



# Out of Options: Addressing Inequities in Care for Texans with Intellectual and Developmental Disabilities (IDD) and Mental Illness

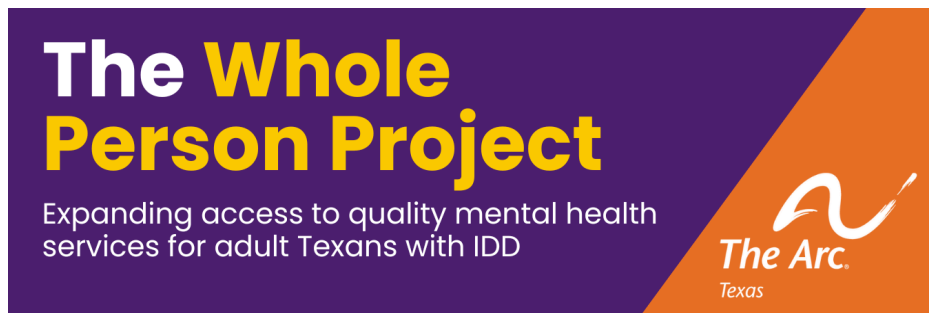
*Investigative report and recommendations by The Arc of Texas*

*December 5, 2024*

*This report is authored by Alex Stuckey, Investigative Reporter for the [Whole Person Project](#), an initiative of The Arc of Texas which seeks to expand access to quality mental health services for adult Texas with IDD.*

*[Watch this 2-minute video](#) to get a brief overview before diving into the report.*

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Jenni Johns<sup>1</sup> turned her home into a makeshift psychiatric ward after her son, Sean, was denied admission to private mental hospitals all over Texas.

Melinda Tolentino was separated from her family for seven months, helping an ailing parent in another state while her husband stayed in Texas searching for care for their daughter, who'd been on a waitlist for a Medicaid waiver for over a decade.

Shantel Taylor watched in anguish as her son, Kai'Yere Campbell, sat in a jail cell for months – covered in sores – waiting to come to the top of a 2,000-person list for a state psychiatric bed.

All three families have adult children with co-occurring intellectual and developmental disabilities (IDD) and mental disorders, and all three have been failed by state systems ill-equipped to handle their dual diagnoses.

Until the mid-twentieth century, scientists and clinicians outright denied people with IDD could experience psychiatric disorders<sup>2</sup>. Often, psychiatric symptoms were (and still are) misattributed to a person's intellectual or developmental disability. But in reality, about one-third of the estimated 500,000 Texans with an IDD diagnosis also have a mental health condition<sup>3</sup>.

The Centers for Disease Control and Prevention found that adults with disabilities experience mental distress five times more frequently<sup>4</sup>. They are confronted with abuse, neglect, and other trauma at higher rates than the general population, putting them at risk for post-traumatic stress disorder<sup>5</sup>.

But the damage of previous assumptions remains. Many behavioral health services fail to cater to people who are neurodivergent or have IDD.

People with an IQ below 70 can be excluded from many psychiatric hospitals. Group homes often aren't equipped to handle severe mental health symptoms. Local IDD Authorities (LIDDAs) don't do in-depth mental health screenings. It doesn't help, either, that there is a tendency to misattribute mental health symptoms to IDD, that communication barriers may be present, or that mental health symptoms might present differently<sup>6</sup>.

This report outlines the gaps – and some successes – in services for people with this dual diagnosis. It's time to fix this inequity in services and help Texans get the care they need and deserve.

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<sup>1</sup> The names of Jenni and her son, Sean, have been changed to protect their identity.

<sup>2</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8613764/>

<sup>3</sup> <https://www.pacstx.org/wp-content/uploads/2023/01/What-is-IDD-2023-Flyer-.pdf>

<sup>4</sup> <https://www.cdc.gov/ncbddd/disabilityandhealth/features/mental-health-for-all.html#:~:text=Adults%20with%20disabilities%20report%20experiencing.14%20days%20in%20a%20month.>

<sup>5</sup> <https://www.hhs.texas.gov/about/process-improvement/improving-services-texans/behavioral-health-services/mental-health-wellness-people-intellectual-developmental-disabilities#:~:text=People%20with%20IDD%20experience%20trauma.the%20M%20DID%20D2.>

<sup>6</sup> <https://www.milbank.org/quarterly/opinions/meeting-the-mental-health-needs-of-americans-who-live-with-intellectual-and-developmental-disabilities/>

# Acronyms and Definitions

**Intellectual and Developmental Disabilities (IDD):** These two diagnoses are chronic, lifelong, and commonly require long-term intervention.

- Intellectual disability: A disability impacting about 6.5 million people in the U.S. that typically occurs before a person turns 18 and significantly affects intellectual functioning and day-to-day life skills, including communication and taking care of themselves.
- Developmental disability: A disability that results in mental and/or physical impairment that manifests before a person turns 22. This impairment limits three or more life activities, such as self-care, mobility, and the ability to live independently.
- Examples of IDD include:
  - Down Syndrome: Physical and cognitive symptoms that occur when a person has an extra copy, or part of a copy, of chromosome 21.
  - Autism: A neurological and developmental disorder that affects how someone communicates, learns, and acts.
  - Fetal Alcohol Spectrum Disorder (FASD): A group of conditions that occur if a mother drinks alcohol during pregnancy, which can affect a person physically, mentally, or both.
  - Cerebral Palsy: A neurological disorder that permanently affects muscle coordination and body movement.
  - Attention Deficit/Hyperactivity Disorder (ADHD): A disorder characterized by impulsivity, hyperactivity and an inability to pay attention.
  - Tourette Syndrome: A disorder identified by sudden, involuntary sounds or movements known as tics.
  - Seizure Disorders: A set of disorders distinguished by sudden, uncontrolled electrical activity bursts in the brain. Epilepsy is the most common cause.

**Community First Choice (CFC):** A program available to people with or without a Medicaid waiver that provides waiver-like services – such as habilitation and personal assistance – to individuals enrolled in Medicaid.

**Community Mental Health Act:** A law signed in 1963 by President John F. Kennedy providing states with federal funding to build mental health centers so individuals with mental illness could access services in their communities and avoid institutionalization.

**Continuity of Care Query (CCQ):** A process by which county jail correctional officers run an individual's information against a database that instantly informs them if someone has received public mental health services in the past three years.

**Forensic Clearinghouse List:** A waitlist created in 2006 for criminal defendants waiting for a bed in the state psychiatric hospital system.

**General revenue-funded services:** Safety net services, run by the LIDDAs, that act as a stopgap for people waiting for their names to come to the top of a Medicaid waiver list.

**Incompetent to Stand Trial:** An individual is found incompetent to stand trial if experts believe they are unable to understand criminal proceedings and participate in their own defense. In Texas, people found incompetent to stand trial are typically sent for competency restoration, which consists of training and education about the court process and medication management. This treatment can happen in a state psychiatric hospital or one of the following alternatives:

- **Outpatient Competency Restoration (OCR):** Court-ordered treatment in the community. The first pilot program began in 2007.
- **Jail-Based Competency Restoration (JBCR):** Court-ordered treatment in a county jail. The first pilot program began in 2018.

**Individualized Education Program (IEP):** A document that outlines the special education services and supports that a student aged three to 21 receives in public school if they have a disability that affects their performance. An IEP is required – and free – under the federal Individuals with Disabilities Education Act (IDEA).

**Intermediate Care Facilities for Individuals with an Intellectual Disability or Related Conditions (ICF/IID):** Community-based residential settings where people with an intellectual disability (and related conditions) can receive treatment and services. If someone enters an ICF/IID, they do not lose their spot on the Medicaid waiver waitlists.

**Local Intellectual and Developmental Disability Authorities (LIDDAs):** There are 39 LIDDAs across Texas, which serve as the single point of entry for individuals seeking publicly-funded services for IDD in their community. This is where people are screened for IDD, provided services, and, if applicable, added to waitlists (also known as interest lists) for Medicaid waiver services. A list of LIDDAs and the counties they serve can be found [here](#).

**Local Mental Health Authorities and Local Behavioral Health Authorities (LMHAs/LBHAs):** There are 37 LMHAs and two LBHAs across Texas that provide community-based mental health services to individuals in their specific geographic areas. A list of LMHAs/LBHAs can be found [here](#).

**Medicaid Waiver Programs:** States can use Medicaid funds for home and community-based services and other healthcare needs, allowing people with disabilities to live in the community instead of an institution. There are six waivers for people with disabilities available in Texas:

- **Home and Community-based Services (HCS):** Provides services to adults and kids with an intellectual disability or related condition who live in a group home with four or fewer people, their own home, or a family member's home.
- **Texas Home Living (TxHmL):** Provides services to adults and kids with an intellectual disability or related condition who live in their family's home or their own home.
- **Community Living Assistance and Support Services (CLASS):** Provides home and community services to adults and kids with an intellectual disability or related condition that occurred before the age of 22.
- **Deaf Blind with Multiple Disabilities (DBMD):** Provides services to adults and kids who are deaf-blind or have a condition that leads to deaf-blindness and have another disability.
- **Medically Dependent Children Program (MDCP):** Provides services to adults and kids age 20 and younger who are medically fragile so they don't have to live in a nursing home.

- **STAR+PLUS Home and Community Based Services (STAR+):** Provides services for adults age 21 and older to keep them in their community and out of a nursing home.

**State Supported Living Centers (SSLCs):** Campuses for people with IDD that provide 24-hour residential and behavioral treatment services, skills training, therapies, and vocational programs. There are 13 locations across Texas.

**Texas Commission on Law Enforcement (TCOLE):** The state regulatory agency created in 1965 that develops and enforces standards for all peace officers in Texas, including corrections officers.

**Texas Commission on Jail Standards (TCJS):** A regulatory body created in 1975 to oversee county and privately operated municipal jails.

**Texas Health and Human Services Commission (HHSC):** The state agency that manages programs to help families with health care, food, and safety. HHSC oversees mental health and IDD services across Texas.

**The Intellectual and Developmental Disability Advisory Committee (IDDAC):** The 87th (2021) Texas Legislature required the Texas Commission on Jail Standards to create this committee to advise them on issues encountered by inmates with IDD.

**The Texas Sunset Advisory Commission:** A 12-member legislative commission that examines the performance of state agencies and determines if they are still needed.

# Identifying Mental Health Disorders in People with Intellectual and Developmental Disabilities (IDD)

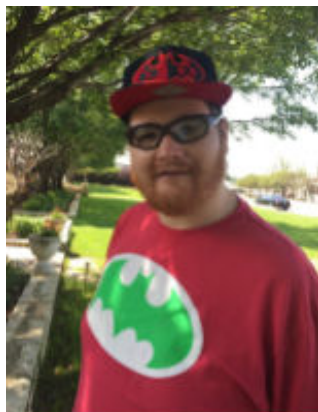
Research dating back to at least the 1990s shows individuals with IDD experience mental health issues just like neurotypical, non-disabled individuals – often at an even higher rate. However, diagnosis overshadowing remains a significant problem.

