



**BD SUMHAC**

Bleeding Disorders Substance Use &  
Mental Health Access Coalition

**Access to Residential Substance Use Disorder  
and Mental Health Treatment Facilities for  
People with Bleeding Disorders**

**Mid Atlantic Region HTC Network meeting  
April 2024**



# BD SUMHAC is a proud recipient of the Hemophilia Alliance Foundation Innovation Grant




BD SUMHAC is grateful to the Hemophilia Alliance Foundation for generously supporting this presentation.



# Introductions

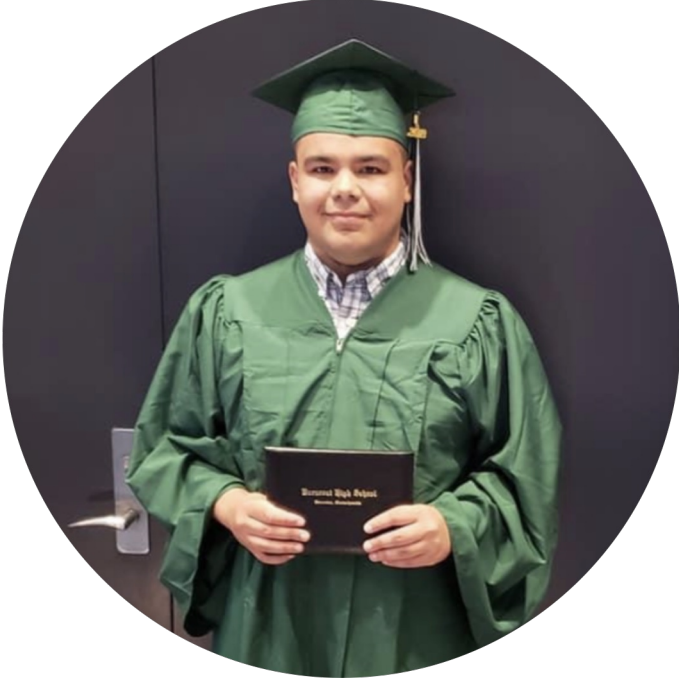
- Kate Reinhalter Bazinsky, MPH (she/her):  
Chair, Bleeding Disorders Substance Use & Mental Health Access Coalition
  
- Joanne Fadale Wagner, MSW, LICSW (she/her):  
Social Work Care Manager, Dartmouth Health Hemophilia Treatment Center  
Member, Bleeding Disorders Substance Use & Mental Health Access Coalition





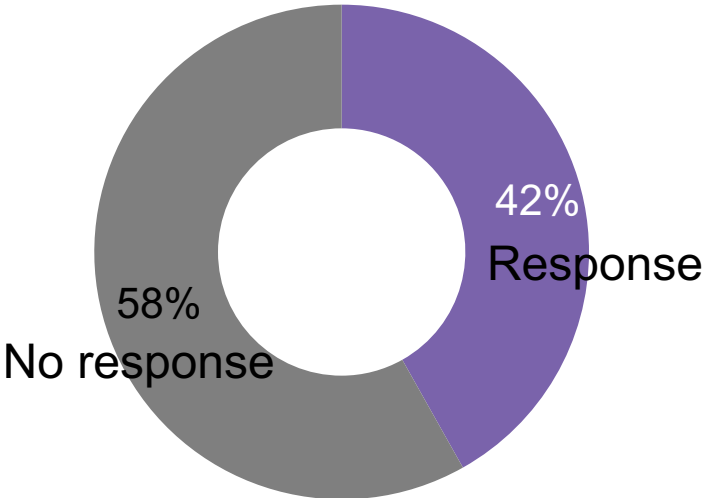
**The mission of the Bleeding Disorders Substance Use and Mental Health Access Coalition (BD SUMHAC) is to advocate for access to appropriate substance use and mental health treatment facilities for all individuals with bleeding disorders, with a focus on inpatient and residential facilities.**

# Derick's story ignites a national advocacy effort



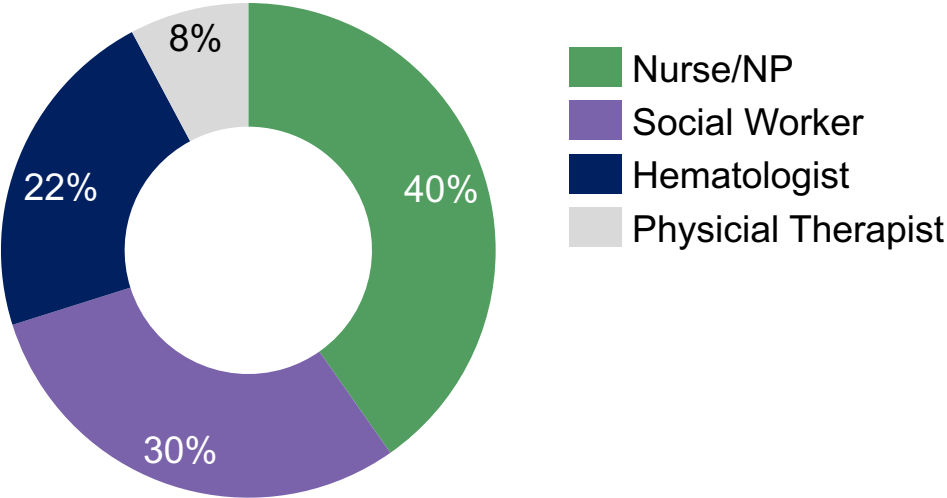
# Strong response from HTC clinician informed analysis

