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November 6, 2023

Melanie Fontes Rainer  
Director, Office for Civil Rights  
Department of Health and Human Services  
Hubert H. Humphrey Building  
200 Independence Avenue, S.W.,  
Washington, DC 20201

**RE: Discrimination on the Basis of Disability in Health and Human Service Programs or Activities [HHS–OCR–2023–0013]**

Dear Director Fontes Rainer,

The American Academy of Neurology (AAN) is the world's largest neurology specialty society representing more than 40,000 neurologists, clinical neuroscience professionals, and students. The AAN is dedicated to promoting the highest quality patient-centered neurologic care. A neurologist is a doctor with specialized training in diagnosing, treating, and managing disorders of the brain and nervous system. These disorders affect one in six people and include conditions such as Alzheimer's disease, stroke, migraine, multiple sclerosis, concussion, Parkinson's disease, and epilepsy.

The AAN recognizes the historic nature of the proposed updates to protections for individuals with disabilities under Section 504 of the Rehabilitation Act and lauds the Department of Health and Human Services Office for Civil Rights (OCR) for taking action to ensure robust protections. The AAN is highly supportive of efforts to ensure equitable access to neurologic care across the lifespan and is committed to promoting the highest quality patient-centered neurologic care for everyone. Neurologists treat patients with a wide variety of disabilities that impact activities of daily living and work collaboratively with patients and their caregivers to ensure that care delivery is consistent with relevant ethical and practice guidelines, as well as patients' goals of care. Under Section 504, a disability means with respect to an individual: a physical or mental impairment that substantially limits one or more of the major life activities of such individual; having a record of such an impairment; or being regarded as having such an impairment.<sup>1</sup> The AAN notes that a substantial proportion of neurology patients meet this definition. We appreciate OCR's thoughtful consideration of the factors that impact care delivery for individuals with disabilities in developing this proposed rule.

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<sup>1</sup> 88 Fed. Reg. at 63459

## Medical Treatment

Noting persistent reports of discriminatory medical treatment, OCR proposes to clarify the existing general prohibition on discrimination against qualified individuals with disabilities in the context of medical treatment. Specifically, this proposed rule prohibits the use of discriminatory methods of administration, criteria, and protocols, including discrimination in the allocation of scarce healthcare resources. OCR identifies four critical topic areas for which the existing prohibition needs to be clarified: organ transplantation, life sustaining treatment, crisis standards of care, and participation in clinical research. While the AAN believes clarification of existing obligations is necessary to ensure equitable access to healthcare for individuals with disabilities, the AAN is concerned about the application and enforcement of this proposal, given the inherent complexity of delivering individualized, patient-centered neurologic care.

Under this proposal providers would be banned from the following:

- Denying or limiting medical treatment to a qualified individual with a disability when the denial is based on bias or stereotypes about a patient's disability; judgments that an individual will be a burden on others due to their disability, including, but not limited to, caregivers, family, or society; or a belief that the life of a person with a disability has a lesser value than that of a person without a disability, or that life with a disability is not worth living.
- Providing an individual with a disability different treatment than the professional would provide an individual without a disability seeking assistance with the same condition when there is nothing about the disability that impairs the effectiveness, or ease of administration of the treatment itself or has a medical effect on the condition to which the treatment is directed.
- Discriminating on the basis of disability in seeking consent for the decision to treat or to forego treatment by, for example, unduly pressuring a person with a disability or their authorized representative to conform to the treating professional's position.
- Conditioning access to treatment for a patient with a disability or their authorized representative agreeing to a particular advanced care planning decision when they would not implement or enforce such a requirement on a similarly situated nondisabled patient.

The AAN appreciates OCR's clarification that nothing in this proposal "requires the provision of medical treatment where the recipient has a legitimate, nondiscriminatory reason for denying or limiting that service or where the disability renders the individual not qualified for the treatment."<sup>2</sup> Although this clarification is helpful, the AAN is deeply concerned that these proposals may have unintended detrimental consequences on the delivery of care for neurologic patients receiving care for a variety of conditions that result in disability. Additionally, the AAN requests clarification regarding how providers are expected to document legitimate, nondiscriminatory reasons for denying or limiting a service. The AAN recommends that OCR issue guidance regarding how a provider is expected to do so, including in cases in which a medication is commonly prescribed off-label.

