



November 8, 2023

U.S. Department of Health and Human Services
Office for Civil Rights
Attention: Disability NPRM, RIN 0945-AA15
Hubert H. Humphrey Building
Room 509F
200 Independence Ave SW
Washington, DC 20201

Re: Proposed Rule, Discrimination on the Basis of Disability in HHS Programs or Activities, RIN 0945-AA15

Dear Ms. Melanie Fontes Rainer,

The Bleeding Disorders Substance Use and Mental Health Access Coalition (BD SUMHAC) is a national coalition of non-profit organizations that advocates for access to inpatient and residential substance use disorder (SUD) and mental health (MH) treatment for people with bleeding disorders (BD). Our organization has worked with people with bleeding disorders across the country who have been denied access to behavioral health treatment they need because of their bleeding disorder. We deeply appreciate the Department of Health and Human Services' strong commitment to the prohibition of discrimination against people with disabilities. We believe the clarification in the Proposed Rule (NPRM, 88 FR 63392) that section 504 of the Rehabilitation Act of 1973 prohibits discrimination in the area of medical treatment is extremely important and are grateful for the opportunity to submit comments.

Background on the Bleeding Disorders Substance Use and Mental Health Access Coalition (BD SUMHAC)

People with BD (including hemophilia and von Willebrand disease, among others) have complex, lifelong needs. They depend on ongoing use of prescription medications (infused clotting factors or injectable factor mimetics) to treat or avoid debilitating bleeding episodes that can lead to advanced medical issues. Current treatments and medical care are highly effective and allow individuals to lead healthy and productive lives in the community.

However, although most persons with BD are stable and effectively manage their condition through self-infusions of medication that do not require physician or provider supervision, they are frequently denied access to needed treatment at SUD and MH facilities because of the facility's fear, bias related to concerns about medical complexity, or internal policies that limit access to needles. The denials occur even though infusions can be accommodated through very reasonable and minor modifications (e.g., supervision by provider staff or contracted outside personnel). Furthermore, although persons with milder forms of BD may have only infrequent need for infusions, they too are often automatically denied access. People with BD, regardless of severity, are entitled to protections against discrimination on the grounds of disability, including Section 504 regulations requiring reasonable accommodation.

In 2021, a 20-year-old individual with BD asked his hemophilia treatment center (HTC) for help finding a residential treatment facility for his SUD. The nurse called many residential SUD treatment facilities, but none would take a person with a BD who required intravenous infusion medication. Without access to appropriate treatment, the young man overdosed and died. Unfortunately, this was not an isolated incident. BD SUMHAC conducted a national survey of federally-funded hemophilia treatment centers (HTC) and found that 83% of HTC providers who have attempted to refer people with bleeding disorders to treatment had received denials because of their bleeding disorders. BD SUMHAC is aware of denials in 21 different states.

Following this tragedy, the BD community rallied to establish BD SUMHAC. This coalition includes members from the Hemophilia Federation of America, the National Bleeding Disorders Foundation, hemophilia treatment centers, local BD chapters, and the BD community. BD SUMHAC's mission is to advocate for access to appropriate inpatient and residential SUD and mental health treatment facilities for all individuals with BD, with a focus on inpatient and residential facilities.

Comments on Proposed Rule - Medical Treatment

Example of Discriminatory Provision of Medical Treatment to People with Disabilities

Question two in the Medical Treatment portion of this proposed rule asked us to provide examples of the discriminatory provision of medical treatment for people with disabilities.

The proposed rule states that “flawed perceptions, stereotypes, and biases about individuals with disabilities can lead to prohibited discrimination” under Section 504. In over 20 states, BD SUMHAC and its partners have witnessed how such flawed perceptions by providers of inpatient/residential SUD and mental health treatment are directly leading to discriminatory denials for people with BD.

