Written Statement for the Record

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for the

U.S. Senate Budget Committee Hearing on Medicaid (August 4, 2026)

Chairman Johnson, Ranking Member Merkley, and Members of the Committee:

Thank you for holding a hearing focused on Medicaid, a critical program for the health, independence, and community participation of people with spinal muscular atrophy (SMA) and others with disabilities and chronic conditions. Cure SMA, which represents children and adults with SMA in Wisconsin, Oregon, and across the country, is pleased to share the daily-living reality and perspective of the SMA community, who rely on Medicaid for caregiving and other essential healthcare and supports.

MEDICAID CAREGIVING: COMPLEX, SKILLED AND ESSENTIAL FOR SMA COMMUNITY
SMA is a rare, progressive neuromuscular disease that causes significant muscle weakness, often leading to full paralysis, affecting a person's ability to breathe, swallow, cough, and move. Due to debilitating SMA symptoms, most individuals with SMA rely on caregivers to assist with daily activities. A **Wisconsin woman with SMA** said, "*My caregivers assist with nearly every daily task—getting dressed, bathing, preparing meals, brushing my hair, transferring between my bed and wheelchair, using medical equipment to support my breathing, and positioning me safely throughout the day and night."* An **Oregon woman said her nephew with SMA** *"requires round-the-clock care to live."*

Daily functions include routine tasks such as dressing, grooming, and bathroom support and complex activities such as respiratory support, nutrition assistance, and safe patient lift. One **young professional with SMA**, for example, cannot clear mucus from his lungs on his own due to weak chest muscles. He said, *"If the mucus in my lungs is not cleared, it settles and can quickly turn into pneumonia — something I was hospitalized for repeatedly as a child, before I had consistent, well-trained caregivers."* His health would be compromised without the daily support of a trained caregiver to perform a precise, manual cough-assist technique, applying exactly the right pressure in exactly the right place to prevent pneumonia or injury, which can occur if in the wrong spot or with too much pressure.

Medicaid is the primary funder of caregiving and other long-term services and supports for individuals with SMA and others with significant disabilities and chronic conditions.[i] Before HCBS waivers existed, the only alternative for individuals who required skilled care was a nursing home — a setting that is not only more costly but often leads to increased hospitalizations and reduced health outcomes, compared to care provided in the home and community.[ii] *"You go for hours without anyone attending to any of your needs. You are isolated and alone,"* a **woman with SMA** shared about her two years living in a nursing home before accessing community care.

MEDICAID ALLOWS PEOPLE WITH SMA TO WORK & CONTRIUTE TO COMMUNITIES
SMA affects physical ability, not cognitive ability. People with SMA are top students, entrepreneurs, parents, spouses, co-workers, board members, volunteers, and valued community members. But every one of those roles depends directly on access to reliable, skilled caregivers. Consider a **38-year-old adult with SMA** who works full-time from home, lives independently, and serves on the board of a national organization. He utilizes 42 hours of paid caregiving a week, roughly six hours a day, where a paid caregiver comes in for a three-hour morning shift to transfer him from his bed to his power wheelchair, use the bathroom, shower, dress, eat, and start his workday, and then a final three-hour shift in the evening to transition him out of his home workstation, use the bathroom, eat, run essential errands, and get dressed and transferred to his bed. This support allows him *to "work and be a taxpaying citizen."* Another **adult with SMA** said: *"Without caregivers, I would be confined to a nursing home, unable to be employed, never having attended school, and unable to be a spouse."*

MEDICAID CUTS & CHANGES CAN LIMIT NEEDED CAREGIVING HOURS & SUPPORT
Despite how essential Medicaid and its caregiving support are for people with SMA, most in the SMA community struggle to access the care they need to maintain their health, live independently, and work and contribute to their community. Based on a national survey, Cure SMA found that 86% of individuals with SMA struggle to find caregivers and 62% struggle to retain them for the Medicaid hours they are approved to receive, with nights and weekends being the hardest shifts to fill — even though the need for care does not end during these times.[iii] In addition, nearly 40% of individuals with SMA report receiving far fewer caregiving hours from their state than they need to live independently, and requests for additional hours are frequently denied.[iv]

The consequences of caregiving gaps include missing work, missing school, missing medical appointments, canceling community activities, and experiencing injury or hospitalization. Referring to the 38-year-old full-time worker with SMA, he does not have paid caregiving support from 9 a.m. to 6 p.m. and then again from 9 p.m. to 6 a.m. Due to severe muscle weakness and motor function loss, he cannot use the bathroom during the day on his own or reposition himself in bed at night. Current caregiving limits put him at real risk of dehydration, urinary infections, pressure sores, falls, and other serious problems. Cure SMA and the SMA community are especially concerned that Medicaid cuts or policy changes, while not intended to hurt people with SMA, could in fact result in additional cuts to hours and eligibility at the state level, as we are already experiencing due in part to H.R. 1 implementation.[v] For example, the SMA community in Ohio joined other advocates to defeat a recent state proposal that would have ended a vital Medicaid caregiving option used by many people with SMA.[vi] *"We have always had trouble finding nursing or caregivers that are not scared off by their needs,"* said a **mother of two adult children with SMA** who educated against the proposed cuts to paid family caregiving. Federal or state changes that reduce Medicaid caregiving support by even an hour or two for individuals with SMA could have serious health, independent living, and community participation consequences.

CURE SMA & SMA COMMUNITY REQUEST: PROTECT MEDICAID HOME CARE
While SMA is a devastating, complex medical condition, people with SMA are thriving and contributing to their communities because of access to Medicaid-funded caregiving and

medical equipment such as power wheelchairs and ventilators. Medicaid is vital for people with SMA. It is their lifeline to work, school, independent living, and community participation. Cure SMA and the SMA community urge this Committee to reject efforts to include Medicaid cuts or policy changes in reconciliation or other future legislation. Individuals with SMA already struggle to access the support they need to survive. Additional changes that lead to cuts in caregiving hours or other limits to essential support will make life harder for children and adults with SMA. As **one person with SMA** put it, *"Every day, every action, every dream, every simple task is blurred by SMA."* Cure SMA respectfully asks Congress to consider the health and everyday living needs of people with SMA as you consider policy changes. We ask that you don't unintentionally advance a policy that further blurs, impedes, or restricts the ability of people with SMA to take action, achieve their dreams, or perform simple tasks.

Thank you for considering the views of Cure SMA and the SMA community that we represent.

[i] Centers for Medicare and Medicaid Services: https://www.medicaid.gov/medicaid/long-term-services-supports
[ii] Community Living Policy Center HCBS Improves Outcomes While Reducing Costs: https://heller.brandeis.edu/community-living-policy/research-policy/publications/pdfs/briefs/hcbs-improve-outcomes-and-reduce-costs.pdf
[iii] Cure SMA Stuck Insite Caregiving Report: https://www.curesma.org/wp-content/uploads/2024/02/2024_Advocacy_StuckInside_FactSheet_V2.pdf
[iv] Cure SMA Stuck Insite Caregiving Report: https://www.curesma.org/wp-content/uploads/2024/02/2024_Advocacy_StuckInside_FactSheet_V2.pdf
[v] Georgetown University: https://ccf.georgetown.edu/2026/07/02/how-h-r-1-cuts-and-changes-to-medicaid-played-out-in-2026-state-legislative-sessions-part-2/
[vi] Statehouse News Bureau, Provision Banning Ohio Medicaid Payments to Family Caregivers Stripped from Anti-Fraud Bill: https://www.statenews.org/government-politics/2026-06-09/provision-banning-ohio-medicaid-payments-to-family-caregivers-stripped-from-anti-fraud-bill