### HTC Response Rate Across US



59 HTCs, representing 42% of HTCs in the US, responded

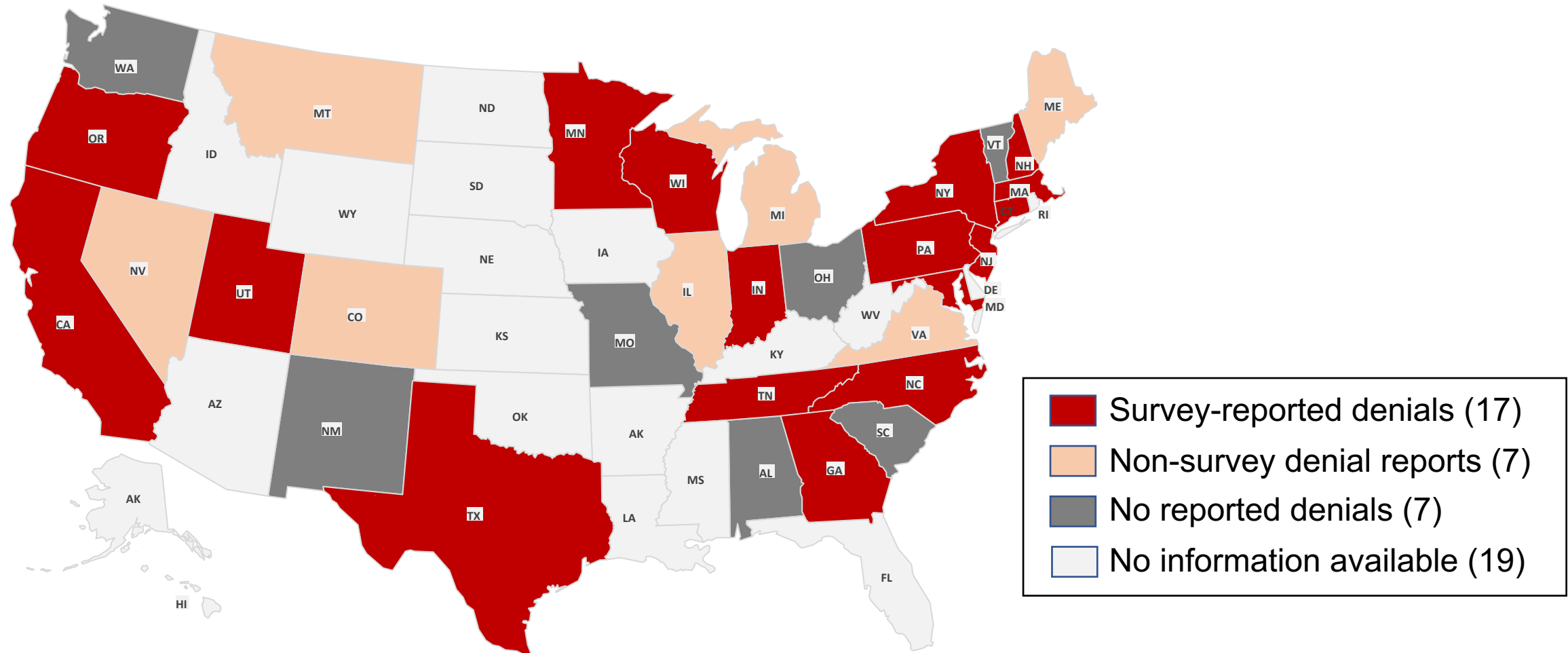
### Wide Range of Clinician Types Represented *n=77 Individual Responses*



All targeted provider groups represented in our sample, giving a **robust view of the issue** of clinician perspective.

