



Mental Health/Suicide Prevention Recommendations

Introduction

People with disabilities are significantly more likely than those without disabilities to report suicidal ideation, suicide planning, and suicide attempt.¹ Therefore, the Center for Dignity in Healthcare for People with Disabilities conducted a gap analysis to assess the mental health care resources and access for people with disabilities, including suicide prevention efforts, and healthcare inequities. A gap analysis is a tool that is used to help investigate and create a plan to fix a problem or issue, utilizing a 4-step process to identify the current state of an issue, identify the ideal future state, find the gaps between the two, and then create a plan to close those gaps.

The Mental Health and Suicide Prevention Subcommittee of the Center for Dignity in Healthcare for People with Disabilities has identified and addressed the healthcare inequities highlighted by the Center's gap analysis through five recommendations. If followed, our goal is for these recommendations to begin to reduce those gaps in mental health services provided to people with disabilities, and particularly those with intellectual and developmental disabilities (I/DD).

Diagnostic Overshadowing

Diagnostic overshadowing occurs when health care providers and clinicians wrongly attribute emerging health concerns to existing disabilities and/or their known correlates.

Professionals often wrongly assume that symptoms are attributed to one diagnosis and do not take other factors into consideration. When mental health concerns are attributed to a person's disability, clinicians do not properly identify and treat their mental health conditions.

For example, a clinician might explain away sudden self-injury by saying "Don't all people with autism slap themselves?" - Center for START Services¹

Recommendations:

- 1) Listen to the ways that people are expressing what is happening to them seriously and explore them in whatever ways you can. Rule out underlying medical conditions and make sure the patient is not in pain
- 2) Normalize the expectation that physicians should consult with fellow clinicians.
3. Provide training for clinicians/providers specifically, including considerations for avoiding Diagnostic overshadowing.

4. Avoid implicit and explicit bias- training should be aimed at removing assumptions about a person's disability. Outside considerations, such as a person's environment, gender, etc, should be accounted for when making a diagnosis.

Healthcare Professional Training

Additional training, in terms of amount and rigor, is needed for healthcare professionals to support people with I/DD and co-occurring mental health concerns. It is not uncommon for healthcare professionals to complete their formal education without having interviewed, examined, or treated a person with I/DD.^{[1][2]} As a result, professionals are less confident and competent in treating this population.^[3] Training standards for medical treatment, mental health treatment, and associated treatment services (e.g., speech-language pathology, occupational therapy, behavioral services, etc.) lack sufficient requirements to ensure high quality care for people with I/DD. To address these gaps in training, we strongly recommend that those receiving degrees related to the mental and physical health professions, to create rotations and internships in order to provide experiences with individuals with I/DD who have mental health conditions. At a minimum, we recommend that graduate programs provide experiences (e.g., volunteering, research, coursework, etc.) that facilitate meaningful interactions with people with a wide range of disabilities. Additionally, we recommend that all healthcare professionals, regardless of their field of study or practice, obtain training or consultation to recognize that the signs and symptoms of mental health conditions may present differently in patients with I/DD so they, at minimum, recognize when a referral is indicated. Many mental health diagnoses manifest very differently among people with I/DD. For example, while some may have the classic symptoms for affective or anxiety disorders, they might also present as aggression or self-injurious behavior for people with I/DD.²

Between 70% and 85% of persons with intellectual developmental disabilities referred for psychiatric assessment are found to have one or more untreated, undertreated, or undiagnosed co-occurring non-neuropsychiatric medical problems influencing mental health and behavior (Ryan and Sunada, 1997; Sundheim et al 1998)

Between 60% to 100% of persons with intellectual disabilities experience severe trauma, usually abuse (Sobsey 1994). Some (but, of course, not all) of those who endure trauma develop post-traumatic stress disorder. This condition produces a number of symptoms which can easily simulate psychosis (see examples above) but require an entirely different treatment approach.

Finally, to best meet the mental health needs of people with I/DD, additional training and resources are needed within established community crisis services to address acute mental health concerns and suicidality. Patients with I/DD get denied access to inpatient and crisis services regularly based solely on a diagnosis of an intellectual disability. Outside of the crisis support system, additional training (whether of psychologists, psychiatrists, counselors, etc.) in evidence based talk therapy, adapted for increased accessibility as needed, can increase access to this vital support for people with I/DD and mental health concerns. This will aid in preventing problems from exacerbating to the point of suicidality or other significantly adverse outcomes because of the lack of appropriate care. Increased training requirements and opportunities in resilience-based trauma-informed care, understanding behavior, supporting non-traditional communicators, and person-centered care, as well as a more robust

understanding of disability service systems would all help to develop a more rigorously equipped pool of healthcare professionals.

Increased Knowledge of Mental Health Presentation Among People with Disabilities

In the United States, 1 in 4 adults—61 million—have a disability, according to research from the Centers for Disease Control and Prevention. In 2018, an estimated 17.4 million (32.9%) adults with disabilities experienced frequent mental distress, defined as 14 or more reported mentally unhealthy days in the past 30 days, compared to 7.2% of those without disabilities.^[4]

Approximately 7 million Americans (1.5% to 3%) have an intellectual or developmental disability, and researchers estimate that between 33% and 40% of people with IDD also have mental health disabilities. For example, in one study examining death records, autistic persons died by suicide at a 10.8% prevalence rate as compared to 1.1% for non autistic persons³. No information regarding these factors are currently available within the research on the broader disability community.

