IDD Champions

Collaborating for Inclusive Solutions

BEXAR COUNTY
IDD Champions Community Survey

June 2025

The Arc of San Antonio
Brighton Center Here there are only Abilities.
ABC of Southwest Texas
Respite Care Caring for children with special needs
Morgan's MAC Multi-Assistance Center
SALife Academy Doing Life Together

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EXECUTIVE SUMMARY

Background and Purpose

In Fall 2024, a coalition of Bexar County nonprofits came together in response to a shared recognition: families caring for individuals with intellectual and developmental disabilities (IDD) were navigating a fractured and under-resourced system, mainly on their own. Two key catalysts helped launch this effort: the Texas Cavaliers requested input on systemic solutions to support the IDD community, and a major Texas-based foundation expressed interest in backing policy reform. These conversations confirmed a pressing need for a coordinated, community-led approach to assessing and improving the local IDD ecosystem.

By December 2024, a core stakeholder group was formed, including ABC of Southwest Texas, Brighton Center, Morgan's Multi-Assistance Center (The MAC), Respite Care of San Antonio, The Arc of San Antonio, and SA Life Academy. Their goal: to develop a hyperlocal, participatory study that identified immediate needs and long-term priorities for families and individuals with IDD. This work was guided by principles of Community-Based Participatory Research (CBPR) and Utilization-Focused Evaluation (UFE), ensuring the people most affected by the system were at the center of the research.

A comprehensive survey was launched in Spring 2025, drawing over 800 responses from caregivers, educators, and community members. Findings are already shaping local strategy, with the first endorsed project—a guided, IDD-specific resource directory through SACRD—having secured two-thirds of the required funding and is underway.

75% of families find it difficult to access services when they need them.

Key Findings

1. Families Are the System

- Parents and caregivers act as full-time care coordinators, managing referrals, appointments, waitlists, and services across disconnected agencies.
- Nearly 50% of respondents said coordination between service providers was “not well” or “not at all” effective.

2. Delays in Diagnosis Undermine Early Support

- Many caregivers suspected developmental concerns within the first year of life, yet experienced long delays in receiving a diagnosis due to systemic barriers and provider dismissal.
- Despite existing eligibility for Early Childhood Intervention (ECI), too many families reported not being referred in time or not receiving services until delays became severe

3. Access to Services Is Delayed and Dependent on Privilege

- Long waitlists (often 6–12 months or more) are the norm across therapy, day programs, and medical care.
- Services are even more limited for adults with IDD, rural families, and those with complex behavioral or medical needs.

4. Respite and Individualized Skills and Socialization Services (ISS) Are Severely Under-Resourced

- One-third of caregivers report having no one to help them take a break.
- Even when families are eligible for respite or day programs, they often cannot access the services due to provider shortages, funding shortages, or restrictive admission criteria.

5. Caregiving Carries Economic Costs

- 32% of caregivers have quit a job, and 23% have reduced hours due to caregiving demands.
- Families describe financial instability, reduced earning potential, and career sacrifice, often without employer accommodations or public support.

6. Future Planning Is a Source of Fear

- Over 80% of caregivers reported having no plan or vague ideas about their loved one’s adult care.
- Waitlists dominate this process; many families apply early, then wait years with no updates or guidance.

Community Priorities and Immediate Action

During data review meetings in April 2025, the nonprofit ecosystem identified top priorities based on community input:

Short-Term (3–6 months)

- Launch SACRD’s guided IDD resource directory (in progress)
- Share findings widely to influence funding, policy, and program design
- Create a centralized, living list of local waitlists and availability by service type

Mid-Term (1–3 years)

- Build an IDD Council for systems alignment and advocacy
- Create navigator programs and peer mentorship models for families
- Expand ECI awareness and referral systems, especially in healthcare and early education settings
- Expand respite and ISS services, especially for adults

Long-Term (3+ years)

- Establish real-time service dashboards
- Develop a countywide coordination infrastructure
- Invest in early intervention workforce development and family-centered early supports
- Advance adult care planning, supportive housing, and caregiver compensation models

Many families encountered dismissive doctors, insurance denials, or outdated protocols that delayed evaluations.

