



# BD SUMHAC

Bleeding Disorders Substance Use &  
Mental Health Access Coalition

## Equitable Access to Behavioral Health Treatment for the Bleeding Disorders Community

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# About Bleeding Disorders



# Bleeding disorders (BD) are rare, genetic, life-long conditions



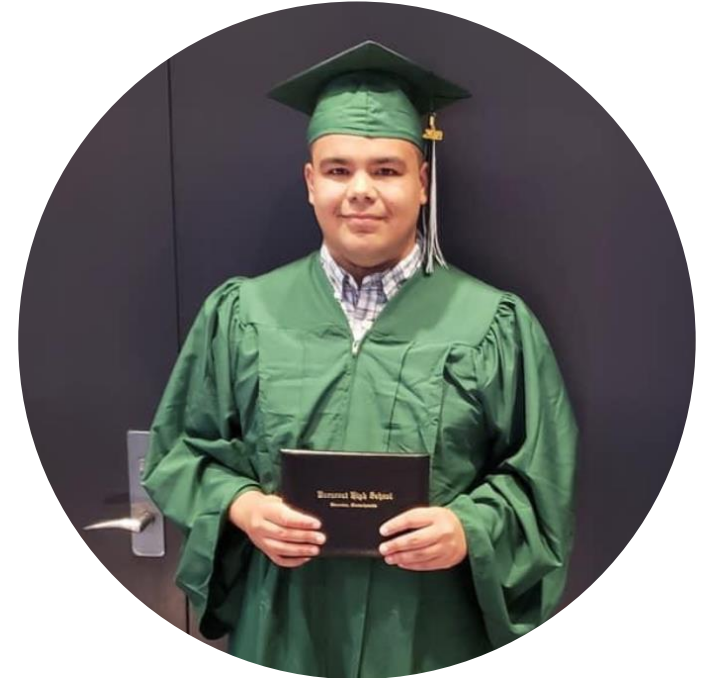
- Hemophilia, von Willebrand's Disease, Platelet Dysfunction, Factor Deficiencies, among others
- No cure but treatments are very effective
- People who follow their established individualized bleeding disorder treatment plans are typically medically stable and do not typically bleed spontaneously
- Treatments can be infusions, injections, or oral medications
- A person born with a bleeding disorder today has average life-expectancy and can lead full, healthy, and active lives without restrictions (except for high contact sports)



# History of BD SUMHAC



# Derick's story ignites a national advocacy effort



# Bleeding Disorders Substance Use and Mental Health Access Coalition (BD SUMHAC)

- A diverse stakeholder coalition with representatives from:
  - National Hemophilia Foundation
  - Hemophilia Federation of America
  - Hemophilia treatment center providers
  - Local chapters
  - Community members
- **Mission Statement:** The mission of the coalition is to advocate for access to appropriate substance use and mental health treatment facilities for all individuals with bleeding disorders, with a focus on residential and inpatient facilities.



# Why this work matters: Access to residential/inpatient treatment is a health equity issue

**Problem:** Individuals with bleeding disorders are often denied access to residential/inpatient substance use and mental health treatment facilities, despite being medically stable and appropriate for admission.

Every person should have equal access to residential/inpatient substance use and mental health treatment facilities, *regardless of:*

- the presence of stable comorbidities/ pre-existing conditions,
- their ability to clot,
- the treatments/medications they use, or
- the state they live in.

