ago would receive 20 or more applicants. Today, he is unable to fill open PCA positions due to a lack of candidates. Many in the SMA community point to low pay and limited advancement opportunities for reasons they are unable to recruit and retain direct care workers. The Education and Labor Committee's Build Back Better Act section includes important provisions that would help address the caregiving challenges faced by individuals with SMA and other disabilities.

Part 4 of the bill would make available grants to states and other entities to address the recruitment, education, retention, and career advancement of the direct care workforce, including PCAs who assist individuals with SMA. The grant program would help develop and implement urban and rural strategies and best practices to strengthen the direct care workforce, which would in turn boost care quality and consistency for individuals with SMA and others who receive home and community-based services. Section 25006 would establish a technical assistance center at the U.S. Department of Health and Human Services to assist grant recipients and other caregiving entities with recruiting and retaining direct care workers.

**As a Member of the Education and Labor Subcommittee, we ask that you support the direct care workforce provisions to increase the availability of direct care workers for individuals with SMA and other disabilities.** 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](mailto: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