# Meeting the Mental Health Needs of Individuals with Intellectual and Other Developmental Disabilities

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**POLICY BRIEF**

Hogg Foundation *for* Mental Health

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## The Issue

Individuals with intellectual and other developmental disabilities (IDD) and co-occurring mental health conditions often lack access to quality mental health services and trauma-informed care despite the fact that they experience mental health conditions at three to four times the rate of those without disabilities.[1] The lack of access to appropriate mental health diagnosis, treatment, services, and supports results in lost opportunities for recovery from mental health and/or substance use conditions.

Depression and anxiety are the two most frequently identified mental health conditions in people with IDD but are certainly not the only ones.[2] Research indicates an over-representation of schizophrenia in people with IDD compared to the general population.[3] Post-traumatic stress has also been identified as a significant cause of mental health concerns in people with IDD.[4]

## Depression and anxiety are the two most frequently identified mental health conditions.

Unfortunately, treatment practices have yet to catch up with the reality that people with IDD live with, and can recover from, serious mental health conditions. Too often, systems of care for people with IDD focus on controlling and managing challenging behaviors without adequate consideration of the potential for underlying mental health conditions, trauma, or unseen medical conditions. Treatment often continues to focus on developing behavior management plans to promote compliance or the use of medications to control behaviors. In both cases, treatment is targeting the behavior and not the actual mental health condition, potentially *causing* the behavior and making recovery unlikely.

# Background/History

Approximately 1 to 3 percent of the United States population has a diagnosed intellectual or other developmental disability.[5] Within the state of Texas, an estimated 500,000 individuals live with IDD.[6] People with IDD experience mental health conditions just as people without a diagnosed disability do – this is referred to as *co-occurring conditions.*

## 1-3%
**of the US population has a diagnosed intellectual or other developmental disability.**



The most current data reports that around 36 percent of individuals with IDD in Texas have a co-occurring mental health diagnosis.[7] This represents a much higher prevalence than mental health conditions experienced by those without disabilities (approximately 20 percent).[8] The percentage of people with co-occurring conditions is likely higher due to the difficulty people with IDD have accessing mental health services, diagnostic overshadowing, and the lack of streamlined data collection.

People with IDD are also more likely than those without a disability to experience trauma, including abuse and neglect, and subsequently develop post-traumatic stress disorder (PTSD).[9] Adding to the complexities of diagnosing multiple conditions, differences in verbal communication in some people with IDD can complicate assessment, treatment, and recovery.

Due to different communication styles and other factors related to someone's IDD, those with IDD may not receive the treatment they need for their mental health condition. Providers can often misattribute mental health symptoms to a person's disability, which is commonly known as *diagnostic overshadowing*. Further, depending on the severity of the disability, a person with IDD may have difficulty processing health information or understanding their specific diagnoses.[10]

In the past, people with IDD often only received mental health treatment as residents of institutions.[11] The treatment often consisted primarily of medication prescribed to

control behavior. Community mental health services for individuals with IDD was, and often continues to be, difficult to access. However, Texas and the nation have made shifts in community-based programs in an attempt to provide more integrated care. Today, many Texans with IDD seek mental health services from local intellectual and developmental disability authorities (LIDDAs), local mental health authorities (LMHAs), and through other types of community providers. However, lack of coordination among IDD and mental health agencies continues to cause barriers to services, gaps in access to services, and difficulty with service navigation and delivery.

# Evolving Systems

While access to mental health services for individuals with IDD continues to be a challenge, both advocates and policymakers have become more aware of the systemic gaps and barriers to services. Consequently, some efforts have been made to address ongoing concerns and barriers:

**Table 1: Recent Strategies to Build Awareness and Address Access to MH Services for People with IDD**

| Organization | Action Taken |
|---|---|
| **Statewide Behavioral Health Coordinating Council (SBHCC)** | In 2017, the SBHCC was required to develop a five-year Texas Statewide Behavioral Health Strategic Plan to address the behavioral health needs of Texans.  Lack of access to behavioral health services for individuals with IDD was identified as a major systemic gap (Gap #9).<br><br>In 2019, the strategic plan update included the Foundation for the IDD Strategic Plan. In January 2022, the Statewide Intellectual and Developmental Disabilities Strategic Plan was released. While the needs of this population are great and varied, the plan included: |

- 2018 HHSC survey indicated that only 32.6% of family and friends of individuals with IDD were satisfied with the behavioral health services available to them;

- 2019 plan identified the lack of community-based services for people with IDD as a major gap (Gap #3); and

- 2022 report included Recommendation 2.5: Expand Mental Health and Crisis Supports for People with IDD.

