



Make today a breakthrough.

June 10, 2021

Dear Representative:

As you consider which investments to include in the next recovery package, **Cure SMA asks that you directly address the direct care worker shortage that is impacting the caregiving and everyday living needs of individuals with spinal muscular atrophy (SMA)**, a degenerative neuromuscular disease that robs individuals of physical strength and their ability to eat, walk, and breath.

The [New York Times](#) recently highlighted the caregiving crisis that exists in the U.S. by featuring a family with a 7-year-old child with SMA who requires full-time, intensive in-home care. The article described how the boy's parents needed to schedule different sleep shifts to care for their child in case one of their in-home nurses failed to show up or unexpectedly canceled their shift. Serving as a back-up caregiver to their child was on top of their regular full-time work and parental responsibilities.

The caregiving challenge faced by the family featured in this news article is not unique within the SMA community. More than 45% of individuals with SMA and families with SMA reported that they faced limitations during the COVID-19 emergency in accessing essential SMA-related services, such as personal care attendants (PCAs) and in-home nurses or health aides. Throughout the COVID-19 pandemic, backup caregivers, finding caregivers, and emergency respite were among the most requested unmet needs of the SMA community. At the beginning of the pandemic, one individual with SMA worried that *"my one and only caregiver will quit because I don't have enough personal protective equipment."*

While the caregiving shortage has worsened due to COVID-19, individuals with SMA and their families reported difficulty, prior to the pandemic, in finding and keeping quality, reliable caregivers. Caregiving support was identified as 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. The number of caregiving support hours approved through Medicaid often fails to meet actual caregiving needs. A person with SMA requires two or three caregivers, on average, to assist with daily living needs, such as getting dressed, attending school, and help at bedtime. Many adults (39%) and children (25%) with SMA require more than 20 hours of caregiving assistance every week. Access to caregiving services, such as PCAs, is essential, not optional. *"Professional caregivers are so vital for all people and a healthy community, society and world,"* one adult with SMA said. Related to the current caregiver shortage, another person with SMA said, *"This creates an urgent situation for those of us living independently with the help of PCAs. When my caregiver doesn't show up, I can't get out of bed or make it to work. They are essential."*

Recognizing the essential nature of in-home services that help individuals with disabilities and older adults maintain their health and live independently, Congress included additional Medicaid [resources](#) to help states address the COVID-19-related caregiving crisis. As you know, [Medicaid](#)



is the primary provider of long-term care, such as PCAs and home health aides, in this country. However, the American Rescue Plan federal match increase for Medicaid home and community-based services (HCBS) was temporary. **The caregiving challenges that face the SMA community are not temporary and will continue, well past the March 31, 2022 end date associated with the temporary Medicaid increase to states.**

Cure SMA respectfully asks that you address our country's caregiving shortage by investing in Medicaid HCBS in the next recovery package. The current \$400 billion Medicaid HCBS proposal, for example, would help states address the systemic caregiving recruitment and retention challenges in their states and, most importantly, ensure that individuals with SMA and others can access the in-home assistance they need to live independently and to participate in their communities. 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,

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