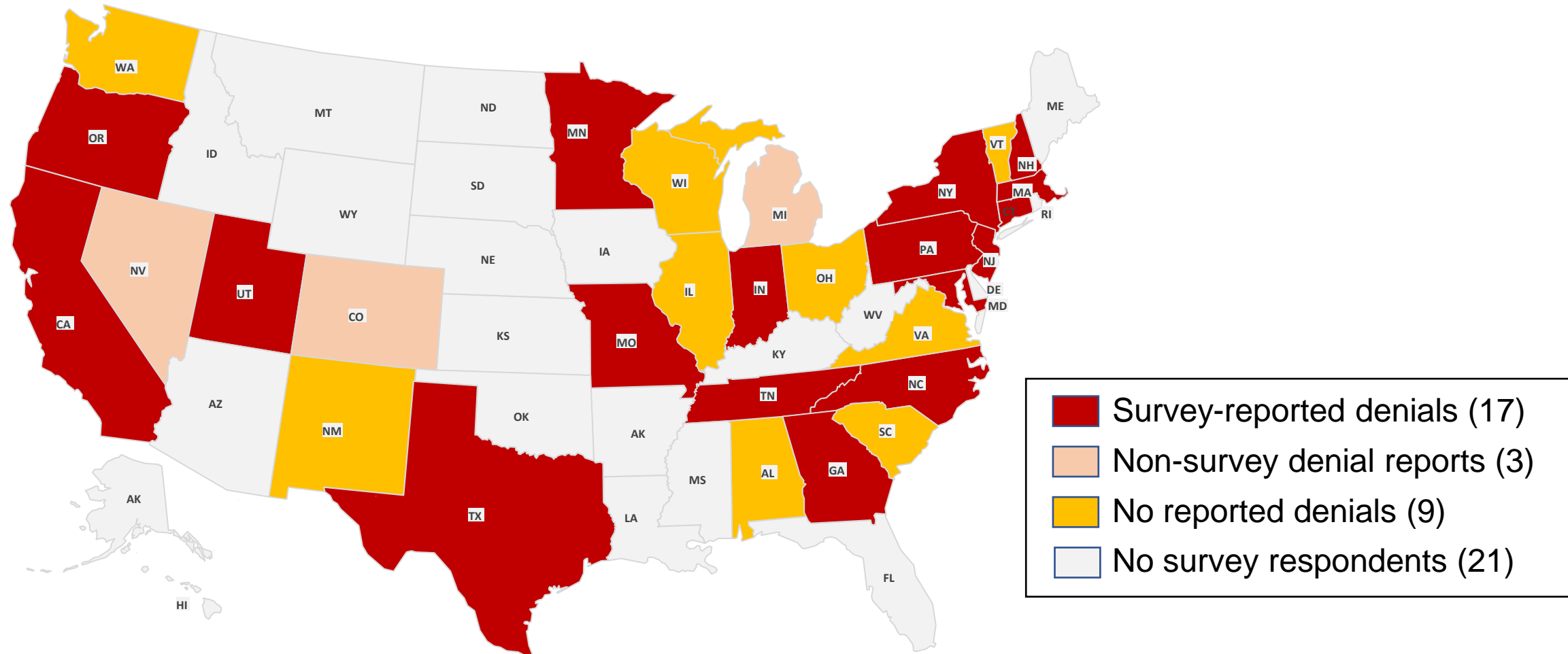


# Data Collection