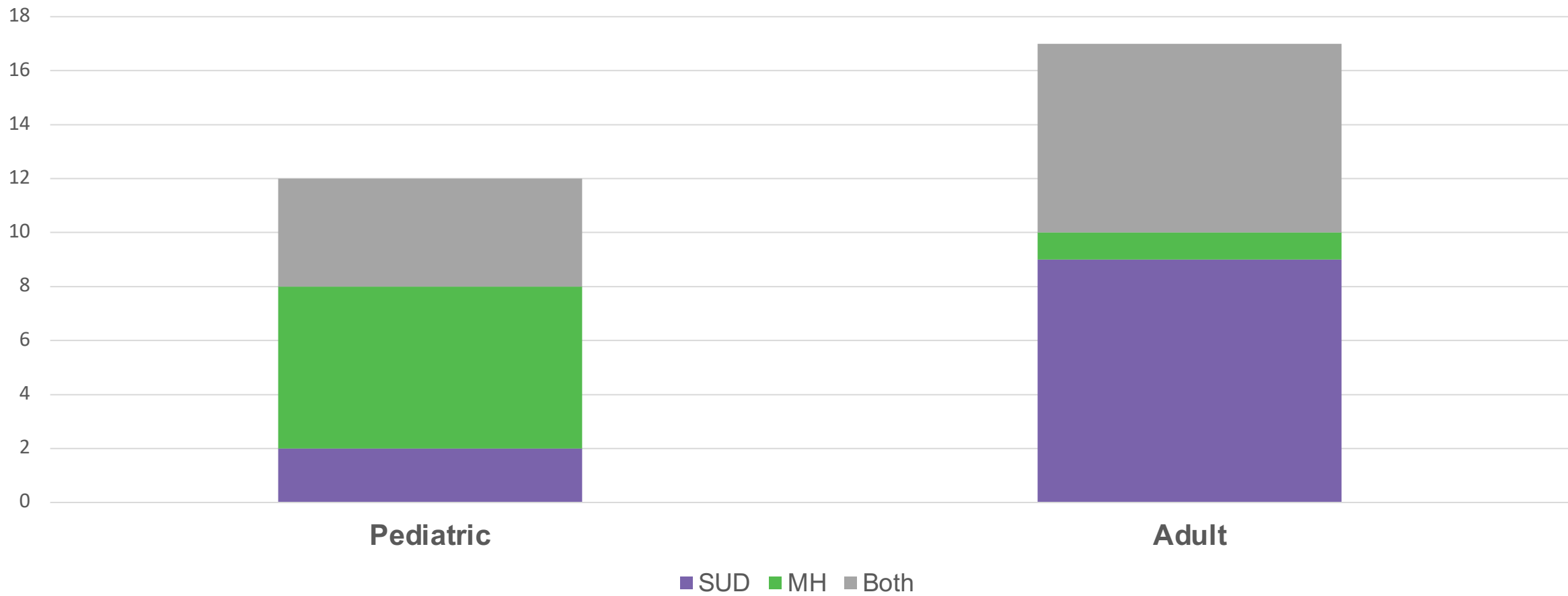


# 83% of providers who attempted to refer a patient with a BD reported a denial



# Denials impacted both pediatric and adult populations

Denials by Type and Age





# Why this work matters: Equity for BD community

## BD community needs access:

- Up to 58% people with BD report significant symptoms of anxiety
- Up to 63% people with BD report significant symptoms of depression
- People with BD use pain management strategies that can potentially lead to dependency
- If people are not able to access BH treatment, the consequences can be disastrous and even fatal.



# What is causing denials to care?

## 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

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

## Insurance issues

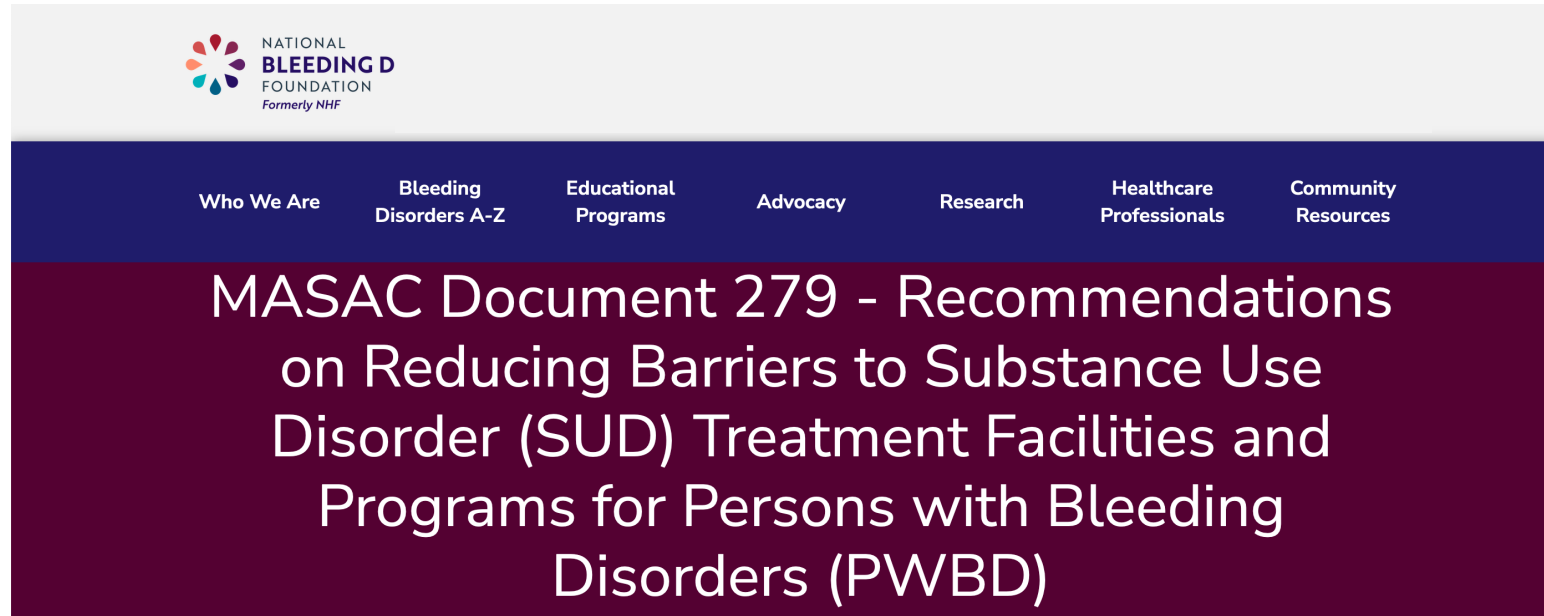
- “Insurance issues... Large co-pay”
- “Mostly insurance issues or not qualified getting approval for factor”
- “Factor not being covered”

## Access to factor

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



# Bleeding disorder experts: BD should not prevent access to SUD treatment



“Provided a person with a bleeding disorder is stable\* and can maintain their established treatment protocol, having an inheritable bleeding disorder should not preclude a person from receiving SUD treatment in a residential/inpatient setting.”

\*see section III for definition of stability from a BD perspective



# MASAC 279: Recommendations for HTC's

## Build relationships

- “establish relationships with their preferred residential/inpatient SUD treatment facilities prior to need.”

## Educate and collaborate

- “educating facilities about BD and collaborating with SUD facility staff about the best way to ensure that the PwBD is able to maintain their established BD treatment protocol while receiving treatment at the facility.”

## Advocate for access

- “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.”