Other gaps identified relating to IDD and behavioral health services included ease of system navigation, workforce shortage, and lack of coordinated efforts among agencies.

**Texas Health and Human Services Commission (HHSC) Legislative Appropriations Request**

In 2018, HHSC requested approximately $44 million to develop crisis services, respite options, and community mental health services for individuals with IDD. Of the $44 million requested, the 85th Texas Legislature only appropriated approximately $7 million, limiting HHSC's ability to make comprehensive changes. HHSC was able to conduct pilot activities and coordinate a learning community of providers to begin sharing strategies on how best to provide the needed services.

Starting in 2020, five local authorities engaged in pilot activities referred to as the Outpatient Biopsychosocial Approach for IDD Services (OBI) pilot.[12] The OBI pilot currently serves 135 individuals with IDD in an outpatient mental health setting. Data from the pilot will not be available until 2023.

**HHSC Continuum of Care Workgroup**

HHSC has an internal workgroup that meets to discuss the cross-division needs of people with IDD. The workgroup has had success in transitioning nine individuals with IDD from state supported living centers (SSLCs) to community settings.[13]

| | |
|---|---|
| **Tarrant County LMHA** | The START Program was developed to provide community-based crisis intervention for people with IDD and mental health needs.[14] Overall, these programs aim to improve the delivery system for people with IDD and co-occurring mental illness.<br><br>Currently, the only START-certified program in Texas is located at the Tarrant County LMHA.[15] This center has a full clinical team, provides crisis response, and has a resource center.[16] While data has shown the effectiveness of START initiatives, the cost of implementation has made it difficult for other LMHAs to replicate. |
| **HHSC Medicaid Waivers** | Medicaid waivers for individuals with IDD (Home and Community-based Services and Community Living Assistance and Support Services, Texas Home Living, and the Deaf/Blind Multiples Disabilities waivers) offer Medicaid services including psychological services. These often take the form of behavior management for individuals with IDD. Access to meaningful mental health services is still severely limited by the absence of mental health providers willing to serve this population. Additionally, due to the extensive waiting lists associated with these programs, these services are not available to many who need them. Interest list totals for 2021 are provided on page 11 of this brief. |
| **National Child Traumatic Stress Network** | Development of a series of fact sheets for parents and other caregivers focusing on IDD and trauma: https://www.nctsn.org/resources/children-with-intellectual-and-developmental-disabilities-can-experience-traumatic-stress-for-parents-and-caregivers |

| **National Child Traumatic Stress Network and the Hogg Foundation for Mental Health** | The Road to Recovery: Supporting Children with Intellectual Disabilities Who Have Experienced Trauma – a training curriculum and toolkit developed for caregivers and providers through a partnership between NCTSN and the Hogg Foundation. The Hogg Foundation also funded a grant that provided over 40 trainings across Texas. A current Hogg Foundation grant awarded to the Texas Center for Disability Studies is developing master trainers so that the training will be available across Texas. This training toolkit is also available in Spanish. The toolkit is available at no charge to anyone at https://www.nctsn.org/resources/road-recovery-supporting-children-intellectual-and-developmental-disabilities-who-have |
|---|---|

## Challenges and Barriers Creating Gaps in Services

While awareness of co-occurring IDD and mental health conditions has increased and some progress has been made, significant challenges remain. Some of the ongoing gaps and barriers include:

### Diagnostic Overshadowing

When individuals with IDD and co-occurring mental health conditions do receive treatment, they often experience "diagnostic overshadowing."[17] When a provider focuses on aspects of the person's IDD with little consideration of underlying mental health conditions or trauma, mental health conditions remain unidentified and untreated.