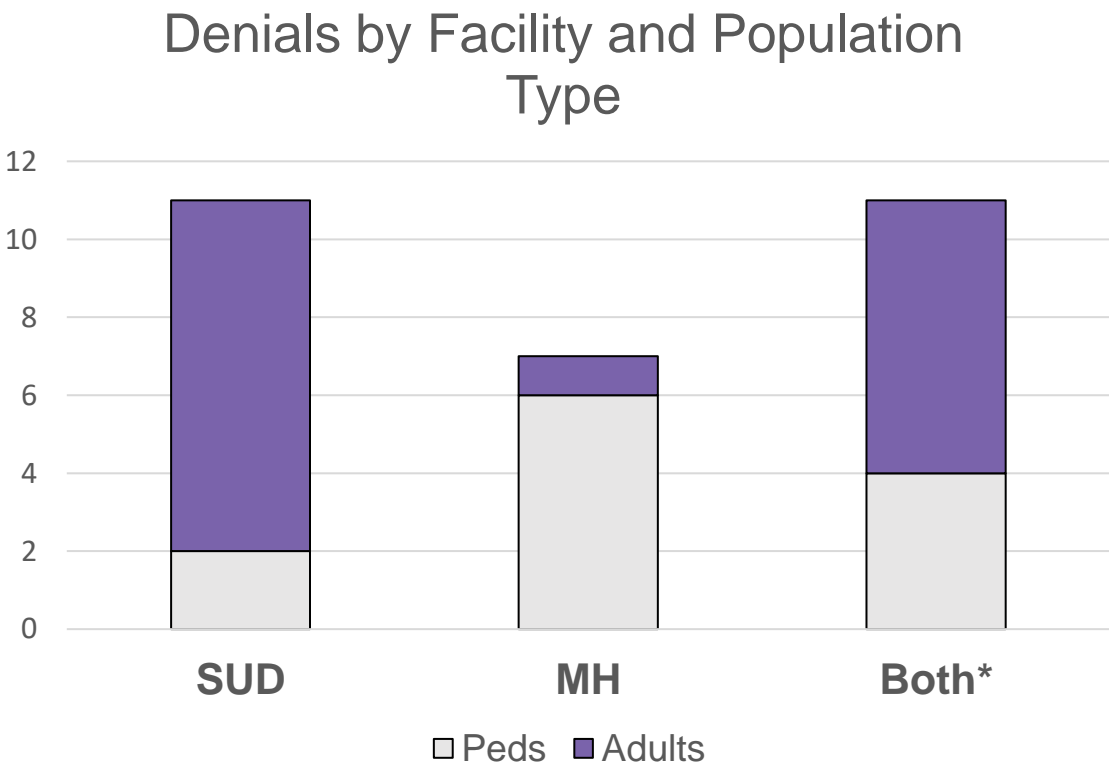
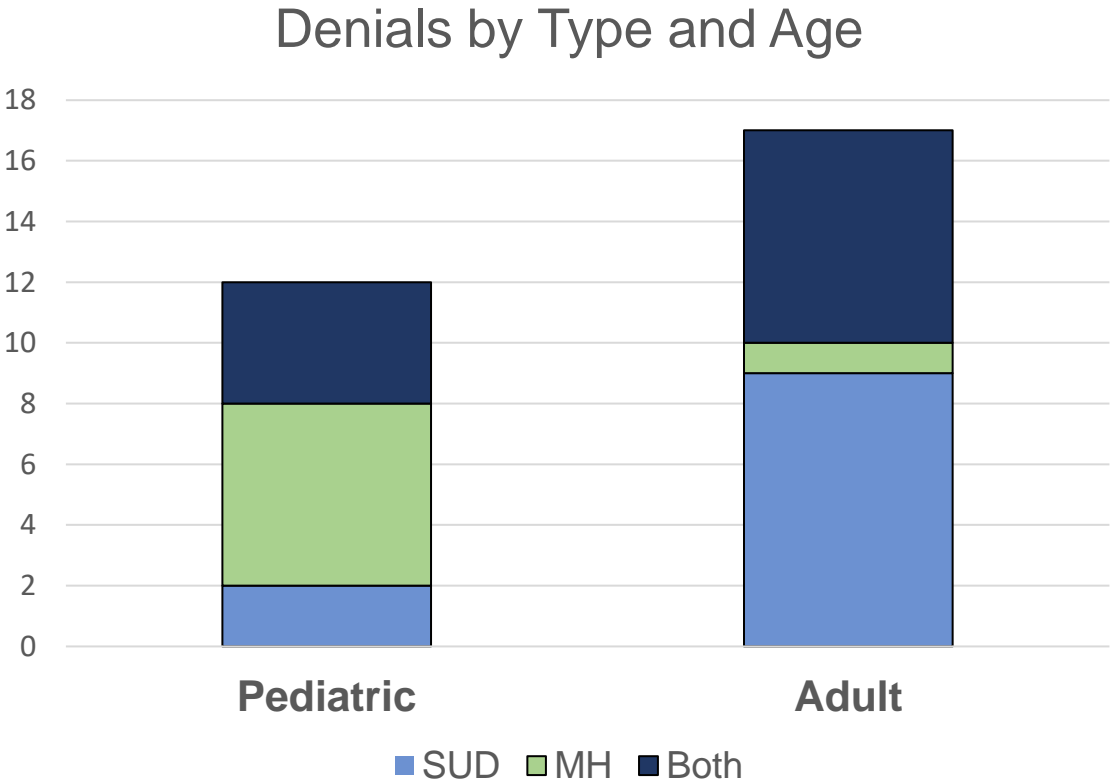




