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ALS United Greater New York
ALS Northwest
I AM ALS
ALS United Georgia
ALS United

June 16, 2025

The Honorable John Thune Majority Leader U.S. Senate Washington, DC 20510	The Honorable Chuck Schumer Minority Leader U.S. Senate Washington, DC 20510

Re: Impact of the One Big Beautiful Bill Act on the Neuromuscular Disease Community

Dear Majority Leader Thune and Minority Leader Schumer,

On behalf of the 41 undersigned organizations serving individuals affected by neuromuscular conditions, we urge you to reject cuts to affordable health insurance coverage and services in the reconciliation legislation and instead focus on opportunities to strengthen access to affordable care for the estimated 300,000 Americans affected by neuromuscular diseases.

Neuromuscular diseases, all of which are rare diseases, feature progressive muscle weakening. While each disease varies in its progression, affected muscles, and symptoms, and every individual's journey with neuromuscular disease is unique, all deserve access to comprehensive neuromuscular care. Nearly 40% of the neuromuscular community relies on Medicaid[1] for key services, including home care, specialists, therapies, equipment, and more.

The proposals passed by the House and under consideration in the Senate amount to unprecedented cuts to Medicaid and will reduce access to affordable health coverage for millions of Americans. Our organizations are seriously concerned that this legislation would raise out-of-pocket costs, impose costly administrative hurdles, and seriously reduce state Medicaid funding, jeopardizing timely access to necessary care. For the neuromuscular community, these delays risk irreversible disease progression.

Raising Out-of-Pocket Costs

The proposals under consideration will raise costs for the neuromuscular disease community in several harmful ways, including mandatory cost sharing at up to $35 per service for those qualifying for Medicaid based on income between $15,650 and $21,597 (in 2025). While many within the neuromuscular community qualify for Medicaid due to disability, for others, their disease may have yet to progress to the extent to qualify as medically frail under rigid definitions in the legislation. Neuromuscular diseases feature progressive and irreversible muscle weakening and damage, but for certain diseases, the condition may not be consistently severe enough (at least not yet), requiring Medicaid qualification via income. Others may be struggling to obtain a definitive neuromuscular diagnosis, hindering their ability to qualify through a serious or complex medical condition.

For this population already managing complex conditions, paying up to $35 more per service would place care financially out of reach, likely resulting in families foregoing needed care or coverage altogether. Research indicates that in states with cost sharing, such policies have led to reduced coverage, lowered access, and increased financial burden, with enrollees experiencing harsh consequences for nonpayment and confusion over premium policies[2]. Further raising costs, the legislation limits how far back Medicaid programs are allowed to reimburse for covered expenses from three months to one month. This will raise costs incurred by new enrollees by disallowing Medicaid programs from covering services during this period. As this bill makes Medicaid more costly, it also makes accessing private insurance more expensive as well by failing to extend the Advanced-Premium Tax Credits (APTCs), critical to the ability of millions of Americans to afford premiums in private insurance plans. Without the APTCs, the CBO estimates that at least five million fewer Americans will be able to afford their premiums and thus go uninsured.

Imposing Administrative Barriers

The legislation places undue burdens on access to care for the neuromuscular community by making it highly likely that someone will lose coverage due to no fault of their own, but for

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[1] https://www.mda.org/science/movr

[2] https://www.kff.org/medicaid/issue-brief/understanding-the-impact-of-medicaid-premiums-cost-sharing-updated-evidence-from-the-literature-and-section-1115-waivers/

procedural reasons. By instituting work (or "community engagement") requirements, this bill is poised to remove millions from Medicaid coverage for solely administrative reasons. While the bill intends to carve out those with disabilities, such carve-outs have failed in practice, as seen in state experiments with work requirements in Georgia and Arkansas. In Georgia, less than 7,000 of an eligible 345,000 people received coverage after 20 months[3]. In Arkansas, an estimated 95% of those caught up by the work requirement were working or otherwise should have met an exception to the requirement, yet nearly a quarter lost coverage in the seven months before the program was halted by federal courts.

Through these mandates, the bill inevitably raises barriers for the neuromuscular community to maintain their benefits by requiring repeated eligibility checks, fostering an environment where individuals are highly likely to lose coverage for procedural reasons, even when they are eligible for benefits.

