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Accessibility of substance use disorder services for the d/Deaf and Hard of Hearing community Kimberly Miller HSP 385, Applied Research Methods

Abstract

The d/Deaf and Hard of Hearing (d/D/HH) community faces considerable barriers to public services, including medical care. Research relevant to this population across several domains still needs to be explored. What is available is seriously outdated, with very little new research published in the past decade. A review of available studies suggests that this population experiences a high prevalence of risk factors for increased health concerns, including mental health and severe substance use disorders (SUDs). Given the elevated prevalence within the d/D/HH population of childhood maltreatment, trauma, depression, and Posttraumatic Stress Disorder (PTSD), and the links between these negative experiences and disorders with SUDs, it is not a leap to conclude that the d/D/HH may have a significant need for SUD services. However, the d/D/HH population has several unique needs that must be met. Few SUD providers offer specialized services for the d/D/HH community, and standard SUD service providers are generally unprepared to meet their specialized needs. These include cultural sensitivity and linguistic accommodations across all services, from screening and assessment, detox, and inpatient services to recovery support programs. This pilot study will explore the need for SUD services within the d/D/HH population and their barriers to accessing them. Previous research and self-interviews of d/D/HH individuals who have received SUD services within the past two years conducted as part of this study will be reviewed and analyzed to determine the degree of accessibility offered by SUD service providers and the need for further research into this issue. Because of the lack of d/D/HH voices in the development of policies affecting this population, I felt it was imperative to use self-interviews relating to lived experiences of receiving SUD services from d/D/HH participants to collect the data vs. surveying facilities' accommodation readiness.

Accessibility of substance use disorder services for

the d/Deaf and Hard of Hearing community

The d/Deaf and Hard of Hearing (d/D/HH) community faces considerable barriers to public services, including medical care. Research relevant to this population still needs to be explored. What is available is seriously outdated, with very little new research published in the past decade. Methodological issues, such as small sample sizes, sampling methods, and linguistic challenges, leave many studies riddled with questionable reliability and ethical concerns (Anderson, 2018; James et al., 2022). For example, many studies focus on people with disabilities as a general population but rarely focus on the specific issues relating to the d/D/HH experience. These challenges leave the d/D/HH voice unheard concerning health care and their needs unmet.

A review of available studies suggests that this population experiences a high prevalence of risk factors for increased health concerns, including mental health and severe substance use disorders. More studies on the health care disparities in the d/D/HH community, including the accessibility of services, are essential to assess needs and barriers better and develop specialized services for this population. The goal of this paper is to explore how accessible substance use disorder services are for the d/D/HH community.

Literature Review

People who experience significant hearing loss are members of one of the most diverse groups in the world. Within this community, the term "d/Deaf/Hard of Hearing" (d/D/HH) is often used as a show of solidarity in the experience of living with hearing loss. It is widely accepted that "deaf" refers to the medical condition and some of the people who experience

it. <u>Hard of hearing people experience hearing loss but typically are not entirely deaf and</u> generally identify with hearing culture. <u>Deaf</u>, capitalized, refers to people with hearing loss who identify with a unique culture and languages based on the experience of deafness and the use of signed languages. Hearing loss is a spectrum with a wide range of lived experiences that is beyond this paper's scope but has a significant impact on accessibility issues.

Substance use is strongly linked to trauma. Surveys of adolescents in substance use treatment report that 70% of the patients had a history of trauma exposure. There is also a high comorbidity between Posttraumatic Stress Disorder (PTSD) and substance use disorders (SUDs). Up to 59% of youth diagnosed with PTSD develop SUDs (Khoury et al., 2010). Given the elevated prevalence within the d/D/HH population of childhood maltreatment, trauma, depression, and PTSD, and the links between these negative experiences and disorders with SUDs, it is not a leap to conclude that the d/D/HH may have a significant need for SUD services.

Schenkel et al. (2014) cite that people with disabilities are at a significantly increased risk of childhood maltreatment, 3.44 times higher than those without disabilities. They also experience more types of maltreatment starting at a younger age than non-disabled people, mainly in the home or specialized school settings. Also, a greater risk of neglective outcomes due to ineffective communication, such as parental frustration or fund of information deficits, has been linked to elevated rates of trauma and PTSD in d/D/HH adults.

