

## November 13, 2023

Xavier Becerra Secretary, U.S. Department of Health & Human Services Hubert H. Humphrey Building, Room 509F 200 Independence Avenue SW, Washington, DC 20201

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

Submitted via <u>regulations.gov</u>.

**<u>RE:</u>** "Discrimination on the Basis of Disability in Health and Human Service Programs or Activities"

Dear Secretary Becerra and Director Fontes Rainer,

United States of Care (USofCare) is pleased to submit comments to the U.S. Department of Health and Human Services (HHS) in support of the proposed rule entitled "Discrimination on the Basis of Disability in Health and Human Service Programs or Activities." <a href="USofCare">USofCare</a> is a nonpartisan nonprofit working to ensure everyone has access to quality, affordable health care regardless of health status, social need, or income. We advocate for new <a href="Solutions">Solutions</a> that people of every demographic tell us will bring them peace of mind and make a positive impact on their lives. Through <a href="Our work">Our work</a>, we are able to identify <a href="Unique perspectives">Unique perspectives</a> from people on the ground to amplify on both the state and federal levels.

Aligned with USofCare's vision of a health care system that provides people with high-quality, personalized care that meets their unique needs at a price they can afford, the proposed rule makes progress towards health equity and improved health outcomes. USofCare applauds the Department of Health and Human Services (HHS) for its efforts to modernize its regulation of Section 504 of the Rehabilitation Act of 1974 and strengthen anti-discrimination protections for disabled people.¹ If enacted, the rule will institute direly-needed provisions to the Department's Section 504 guidance, including an explicit prohibition on medical treatment denials or limitations that are based on bias, stereotypes, or judgments about an individual's disability or their quality of life, as well as establish requirements for accessible Medical Diagnostic Equipment (MDE). The proposed rule will not only allow for HHS's Section 504 regulation to be consistent with modern disability rights law, but it will ensure that disabled people are provided with the dignity and respect they are entitled to when seeking medical care.

While landmark legislation like the Americans with Disabilities Act of 1990 and the Affordable Care Act of 2010 implemented anti-discrimination protections for disabled people, there is considerable work left to be done. Compared to their nondisabled peers, disabled people are more likely to report poorer overall health, decreased access to care,

<sup>&</sup>lt;sup>1</sup> Note: USofCare utilizes "disabled people" to honor identity-first language throughout our comments. We acknowledge and respect that disability identification terms vary from person to person.

and <u>distrust</u> their providers and the health system at large, and we applaud HHS for taking action to prioritize the health and wellbeing of disabled people through this proposed rule. Strikingly, in 2022, <u>32% of disabled adults</u> in the U.S. experienced discrimination in health care settings, compared to 10% of nondisabled adults. These experiences and outcomes are especially prevalent among disabled people of color, disabled women, disabled members of the LGBTQ+ community, and disabled people with additional marginalized identities, who also experience discrimination due to their race, ethnicity, gender, sexual orientation, and language in addition to their disability, often creating a compounding effect.

"If you're poor, or don't have a job, or you're on Medicare, Medicaid, or you're disabled, navigating the [healthcare] system feels like there's no safety net, and it's difficult to get good care. It's almost impossible."

~ White man, Illinois

A long, ugly history of medical ableism and eugenics has perpetrated incorrect, yet pervasive, <u>assumptions</u> held by the health care system that conflate disability with disease, promote the idea that disability is against the "ideal" human form, and ultimately uphold dangerous biases that view disabled people as disposable, inhuman, or less valuable than their nondisabled peers. A lack of understanding among health care providers about disability has resulted in adverse outcomes for disabled people, ranging from physically and emotionally traumatizing experiences seeking care, misdiagnosis and mistreatment, and <u>skipping or delaying</u> care altogether. Because of this, **USofCare supports the proposed rule's clarification to prohibit medical treatment denials, limitations, and quality metrics that are based on bias, stereotypes, or judgments about a person's disability or quality of life and urges HHS to finalize these rules.** 

Foundational to USofCare's advocacy work is increasing access to life-saving preventive care services. Disabled people are <u>less likely</u> to receive critical preventive care services such as Pap smears and mammograms because of a <u>lack of available</u> accessible Medical Diagnostic Equipment (MDE) and a lack of staff training on how to operate accessible MDE; providers may also deny disabled patients screenings due to their aforementioned biases about the disabled patient's needs and decision-making abilities. **USofCare commends the proposed rule for increasing the availability of accessible MDE**, such as exam tables and weighted scales, and ensuring that staff are trained to adequately utilize and operate it. Doing so will increase utilization of preventive services and ensure that disabled patients are being provided with culturally responsive care.

Thank you for taking a historic step to update the Department's regulations of Section 504 of the Rehabilitation Act of 1973. **USofCare encourages the Department to continue** centering the needs of disabled people in its regulations and applauds HHS's work to ensure disabled people are provided with the dignity, autonomy, and respect that they deserve in health care settings. Please reach out to Orla Levens at OLevens@usofcare.org with any further questions.

Sincerely,

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**Lisa Hunter (she/her)** Senior Director for Policy & External Affairs United States of Care