## Workforce Shortage and Provider Competency

Few would argue that Texas has an adequate number of mental health professionals in the workforce. Further, data shows that there is a severe lack of trained healthcare professionals who can provide competent care for individuals with co-occurring mental health conditions and IDD. Many mental health providers not only report not receiving any formal training but feel apprehensive toward serving people with IDD.[18]

## Diversity, Equity, and Inclusion

There is little data available on the impact on people with IDD and a co-occurring mental health condition who have historically been marginalized within the mental health community. Further efforts are needed to identify how the intersection of race, ethnicity, sexual identification and orientation, religion, and more, affect access to services.



## Communication Differences

Differences in communication can make it difficult to assess, diagnose, and treat mental health conditions in people with IDD.[19] Additional time is often required to more adequately understand what the individual is experiencing and to accommodate the individual's optimal mode of communication. Extended interviews with family and caregivers may be required to obtain information needed for assessment. Those should be included and covered through the individual's service array.

## Mental Health Supports in Schools

It is estimated that fifty percent of children with IDD have a co-occurring mental health condition.[20] However, children with IDD are just as susceptible, if not more, to the diagnostic overshadowing that adults with IDD encounter. According to the Coalition of Texans with Disabilities, "unaddressed mental health conditions can impede academic success, impact social emotional wellbeing, and compound existing developmental delays."[21] Rather than needed support and services, many children with IDD and co-occurring mental health conditions often receive disciplinary measures.

## Service Navigation and Cross-Agency Coordination

People with IDD and co-occurring mental health conditions often face a "cascade of disparities" when trying to access adequate healthcare.[22] IDD services are often separated and siloed from mental health services. When people with IDD need services for mental health, they often must seek care at either an IDD agency or a mental health agency. Too often they are directed to IDD services without consideration of their mental health needs. These siloed services add an additional barrier to accessing care.

## Data Collection Issues

There is no universally accepted definition for IDD among state agencies in Texas.[23] Lack of consistency negatively impacts who is eligible to receive services and how data is collected for various programs. Often, "if the data doesn't exist, the problem doesn't exist" and it is difficult to convince policymakers to invest funding for necessary resources.

## Waitlists for Home and Community-Based Services

Waitlists can be up to 13 years for people seeking care through Medicaid Home and Community-Based Services (HCS) waivers, as the interest list far surpasses the total slots released for these programs each biennium.[24] HCS waivers can fund individualized services, such as community-based living or respite services, that adapt throughout the individual's lifetime based on the individual's needs.[25]

**Table 2: Interest List and Waiver Caseload Summary as of October 2021**

| Item | Class | DBMB | HCS | MDCP | STAR+ | TxHmL | Totals |
|---|---|---|---|---|---|---|---|
| **Previous Biennium counts** (As of August 31, 2021) | 76,578 | 1,157 | 109,300 | 8,708 | 24,069 | 95,758 | 315,570 |
| **Enrolled*** | 192 | 0 | 238 | 5 | 206 | 16 | 657 |
| **Denied/Declined/Withdrawn*** | 504 | 3 | 159 | 52 | 716 | 33 | 1,467 |
| **Pipeline*** | 2,179 | 61 | 892 | 272 | 3.630 | 248 | 7,282 |
| **Total Releases this Biennium** (Since September 1, 2021) | **3,017** | **64** | **402** | **330** | **6,109** | **200** | **10.122** |
| **Added this Biennium** (New Requests) | 915 | 41 | 947 | 365 | 3,418 | 885 | 6,571 |
| **Current Interest List Counts** (As of October 31, 2021) | **77,157** | **1,189** | **109,809** | **8,738** | **24,755** | **96,569** | **318,217** |

*Released/Removed from Interest list, Source: https://www.hhs.texas.gov/about/records-statistics/interest-list-reduction/interest-list-waiver-caseload-summary-archive#Oct21_3.

## Behavior Management

Many people fail to recognize that behavior may be a form of communication or response to trauma – not a symptom of a person's disability. Because of this misinterpretation, people with IDD and mental health concerns often receive treatment in the form of behavior management or psychotropic medications instead of traditional counseling interventions and other mental health supports.[26] This mistake can prevent individuals from receiving effective mental health care and limit opportunities for recovery. Behavior management doesn't typically work if the underlying cause of the behavior (e.g., trauma, mental health condition) is not addressed.

