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November 13, 2023

The Honorable Xavier Becerra
Secretary
U.S. Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

Melanie Fontes Rainer
Director
Office for Civil Rights
U.S. Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

Dear Secretary Becerra and Director Rainer:

I write to express my support for the proposed rule entitled “Discrimination on the Basis of Disability in Health and Human Services” (Proposed Rule) that updates the U.S. Department of Health and Human Services’ (HHS or the Department) regulations implementing Section 504 of the *Rehabilitation Act of 1973* (Section 504).¹ Importantly, the Proposed Rule clarifies and updates the prohibitions against discrimination on the basis of disability by recipients of federal financial assistance in programs and activities related to health care and human services.

I was particularly pleased to note that the Proposed Rule includes enforceable standards for accessible medical equipment, an issue that I urged the Department to address in a letter dated June 28, 2022. For too long, people with mobility impairments and other disabilities have faced significant barriers to accessing basic health services, which has contributed to people with disabilities experiencing higher rates of preventable disease and worse health outcomes than the general population.² Equipment such as accessible exam tables, mammography machines that

¹ Discrimination on the Basis of Disability in Health and Human Services, 88 Fed. Reg. 63392, (Sept. 14, 2023) (to be codified at 45 C.F.R. Part 84).

² See, e.g., National Council on Disability, *Enforceable Accessible Medical Equipment Standards – A Necessary Means to Address the Health Care Needs of People with Mobility Disabilities* (May 20, 2021), https://ncd.gov/sites/default/files/Documents/NCD_Medical_Equipment_Report_508.pdf (hereinafter 2021 NCD Report).

are usable by women who are wheelchair users, and even scales that can accommodate a wheelchair are critical to ensuring that disabled patients receive the same high-quality care as their non-disabled counterparts. However, I am concerned that Section 84.92(b), which outlines the scope of the requirement, may be too limited. The Department reasons the proportion of accessible medical equipment is analogous to the number of accessible parking spaces needed. However, it is not at all clear that the proposed requirements are sufficient to ensure access. Additionally, a rule that requires old equipment that is being retired to be replaced with accessible equipment would encourage manufacturers to produce accessible equipment as the standard and lead to greater access over time.

During the COVID-19 public health emergency, we all learned to rely on remote methods as a way to deliver and receive critical services, including health care and human services programs and activities. The regulations implementing Section 504 were drafted decades before smart phones, personal computers, self-service kiosks, and the internet, and therefore, they did not address the emerging accessibility challenges created by these technologies and our increased reliance on them. The Proposed Rule establishes clear standards for web and mobile accessibility that are consistent with the recently proposed rule from the Department of Justice with respect to Title II of the *Americans with Disabilities Act*.³ These standards will help to eliminate the roadblocks that currently prevent people with a variety of disabilities from fully benefiting from the technological advancements that have revolutionized not only health care, but nearly every aspect of our lives. However, I am concerned that the specific exceptions outlined in Section 84.85 are too broad and may unnecessarily ensure that certain kinds of content remain inaccessible in perpetuity. The Department should consider simply requiring content to be accessible unless that would constitute a fundamental alteration or undue burden, which is a long-standing and workable analysis.

The Proposed Rule also reinforces the “integration mandate” recognized in *Olmstead v. L.C. (Olmstead)*,⁴ finding that people with disabilities have a right to expect that programs and activities funded through HHS will be administered in the most integrated setting appropriate to the needs of the person with a disability. Since the *Olmstead* decision, spending on home-and community-based services (HCBS) has increased dramatically in relation to spending on institutional care, increasing from 12 percent of Medicaid Long-Term Services and Supports (LTSS) in Fiscal Year (FY) 1989 to 59 percent in FY 2019.⁵ This investment in HCBS is critical to people with disabilities being able to lead full and independent lives where they have the opportunity to participate in all aspects of American life, including competitive integrated employment.

I also applaud the Department for including “supported decision-making” as an example of a reasonable modification in the context of the administration of health and human services

³ Nondiscrimination on the Basis of Disability; Accessibility of Web Information, 88 Fed. Reg. 51948 (proposed Aug. 4, 2023) (to be codified at 28 CFR 35).