The survey conducted by BD SUMHAC showed that there were a number of explanations for the denials of people with bleeding disorders, including concerns about the use of infusion medications, needles, insurance issues, and access to medication. However, one of the primary reasons reported in the survey was a general concern about the complexity of a rare, unfamiliar medical condition and a fear regarding the facility's ability to manage the condition. Providers reported that facilities explained the denial of people with bleeding disorders using the following language:

- “Medical condition and medication [was] too complex”
- “Did not manage diagnosis”
- “Afraid they will bleed due to the behavior or withdrawal”

BD SUMHAC's research shows that behavioral health providers and facilities are in fact making blanket exclusions of any patient with BD based on flawed perceptions and stereotypes about the complexity of BDs, and without any individual assessment of the severity of their condition or frequency of needed infusions. This bias and the resulting treatment denials are negatively impacting our community through avoidable pain, suffering, and loss.

NBDF's Medical and Scientific Advisory Council (MASAC), an expert body composed of physicians, scientists, and other medical professionals with a wide range of expertise on BD, blood safety, and infectious disease as well as representatives from government agencies, and people with BD, recently approved a relevant statement affirming that categorical exclusion of

BD patients from SUD facilities are medically unwarranted. The MASAC recommendation states that,

Provided a person with a bleeding disorder (PwBD) is stable and can maintain their established treatment protocol, having an inherited bleeding disorder should not preclude a person from receiving SUD treatment in a residential/inpatient setting. PwBD who are stable and well-maintained on their medication typically live in the community and do not require any direct medical supervision related to this condition. They typically lead full, active, and independent lives. There are no restrictions for activities except participation in contact or collision sports/activities that could result in significant physical injury.

While there may be certain circumstances in which a person's BD is not stable, calling into question their eligibility for residential SUD/MH treatment, it is essential that the facility does not make this assumption.

The American Society of Addiction Medicine (ASAM), which establishes national guidelines for placement, continued stay, and transfer/discharge of patients with substance use disorder and co-occurring conditions, agrees with MASAC. According to the recently released, 4th Edition of the ASAM Criteria:

A program's admission criteria should not exclude patients based solely on a current or past diagnosis; appropriateness of the admission should be determined by the current severity and acuity of co-occurring concerns and associated risks across dimensions as outlined in the Dimensional Admission Criteria. If a patient's condition can be self-managed (eg, by self-administering pharmacotherapy for hemophilia) or managed effectively by an external provider, their co-occurring condition should not be used as a reason for exclusion from any level of care.

The ASAM criteria clearly states that the presence of a bleeding disorder should not in any way automatically disqualify a person from accessing SUD treatment facilities.

Although Section 504 and later the Americans with Disabilities Act (ADA) allowed for denials where "there exists a high probability of substantial harm" to either the individual or others, Congress has made clear that this determination "must be based on individualized factual data...rather than on stereotypic or patronizing assumptions and must consider potential reasonable accommodations." The blanket exclusion of any patient with BD issued by inpatient SUD/MH providers fails this basic test as it lacks (1) any individualized assessment of whether their need for injections or intravenous infusions would pose any risk of harm to themselves or other patients or (2) any consideration of potential reasonable accommodations.

This proposed rule presents an opportunity to address this issue at its core, and we will explain how HHS can clarify the NPRM to ensure that people with bleeding disorders are not excluded from behavioral health treatment because of a behavioral health facility's unfounded fears.

Clarify 84.56(b)(1)(i) to include bias regarding medical complexity

Given the background and examples stated above, we support the intent behind this proposed rule but recommend HHS clarify proposed paragraph 84.56(b)(1)(i), which confirms the prohibition against denying or limiting medical treatment based on bias or stereotypes, to include bias regarding the medical complexity of an unfamiliar medical condition that constitutes a disability.

