

# **IDD/Mental Health Practice in Texas**

# A Supplement to the Complex Mental Health Needs of People with IDD Gap Analysis Framework

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# **Table of Contents**

# **Executive Summary**

# Methodology

# How to Use this Framework

## Framework

Framework at A Glance

Awareness

Access

Quality of Care

Diagnosis

Treatment

## **Special Populations**

**Rural Communities** 

Aging People with IDD

Racially- & Ethnically-Diverse People with IDD

People with Autism Spectrum Disorder

People with Down Syndrome

Incarcerated People

# **Special Issues**

Family/Caregiver Stressors

Covid-19

Trauma & PTSD

Treatment in a School Setting

Foster Care and Residential Facilities

#### Sources

# **Executive Summary**

The core *Complex Mental Health Needs Gap Analysis Framework* describes key opportunities and challenges associated with stages of mental health care for PwIDD: Awareness, Access, Diagnosis, Quality of Care, and Treatment. It also addresses special populations and issues that represent important distinctions in the delivery and receipt of mental health care for/by PwIDD.

Originally, the framework was to include Texas-based research in order to get a clear picture of how these opportunities and challenges are addressed in the state. While some research sources were identified and incorporated into the framework, the vast majority of Texas-based information was overly broad or inconclusive/incomplete. Thus, we felt inclusion of this information would weaken the core framework and may lead to a false impression of the state of practice in Texas. At the same time, we wanted to provide some information about Texas-based practice to enable practitioners and policymakers to gain a broad view of mental health care for PwIDD in Texas.

This supplement addresses the core framework's opportunities and challenges, providing brief descriptions of legislation, state and local government programs or efforts, university and nonprofit programs, and other efforts that may address areas of need. This is not intended to be a directory of resources or a comprehensive listing of every resource related to a particular framework topic. It is intended to provide Texas-based context for the larger framework.

It must also be emphasized that, for the most part, these resources are not research based nor do they have efficacy data to demonstrate their effectiveness in improving service access/delivery. For example, guidelines for the incarceration of PwIDD in Texas exist—but it is unclear the extent to which they are actually used or how effective they may be in preventing PwIDD who are suffering from mental health crises from being incarcerated inappropriately. However, this supplement may provide broad information about areas that need to be improved and/or expanded. It can also be used as a starting point for those researching or working in this specific area of practice.

Overall, this analysis of practice paints an image of a state grappling with bureaucracy. Multiple reports from multiple agencies describe a distinct lack of coordination of effort or attention to PwIDD across agencies that address mental health. While it is clear that agency coordination is becoming a priority, it is difficult to discern any specific progress in this area. The report, *Strong Families, Strong Communities: Moving our Behavioral Health Workforce Forward*, is a good example of how agencies can focus on practical actions needed to improve services in that it clearly summarizes all of the agency's prior efforts, specifically describes barriers to implementation, and delineates next steps. It remains to be seen, however, if the agency moves forward in a meaningful and timely manner and whether these efforts will ultimately have the intended positive impact on service delivery.

While state agencies struggle to organize, coordinate, and move forward on mental health issues for PwIDD at the macro level, PwIDD and their caregivers are left in the lurch at the micro level. Disparate programs, resources, organizations, and efforts work to address specific needs. Yet, finding and evaluating these efforts is challenging—even for trained researchers. In most cases, evidence of effectiveness is lacking. In addition, these efforts tend to reinforce the caregiver as having primary responsibility as care finder/provider, rather than alleviating these already over-stressed individuals. Emphasis at the micro level should be on demonstrating efficacy of specific efforts, amplifying their availability, and easing access to them for overburdened PwIDD and their caregivers.

Notable areas of emphasis or progress in Texas include:

- Increased attention to trauma-informed care for PwIDD.
- Increased attention to the IDD/Mental Health/Justice System pipeline.
- Family/caregiver training and support resources.

Notable areas of few or no resources for PwIDD and co-occurring mental health conditions in Texas include:

- Minimizing stigma and the secrecy (and lack of care) that results.
- Recruitment and training of mental health care professionals with specific expertise in IDD/MH co-occurrence.
- Financial relief for PwIDD and their families, including direct support, insurance coverage for mental health care, and incentives for service providers to address mental health.
- Lack of use of diagnostic tools and approaches specifically designed to identify mental health conditions in PwIDD, particularly with respect to communication difficulties.
- Tools, approaches, and resources across all domains that address multiply-marginalized people—those with IDD, mental health conditions, and other aspects of identity that marginalize them such as race/ethnicity, language, gender identity, etc.
- Efforts to reduce bias in the mental health field against PwIDD who have communication difficulties and to train practitioners to communicate more effectively.
- Use of specialized, promising approaches such as the Restorative Integral Support (RIS) model.
- Availability of specialized hospital units for PwIDD and co-occurring mental health conditions.
- Availability of information, programs, or resources on the placement of children with IDD and co-occurring mental health conditions into the foster care system.
- Availability of information, programs, or resources specific to people with Down Syndrome and co-occurring mental health conditions.

## Awareness

## **Opportunities**

#### Caregiver Education

# Mental Health Wellness for Individuals with Intellectual and Developmental Disabilities (MHW-IDD)

Summary: Texas Health and Human Services, through University of Texas Health Science Center at San Antonio, offers free online training courses for service providers and caregivers on co-occurring IDD and mental health conditions, including:

- Co-occurring disorders
- Trauma-informed care
- Behavior Support
- Genetic Syndromes
- Medical Diagnoses

#### **NAMI Texas**

Summary: NAMI Texas and its affiliate chapters (linked from NAMI Texas's main site) offer a variety of online training programs for parents and family members of people with mental health conditions. However, none of the groups are specific to loved ones of people with co-occurring conditions.