Anderson et al. (2018) reviewed the 2013-2014 data from the National Health and Nutrition Examination Survey, comparing alcohol and drug use between participants based on their hearing status. The results revealed that d/D/HH respondents when they used substances, tended to be heavy users. d/D/HH participants reported they were more likely to consume

alcohol and use cannabis regularly and heavily. Health illiteracy due to language barriers was cited as a primary factor in the development of SUDs among d/D/HH, in particular regarding the health risks of substance use and binge drinking and what constitutes a substance use disorder.

However, the d/D/HH population has several unique needs that need to be met within such services that hearing-centric SUD services are generally unprepared to meet. These include linguistic needs such as counselors fluent in ASL or clinically trained and certified interpreters, used either in person or through Video Remote Interpreting (VRI). Written materials such as documents, educational material, Release of Information (ROI) forms, assessments, treatment plans, and informed consent forms may need to be translated into ASL, and the client's answers translated into English. Appointments may need to be scheduled to allow more time for communication and accuracy. Video educational material may need to be captioned, and video phones may be required to schedule appointments or call referred services (Yates & Dreany-Pyles, 2017).

There are potential financial barriers. Only 54% of d/D/HH are employed in the US (NDC, 2023). Although most d/D/HH people in the US have health insurance, many are on Medicaid or Medicare, which may have limitations and restrictions about the type and location of care. For example, a lack of local agencies that provide accessible services may require extensive travel (and additional expense) for the client, particularly for inpatient treatment.

Sometimes, clients may only find accessible care in a state other than where they reside. Medicaid benefits are generally not transferable to other states than the one in which they are issued without special permission, and benefits do not always adequately cover the costs.

Moreover, accommodations and specialized programs for the d/D/HH are expensive, and not all agencies have the funds to adequately support such practices (Titus & Guthmann, 2010).

Cultural competence is also a requirement for accessible services. The counselors should be d/D/HH informed of the unique experiences, expressions, and understanding of concepts – including that of deafhood (cultural view of deaf) vs. disability (medical view of deaf) (Ladd, 2005) – of this population. Furthermore, support and follow-up programs need to be culturally sensitive, such as linguistic access to support meetings, preferences about a hearing or d/D/HH sponsor, or if sober housing is d/D/HH friendly and accessible (Yates & Dreany-Pyles, 2017). For example, Oxford Houses are self-sustaining programs where the clients pay rent. Many d/D/HH lack employment, especially if they had to relocate for services and may be unable to pay for these housing options (Alverez et al., 2006).

There are also considerable risks of increased isolation of individuals with mental health concerns or SUDs within this population because of the stigma against mental and behavioral health conditions, as well as the challenge of cutting off former substance-using friends and changing social circles to maintain sobriety (Alverez et al., 2006; Yates & Dreany-Pyles, 2017; Missouri Department of Mental Health, 2014).

Methods

The research followed a two-stage approach. The first stage involved developing the survey question and research protocol, and the second stage focused on piloting the research method.

Stage 1: Research Protocol Development

Due to the stigma within the d/D/HH population concerning mental and behavioral health needs and substance use disorders and the high degree of association within the relatively small

community, utmost care must be taken to protect the identities of the respondents and participants in this study. Furthermore, to be ethical regarding cultural sensitivity and linguistic accessibility, it is best not to conduct this research without thorough oversight from a culturally competent professional. Therefore, I have approached a professional who has experience with the screening, assessment, treatment, and follow-up of substance use disorders within the d/D/HH community for feedback on the development and design of this pilot study.

Dr. Deb Guthmann has extensive experience working with and advocating for the d/D/HH community for over 40 years as a hearing ally. She is also a nationally recognized lecturer, administrator, researcher, and educator. Dr. Guthmann was the founding Director of one of the only inpatient SUD treatment facilities in the United States for d/D/HH, the Minnesota Substance Use Disorder Program for the Deaf and Hard of Hearing. She has developed written and ASL videotaped materials designed explicitly for d/D/HH individuals in SUD treatment and training. She is the editor and contributor of the book, "Deaf People in the Criminal Justice System: Selected Topics on Advocacy, Incarceration and Social Justice." She was also an advisor for the award-winning film "Being Michelle," the true story about a Deaf woman with autism who survived incarceration and abuse and has used art to help her heal.