# ASAM CRITERIA<sup>®</sup>

- National set of voluntary guidelines for SUD placement.
- States and other payers often incorporate the ASAM guidelines into their payment policies/ coverage determinations.

## Level 1

- OUTPATIENT TREATMENT

## Level 2

- INTENSIVE OUTPATIENT/HIGH-INTENSITY OUTPATIENT TREATMENT

## Level 3

- RESIDENTIAL TREATMENT

## Level 4

- MEDICALLY MANAGED INPATIENT TREATMENT



# National SUD leaders support access for people with chronic conditions, including BD

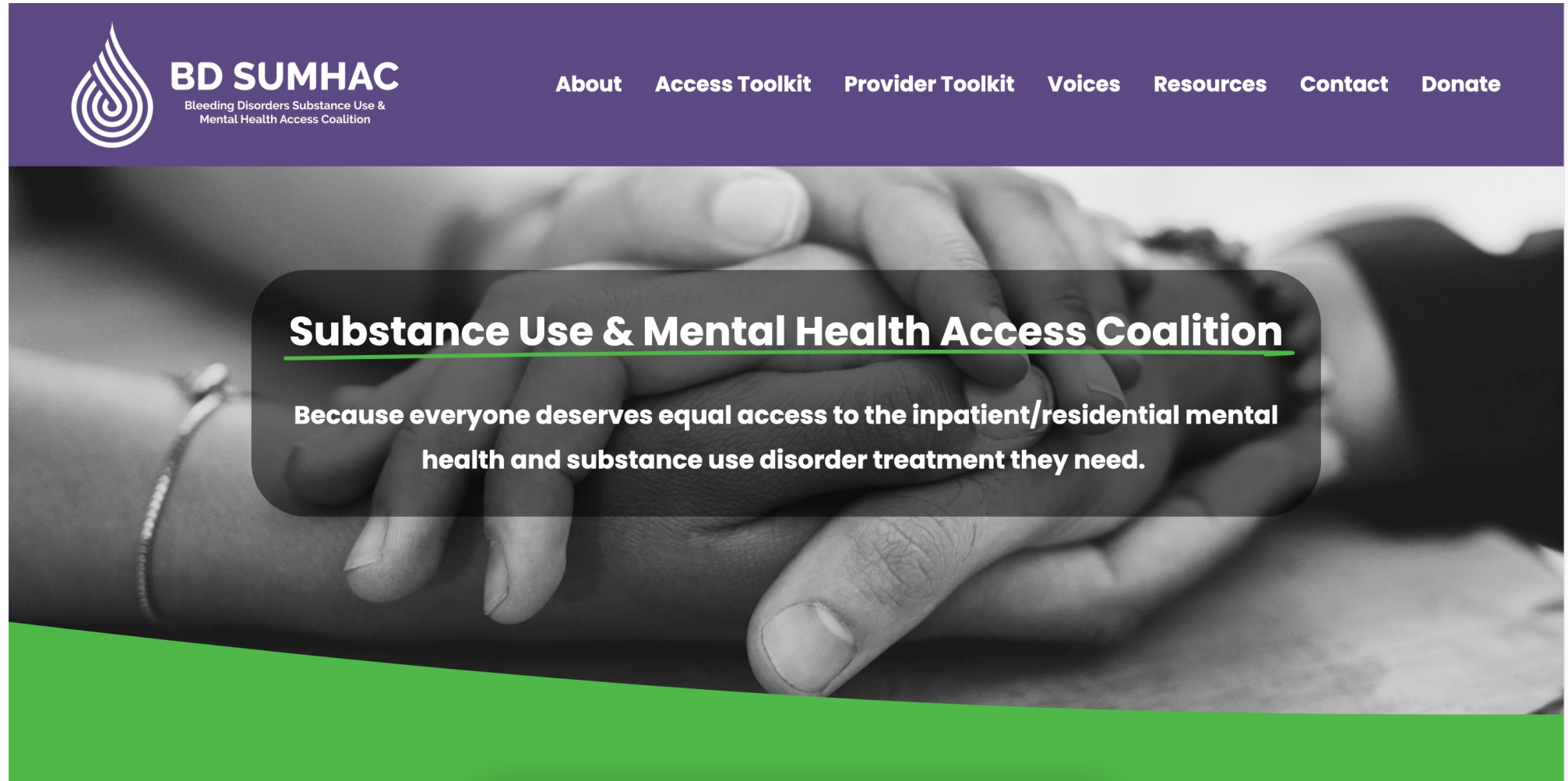
American Society of Addiction Medicine (ASAM)'s new language in the 4<sup>th</sup> Edition of the ASAM Criteria :

“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.”

(Released on October 5, 2023)



# Resources to help individuals who have been denied access



The image shows a screenshot of the BD SUMHAC website. The header is purple and contains the logo on the left, which is a stylized flame or drop shape. To the right of the logo is the text "BD SUMHAC" and "Bleeding Disorders Substance Use & Mental Health Access Coalition". Further right in the header are navigation links: "About", "Access Toolkit", "Provider Toolkit", "Voices", "Resources", "Contact", and "Donate". The main content area features a black and white photograph of several hands clasped together in a supportive grip. Overlaid on this image is a dark rounded rectangle containing the text "Substance Use & Mental Health Access Coalition" in white, underlined. Below this, in smaller white text, is the statement: "Because everyone deserves equal access to the inpatient/residential mental health and substance use disorder treatment they need." A green diagonal bar is visible at the bottom left of the main content area.