#### Institute for Person-Centered Practices

Summary: Founded in 2010 as a collaboration between the University of Texas and Texas A & M University, the Center provides training in person-centered practices. While the training does not focus on mental health, specifically, person-centered thinking in planning and decisionmaking is an important part of mental health care.

#### Texas Center for Disability Studies – Road to Recovery: Trauma Informed Care

Summary: The program trains master trainers to provide trauma-informed care across the state of Texas. Anyone interested in making a difference in the mental health care received by PwIDD can apply to become a master trainer. Currently, there are 15 Master Trainers across Texas.

## Challenges

#### Lack of Knowledge

#### Navigate Life Texas

Summary: Navigate Life Texas provides a basic overview of dual diagnosis and how to recognize when a child with IDD may also be suffering from a mental health condition. This page also debunks myths about IDD and mental health (e.g., that PwIDD cannot also have a mental health condition, that PwIDD cannot be effectively treated for IDD). The site includes links to related

topics, including how to find help for mental health conditions, mental health training offered by organizations outside of Texas, etc.

<u>Texas Health and Human Services – Office of Disability Prevention for Children (ODPC) – Area</u> of Focus (Early Identification, Diagnosis, and Intervention; Promoting Mental Health Wellness for IDD)

Summary: The ODP addresses very briefly the prevention and recognition of mental health conditions in children with IDD, including a very brief PDF linking to external resources.

### <u>Texas Health and Human Services – Mental Health Wellness for People with Intellectual &</u> <u>Developmental Disabilities</u>

Summary: Texas Health and Human Services web site includes a page describing co-occurring IDD/mental health conditions. It also includes a list of resources (including the training described above) that caregivers can use to learn more.

#### <u>Mental Health Wellness for Individuals with Intellectual and Developmental Disabilities</u> (MHW-IDD)

Summary: Texas Health and Human Services, through University of Texas Health Science Center at San Antonio, offers free online training courses for service providers and caregivers on co-occurring IDD and mental health conditions, including:

- Co-occurring disorders
- Trauma-informed care
- Behavior Support
- Genetic Syndromes
- Medical Diagnoses

#### **Project TEDD: Training Educators in Dual Diagnosis**

Summary: This program at Texas Tech University trains K-12 educators to recognize and treat co-occurring IDD and mental health conditions. While not specifically directed to caregivers or to health care practitioners, enabling early (childhood) diagnosis and treatment by empowering educators could be an effective way to stem the tide of future IDD/MH crises.

#### Stigma and Secrecy

#### Mental and Behavioral Health - Navigate Life Texas

Summary: Navigate Life includes a web page that addresses stigma directly, emphasizing that children and families struggling with mental health conditions are not alone. The page also provides links to more information, support groups, etc.

#### NAMI Texas

Summary: NAMI Texas chapters (linked from NAMI Texas's main site) run virtual support groups for parents and family members of people with mental health conditions. However, none of the groups are specific to loved ones of people with co-occurring conditions.

# Access

# **Opportunities**

#### Financial Relief

#### Rx Savings Coupon from NAMI Texas – National Alliance on Mental Health (NAMI) Texas

Summary: The National Alliance on Mental Illness, Texas chapter, provides a printable discount prescription card for Texas residents, which can be used at major pharmacies to defray the cost of prescriptions for mental health conditions.

#### Texas NAMI (National Alliance on Mental Illness): Types of Health Insurance

Summary: NAMI also provides a good overview of available insurance options for PwIDD who have mental health conditions. It describes availability and benefits of private insurance, Medicaid and Medicare, CHIP, and Tricare/VA Health.

#### 2020 Revised Texas Promoting Independence Plan

Summary: The 2020 Revised Texas Promoting Independence Plan describes current and planned supports to ease overall financial distress for PwIDD. Specifically:

- Addressing affordable housing through partnerships with other Texas agencies, including housing specifically for those with mental health conditions;
- Several projects aimed at reducing waiver interest lists or filling service gaps for those on interest lists.

#### Health Insurance Premium Payment (HIPP) Program

Summary: HIPP is the Texas Medicaid program that helps families pay for employer-sponsored health insurance premiums, which can defray costs and expand the number and type of providers the person seeking treatment can see.

#### State Medicaid Agency Incentives:

#### Expansion of Managed Care – Texas Health and Human Services

Summary: Texas Health and Human Services' Executive Commissioner has been working to expand and adapt managed care in Texas beginning in 2015. Specific plans to address mental health care for PwIDD within the managed care system have not been addressed, however, this effort would be a logical place to advance incentives for MCOs to provide better mental health care.

#### SB 1177, 86th Regular Session

Summary: Passed in 2019, this bill enables Managed Care Organizations (MCOs) to offer evidence-based services to clients from the state Medicaid managed care advisory committee's list in lieu of services on the current Medicaid-approved list. This effectively expands the available mental health services MCOs can offer clients.