Stage 2: Pilot Study

Participants

Volunteer participants were selected from individuals in the d/Deaf/Hard of Hearing (d/D/HH) community who have sought out substance use disorder services such as assessment, inpatient or outpatient treatment, client-led support groups such as Alcoholic Anonymous or Deaf of Drugs and Alcohol (DODA), and follow-up services within the past two years.

Participants were recruited through the d/D/HH community online forums, with information for private contacts that the community cannot track. The respondents are screened for regional locations to increase the likelihood of experiences with multiple agencies being included.

Because this is a pilot study, 3 participants were chosen.

Materials

This study uses a qualitative research method, asking the participants to recount their experiences with receiving substance use disorder services as a d/D/HH person. Self-interviewing, a form of interviewing, was adapted to be linguistically appropriate for d/D/HH participants (Allett et al., 2011). Because of the challenges this population faces with linguistic accessibility, the self-interview was administered as a video in ASL or digitally in written English, according to each participant's preferences.

The self-interview presents one open-ended question with certain parameters, "Please share with the research team your experiences concerning accessibility when seeking substance use disorder services." Specific parameters are given (see Appendix Instructions, 4 a, b, c) for the question to ensure inclusion of critical data in the answers. Prompts were also provided to be used as desired by the participant (see Appendix). The participants are asked to record their responses using a video of ASL or in a written format, according to their preference.

Procedure

Participants are asked what their preferred method of communication would be: ASL or written format. They are then provided with either a video recording of the study question, "Please share with the research team your experiences concerning accessibility when seeking substance use disorder services," and instructions on how to complete the self-survey. The instructions ask the participant to specify the type of services they received: screening,

assessment, inpatient, outpatient, detox, individual or group counseling, or both, and any other services such as housing and client-led support groups such as Alcoholics Anonymous, Narcotics Anonymous, Smart Recovery, etc. They are also asked to specify if the services were received in person or through telehealth, if they are currently in recovery, and how often they have participated in treatment. The participants are invited to use the prompts provided (see Appendix) to facilitate their sharing of their experiences, feelings, and perceived results of the services received.

Data recorded in ASL is first interpreted and transcribed into English. Then, all data offered by the participants is analyzed. The type, duration, and frequency of services received are noted. References to the availability of accommodations, the presence - or lack thereof - of barriers in language, attitudes - perceived or actual - from service professionals and peers, feelings about a sense of safety and belonging or a lack thereof, access to written and video material, presence of learning and skill building, and perceived overall results of services obtained is pulled from the data, charted, analyzed, and the results shared with the participants and in this space.

Results

Dr. Guthmann and I discussed the research project and the methods I developed to gather data. We discussed the need for culturally and linguistically appropriate services for this community and the barriers the d/D/HH population faces when seeking SUD services. We also discussed the challenges of the availability of such services for this community, and she voiced concern that research and services have regressed in recent years.

We discussed the importance of d/D/HH voices in research and agreed that the selfinterview approach would be an appropriate method to achieve that. We also discussed financial challenges d/D/HH clients might face in securing services, such as Medicaid restrictions on outof-state services and costs of traveling to distant, albeit otherwise accessible agencies for the
individuals. For example, a d/D/HH individual from Kitsap County who receives Medicaid in
Washington state would have to travel to Vancouver or Bellingham, several hours distant in
opposite directions, for services. She also reminded me to consider differentiating between
inpatient and outpatient services received.

I would like to thank Dr. Guthmann for her time and valuable input in developing this study. Her feedback helped me focus the direction of the study and develop parameters and questions that would most likely generate rich data for analysis. I greatly appreciate her experience in the field and willingness to guide me.