Too often, symptoms of a mental health condition are attributed to an individual's intellectual or developmental diagnosis, meaning they do not get appropriate care until a crisis develops.

“Too many systems of care for people with IDD continue to focus on controlling and managing challenging behaviors without adequate consideration of the potential for underlying mental health or medical conditions as the cause of the behavior,” The Hogg Foundation for Mental Health wrote in a recent policy recommendation<sup>7</sup>. That results, the foundation wrote, in behavior management plans that focus on compliance or medication to control behavior instead of treating the underlying condition. This makes recovery “unlikely,” the organization continued.

Early identification and appropriate assessment are essential to ensure individuals with IDD receive the care they need when they need it.

## Local Intellectual and Developmental Disability Authorities' Screenings



*The signs of Morgan Dooley's mental illness came barreling toward his mom, Michelle, like a freight train when he was eight years old. The hitting. The biting. The radical mood swings. Morgan couldn't express what was wrong: Landau Kleffner Syndrome left him nonverbal and prone to seizures. Michelle called their Local IDD Authority (LIDDA), where case managers, for so many years, had been instrumental in getting Morgan the care he needed. Morgan's case manager sent him to the Local Mental Health Authority (LMHA), which is co-located with the LIDDA but operates in a silo from it. The LMHA diagnosed him with bipolar disorder, but beyond that, Michelle said they didn't know what to do.*

*Morgan Dooley (courtesy) Though they offered therapy, none of their counselors knew how to work with people with IDD, Michelle said – particularly someone who does not speak. They also couldn't find any privately-paid therapists locally who could work with Morgan. The best they could do was medicate him. But the medication turned him into a drooling zombie and, frankly, wasn't addressing the underlying issues.*

*Then, when Morgan was 10, he and Michelle met with an LMHA psychiatrist. Morgan was clearly upset, grunting and fidgeting in his chair. The doctor, Michelle said, called Morgan the “R” word. He said Morgan needed to settle down and that he would never understand.*

*Morgan pinned him against the wall.*

<sup>7</sup> [https://utw10282.utweb.utexas.edu/wp-content/uploads/2015/09/MH\\_IDD-Policy-Rec\\_0801141.pdf](https://utw10282.utweb.utexas.edu/wp-content/uploads/2015/09/MH_IDD-Policy-Rec_0801141.pdf)

*It was the first of dozens of times Morgan was sent to a psychiatric ward by the LMHA in a desperate attempt to control the symptoms of his bipolar disorder. But no one, it seemed, could help her son. Morgan is now 39 and living in a group home. He loves going to the movies and shopping at Walmart with his mom.*

*Michelle gave up on getting help from their LMHA more than a decade ago, opting instead to track down a willing therapist on her own. Things are good for now, but Michelle worries about the day Morgan's therapist moves or has to stop working with him. Without an LMHA to fall back on, she'll be back at square one.*

*"We've got a long way to go," Michelle said. "They really don't know what to do with dually diagnosed people." [Watch this 3-minute video](#) to learn more about Morgan's story.*

Texas has 39 LIDDAs that act as the single entry point for general revenue-funded IDD services. They provide information about services, determine eligibility, and help enroll people in those services. Some even provide short-term placement for individuals in crisis.

When someone first approaches a LIDDA for help, an assessment is conducted to determine if that person has an intellectual or developmental disability and is eligible. They collect documents such as school Individualized Education Program (IEP) records, previous psychiatric treatment records, and any records from private IDD-related services. During that process, a psychologist tests for IQ and adaptive behavior. The potential client undergoes a suicide screening to determine their current risk, and staff are trained to monitor a person's health at every encounter. Individuals who request to have themselves or their loved ones added to a waitlist for services fill out a questionnaire that asks about any mental or behavioral health diagnoses. However, LIDDAs do not conduct a formal behavioral health assessment. "We ask those questions not so much to screen their mental health status today ... but it's to try and determine, 'Are they at the right door?'" said Shena Ureste, CEO of the Texana Center in Rosenberg, which serves as both the LIDDA and the LMHA for six counties including Fort Bend.

If mental health is more of a concern than IDD, LIDDA personnel refer the individual to the local LMHA. The two entities may be co-located but have separate administrative authorities and, therefore, separate screening processes.

#### **The Arc of Texas recommends:**

- **LIDDAs should enhance screenings for mental health during intake and assessment.**
  - **Stakeholders also suggested this in the [January 2022 Statewide Intellectual and Developmental Disabilities Strategic Plan](#) as a way to identify mental health issues early.**

#### **County Jail Screenings**

*Lisa Foster watched her son, Robert "Rico" Terry, leave for the bus station near her home on a Thursday afternoon in May 2023. "Be careful," she called out the door. "I love you."  
"OK, mom. I love you, too," he called back. Lisa expected him to return in a few hours.*



*He never did.*

*Lisa and her boyfriend frantically called friends, family, and hospitals – anyone they could think of – to find her son, who has schizophrenia and a developmental disability.*

*Two days later, on May 13, 2023, they learned he'd been booked into the Harris County Jail on a felony retaliation charge.*

*Lisa felt sick. Her son had been in and out of jail for years, sleeping in the woods and doing any drugs he could get his hands on. But about a year ago, Lisa had finally convinced him to move in with her. She got him mental health care and a formal diagnosis. She got him on medication. He seemed to be improving.*

*But now that he was back in jail, she feared what would happen if he didn't get the medication he'd grown to depend on. She called the jail's chaplain first, she said, but didn't get an answer. Then she called the jail's medical team, she said, outlining his diagnoses and medications. But a mental health and IDD evaluation wasn't ordered for Rico until May 16, 2023 – three days after his arrest.*

*He had been dead for more than two hours by the time a judge signed the evaluation order. The medical examiner listed Rico's cause of death as undetermined. Still, a lawsuit filed by the family states that he [vomited repeatedly, foamed at the mouth](#), and experienced multiple instances of unconsciousness before he died.*

*Lisa has been living in anguish since his death. She hasn't been able to hold a job. The nightmares of what happened to Rico plague her every night. She doesn't understand why Rico wasn't flagged immediately by police officers as mentally ill and taken, instead, to a mental health hospital. She's even more confused about why he wasn't identified as mentally ill in jail and taken to a special unit – especially after she called.*

*If he had been, he might still be alive.*

*"People who are suffering from a mental disorder ... they ought to be treated in a different manner," Lisa said. "All you have to do is talk to them differently."*

During the 80th (2007) legislative session, Texas lawmakers passed [SB 839](#), requiring the Department of State Health Services (DSHS) and the Department of Public Safety (DPS) to create an instantaneous identification system for offenders with special needs.

The process, known as a Continuity of Care Query (CCQ), replaced the previous system<sup>8</sup>, which required Community Mental Health Centers to manually check an inmate's name within 72 hours of receiving it from the local jail.

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<sup>8</sup> The old system was called the Client Assignment and Registration System (CARE check system)

Under the new system, personnel at correctional institutions use DPS' Texas Law Enforcement Telecommunications System (TLETS)<sup>9</sup> to run a CCQ on an individual when they are being processed into the facility. They then get an alert if someone has received, or might have received, publicly-funded care through any of the following means in the previous three years: A state psychiatric hospital, an LMHA or LBHA, or a state-funded, contracted private psychiatric bed.

The three-year time frame “was based on the technical complexities of the TLETS data-matching methodology and its operationalization in the field,” said Tiffany Young, HHSC spokeswoman. If there is an exact or probable match, the system spits out the name of the LMHA or LBHA that most recently provided services. The jail is then required to notify the appropriate LMHA or LBHA to connect the inmate to resources.

By 2013, all Texas county jails were using CCQ for their inmates, and [more than 40 percent of bookings across the state](#) were for people who had an exact or probable CCQ match, according to an April 2014 handout from Every Texan (formerly known as the Center for Public Policy Priorities).

The CCQ is conducted alongside a mental health and suicide risk screening that includes self-reported questions and jailer observations. If an inmate is exhibiting signs of mental illness, the sheriff has to alert a magistrate within 72 hours.

The screening was revised after the death of 28-year-old Sandra Bland in 2015, who hung herself in the Waller County Jail shortly after being arrested for a traffic violation. The original screening form asked inmates to self-report mental health, IDD, and medical problems, as well as state whether they felt suicidal or depressed. However, the revised form uses multiple questions to try to get at the same information in a different way. It also gives jailers instructions on responding to the answers.

In 2020, [the ability to determine if someone has an IDD diagnosis](#) was added to TLETS. “Utilizing the same format and process as the CCQ check, this additional feature is part of the continuing effort to identify and connect inmates with mental health or IDD issues with resources that are available,” wrote Brandon Wood, executive director of the Texas Commission on Jail Standards (TCJS), in a September 2020 memorandum to sheriffs and jail administrators. The enhancement of the CCQ process [allows jails to identify individuals with IDD who have been served by a LIDDA](#) in the last three years and automatically informs LIDDAs if a match is made. However, the amount of time it takes to alert LIDDAs can vary.

Nearly 20 LIDDAs surveyed by The Arc of Texas (June-July 2024) said they are alerted to a client being in jail within 24 hours of booking. Others receive a weekly TLETS report for the jails in their catchment areas. But Camino Real Community Services, the LIDDA that serves nine counties including Atascosa, gets a monthly report, meaning it could take 30 days to learn if one of their clients is in jail, said Inez Longoria, the LIDDA's access and intake director.

Hill Country Mental Health and Developmental Disabilities Centers, a LIDDA that serves 19 counties in central Texas, has struggled to receive accurate CCQ notifications, said Analaura McCrae, the

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<sup>9</sup> TLETS uses an electronic data exchange process with HHSC's Clinical Management Behavioral Health System (CMBHS) to search for matches based on demographic data

center's director of IDD authority. "Occasionally, it has been the following day, but more often than not, we are made aware of an individual we serve being incarcerated by other means and may not ever receive a CCQ notification," she said. "I think there is a need for more training directed to law enforcement to better understand the importance of the TLETs process."

**The Arc of Texas recommends:**

- **Increase the number of years searched through CCQ.**
  - **Mental health and IDD diagnoses can be lifelong disorders. Under the current system, people are only flagged if they received public services within 3 years of incarceration.**
  - ***The Texas Commission on Jail Standards and the Intellectual and Developmental Disabilities Advisory Committee have suggested similar recommendations.***
- **Look beyond publicly funded services.**
  - **Right now, the system only flags individuals who have received care through a publicly funded entity. This completely misses anyone who has received private or school-based services.**
  - **Additional data points—such as Individualized Education Programs (IEPs) provided in school settings—could help identify inmates with IDD.**
  - ***The Texas Commission on Jail Standards and the Intellectual and Developmental Disability Advisory Committee have suggested similar recommendations.***
- **Ensure LMHAs and LIDDAs receive instantaneous notification.**
  - **While some LIDDAs learn within 24 hours that a current or former recipient of services was in jail, others don't find out for up to a month. This should be rectified to ensure no one falls through the cracks of the system.**

## Access to Services

More than 70 years ago, the United States began making moves toward prioritizing community interventions over the institutionalization of people with mental health conditions and disabilities.