#### Recruitment of Mental Health Care Professionals

#### Strong Families, Supportive Communities: Moving Our Behavioral Health Workforce Forward

Summary: This report summarizes previous reports produced by the Behavioral Health Unit of Texas Health and Human Services. It assesses efforts to reach previously-stated goals and includes recommendations for advancing these goals in the future. It is important to note that this report and its contents are not specific to PwIDD with co-occurring mental health conditions. In other words, the specific recruitment efforts it summarizes are not necessarily focused on recruiting mental health care providers willing or trained to work with PwIDD. Given that this effort is aimed at creating a comprehensive and unified approach to recruitment, it is the logical place to increase attention to this challenge.

#### Harris Center Career Fair for Licensed Mental Health Care Professionals

The Harris Center in Houston offered a career fair specifically aimed at recruiting mental health care professionals with a desire to work with PwIDD. It is unclear whether the effort yielded the desired results, however, is an example of an activity designed to recruit professionals with a specific desire to work with PwIDD.

#### Community Living Policies

#### 2020 Revised Texas Promoting Independence Plan

Summary: The Texas Promoting Independence Plan (Plan) was developed in response to the United States (U.S.) Supreme Court's Olmstead ruling, which requires states to provide long term services and supports in the most integrated setting possible. The plan is updated periodically to demonstrate the policies and programs being implemented at a state level to ensure that PwIDD have higher levels of community integration.

#### Texas Health & Human Services Independent Living Services

Summary: Centers for Independent Living (CILs) are the local agencies tasked by the state to provide services to help people with IDD build skills and confidence to live independently and more fully participate in their communities.

#### Intellectual & Developmental Disability System Redesign Advisory Committee

This committee of Texas Health and Human Services focuses on revising and improving services to people with IDD, including an emphasis on services that increase people's access to and involvement in the community.

#### **Texas Independent Living Council**

Summary: The Council is a nonprofit organization tasked with developing and monitoring the State Plan for Independent Living, encompassing all areas of community integration.

# Challenges

#### **Financial Distress**

See related opportunity, *Financial Relief*, above.

#### Lack of Technological Infrastructure

<u>Texas Technology Access Program (TTAP) – Texas Center for Disability Studies the University</u> of Texas at Austin

Summary: The Texas Technology Access Program (TTAP) promotes independence for PwIDD by providing access to assistive and communication technology.

#### The Harris Center Awarded \$836,243 for Telehealth Services Infrastructure

While the Harris Center for Mental Health and IDD had previously been providing Telehealth services, it recently was awarded a nearly \$100 million grant through the CARES act to improve infrastructure, enabling the Center to increase its teleservice offerings in order to further limit the spread of Covid-19.

#### Hogg Foundation for Mental Health: A Guide to Understanding Mental Health Systems and Services in Texas

Summary: Over the past decade, legislation and changes to Medicaid reimbursement rates and procedures have increased the type and number of mental health services that can be provided by telemedicine, which directly impacts people with IDD who are home-bound or have mobility issues, are aging, or living in rural locations.

#### Waitlists

#### Navigate Life Texas - Waivers

Summary: Navigate Life provides a summary of the Medicaid waiver interested (wait) list

#### Texas Health and Human Services, Interest List Reduction

Summary: While the Texas legislature has provided additional funding to the Department of Aging and Disability Services (DADS) to reduce the number of individuals on interest (wait) lists for services, as more individuals become eligible the counts are actually increasing rather than decreasing.

#### Medicaid Waiver Programs Interest List Study

Summary: A 2020 study conducted by Texas Health and Human Services compared efforts in Texas to reduce interest list number with those employed in other states. The report identified three core strategies that could be used to reduce interest list counts:

- Addressing gaps in real-time information about the needs of individuals currently on waiver interests lists.
- Prioritizing populations and individuals with the highest level of service needs.

• Increasing interest list reduction allocations and targeting additional funding for priority populations.

#### Insufficient Insurance Coverage

#### Insurance- National Alliance on Mental Health (NAMI) Texas

Summary: NAMI Texas's web site provide a basic overview of insurance as a critical tool in access to mental health care, including information on accessing and using insurance and a discussion of parity (that mental conditions should have equal coverage in policies to other health conditions).

#### Mental Health Parity: Know Your Rights - The Hogg Foundation

Summary: This article with accompanying fact sheet outlines consumers' rights with respect to mental health condition parity in private insurance. These protections were provided to Texas consumers under 2017 House Bill 10.

#### **Provider Scarcity**

#### Addressing Texas's Psychiatrist Shortage - Texas A & M University

Summary: In response to the significant shortage of mental health providers, Texas A&M was awarded a grant from the Texas Higher Education Coordinating Board to create a plan to train new psychiatrists in the mostly-rural area. The program will also increase the number of residents serving the area. While not specifically aimed at PwIDD, if successful the program could be replicated with an emphasis on this underserved population.

#### The Mental Health Workforce Shortage in Texas, Department of State Health Services

Summary: In 2014, House Bill (H.B.) 1023 required the Texas Health and Human Services Commission (HHSC) to research and analyze the state's mental health workforce shortage. The report found that not only did the state have a significant shortage of qualified mental health care providers, but that as qualified providers retired, Texas institutions of higher learning were not producing enough new graduates to keep the pipeline full. The report details numerous strategies to address qualified provider scarcity. Again, while not specifically directed toward health care professionals trained to serve PwIDD, the broad recommendations could apply.