**BD SUMHAC**  
Bleeding Disorders Substance Use & Mental Health Access Coalition

[About](#) [Access Toolkit](#) [Provider Toolkit](#) [Voices](#) [Resources](#) [Contact](#) [Donate](#)

**Substance Use & Mental Health Access Coalition**

Because everyone deserves equal access to the inpatient/residential mental health and substance use disorder treatment they need.



# Provider Toolkit includes many resources



## Assessment & treatment options

Assessment & treatment options  
Considerations for referrals to MH/SUD facilities



## Printable Resource Guides and Letter Templates

A series of educational documents for facilities  
Editable letter templates to send to facilities



## Responding to a Behavioral Health Facility Denial

Step by step process for response



## Brainstorming Creative Solutions with Facilities

Creative suggestions for overcoming facility barriers





# Steps for responding to denials

1. Confirm the the denial was due to the person's bleeding disorder
2. Contact the BD SUMHAC Advocates for support
3. Educate the facility staff about bleeding disorders
4. Assure the inpatient/residential facility of the stability of the patient
5. Request "reasonable accommodations" under the Americans with Disabilities Act
6. File a discrimination complaint with the federal Department of Health and Human Services Office of Civil Rights
7. Contact your state's Ombudsman or Office of the Inspector General
8. Consider alternatives to inpatient/residential treatment



# BD SUMHAC Advocates Program

(in development)

For help with a denial, contact:

**Ryan Faden**

National Bleeding Disorders Foundation

(929) 687-3462

[rfaden@hemophilia.org](mailto:rfaden@hemophilia.org)

**Mark Hobraczek**

Hemophilia Federation of America

(202) 836-2530

[m.hobraczek@hemophiliafed.org](mailto:m.hobraczek@hemophiliafed.org)





Scan the QR code  
to find the Provider  
Toolkit!

[www.bdsumhac.org](http://www.bdsumhac.org)



**BD SUMHAC**

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# Access Toolkit for people with BD

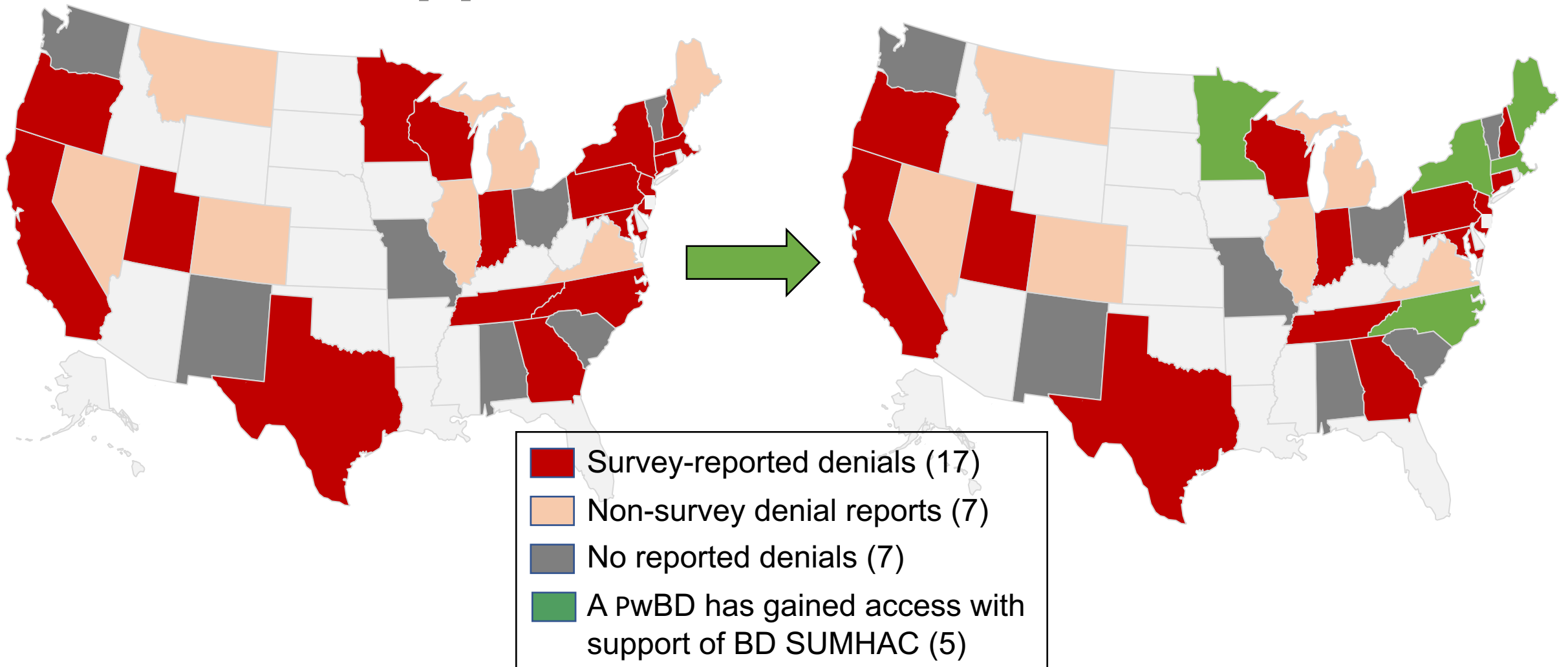
**Use the QR code to visit the BD SUMHAC website and find the BD SUMHAC Access Toolkit**

**Contents of the BD SUMHAC Access Toolkit:**

- 1. Talking with a provider about the options for addressing your substance use or mental health concerns**
- 2. Preparing for a referral to inpatient/residential substance use or mental health treatment**
- 3. Discussing bleeding disorders with a treatment facility**
- 4. Responding to treatment facility denials**