The advent of psychiatric medication, such as Thorazine, made institutionalization unnecessary for some. The thrum of voices denouncing intolerable conditions in mental health hospitals grew from a whisper to a roar. By 1963, President John F. Kennedy signed the Community Mental Health Act, which funneled federal funding to states to construct centers that would provide treatment and diagnosis services in the community.

Mental institutions began to empty and, then, close.

However, over the years, these centers were never adequately funded. People in need of help couldn't get it in their community, so they ended up in crisis, turning to psychiatric hospitals for help.

There simply weren't enough beds at the remaining psychiatric facilities to meet the demand. To make matters worse, the Texas Legislature delivered two devastating blows to community services in an eight-year period – cuts experts say they still haven't recovered from:

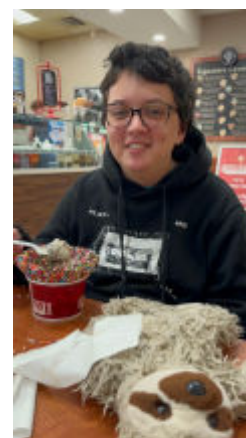
- In 2003, Texas lawmakers cut \$100 million from community mental health services while narrowing the scope of who can receive care from LMHAs. Emergency rooms started filling up with patients who had a mental illness. So, too, did jails.
- In 2011, the LIDDAs were hit. Texas lawmakers cut nearly \$60 million from general revenue-funded services for people with IDD, many of whom were waiting for a spot in federally funded programming. The waitlist for these services skyrocketed.

Now, people with mental health and IDD diagnoses are left with few options – everywhere they turn, they're met with waitlists that can stretch on for, sometimes, 17 years. And it can have devastating consequences.

### Medicaid Waivers and General Revenue Services

*Melinda Tolentino slammed the car's lock button so hard her knuckles turned white as she flew 70 miles per hour down the highway. Her daughter, Savannah, sat in the backseat, repeatedly trying to wrench open the door and throw herself out of the car. "I hate you! I want to die! I want to kill you!" Savannah screamed at her mother.*

*Panic rose in Melinda's chest as she silently counted down the mile markers until the next offramp. Before they could make it, Savannah reached forward from the back seat and dug her fingernails into her mother's throat. Melinda managed to talk her daughter into releasing the chokehold – but that July day in 2024 was the third time Savannah had attacked her mother in less than a week. Previously, Savannah had only attacked her father.*



Savannah Tolentino  
(courtesy)

*The Tolentinos had to find a living solution for their only daughter – and they had to find one now.*

*Savanah, 21, has an intellectual disability and an IQ of 53. But her mental health issues didn't crop up until the 10th grade. That's when she saw Boss Baby for the first time. In it, Alec Baldwin's character, Boss Baby, declares that the Hansel and Gretel fairy tale is about cannibalism. Savanah became obsessed with this idea and started voicing intrusive thoughts about killing and eating her teachers. She was soon diagnosed with severe obsessive-compulsive disorder with intrusive thoughts, bipolar disorder, and anxiety panic disorder.*

*Now an adult, Savanah's mental illness is getting more and more difficult for Melinda and her husband, John, to handle. They want to secure her placement in a group home, but there's one major problem: The waitlist for the Home and Community-based Services (HCS) Medicaid waiver is almost 125,000 people long<sup>10</sup>.*

*The Tolentinos placed Savanah on the waitlist almost a decade ago, when she was 12, but she likely still has another five years before she gets a spot. So the family has been stuck – Melinda living in Colorado, caring for her ailing mother, and John living in Texas with Savanah until they find her a stable place to live with the services she needs.*

*In the absence of an HCS waiver, they are trying to get her placed in an Intermediate Care Facilities for Individuals with an Intellectual Disability or Related Conditions (ICF/IID). These facilities provide residential and habilitation services for individuals with IDD. She's already been denied from one facility after just a week. They couldn't handle her mental health-related behaviors, Melinda said. "It shouldn't be this hard," Melinda said. "There is no place for our adult children. I am hanging on by a Jesus strand here."*

*When we spoke to Melinda in September 2024, Savanah was trying out her second ICF. The couple is cautiously optimistic, so John has moved to Colorado, ending their seven-month stint apart. Hopefully, this ICF holds.*

Texas has six Medicaid waiver programs for people with disabilities. These programs allow Texas to use state and federal funds for services to keep residents in their community and out of institutions, by providing therapies, short-term relief for caregivers (respite care), and personal care (e.g., bathing and dressing). However, more than 176,000 people<sup>11</sup> are waiting for care through one or more of these programs, a 73 percent increase since 2015. In that time, enrollment has increased by less than a third.

Some Texans have been waiting nearly 20 years for services.

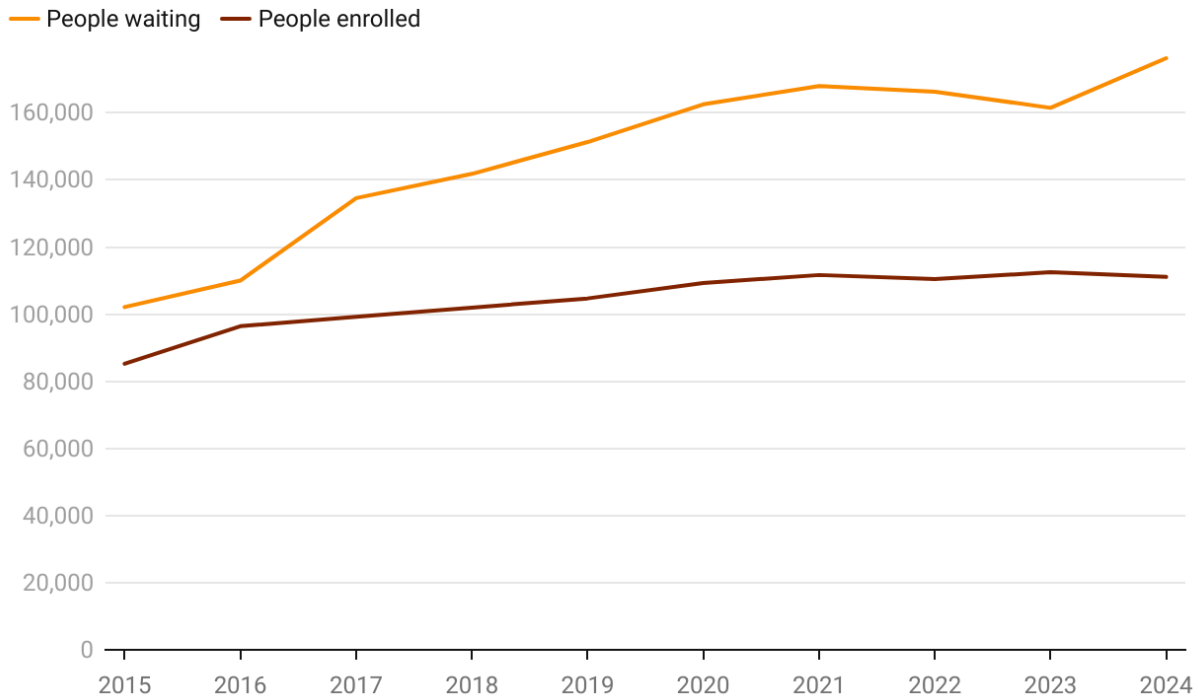
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<sup>10</sup> As of June 30, 2024

<sup>11</sup> As of June 30, 2024

## Texans with disabilities waiting for Medicaid waiver services

Texas has six Medicaid waiver programs available to Texans with intellectual and developmental disabilities. The number of people waiting for all six programs combined has increased 73 percent between June 2015 and June 2024.



*\*While Texans often are on multiple waitlists at a time, this data represented the unduplicated count of people waiting each year.*

Chart: The Arc of Texas • Source: Texas Health and Human Services Commission • Created with Datawrapper

The six Medicaid waiver programs for people with disabilities are<sup>12</sup>:

- Home and Community-based Services (HCS): Provides services to adults and kids with an intellectual disability or related condition who live in a group home with four or fewer people, their own home, or a family member's home.
  - Enrollment: 31,206
  - Waitlist: 124,409
- Texas Home Living (TxHmL): Provides services to adults and kids with an intellectual disability or related condition who live in their family's home or their own home.
  - Enrollment: 3,428
  - Waitlist: 112,021
- Community Living Assistance and Support Services (CLASS): provides home and community services to adults and kids with an intellectual disability or related condition that occurred before the age of 22.
  - Enrollment: 6,297

<sup>12</sup> Waitlist and enrollment numbers are as of June 2024 with the exception of the STAR+ enrollment number, which is as of August 2024. The waitlist numbers are a duplicated count.

- Waitlist: 89,633
- Deaf Blind with Multiple Disabilities (DBMD): Provides services to adults and kids who are deaf-blind or have a condition that leads to deaf-blindness and have another disability.
  - Enrollment: 343
  - Waitlist: 2,107
- Medically Dependent Children Program (MDCP): Provides services to adults and kids aged 20 and younger who are medically fragile so that they don't have to live in a nursing home.
  - Enrollment: 6,619
  - Waitlist: 5,716
- STAR+PLUS Home and Community Based Services (STAR+): Provides services for adults age 21 and older in an effort to keep them in their community and out of a nursing home.
  - Enrollment: 63,208
  - Waitlist: 5,372

Over the years, the state has taken steps to alleviate the waitlist but it has not kept up with the demand for services.

In 2015, for example, HHSC added the Community First Choice program to the Medicaid State Plan. This program provides waiver-like services – such as habilitation and personal assistance services – to individuals enrolled in Medicaid. Program participants can be on a waiver waitlist. There is no waitlist for services because it is a state plan benefit.

During the 2021 legislative session, lawmakers invested \$77 million to add 1,549 slots for the Medicaid waivers. However, with more than 170,000 people waiting for services at the time, that represents less than 1% of people waiting. It hasn't even made a dent.

Texas has general revenue-funded safety net services, provided by the LIDDAs, that act as a stopgap for people waiting for their name to come to the top of a waiver list. But much like the Medicaid waiver programs, there aren't enough slots – or enough funding. This is mainly due to \$60 million in budget cuts made by the Texas Legislature in 2011, from which the system has never recovered. As of June 2024, nearly 13,500 people were waiting for these stopgap safety net services.