#### Strong Families, Supportive Communities: Moving Our Behavioral Health Workforce Forward

Summary: This report summarizes previous reports produced by the Behavioral Health Unit of Texas Health and Human Services. It assesses efforts to reach previously-stated goals and includes recommendations for advancing these goals in the future. It is important to note that this report and its contents are not specific to PwIDD with co-occurring mental health conditions. In other words, the specific recruitment efforts it summarizes are not necessarily focused on recruiting mental health care providers willing or trained to work with PwIDD. Given that this effort is aimed at creating a comprehensive and unified approach to recruitment, it is the logical place to increase attention on this challenge.

# Diagnosis

# **Opportunities**

#### Assessment Tools

#### <u>Texas Statewide Behavioral Health – Strategic Plan Update and the Foundation for the IDD</u> <u>Strategic Plan</u>

Summary: The Strategic Plan addresses the need for wider use of mental health assessments to ensure more people receive care and:

- To prevent inappropriate entry into the criminal justice system.
- To build mental health care capacity in public school systems.
- To ensure coordination of care across agencies.

However, the plan does not refer to any current or planned efforts to ensure that these assessments are appropriate for PwIDD. In fact, the gap analysis survey implemented as part of this plan indicated the area of co-occurring IDD and mental health conditions was the most significant gap in care. Within that gap, a third of each stakeholder group (family/friend, service provider, partner agency) identified assessments that identified substance abuse and mental health disorders in PwIDD as a gap.

#### Texas Child & Adolescent Needs & Strengths Assessment (CANS)

Summary: The CANS is a trauma-informed assessment and communications tool designed to streamline diagnostic testing to support treatment/service planning. While the assessment does not diagnose mental health conditions, its approach to assessing PwIDD is relevant to the discussion of why and how diagnostic tools made for the general population do not work for PwIDD.

#### Multi-Dimensional Assessment Process

#### 2020 Revised Texas Promoting Independence Plan – Texas Health and Human Services

Summary: The 2020 Revised Plan recommends developing a single assessment tool to be used when a person seeks help via IDD authorities or behavioral/mental health centers to determine the appropriate services. This is not, per se, a diagnostic tool that would facilitate accurate diagnosis of specific conditions. However, it is an example of how looking at the whole person and coordinating efforts across IDD and mental health domains can better serve PwIDD in Texas.

## Challenges

#### Comorbid Conditions

Policy Recommendation: Addressing the Mental Health and Wellness of Individuals with Intellectual Disabilities

Summary: This policy paper describes the prevalence of co-occurring IDD and mental health conditions and emphasizes that too often, practitioners view behavior as primarily a function of

IDD, often missing the mental health condition. It proposes a number of policy recommendations to ensure that PwIDD and co-occurring mental health conditions are accurately diagnosed.

#### Insensitive Diagnostic Approaches for Racially- and Ethnically-Diverse Populations

Texas Cultural Competence Guidelines for Behavioral Health Organizations – Texas Health & Human Services

Summary: A document containing written guidelines for organizations providing services through the Behavioral Health Unit of HHS describes methods to ensure cultural competency. However, it is not dated and does not bear the insignia of Texas HHS, and it is therefore unclear whether these guidelines are in force. In addition, this information is not specific to PwIDD. However, organizations serving PwIDD with mental health conditions through Behavioral Health would ostensibly need to meet these cultural competency guidelines.

#### ACT LEND – Texas Center for Disability Studies, The University of Texas At Austin

Summary: The Autism Consortium of Texas (ACT) LEND offers training to graduate students, family members, and self-advocates in culturally informed diagnosis.

#### Texas Child & Adolescent Needs & Strengths Assessment (CANS)

Summary: The CANS is a trauma-informed assessment and communications tool used to aid in service planning. While it does not diagnose mental health conditions, its approach to cultural competency could be used as a model for similar diagnostic tools.

#### Disability-Insensitive Diagnostic Approaches

Policy Recommendation: Addressing the Mental Health and Wellness of Individuals with Intellectual Disabilities

Summary: This policy paper describes several ways in which diagnostic approaches for mental health are not appropriate or not sensitive enough to enable accurate diagnoses for PwIDD. For example, the communication challenges some PwIDD have may preclude them from using some mental health assessments.

#### Texas Child & Adolescent Needs & Strengths Assessment (CANS)

Summary: The CANS is a trauma-informed assessment and communications tool used to aid in service planning. It is specifically designed for PwIDD and is sensitive to their communication needs. While it does not diagnose mental health conditions, its approach could be used as a model for similar diagnostic tools.

# **Quality of Care**

# **Opportunities**

#### Service Coordination

## <u>Strategic Plan Update and the Foundation for the IDD Strategic Plan – Texas Health and</u> <u>Human Services</u>

Summary: This version of the statewide plan identifies coordination of behavioral health as a persistent gap and describes broad goals and strategies to be used to coordinate care across agencies. However, this section of the plan does not refer to coordination with Disability Services or PwIDD specifically. In a separate section of the plan focusing on IDD, coordination across agencies is again identified as a significant gap. Ostensibly, goals and strategies to address this gap will be evident in the creation of the Texas Statewide IDD Strategic Plan. However, information on the timeline and progress of development of this plan could not be located.

#### **Community Resource Coordination Groups**

Summary: Community Resource Coordination groups (CRCG) were developed specifically to ensure easy access to services provided across agencies to PwIDD and their families. Services begin with development of an individualized service plan and services are identified to support the plan.