Should the NPRM clarify this section, then if a person has received medical clearance for admission to an inpatient or residential MH or SUD treatment facility, the facility cannot exclude the individual on the basis of assumptions about the complexity of managing that person's disability (amount of staff time or expertise required). Before denying the individual with a disability access to medical treatment, the behavioral health facility would be required to confirm their understanding of the person's medical condition with the person's medical team. The facility would then learn about the types of support necessary to appropriately treat the individual, and make reasonable accommodations to ensure access, if medically appropriate. Consistent with Section 504, if the person's disability requires special monitoring, medical treatment, or expertise that would place an undue burden on the facility, then it would not be necessary to accommodate the individual. The facility, however, should not assume that the individual would be an undue burden without first speaking with the patient's medical team, and validating their preconceived notions of what it takes to manage a person with a bleeding disorder.

Consider the example of a person with BD who is seeking admission to an inpatient SUD treatment facility. This individual self-manages their condition in the community without medical oversight and the individual's hematologist does not recommend medical oversight of their self-administration of medicine. In this case, a determination by a facility that the person's BD requires medical expertise and oversight in an inpatient SUD would be based on bias and stereotypes and therefore prohibited. The facility should have made an informed decision based on information provided by the person with BD and their medical team. Similarly, refusing access to an inpatient mental health treatment facility to a similar person with a stable bleeding disorder that is self-managed in the community, based on unfounded assumptions about the medical complexity of the condition and the medical oversight that it would require, would be prohibited under this paragraph.

We recommend that proposed paragraph 84.56(b)(1)(i), which confirms the prohibition against denying or limiting medical treatment based on bias or stereotypes, include bias or assumptions regarding the medical complexity of an unfamiliar medical condition that constitutes a disability.

"Separately Diagnosable"

Proposed § 84.56(b)(2) addresses situations where a person with a disability seeks or consents to treatment for a separately diagnosable symptom or medical condition, whether or not the symptom or condition is itself a disability or is causally connected to the disability that is the basis for coverage under section 504. People with BD and SUD/MH issues have two separately diagnosable conditions. The examples in this letter clearly outline that individuals are being denied treatment for SUD/MH because they have a BD. This section makes clear that a recipient may not deny or limit clinically appropriate treatment if it would be offered to a similarly situated individual without an underlying disability. BD SUMHAC strongly supports this clarification and seeks additional information on how this will be monitored and enforced.

People with BD who have behavioral health issues should not have to choose between treatment for their BD and treatment for their behavioral health issue. Treating both is essential to their overall health and well-being. Without access to their BD medication, these individuals could experience life-threatening bleeding episodes, but without SUD or MH treatment they

could endanger themselves as they face risks such as overdose or suicide. BD SUMHAC has seen these unfortunate consequences play out.

Patient Autonomy, Providing Information (84.56(c)(3)), and “Undue Burden”

As the NPRM states, patients should have autonomy in choosing their medical treatment that is uninhibited by their disability. The proposed rule notes that “By denying patients with disabilities the opportunity to make their own decisions regarding whether to receive or continue medically effective life-sustaining care, recipients override patient autonomy in favor of their own beliefs regarding the value of the lives of individuals with disabilities who are dependent on others.” Patients with medical conditions that constitute a disability should have the opportunity to explore their treatment options in the same way as a non-disabled individual.

For example, if a person with a bleeding disorder inquires about admission to an inpatient/residential SUD or mental health treatment facility, the facility should have a discussion with the person with BD, their caregivers, and their other medical providers about the treatment options available to the patient. Section 84.56(c)(3) discusses the information exchange between the recipient and the patient, but as written, it focuses on one-way communication from the facility to the patient. We suggest that the rule should recognize the importance of two-way information sharing. Otherwise, a facility may wrongly deny a patient with a complex medical condition that qualifies as a disability, because they judge incorrectly that the patient may place an undue burden on others because of their disability, even if the patient is self-managed.

Proposed paragraph (b)(1)(ii) prohibits denying or limiting medical treatment based on judgments that an individual will be a burden on others due to their disability, including but not limited to caregivers, family, or society.

