Make today a breakthrough.

June 5, 2025

The Honorable John Thune
Majority Leader
United States Senate
Washington, DC 20510

The Honorable Charles Schumer
Minority Leader
United States Senate
Washington, DC 20510

The Honorable Mike Crapo
Chairman, Senate Finance Committee
United States Senate
Washington, DC 20510

The Honorable Ron Wyden
Ranking Member, Senate Finance Committee
United States Senate
Washington, DC 20510

Re: SMA Community Concerns & Perspective on Proposed Medicaid Cuts & Changes

Dear Majority Leader Thune, Minority Leader Schumer and Senators Crapo and Wyden,

As the U.S. Senate considers H.R. 1, Cure SMA wanted to share the concerns and perspectives of individuals with spinal muscular atrophy (SMA) and their families about the proposed cuts and changes to Medicaid.

SMA is a neuromuscular disease that impacts children and adults in all 50 states. The degenerative disease causes debilitating muscle and motor function loss that impacts their ability to perform basic, everyday activities such as eating, crawling, and walking. Cure SMA is the national organization that supports and represents individuals with SMA and their families, many of whom receive healthcare and caregiving services through Medicaid.

Adults with SMA and parents of children with SMA are deeply concerned that H.R. 1 could negatively impact their ability to access Medicaid healthcare and caregiving at the state level. Due to muscle weakness caused by SMA, many individuals with SMA rely on Medicaid-funded caregivers to assist with daily activities such as getting in and out of bed, dressing, using the bathroom, and eating. In addition, Medicaid provides essential healthcare, including access to treatments, physical and occupational therapies, and medical equipment. *“Medicaid is vital to every aspect of my life,”* said an **individual with SMA**.

Under H.R. 1, states would receive significantly less federal funding for Medicaid, according to the Congressional Budget Office. Children and adults with SMA already face significant barriers under current funding levels that limit access to Medicaid caregiving and healthcare. *“I currently receive only 38 hours of Medicaid caregiving services a week when I need 60 hours to live independently,”* said a **38-year-old adult with SMA** who, despite working full-time, lives with her parents because she has no other backup caregivers. A **30-year-old woman with SMA** who also lives with her parents due to a lack of Medicaid caregiving support said, *“My state is already trying to reduce caregiving hours. I’m very worried that this will be the first target if funding is reduced.”* People with SMA also report access barriers related to treatments, physical and occupational therapies, and medical equipment such as power wheelchairs. Reducing federal Medicaid funding to states could further strain states’ ability to meet their residents’ healthcare needs, particularly caregiving and other non-mandatory Medicaid services. A

mother of a child with SMA said, *"My state receives a great deal of funding from the federal government to fund Medicaid and caregiving waivers. Without that funding I'm extremely worried that my daughter will lose her caregiving and/or Medicaid healthcare access."*

Under H.R. 1, states must add new processes to verify compliance with proposed Medicaid-related requirements. Individuals with SMA and families with SMA already experience challenges in meeting existing administrative requirements for current Medicaid policy. The annual Medicaid redetermination process for a **41-year-old with SMA** requires *"proof of my medical diagnosis, expenses, living conditions, etc. The application is several pages long, and very detailed."* Another **adult with SMA** said, *"My renewal process always seems to be a problem. I follow all the rules and submit all required documentation, but it always comes down to the wire. It's a completely stressful process."* Due to their SMA symptoms, individuals with SMA may also need help from others to collect, print, and mail the required documents, which can slow down the process. Adding new complexities to an already burdensome and oftentimes lengthy renewal process could result in gaps or loss of Medicaid coverage for people with SMA, despite intentions and proposed exemptions. A **48-year-old with SMA** said, *"The process is difficult and disorganized enough as it is currently. I absolutely have concerns"* about new compliance requirements.

Individuals and families affected by SMA face daily difficulties and significant barriers due to their SMA. Medicaid is a key government program that helps address these significant challenges. Medicaid healthcare, caregiving, and other services make it possible for children and adults with SMA to attend school, work, live independently, participate in their community, and maintain their health and independence. As one adult with SMA put it, **Medicaid is a lifeline, not a line item for the SMA community**. Cure SMA urges Congress to reduce barriers and increase and improve access to these essential services. Please fully consider the urgent and everyday needs of individuals with SMA and potential secondary impacts that federal Medicaid cuts and changes may have at the state-level that could add, not reduce, challenges and barriers faced by the SMA community.

Thank you for considering the views of individuals and families with SMA. Please don't hesitate to contact Cure SMA if you need any information or would like to connect with individuals and families with SMA in your state. Your staff can contact Maynard Friesz, Cure SMA Vice President for Policy & Advocacy, at maynard.friesz@curesma.org or 202-871-8004.

Sincerely,

K.A. Hobby

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President
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