#### Integrated Care

#### Local IDD Authority (LIDDA) – Texas Health and Human Services

Summary: Local IDD Authorities provide intake and service coordination for PwIDD in Texas. Services span a variety of high-need areas, such as transportation, housing, employment, etc. While the LIDDA would be the logical entry point for mental health services, as the abovementioned strategic plan notes, access to mental health services through the IDD service system is not happening.

#### Mental Health Wellness for Individuals with Intellectual and Developmental Disabilities

Summary: Texas Health and Human Services provides online continuing education courses for health care professionals. One of the modules addresses integrated care specifically.

#### Support & Empowerment for Older Adults with IDD & their Caregivers

Summary: This free program offered by local authority the Alamo Area Council of Governments provides training to older adults with IDD and their caregiver(s) in health and wellness, including health, finances, spirituality, caregiver care, nutrition, and physical fitness. While this is a beneficial source of information, it again puts the onus of care on the PwIDD and/or their caregiver.

#### Multi-Disciplinary Training

#### Mental Health Wellness for Individuals with Intellectual and Developmental Disabilities

Summary: Continuing education modules for both direct service workers and healthcare professionals describe how to care for PwIDD who have co-occurring mental health conditions. The training was developed and is hosted by the University of Texas Health Science Center at San Antonio.

#### Project TEDD: Training Educators in Dual Diagnosis – Texas Tech University

Summary: This project trains K-12 educators to work with children dually diagnosed with IDD and mental health conditions. The program will build capacity in identification, referral, assessment, behavior, and academic best practices using a train-the-trainer model.

#### Person-Centered Care

#### 2020 Revised Texas Promoting Independence Plan

Summary: Federal and state regulations require a person-centered thinking approach in planning supports for PwIDD. While the approach described in this document does not specifically relate to mental health care or care planning, the principles could be applied to this domain.

#### Institute for Person-Centered Practices – Texas Center for Disability Studies

Summary: The Institute for Person-Centered Practices, a program of the Texas Center for Disability Studies, supports person-centered thinking across domains of IDD services. While the Institute does not specifically provide mental health care training, its core principles could be applied to this domain.

#### **Community Resource Coordination Groups**

Summary: Community Resource Coordination groups (CRCG) emphasize development of service plans that are based on the specific needs of PwIDD. Services stem from the person's needs, with an emphasis on service in home/community settings.

#### **Explanation of Services and Supports: Intellectual and Developmental Disabilities**

Summary: The Explanation of Services and Supports emphasizes that all service planning starts with a person-centered plan. However, it does not specify mental health care as a service to be provided for in the plan.

#### **Culturally Competent Practitioners**

## <u>Texas Cultural Competence Guidelines for Behavioral Health Organizations – Texas Health &</u> <u>Human Services</u>

Summary: A document containing written guidelines for organizations providing services through the Behavioral Health Unit of HHS describes methods to ensure cultural competency. However, it is not dated and does not bear the insignia of Texas HHS, and it is therefore unclear whether these guidelines are in force. In addition, this information is not specific to PwIDD.

However, organizations serving PwIDD with mental health conditions through Behavioral Health would ostensibly need to meet these cultural competency guidelines.

#### ACT LEND – Texas Center for Disability Studies, The University of Texas At Austin

Summary: The Autism Consortium of Texas (ACT) LEND offers training to graduate students, family members, and self-advocates in culturally informed diagnosis, support, and advocacy for children with autism spectrum disorder and other developmental disabilities through the Association of University Centers on Disabilities (AUCD).

#### Autonomy

#### Raising the Voices of Individuals with IDD - Hogg Foundation for Mental Health

Summary: This brief article describes the self-advocacy journey of a PwIDD who became a strong advocate and activist for PwIDD who have survived sexual assault.

#### <u>Texas Advocates – Programs</u>

Summary: Texas Advocates is the state's largest self-advocacy group for PwIDD. The group holds an annual convention and implements diverse projects and programs aimed at amplifying the voices of PwIDD in Texas policy and practice. This year's convention (August 2021) focuses on mental health.

#### Advocacy – MHMR of Tarrant County

Summary: This mental health authority emphasizes self-determination of PwIDD in its service model. The authority has two self-advocates and one parent advocate on staff to help PwIDD advocate for their needs and plan their services.

## Challenges

#### Fragmentation of Services

See related opportunity, *Service Coordination*, above.

#### Integrated Care

#### Local IDD Authority (LIDDA) – Texas Health and Human Services

Summary: Local IDD Authorities provide intake and service coordination for PwIDD in Texas. Services span a variety of high-need areas, such as transportation, housing, employment, etc. While the LIDDA would be the logical entry point for mental health services, access to mental health services through the IDD service system needs significant improvement.

#### Support & Empowerment for Older Adults with IDD & Their Caregivers

Summary: This free program offered by local authority the Alamo Area Council of Governments provides training to older adults with IDD and their caregiver(s) in health and wellness, including health, finances, spirituality, caregiver care, nutrition, and physical fitness. While this is a beneficial source of information and a good example of integrated care, it again puts the onus of care on the PwIDD and/or their caregiver.

#### Systemic Barriers to Integrated Care

#### Statewide Behavioral Health Strategic Plan

Summary: Texas Health and Human Services plans to develop a statewide IDD strategic plan, based on the gap analysis conducted as part of the Texas Statewide Behavioral Health Strategic Plan Update (2019). A primary goal of this effort is to "unify Texas' approach to address systemic barriers and challenges in the IDD system." (p. 121) It is not clear what the status of this effort is.

