

Learning from the Disability Community to Address Barriers to Mental Health Care

Kimberly Aguillard

NASEM Workshop on Essential Health Care Services Related to Anxiety and Mood Disorders in Women

April 2024



People with disabilities* in the United States

- / One in four Americans (61 million) live with disabilities**
- / Federal definition: substantial limitation in major life activities**
- / Categories: physical, cognitive, sensory disabilities**
- / Certain groups have higher rates of disability: Adults aged 65+, Alaska Natives/Non-Hispanic American Indians, and women**

*Throughout this presentation, I use both person-first language (e.g., 'person with a disability') and identity-first language (e.g., 'disabled person') interchangeably. While person-first language is still touted among social scientists and other professionals, identity-first language is preferred by many in disability communities to recognize disability as a valued cultural and political identity.



Women with disabilities

- / Experience higher rates of poverty, lower employment, and lower wages than men with disabilities**
- / Juggle competing employment, caregiving, transportation, and household demands, along with disability-related concerns**
- / Face social prejudice, marginalization, and violence rooted in pervasive societal sexism and ableism**
- / Face higher rates of violence-related distress, anxiety, and depression than women without disabilities**



Increased mental health risks for people with disabilities

- / Negative stereotypes, ableist microaggressions, and discrimination**
- / Traumatic, invasive treatments or extreme pain related to disabilities**
- / Isolation, abuse from caregivers, and lack of access to proper care**
- / Physical and communication barriers reduce access to community resources and activities**



Socioeconomic barriers to mental health care

- / People with disabilities are nearly three times as likely to live in poverty compared to those without disabilities**
- / Employment discrimination hinders securing full-time positions, leading to part-time or temporary work without health care benefits**
- / Mental health expenses not covered by insurance pose financial strain**
- / Government benefits for healthcare often fall short, necessitating prioritizing physical care over mental health concerns**



Access barriers to mental health care

Physical environment:

- / Lack of transportation, especially in rural areas with limited public options
- / Offices often inaccessible for wheelchair users or those with mobility devices

Digital accessibility:

- / Websites lack features for assistive technologies; videos frequently lack captions or audio descriptions
- / Telemental health platforms lack accessibility features for communication, navigation, and interaction

Relay services:

- / Agencies lack familiarity with relay services for people with hearing or speech disabilities or resources for sign language interpreters, causing appointment delays



Awareness and attitudinal barriers to mental health care

- / **The medical community often solely focuses on physical symptoms, neglecting mental health issues**
- / **Doctors attribute mental health conditions to disabilities, rather than recognizing them as separate challenges**
- / **Limited knowledge and stereotypes among providers lead to misconceptions about abilities, undermining autonomy**

“We had gone in for family counseling. The first thing that was said to me was, in front of my daughter, ‘Well, as a blind mom you’re not going to know what emotions your daughter has, so you’re going to have a hard time knowing how she’s feeling about different things that are going on in her life.’” –Blind woman**

**Quotations are taken from key informant interviews conducted as part of the Rural Safety and Resilience Study; see Aguiard et al. (2022).



Awareness and attitudinal barriers to mental health care (cont.)

- / **Mental health providers may view the disability as the main problem, rather than acknowledging it as one aspect of the person's identity**
- / **Anticipating disability-related stigma from providers makes people with disabilities less likely to use mental health services**

“I encountered the same ableist message over and over again— people assumed I wanted to talk about my disability in a way that was focused on ‘overcoming’ or ‘coming to terms’ with my disabilities. I’m proud of my disabilities. They are my identity, culture, and a source of pride.” –Woman with a mobility impairment

“I switched therapists a couple of times because of this. They didn’t focus on the healing process and the coping process. They were too focused on the disability.” –Blind woman



Communication and therapy approach barriers to mental health care

- / Mental health providers lack training in accommodation strategies, contributing to accessibility barriers**
- / Diagnostic tools often fail to accommodate disabilities, resulting in misdiagnosis and inaccurate results**
- / Therapists primarily use verbal therapy, lacking training to adapt communication for diverse needs**



Value of disability-informed mental health services

/ Research indicates that disabled individuals value working with providers who understand or share their disability

“After that my vision and hearing deteriorated. I got lost once and never made it to her office. She volunteered to provide transportation as I had become too nervous of using public transportation, not able to see and hear the bus and its driver and fearing being dropped off at the wrong place. As I continued to lose both vision and hearing, it became a struggle to communicate with her, needing many repeats, and she was patient with me. Once I adapted to cochlear implants, communication was better.” –Woman with Usher Syndrome

“This therapist was neurodivergent. He was so blunt and literal, and he spoke of practical solutions, gave me actionable homework to do, told me the neuroscience and the why behind what changing my actions would do to change my mind. I don’t think I would ever have been helped by a neurotypical therapist. It would’ve just been more masking and being taught to perform against my neurology.” –Autistic woman



Solutions to address barriers to mental health care

- / Allocate resources for research and accessible support programs addressing mental health challenges for people with disabilities, with specific attention to women**
- / Promote representation of people with disabilities in the mental health workforce**
- / Require trainings to reduce disability stigma and enhance disability competency among mental health professionals**
- / Defer to the disability community for informing provider competencies**
- / Prioritize making physical and digital environments and technology innovations accessible**



References

Aguillard , K., Hughes, R. B., Schick, V. R., McCurdy, S. A., & Gemeinhardt, G. L. (2022). Mental Healthcare. *Violence and victims*, 37(1), 26-43.

Dembo, R. S., Mitra, M., & McKee, M. (2018). The psychological consequences of violence against people with disabilities. *Disability and health journal*, 11(3), 390-397.

<https://www.sciencedirect.com/science/article/abs/pii/S1936657418300074?via%3Dihub>

Dunn, D. S. (2019). Outsider privileges can lead to insider disadvantages: Some psychosocial aspects of ableism. *Journal of Social Issues*, 75(3), 665–682. <https://doi.org/10.1111/josi.12331>

Manning, R. B. III, Cipollina, R., Lowe, S. R., Bogart, K. R., Ostrove, J. M., Adler, J. M., Nario-Redmond, M. R., & Wang, K. (2023). Barriers to mental health service use among people with disabilities during the COVID-19 pandemic. *Rehabilitation Psychology*, 68(4), 351–361.

<https://doi.org/10.1037/rep0000512>