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## Introduction

The United States is currently experiencing both a mental health and an opioid epidemic.<sup>1</sup> People with inherited bleeding disorders are not immune to these issues, in fact, recent studies showed that adults with hemophilia have been found to have high rates of depression, and both depression and anxiety are underdiagnosed in people with hemophilia.<sup>2</sup> People with inherited bleeding disorders are at risk for both acute and chronic pain.<sup>3</sup> Chronic exposure to opioids to treat pain can lead to dependency and a potential substance use disorder.<sup>4</sup> Additionally, individuals who are prescribed opioids, especially those prescribed opioids for longer than five days, are at greater risk of chronic opioid use.<sup>4</sup> In the United States, people with inherited bleeding and substance use and/or mental health disorders are often denied access to residential behavioral health treatment facilities despite being medically stable and meeting all admission criteria.

## Research Statement

To understand the rate of denials of referrals by Hemophilia Treatment Center (HTC) providers to residential behavioral health treatment facilities for people with inherited bleeding and substance use and/or mental health disorders to determine whether current admissions policies are creating inequitable access for the bleeding disorders community.

## Methods

The Bleeding Disorders Substance Use and Mental Health Access Coalition (BD SUMHAC) electronically surveyed the United States Hemophilia Treatment Center Network (USHTCN) providers from February to May 2022. The survey asked demographic information and experience(s) with people with bleeding and substance use and/or mental health disorders. The survey was sent to providers in 140 federally supported USHTCN.

## Results

Responses were received from 59 HTCs (42%). 77 individuals responded; 24 nurses, 22 social workers, 17 physicians, 7 nurse practitioners, and 7 physical therapists. 29 HTC providers referred patients with inherited bleeding disorders to residential behavioral health treatment (substance use and/or mental health), of which 24 reported denials for admission due to the patient's diagnosis of a bleeding disorder (82.7%). Pediatric and adult patients were denied care [figure 1] and care was denied for mental health and substance use treatment facilities [figure 2]. Reported denials were seen across the United States [figure 3]. Providers reported many reasons for denials [figure 4]. In response to these results, BD SUMHAC created an advocacy road map and are actively making changes at the state and federal level in the United States [figure 5].

Figure 1. Denials by Age

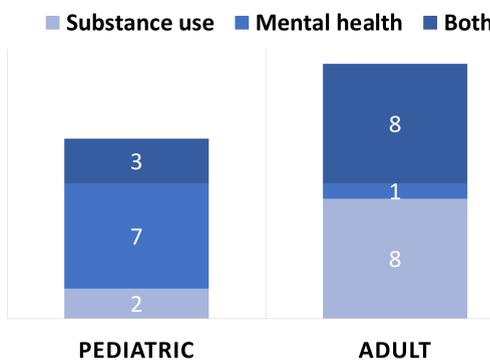


Figure 2. Denials by Facility Type

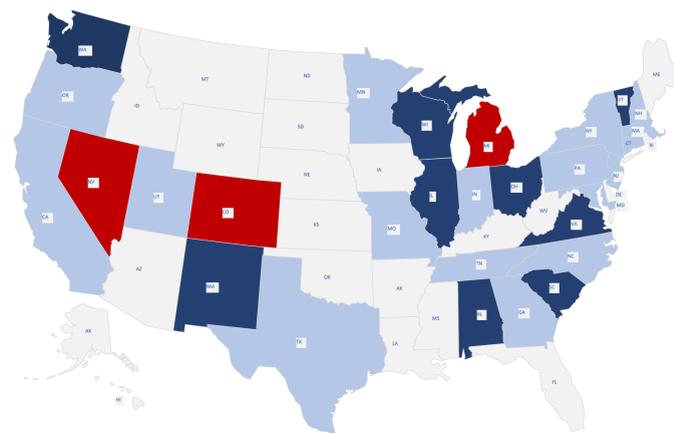
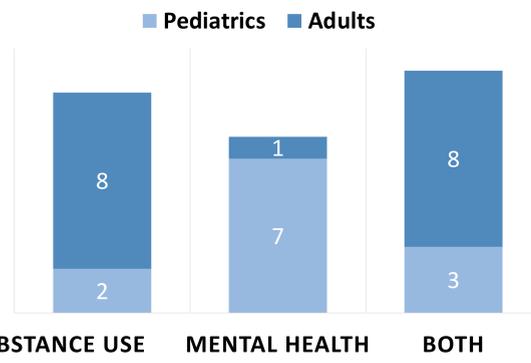


Figure 3. Denials by State

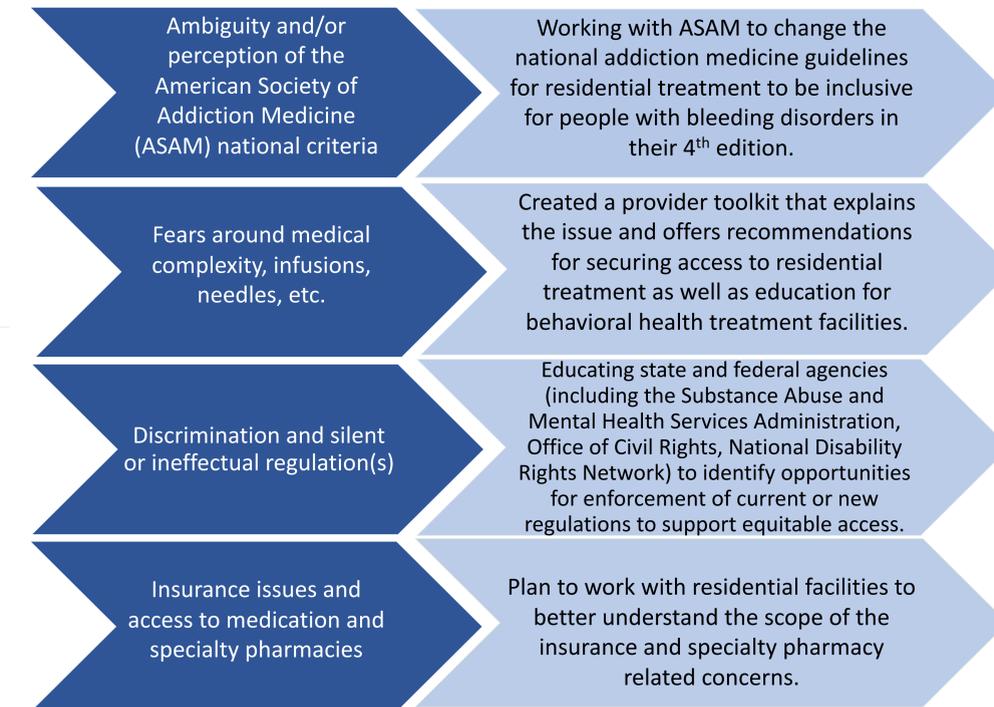
- Reported denials (17 states)
- Non-survey denials (3 states)\*
- No reported denials (9 states)
- No respondents (21 states)

\* After the survey data was collected, 3 additional denials were reported which we did not include in our data.

Figure 4. Reasons for Denials

Infusions	"They did not give IV medication/infusions, needs ASAM level 4" "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	"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 and/or 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..."

Figure 5. Advocacy Road Map



## Conclusion

In the United States, people with inherited bleeding and substance use and/or mental health disorders have difficulty accessing appropriate care due to their bleeding disorder. Access to treatment is a health equity issue. Every person should have equal access to residential treatment regardless of their ability to clot, treatments they use, or state of residence. BD SUMHAC is working with bleeding disorder providers as well as advocating on the state and federal level to address this inequity.

## References

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