

September 4, 2025

The Honorable Jason Smith
Chairman
U.S. House Ways & Means Committee
Washington DC 20515

The Honorable Richard Neal
Ranking Member
U.S. House Ways & Means Committee
Washington DC 20515

The Honorable Ron Estes
Chairman
U.S. House Social Security Subcommittee
Washington DC 20515

The Honorable John Larson
Ranking Member
U.S. House Social Security Subcommittee
Washington DC 20515

The Honorable Darin LaHood
Chairman
U.S. House Work & Welfare Subcommittee
Washington DC 20515

The Honorable Danny Davis
Ranking Member
U.S. House Work & Welfare Subcommittee
Washington DC 20515

Dear Chairmen Smith, Estes, and LaHood and Ranking Members Neal, Larson, and Davis,

Thank you for holding a hearing on the barriers faced by people with disabilities. Cure SMA, which represents individuals with spinal muscular atrophy (SMA), urges you to use the upcoming hearing to highlight and address an outdated policy that severely limits the ability of people with SMA and other disabilities to work, save, and marry. Later this month, more than 150 SMA community advocates, including adults with SMA impacted by this policy, will be on Capitol Hill urging Congress to pass the Supplemental Security Income (SSI) Savings Penalty Elimination Act (H.R. 2540) to help address this harmful barrier.

SMA is a debilitating neuromuscular disease that causes irreversible nerve damage and severe muscle loss, impairing a person's ability to walk, breathe, and perform daily activities. The disease affects children and adults in all 50 states. Cure SMA is the national organization advocating for individuals with SMA and their families in your states and across the country.

Because of debilitating symptoms caused by SMA, many individuals with SMA rely on SSI for basic needs such as food and housing. As one adult with SMA explained, *"SSI is vital to people with disabilities like me."* Another person with SMA described the program as a *"financial lifeline."* Individuals with SMA may qualify for SSI because their disability results in "marked and severe functional limitations", under Social Security Administration (SSA) rules,ⁱ and they meet very low income and asset thresholds. Adults with disabilities over 18 must also demonstrate an inability to work or earn at a substantial gainful activity level.ⁱⁱ These SSI policies prevent people with SMA and other disabilities from saving, getting married, and pursuing work.

Outdated Policy Limits Savings

Under current law, individuals receiving SSI may not have more than \$2,000 in assets, a limit that includes cash, bank accounts, stocks, and life insurance.ⁱⁱⁱ As one woman with SMA said, *"This \$2,000 limit is extremely dated and cruel when we have extremely high medical and*

durable equipment costs that non-disabled people don't have. How do they expect us to get by in life?" Another adult with SMA added, "Because of the low limit, it is impossible to be able to save for any emergencies that may come up, such as car repair or broken appliances."

Even exceeding the asset limit by one penny can cause loss of SSI benefits—and, in some cases, Medicaid services, which are often tied to SSI eligibility. Many people with SMA depend on Medicaid caregiving services for essential daily support such as grooming, bathroom assistance, and wheelchair transfers. One individual with SMA described declining a savings bond Christmas gift from her grandparents out of fear of exceeding the limit. The SSI asset cap has not been raised since 1989. The SSI Savings Penalty Elimination Act would increase the individual asset limit from \$2,000 to \$10,000 and index it to inflation, which would promote financial security and freedom for people with SMA and other disabilities.

Outdated Policy Limits Marriage

For married couples, the SSI asset limit is just \$3,000 (only \$1,000 higher than the individual limit rather than double) while their monthly benefit is also reduced. This creates a discriminatory marriage penalty. As one adult with SMA said, *"Two people have more costs than one. The fact that the asset limit only raises by \$1,000 is insane."* Another explained that her first step after getting engaged was to meet with SSA staff to assess how marriage would affect her and her fiancé: *"We should not be penalized for loving and wanting to be with another person."*

Despite these barriers, many still choose marriage, though at a financial risk. A newly married woman with SMA said, *"Marriage is an important and sacred part of my religion that I didn't want to give up."* Another person with SMA lost her SSI for a month after getting married because they exceeded the \$3,000 married couple limit. *"Luckily, we corrected that problem and were reinstated in the program. But the low married asset limit makes it impossible to save for a home or to be financially prepared for an emergency vehicle repair,"* she said. The SSI Savings Penalty Elimination Act would raise the married couple limit to \$20,000, double the individual limit, and index it to inflation, eliminating that part of SSI's disability marriage penalty.

Outdated Policy Limits Work and Financial Independence

For individuals with SMA who want to pursue employment, the SSI asset limit creates a significant work disincentive. One adult with SMA explained, *"I have SMA and this cap is hugely debilitating, it prevents me from saving money and pursuing employment as I would lose benefits necessary for my health."*

Although Social Security offers programs such as Ticket to Work, many individuals with SMA remain concerned that their earnings or savings will jeopardize their benefits. *"Many people I know are so scared that they choose not to work at all and live with some financial stress constantly,"* one employed adult with SMA said. A parent added, *"These benefits should reward individuals who are able to still work, not penalize them."*

Those who do work often face complex and punitive systems. A part-time worker with SMA said, *"I claim my wages monthly. My SSI payment is based on income from two months earlier. If I earn more later, SSI counts it as an overpayment, and I have to pay money back. With such a low asset limit, I don't have resources to cover that."* More than 40 percent of

individuals with SMA reported working only part-time to stay below a financial threshold for healthcare or other public benefits such as SSI.^{iv}

In addition, current law jeopardizes the long-term financial security of a worker with disabilities. An older adult with SMA said, *"I got a job after being on SSI for 7 years. I have always had to opt out of employer-sponsored retirement accounts because of the SSI and Medicaid resource limits."* Another adult with SMA declined her employer's 401K match for fear of losing her SSI. Now a full-time employee and no longer receiving SSI, she said, *"I often wonder where I would be today, financially, if I was able to accept the initial \$500 investment or matching gifts offered through my employer's 401K savings program."* The SSI Savings Penalty Elimination Act would increase the individual and married asset limits, helping address these challenges and allowing people with disabilities to build greater financial stability.

CONCLUSION

Cure SMA and the SMA community thank Congress for examining barriers to employment, savings, and marriage. We urge the committee to advance commonsense solutions such as the SSI Savings Penalty Elimination Act to help update these outdated and harmful restrictions. Your staff can reach out to Cure SMA through Maynard Friesz, Vice President for Policy and Advocacy at Cure SMA, at 202-871-8004 or maynard.friesz@curesma.org.

Sincerely,



Kenneth Hobby
President



Maynard Friesz
Vice President of Policy

ⁱ SSI Eligibility Requirements, Social Security Administration, <https://www.ssa.gov/ssi/text-eligibility-ussi.htm>

ⁱⁱ Understanding SSI if you Have a Disability or are Blind, Social Security Administration, <https://www.ssa.gov/ssi/text-disable-ussi.htm#sqact>

ⁱⁱⁱ Understanding SSI Resources, Social Security Administration, <https://www.ssa.gov/ssi/text-resources-ussi.htm>

^{iv} State of SMA Report, Cure SMA, https://www.curesma.org/wp-content/uploads/2025/04/State-of-SMA-Report2024_vWeb-4.pdf#page=20