**The Arc of Texas recommends:**

- **Increase funding for Medicaid waiver programs to keep pace with the growing demand for services and supports that allow individuals with IDD to live independently in their communities.**
- **Increase funding for stopgap services provided by LIDDAs.**
- **Revise how the Medicaid waiver program waitlist is managed using input from stakeholders, including individuals with IDD, their families, service providers, and advocacy organizations.**
  - **During the 87th Texas Legislative session (2021), Gov. Greg Abbott vetoed a bill (HB 4571) that the Arc of Texas championed, which would have created a new Statewide Intellectual and Developmental Disabilities Coordinating Council to help create a purposeful review of the entire IDD system, with a focus on providing coordinated care to ensure high-quality, cost-effective services.**

## State Psychiatric Hospitals



Kai'Yere Campbell (courtesy)

*Shantel Taylor's hand rushed to cover the gasp that snuck from her lips when she visited her son, Kai'Yere Campbell, at Tarrant County Jail earlier this year. Kai'Yere's body was covered in sores. He'd lost so much weight, his arms looked like match sticks poking out of the sleeves of his baggy jumpsuit. His hair was matted and unkempt from weeks without a brush.*

*Ever since Kai'Yere was arrested in December 2023 at his Fort Worth group home for allegedly assaulting an employee, Shantel had been saying her son did not belong in jail. Kai'Yere, age 21, has the mental capacity of an 8-year-old. Diagnosed with autism as a child and schizophrenia as an adult, Kai'Yere needed mental health care, not a cage. But so did hundreds of others in jails across the state.*

*Two months after Kai'Yere's arrest, the Tarrant County District Court found him incompetent to stand trial. They ordered him to undergo competency restoration, a process in which an individual receives education in court proceedings and mental health services such as medication management. Though Tarrant County inmates have access to both outpatient and jail-based competency restoration, Kai'Yere was ordered to a state mental health facility. He was about 2,000th in line.*

*["What is the point in putting him on a waitlist](#) to restore competency when he's not going to retain any information?" Shantel told KERANews in June. "He's going to sit there and hallucinate the entire time."*

*By May 2024, Shantel had had enough. Her son's disability meant his competency would never be restored. She started calling advocates, county commissioners, lawmakers – anyone she could think of who might be able to get her son out of jail. [More than 8,000 letters were sent](#) to state and local officials, calling on the district attorney to drop the charges and the LMHA to get Kai'Yere into one of Texas' 13 State Supported Living Centers (SSLC), residential campuses for people with IDD that provide 24-hour services.*

*The latter plea was answered. In July, Kai'Yere was transferred to an SSLC. The charges have yet to be dropped, but Shantel can sleep easier knowing that her son receives the care he needs. "He's in the proper place. He's doing better," Shantel said. "But the competency is not there."*

Texas' nine state psychiatric hospitals and one residential youth center are meant to act as a safety net service for people who cannot afford other types of care. But demand has exceeded the beds available, and as of June 2024, about 1,850 people were waiting. That's a 500 percent increase since June 2015, when about 300 people were waiting. Now, the average wait for a maximum security bed is more than a year, and about six months for a minimum security bed.

The problem can be traced back to the early 2000s when lawmakers cut \$100 million from community mental health services and simplified the process of finding a person incompetent to stand trial—changes that left the state unable to keep up with the fast-paced population growth it had been



experiencing for decades. Advocates recommend that states have 50 public psychiatric hospital beds per 100,000 people.

When those cuts were made in 2003, there were 10.7 beds per 100,000 people. Now, there are 6.9.

It doesn't help that so many people are coming to the hospitals from jail after being found incompetent to stand trial or not guilty by reason of insanity. This population makes up 72 percent<sup>13</sup> of state hospital patients, meaning there is significantly less room for individuals who might be committed by family members or looking for help themselves.

Lawmakers have taken steps to address and alleviate the waitlist, but it hasn't been enough. Nearly ten years ago, the Joint Committee on Access and Forensic Services was created to study the waitlist and make recommendations. More recently, lawmakers have been in the process of funding a \$2 billion plan to make hundreds of additional beds. They passed laws that allowed for discretion in who needs maximum security care and allocated tens of millions of dollars to local needs, including diversion programs.

In 2023, to address nearly 2,000 staffing vacancies at state hospitals, HHSC [allocated \\$148 million toward salary increases](#) for employees, including registered nurses, psychiatric nursing assistants, direct support professionals, and food service workers. They also funded two competency restoration alternatives to remove people from the psychiatric hospital waitlist.

Those two alternatives are:

- Outpatient Competency Restoration (OCR), which takes place in the community. The first pilot program began in 2007. Fifteen LMHAs or LBHAs — which serve 51 counties — have HHSC-funded programs.
- Jail-Based Competency Restoration (JBCR), which takes place in a county jail. The first pilot program began in 2018. Twenty LMHAs or LBHAs have programs<sup>14</sup> available to people in 30 counties.

About 27 percent of Texas' 254 counties have at least one of these alternative programs available to their defendants. Put another way, there are still about 8.6 million people who would not have access to competency alternatives should they need them. That doesn't make a dent when you consider that nearly every person on the state hospital waiting list is waiting for a bed because they need competency restoration services.

Competency restoration isn't perfect, though. The programming focus is limited to legal education, management of symptoms, and stabilization. It does not connect a person to a fully developed plan for treatment. "It is important to note that [\[competency restoration\] is not designed to be an avenue to ongoing treatment for people with \[mental illness\] or IDD,](#)" according to the March 2024 Texas Competency Restoration Guide. "A person may be connected to ongoing treatment over the course of their engagement in [competency restoration], but connection to ongoing treatment is not a requirement for successful program completion. [Competency restoration] is intended only to ensure that criminal proceedings may resume."

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<sup>13</sup> As of June 2024

<sup>14</sup> Sixteen of these LMHAs/LBHAs have HHSC-funded programs. But four counties have chosen to prioritize local funding for these services independent of the state.

It's also not for everyone. While it can be helpful for individuals who are decompensating (for reasons including not taking their prescribed antipsychotics), there are individuals with IDD who cannot be restored. Depending on the severity of their diagnosis, some experts say they might not have the mental capacity to be educated in court proceedings or understand the consequences. There needs to be a better option for individuals who fall into this bucket.

### **The Arc of Texas Recommends:**

- **Increase funding for LMHAs and LIDDAs so they can provide services in the community and prevent crises.**
- **Increase funding for state psychiatric beds.**
- **Increase funding for wages and other retention incentives for state psychiatric hospital workers.**
- **Fund more competency restoration alternatives.**
- **Invest in Coordinated Specialty Care (CSC) teams, which are designed to catch someone within the first two years of their first episode of psychosis (FEP) so that they can receive access to care and services and don't end up deteriorating to the point of no return.**
  - **Texas currently has 48 CSC teams across the state, but about 100 teams are needed to capture the approximately 3,000 Texans who experience FEP each year.**

### **Diversion Centers**

*Janieya McDowell's life spiraled out of control after her older brother, Jaquaree Simmons, was beaten to death in February 2021 in the Harris County Jail.*

*The two were tight, bonding over their love of dance. Jaquaree was Janieya's confidante – she told him things she never told anyone else. She didn't know how to cope with such a heavy loss. She started doing drugs. She started disappearing for days at a time, returning home dirty. She started seeing and hearing things that weren't there.*

*Janieya soon was diagnosed with schizophrenia, a disorder that only exacerbated her debilitating Attention-Deficit/Hyperactivity Disorder (ADHD). Her ADHD was so severe she barely made it through 9th grade before dropping out.*

*Two years after Jaquaree's death, Janieya had utterly fallen apart. She often hung out at a gas station in north Houston, begging for money. The gas station's security guard constantly asked her to leave, but Janieya always returned, clutching a styrofoam cup ready to receive coins and rambling at patrons as they walked through the double glass doors.*

*Eventually, the security guard had enough. In November 2023, the guard called the police. Janieya received a criminal trespass warning the first time. The second time, she left the vicinity before police arrived. The third time, Janieya was arrested for criminal trespass, a misdemeanor, and taken to Harris County Jail. But the trauma of incarceration – particularly in the facility where her brother was killed – could have been avoided amid Janieya's already difficult circumstances. Police could have*

taken her to Harris County’s jail diversion center, which has been around since 2018 and provides an alternative to jail time for people in crisis who commit low-level offenses. It connects them with services such as psychiatric care, medication management, and even housing opportunities.

Janieya’s arresting officer called the county District Attorney’s Office before taking her into custody. An assistant district attorney said there was “no mental health history for the defendant’s three prior Harris County arrests.” The officer wrote in the report that they didn’t find Janieya to be in a mental health crisis. A mental health evaluation was ordered for Janieya the day after she was booked in jail. She was released on bond the same day.

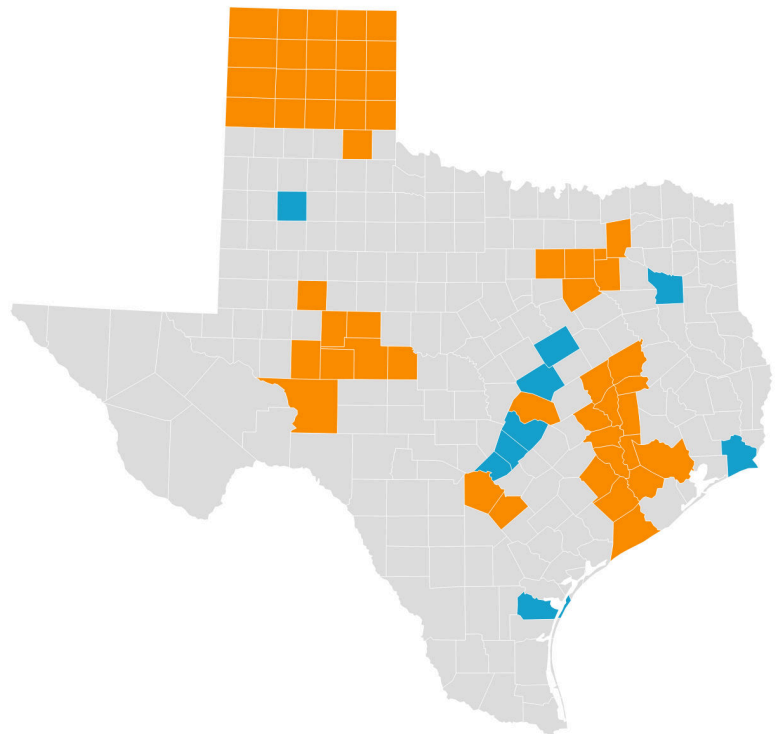
Just days later, Janieya returned to the gas station and was arrested for criminal trespass twice more in the first two weeks of December. Then, two days before Christmas, Janieya again trespassed at the gas station. After she refused to leave, a security guard handcuffed her. Janieya scratched and kicked the security guard and their partner. She was charged with assault on a security officer – a felony charge that made her ineligible for the diversion center.