#### **HHSC Blueprint for a Healthy Texas**

Summary: Texas Health and Human Services' operational plan, Blueprint for a Healthy Texas, indicates that improving timely and efficient access to services is a priority. Part of this effort will be to review multiple agencies' reports and develop recommendations. The Blueprint also indicates that HHS will implement a pilot program to provide outpatient mental health services to PwIDD. No update or progress on these activities has been found.

#### Negative Attitude of Health Care Providers

#### Mental Health Wellness for Individuals with Intellectual and Developmental Disabilities

Summary: Texas Health and Human Services provides online continuing education courses for health care professionals. One of the modules addresses effective communication with PwIDD. Another module addresses trauma-informed care for PwIDD.

#### ACT LEND – Texas Center for Disability Studies, The University of Texas At Austin

Summary: The Autism Consortium of Texas (ACT) LEND trains graduate students, including in the mental health disciplines, in culturally informed diagnosis, support, and advocacy for children with autism spectrum disorder and other developmental disabilities.

#### Lack of Specialized Training of Mental Health Professionals:

#### Mental Health Wellness for Individuals with Intellectual and Developmental Disabilities

Summary: Texas Health and Human Services provides online continuing education courses for health care professionals in:

- Integrated healthcare;
- Communication with PwIDD;
- Trauma-informed care for PwIDD.

#### Poor Provider Communication

#### Mental Health Wellness for Individuals with Intellectual and Developmental Disabilities

Summary: Texas Health and Human Services provides online continuing education courses for health care professionals, including a module on communicating with PwIDD. This module emphasizes behavior as a communication and use of effective communication to plan and deliver service.

# Treatment

# **Opportunities**

#### Telehealth

#### 2020 Revised Texas Promoting Independence Plan

Summary: Recommendations in the 2020 revised plan including providing services (which could include mental health) via telehealth where the client agrees to it. The recommendations include payment parity for telehealth services and the creation of a mechanism for determining when telehealth might be appropriate.

#### Strategic Plan Update and the Foundation for the IDD Strategic Plan

Summary: The Strategic Plan Update and the Foundation for the IDD Strategic Plan states the benefits of technological advancements, such as telehealth and telemedicine, in providing greater access to the care PwIDD might need, which could include mental health. The plan also highlights efforts to expand telehealth and telemedicine through increased funding.

#### Telemedicine, Telehealth, and Home Telemonitoring Services in Texas Medicaid

Summary: This report describes the telemedicine, telehealth, and home telemonitoring services in Texas Medicaid. It highlights the number of clients utilizing these services and the number of providers offering them, noting that the increase in telemedicine has allowed individuals greater access to treatment and care, shorter wait times for appointments, and 24/7 access to crisis respite. The report also highlights specifically the treatment of behavioral health conditions using telemedicine and telehealth services.

#### Appropriate Use of Medication

#### Navigate Life Texas

Summary: Navigate Texas's summary of co-occurring conditions includes information for parents on discussing medication related to a mental health condition with the child's health care provider. This includes avoiding over-medication or contra-indicated medications.

#### <u>Addressing the Mental Health and Wellness of Individuals with Intellectual Disabilities (IDD) –</u> <u>Hogg Foundation</u>

Summary: This set of policy recommendations emphasizes the over-use of medication in PwIDD to control behavior, rather than addressing the underlying mental health condition. It emphasizes the use of non-pharmacological treatments for mental health conditions in PwIDD.

#### Legally Adequate Consent – Disability Rights Texas

Summary: This article describes the rights of people with disabilities in refusing medication.

#### Psychotherapy

Addressing the Mental Health and Wellness of Individuals with Intellectual Disabilities (IDD) – Hogg Foundation

Summary: This set of policy recommendations emphasizes that many "traditional" psychotherapies are not used with PwIDD and co-occurring mental health conditions, despite research findings indicating they can be effective.

#### The Restorative Integral Support (RIS) Model

No resources specific to the use of RIS with PwIDD and co-occurring mental health conditions in Texas were found.

#### Crisis Behavior Intervention Services

#### HHSC Crisis Services Guide

Summary: This guide describes crisis-related services across the state by Local Mental Health Authorities and Local Intellectual and Developmental Disability Authorities. Some of these services include crisis hotlines, mobile crisis outreach teams (MCOTs), and mental health deputies (MHDs).

#### IDD Crisis Services (Various MH/BH/IDD Centers)

Summary: Many of the local authorities that provide mental health, behavioral health, and IDD services are using crisis interventions, including dual-diagnosis clinics, mobile response teams, and crisis respite.

## Challenges

#### Medication Inaccuracies

See related opportunity, Appropriate Use of Medication, above.

#### Lack of Trauma-Informed Care:

Trauma-Informed Care, and Intellectual and Developmental Disabilities

Summary: The Hogg Foundation for Mental Health has a podcast episode focusing on Trauma-Informed Care. Additionally, the podcast blog post provides information on unrecognized trauma, treatment that worsens trauma, and how to focus on healing trauma and IDD.

#### **Grief Informed & Trauma Informed Practices**

Summary: The Texas Education Agency has information regarding Grief Informed & Trauma Informed Practices that should be implemented in schools given their role as a critical system of support. Several of the resources listed refer specifically to trauma-informed care for children with IDD.