Limiting State Funding Mechanisms

Other proposals in the package risk additional strains on state budgets, including the freeze on current provider tax rates and moratorium on any new provider taxes, one of the few mechanisms available to states to fund their share of Medicaid costs. Taking away this mechanism, while simultaneously reducing federal funds to states for Medicaid, risks cuts to critical services in neuromuscular care, especially in rural areas that already struggle to meet community need on thin margins. As a February blog from the Georgetown Center for Children and Families pointed out, provider taxes are critical to helping states weather times of economic downturn, with research finding that state use of provider taxes increases during and after recessions, when more rely on Medicaid for care[4]. Protecting states' abilities to use provider taxes as a funding mechanism during budget shortfalls is key to preserving program integrity in future recessions, pandemics, or other public health crises. In addition, provider taxes are an important element of ensuring access where care can be difficult to find, as the revenues raised are commonly reinvested into raising the reimbursement rates for a variety of safety-net providers, including rural hospitals and home health care providers.

Medicaid, and the provider taxes that pay for it, is vital for many in the community to live independently. Individuals affected by neuromuscular diseases depend on Medicaid for access to home and community-based services that empower them to live and work in their own communities, avoiding unnecessary, costly institutionalization. Medicaid is the primary payer of all home care, covering nearly 70 percent of home and community-based services[5]. Medicaid cuts, particularly any provider tax freeze, will have dire implications on access by altering financing in a manner that places serious pressure on states, which will be forced to raise taxes, reduce coverage, or cut payment rates to home care workers and other providers. Any of these outcomes will negatively impact the neuromuscular community, with states already struggling to meet demand for care. In 2024, the average time spent on a waiting list for home and

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[3] https://www.kff.org/medicaid/issue-brief/5-key-facts-about-medicaid-work-requirements/
[4] https://ccf.georgetown.edu/2025/02/04/medicaid-provider-taxes-a-critical-source-of-medicaid-funding-for-states/
[5] https://www.kff.org/medicaid/issue-brief/what-is-medicaid-home-care-hcbs/

community-based services was 40 months[6], delays likely to grow longer should the proposals be enacted.

Conclusion

Nonpartisan estimates from the Congressional Budget Office show that the changes to Medicaid and the ACA marketplace included in the legislation passed by the House and under consideration in the Senate could result in as many as 16 million people losing their health coverage over the next 10 years[7]. Given the neuromuscular community's high utilization of Medicaid, those at risk of losing coverage would likely include people living with neuromuscular diseases at the heart of the missions of our organizations. On top of the devastating cuts to Medicaid and the ACA, this legislation could force upwards of $500 billion in cuts to Medicare over 10 years, limiting care for the neuromuscular community on Medicare, especially those living with amyotrophic lateral sclerosis (ALS) or other Medicare-qualifying neuromuscular diagnoses.

While some have claimed that people with disabilities or serious health conditions, such as the neuromuscular conditions our organizations represent, will be protected from such cuts, we know members of the neuromuscular disease community will inevitably fall through the cracks. With access to necessary care and services at risk, the stakes could not be higher for families affected by neuromuscular conditions.

We urge the Senate to consider the perspectives of the neuromuscular community and reject cuts to care in the reconciliation package. If our collective expertise on the experience of individuals affected by neuromuscular conditions can serve as a resource to you in understanding the potential impacts of policies on our communities, please contact Shannon Wood, Director of Disability Policy, Muscular Dystrophy Association, at swood@mdausa.org.

Sincerely,

All Wheels Up
ALS Association
ALS Network
ALS New Mexico
ALS Northwest
ALS United
ALS United Connecticut
ALS United Georgia
ALS United Greater Chicago
ALS United Greater New York
ALS United Mid-Atlantic
ALS United North Carolina

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[6] https://www.kff.org/medicaid/issue-brief/a-look-at-waiting-lists-for-medicaid-home-and-community-based-services-from-2016-to-2024/#:~:text=How%20long%20do%20people%20on,from%2036%20months%20in%202023.

[7] https://democrats-energycommerce.house.gov/sites/evo-subsites/democrats-energycommerce.house.gov/files/evo-media-document/cbo-emails-re-e%26c-reconcilation-scores-may-11%2C-2025.pdf

ALS United Rocky Mountain
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CMTA (Charcot-Marie-Tooth Association)
Coalition to Cure Calpain 3
Cure CMD
Cure LGMD2i Foundation
Cure VCP Disease
Friedreich’s Ataxia Research Alliance (FARA)
FSHD Society
Genetic ALS & FTD: End the Legacy
Hereditary Neuropathy Foundation
I AM ALS
Kennedy's Disease Association
Kindness Over Muscular Dystrophy
Les Turner ALS Foundation
LGMD Awareness Foundation
LGMD2D Foundation
Little Hercules Foundation
Live Like Lou Foundation
Muscular Dystrophy Association
Myasthenia Gravis Association
The Myositis Association (TMA)
Myositis Support & Understanding
Myotonic Dystrophy Foundation
National Ataxia Foundation
Parent Project Muscular Dystrophy
Speak Foundation
United Mitochondrial Disease Foundation