<u>Limitations and strengths</u>

There are some limitations in this study. First, this is a pilot study, so the sample size is very small and, therefore, not generalizable to the d/D/HH community. More research with larger samples is necessary. Deafness is a spectrum that creates a wide range of experiences and perspectives among individuals within the d/D/HH community. This study does not take into account intersectionalities many d/D/HH individuals experience, such as DeafBlind, DeafDisabled, BIPOC Deaf, or queer Deaf, that may contribute to barriers faced in seeking SUD services. Larger samples would allow for a much more accurate assessment of the community's experience with substance use disorder services.

Leaving the interview open-ended and using suggested prompts versus specific, required questions to be answered leaves the study vulnerable to missing data due to the participant not sharing specific details deliberately or unintentionally. A larger sample increases the likelihood of

essential data being captured by the interviews, including emerging patterns that offer a more stable picture of similar experiences among services received.

However, the strength of this study is the focus on the d/D/HH voice and experience from their perspective. Few studies on the needs of this community allow individuals to speak freely of their experiences, which can generate data with depth and meaning. Also, the study is designed, administered, and analyzed by a Deaf researcher with support from a culturally and linguistically skilled professional in SUDs. This perspective facilitated the generation of questions and prompts that are culturally significant to this community. In contrast, most research is designed by hearing individuals rather than d/D/HH researchers who understand the unique needs and culture of the d/D/HH population. Research that includes Deaf voices and is created by Deaf researchers enhances relevancy and accuracy (Barnett, 2011).

Discussion

92% of all children with hearing loss are born to hearing parents, and only about ¼ of those families learn ASL (James et al., 2022). A significant proportion of those families receive guidance from professionals with oralist and audist views who insist that the child will suffer developmentally for learning ASL. This attitude, now repeatedly proven false, has and is still leaving many d/D/HH in a communication limbo of sorts, often with some degree of language deprivation, sometimes severe (Lane, 1999; Humphries et al., 2012; Hall et al., 2019).

It is estimated that only 500,000 people in the United States use ASL, out of approximately 2 million who are fully deaf and 48 million who have significant hearing loss (Lacke, 2020). d/D/HH individuals who do not use ASL may prefer various other forms of communication, including speech and lipreading English, written English, captions or speech-to-

text, or other forms of manual language such as Signed Exact English. However, because English is a second language for many d/D/HH, the reading and writing proficiency level of a d/D/HH individual may be insufficient for full access (Yates & Dreany-Pyles, 2017). Furthermore, lipreading is only about 30-40% accurate, and speech-to-text technology is fraught with inaccuracies. These situations leave a d/D/HH individual who does not use ASL with inadequate access to communication with others.

Language barriers are generally the first thing that comes to mind when a hearing person encounters d/D/HH people. However, the overarching nature and complexity of those barriers and the consequential experiences many d/D/HH face because of them are often overlooked. Studies report elevated rates of trauma and Posttraumatic Stress Disorder (PTSD) symptoms in d/D/HH adults (Schenkel et al., 2014), and emotional maltreatment scores are reported at significantly higher rates by d/D/HH than hearing. Emotional maltreatment is often associated with low self-esteem, depression, feelings of shame, and worthlessness. (Schenkel et al., 2014). It was also found that language barriers significantly affect accessibility and cultural competency in health care, particularly in mental and behavioral health, for the d/D/HH. Furthermore, these issues are linked to significant disparities in health outcomes for this population (Wilson & Wells, 2009; Kapoor et al., 2023).

Language is crucial in developing a fund of information about health, proper care, coping strategies, what constitutes abuse, and safety behaviors (Schenkel et al., 2014). Many d/D/HH struggle with fund of information deficits and a lack of agency in navigating their health care, including substance use services. Language deprivation (LD) is linked with learning difficulties, poor emotional regulation, and an increased tendency toward unregulated externalization of

emotions. Moreover, large numbers of d/D/HH mental health clients in Intensive Outpatient and Outpatient programs show some degree of LD (James et al., 2022).

What programs and tools exist for substance use disorder services are designed by hearing people for a hearing client base. There are no validated assessment tools or treatment programs for the d/D/HH population (Titus & Guthmann, 2010). Little work has been done to adapt existing programs or tools for this population. To date, Signs of Safety is the only program that has been adapted and is still in the validation process (Anderson et al., 2021).

