July 21, 2026

SUBMITTED ELECTRONICALLY

The Honorable Robert Kennedy
Secretary
Department of Health and Human Services
200 Independence Avenue SW
Washington, DC 20201

The Honorable Mehmet Oz
Administrator
Centers for Medicare and Medicaid Services
Department of Health and Human Services
7500 Security Boulevard
Baltimore, MD 21244

Re: Notice of Proposed Rulemaking, Medicaid Program; Medicaid Managed Care State Directed Payments and Medicaid Fee-for-Service Targeted Medicaid Practitioner Payments

Dear Secretary Kennedy and Administrator Oz:

Thank you for the opportunity to submit comments on the Notice of Proposed Rulemaking (NPRM) on Medicaid Managed Care State Directed Payments and Medicaid Fee-for-Service Targeted Medicaid Practitioner Payments ("SDP NPRM").

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.

From the outset, we echo the comments and concerns of our colleagues at the Consortium for Constituents with Disabilities and the Partnership to Protect Coverage, but we wanted to highlight our particular concerns surrounding implications for Home and Community Based Services (HCBS) and its impact to the neuromuscular disease community (NMD). The limitations set out in PL 119-21 will lead to harmful funding losses for states – an estimated $149 billion over ten years in reduced federal funding, according to the Congressional Budget Office (CBO).[1] However, the SDP NPRM goes far beyond the limitations established by Congress with

[1] Congressional Budget Office, "Estimated Budgetary Effects of Public Law 119-21, to Provide for Reconciliation Pursuant to Title II of H. Con. Res. 14, Relative to CBO's January 2025 Baseline," (July 21, 2025) available at https://www.cbo.gov/publication/61570.

no adequate legal justification, and will lead to massive additional funding losses which will harm access to care for those in the neuromuscular disease community, particularly for those that rely on home and community based services, for care. CMS has estimated that its regulation will reduce federal funding for states by $515 billion over ten years– well over three times the CBO estimate based on the actual letter of the law.[2] While PL 119-21 does apply new payment limits to certain providers, the NPRM goes much farther than the law by assessing limitations on *all* types of providers. The Medicaid and CHIP Payment and Access Commission estimated that 10% SDPs enhance payments for Home and Community Based Services (HCBS) providers, 11% for physicians.[3]

HCBS is vital for members of the NMD community to live their daily lives with their communities which is of particular importance given the upcoming community engagement requirements for Medicaid through which many community members receive HCBS.[4] Many in the community are only able to work *because* of the support they receive via HCBS, so limiting those services in this way will create an incredibly harmful feedback loop. Further, given the caregiving crises that we find ourselves in across professional and family caregiving it is vitally important to ensure that HCBS and other services are not impeded. It can take years for those living with NMDs to get off wait lists for HCBS, and there are massive workforce shortages across the field of HCBS.[5] This rule will serve to exacerbate that shortage. Under the law Congress clearly intended to protect these providers and their patients who rely on these enhancements to provide access to care. For the forgoing reasons, CMS should revise the rule to bring it into compliance with the law.

We are grateful for the opportunity to comment on the SDP NPRM. For questions regarding MDA or the above comments, please contact me at jcartner@mdausa.org.

Sincerely,

[2] This figure of $515 billion includes $510.1 billion from SDP policy plus $5.34 billion of impacts on "other policy," including the fee-for-service limits proposed in the rule.

[3] Medicaid and CHIP Payment and Access Commission, "Directed Payments in Medicaid Managed Care" (October 2024). available at https://www.macpac.gov/publication/directed-payments-in-medicaid-managed-care.

[4] Mohamed et al. "Medicaid Home Care in 2025" (Jan 5th 2025) available at https://www.kff.org/medicaid/medicaid-home-care-hcbs-in-2025/

[5] Johns Hopkins, "What is the Caregiver Crisis" (July, 28th 2025). Available at https://publichealth.jhu.edu/2025/what-is-the-caregiver-crisis

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