MDA®
Muscular
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Association

December 2, 2025

Chairman Rick Scott
Senate Special Committee on Aging
628 Hart Senate Office Building
Washington, DC 20515

Ranking Member Kristen Gillibrand
Senate Special Committee on Aging
628 Hart Senate Office Building
Washington, DC 20515

Dear Chairman Scott & Ranking Member Gillibrand,

On behalf of the Muscular Dystrophy Association (MDA) and in service to the neuromuscular disease community, thank you for the opportunity to submit an organizational statement on the importance of programs which support community living for people with disabilities in response to the full committee hearing titled: “Aging in Place: The Impact of Community during the Holidays”.

For 75 years, MDA has led the way in accelerating research, advancing care, and advocating for families in the neuromuscular community. Our mission is to empower people affected by muscular dystrophy, ALS, and hundreds of other neuromuscular conditions to live longer, more independent lives, and the programs described in this statement – notably, home and community-based services (HCBS) and Centers for Independent Living (CILs) – are key to achieving that mission.

*HCBS & the Neuromuscular Community*

Neuromuscular diseases are complex, rare, genetic diseases defined by muscle weakening and often leading to some level of disability. While each disease varies in its progression, affected muscles, and symptoms, and each individual’s journey with neuromuscular disease is unique, many rely on HCBS funded by Medicaid in order to live independently and thrive in their communities. These services support people with disabilities in daily tasks including bathing, getting dressed, taking medications, preparing meals, shopping for groceries, and more. As Bryce in Ohio shared with the Dayton Daily News[1] this year:

*“Living with spinal muscular atrophy (SMA) presents unique challenges, but my day starts the same as everyone else’s. I wake up, read some news and begin my morning routine that*

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[1] https://www.daytondailynews.com/local/voices-congress-cuts-medicaid-but-the-fight-isnt-over/XKS2QI4YQZG2HBVLCOYOHMCXQE/

*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 was my only outing for the day. With Don, I go grocery shopping, find fulfillment in work, spend more time with friends, and truly experience what life has to offer – in large part, thanks to Medicaid. 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."*

Despite the important role of HCBS in enabling independent living, these services can be extraordinarily difficult to access due to decades of underinvestment. HCBS is not a mandatory benefit under Medicaid, despite being the primary payer for 60% of home and community-based services. This can lead to lack of adequate funding that in turn leads to long waiting lists for services, and ultimately, unnecessary institutionalization, an affront to the promise of *Olmstead*, which held that segregation of people with disabilities is discrimination, in violation of Title II of the Americans with Disabilities Act.

It is important to uplift the key role of Medicaid in enabling community living for the neuromuscular disease community, especially given the devastating cuts the program saw this summer. As MDA repeatedly warned during the budget reconciliation process, the cuts to Medicaid in the One Big Beautiful Bill Act are likely to lead to further reductions in HCBS and longer waiting periods for life-enabling services. These cuts, and in particular, the restrictions on provider taxes, will have dire implications on access by altering Medicaid financing in a manner that places serious pressure on states, which will be forced to reduce coverage or cut payment rates to home care workers and direct support professionals. This will negatively impact the neuromuscular community's ability to receive the care they need to thrive. As Bryce continued, without Medicaid-funded HCBS, his independence is uncertain:

*"I may not be able to get 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. I need my job to pay for my housing, groceries, and bills. It's because I have a caregiver funded through 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 where I need to go. Without Don, I would be trapped inside an apartment I can no longer afford."*

Bryce is not the only member of the neuromuscular community to uplift the importance of HCBS in light of Medicaid cuts, now realized. Shelley, another Ohioan, shared in the Ohio Capital Journal[2] this year:

*"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 makes 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.*

*Any cuts or barriers to enrollment will have cascading impacts across the United States, putting the health and independence of Medicaid beneficiaries at risk. For those of us living with neuromuscular diseases, Medicaid allows us to pay 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 medications, and have increased difficulty affording the homecare assistance we need to be healthy and fulfilled."*

Eric, an attorney in West Virginia living with SMA type 2, wrote in the Charleston Gazette-Mail[3]:

*"Medicaid's HCBS waiver programs are what make independent living possible for people like me. These programs, like West Virginia's Aged and Disabled Waiver (ADW), allow individuals to remain in their homes with attendant care, rather than being institutionalized. I've used these services not to survive but to contribute. To work. To live.*

*I was fortunate to have parents who could care for me until I went to college. I developed a plan, depending on my health, to find a job that I could physically do to increase my independence (although some might argue that being an attorney is my biggest disability). State waiver programs gave me a shot, one that lets people like me potentially contribute as part of the taxpaying workforce.*

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[2] Medicaid enables fulfilling livelihoods in Ohio and across America • Ohio Capital Journal

[3] https://www.wvgazettemail.com/opinion/op_ed_commentaries/eric-arnold-look-both-ways-before-crossing-out-medicaid-opinion/article_2f42dfc4-fa2a-4503-b62b-f77762cd79e6.html

*When waiver programs get slashed, families will be forced to adjust their jobs – or leave them entirely – to provide the care no longer funded. The cost of private, in-home attendant care is staggering, especially for a workforce already gutted by the economy and the opioid crisis. Or they'll be left with no choice but to place their loved one in a care facility. Those will quickly become oversaturated, driving demand for help in jobs like certified nurse aides, orderlies, and home health techs – roles that already struggle to recruit without substantial pay increases. And those increases? They'll either cut into a family's budget, or the state's. And here's what every West Virginian already knows: when faced with that choice, most families will walk away from taxable work to become unpaid caregivers."*

MDA supports policies that strengthen access to HCBS and eliminate waitlists through increased Medicaid and grant funding, as well as increase the availability and quality of the direct care provider workforce. At a minimum, MDA urges members of the Senate Special Committee on Aging to support the HCBS Relief Act (S. 2076/H.R. 2049), which would increase the federal Medical Assistance Percentage (FMAP) by 10 points for HCBS provided in FY26 and FY27 for the purposes of enhancing, expanding, or strengthening HCBS. Examples of permitted activities include increasing reimbursement rates for home health aides; providing paid sick days and medical leave; providing HCBS to those on waiting lists; and to recruit new home health workers.

*Centers for Independent Living (CILs) & the Neuromuscular Community*

In addition to HCBS, Centers for Independent Living, or CILs, are essential to achieving MDA's mission of empowering the neuromuscular community to live longer, more independent lives. These centers, a product of the disability rights movement, uniquely center the agency of people with disabilities by being operated and staffed by people with disabilities themselves, focused on community integration, advocacy, and peer support. Importantly, CILs are centered in the community, and help individuals live independently within their own homes (as opposed to providing residential or institutional care) by connecting the community with skills, transition services, advocacy, and peer support.

MDA thanks the Committee for convening this hearing and uplifting the important role of HCBS and CILs in enabling community living for people with disabilities. We urge the Committee to continue to shine a light on how we make these services more comprehensive and accessible for all. In addition, we urge the Committee to study and strengthen the many other programs that enable individuals affected by neuromuscular conditions to fully participate in the community, including: educational supports provided through the IDEA; housing programs that serve people with disabilities; legal assistance through state protection and advocacy systems; vocational rehabilitation services that open doors to employment; and other programs powering independence for individuals with disabilities.

If you have questions regarding MDA's comments, please contact Shannon Wood, Director of Disability Policy at swood@mdausa.org.

Sincerely,

Shannon Wood
Director of Disability Policy
Muscular Dystrophy Association