Hogg Foundation *for* Mental Health

Request for Information
Public Health Committee – Charge 3
October 17, 2020

Meeting the Mental Health Needs of Individuals with Intellectual Disabilities

People with intellectual disabilities (ID) experience mental health conditions and the impact of trauma at much higher rates than those without disabilities. Texas should prioritize change within the service delivery systems and promote practices to ensure recovery-focused, appropriate mental health care, and trauma-informed care for individuals with ID.

Intellectual disabilities are a type of developmental disability that impacts cognitive and adaptive functioning. People with intellectual disabilities (ID) experience a higher rate of mental health conditions than the general population. The prevalence of diagnosed mental health conditions in individuals with ID is estimated to be between 32 percent and 40 percent, compared with approximately 20 percent in the general population.[1] Additionally, studies have shown that diagnosed mental health conditions in individuals with ID can be more severe and more difficult to diagnose than in the general population.[2] Yet, while people with ID are more likely to have a co-occurring mental health disorder, they often do not have access to appropriate mental health care.[3,4,5] Service delivery is particularly fragmented for this population, as services may come from the mental health agencies or the ID agencies, but rarely both.[6] Additionally, services for people with ID often focus on behavior management rather than mental health treatment and support.

The public mental health system in Texas is based on the belief that recovery is possible, however this is rarely applied to individuals with ID and co-occurring mental health conditions. Access to evidence-based treatment and recovery support services is crucial for achieving recovery. Unfortunately, often the first line of "treatment" for an individual with ID is limited to psychopharmacology—psychotropic drugs are frequently used to control and manage behaviors, which may address the symptoms but not the illness.[7] This approach significantly reduces opportunities for recovery, and may serve to perpetuate any challenging behaviors.

People with ID face a "cascade of disparities" when accessing healthcare.[8,9] Access to appropriate mental health treatment remains particularly difficult for many in this population. Barriers to receiving appropriate mental health care include lack of formal training for providers, diagnostic overshadowing (attributing behaviors to the disability and not assessing for mental health conditions), unwillingness of providers to serve people with ID, difficulty in facilitating communication between consumers and providers, and trouble navigating complex systems.[10] In a 2014 survey, it was revealed that 90.2 percent of psychiatrists felt "they lacked specific training in treating and diagnosing mental health conditions in the ID population."[11]

Current Landscape

The Statewide Behavioral Health Strategic Plan identified "Behavioral Health Services for Individuals with Intellectual Disabilities" as a major gap (Gap 9) in our current mental health system of supports and services. The inclusion of Gap 9 in the strategic plan offers future opportunities for increasing access to quality mental health services for both children and adults with ID. While some efforts are underway to address this gap, the 2019 HHSC exceptional item #22 was significantly underfunded. This funding request proposed by the commission prior to

the 86th Legislative Session offered opportunity for increasing mental health services for individuals with ID. The limited funds that were appropriated are being used to develop a learning collaborative and service provision pilot at five sites that is scheduled to be operationalized in 2021.

Trauma-Informed Practices

People living with IDD experience abuse, neglect, bullying, isolation, institutionalization, and other forms of trauma at two to three times the rate of those without IDD.[12] Research suggests nearly 30 percent of individuals with IDD have histories of physical and sexual abuse, and the actual rate may be even higher due to underreporting and lack of recognition by family and other caregivers. [13] In one study, nearly 75 percent of participants with IDD reported having experienced at least one traumatic event in their lifetime, increasing the likelihood of developing a mental health condition. [14] People with IDD experience the depression, anxiety, post-traumatic stress, and other symptoms associated with traumatic experiences.

As recognition of trauma and its impacts on mental health grows, individuals and organizations on the forefront of treatment and support for people with MH/IDD are shifting the conversation to include trauma-informed practices. Instead of asking "what's wrong with this person," we should be asking "what happened to this person, and how can we support them?"[15] Instead of trying to manage and control behaviors, we should be offering positive support and treatment. While trauma is not the only cause of mental health challenges in people with disabilities, it is significant and requires attention.

The Hogg Foundation for Mental Health and the National Traumatic Stress Network partnered to create a comprehensive training toolkit, *The Road to Recovery: Supporting Children with Intellectual and Developmental Disabilities Who Have Experience Trauma.* This toolkit is now available in both English and Spanish, free of charge, on the NCTSN website. It can be found at https://www.nctsn.org/resources/road-recovery-supporting-children-intellectual-and-developmental-disabilities-who-have

Recommendations:

- Incorporate the treatment and support needs of individuals with ID into the state mental health plan;
- Devote adequate financial resources to treatment, services, and supports;
- Create a paradigm shift to move from "controlling and managing behaviors" to a culture of supporting the mental health recovery of individuals with ID;
- Create trauma-informed ID systems of care;
- Remove systemic barriers in the public mental health system that prevent individuals from receiving both ID and mental health services;
- Prioritize efforts to build awareness and foster education for providers, families, and individuals; and
- Build the workforce capacity of mental health providers willing to provide services to individuals with ID.

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