Call to Action

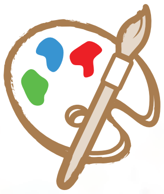
In Bexar County, nearly half of caregivers report severely inadequate coordination between service providers, forcing them into full-time care coordination roles. Over 80% have no clear plan for their loved ones. Families face economic hardship, with one-third leaving their jobs due to caregiving demands. Immediate action is needed. The data presented in this report urgently support local advocacy for increased state investment in IDD services, reduction of Medicaid waiver waitlists, and policy reform for better caregiver financial support. One of the most urgent findings is that many children missed the opportunity for early supports due to delayed diagnosis and inadequate referrals to ECI, despite clear signs of concern. Families often "knew something was wrong" long before the system responded.

We must act earlier. When providers, educators, and case managers are trained to recognize early signs of IDD and refer families to ECI, outcomes improve dramatically. We must build a responsive, family-centered approach that prioritizes early diagnosis and early intervention as foundational strategies—not optional services.

This report is more than a data brief—it's a call to action. It affirms what many families have been saying for years: the current system is too complex to navigate, slow to respond, and disjointed to meet the full spectrum of needs. But it also highlights the power of community, collaboration, and shared momentum.

Bexar County has a chance to lead. With the SACRD project underway and a growing network of nonprofit stakeholders, we are poised to build a more navigable, compassionate, and effective system for people with IDD and their families. However, lasting change will require continued investment, family voice, and cross-sector partnership.

> **Let this study be the beginning... not the end, of a stronger, smarter, and more inclusive future.**



Background

Intellectual and developmental disabilities affect roughly 7–8 million Americans (about 3% of the population). When including broader developmental disabilities (such as autism, cerebral palsy, and ADHD), the number rises – one analysis estimates around 16 million Americans (approximately 5% of the population) live with IDD.[1] About 1 in 6 U.S. children (17%) aged 3–17 have at least onedevelopmental disability according to recent national survey data.[2] This category is broad – it includes intellectual disability (ID), autism spectrum disorder (ASD), attention-deficit/hyperactivity disorder, learning disabilities, and other developmental delays. For intellectual disability alone, roughly 2–3% of U.S. children have an intellectual disability.

Texas has a large and growing population. The Texas Department of Health and Human Services estimates that 485,000 (1.6%) children and adults in Texas have an intellectual or developmental disability. Applying a 2–3% rate to Texas's population yields roughly 580,000–870,000 individuals, so the frequently reported 485,000 represents a more conservative count.

A 2022 study published by the United Way of San Antonio and Bexar County, and a resulting Summit hosted in early 2023, revealed that 26% of San Antonio military families have a member with special needs. Many military families specifically request transfer to San Antonio for better access to specialty care. The report prioritized the need for additional childcare options for children with IDD and other conditions.

Texas's capacity to serve the IDD population is limited relative to the need. Out of 485,000 Texans with IDD, again a conservative estimate, only about 97,000 individuals are currently being served with long-term IDD services.[3] These services include Medicaid waiver programs (like the Home and Community-Based Services (HCS) program and others), intermediate care facilities, and state-supported living centers. Texas is known for its extensive "interest list" (waiting list) for IDD Medicaid waivers. Texas leads the nation with the largest waitlist – over 311,000 people with IDD were on the waiver interest list in FY2023.[4] This means a newly eligible person could wait 10–15 years before receiving community-based services, a situation advocates often highlight as a crisis. The waitlist number also essentially mirrors the count of those not receiving formal services; it implies that hundreds of thousands of Texans with IDD rely on family support or minimal state support while they wait. Families and service providers are well aware that the current service availability in Texas does not meet the needs.

> **Out of 485,000 Texans with IDD, a conservative estimate, only about 97,000 individuals are currently being served with long-term IDD services.**

In Bexar County, child maltreatment remains a pressing concern, with rates among the highest in the state. The Texas Department of Family and Protective Services (DFPS) reports that Bexar County also led all counties in child removals due to abuse/neglect (1,353 removals in FY2024). Additionally, there were 2,250 alleged and validated adult victims of abuse with a disability in Bexar County in FY 2024. This vulnerable population, children with disabilities, is disproportionately affected by abuse. Research indicates that children with disabilities are nearly four times more likely to become victims of abuse or neglect than their non-disabled peers. Consistent with this, children with special needs are overrepresented in the child welfare system: while only about 5% of Texas school-age children have a disability, an alarming 53% of children in DFPS foster care have at least one diagnosed disability. Research indicates children with disabilities are nearly four times[5] more likely to be abused or neglected than non-disabled children, with a 31% abuse prevalence rate compared to

9% among non-disabled children. According to the Texas Department of Family & Protective Services (DFPS) data for FY24, Bexar County (Region 8a) led the state in adoptions of children with disabling conditions, accounting for 16.6% of the state's total with 181 adoptions. Studies[6] show children with disabilities in foster care face higher risks of mortality and are less likely to achieve permanent placement. These statistics underscore how profoundly children with disabilities are at risk in Bexar County's ongoing child abuse crisis. Data also confirms higher disability rates among children in foster care.

