DeafHealth.

November 10, 2023

U.S. Department of Health and Human Services
Office for Civil Rights
Attention: 504 NPRM (RIN 0945-AA15)
Hubert H. Humphrey Building
200 Independence Avenue SW
Washington, DC 20201

Filed electronically at http://www.regulations.gov

Re: 504 NPRM (RIN 0945-AA15), Discrimination on the Basis of Disability in Health and Human Service Programs or Activities

Dear Secretary Becerra and Director Fontes Rainer,

Thank you for the opportunity to provide comments on the Office for Civil Rights (OCR)'s proposed rulemaking, "Discrimination on the Basis of Disability in Health and Human Service Programs or Activities ("Proposed Rule")."[1] DeafHealth (www.deafhealthaccess.org) is the patient advocacy division of Communication Service for the Deaf, Inc. ("CSD"), a pioneering non-profit organization that has been championing Deaf rights since 1975.

DeafHealth is a radically different healthcare advocacy organization that is Deaf-led, Deaf-operated, and Deaf-community-centered. We are grateful for your continued leadership effecting civil rights for marginalized communities. Particularly, we commend your powerful acknowledgement of the current status quo in accessing medical care as a person with a disability:

> "…pervasive discrimination...."[2]

Your attention given to the staggering statistics of discrimination faced by people with disabilities in accessing basic healthcare also warrants repetition here:

> "[O]nly only 40.7% of physicians surveyed were confident of their ability to provide the same quality of care to patients with disabilities and only 56.5% strongly agreed that they welcome patients with disabilities into their practices;"[3]

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[1] Discrimination on the Basis of Disability in Health and Human Service Programs or Activities, 88 Fed. Reg. 63392 (proposed Sept. 14, 2023) (to be codified at 45 C.F.R. pt. 84).
[2] Fact Sheet: Nondiscrimination on the Basis of Disability Proposed Rule Section 504 of the Rehabilitation Act of 1973 (2023), https://www.hhs.gov/civil-rights/for-individuals/disability/section-504-rehabilitation-act-of-1973/fact-sheet/index.html
[3] 88 Fed. Reg. at 63394 (citing Lisa I. Iezzoni et al., *Physicians' Perceptions of People with Disability and their Health Care,* 40 Health Aff. 297 (Feb. 2021), *https://pubmed.ncbi.nlm.nih.gov/33523739/* (citing GL Albrecht et al., *The Disability Paradox: High Quality of Life Against All Odds,* 48 Soc. Sci. Med., 977 (1999)).

and

> "[s]tereotypes about the value and quality of the lives of people with disabilities have led to discriminatory medical decisions in both the provision and denial of medical treatment."[4]

Your acknowledgement of this decades-long oppression while bold and profound, is not surprising to those of us who live this experience.

We are bewildered, however, that the textual clarifications proposed are even needed. Section 504 of the Rehabilitation Act ("504") is nearly 50 years old. The resounding letter of this law is to protect individuals against discrimination based on their disability. 504's premise is straightforward: equal treatment.

And yet, as your long list of case summaries astutely illustrate, most people are ignorant of this discrimination, especially, and ironically, doctors and lawyers.[5] Those with self-serving agendas have prejudicially split hairs repeatedly under a guise of ambiguity. Or at best, too many medical providers are oblivious to the disability experience or the plain meaning of the law.

We have concluded, then, that 504 needs teeth just as much as text. In effectively challenging the status quo here, we additionally see an opportunity to educate and enforce:

- the letter of the law is to ensure equal access;
- medical providers have a lawful duty to understand and follow the law; and
- the consequences of noncompliance will be severe … because otherwise, the consequences have outrageously fallen to people with disabilities as significant health disparities and poorer health outcomes.[6]

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[4] *Id.*, (citing Tara Lagu et al., `*I am Not the Doctor For You:' Physicians' Attitudes About Caring for People with Disabilities, supra* note 39). ("Many physicians also expressed explicit bias toward people with disabilities and described strategies for discharging them from their practices. Physicians raised concerns about the expense of providing physical and communication accommodations, including insufficient reimbursement for physicians' efforts and competing demands for staff time and other practice resources. Many participants described caring for very few patients who need accommodations, with little acknowledgment that the barriers to obtaining care and inability to track or respond to accommodation needs could lead to an underidentification of the number of people with disabilities who seek care.").

[5] We thank the OCR team in dutifully researching these ardent cases to better understand the divergence with existing civil rights law. This casual and categorical observation about attorneys and doctors is made only by the author, who happens to be an attorney.

[6] Those consequences being significant health disparities and poorer health outcomes for individuals with disabilities, as recognized at 88 FR at 63394 (citing Nat'l Council on Disability, Bioethics and Disability Report Series (2019), https://ncd.gov/publications/2019/bioethics-report-series; Tara Lagu et al., *The Axes of Access—Improving Care Quality for Patients with Disabilities,* 370 New Eng. J. Med. 1847 (May 2014); Tara Lagu et al., *Ensuring Access to Health Care for Patients with Disabilities,* 175 JAMA Internal Med. 157 (Dec. 2014); Tim Gilmer, *Equal Health Care: If Not Now, When* ?, New Mobility (July 2013), http://www.newmobility.com/equal-health-care-if-not-now-when; Gloria L. Krahn et al., *Persons with Disabilities as an Unrecognized Health Disparity Population,* 105 Am. J. of Pub. Health (Suppl 2) S198 (S198–S206) (2015); Kristi L. Kirschner et al., *Structural Impairments that Limit Access to Health Care for Patients with Disabilities,* 297 JAMA 1121 (2007)).

Thus, we urge you as you consider the Proposed Rule, please also promote further provider education, increased OCR enforcement, and a plain legal presumption for courts that as a matter of construction, in medical treatment settings, protection for the individual with the disability must prevail.

Thank you for your consideration of our overarching comments. In addition, as follows, we also have specific feedback to the provisions regarding medical treatment under the Proposed Rule.

First, we appreciate that Section 84.56(b)(1) is straightforward and explicit, as it should be. The same is true for Section 84.56(b)(3). We further recognize, as you do, in Section 84.56(c)(2), that consent is a pillar of recognizing our autonomy and the dignity of our participation as persons with disabilities.

Unconditionally, telehealth platforms must be made accessible. We agree that voluntary compliance is insufficient. We ask you to weigh the burden of pervasive systemic discrimination against the difficulties in defining and measuring compliance. Consistently, we agree that only finding noncompliance where nonconformance impacts the right to equal access puts an unfair burden on an already oppressed population.

DeafHealth thanks you for your work pursuing and enforcing equitable standards in healthcare and promoting dignified treatment for all people with disabilities. Thank you again for the opportunity to provide comments on the Proposed Rule, and for your consideration of our comments.

Sincerely,

Jessica Kennedy

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DeafHealth President

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Cc: Christopher Soukup, CSD CEO