

Congress of the United States
Washington, DC 20515

March 26, 2024

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

Re: Proposed Rule on Discrimination on the Basis of Disability in Health and Human Service Programs or Activities, 88 Fed. Reg. 63392

Dear Secretary Becerra,

On September 14, 2023, ahead of the 50th anniversary of the Rehabilitation Act, the Department of Health and Human Services (HHS) announced a proposed rule updating the implementation of this important law.¹ We welcome the Department's expansion and modernization of disability non-discrimination protections that help ensure disabled Americans have equitable access to medical care. We urge HHS to further strengthen the proposed nondiscrimination protections to guarantee that individuals with rare or complex conditions have equal access to substance use disorder and mental health treatment facilities. Specifically, we urge the Department to clarify that discrimination based on bias includes bias regarding complex medical, rare, or unfamiliar conditions that constitute a disability.

We have heard from providers that patients across the country with conditions such as bleeding disorders, cystic fibrosis, Type 1 Diabetes, and autoimmune conditions have been denied care at inpatient psychiatric care facilities due to their rare or complex conditions.² Providers and facilities that are rejecting these patients are acting on bias or stereotypes of the rare or unfamiliar condition. This bias or stereotyping can affect the care and management of conditions. As one survey found, in at least 20 states, patients with bleeding disorders were denied placement at a residential mental health or substance use treatment facility because of their condition.³ One of the primary concerns identified was the complexity of a rare, unfamiliar medical condition and fear that the facility could not manage the condition.⁴ For bleeding disorders as well as other qualifying disabilities, we have heard about facility concerns regarding the use of infusions, medications, and needles, even when a patient can self-administer and self-

¹ Press Release, *HHS Issues New Proposed Rule to Strengthen Prohibitions Against Discrimination on the Basis of a Disability in Health Care and Human Services Programs*, U.S. Department of Health and Human Services (Sept. 7, 2023), <https://www.hhs.gov/about/news/2023/09/07/hhs-issues-new-proposed-rule-to-strengthen-prohibitions-against-discrimination-on-basis-of-disability-in-health-care-and-human-services-programs.html>.

² Email to Office of Senator Markey (Jan. 10, 2024), on file with the Office of Senator Markey.

³ J. Bottacari et al., *Equitable Care for Individuals with Inherited Bleeding and Substance Use and/or Mental Health Disorders* (June 25, 2023), <https://isth2023.eventscribe.net/fsPopup.asp?efp=VVhMVFVTWIIxNjMzNQ&PresentationID=1255636&rnd=0.5060874&mode=presInfo>.

⁴ *Id.*

manage their care. Providers and clinics should work with patients to make appropriate accommodations and care plans rather than deny them entry when specialists refer them.

It is especially disconcerting that these patients are experiencing denials in the face of guidance from leading medical organizations such as the Medical and Scientific Advisory Council (MASAC) and the American Society of Addiction Medicine (ASAM) that health care providers should not consider the presence of medically complex and rare conditions in determining whether a person should receive care.⁵ HHS, through the Substance Abuse and Mental Health Services Administration, has already taken steps to clarify the role of providers at substance use treatment centers in caring for patients with chronic conditions, including those whose conditions may involve needles or infusion.⁶ But we urge further action. Patients with complex or rare conditions are not burdens on their providers or treatment centers, but rather people in need of care and support. We believe that this proposed rule is an opportunity to offer patients the clarity that their rare or unfamiliar condition is protected against health care discrimination.

For this reason, we request that HHS amend the proposed rule to specify that it includes bias regarding the medical complexity of an unfamiliar medical condition that constitutes a disability. The proposed rule recognizes that “flawed perceptions, stereotypes, and biases about individuals with disabilities can lead to prohibited discrimination” and would prohibit “denying or limiting medical treatment to a qualified individual with a disability when the denial is based on (i) bias or stereotypes about a patient’s disability; (ii) judgments that an individual will be a burden on others due to their disability, including, but not limited to, caregivers, family, or society.”⁷ We encourage HHS to add language specifying that the biases described in the rule include flawed bias or stereotypes about patient’s conditions, particularly those that are rare, uncommon, or complex.

People with disabilities should not be denied access to medical care they need, including mental or behavioral health care. We welcome HHS’s revising the proposed rule to protect access to mental and behavioral health facilities for people with complex, rare, or unfamiliar conditions. We believe this clarification would ensure that patients with rare or complex conditions received the services and supports that they need for their recovery.

⁵ “Every person, assuming they are medically stable and otherwise appropriate for admission, should have equal access to residential/inpatient SUD treatment facilities, regardless of their inherited bleeding disorder diagnosis, the treatments/medications they use, or state in which they live.” *Recommendations on Reducing Barriers to Substance Use Disorder (SUD) Treatment Facilities and Programs for Persons with Bleeding Disorders (PWBD)*, National Bleeding Disorders Foundation (2023), <https://www.hemophilia.org/sites/default/files/document/files/MASAC-substance-use-disorder-treatment.pdf>; “If a condition can be self-managed by the patient (e.g., a blood clotting disorder) or managed effectively by an external provider, it should not be used as a reason for exclusion from any level of care.” *Proposed Updates to The ASAM Criteria*, 4th Ed., ASAM (Oct. 2022), [https://sitefinitystorage.blob.core.windows.net/sitefinity-production-blobs/docs/default-source/publications/criteria-4th-edition/asam-criteria-4th-ed-standards-public-comment-final-\(1\).pdf?sfvrsn=593c955a_3](https://sitefinitystorage.blob.core.windows.net/sitefinity-production-blobs/docs/default-source/publications/criteria-4th-edition/asam-criteria-4th-ed-standards-public-comment-final-(1).pdf?sfvrsn=593c955a_3).

⁶ *Diabetes Care for Clients in Behavioral Health Treatment*, SAMHSA (2023), <https://store.samhsa.gov/sites/default/files/sma13-4780.pdf>.

⁷ *Discrimination on the Basis of Disability in Health and Human Service Programs or Activities*, 88 Fed. Reg. 63392 (Sept. 14, 2023), <https://www.govinfo.gov/content/pkg/FR-2023-09-14/pdf/2023-19149.pdf>.

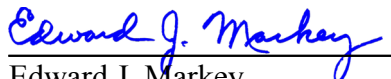
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We appreciate your work on this critical topic and your consideration of our request.

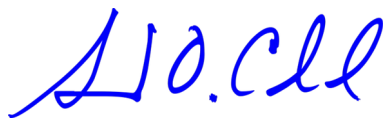
Sincerely,



Edward J. Markey
United States Senator




Joe Courtney
Member of Congress



Salud Carbajal
Member of Congress



Paul Tonko
Member of Congress



Stephen F. Lynch
Member of Congress