These statistics underscore how profoundly children with disabilities are at risk in Bexar County's ongoing child abuse crisis. The urgency to intervene early, through developmental screening, prompt referral, and robust Early Childhood Intervention (ECI) services, is evident. Early intervention not only mitigates delays but also strengthens protective factors for children already facing adversity. By acting sooner, we can prevent the worsening of conditions that lead families into crisis systems.

> **A newly eligible person could wait 10–15 years before receiving community-based services.**

In Fall 2024, two pivotal events inspired a coalition of nonprofits focused on the Intellectual and Developmental Disabilities (IDD) ecosystem to align. First, the Texas Cavaliers committed to supporting the IDD community and asked, "If you could design one or two system-wide improvements, what would you need?" Shortly after, a large state-based philanthropic foundation expressed interest in funding policy efforts for the IDD community by establishing an organization to work at the state level. These events confirmed the need for San Antonio and Bexar County to draw upon their strength as a collaborative and compassionate community.

By December 2024, a stakeholder group will be formed to undertake the necessary systems work. The collaborative backbone included ABC of Southwest Texas, Brighton Center, The MAC, Respite Care of San Antonio, The Arc of San Antonio, and SA Life Academy.

The group's overarching goal was to develop a hyperlocal study that all IDD-focused nonprofits could use to improve programs and services at the micro level while identifying system improvements at the macro level. The stakeholders developed a timeline and identified data sources, including the need for a community survey. They intentionally targeted the IDD population while acknowledging that the broader disability community could benefit from their work.

The plan was to release a comprehensive study in the first half of 2025 alongside the community of nonprofits serving the IDD population. This study aims to outline the needs, gaps, and strengths and prioritize systemic solutions to inform the broader community. The work would continue beyond the study's release, catalyzing change driven by stakeholders in partnership with the community.

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[1] CDC MMWR, Surveillance Summaries / March 27, 2020 / 69(4);1–12)

[2] Li, Q., Li, Y., Zheng, J. et al. Prevalence and trends of developmental disabilities among US children and adolescents aged 3 to 17 years, 2018–2021. Sci Rep 13, 17254 (2023).

[3] See **Time to Care** for more detailed data

[4] https://www.kff.org/medicaid/state-indicator/number-of-people-waiting-for-hcbs-by-target-population-and-whether-states-screen-for-eligibility

[5] **Maltreatment and disabilities: a population-based epidemiological study - ScienceDirect**

[6] www.contemporarypediatrics.com/view/new-research-finds-significant-challenges-for-children-with-disabilities-in-foster-care

Nonprofits Invited to Participate in Shaping the Study

Core Stakeholders (working collaboratively since Fall 2024):

- ABC of Southwest Texas
- Brighton Center
- Morgan's MAC
- Respite Care of San Antonio
- San Antonio Life Academy
- The Arc of San Antonio

Organizations That Attended Both Community Meetings:

- Alamo Area Community Network
- disABILITYsa
- Kinetic Kids
- Mission Road Ministries
- TEAMability

Organizations That Attended One of Two Meetings:

- AACOG
- Autism Community Network
- Children's Association for Maximum Potential
- Reaching Maximum Independence
- Rise School of San Antonio
- Southwind Fields
- Special Reach
- The Center for Health Care Services

Additional Organizations Invited:

- Autism Lifeline Links
- ConnectAbility
- Down Syndrome Association of South Texas
- RISE Equestrian
- Spina Bifida Texas

The Study Timeline

December 2024 through March 2025:

- Meet with the IDD nonprofit ecosystem to share plans and gain feedback
- Share plans with multiple philanthropic leaders (attendees included the Kronkosky Charitable Foundation, Texas Cavaliers, and United Way of San Antonio & Bexar County. Several other funders were unable to attend).
- Outreach for data sources at the federal, state, and local levels
- Develop and launch a community survey

April 2025:

- Evaluate preliminary data
- Reconvene the IDD nonprofit ecosystem to view data and provide input on prioritization.