Specialized substance use disorder services for the d/D/HH are rare. Because the d/D/HH community is relatively small (5% of the population), those requiring SUD services are a low-incidence population, making it challenging to aggregate "critical mass" to incite developing and maintaining specialized programs. Such programs are expensive, some have low census, and they are difficult to staff with specially trained and credentialed counselors (Titus & Guthmann, 2010). There are only three such programs in the United States.

One program is in Minnesota (M Health Substance Use Disorder Lodging Plus Program); a second is in Ohio at Wright State University (Substance Abuse Resources and Disability Issues - SARDI); the third is in Georgia through the Department of Behavioral Health and Developmental Disabilities (DBHDD). The DBHDD works with Caring Works, Inc. to provide an inpatient, men-only program (Caring Works, n.d.). Minnesota has an intensive outpatient program with a residential component (Minnesota Substance Use Disorder Treatment Program, n.d.). SARDI in Ohio utilizes telehealth for administering services, including group support programs through the Deaf Off Drugs and Alcohol (DODA) online network, such as Alcoholics Anonymous (SARDI Program, n.d., a; SARDI Program, n.d., b).

These specialized programs have limitations, including capacity, challenges due to state Medicaid restrictions for out-of-state patients, limited services for women, and difficulties procuring enough funding and specially trained staff to meet the client's needs. However, they are essential for this population because they allow d/D/HH clients to be placed with people who share common experiences and can identify with each other. They also reduce the risks of enabling, through patronizing and pathologizing, that occur with hearing staff working with d/D/HH clients (Titus & Guthmann, 2010).

Agencies and programs that are primarily hearing-centric are much more common and may be more accessible regarding locale. Although they may be able to hire interpreters or use VRI and CART services to assist with appointments and sessions, these are only generally available during formal activities. This restricts clients' access to social interactions with peers, including needed support from sponsors, making establishing recovery support networks very difficult. Furthermore, being forced into mainstream treatment services may also be viewed as being expected to assimilate into hearing culture, which is a very sensitive issue within the d/D/HH community (Alverez et al., 2006).

Support groups often run on tight budgets funded by donations and cannot afford to hire interpreters or CART services for meetings and activities (Yates & Dreany-Pyles, 2017; Alverez et al., 2006). These challenges are particularly difficult to navigate for sober housing and inpatient programs, where there are many hours of social interaction between peers and staff outside of formal treatment sessions. The isolation associated with the lack of social communications outside of treatment activities is potentially triggering for d/D/HH.

Because of these and many other challenges d/D/HH individuals face when trying to access mental and behavioral healthcare, there is also significant mistrust within the community

for hearing professionals in the field. Barriers, including attitudes, linguistic power differentials, and lack of cultural competency experienced in hearing-centric facilities, have sometimes caused repeated traumatization through microaggressions, communication struggles, isolating experiences, misdiagnoses, inappropriate treatment plans, dangerous medicine management, delayed or denied care, all of which are often triggers for substance use in this population.

There have been multiple lawsuits citing increases in patient stress, diminished patient-centered care, and healthcare-associated trauma. There have been many cases where d/D/HH ASL users have been denied effective communication while in mental health and substance use disorder treatment (James et al., 2022). The Americans with Disabilities Act of 1990, Section 1557, states that facilities that receive federal funds are required to provide "reasonable accommodation" for people with disabilities who are seeking services. James et al. analyzed Substance Abuse and Mental Health Services Administration (SAMHSA) data from 2019 on the prevalence of ADA compliance in facilities in the United States. They found that most SUD treatment facilities that receive federal funds are not compliant - 59%. 85% of facilities that did not accept government funds for payment are non-compliant. Thirty-five states had rates of 50% or more of non-compliance.