Too often, the public as well as therapists and health care providers do not recognize the mental health conditions these individuals face due to “diagnostic overshadowing” or ableism. The combination of intellectual and developmental conditions with mental health disabilities can be complex. There is risk of diagnostic overshadowing which occurs when a person’s mood or behavior is attributed to their diagnosis, such as Down syndrome or autism or when a person’s mental health condition is not seen in concert with I/DD. Ableism, which is prejudice or discrimination against people with disabilities, is often implicit. Many therapists are not properly trained to, nor do they have experience individualizing care for people with IDD. They may assume that symptoms of a mental health disability are attributable to IDD, rather than the mental health disability. This can be confusing for individuals, families as well as providers and first responders.

Communication-related disabilities or aspects of disability can make it much more difficult for some with IDD to provide a clear explanation of what they are feeling, thinking, and experiencing, further complicating the diagnostic process. Behavior that is communicating pain or other health concerns can often be mistaken for a mental health process or behavior problem. In addition to raising awareness about the common co-occurrence of IDD and mental health disabilities within the medical professions and the general public, it is important that people with disabilities themselves and those that support them are made aware of their increased risk. Mental health care needs to be accessible and society needs to be aware of availability of this treatment within and outside of the disability community. A particularly effective way of creating this awareness would be to facilitate dialogue about mental health within the systems of peer-to-peer support that already exist in the disability community.

Improved Healthcare System

People with disabilities experience significant, persistent barriers to equal health care access. During difficult moments, disabled persons should still have the opportunity to participate in treatment goals and design as possible. Barriers can be financial, systemic, physical, programmatic, or communication-related. Physical barriers can include architectural barriers that prevent the person from entering the clinic or hospital and devices/signage that are inaccessible. Programmatic barriers may involve refusing to treat the person as the decision-maker with respect to their health care or to provide them with reasonable accommodations. Communication barriers can include refusal to provide people with disabilities with effective communication supports during the health care visit, or a refusal to grant them access to their own supports. These barriers tend to be exacerbated when the person identifies as LGBTQ+ and/or as a person of a color so that they are multiply marginalized by some combination of racism, ableism, sexism, and homophobia.

In addition to access barriers, people with disabilities can face outright denials of care. People with disabilities face discrimination with respect to lifesaving care based on ableist attitudes about their quality of life, such as through the use of value assessments that limit the treatments available to them because those assessments use discriminatory metrics (i.e. [Quality Adjusted Life Years](#)) or by denying them direct access to lifesaving treatments – such as an organ transplant or ventilator – due to the belief that their lives are of lower quality. In this same way, people with disabilities who express suicidality may not even be offered suicide prevention interventions because their lives are undervalued and their desires considered “rational.” Concerted efforts to educate medical professionals and the general public about the complex lived realities of disability may reduce or eliminate many of these barriers.

Financial Barriers to Services

In addition to the physical, programmatic, or communication barriers highlighted above, there are several financial barriers to mental health services that exist for people with disabilities. First, the patchwork of insurance coverage that exists in the United States makes accessing therapy and mental health services into a complex and burdensome process. This level of complexity is difficult for anyone to navigate when trying to access mental health care, but especially for those with I/DD.

Of course, many people with disabilities do not have any insurance coverage of mental health services at all. However, even in the best case scenario when a person has high quality insurance, they may still be left with heavy financial burdens when trying to access care that can be difficult for someone on a fixed income, such as Social Security Disability (SSDI). This is any mental health care providers do not take insurance and most mental health services require a copay.

Further, many mental health care providers may be hesitant to treat people with disabilities because of the assumption that treatment may take more time and effort than is typical, which would not be reimbursed adequately. While it may be true in some cases that it takes longer to treat some people because of co-occurring disabilities, (such as speech impairments, wheelchair transfers, or neurodivergence) it is important to note that not all people with disabilities or I/DD will take more time to treat. Thus, it would be unfounded and discriminatory

to make these assumptions. In the cases that it is true that treatment would take more time and the provider would not be reimbursed adequately, it is imperative to understand that this person still has a right to treatment under the Americans with Disabilities Act (ADA). Cost efficiency is not the only value and profit should not be valued more than the person.

Future Directions for Research and Policy

A well-established research base that indicates that individuals with IDD are more likely to have a mental health condition than the general population, but there is a critical lack of research related to this co-occurrence and the needed treatments, as well as suicide prevention for this population. Research is needed to understand the specific mechanisms that create the co-occurrence of particular mental health conditions among individuals with particular IDD diagnosis, to test and determine efficacy for evidence-based mental health treatments, and to develop effective tools for identifying and treating suicidality among individuals with IDD.

In addition, general research about mental health conditions and suicidality should include people with intellectual and developmental disabilities, particularly those with intellectual disabilities. Historically, this population has not been included in psychiatric research and development efforts, despite their increased likelihood of experiencing a mental health condition in their lifetime. A research agenda related to mental health and suicidality among individuals with IDD should also include high-quality research related to the other priorities of this subcommittee, including methods for improving healthcare professional training and access to care, in order to determine the most effective means of intervention with the most meaningful impact on the experiences of individuals with IDD.

Key Recommendations

- Enhanced training for both pre-professionals and current clinicians and therapists providing mental health and suicide prevention counseling. Too often, these providers have little or no training in diagnosing or treating individuals with disabilities.
- Greater public awareness of the higher prevalence of mental health conditions of people with disabilities
- Better diagnosis and treatment- which includes more inclusive screening and evaluation tools that address the needs of individuals with intellectual disabilities and/or lower literacy levels, as well as therapies that also take these needs into consideration.
- Improved Research- Since policy revisions rightfully rely on data to support necessary changes, more research is needed to determine what types of training improve outcomes, what tools lead to better diagnostics and treatments, and what healthcare systems modifications are needed to ensure people with disabilities receive the equitable and appropriate mental health care they deserve.

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