⁴ *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581 (1999).

⁵ Colello, K. (2022) *Medicaid Coverage of Long-Term Services and Supports*. CRS Report for Congress. Order Code R43328.

programs. The need to obtain informed consent for medical treatment can unfortunately be used as a reason to impose unnecessary guardianships that can have profoundly negative impacts in the lives of people with disabilities; the use of supported decision-making may prevent this outcome.⁶

As noted in the explanation provided with the Proposed Rule,⁷ the Department has chosen to include “solely” in the general prohibition against discrimination in Section 84.68(a) in order to be consistent with the statutory language. Although this is couched as a technical amendment, given the complicated judicial history of this phrase, I urge the Department to take care to clarify in the regulation or at least in guidance that this statutory phrase should be interpreted broadly to prohibit disability discrimination consistent with congressional intent.

Parents of young children with disabilities experience disproportionate childcare challenges and consequences from not finding care. According to a 2016 Early Childhood Program Participation Survey, parents of young children with disabilities are three times more likely to experience job disruptions because of problems with childcare than parents of non-disabled children.⁸ The Proposed Rule includes clarifications to ensure that the regulations are clear with respect to their applicability to federal childcare programs. “Day care” has been part of the regulation for nearly five decades and the Proposed Rule merely proposes to update the language to “childcare” in two sections.⁹ This clarification is consistent with the requirements of Section 504 itself to ensure federally funded assisted programs are accessible to families who have children with disabilities.¹⁰

Finally, I was pleased to see that the regulations address long-standing issues of discrimination in the child welfare system. Since the National Council on Disability published its groundbreaking report, *Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children*,¹¹ researchers have continued to document that parents with disabilities are routinely discriminated against in the child welfare, family law, and adoption and foster care systems.¹² These regulations represent a significant step in preventing discrimination against parents and prospective parents with disabilities and toward ensuring that parents with disabilities who do

⁶ See e.g., National Council on Disability, *Beyond Guardianship: Toward Alternatives That Promote Greater Self-Determination for People with Disabilities* (March 22, 2018).

⁷ Discrimination on the Basis of Disability in Health and Human Services, 88 Fed. Reg. 63392, 63473, (Sept. 14, 2023).

⁸ Cristina Novoa, *The Child Care Crisis Disproportionately Affects Children with Disabilities*, Center for American Progress (Jan. 29, 2020), <https://www.americanprogress.org/article/child-care-crisis-disproportionately-affects-children-disabilities/>.

⁹ Nondiscrimination on the Basis of Handicap, 42 Fed. Reg. 22676, 22683 (May 4, 1977) (codified at 45 C.F.R. Part 84); Discrimination on the Basis of Disability in Health and Human Services, 88 Fed. Reg. at 63471.

¹⁰ 29 U.S.C. § 794.

¹¹ National Council on Disability, *Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children* (Sept. 27, 2012), https://www.ncd.gov/sites/default/files/Documents/NCD_Parenting_508_0.pdf.

¹² Sasha Albert, et al., *Advocates, Attorneys, and Legislators on Passing Legislation That Protects the Rights of Parents with Disabilities* (August 2020). <https://heller.brandeis.edu/parents-with-disabilities/pdfs/passing-legislation.pdf> (last visited Nov. 2, 2023).

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Director Fontes Rainer
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come into contact with the child welfare system are provided with the supports they need to keep their families together.

In total, these regulations represent the most significant updates to HHS's regulations aimed at preventing disability discrimination since the original regulations were promulgated 50 years ago. People with disabilities enjoy greater equality and opportunity today than they did when Judy Heumann and others took over the HHS office in San Francisco to demand that the agency implement Section 504, but we still have a way to go to achieve the goal of providing people with disabilities with equal opportunity, full participation, independent living, and economic self-sufficiency. With this Proposed Rule, the Department of Health and Human Services is demonstrating tremendous leadership and charting a course to achieve the goal of real equality and universal access for people with disabilities. I thank you for your work and urge finalization of the Proposed Rule as expeditiously as possible.

Sincerely,



Robert C. "Bobby" Scott
Ranking Member