



January 20, 2026

U.S. Department of Health and Human Services  
Office for Civil Rights  
Hubert H. Humphrey Building, Room 509F  
200 Independence Avenue SW, Washington, DC 20201

*Submitted electronically*

**RE: RIN 0945-AA27**

**Nondiscrimination on the Basis of Disability in Programs or Activities Receiving Federal Financial Assistance**

In service of the neuromuscular disease (NMD) patient community, the Muscular Dystrophy Association (MDA) writes to express our strong opposition to the U.S. Department of Health and Human Services' (HHS) proposed rule "Nondiscrimination on the Basis of Disability in Programs or Activities Receiving Federal Financial Assistance." Section 504 ("Sec. 504") is a foundational piece of the disability rights framework prohibiting discrimination on the basis of disability in programs and activities that receive Federal financial assistance and in programs and activities conducted by any Federal agency.<sup>1</sup> As such, we urge HHS not to repeal the expansion of nondiscrimination updates in the 2024 Final Rule (hereinafter 2024 Rule) given its sweeping impact on the neuromuscular disease community that we serve.

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.

**The importance of the Updates to Section 504:**

Concerningly, an alternative HHS considers is a full repeal of the 2024 Rule.<sup>2</sup> The 2024 Rule is full of incredibly important updates for the NMD community across many areas. As we noted in our comments at the time,<sup>3</sup> the 2024 Rule clarified prohibitions on discrimination in medical decision-making, updated standards for diagnostic medical equipment, assessed opportunities to bolster enforcement mechanisms, expanded opportunities for participation in clinical research, banned the use of value assessments, and updated the integration mandate as laid out in

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<sup>1</sup> 29 U.S.C. 794

<sup>2</sup> <https://www.federalregister.gov/documents/2025/12/19/2025-23484/nondiscrimination-on-the-basis-of-disability-in-programs-or-activities-receiving-federal-financial#addresses>

<sup>3</sup> <https://d3dkdvqff0zqx.cloudfront.net/groups/mda/attachments/11.13.23%20MDA%20Comments%20to%20HHS%20on%20Sec.%20504%20Update.pdf>

Olmstead v. L. C., 527 U.S. 581 (1999). Each of these updates, and many others, are of monumental importance to both the NMD community, and the disability community generally. These updates allow those with disabilities to participate much more broadly in public life and should be protected as robustly as possible. This especially considering that, by the Department's own admission, the updates HHS is considering addressing as they relate to gender dysphoria are in the preamble and therefore is not legally enforceable.<sup>4</sup> HHS has also already made its position as to the lack of enforceability clear in the federal record.<sup>5</sup> While we disagree with that characterization from an access perspective, (see below), at a minimum there is no need to disturb Sec. 504 broadly considering the vital importance of the underlying rule and the non-binding nature of the issue under consideration.

### **The Precedent contemplated by the NPRM:**

As a foundational matter, MDA's position is that all members of our community should receive the care they need.<sup>6</sup> HHS's contemplation of the excising gender dysphoria from consideration as a disability receiving protection under Sec. 504 sets a dangerous precedent to remove a class of individuals from consideration by a federal statute on the basis of disfavor of a treatment paradigm. Of note for the NMD community have been various efforts for recognition of therapies approved via the accelerated approval process particularly where gene therapies are concerned. If the federal government can excise a class of individuals from federal protection, what is to stop the government from continuing this slide on the basis of a lack of "sufficient" evidence to prove their status for protection. HHS should set aside its consideration of gender dysphoria as it applies to Sec. 504, particularly because, again, as HHS notes, the case most on point, albeit not federally binding, holds that gender dysphoria can apply to Sec. 504.<sup>7</sup>

Finally, it is also of concern that HHS seeks to start and stop its analysis of gender dysphoria as it applies to Sec. 504 with the DSM-3 rather than the DSM-5. This is of particular concern to the NMD community due to the fact that medical standards are constantly shifting for our community. Advancements are being made consistently and best practices are often updated. For HHS to assert that they must only use the medical knowledge that they had at any given time a rule is promulgated is of particular concern for evolving and progressive medical fields. Further, HHS' assertion that they must only use medical knowledge from the time of finalization is flawed both on the basis that the update which promulgated the rule at controversy *is* an example of HHS updating its standards based on shifting understanding of shifting medical and societal standards,<sup>8</sup> and flies in the face of other examples of administrative bodies empowered to

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<sup>4</sup> 2025-06127 (90 FR 15412) <https://www.federalregister.gov/documents/2025/04/11/2025-06127/nondiscrimination-on-the-basis-of-disability-in-programs-or-activities-receiving-federal-financial>

<sup>5</sup> *Id.*

<sup>6</sup> <https://d3dkdvqff0zqx.cloudfront.net/groups/mda/attachments/1.24.2025%20Kansas%20v.%20US%20AMICUS%20BRIEF%20FINAL.pdf>

<sup>7</sup> *Williams v. Kincaid*, 45 F.4th 759 (4th Cir. 2022), cert. denied, 600 U.S. (2023)

<sup>8</sup> <https://www.federalregister.gov/documents/2024/05/09/2024-09237/nondiscrimination-on-the-basis-of-disability-in-programs-or-activities-receiving-federal-financial>

modernizing their understanding of evolving standards.<sup>9</sup> In light of HHS' ability to reconsider evolving medical standards, they should at a minimum do so here, if not set aside this rulemaking entirely.

**Conclusion:**

We are grateful for the opportunity to comment on the Department of Health and Human Service's updates to Section 504 of the Rehabilitation Act. For questions regarding MDA or the above comments, please contact Joel Cartner, Director, Access Policy at [jcartner@mdausa.org](mailto:jcartner@mdausa.org).

Sincerely,



Joel Cartner, Esq.  
Director, Access Policy  
Muscular Dystrophy Association

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<sup>9</sup> OMB circular 119 <https://www.whitehouse.gov/wp-content/uploads/2017/11/Circular-119-1.pdf>. See also, Appropriate Use of Voluntary Consensus Standards in Premarket Submissions for Medical Devices Guidance for Industry and Food and Drug Administration Staff Document issued on September 14, 2018.

<https://www.fda.gov/media/71983/download>

MDA comments (HHS) proposed rule “Nondiscrimination on the Basis of Disability in Programs or Activities Receiving Federal Financial Assistance.” Page | 3