May through June 2025:

- Develop a community report
- Host release via press conference, including the IDD ecosystem, philanthropy, and media

July 2025 and Beyond:

- Stakeholders work on key priorities identified in the study
- Strengthen the collaborative backbone to address systemic needs

Framework Selected for Survey Design

Community organizations are often hesitant to lead their own data collection projects. However, the IDD Champions group included individuals with training and experience leading large-scale data collection efforts and a deep commitment to community-led, community-owned data processes. Community-led data processes are rooted in the belief that the community owns the knowledge generated within it. Community-Based Participatory Research (CBPR) is a research method primarily led by academic institutions collaborating with the community, developed by Meredith Minkler and Nina Wallerstein. Stakeholders opted for an entirely community-led process, more in line with the framework of the former Data Center in Oakland, which assumes that community-based practitioners can learn and lead their own data collection, analysis, and dissemination.

The core principles of Community-Based Participatory Research (CBPR) are:

- Recognize the community: View the community as a unit of identity
- Build on community strengths: Use the community's resources and strengths
- Collaborate: Involve all partners in all phases of the research
- Integrate knowledge and action: Ensure that all partners benefit from the research
- Promote co-learning: Create an empowering process that addresses social inequalities
- Use a cyclical process: Use an iterative process
- Consider health holistically: Address health from both positive and ecological perspectives
- Disseminate findings: Share the findings and knowledge with all partners
- Commit long-term: Ensure that all partners are committed to the long-term research
- Balance research and action: Find a balance between knowledge generation and intervention

Utilization-Focused Evaluation (UFE) emphasizes the importance of involving stakeholders in the evaluation process, from planning to disseminating results. This means that stakeholders are consulted on the evaluation's purpose, design, and methods, as well as the interpretation and use of the findings. The goal of UFE is to generate evaluation findings that are actionable, credible, and relevant to stakeholders. This means the evaluation is designed to meet stakeholders' specific needs and address their questions and concerns. The focus is on ensuring that the evaluation findings inform decisions about program improvement, rather than simply assessing program performance.

Survey Development and Dissemination

Key stakeholders and the broader IDD service provider ecosystem provided input for the survey design. The survey was translated into Spanish and widely shared with QR code options. The collaborative nature of the study, along with the inclusion of community stakeholders, resulted in a significant response rate.

IDD Is Largely Not Represented in Public Data

Initial attempts to find local data sources on IDD proved challenging. IDD is not clearly defined in many organizations' data and may be included broadly in “mental health” or “disability”. While there are many individuals with both a mental health diagnosis and a diagnosis that is part of the definition of IDD, these are distinct issues with distinct needs.

Key Finding: Data on IDD needs to be collected as a discrete category by local service providers and systems to better estimate and analyze the unmet need and its impact on the community.

Next Steps

As the data started to come in, it became clear that a project in its infancy during the initial dreaming phases of this project was urgently needed. A new collaboration with the San Antonio Community Resource Directory (SACRD) was developed to serve the needs of the IDD community. Over the years, many attempts have been made to build a comprehensive resource directory. Those attempts, while valiant, were not sufficiently maintained. The only nonprofit with a core competency to actively support an up-to-date resource directory is SACRD. SACRD is open to the public via its website, is free to use, and allows the end user to remain anonymous.

Key Finding: Data on IDD needs to be collected as a discrete category by local service providers and systems to better estimate and analyze the unmet need and its impact on the community.

Five years ago, when SACRD launched a mental health-focused guided resource directory, the opportunity to build upon that successful effort emerged. The guided directory enables an end user to select a few key options and access resources tailored to their needs. The idea of creating an IDD-focused, guided resource directory became our collaboration's first endorsed project.

The project will cost $150,000; two gifts—one from the Texas Cavaliers and another from the San Antonio Area Foundation—have already secured two-thirds of that funding. Enough funding has been confirmed to start the project, which will involve nonprofit case managers, social workers, and families who will participate in interviews and focus groups to help create the guided process. We believe that families will utilize this guided resource, and nonprofit case managers and social workers will heavily rely on the developed resource.