# Individuals with BD get access with BD SUMHAC support



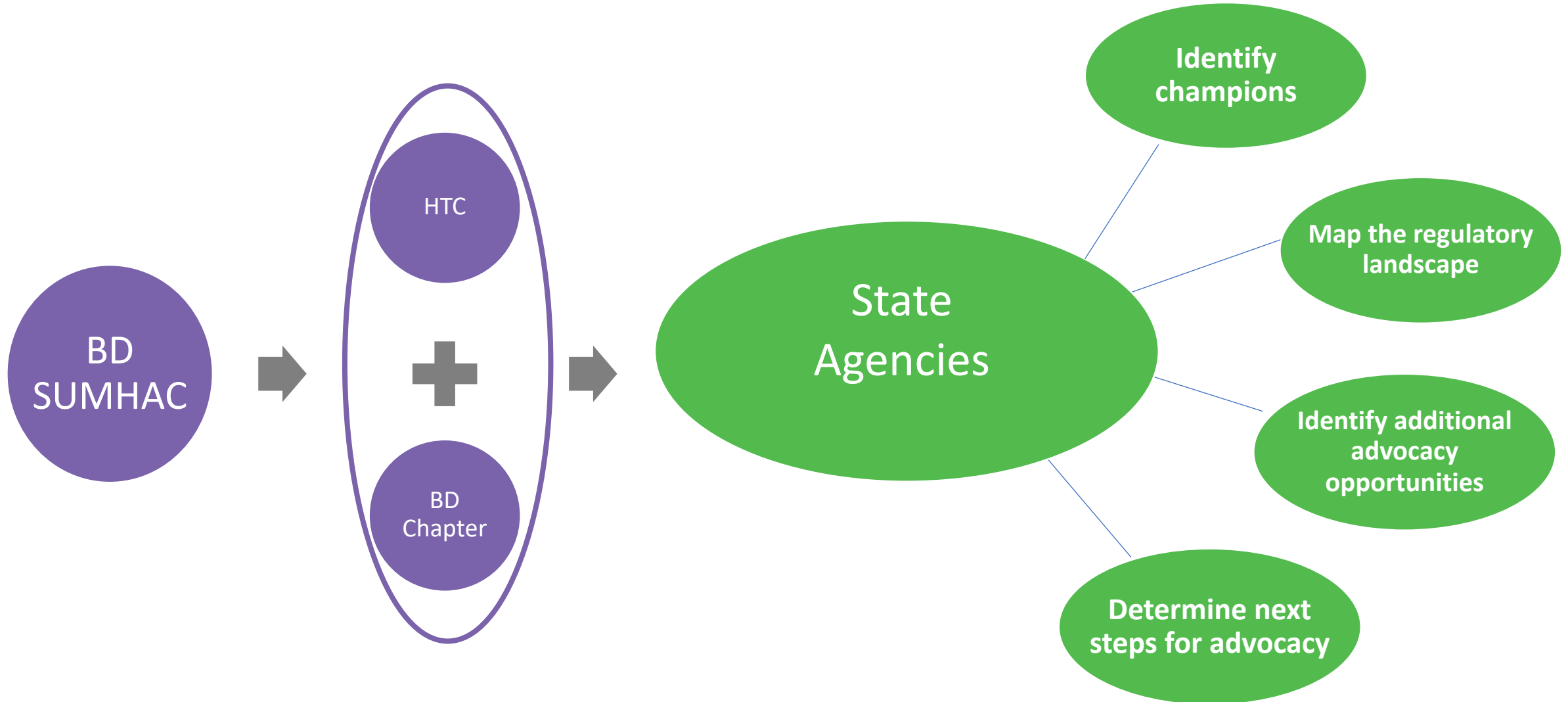
# Federal Advocacy

- Congress (Washington Days/ HFA Fly-in)
  - Proposed updates to HHS' regulations implementing Section 504 of the Rehabilitation Act of 1973
  - New rule seeks to address discrimination on the basis of disability in accessing medical care
- Meetings with the administration
  - Substance Abuse and Mental Health Services Administration (SAMHSA)
  - Office of Civil Rights (OCR)
- Accreditation organizations? (Joint Commission/ CARF)