Texans across the state have access to various crisis and diversion programs through their LMHA/LBHAs or LIDDAs, including mobile crisis outreach teams, crisis intervention specialists, and mental health deputies. However, few have access to physical centers where individuals experiencing a mental health or IDD crisis can be taken instead of jail. These centers provide an alternative to incarceration for low-level offenders and immediately connect people in crisis with services such as medication management, psychiatric care, and even housing and employment opportunities. There are at least 18 centers already operating or in the works, available to Texans in 48 counties. There also are four “drop off centers” across the state (serving 15 counties)<sup>15</sup>, where law enforcement can bring someone in crisis or a person can seek services for themselves, all with the goal of keeping someone out of jail or an emergency room.

### Texas counties that have or will have access to jail diversion or drop off centers

The Arc of Texas determined that at least 62 counties have or will have access to 22 jail diversion centers or drop off centers.

■ In works ■ Operational



Map: The Arc of Texas • Source: Texas Health and Human Services Commission, Local Mental Health Authorities • Created with Datawrapper

<sup>15</sup> The counties served are Brazos, Burleson, Grimes, Leon, Madison, Robertson, Washington, Wilson, Dallas, Ellis, Hunt, Kaufman, Rockwall, Navarro and Howard.

The Harris Center opened its 36-bed Judge Ed Emmett Mental Health Diversion Center in 2018. The program is voluntary and only available to individuals accused of nonviolent, misdemeanor offenses. Between 2018 and 2023, nearly 9,000 people went to the center instead of jail, and those diverted were 1.3 times less likely to be booked in jail on another charge.

[“Our team at the Harris Center works hard every day](#) to try and reduce the footprint of the criminal justice system in the lives of those we serve with serious mental illness,” Wayne Young, CEO of the Harris Center, told the Houston Chronicle in 2021. “We continue to look for ways to reduce the interactions that occur between those we serve and law enforcement as a result of their illness.”

Law enforcement from Fort Bend, Austin, Colorado, Matagorda, Waller, and Wharton counties can—and do—bring folks to the Texana Crisis Center in Rosenberg. The center opened in 2014 and has a crisis residential unit and an extended observation unit that provides emergency services for 48 hours. But this unit is only for people with mental illness. In 2023, on average, nearly 684 people were admitted to the center and stayed for six days. Most were brought in by law enforcement.

Some diversion centers have been underutilized, however. Tarrant County’s Mental Health Jail Diversion Center opened in January 2022 with the capacity to admit 30-40 people each day. However, in the year since it opened, there were no more than 30 admissions per month. The county’s sheriff, Bill E. Waybourn, in March 2023, wrote a letter to the center’s advisory committee expressing frustration with the numbers. “It has been just over a year, and business is slow,” he wrote. “There was one person once this week. Currently, in the jail, we have 80 misdemeanor inmates that are incompetent to stand trial.”

Using Harris County as a model, the county soon after expanded the eligible charges to include misdemeanor theft, marijuana possession, disorderly conduct, false report, and terroristic threat without violence. Previously, only criminal misdemeanor trespass was eligible. In the first seven months of 2024, the center averaged 143 diversions each month, up from 68 in 2023. Still, public officials say the diversion center could be helping more people. The issue, however, comes down to better training.

State Rep. Nicole Collier, a Democrat from Fort Worth, discussed the topic at a listening session held there in July, focused on mental health crises and incarceration. “Each law enforcement agency has the ability and authority to require more training,” Collier said. “They must also have mental health diversion training.”

Lack of training on what the diversion center is and how to use it was a repeated issue after Dallas County opened its Deflection Center in September 2022. The goal was to serve 450 people in its first year. But four months in, they were already struggling. In March 2023, officials told the Dallas County Behavioral Health Leadership Team that frontline officers did not know about the center, nor had they seen the training video or the bulletin. Only about 266 people were brought to the center that first year, though utilization has increased since then.

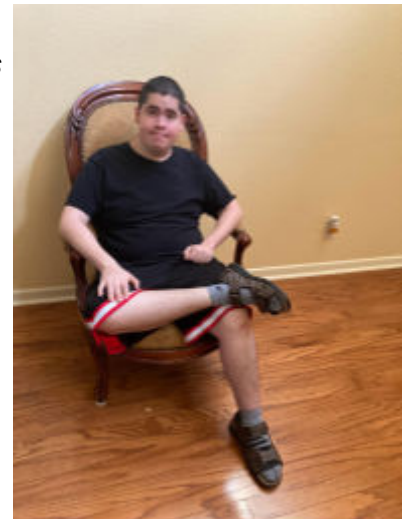
### **The Arc of Texas Recommends:**

- **Require more mental health and IDD training for law enforcement through the Texas Commission on Law Enforcement (TCOLE) or the agencies.**
- **In counties with a diversion center, build-in training for law enforcement on how and when to use the center.**
- **Increase the number of diversion centers across the state, with buy-in from local law enforcement.**

### **State Supported Living Centers**

*Columba Wilson kept her grandson's aggressive behavior contained to their San Antonio home for more than a decade. The verbal differences that came with Cristian Martinez's autism diagnosis made him prone to frustration and fits of anger. He would break things and slam his head into windows.*

*A growth spurt and the onset of schizophrenia in Cristian's late teens raised the stakes. He started striking Columba and her husband, Ron, slamming them against walls, pulling out their hair from the root, and biting them. In February 2024, it became too much for the elderly couple to handle. Against her better judgment, Columba found a group home that would take Cristian – and that's when the real trouble started.*



Cristian Martinez (courtesy)

*Cristian, now 20, began running away from the group home and destroying property. On at least two occasions, police were called to deal with his destructive, aggressive behavior. He was taken to a hospital on an emergency detention order both times.*

*Then, in June, Cristian launched a rock through a neighbor's window, causing more than \$750 worth of damage. He was arrested for misdemeanor criminal mischief and taken to Bexar County Jail. Columba bailed him out as soon as possible, but it was not safe to keep him at home, and she recognized it was no longer safe to keep him in a group home.*

*She was entirely out of options.*

*Columba felt sick as she advocated for placement at a State Supported Living Center, where her grandson could receive 24/7 care with licensed professionals trained to deal with someone as aggressive as Cristian. "An SSLC is not my choice, but that's the only place he's going to be safe," Columba said. "I'm 76 years old ... Physically, we cannot handle him anymore."*

Texas currently has 13 State Supported Living Centers (SSLCs), campuses considered the last resort for care where people with IDD live and receive services 24/7. The centers have been contested for years, both because enrollment has steadily decreasing for decades and because of safety and quality of care concerns. In 1974, a lawsuit was filed aiming to improve conditions at the then-15 SSLCs and transition more residents to programs in the community. The centers were placed under court monitoring until 1995, when the state agreed to close the Travis and Fort Worth locations.



Then, in 2009, the centers were again in hot water when the [U.S. Department of Justice \(DOJ\) and the state of Texas entered into a settlement](#) agreement following numerous allegations of civil rights violations, such as abuse, neglect, and deaths. Under the agreement, the DOJ conducts reviews every six months to ensure the state complies with agreed-upon improvements in the use of restraint, training programs, medical services, and psychiatric and nursing care.

Budget cuts to local services in 2003 meant more and more people with disabilities and mental health issues were winding up in crisis, interacting with law enforcement and being booked into county jails. Once they were found incompetent to stand trial, they needed somewhere to go for competency restoration services. So, in 2009, lawmakers passed a bill that [required the state to establish an SSLC specifically for alleged offenders](#): Mexia SSLC in Limestone County<sup>16</sup>.

By the 83rd (2013) Texas Legislative Session, all 13 SSLCs still had not come into compliance with the DOJ's requirements. A pair of bills were filed to give the state authority to shutter their doors, though they ultimately failed. The following year, the Sunset Advisory Commission issued a scathing report highlighting the centers, saying [decreased enrollment, costly services, and safety issues made it necessary to begin closing facilities](#). Enrollment in SSLCs had been on a steady decline for decades. In 1996, the centers were home to about 6,000 residents. By 2013, that number had fallen to 3,600. "If the centers continue to lose residents at the same rate, in 10 years, they will hold fewer than 2,000 residents or 85 percent fewer than they were built for," the report stated. In fiscal year 2013, the state spent \$661.9 million to serve 3,650 SSLC residents. It costs \$113,000 more each year to serve someone at an SSLC compared to a group home in the community. To make matters worse, none of the 13 centers had met even half of the DOJ settlement requirements – despite five years to do so. The SSLC in Richmond, for example, had only met 18 percent of them.

The commission recommended lawmakers close six of the 13 centers by 2022, suggesting the money saved be used to expand care in the community for high-need individuals previously served by the centers. More specifically, the commission suggested Texas increase the number of crisis intervention teams statewide and add a reimbursement level that motivates providers to open group homes for high-need individuals. "While Texas has an ongoing need for maintaining several of its better-run SSLCs, the state can no longer afford to delay action on closing a large number of its seriously problematic and costly ones," the report stated.

It didn't happen. Bills were filed to implement this recommendation, but they again did not pass. In fiscal year 2024, 2,600 people lived in the 13 SSLCs across the state, and [the centers were still monitored by the DOJ](#).

The waitlist for Medicaid waivers has increased dramatically, and more than 13,000 people are waiting for LIDDA-provided general revenue services as of June. State psychiatric hospitals are virtually inaccessible to someone not coming through the criminal justice system. More and more disabled individuals are struggling to find services in the community.

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<sup>16</sup> Though Mexia was the only designated location to initially serve forensic patients for almost 10 years, the state started sending alleged female offenders to the San Angelo SSLC in Tom Green County to separate the two. San Angelo was officially designated as a forensic location in 2017.

Each SSLC has its own waitlist. In May 2024, people admitted to five of the 13 SSLCs did not have to wait for a bed. At three, people admitted had to wait more than 150 days, on average, with the highest average wait time being 213 days for the Richmond SSLC.

Wait times have increased since September 2016, when individuals admitted to SSLCs waited no more than 19 days, on average, for a bed. The state does not have access to data for the Rio Grande SSLC because “the records have been largely paper-based, with years prior to 2019 subject to required shredding/document retention,” said HHSC spokeswoman Tiffany Young.

