The Arc of Texas



Whole Person Project

March 2022

Background

In the U.S., individuals with intellectual and developmental disabilities (IDD) make up 1-3% of the general population¹. Research shows, however, that individuals with IDD are 3-4 times more likely to have a mental health (MH) disorder, a rate disproportionately higher than the general population . People with IDD can develop mental health disorders at a higher rate than the general population due to increased likelihood of experiencing trauma through abuse, neglect, and/or exploitation².



Although this population is more likely to develop a MH condition, they are less likely to have access to appropriate and timely mental health supports and services³. Texas is no exception. Barriers to care often are compounded by an untrained workforce and siloed service system. A lack of culturally⁴ and disability-competent assessments by skilled staff can result in diagnostic overshadowing and medication masking. Further, an untrained individual may struggle to properly diagnose due to communication deficits, atypical presentation of the disorder, and episodic presentation of symptoms⁵. When individuals with IDD do not have access to the MH services they need and barriers prevail, crises can occur. The National Alliance on Mental Illness defines a mental health crisis as "any situation in which a person's behavior puts them at risk of hurting themselves or others and/or prevents them from being able to care for themselves or function effectively in the community." If a crisis occurs, individuals are at tremendous risk of institutionalization and/or involvement in the criminal legal system⁶.

Background

The Whole Person Project of The Arc of Texas was established to eliminate the barriers to care for Texans with IDD and co-occurring MH conditions. The project will establish and enhance supports and services through evidence – based, long-term training, and technical assistance for healthcare providers who wish to provide quality and timely mental health services to people with IDD. Through stakeholder collaboration, it will assess what Texas policies need to be addressed to ensure that all Texans with IDD have access to the mental health services they need to live healthy, meaningful lives within their community.



The Arc of Texas worked with the Center for START Services (CSS) to conduct a provider systems analysis in Texas. The results from the study indicate a need for increased access to cross-training, information sharing, and collaboration throughout the health service delivery system.

Results

What did we uncover through our Texas provider system analysis?

More than 400 Texans, including IDD and MH providers, mobile crisis providers, local IDD and MH authority staff, advocacy organizations, criminal legal professionals, and individuals with IDD and their family members, were interviewed by CSS staff to inform how best to build capacity in the IDD-MH system to provide equitable access to MH care. Four areas of training needs were identified by participants in the study:

Crisis Prevention & Intervention

Community Mental Health Providers

IDD Service System Community Education

Crisis Prevention & Intervention

Respondents identified a lack of expertise in IDD-MH for first responders and families, which remains a barrier to effective crisis intervention and treatment. In addition to training to better prepare crisis responders, providers and families alike indicated a need to learn what resources exist in their community as preventative measures.

Recommendation: Improve crisis prevention and intervention by providing MH and IDD training for in-patient providers, law enforcement personnel, and criminal legal system professionals. Improve the capacity of the entire system of support ranging from medical, mental health providers to law enforcement to reduce instances of MH crisis among individuals with IDD and improve interventions when a crisis does occur.

Results

Community Mental Health Providers

The systems analysis indicated that IDD training and education is needed for mental health providers, including therapists, psychiatrists, and prescribers. Half of respondents reported no access to or knowledge of psychiatric services from qualified psychiatrists. Although qualified experts exist in Texas, there is a dearth of these staff, which often exacerbates reactive responses to mental health symptoms and increases demand for acute care. The availability does not currently meet the demand. For example, there are long waiting lists to receive services and few MH/IDD experts who accept Medicaid. Further, community mental health services are largely limited to medication management.

Recommendation: Increase the number of qualified psychiatrists with treatment experience serving those with IDD through training. This training should dispel the belief that people with IDD are unable to actively participate in or benefit from therapy or other MH services.

IDD Service System

Respondents indicated a significant need for improved collaboration between IDD and MH service providers and enhanced training on the signs and symptoms of MH conditions in people with IDD. Practitioners recognize the gaps in their own expertise and training, with 97% of IDD providers reporting a need for additional IDD-MH focused training. Because families know their loved ones with IDD best, ensuring they are aware of the signs and symptoms of MH conditions in people with IDD would improve their ability to advocate and get what they need within the IDD service system.

Recommendation: Improve collaboration between IDD and MH service providers, which includes improving their understanding of the signs and symptoms of MH conditions in people with IDD. Provide education and navigation support for families.

Results

Community Education

Community education can help to reduce stigma surrounding disability and MH conditions and promote a positive, inclusive, and connected mental health environment. The analysis supported that a sense of community connection is a protective factor against mental health crises. When a person feels validated, engaged, and integrated within their community it fosters improved quality of life. Change in the perception of disability and MH often starts with individuals; moves to families, the workplace, and schools; and ends with community leaders who are then equipped to maintain formal and informal community education efforts surrounding disability and MH.

Recommendation: Offer training sessions that include formal classes regarding disability acceptance and constructive mental health promotion or informal conversations between community members. Promote and increase connections to the community among people with IDD through existing channels such as inclusive public education, competitive integrated employment, and Medicaid Home and Community Based Services (HCBS). For example, funding existing services such as the Medicaid HCBS interest list can integrate more Texans with IDD into the community, acting as a preventative strategy for mental health crises.

Sources

¹ Pouls, K, et al. "Adults with intellectual disabilities and mental health disorders in primary car." British Journal of General Practice 13 December 2021. https://bjgp.org/content/bjgp/early/2021/12/10/BJGP.2021.0164.full.pdf>.

² Trauma and Intellectual/Developmental Disability Collaborative Group. The impact of trauma on youth with intellectual and developmental disabilities: A fact sheet for providers. Los Angeles, CA, and Durham, NC: National Center for Child Traumatic Stress, 2020.

³ Hogg Foundation for Mental Health. (2018). Addressing the Mental Health and Wellness of Individuals with Intellectual Disabilities. Retrieved 2 2, 2022, from https://utw10282.utweb.utexas.edu/wp-content/uploads/2015/09/MH_IDD-Policy-Rec_0801141.pdf.

⁴ Bailey, M and I. A. Mobley. "Work in the Intersections: A Black Feminist Disability Framework." Gender & Society (2018).

⁵ Hood, Julia, Ph.D., BCBA, NCSP. "Mental Health Awareness and Intellectual and Developmental Disability (IDD)." Valley Behavioral Health. 18 May 2020. <https:// valleycares.com/blogmental-health-awareness-and-intellectual-and-developmental-disability-idd/>.

⁶ National Institute of Mental Health. Prevalence of Any Mental Illness (AMI). n.d. 3 2 2022. <https://www.nimh.nih.gov/health/statistics/mental-illness#part_2539>.

⁷ Grosso, E, et al. "State of Texas Training Needs Evaluation: An Analysis of Training Needs for IDD-MH Systems, Services, and Supports." 2021.

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About The Arc of Texas

The Arc of Texas is a statewide advocacy and membership organization that supports and advocates for the human rights and self-determination of Texans with intellectual and developmental disabilities (IDD). We work with and alongside individuals with IDD and their families to identify barriers and solutions to inclusive education, competitive integrated employment, quality community-based services and supports, and access to civil rights and justice.

The Arc of Texas envisions a world where Texans with IDD are included in their communities, where quality supports and services are available to meet their needs and choices. The Arc of Texas prioritizes policies and legislation that advance the equality and civil rights of Texans with IDD, specifically related to inclusive education, competitive integrated employment, quality community services and supports, and access to civil rights and justice.