Strategic Plan Update and the Foundation for the IDD Strategic Plan

Summary: The Strategic Plan Update and the Foundations for the IDD Strategic Plan is a fiveyear strategic plan to address gaps in the behavioral health services system. Within this plan, there are various mentions of the issue of trauma and implement trauma-informed care practices.

#### Road to Recovery: Trauma Informed Care – Texas Center for Disability Studies

Summary: The Road to Recovery (R2R) project focuses on trauma-informed care for PwIDD in Texas through a "master trainer" program.

#### Mental Health Wellness for Individuals with Disabilities (IDD)

Summary: Both the free care provider training and the paid continuing education training include a module on trauma-informed care for PwIDD.

#### Lack of Specialized Hospital Units:

#### The New Post-Hospitalization Crisis Residential Unit – Harris Center for Mental Health and IDD

Summary: The Harris Center for Mental Health and IDD describes its new post-hospitalization crisis residential unit, funded by the Texas 1115 Healthcare Transformation Waiver. This unit specifically aims to reduce subsequent hospitalizations, involuntary institutionalizations, and incarcerations of PwIDD and co-occurring mental health conditions.

#### Unnecessary Institutionalizations

#### Strategic Plan Update and the Foundation for the IDD Strategic Plan

Summary: The Strategic Plan Update and the Foundations for the IDD Strategic Plan describes how sudden changes in the needs of PwIDD (which can include mental health care needs) can result in institutionalization when the primary care provider is the person's family. It describes the need to provide additional care services through Health and Human Services (via LIDDAs) to prevent this from happening.

#### Intellectual & Developmental Disability System Redesign Advisory Committee

Summary: One of the charges of this committee is to identify additional long-term services and supports that can reduce the need for institutionalization.

#### The New Post-Hospitalization Crisis Residential Unit – Harris Center for Mental Health and IDD

Summary: The Harris Center for Mental Health and IDD about a new post-hospitalization crisis residential unit, funded by the Texas 1115 Healthcare Transformation Waiver. This unit specifically aims to reduce subsequent hospitalizations, involuntary institutionalizations, and incarcerations of PwIDD and co-occurring mental health conditions.

#### Inappropriate Out-of-Home Placement of Children and Youth

**Community Resource Coordination Groups** 

Summary: The Community Resource Coordination Groups web site provides information on new legislation that will establish a system where children under the age of 12 will be referred for service coordination and offered tuition and fee waivers programs when eligible.

# **Special Populations**

#### Incarcerated Individuals

#### Criminal Justice Issue Brief – Texas Council for Developmental Disabilities

Summary: The Criminal Justice Issue Brief from the Texas Council for Developmental Disabilities shows the most current information for Detainees, Alleged Offenders, and Offenders with IDD. Some of the topics mentioned include Local Jails, State Jails, State Supported Living Centers, State Prisons, etc.

#### **Community Resource Coordination Groups**

Summary: The Community Resource Coordination Groups web site provides information on new legislation that will establish a system where children under the age of 12 will be referred for service coordination as an alternative to adjudication. Additionally, youth who have had experience with foster care or with adoption will be offered tuition and fee waivers programs when eligible.

<u>Texas Juvenile Mental Health and Intellectual and Developmental Disabilities Law Bench Book</u> <u>– Judicial Commission on Mental Health – First Edition 2020 – 2021</u>

Summary: This Bench Book functions as a guide for Texas judges hearing cases regarding youth with mental illness and/or IDD. It is designed around the Sequential Intercept Model (SIM), which identifies strategies and entry/exit points for youth with IDD and Mental Illness to/from the juvenile justice system.

#### **Detention of Person with IDD**

Summary: This document is a comprehensive study on the best practice standards for the detention of individuals with Intellectual and Developmental Disabilities. It also includes a few specific recommendations for future activities.

#### The Arc of Texas 2021 Public Policy

Summary: The Arc of Texas works to ensure the civil rights of PwIDD. The organization seeks to implement solutions through legislation to tackle the struggles of those with IDD and their families. This web site summarizes current efforts.

#### **Rural Communities**

#### All Texans Access Report Part 1: Background

Summary: This government document summarizes how addressing the issue of access to mental health services in rural communities has significantly addressed the mental health crisis among Texans living in these areas. The report specifically mentions the mental health needs of PwIDD living in rural Texas.

#### Tips for Raising a Child with Special Health Care Needs in a Rural Setting

Summary: This source provides tips for parents raising children with disabilities and special health care needs in a rural setting. Some of the tips include finding health care services, school choices, and how to connect with other parents in said community.

#### Strategic Plan Update and the Foundation for the IDD Strategic Plan

Summary: The Strategic Plan Update and the Foundation for the IDD Strategic Plan addresses some of the unique needs for individuals with IDD living in rural areas. The document mentions how technological advancements such telehealth and telemedicine have allowed greater access to services they need without the need of extensive transportation times. Additionally, it mentions how Texas A&M University-Commerce's Rural Mental Health Outreach Initiative created a program to develop strategies for the mental health of PwIDD in those in rural areas.

#### Down Syndrome

No resources specific to mental health of people with Down Syndrome in Texas were found.