### **The Arc of Texas Recommends:**

- **Begin closing underperforming and underutilized SSLCs in phases, redirecting the money saved to expand community-based programs such as crisis services, day habilitation, and intensive residential support options for people transitioning out of institutional care.**
  - **This also was recommended by the [Sunset Advisory Commission in August 2014](#).**

### **Private Psychiatric Hospitals**



Sky Holak (courtesy)

*A few days into Sky Holak’s first stint in a private psychiatric hospital, his mom, Pam, knew it wasn’t the right fit for her son. He wasn’t bathing himself. He wasn’t brushing his hair. He wasn’t wearing shoes. Pam was afraid this would happen – that the Houston hospital wouldn’t be able to tend to the needs of her intellectually disabled son. But she didn’t have a choice.*

*Since his mid-20s, Sky had been getting violent with his parents. Anytime he was triggered – and they weren’t sure what did it – he would break glass and tear up their home. Pam wanted to keep her son out of a group home for as long as possible, so she managed the best she could.*

*But Sky’s behavior finally hit a breaking point in 2018, and his psychiatrist recommended a hospital in Houston. The hospital simply couldn’t meet his needs. Pam begged them to help him bathe and get dressed – to brush his hair at least. They told her it wasn’t part of their job description.*

*So the next time Sky needed a psychiatric hospital, Pam drove him to Clear Lake. The same thing happened. Still, she fought against moving her son to a group home. She hired a personal care attendant to work with Sky, supplementing the HCS waivers’ meager pay with her savings so he didn’t lose care. But the minute the attendant went home for the day, Sky would get violent, and Pam couldn’t afford to pay someone to stay with him 24/7.*

*Before long, Sky’s violence became too much again. Pam drove him back to the hospital in Clear Lake, but they refused to take him. His behavior was too much for them to handle, they said.*

*Broken-hearted, Pam caved and moved Sky into his first group home two years ago and a second one this summer when the first didn't out.*

*He's doing well at this new location, but it's not what she wanted for her 35-year-old son. "There's not really any help for these adults," Pam said. "There needs to be more help out there, and I just don't see it."*

The Arc of Texas surveyed 25 licensed, private psychiatric hospitals in the state to better understand their policies surrounding people with IDD and mental health issues. Many hospital representatives said they admit individuals with IDD on a case-by-case basis – but the person must be able to participate in group therapy. They also must be able to complete daily living tasks, such as feeding, bathing, and ambulating, because hospitals do not have the staff to help them.

At least 10 hospitals said they have an IQ cutoff of around 70, though there can be exceptions. But this cutoff excludes a huge swath of people who receive services from their local LIDDA. For example, only individuals with an IQ lower than 70 are eligible for Medicaid waiver services, a group of programs currently serving more than 110,000 people.

"Persons with IDD/MI [(mental illness)] currently do not have equal access to psychiatric inpatient treatment," Dr. Jackie Keith wrote in a U.S. Public Policy Update published in the May/June 2017 edition of *The NADD*<sup>17</sup> *Bulletin*. "As the movement toward deinstitutionalization moves forward, this problem cannot be ignored. Not only is it wrong to discriminate based on disability, communities need to be equipped to provide for the service needs of this population of citizens."

Additionally, research has shown that people with IDD can benefit from group therapy. A paper published in 2021 in the *Journal of Psychosocial Rehabilitation and Mental Health*<sup>18</sup> demonstrated the usefulness of group psychotherapy for this population in a daycare psychiatric rehabilitation setting. While participants' intellectual limitations did pose a challenge, consistency and patience helped overcome the obstacles. "In the group work, members themselves help each other in expressing the problem, and in finding out effective ways of solving them," according to the paper. "Adults with IDD in the group begin to feel that they are not only here to get help, but they can also help others."

If someone is not admitted to an inpatient facility because of their IDD diagnosis, many of the hospitals surveyed said they refer them back to the local LMHA or LIDDA. If it's an emergency, they refer them to an emergency room.

El Paso-based Rio Vista Behavioral Health Hospital, a 132-bed facility, is building a 20-bed unit for people with IDD and mental health diagnoses, said Mario Herrera, the hospital's director of business development.

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<sup>17</sup> NADD stands for National Association for the Dually Diagnosed, a nonprofit that advocates for people with developmental disabilities and mental health conditions.

<sup>18</sup>

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8443245/#:~:text=Individuals%20with%20IDD%20have%20similar.attending%20vocational%20day%20care%20program.>



### **The Arc of Texas Recommends:**

- **Change admission criteria for psychiatric inpatient treatment so it is no longer exclusionary.**
- **Add IDD units to inpatient psychiatric hospitals.**

### **Outpatient Biopsychosocial Approach for IDD Services**

*Jacob Lancaster took a break from a pool game with his dad, Kevin, in July to watch a stranger expertly pocket a ball on the table next to them. “Good shot!” Jacob said. “That was a hard move.” He grinned at the man. “I’m proud of you.”*

*Kevin stared at his son, flabbergasted: The 35-year-old would never have willingly interacted with a stranger five years ago. Jacob has an intellectual disability and has the mental capacity of a 13-year-old. For years, he’d struggled with social interactions and daily activities such as cooking, cleaning, and caring for himself. That, no doubt, fueled his debilitating episodes of depression, which surfaced in 2019. Kevin took Jacob to their LIDDA, Bluebonnet Trails Community Services, that year for help.*

*But, the programs available didn’t address Jacob’s IDD and mental health issues simultaneously. Then, in 2022, Jacob’s case manager suggested they try the Outpatient Biopsychosocial Approach for IDD Services (OBI) program.*



Jacob Lancaster (courtesy)

*OBI is an outpatient program that serves individuals with a dual diagnosis of IDD and mental health. It turned out to be everything Jacob had been needing. In the year or so Jacob spent in the OBI program, Bluebonnet employees worked with him to get his medication stabilized and taught him coping skills for his depression. He learned how to ride a bike and cross the street without getting hit by a car, and his case manager spent months teaching him how to use Uber to foster more independence.*

*Kevin watched as his son’s bouts of depression all but ceased. Now, Jacob can get to his job at the community food bank all by himself. He still lives at home with his dad, but he can cook and clean and even take his medication on his own. And, as evidenced by their pool game in July, his capacity for social interactions has grown tenfold. “It has provided him a lot more confidence more than anything else,” Kevin said. “Five years ago, he would have never gotten out of that comfort zone that he was in and told someone they made a really nice shot.”*

The Outpatient Biopsychosocial Approach for IDD Services (OBI) was funded as a pilot program in the 86th (2019) Legislative Session. Using \$1.5 million in appropriations each year that biennium, HHSC contracted with five LIDDAs to create outpatient programs to bridge the gap between IDD and mental health services for people with these dual diagnoses. Essentially, it expanded the IDD Crisis Continuum of Care to include mental health care – breaking down silos that had existed for decades.

The five LIDDAs tapped to launch this pilot – and continue to receive this funding – are:

- Bluebonnet Trails Community Services

- Integral Care
- Lakes Regional Community Center
- MHMR of Tarrant County
- The Harris Center for Mental Health and IDD

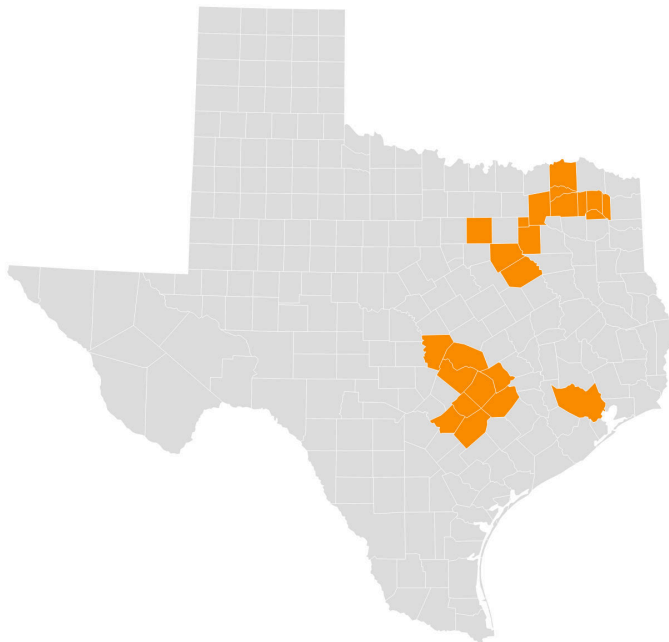
“This is a very overlooked population,” said Melanie Babbitt, licensed practitioner of the healing arts supervisor with Integral Care’s OBI program. “A lot of systems are not set up to be cognitively accessible, and a lot of providers don’t feel equipped to work with them.” OBI works to bridge that gap.

The program focuses on helping individuals with dual diagnoses overcome crises and gain skills to be successful in their community. The idea is to keep them out of institutions – whether it be a hospital, SSLC, or jail. When someone is referred to the program, they undergo a biopsychosocial assessment to determine their wants and needs, services they currently are receiving, and gaps in care they are experiencing. A case manager then creates a person-centered recovery plan that might include skills and communication training, anger management, coping strategies, and therapy. It also focuses on the family, providing education about their loved one’s mental illness and how to manage it.

The OBI program “knocks out the stigma of mental illness and makes sure the family with the loved one is not assuming their behaviors are because of IDD,” said Andrea Richardson, CEO of Bluebonnet Trails. “They are understanding more about the loved one who is appearing in crisis and what, as a family, they can do about it.”

**Counties with access to the Outpatient Biopsychosocial Approach for IDD Services (OBI) program**

Only 23 of the state’s 254 counties have access to OBI programming through the five LIDDAs funded. That means two-thirds of the state’s 30.5 million people are without these vital services.



Map: The Arc of Texas • Source: Texas Health and Human Services Commission • Created with Datawrapper

Each location is required to serve 25 people each month, and the average length of stay in the program is around a year. This small number of participants allows for a truly hands-on approach to care, which helps people avoid crises. At Bluebonnet Trails, for example, a case manager rode the bus with one participant for six months until that person understood the stops, how to pay, and how to stay safe. That participant, Richardson said, can now go to the movies, volunteer in the community, and have more agency in their life because of this help.

In the program's first year across all five LIDDAs, 132 people received services – and [87 percent avoided hospitalization and incarceration](#) in a 12-month period. But there aren’t nearly enough slots to meet the needs. This summer in Harris County – Texas’ most populous county with 4.8 million people – the

Harris Center had a yearlong waitlist with 170 people waiting for an OBI slot.

More funding is needed for this vital program – not just in Harris County but across the state, said Charles Kerlegon, director of the center’s IDD Services Division. “Any time you start saying there’s a waitlist or an interest list, then that is a telltale sign there is a need,” Kerlegon said. “I can only imagine across the state what that need is.”

**The Arc of Texas Recommends:**

- **Increase funding for existing OBI sites:**
  - **At least three sites have a waitlist for the program, and each says they would benefit from additional funding.**
- **Add more OBI sites across the state:**
  - **With just five LIDDAs offering this program, only 23 of the state’s 254 counties are being served. That means 20.1 million people cannot access an OBI program.**
- **Collect more meaningful data:**
  - **OBI sites are required to submit quarterly reports to HHSC detailing who received skills training and how many people were admitted to a hospital or incarcerated before and during their participation.**
  - **Experts say data looking at what goals participants attained, including employment and volunteer opportunities, and whether they are more engaged in the community would go a long way in showing the program’s impact.**

## Workforce

A qualified workforce is vital to offering people with IDD the array of service options necessary to stay healthy and live as independently as possible. But Texas has historically underpaid the people who do this important work, and it has had disastrous consequences.