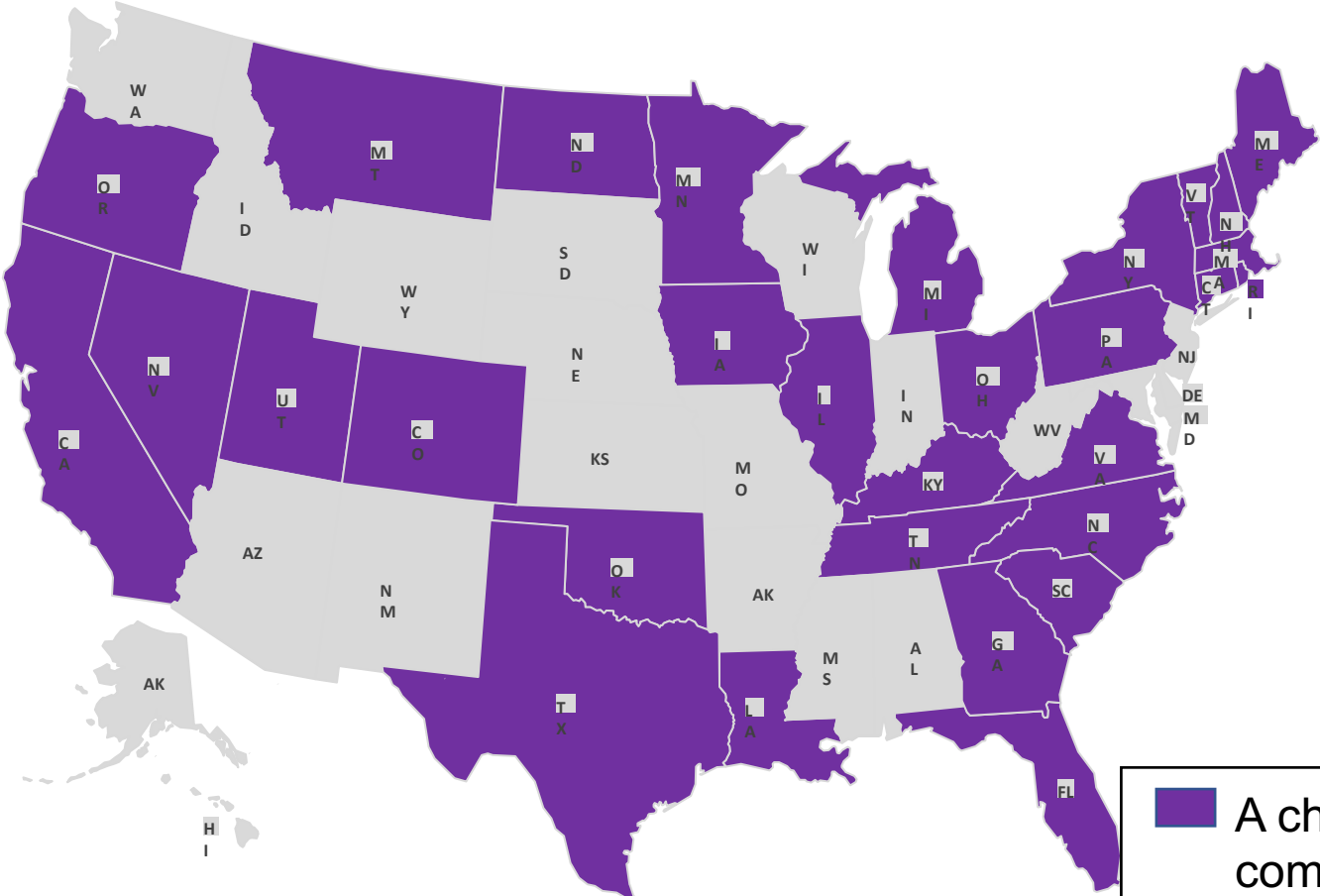
**\*Looking for advocates to help with our Federal Advocacy workgroup!\***



# State Advocacy Program: MI, MN, MT, NC, TX



# The BD community is united in advocacy



NATIONAL  
**BLEEDING DISORDERS**  
FOUNDATION  
*Formerly NHF*



■ A chapter, HTC, or community member living in the state is actively involved in the coalition







Learn more and get  
involved in BD  
SUMHAC today!

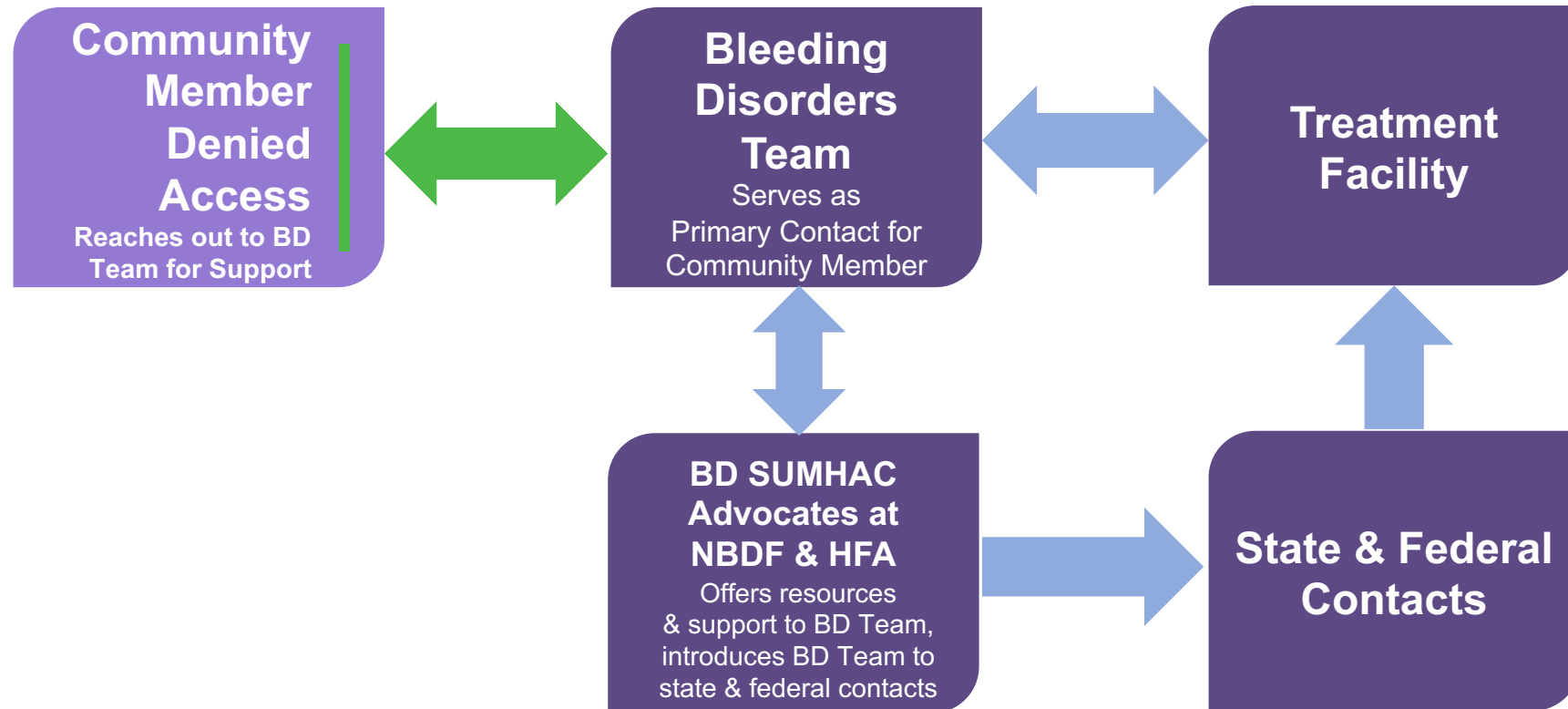
[www.bdsumhac.org](http://www.bdsumhac.org)



