MDA® | Muscular Dystrophy Association

June 3, 2026

The Honorable Brandon Gill, Chairman	The Honorable Lateefah Simon, Ranking Member
Task Force on Defending Constitutional-Rights & Exposing Institutional Abuses	Task Force on Defending Constitutional-Rights & Exposing Institutional Abuses
House Committee on Oversight & Government Reform	House Committee on Oversight & Government Reform
2157 Rayburn House Office Building	2157 Rayburn House Office Building
Washington, DC 20515	Washington, DC 20515

RE: Task Force on Defending Constitutional Rights and Exposing Institutional Abuses Hearing on 'Universal Basic Fraud: Vulnerabilities in Medicaid Waiver Programs'

Dear Chairman Gill and Ranking Member Simon,

In service to the neuromuscular disease community, the Muscular Dystrophy Association (MDA) writes to uplift the importance of home and community-based services in supporting the independence, self-determination, and community integration of people with disabilities, including those affected by neuromuscular diseases. We urge you to reject rhetoric that impugns the valuable work of paid and family caregivers and refrain from any action that could result in even further cuts to Medicaid.

MDA is the #1 voluntary health organization in the United States for people living with muscular dystrophy, ALS, and related neuromuscular diseases. For over 75 years, MDA has led the way in accelerating research, advancing care, and advocating for the support of our community. MDA's mission is to empower the people we serve to live longer, more independent lives.

While each disease varies in its progression, affected muscles, and symptoms, and every individual's journey with neuromuscular disease is unique, neuromuscular diseases generally cause muscle weakness, fatigue, and are progressive, meaning symptoms grow worse over time. Some neuromuscular diseases are present at birth, while others manifest in childhood or adulthood. Neuromuscular diseases are rare, with most caused by changes in one or more genes.

Over 40% of the neuromuscular disease community relies on Medicaid for access to services and supports that enable them to safely live at home and thrive in their own communities, as opposed to expensive and isolating institutional settings. For individuals living with a neuromuscular disease, home health and personal care services are a lifeline that make independent living possible. By supporting people with disabilities with daily living tasks, personal care attendants empower individuals affected by neuromuscular diseases to contribute to their communities and remain close to their loved ones. Home and community-based services are not just a winning solution for individuals affected by neuromuscular diseases; they also save taxpayer dollars. According to a brief from the Community Living Policy Center at the Lurie Institute for Disability Policy at Brandeis University, in 2023, the average annual Medicaid long-term support services expenditures were $17,298 per person for individuals receiving home care and $54,462 for individuals in institutional settings.[1] Beyond good economic sense, community integration is a right protected by federal law and the U.S. Supreme Court, which found in *Olmstead v. LC* that unjustified segregation of people with disabilities is disability discrimination in violation of Title II of the Americans with Disabilities Act.[2]

While it may be true that spending on home and community-based services has risen, that growth can be attributed to intentional policy decisions intended to expand access and enrollment to these services that enable people with disabilities to age in their communities by rebalancing funding away from institutions. These policy decisions have led to fewer individuals being required to enter institutional settings for care, which is significantly more expensive for both families and the state.

We respectfully reject the harmful narrative[3] that family caregiving is rife with fraud. Family caregivers are vital to the lives of the neuromuscular disease community, managing complex tasks in neuromuscular care and filling major gaps left by insurance and decades of underinvestment in the direct care workforce. Reimbursement for these services *is* and must remain allowable under the Medicaid statute.[4] Family caregivers provide these services at the cost of their own physical health, time, and at a rate, as noted above, cheaper than that provided by institutions. Many family caregivers are forced to leave the workforce in order to provide this care. When that happens, Medicaid reimbursement is key in helping families remain afloat financially. Congress should look to strengthen these supports that keep the care ecosystem from collapsing.

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[1] Carpenter, A., Stepanczuk, C., Murray, C., & Wysocki, A. (2025). Trends in users and expenditures for Home and Community-Based Services as a share of total Medicaid Long-Term Services and Supports users and expenditures, 2023. Mathematica for Centers for Medicare and Medicaid (CMS). https://www.medicaid.gov/medicaid/long-term-services-supports/downloads/ltss-rebalancingbrief-2023.pdf. *See also,* Caldwell *et al, Community Living Policy Center* Home and Community-Based Services Improve Outcomes While Reducing Costs April 2026. https://heller.brandeis.edu/community-living-policy/research-policy/publications/pdfs/briefs/hcbs-improve-outcomes-and-reduce-costs.pdf

[2] https://archive.ada.gov/olmstead/olmstead_about.htm

[3] *See, Para* 4. https://oversight.house.gov/wp-content/uploads/2026/05/Ltr-to-Ohio-Dept-of-Medicaid.pdf

[4] *See generally, Social Security Act* Sec.1915

For people affected by neuromuscular diseases, the shift away from institutions and towards community care is deeply meaningful. It respects their autonomy by centering their decision-making in their own lives, and empowers them to achieve their personal goals. Given the focus of today's hearing, we are uplifting the stories of two Ohioans affected by neuromuscular disease to share how the state's home and community-based services improve their lives:

Shelly Johnson, an MDA advocate living with muscular dystrophy in Columbus, shared in an April 28, 2025 op-ed in the Ohio Capital Journal:[5]

> *"Many think Medicaid is simply government-subsidized health insurance, but for me, and millions of others like me, it is so much more. It allows me to live independently in a home that I own. It pays for modifications like a ramp and roll-in shower that make life's routines easier. Most importantly, Medicaid pays the wages of my caregivers who support my personal care needs and household tasks. As a 59-year-old, it enables me to stay employed, leave the house, and live a fulfilling life. Without it, these things would be impossible because I would be stuck in bed with no one to care for me. For those of us living with neuromuscular diseases, Medicaid allows us to plan for long-term care.*
> *If Medicaid suffers funding cuts, the consequences will be significant. We will likely face delayed treatments, be unable to afford life-saving medication, and have increased difficulty affording the homecare assistance that we need to be healthy and fulfilled. Medicaid is a pathway to better health outcomes, financial stability, and an overall higher quality of life. Preexisting health care issues, like lengthy home care waitlists, nursing shortages, and hospital closures are likely to follow as well, compounding the negative impacts. Affordable and adequate health care is not a luxury; it's a necessity."*

Shelly's life has been disrupted by Ohio's current 6-month hiring moratorium for Medicaid independent care providers. This month, she shared with MDA that she cannot hire anyone new to care for her until the moratorium is lifted. She prays that no one currently working for her gets sick, starts a family, or leaves during that time, as there will be no one to fill the gap. These restrictions impact access to care while doing nothing to address fraud.

Similarly, Bryce Madsen, an MDA advocate living with spinal muscular atrophy (SMA) in Dayton, shared in a 2025 op-ed following last year's vote to pass the largest cuts to Medicaid in history:[6]

> *"Living with SMA presents unique challenges, but my day starts the same as everyone else's. Everything just looks a little different. I wake up, read some news and begin my morning routine that my Don, my caregiver, helps me to do. Medicaid has enabled me to keep Don employed, and he has given more than a helping hand and increased mobility. He gives me independence and hope. Before I had a caregiver, most of my summers were spent taking my wheelchair around the same neighborhood path, and that would be my only outing for the day. With Don, I go grocery shopping, find fulfillment in work, spend*

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[5] https://ohiocapitaljournal.com/2025/04/28/medicaid-enables-fulfilling-livelihoods-in-ohio-and-across-america/
[6] https://www.daytondailynews.com/local/voices-congress-cuts-medicaid-but-the-fight-isn-t-over/article_cdfad28e-a417-510e-bb2e-b591a98e15d3.html

> *more time with friends, and truly experience what life has to offer – in large part, thanks to Medicaid.*
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> *Medicaid gives me the freedom to live my life. It's far more than insurance. It gives me the ability to interact with the world around me, to find purpose in work, and to thrive in my community. Without Medicaid, my independence will be uncertain. I may not be able to go to appointments, get out of bed, or put a shirt on in the morning. I already budget meticulously because I can only physically work so many hours, and I can't afford to work any fewer hours.*
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> *I need my job to pay for my housing, groceries, and bills. It's because I have a caregiver funded by Medicaid that I can work at a job I love. I can spend time with loved ones and fully embrace each day because he can transport me to where I need to go. Without Don, I would be trapped inside an apartment I can no longer afford.*
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> *Medicaid cuts will have severe impacts on the millions of people like me who rely on this program to be productive. The government encourages everyone to contribute to society and to experience the full freedom of the American Dream that our country has been built upon. If we cannot get to our jobs, our friends, or our lives because we can't afford to leave the house, what independence is left for us? Medicaid is the sole protector of my American freedom."*

While MDA supports holding fraudsters accountable across health insurance programs, efforts to fight fraud must be precise and collaborative with the disability community and not used as a pretext for cutting the services that support independence and community living for people with disabilities. It is important to note that there are already strong guardrails in place around home and community-based services, including institutional level of care standards, lengthy approval processes, electronic visit verification, and cost neutrality requirements. Further, there are mechanisms such as actions taken by Attorneys General and the Office of the Inspector General, q*ui tam* proceedings, provider screenings, and data analytics, which enable governments to identify bad actors without impacting services.[7]

We urge the Task Force and the broader Committee to reject framing of home and community-based services as inherently suspicious, and to consider the success of these services in furthering the American dream for individuals with serious health needs, including those living with neuromuscular conditions. Additionally, we urge the Task Force to consider the outcome of further reductions to home and community-based services: significantly higher spending on institutions.

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[7] https://d3dkdvqff0zqx.cloudfront.net/groups/mda/attachments/3.17.2026%20MDA%20statement%20EC%20oversight%20Medicaid%203-16-25%20Final.pdf

Thank you for considering Shelly, Bryce, and others living with neuromuscular conditions in today's hearing. If you have questions regarding MDA's comments, please contact Shannon Wood, Director of Disability Policy at swood@mdausa.org.

Sincerely,

Shannon Wood

Shannon Wood
Director of Disability Policy
Muscular Dystrophy Association