Community Data Analysis

In a late April 2025 meeting, representatives from the IDD nonprofit ecosystem split into two groups to review over seven hundred pre-categorized comments from two separate questions. One question involved how survey respondents would prefer to spend one million in funding, and another asked what one service or program was missing from our community. From there, the groups reviewed the categorized comments and brainstormed what could be accomplished in months, what could be achieved in one to three years, and what should be prioritized that may require several years due to the funding and/or time needed. The results follow, and while each group had a separate set of survey response comments, their recommended priorities were strikingly similar.

TABLE 1: **Early Priorities**

Three-to-six-month priorities (Similar themes are color-coaded)	One-to-three year priorities	Three or more years' priorities
As we push forward with our SACRD collaboration, all IDD-focused nonprofits commit to using this resource. **Support the project we have prioritized with SACRD to create an updated, guided resource directory.** Develop a real-time wait list by service category and age to see where gaps exist (precursor to a project in later years for a real-time availability portal for services) **Create a shared, collaborative communication strategy so that the community is aware of what is available.** **Develop an IDD Council** **Provider Communication Group - Keep these gatherings going.** **Build an IDD Advocate program to create ad-hoc support, mentors, and an extension of case management (utilize the CASA Advocate type model)** **Parent mentor group** Evaluate working alongside Alamo Area Community Network (AACN) as a nonprofit-to-nonprofit intra-agency referral strategy, as SACRD becomes the publicly available resource directory. Create a survey data summary sheet.	Funding for case management & recruitment as a core function, along with a pipeline strategy to attract quality staff Create a case statement around what happens when we do not invest in the IDD community. Create a position at the City or County level to convene the IDD community and develop dashboards and strategies. Expand capacity for adult dayhabilitation and overall respite services. Develop an electronic tool that provides real-time vacancies /openings for programs and services (ex, 3 open toddler spots for childcare, 10 for summer camp, 5 for adult dayhabilitation)	Adult Care Planning (holistic approach to housing, medical, etc.)

The key stakeholders will continue meeting at a defined rhythm to complete the project with SACRD and determine how to complete the priorities indicated by the community.

Survey Data Analysis

The overwhelming majority of survey respondents were caregivers. For this report, we have focused the analysis on caregivers and will release separate data reports on community members and the nonprofit workforce. We analyzed the caregiver responses to look for significant differences between parents of adults and parents of minors. We also analyzed survey data to identify significant differences among caregivers by income and zip code. No statistically significant differences were found.

Caregiver Responses

Demographics

Caregiver responses were primarily in English, with 96.4% (468 respondents) completing them in English, while a smaller percentage (3.6%, 18 respondents) completed them in Spanish. Among the respondents residing in Bexar County, the majority (74.11%, 292 respondents) have lived there for over 10 years, presumably familiar with available community resources.

Respondents identified predominantly as White (46.19%, 182) and Hispanic or Latino (41.62%, 164). Smaller groups included Black or African American respondents (7.11%), Asian or Asian American respondents (1.78%), and American Indian or Alaska Native respondents (0.51%).

Most respondents fell within the 35-44 (29.95%, 118 respondents) and 45-54 (29.44%, 116 respondents) age brackets. Additionally, 19.54% of respondents were between 55 and 64, while 10.66% were 65 years old or older, indicating that caregivers are not typically in early adulthood.

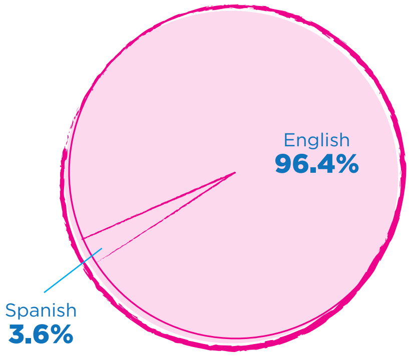
The gender representation among respondents was overwhelmingly female, with women accounting for 90.61% (357 respondents) of the survey completions. Men comprised 8.88% of the respondents, with minimal representation from non-binary individuals and those who preferred to self-describe (0.25% each).

Financially, respondents reported an average income of approximately $90,340, with a median income of $70,000, suggesting a moderate to relatively comfortable economic demographic. Most respondents were parents of children under 18 with intellectual or developmental disabilities (51.61%, 305 respondents), followed by parents of adult children with similar disabilities (38.92%, 230 respondents). A smaller segment included other family caregivers and siblings. The largest subgroup of parents caring for children under 18 had children aged between 6 and 10 years old (33.70%, 93 respondents), followed by those with teenagers aged 14 to 17 (21.38%, 59 respondents).