## Prescription of Psychotropic Medications

Often, the first line of "treatment" is psychopharmacological, with psychotropic drugs being used to control behavior rather than addressing an underlying mental health condition. Consequently, standard psychosocial, mental health, and cognitive behavioral treatments have not been readily available or comprehensively studied, though there is strong evidence that "many individuals gain benefit from these interventions."[27]

## Integrated Health Care

For individuals with IDD and co-occurring mental health conditions, short-term emergency care can be easier to access than long-term integrated care in Texas. Addressing all the health care needs (prevention, acute care, mental health, etc.) of individuals with IDD is vital to their long-term health and wellness.

## Criminal Justice

People with IDD are overrepresented in the U.S. jail and prison systems, as they make up 3 percent of the total U.S. population but represent about 10 percent of the jail and prison population.[28] Within the criminal justice system, adults with IDD struggle to receive adequate mental health services due to lack of available support or misidentification of their IDD.[29]
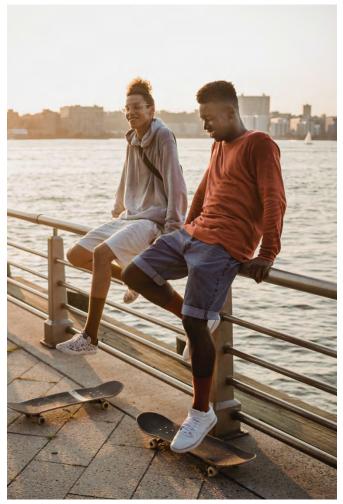
## COVID-19 and Telehealth

While the COVID-19 pandemic has affected everyone, special considerations should be made for individuals with IDD during and post-pandemic. Researchers have expressed heightened concern for children with IDD and the mental health implications of the pandemic. Researchers maintain that social isolation and its effects are extremely unfamiliar and difficult to understand for children, especially those experiencing developmental and intellectual delays.[30]

In the age of a global pandemic, many people have turned to telehealth to receive vital mental health services. Some studies show that telehealth provides effective, accessible mental health treatment for people with IDD.[31] Further efforts to expand telemedicine and telehealth access can fill a gap in services for many people seeking mental health services.

## Access to Mental Health Services

People with IDD and mental health concerns often qualify for Medicaid services. However, many individuals with IDD struggle to access adequate services that are available. Within Medicaid, the number of mental health providers that are willing to work with individuals with IDD is limited.

## Mental Healthcare for Caregivers of People with IDD

Many people with IDD do not need a guardian, however, there is some benefit from having a caregiver such as a family member. Navigating the complex systems of care for people with IDD not only puts a strain on the individual, but also on the caregiver or appointed guardian. In a 2013 survey of caregivers for people with IDD and mental health conditions, caregivers report that they often have to fight to get services for their loved one, along with battling to gain recognition and support for their own mental health needs.[32]

# Recommended Strategies for Improving Access to Services

## Interagency Collaboration

Services must be easily accessible through both mental health and IDD agencies in order to better serve people with IDD who have a mental health condition. In recent years, the combination of the IDD and Behavioral Health Services department within HHSC has eased some of the burden of service navigation for individuals with IDD and mental health concerns. The continuation of interagency collaboration can significantly improve the process of seeking out mental health services for people with IDD.

## Funding for Mental Health Services for Children and Adults with IDD

Funding for mental health services for individuals with IDD should be a priority for state agencies, legislators, and other policymakers. Some services, such as the OBI pilot program, have already yielded promising results but cannot expand their capacity without significant funding increases. Information garnered from the pilot programs funded by the 86th legislature should be used to replicate and expand services throughout Texas.

Waiver programs, when accessed, can significantly improve quality of life for people with IDD and co-occurring mental illness. However, the waiting lists for these programs exceed ten years. General revenue funding is needed to increase capacity at the local community centers for providing mental health services specifically to individuals with IDD.