For example, a facility would violate § 84.56(b)(1)(ii) if it denied a medically indicated placement for inpatient MH treatment based on the facility’s assumption that a disabled individual’s stable chronic condition would place an unfair burden on the facility’s staff - even if the individual’s condition is typically managed in the community, and even if the individual’s specialist determines that their disability requires no medical oversight or expertise.

We recommend that the language be revised to include the importance of information flow from the patient and other medical providers to the recipient.

Conclusion

BD SUMHAC appreciates the opportunity to provide comments and recommendations to help ensure that this proposed rule reaches its full potential. We are committed to ensuring that people with bleeding disorders have access to the treatment that they need and deserve. We thank you for your work towards equitable access to medical care for all people with disabilities.

If you have any questions or would like to follow-up with BD SUMHAC about this comment letter or any additional issues, please contact our Chair, Kate Bazinsky, at kbazinsky@bdsuhac.org.

Thank you for your consideration.

Sincerely,
The Bleeding Disorder Substance Use and Mental Health Access Coalition

The Bleeding Disorder Substance Use and Mental Health Access Coalition Members include:

National Organizations:

- [Hemophilia Federation of America](#)
 - Miriam Goldstein: *Director of Policy*
 - Mark Hobracszk: *BD SUMHAC Advocate & Senior Manager for Policy*
- [National Bleeding Disorders Foundation](#)
 - Nathan Schaefer, MSW: *Senior Vice President of Public Policy & Access*
 - Matt Delaney, *Government Relations Specialist*
 - Bill Robie, *Director, State Government Relations*

Local Bleeding Disorder Community Chapters

- [Bleeding Disorders Alliance of North Dakota](#)
 - Miranda Solem, MA, LADC: *Director, Community & Residential Mental & Chemical Health Services*
- [Bleeding Disorders Foundation of North Carolina](#)
 - Gillian Schultz: *Director of Programs*
- [Hemophilia Council of California](#)
 - Lynne Kinst: *Executive Director*
 - Cindy Morales Guzman, *Council Board Member*
- [Lone Star Bleeding Disorders Foundation](#)
 - Melissa Compton, *Executive Director, and Co-Coordinator, of the [Texas Bleeding Disorders Coalition](#)*
- [New England Bleeding Disorders Advocacy Coalition](#)
 - Joe Zamboni, *Advocacy Coordinator*
 - Ann Marie Minichiello: *Massachusetts State Lead*
 - Ziva Mann: *Massachusetts State Lead*
- [New England Hemophilia Association](#)
 - Rich Pezzillo, *Executive Director*
 - Lissa Blanchard, LICSW, *Mental Health Professional Coordinator*
 - Nick McRae, *Board Member*
 - Carolyn Miazga, *Board Member*
- [New York City Hemophilia Chapter](#)
 - Jeremy Griffin, *Executive Director*
- [New York State Bleeding Disorders Coalition](#)
 - Jessica Graham, *Coalition Coordinator*
- [Texas Central Bleeding Disorders](#)
 - Julie Jones, *Executive Director*

- Shanna Garcia, MBA: *Director of Development*

Hemophilia Treatment Center Providers:

- [Center for Bleeding and Clotting Disorders at University of Minnesota Medical Center in Minneapolis](#)
 - Mark Reding, *Director*
- [Dartmouth Health Hemophilia Treatment Center](#)
 - Joanne Fadale Wagner, LICSW: *Social Work Care Manager*
- [Rush University Medical Center Hemophilia Treatment Center](#)
 - Lucy Ramirez, LCSW: *Social Worker*
- [University of California San Francisco](#)
 - Mosi Williams, PsyD, *Social Worker*
- [University of Massachusetts Memorial Hemophilia Treatment Center](#)
 - Jen Feldman, RN, MSN: *Co-Founder of BD SUMHAC, Nurse Coordinator*
- [Yale Center for Bleeding and Clotting Disorders](#)
 - Jacqueline Bottacari, LCSW: *Licensed Clinical Social Worker*