Telehealth and treatment through the Internet have been used within the d/D/HH community for decades with equivalent outcomes to traditional treatment programs. d/D/HH clients have expressed a preference for internet-based treatment services, and there is significant support for the use of telehealth services for psychoeducation purposes (Wilson & Wells, 2009). The development of specialized services administered through telehealth can be more cost-effective with a broader reach using fewer specialized treatment-trained staff. DODA offers access to 12-step and recovery support groups and is partially federally funded. In Ohio, they

also offer group counseling through telehealth (Titus & Guthmann, 2010). Further development of telehealth options for d/D/HH seeking accessible SUD treatment services could be another step in making treatment and outcomes for this population accessible.

Conclusion

Nearly all substance use disorder programs are hearing-centric; they are developed by hearing people for hearing clients. No validated assessments or treatment programs are designed for use with the d/D/HH population. Moreover, despite federal law as laid out in the Americans with Disabilities Act of 1990, there is a high noncompliance rate among SUD treatment facilities in the United States.

Although available studies of d/D/HH substance use are sparse and riddled with issues that bring their validity into question, it is clear that,

- more culturally and linguistically appropriate research is necessary, including d/D/HHdeveloped research,
- 2. there are clear links between trauma and SUDs across all populations and
- 3. d/D/HH experience higher rates of risk factors for developing SUDs than the hearing population.

This population has many unique needs that require accommodations to bridge language disparities, accessibility issues with appointment making, screening, and assessment, documentation, educational materials, therapy sessions, recovery support systems, including housing, and more. This establishes the need for culturally sensitive and linguistically appropriate substance use disorder programs and follow-up sobriety support for this population.

However, there is a lack of specialized SUD services in the United States for the d/D/HH community, only 3 across the entire nation.

Accommodating the needs of this population is nuanced, complex, costly, and leaves many gaps such as lack of access to linguistically and culturally appropriate sober support networks and recovery programs which can impact successful outcomes. Telehealth options appear to be the most accessible system for SUD services for the d/D/HH, but there still few available established services. More research is needed on the accessibility of SUD services for the d/D/HH community and what improvements can be made.

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Appendix

<u>Instructions for the self-survey:</u>

- Choose which format you prefer to participate in: ASL video recording or written English.
- 2. Watch the video or read the documents describing the topic question and suggested prompts. You can use as many or as few of the prompts as you wish, but the more you use, the more information we have to answer the question of how accessible substance use disorder services are for the d/Deaf and Hard of Hearing community.
- 3. Either record your answer in ASL or write them in a format that you are comfortable with. For example, make a list of answers, write a letter, a story, or an essay. There are no right or wrong answers or formats. Your answer can be as long as you wish, and you can take breaks and make changes as you feel is necessary.
- 4. Please include the following in your answer:
 - a. What services did you use? Screening, assessment, inpatient, outpatient, detox, individual counseling, group counseling, support groups, sponsor. Please list all that apply.
 - b. How long have you been in treatment and how many times have you tried treatment?
 - c. Are you currently in recovery? Do you feel the services were helpful for you to maintain your recovery? Why or why not?
- 5. Please return the survey within 7 days of receiving these instructions.

6. This survey is completely voluntary, and you can withdraw at any time by informing us of your wish to do so. If revisiting your experiences with treatment is triggering for you in any way, please be sure to reach out to your support team, a trusted family member, or sponsor for help.

Prompts for use to support self-interview process. Use as many as you feel comfortable using:

- How easy or difficult was it to find services that accommodate d/Deaf and Hard of
 Hearing clients? How far did you have to travel for services? How affordable were
 services? Describe your experience of making appointments with agencies you sought
 services from.
- 2. Describe your language and communication preferences. Were those preferences accepted and supported by the agencies you sought services from?
- 3. Describe your experience with the accommodation provided. Were your requests fulfilled? If not, what was done differently? Was it explained to you why your requests could not be filled? Were you part of the process of finding alternative accommodation?
- 4. Describe any feelings you had while receiving services. These are some feeling words:

 Accepted, included, isolated, different, confused, frustrated, inspired, informed,
 understood. Please share any that come to mind and describe why you felt this way.
- 5. Describe how effective you feel the services were for the treatment of substance use disorders for d/Deaf or Hard of Hearing clients. What was most helpful? What was most difficult or unhelpful? What would work better for you?