Personal care attendants (also known as direct support professionals) – who help people with IDD complete everyday tasks that allow them to remain in the community – make far less than someone who works for HEB, Amazon, or Walmart. As of the 88th (2023) Legislative Session, personal care attendants make a base wage of just \$10.16 an hour. They often do not have benefits. The state has failed to substantially increase their wages over the years, resulting in a crisis-level shortage of workers. Group homes are closing because there aren't enough employees. The ones that stay have attendants working overtime.

Texas colleges and universities aren't training their students to work with people with IDD, leaving individuals who have IDD and a co-occurring mental health issue searching in vain for help. Without intervention from a qualified therapist, they are more likely to end up in crisis – and if they end up in a crisis, they're more likely to interact with law enforcement and wind up in jail. But once they get there, jailers often don't know how to identify or interact with people with IDD, and the state doesn't require training to make sure they do.

At every step, individuals with IDD are met with people who cannot help them – and if they can, there simply aren't enough qualified professionals to go around.

### Personal Care Attendants Shortage

*Ron Attra's 70th birthday came with a difficult realization: He was getting too old to care for his disabled daughter, Ronda. Ronda, then 45, has Spina Bifida, is paralyzed from the waist down, and requires round-the-clock care, made more complicated by her IQ of 62.*

*Reluctantly, Ron found her a group home not far from him in Pearland, where attendants could help her with bathing, eating, and urinary catheterization every few hours. It's been 15 years, and overall, Ronda is happy. She's made friends, received the care she needs, and is pretty peaceful. But the near constant turnover in her caregivers makes her and her father nervous. The problem comes down to pay. "They're very understaffed, they're very underpaid," Ron said. "When you can flip burgers for more than you can make taking care of disabled folks, there's a problem."*

*Every time one of Ronda's attendants quits, and a new one is hired, she and her father must start over. That person must be trained to care for Ronda's needs and learn her quirks, likes, and dislikes. It sets Ronda back. For days, she'll ask her father why her attendant left and when they are coming back. Sometimes, the person who left was a great fit with Ronda, and the new person is not, puncturing Ronda's happy bubble and causing strife. Subconsciously recognizing what's at stake, Ronda's anxiety ramps up.*

*But Ron knows what's really on the line: One wrong decision or misstep could be catastrophic.*

*“She can’t do anything herself,” Ron said. “Without round-the-clock care, Ronda could not survive.”*

About 300,000 personal care attendants work in Texas, responsible for helping disabled individuals—the state’s most vulnerable—with everyday tasks including bathing, dressing, and toileting. But at a base wage of \$10.60 an hour, they trail far behind the rest of the country. The Lone Star State ranks 50th in average hourly wage compared to all 50 states and Washington, D.C. Louisiana is the only state with lower pay than Texas, according to 2023 data compiled by the Bureau of Labor Statistics.

Advocates have been fighting for pay increases for more than a decade. Most recently, before the 88th (2023) Texas Legislative Session, they called for an hourly wage increase to \$17 an hour by fiscal year 2025. Given the \$60 billion in operating surplus and Rainy Day Fund savings available, it seemed possible. Lawmakers responded with just a 30 percent pay raise – to \$10.60 an hour from \$8.11. It was the biggest pay raise lawmakers have ever given attendants, but the Coalition of Texans with Disabilities called it “woefully inadequate” in its 2023 annual report. “We will keep fighting for a higher wage,” the coalition wrote.

The historically low wages have made it hard to find help for individuals living in their homes and group home operators. Two years ago, HHSC surveyed attendants and found that 67 percent of the about 1,800 workers who responded said the pay was too low, and most respondents said they did not receive any benefits. This sentiment – and the continued lack of investment from the state – has translated into a shortage of care for Texans with IDD living at home and a growing number of staff vacancies at group homes and other facilities.

Three organizations representing community-based service providers for people with IDD<sup>19</sup> surveyed providers between December 2022 and January 2023. Providers reported experiencing [a 30 percent staff vacancy rate in their group homes](#). Because of the shortage, the remaining staff worked overtime, and half of the providers had to turn away referrals.

“This was a crisis long before (the) COVID-19 pandemic,” a one-pager released by the organizations stated. “In 2023, the crisis has reached the brink of a catastrophe.”

The problem is so bad that some locations have been forced to close. The survey found that seven ICF providers and 27 HCS providers permanently closed group homes because of staffing difficulties. Six others said they canceled contracts, and many more anticipated [these closures would continue if they could not recruit and retain staff](#).

“With programs and services closing, the ability for the state to maintain an adequate network of community providers and meet federal access standards is in serious jeopardy,” the report stated. “Reduced availability of services jeopardizes the safety and well-being of the people who rely on these services.”

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<sup>19</sup> Providers Alliance for Community Services of Texas (PACSTX), Private Providers Association of Texas (PPAT) and the Texas Council of Community Centers

Megan Karlsen, chief administrative officer at the HCS provider, A Little Something Different, in Houston, said the pay problem has been exacerbated by the increased number of individuals entering group homes who have a mental health issue on top of their IDD diagnosis. “It’s hard enough to get someone who wants to work for (\$10.60 an hour) with a compliant client with IDD,” Karlsen said. There is no additional incentive “for an employee to want to work in a setting with people who have more mental health struggles than people with just IDD.”

Texas Medicaid does not require mental health training for attendants who work in the home with people enrolled in Medicaid waivers. However, state law stipulates that an attendant must be trained based on a person’s needs before they can work with them, which could include mental health-related information. The Deaf Blind with Multiple Disabilities (DBMD) waiver has more specific training guidance, including de-escalation techniques, preventing aggressive behavior, and managing challenging behavior. But the lack of overall mental health training results in a dangerous situation not just for the attendant but also every person living in the home, Karlsen said. The state “wants to put [workers] in a house with individuals with aggression and mental health issues with no training,” she said.

To make matters even more complicated, experts say the same pool of applicants are qualified to support individuals with IDD in the community as in SSLCs, but SSLCs pay significantly more. Last year, HHSC increased the starting pay for direct support professionals in SSLCs to \$17.50-\$21 an hour, making it much more attractive to applicants than working in the community. “When you increase direct care wages in SSLCs substantially but don’t do the same in the community, we lose community workers who know how to interact with and manage this population,” said Danette Castle, senior advisor for the Texas Council of Community Centers.

### **The Arc of Texas Recommends:**

- **Increase pay for personal care attendants in the community, so their hourly wages are on par with attendants who work in SSLCs.**
- **Require mental health and de-escalation training for all direct care workers.**

### **Mental Health Professionals Shortage**



Sean Johns (courtesy)

*The walls of Jenni Johns<sup>20</sup> home in Houston are covered in brightly-colored padding from floor to ceiling. Plexiglass is screwed over the windows and doors in the library. A cattle gate separates the living room in two. Her house has looked like this for three years – so long that it seems almost natural, almost normal. But then she remembers what prompted the remodel. Why a mother of 12 – seven of whom are adopted – had to build an in-house psychiatric ward for her son, Sean.*

*Sean, now 19, has severe autism. He’s nonverbal and has seizures. Doctors have repeatedly told her that his IQ is so low it’s unmeasurable. His entire life – ever since she and her husband adopted him from a Ukrainian orphanage at age 6 – the family has struggled to find him care. On top of*

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<sup>20</sup> The names of Jenni and her son, Sean, have been changed to protect their identity.



*autism, he struggled with mental health issues, such as anxiety and, likely, Post-Traumatic Stress Disorder from his time at the orphanage. But, no therapist would work with him because he could be aggressive and was unable to communicate in a neurotypical way.*

*Jenni fought and fought to find him care, calling therapists all over the city for years, to no avail. As Sean's mental health continued to deteriorate, he started getting more violent.*

*Then, in 2021, when Sean was 16, he started beating Jenni every time she tried to change his diaper. He attacked her other children. She called 9-1-1 and had him taken to a local hospital so he could be stabilized and transferred to inpatient psychiatric care. But as the days stretched on, her hope for that dwindled. None of the hospitals in the state would take him. After a month, she brought him home and designed a setup to keep him and her other children safe.*

*But she still thinks about the struggle to find him mental health care. If she had been able to find him a therapist early on, this all could have been prevented. She wouldn't be living in a homemade psychiatric hospital. And Sean would likely have a very different life.*

Texas already has too few mental health care workers, with [97 percent of its 254 counties](#) federally designated as complete or partial shortage areas<sup>21</sup> in July 2024, according to the Health Resources and Services Administration. However, experts say that number shrinks even lower when you search for mental health professionals who serve people with IDD.

The issue partly comes down to training – or lack thereof.

Multiple national organizations, including the National Association for the Dually Diagnosed (NADD) and Division 33 of the American Psychological Association (focused on advancing research, education, and services for people with IDD and Autism Spectrum Disorder), have pointed out the importance of training clinical psychologists to serve this population. But just two of the 18 Texas colleges and universities with Masters and/or Doctoral Psychology programs with a clinical component surveyed by The Arc of Texas offer IDD training beyond assessment and diagnostic services.

Top-rated schools, such as Rice University, Baylor University, and The University of Texas at Austin, do not have programs that train individuals to treat IDD patients. Abilene Christian University doesn't have a specific IDD track. Still, their Masters of Science in Counseling Psychology trains students to provide therapy in creative ways that could cater to neurodivergent and disabled patients. "A therapist might use virtual reality (VR) therapy to treat anxiety disorders for individuals with IDD by helping them, through exposure, to face and manage their fears of social situations, (and) medical procedures," said Dr. Cherisse Flanagan, the director of graduate programs in the university's department of psychology. Graduate students at Abilene Christian also train at local agencies that serve people with IDD, including the Betty Hardwick Center, a LIDDA that serves five counties<sup>22</sup>.

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<sup>21</sup> HPSA designations are used to identify areas and populations groups in the United States that are experiencing a health care provider shortage. To be designated as a Mental Health Professional Shortage Area, areas must have a ratio of 30,000 citizens to 1 mental health provider, or 20,000 to 1 if there are "unusually high needs in the community." HRSA defines mental health provider in a HPSA as a psychiatrist only, core mental health professional only, or both psychiatrist and core mental health professional.

<sup>22</sup> These counties are Callahan, Jones, Shackelford, Stephens, and Taylor Counties.

At Texas A&M University, doctoral students must have at least five semesters of assessment practicum that includes training in therapy services for persons with IDD, said Rob Heffer, clinic director of the school's psychology clinic.

This isn't just a Texas problem. A 2014 study from Antioch University found that clinical psychology training programs had minimal IDD training<sup>23</sup>. "A lack of professional training in ID [intellectual disability] for psychologists impedes access to quality mental health services for this population," the study stated. "This presents a bind for psychologists who are ethically bound to practice only within the scope of their competence but have limited opportunities for its development."