# National problem: 83% of providers who attempted to refer a patient with a BD reported a denial



# Both peds and adults were denied access to both MH and SUD facilities



# Many reasons underlying the denials

## Infusions

- “They did not give IV medication/infusions”
- “Staff expertise to monitor/administer hemophilia medications is the primary barrier to inpatient psychiatric care.”
- “The facility was unable to manage the patient's factor infusions”

## Needles

- “Needles for infusion”
- “Had a hard time separating access to syringes/needles/self-infusion from "drug paraphernalia" and "IV drug use"
- “They couldn't bring the factor/use needles in the residential program/nursing couldn't administer”

## Medical complexity/ fear and stigma

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

## Insurance issues

- “Insurance issues... Large co-pay”
- “Mostly insurance issues or not qualified getting approval for factor”
- “Factor not being covered”

## Access to factor

- “Freestanding programs generally do not have a way to access factor through their pharmacy...”



# IV Infusion medications for BD

- BD infusions are:
  - fast (usually less than 5 minutes),
  - safe (are not associated with adverse events),
  - do not require IV poles, hanging IV bags, or pumps, and
  - use very small needles (butterfly needles)
  - do not typically require any medical oversight or monitoring that would take them away from the facility
- Many self-infuse but some may need support



# Other BD medications

- The injections used by people with BD are similar to treatments used by individuals with diabetes.
- Some individuals with milder types of bleeding disorders may use oral medication or nasal sprays for treatment of bleeding episodes.
- Use of these infusion/injection medications is part of these individuals' normal activities of daily living.





# Addressing medical complexity concerns



Typically, people with BD who are well-managed on medication:

- have same life expectancy as everyone else
- do not bleed spontaneously
- lead full, healthy, and active lives
- have no restrictions except for high contact sports
- live in the community



# ASAM CRITERIA®

*“The ASAM Criteria is the most widely used and comprehensive set of guidelines for placement, continued stay, transfer, or discharge of patients with addiction and co-occurring conditions.”*

ASAM’s new draft language:

*“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.”*

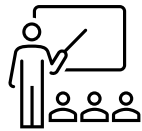


## Best Practices

**For Accessing Residential  
Substance Use Disorder Treatment  
For Individuals With Bleeding  
Disorders**



Draft letter from provider to the SUD facility regarding the stability of a patient with BD



Bleeding disorder basics for residential SUD facility staff



# Americans with Disabilities Act

- The ADA prohibits discrimination on the basis of disability in the provision of health care
- Discrimination includes refusing “to make reasonable accommodations in rules, policies, practices, or services, when such accommodations may be necessary to afford such person with a disability (such as a bleeding disorder) equal opportunity to access medical care”
  - Includes access to inpatient/ residential substance use disorder or mental health treatment



# Reasonable accommodations can include:

- Access to BD medication
- Secure, climate-controlled storage for medication and associated medical supplies
- Time during the day to receive medication in accordance with provider's medication schedule and orders
- Allowing the patient to administer (self-infuse or inject) the medication in the presence of a staff member to ensure that nothing other than the medication is taken
- Identifying a provider either at the facility or an external provider to administer the medication
- Provision of a private space in which to administer the medication



# Partnering with facilities to support patients

- Hemophilia Treatment Centers (HTCs) have a multidisciplinary team to support patients with BD
  - May include hematologist, nurse coordinator, and social worker, etc.
- HTC support may include:
  - Planning for admission requirements
  - Providing medical clearance documents
  - Sharing patient care team resources
  - Answering questions and addressing concerns
  - 24/7 support in the event of an injury or bleeding event
  - Planning support for the patient post-discharge



# Summary: Patients with BD deserve equal access

- Patients with BD who are stable on their individualized treatment plans are not difficult to manage
- They will need reasonable accommodations, as required under the ADA, to ensure that they can access and take their medication as prescribed
- BD providers are eager to support patients with BD and the facilities that treat them



# THANK YOU!



- The mission of the coalition is to advocate for access to appropriate substance use and mental health treatment facilities for all individuals with bleeding disorders.