## Investment in the Behavioral Health Workforce

Texas's current supply of behavioral health professionals is far below the demand.[33] Currently, LMHAs and LIDDAs are losing staff rapidly. Additionally, the number of mental health professionals capable of working with individuals with IDD is even more limited. Strategies to address this shortage include increasing Medicaid reimbursement rates for behavioral health services, expanding telehealth behavioral health services for people with IDD, and investing in graduate education programs for behavioral health professions. More recommendations can be found in the "Strong Families, Supportive Communities: Moving our Behavioral Health Workforce Forward" report written by the Behavioral Health Workforce Workgroup in 2020.[34]

## IDD Training for Mental Health Professionals

Educational requirements for mental healthcare professionals are often set at the national level. However, supplemental education for caregivers and clinicians working with individuals with IDD should be made readily available, accessible, and where appropriate, should be considered required training. Examples of trainings available include:

*Road to Recovery: Supporting Children with IDD Who Have Experienced Trauma* - a training curriculum and toolkit for caregivers and providers working with children with IDD, created through a partnership between the Hogg Foundation for Mental Health and the National Child Traumatic Stress Network. The training is available online after creating a free account at this link: https://www.nctsn.org/resources/road-recovery-supporting-children-intellectual-and-developmental-disabilities-who-have.

HHSC has developed a series of training modules for direct caregivers and professionals supporting individuals with co-occurring mental health conditions and IDD. The training is available online and free to the general public. It can be found at https://training.mhw-idd.uthscsa.edu/.

Agencies and service providers supporting individuals with IDD should consider making this type of training a requirement for service provision.

## Recovery-Focused Mindset

HHSC and other state agencies are implementing recovery-focused interventions for people living with mental health and substance use conditions. However, this recovery-focused approach has yet to be realized in systems of care for individuals with IDD and co-occurring mental health conditions. Expanding opportunities for recovery to people with IDD and mental health concerns fosters a culture of hope and resiliency for these individuals and should be incorporated into the state's behavioral health strategic plan.

## Trauma-Informed Care

Individuals with IDD experience trauma at a higher rate than the rest of the population. However, trauma-informed care has yet to be widely practiced among organizations and clinicians who work with the IDD population. First and foremost, we must change the culture of care and the service provision paradigm to be more trauma-informed. We must begin replacing the question "What's wrong with you?" with "How can I support you?". Trauma-informed clinical interventions already exist and show promising outcomes when used with individuals with IDD, including Trauma-focused Cognitive Behavioral Therapy (TF-CBT) and Eye Movement Desensitization and Reprocessing (EMDR).[35,36] Creating more trauma-informed environments wherever individuals with IDD live, work, or play is essential.

## Improved Data Collection

While many people with IDD and mental health issues receive services from the state, data collection for the utilization of these services remains deficient. Lack of comprehensive data impedes development of a coordinated system of services. Additionally, lack of a consistent definition of IDD among state agencies has caused confusion over eligibility for services and contributed to inaccurate data collection. Requiring comprehensive data collection and creating a consistent definition of IDD among agencies could help to address this major data gap.

## Improved Screening Tools for Service Eligibility

In order to determine an individual's service eligibility, state agencies such as HHSC utilize IQ tests and Adaptive Behavior Level (ABL) assessments conducted by a qualified professional.[37] However, many IDD advocates state that IQ tests do not accurately capture a person's disability and may result in exclusion from necessary services. Many advocates suggest that assessments utilize a strengths-based perspective to perform a comprehensive, person-centered evaluation.[38]

## Inclusivity in Policy Making

Working alongside people with IDD is just as important as speaking with their family members, caregivers, and advocates. Integrating recommendations from people with these lived experiences will result in longer lasting and more effective policy change.

## Conclusion

Despite promising efforts to expand services for individuals with IDD and mental health concerns, there are still sizable gaps in services. The mental health community must continue the conversation to build awareness of the long-ignored mental health needs of people with IDD. The reality remains: when an individual with IDD seeks mental health care, too often the focus turns to managing behaviors without addressing the underlying causes. Higher quality, comprehensive mental health and medical assessments are the first step to identifying causes of challenging behaviors. Quality services, supports, and treatments should always follow. A focus on mental health recovery will benefit the individual as well as providers and staff. Additionally, the cost of outpatient or community-based care for individuals in recovery is much lower than the prohibitive cost of institutionalization. People living with IDD have the same human right to quality mental health services as everyone else and it is up to each of us to ensure that.

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