



Make today a breakthrough.

June 26, 2024

Re: Please Vote to Advance the Think Differently Database Act (H.R. 670)

Dear U.S. House Energy & Commerce Committee Member:

On behalf of individuals with spinal muscular atrophy (SMA) and their families, **Cure SMA asks that you vote YES to advance the bipartisan Think Differently Database Act (H.R. 670) during the Energy and Commerce Committee markup.** H.R. 670 would help increase awareness about caregiving options for individuals with disabilities, including those with SMA, by creating an online, searchable one-stop information clearinghouse of caregiving services.

SMA is a degenerative neuromuscular 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. Individuals with SMA benefit from Medicaid-funded home and community-based services (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 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.

Unfortunately, individuals with SMA face multiple barriers in accessing caregivers and caregiving services, even in understanding what caregiving options are available to them in their states. *"I couldn't find information directly online about the waiver program that I use. I only found out about it through my counselor at the Division of Rehabilitative Services,"* said a woman with SMA. This is a common problem with about [47 percent](#) of individuals with SMA and their families reporting that they struggled to find information about paid caregiving options in their state, according to Cure SMA's recent [Stuck Inside National Caregiving Report](#). A Cure SMA review of state Medicaid webpages found state caregiving information "hard-to-find, confusing, inconsistent, and not consumer-oriented." The SMA community recommended that states be required to share online information about their Medicaid HCBS waiver programs and related caregiving services in a consumer-friendly, plain language format.

The Think Differently Database Act would help address this information gap by creating an interactive, searchable webpage with federal, state, and local information about caregiving services, including Medicaid HCBS eligibility, for individuals with disabilities and their families. Cure SMA worked with the bill's sponsors to expand the scope of the legislation to its current draft to ensure the information is available for all individuals with disabilities. This commonsense solution will help individuals with disabilities and their families better understand caregiving options that may be available to help maintain their health and independence. We respectfully ask that you vote YES on H.R. 670 to advance the legislation to the full U.S. House of Representatives.



In addition to creating an online information clearinghouse of caregiving services, **Cure SMA also asks that you address other caregiving barriers faced by individuals with SMA and their families.** Our national caregiving report found that [86 percent](#) of individuals with SMA and their families struggled to find caregivers and 62 percent reported difficulty retaining caregivers. The SMA community's most difficult caregiving shifts to fill were for nights and weekends. In addition, [41 percent](#) of individuals with SMA said they declined a job or school opportunity that was out of state for fear of losing their caregiving services and [27 percent](#) of adults with SMA said they do not work or work only part-time to maintain their eligibility for caregiving services. **Cure SMA respectfully asks that you support other legislative solutions to the caregiving challenges faced by individuals with SMA and other disabilities, including the bipartisan Supplemental Security Income Penalty Elimination Act (H.R. 5408).**

Thank you for considering the views of the SMA community. 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