[In a March 2024 opinion published in \*The Milbank Quarterly\*](#), Drs. Harold A. Pollack and Kristin Lee Berg wrote that even general psychiatry board certification criteria doesn't require clinical experience in IDD. "This lack of focused training leaves clinicians ill-equipped to [identify] and treat mental health needs of people with IDD, which may reinforce clinicians' [documented reluctance to treat patients with disabilities](#)," Pollack and Berg wrote. Therefore, many people with IDD are unable to receive timely or appropriate care for their mental health concerns.

The Ohio State University in Columbus, Ohio is working to change that. Its Psychology Graduate Program has a specific area focused on IDD, which provides clinical training to students who want to focus on serving this population. Dr. Luc Lecavalier, a professor in the IDD program, said that what sets OSU's psychology department apart is that students who graduate and are licensed to practice have been trained specifically in serving this population through practicums, internships, research, and mentorships. "This is a unique population that has unique needs," Lecavalier said. "Working with them: On some levels, it is the same but also virtually every step of the process is unique."

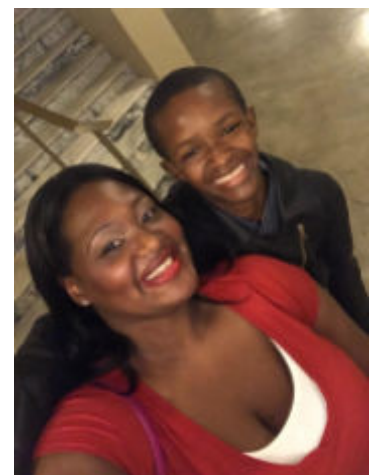
### **The Arc of Texas Recommends:**

- **Build master's programs across the state that focus on IDD and mental health.**

### **IDD Training for Jailers**

*Dallas Garcia did everything she could to make sure Harris County jailers knew her son, Fred Harris, had a low IQ and a history of mental illness after his arrest in October 2021. He wasn't dangerous, she told them, despite his charge of aggravated assault with a deadly weapon. He was simply experiencing a mental health episode when he wandered down the middle of a busy Houston road at rush hour clutching a 4-inch steak knife.*

*She dropped off his IEP as proof that he had special needs. She begged them to place Fred, 19, in a specialized unit instead of with the general population. A detention officer ordered Fred into isolation to keep him safe. Instead, he was placed in a cell with Michael Paul Ownby, a violent offender who had 6 inches and 140 pounds on Fred's 5-foot, 8-inch, 98-pound frame.*



Fred Harris (right) and his mom, Dallas Garcia (courtesy)

<sup>23</sup> Graesser, E. J. (2014). Serving Clients with Intellectual Disabilities: Clinical Psychology Training in APA-Accredited Doctoral Programs. <https://aura.antioch.edu/etds/103>



*Thirty-six minutes later, Ownby started beating Fred with his fists and, later, a shiv, smashing Fred's head into the concrete floor over and over again.*

*By the time detention officers arrived to pull Ownby off him, Fred was unconscious and bleeding. Fred died on Halloween night, three weeks after his arrest; his name added to [the too-long list of mentally ill and intellectually and developmentally disabled Texans](#) who needed help but ended up dying because of what happened in a cage.*

*In 2023, Fred's killer was sentenced to 50 years in prison. But Fred is never coming back. He'll never again play video games with his brother, Dylan, or go to the roller rink with his sister, Asa. He won't get to watch his younger siblings, Jagger and Saturn, grow up. He'll never become the man Dallas hoped and prayed he would be.*

*"Losing a child is a very different feeling ... [it's almost like you've lost half of yourself](#)," Dallas told the Houston Chronicle in 2022. "It's difficult to know he's not coming back, like ever."*

Texas began requiring mental health training for county jailers as part of a package of reforms passed following the death of 28-year-old Sandra Bland in 2015, who hung herself in the Waller County Jail shortly after being arrested for a traffic violation. The Sandra Bland Act, which was passed in 2017, required jailers to receive at least eight hours of mental health training, among other remedies.

"Having a well-trained jailer staff checking cells is important because it allows jailers to identify problems early," according to [former State Rep. Garnet Coleman's 2020 talking points on the bill](#) posted to the Houston Democrat's website. "A properly trained jailer will be able to identify inmates who may be a danger to themselves or others." The act also required all law enforcement officers to complete 40 hours of Crisis Intervention Training and De-Escalation Techniques, which Sgt. Rico Gomez with the Harris County Sheriff's Office said includes some IDD training. Harris County also mandates that all its jailers take the 40-hour mental health certification course, which is not required by the state. This, too, touches on IDD. However, the state does not require jailers to undergo specific IDD training. It wasn't until 2021 that an IDD training program was even developed.

[House Bill 2831](#) was passed during the 87th (2021) Legislative Session. It required the Texas Commission on Law Enforcement (TCOLE) and the Texas Commission on Jail Standards (TCJS) to develop an at least four-hour training program for county jailers on how to interact with people who have IDD. This training also includes techniques to evaluate whether an inmate might have IDD.

The Intellectual and Developmental Disability Advisory Committee to TCJS recommended in its [December 2022 Legislative Report](#) that IDD training be made a supplement to the already required mental health curriculum. That way, they wrote, the state can ensure that all corrections officers receive it. Committee members also recommended the training be updated with help from organizations that are subject matter experts. For example, the updates could include additional advice and methods for interacting with and identifying people with IDD and more information about best practices for people with IDD in a jail setting. This training could also be helpful for other members of the judicial system, such as public defenders and magistrates, to help them better work with defendants with IDD, the committee continued.

**The Arc of Texas Recommends:**

- Require all county jailers to take at least four hours of IDD training, either as a stand-alone curriculum or as a supplement to the mental health training already required.
- Make said IDD training available to other members of the judicial system, such as judges, magistrates, and public defenders.
- Update IDD training to include suggestions from IDD experts as suggested in The Intellectual and Developmental Disability Advisory Committee [December 2022 Legislative Report](#).

# Related: The Arc of Texas' 89<sup>th</sup> Texas Legislative Session Policy Priorities

Note: [Our Policy Priorities for the 89th Texas Legislative Session](#) (also detailed below), provide a roadmap to a future in which barriers to inclusion and accessibility are dismantled, and Texans with disabilities are met with opportunity, respect, and support at every turn. The Whole Person Project report and recommendations offer a large-scale examination of the systemic issues that Texans with dual-diagnoses of IDD and mental disorders face. Thus, many recommendations in this report are not articulated in our 89th Texas Legislative Session Policy Priorities because they require longer-term work.

***“Real change requires all of us. As we advocate together, we call on our state leaders to act boldly, recognizing the urgent need for policies that uplift and include Texans with disabilities.” — Sabrina Gonzalez Saucedo, Director of Public Policy & Advocacy, The Arc of Texas***

## **Pillar: Quality of Life**

**Key Challenges:** More than 180,000 people with IDD are on Medicaid waiver waitlists for vital community-based services. Extended wait times leave families without the necessary supports to promote independence and community integration. Texas is also grappling with a direct care workforce crisis, where direct support professionals—who provide essential assistance to Texans with IDD—are paid just \$10.60 an hour, resulting in high turnover, creating instability in care, and further straining already limited resources.

### **Policy Priorities:**

- **Increase Access to Home and Community-Based Services:** Reduce wait times for services that prevent institutionalization. Improve management of interest lists to achieve timely access to care.
- **Address the Direct Care Workforce Crisis:** Strengthen the direct care workforce through wage parity between direct support professionals assisting people with IDD in the community (\$10.60/hour) and institutional settings (\$19.16/hour).
- **Expand Access to Mental Health Services:** Increase outpatient capacity and availability of mental health services for individuals with IDD by expanding the use of the biopsychosocial model through local IDD authorities.

## **Pillar: Inclusive Education**

**Key Challenges:** Children with IDD face significant barriers to accessing education and early intervention services. School districts are critically underfunded due to outdated special education funding formulas, which result in insufficient resources. Additionally, the limited availability of inclusive postsecondary education programs for students with IDD prevents many from pursuing higher education and expanding employment opportunities.

### **Policy Priorities:**

- **Equitable Funding for Special Education Services:** Implement the Special Education Funding Commission’s recommendation to shift to an intensity-based funding model that addresses each child’s unique educational needs.
- **Promote Safe and Inclusive School Environments:** Address the disproportionate physical restraints students with disabilities experience by enhancing training for educators on effective positive behavior strategies and de-escalation. Ensure students with disabilities are fully included in school safety and emergency planning efforts.
- **Expand Access to Inclusive Higher Education:** Establish funding opportunities for colleges and universities to create inclusive postsecondary programs supportive of the academic and social needs of students with IDD.

### **Pillar: Civil Rights & Justice**

Key Challenges: People with IDD face discrimination and inadequate legal protections, compounded by limited community supports. This issue is even more acute for those with both IDD and mental health conditions who often do not receive timely access to care, leading to crisis. (Up to 30% of incarcerated individuals have IDD—disproportionately high compared to the general population.)

### **Policy Priorities:**

- **Define and Establish an Appropriate Process for Identifying People with IDD:** Ensure an accurate and consistent definition of IDD, while creating a clear, standardized process for identifying individuals with IDD within the criminal legal system to prevent unwarranted executions, promote fairness, and bring Texas into compliance with federal law.
- **Ensure Self-Determination and Protect Rights of Texans with IDD:** Promote policies that empower Texans with IDD to make informed choices and live independently, while safeguarding their rights from discrimination, exploitation, or abuse.
- **Uphold Existing Voting Rights for Texans with IDD:** Ensure the ability to vote privately and independently through access, accommodations, and support.

### **Pillar: Comprehensive Integrated Employment**

Key Challenges: Texans with IDD face disproportionately high unemployment rates—twice that of their non-disabled peers. Discriminatory attitudes, lack of accommodations, and limited access to job training and support services prevent many from securing and maintaining meaningful employment. These urgent barriers impact thousands of individuals across our state. By acknowledging them, we can ensure Texans with IDD have the same opportunities to succeed and thrive as anyone else.

### **Policy Priorities:**

- **Promote Competitive Integrated Employment for Texans with IDD:** Advocate for policies that increase access to competitive, integrated employment opportunities, enabling individuals with IDD to earn competitive wages in inclusive workplaces.
- **Enhance Employment Support Services and Peer Support:** Expand funding for job training, career counseling, on-the-job supports, and peer support programs to help individuals with IDD secure, retain, and succeed in meaningful employment.

- **Eliminate Barriers to Employment for Texans with IDD: Address barriers to employment by advocating for workplace accommodations, inclusive hiring practices, and equal opportunities for career advancement.**

Visit our new website at [www.thearcoftexas.org](http://www.thearcoftexas.org) to learn more.