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<sup>2</sup> 88 Fed. Reg. at 63405

When considering comments in response to this proposed rule, the AAN urges OCR to account for the AAN's position statement on *Ethical Perspectives on Costly Drugs and Health Care* noting that neurologists are "ethically justified in setting limits and denying requests for treatments that are not medically indicated or do not provide meaningful medical benefit."<sup>3</sup> The AAN firmly believes that while strong protections for patients with disabilities are critically necessary, provider decision-making needs to be respected and supported. By definition, all end-of-life care involves addressing disability and it is unwise for OCR to be overly prescriptive in implementing this rulemaking. While OCR is justified in ensuring that scarce healthcare resources are not allocated in a discriminatory manner, determining the most appropriate allocation is highly complex. The AAN firmly believes that efforts to respect patient autonomy are critically necessary and important, but physicians should not feel undue pressure to yield when a particular course of treatment is futile or otherwise clinically inappropriate.

The AAN believes that fears of reprisal may impact care delivery, especially in relation to end-of-life decision making and in critical care delivery. Even if a clinician has a medically sound, non-discriminatory rationale for a particular recommended course of treatment, it is possible that a patient or a caregiver may interpret that recommendation as discriminatory. This risk is particularly acute if family members disagree on the treatment that most aligns with the patient's care goals, in cases in which the patient's clinical status has changed and the patient is not able to communicate their preferences.

As an illustrative example, an AAN member recently cared for a patient who was hospitalized for a stroke and received a plan of care involving rehabilitation. While the patient was waiting to go to rehabilitation, the patient suffered a second stroke on the other side of the brain during the same hospitalization. In stroke, patients' baseline levels of function impact their eligibility for treatment, which rightfully plays a major role in care delivery. After the second stroke, the patient's new baseline changed significantly, and she was not eligible for acute stroke treatment because of this change. The option of hospice care was discussed with the family because continuing aggressive care did not seem to be within the patient's goals of care and could result in patient harm. However, the family was divided regarding next steps, and some family members inquired about pursuing additional aggressive care in spite of the patient's new baseline, which would have made further treatment more harmful than beneficial.

AAN members fear that in similar scenarios, absent further clarification of this proposed rule and subsequent release of relevant guidance, that they are likely to face greater risk of litigation or some other form of investigation to prove that a particular recommended course of treatment is not discriminatory. The AAN is deeply concerned that providers may be incentivized towards practicing defensive medicine and that disabled patients may, in some cases, receive less appropriate care that may not meet the patient's own care goals.

### Additional Areas for Consideration

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<sup>3</sup> Tsou, Amy Y et al. "Ethical Perspectives on Costly Drugs and Health Care: AAN Position Statement." *Neurology* vol. 97,14 (2021): 685-692. doi:10.1212/WNL.00000000000012571

While the AAN appreciates OCR's interest in ensuring that medical treatment is not delivered in a discriminatory manner, the AAN urges the agency to consider ways in which other entities covered under Section 504 may be operating in a discriminatory manner. The AAN notes that many impacted payers do not cover CPT codes that allow equitable care to be delivered to patients with disabilities. Furthermore, inconsistent coverage of telehealth services poses a significant challenge for patients with disabilities.

### Conclusion

The AAN appreciates the opportunity to provide comments to OCR on its proposed expansion of protections for individuals with disabilities. The AAN urges OCR to consider our comments and the need to ensure that provider decision-making isn't inappropriately impacted by fear of litigation. Please contact Matt Kerschner, the AAN's Director, Regulatory Affairs and Policy at [mkerschner@aan.com](mailto:mkerschner@aan.com) with any questions or requests for additional information.

Sincerely,

A handwritten signature in black ink that reads "Carlayne E. Jackson". The signature is written in a cursive, flowing style.

Carlayne E. Jackson, MD, FAAN  
President, American Academy of Neurology