



BD SUMHAC

Bleeding Disorders Substance Use &
Mental Health Access Coalition

Access to Inpatient/Residential Behavioral Health Treatment for People with Bleeding Disorders

Resources for providers who work with people with bleeding disorders

BACKGROUND

People with bleeding disorders (BD) are often denied access to inpatient/residential substance use disorder (SUD) and mental health (MH) treatment facilities, despite being medically stable and appropriate for admission. Access to treatment is a health equity issue. Every individual should have equal access to inpatient/residential behavioral health¹ (BH) treatment, regardless of their ability to clot, treatments they use, or state of residence. The Bleeding Disorders Substance Use and Mental Health Access Coalition (BD SUMHAC) developed a toolkit for medical providers that has recommendations for overcoming common barriers to access.

Use the QR code to visit the BD SUMHAC website and find the Provider Toolkit.

Contents of the Provider Toolkit:

- 1. Assessing patient behavioral health needs and options for intervention**
- 2. Referring people with bleeding disorders to behavioral health treatment facilities**
- 3. Responding to a behavioral health treatment facility denial**
 - Requesting reasonable accommodations for people with BD
 - Brainstorming creative solutions with facilities
 - Filing a complaint with the federal Office of Civil Rights at the Department of Health and Human Services



A NATIONAL ISSUE

In 2022, BD SUMHAC conducted a national survey of hemophilia treatment providers (social workers, hematologists, nurses, physical therapists) that showed 83% of those who attempted to place a patient at a residential SUD and/or MH treatment facility received a denial due to their patient's BD. Both adults and children with BD have been denied access to both SUD and MH facilities. BD SUMHAC is currently aware of denials in 20 states. BD SUMHAC has launched a multi-pronged approach to addressing this important health equity issue.

REASONS FOR DENIALS

According to interviews with HTC providers, people with BD are denied access for many reasons, such as: concern about use of IV or injection medications, needles, fear about the medical complexity of BD, insurance issues, and access to medication.

ROLE OF BLEEDING DISORDER TREATMENT TEAMS IN PATIENT ADVOCACY

According to National Hemophilia Foundation's (NHF) Medical and Scientific Advisory Council (MASAC), HTCs should be the primary advocate for people with BD who have been denied access to a MH or SUD treatment facility because of their BD. According to MASAC, "The role of a comprehensive HTC is to provide holistic, individualized patient care, and to support and advocate for persons with bleeding disorders (PwBD) throughout their lifespan. This includes ensuring that the BD and associated treatments are not barriers to a person's SUD care and that the PwBD can continue to receive the standard of care for their BD while residing in a SUD treatment facility."

¹ In this document, behavioral health includes both mental health and substance use disorders.

PEOPLE WITH BLEEDING DISORDERS ARE PROTECTED UNDER FEDERAL LAW

If a community of people is routinely denied access to BH facilities because of a well-managed health condition, that is not equitable and may be illegal. Specifically, the Americans with Disabilities Act (ADA), requires health care facilities, including inpatient/residential SUD or MH treatment facilities, to make "reasonable accommodations" or changes to "rules, policies, practices, or services" in order to give people with a disability an equal opportunity to access medical care. The ADA protects people with bleeding disorders, and therefore failure to provide a person with BD equal access to inpatient/residential SUD or MH treatment facilities, could be considered discrimination. The provider toolkit has template letters that providers can use to request reasonable accommodations for their patients.

SUPPORTING BEHAVIORAL HEALTH FACILITIES

Staff at BH facilities will likely have very little understanding of BD and will need education and support regarding treatment of people with BD in their care. It is important for facilities to know that you are willing to work closely with them to ensure that people with BD are stable and safe throughout their stay at the facility.

HISTORY OF BD SUMHAC

In 2021, a 20-year-old person with a bleeding disorder who needed residential substance use disorder treatment was repeatedly denied access to facilities because of his BD. Without access to treatment, the patient overdosed and died. Coalition members include the Hemophilia Federation of America (HFA), the National Hemophilia Foundation (NHF), HTC's, local BD chapters, and the BD community.

PARTNERING WITH BD SUMHAC

BD SUMHAC is not an MH or SUD treatment organization. If the coalition is contacted by a person with a BD seeking assistance with overcoming barriers to access MH or SUD treatment, BD SUMHAC will refer them to their BD treatment team. BD SUMHAC will follow up with the BD treatment team directly to offer the providers tools, resources, and support. If the BD treatment team does not feel comfortable or is not able to advocate on behalf of their patient with treatment facilities, it is important to communicate this to BD SUMHAC so that we can connect the person with an advocate at NHF or the HFA.

If your patient has been denied access, please contact the BD SUMHAC advocates at the national BD organizations:

- **BD SUMHAC Advocate at National Hemophilia Foundation:**
Matt Delaney, (212) 328-3780, mdelaney@hemophilia.org.
- **BD SUMHAC Advocate at Hemophilia Federation of America:**
Mark Hobracczk, (202) 675-6984, m.hobracczk@hemophiliafed.org.

If you have any additional questions about the toolkit or would like to help advocate for better access on behalf of the community, please visit www.bdsumhac.org or contact us at info@bdsumhac.org.

BD SUMHAC appreciates the generous support of the following bleeding disorder organizations:

Bleeding Disorders Association of South Carolina
Bleeding Disorders Foundation of North Carolina
Bleeding Disorders of the Heartland
Eastern PA Bleeding Disorders Foundation
Hemophilia Association of San Diego County
Hemophilia Association of the Capital Area
Hemophilia Foundation of Michigan
Hemophilia Foundation of Southern California
Kentucky Hemophilia Foundation
Louisiana Hemophilia Foundation

Lone Star Bleeding Disorders Foundation
New England Hemophilia Association
Northern Ohio Hemophilia Foundation
Pacific Northwest Bleeding Disorders
Rocky Mountain Hemophilia & Bleeding Disorders Association
Southwestern Ohio Hemophilia Foundation
Tennessee Hemophilia and Bleeding Disorder Foundation
Texas Central Bleeding Disorders
Tri-State Bleeding Disorder Foundation
Virginia Hemophilia Foundation

CK Colburn  Keenan Foundation, Inc.