#### Aging PwIDD

#### <u>Support & Empowerment for Older Adults with IDD & their Caregivers – Alamo Area Council</u> of Governments (AACOG)

Summary: The Alamo Area Council of Governments offers a free education program that aims to educate older adults living with IDD and their caregivers. The program is comprised of six classes and covers topics in:

- Health
- Wellness
- Finances
- Spirituality
- Caregiver care
- Nutrition

#### **Texas Aging and Disability Resource Centers (ADRCs)**

Summary: Texas Aging and Disability Resource Centers in Texas aid PwIDD who are aging. Part of the "No Wrong Door" policy, the goal of ADRCs is to minimize the confusion that happens when people need to access services but are eligible for multiple programs across state agencies.

#### Racial and Ethnic Minorities

#### ACT LEND – Texas Center for Disability Studies

Summary: The Autism Consortium of Texas (ACT) LEND's purpose is to train graduate students, family members, and self-advocates in culturally informed diagnosis. Coursework includes seminars, research, presentations, mentorship, and hands-on experiences in both clinical and community-based settings.

#### Autism Spectrum Disorder

#### Mental Health & Crisis Resources - Texas Autism Society

Summary: The Autism Society of Texas provides resources for caregivers of people with Autism Spectrum Disorder. These resources describe what to do in a crisis and organizations that provide non-crisis related mental health care.

#### Texas Child Study Center – Dell Children's Hospital

Summary: The Texas Child Study Center treats children with autism and mental health conditions. This includes psychiatric testing and evaluation, a variety of therapies, family support, medication management, and community-based programs.

# **Special Issues**

#### Family/Friends/Ally/Caregiver Stressors

#### Respite Care for Children with Disabilities – Navigate Life Texas

Summary: Navigate Life summarizes how respite care is needed to alleviate caregiver stress. It also links out to a number of Texas-based respite resources and family support networks.

#### **Texas Parent to Parent**

Summary: Texas Parent to Parent is an organization that helps PwIDD and their caregivers through resource referral, support, and education. The organization uses a parent-to-parent peer support model. The organization addresses mental health topics through information on trauma, a mental health listserv, conference presentations, etc.

#### **NAMI Texas**

Summary: NAMI Texas and its affiliate chapters (linked from NAMI Texas's main site) offer a variety of support groups for parents and family members of people with mental health conditions. However, none of the groups are specific to loved ones of people with co-occurring conditions.

#### Support & Empowerment for Older Adults with IDD & their Caregivers

Summary: This free program teaches older adults with IDD and their caregiver(s) integrated health and wellness topics. It includes a topic on caregiver care.

#### Partners Resource Network

Summary: This organization provides education and support to families of children with disabilities. Training and support cover a broad range of topics typically focused on public education issues. However, it also provides webinars on topics such as managing stress.

#### COVID-19

#### COVID-19 Support Line and Resources - The Harris Center for Mental Health and Disabilities

Summary: The Harris Center is operating a statewide mental-health hotline to address Covid-19 related mental health. While not specific to PwIDD, it is a resource that can be used by both PwIDD and their caregivers.

#### <u>Coronavirus (COVID-19) Information for People Receiving Services – Texas Health and Human</u> <u>Services</u>

Summary: This web page is a hub for information for people receiving services through HHS. It includes mental health and crisis counseling resources, as well as information about changes in access to services.

Texas Covid Stories – Texas Council for Developmental Disabilities

Summary: Texas Council for Developmental Disabilities (TCDD) is collecting stories about the impact Covid-19 has on PwIDD at key points during the pandemic. PwIDD can share their stories through online surveys. They can also read the stories of others gathered at three months after initial shutdown, six months, and one year.

#### <u>Support and Connection: Person-Centered Practices During COVID – Texas Center for Disability</u> <u>Studies</u>

Summary: This training program helps PwIDD and their caregivers create a one-page profile of support needs during COVID-19. Training also addresses COVID-19 related mental health concerns of PwIDD.

#### Impacts of COVID-19 on Long Term Care Facilities - House of Representatives Committee on Human Services Request for Information

Summary: This request for information summarizes some of the negative long-term impacts of the visitation "lockdown" policies in long-term care facilities in Texas. It also addresses impacts related to changes in regulatory oversight.

#### COVID-19 – Disability Rights Texas

Summary: This web page provides resources to Texans with IDD related to COVID-19. This includes articles about how to protect the rights of PwIDD and links to a variety of external resources related to COVID-19 and its impact on PwIDD.

#### Trauma and PTSD

#### Trauma-Informed Care and Intellectual and Developmental Disabilities

Summary: The Hogg Foundation for Mental Health has a podcast episode focusing on Trauma-Informed Care. Additionally, the podcast blog post provides information on unrecognized trauma, treatment that worsens trauma, and how to focus on healing trauma and IDD.

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Summary: Both the free care provider training and the paid continuing education training include a module on trauma-informed care for PwIDD.

#### Treatment in a School Setting

#### **Educational Placements for Students with Disabilities**

Summary: Navigate Life Texas provides an overview of school placements for families raising children with disabilities. While the resource does not specifically address co-occurring conditions, it does address the need for Individualized Education Plans (IEPs) that are specific to the child's needs (which may include co-occurring conditions).

#### Project TEDD: Training Educators in Dual Diagnosis

Summary: This program at Texas Tech University trains K-12 educators to recognize and treat co-occurring IDD and mental health conditions.

#### Foster Care and Residential Facilities

#### **Community Resource Coordination Groups**

Summary: The Community Resource Coordination Groups web site provides information on new legislation that will establish a system where children under the age of 12 will be referred for service coordination and offered tuition and fee waivers programs when eligible.

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