**BD SUMHAC**

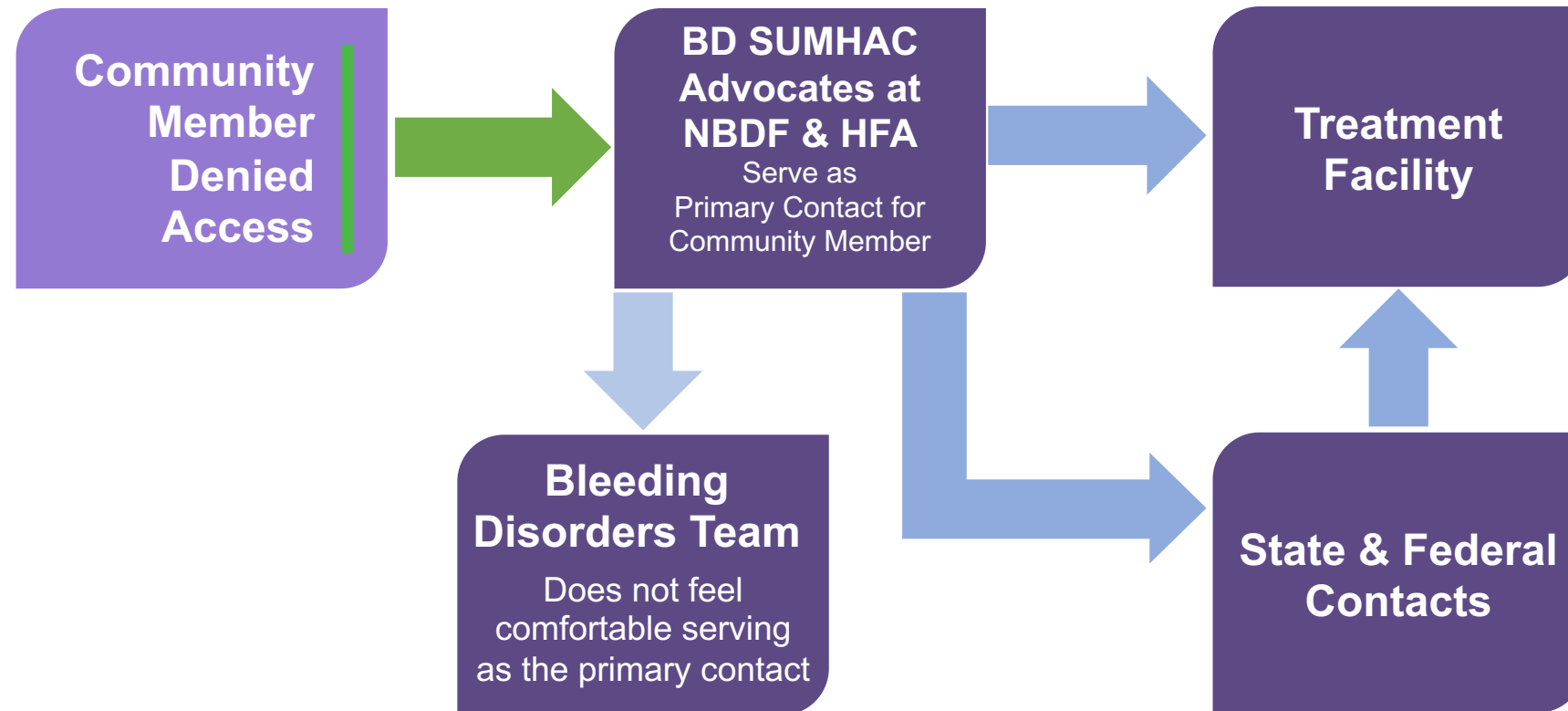
Bleeding Disorders Substance Use &  
Mental Health Access Coalition

# Bleeding disorders team serves as primary contact with support from BD SUMHAC Advocates



# Person Without A Bleeding Disorders Team

Or Whose BD Team Opted Not To Engage



# More structure and clarification needed for the BD SUMHAC Advocates program

- When and how should the Advocates communicate with HTC's when a patient reaches out to the Advocates first?
- What information should the Advocates collect during intake process?
- If the HTC is the lead, how can Advocates best support them?
- Who should chapters contact if a community member reaches out?
  - HTC, BD Team, BD SUMHAC Advocates?
- Under what circumstances can community stories be used?
  - (to improve internal resources/strategy/protocols? advocacy purposes? Etc.)