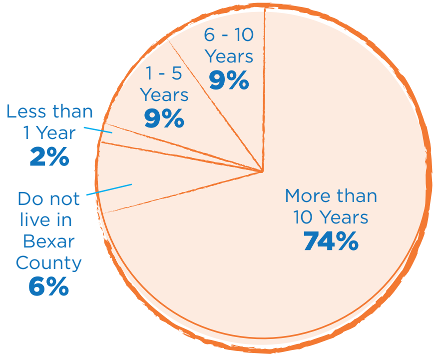
Approximately half of caregivers (54.9%) completed the survey to the last question.

Demographics of the Caregiver Responces Snapshot

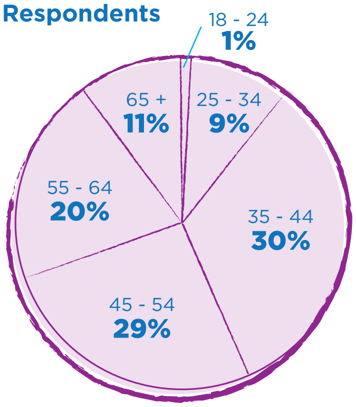
Language of Respondents



Length of Time Living in Bexar County



Age of Respondents



Gender of Respondents

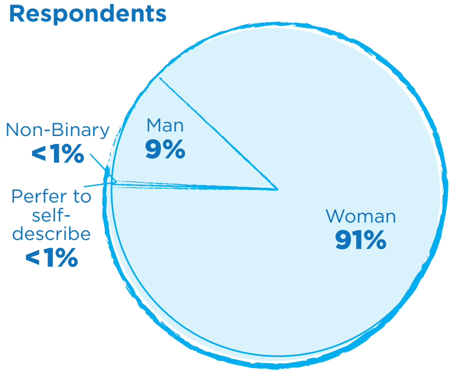


TABLE 2: **Language of Respondents**

	STARTED	COMPLETED
English	852	468
Spanish	32	18
TOTAL	**884**	**486**

TABLE 3: **How long have you lived in Bexar County?**

Less than 1 year	1.78%	7
1 - 5 Years	8.88%	35
6 - 10 Years	9.39%	37
More than 10 Years	74.11%	292
I don’t live in Bexar Co.	5.84%	23
TOTAL		**394**

TABLE 4: **Top 10 Zip Codes of Respondents**

ZIP CODE	COUNT
78209	38
78233	26
78258	26
78253	25
78247	20
78245	19
78218	18
78232	18
78259	18
78249	17

Survey respondents are more likely to be from a zip code with higher incomes and are generally perceived to have more resources. However, despite having a higher income and residing in better-resourced areas of our community, respondents still reported significant and consistent challenges in accessing basic services.

TABLE 5: **What is your Race / Ethnicity?**		
American Indian of Alaska Native	.51%	2
Asian or Asian American	1.78%	7
Black or African American	7.11%	28
Hispanic or Latino	41.62%	164
Middle Eastern or North African	.25%	1
Native Hawaiian or other Pacific Islander	0%	0
White	46.19%	182
Another race	2.54%	10
TOTAL		**394**

TABLE 6: **What is your age range?**		
Under 18	0%	0
18 - 24	1.02%	4
25 - 34	9.39%	37
35 - 44	29.95%	118
45 - 54	29.44%	116
55 - 64	19.54%	77
65 +	10.66%	42
TOTAL		**394**

TABLE 7: **Gender: How do you identify?**		
Man	8.88%	35
Non-binary	.25%	1
Woman	90.61%	357
Prefer to self-describe	.25%	1
TOTAL		**394**

TABLE 8: **Which best describes you?**

I am the parent of a child under the age of 18 with an intellectual or developmental disability	51.61%	305
I am the parent of an adult child OVER the age of 18 with an intellectual or developmental disability	38.92%	230
Other (please specify)	4.57%	27
I am a family caregiver for an adult with an intellectual or developmental disability	3.05%	18
I am the brother or sister of an adult with an intellectual or developmental disability	1.52%	9
None of the above	0.34%	2
TOTAL		**591**

TABLE 9: **For caregivers with children under 18, how old is your child?**

Under 1 Year	.72%	2
1 - 3 Years	9.42%	26
4 - 5 Years	14.49%	40
6 - 10 Years	33.70%	93
11 - 13 Years	16.30%	45
14 - 17 Years	21.38%	59
Over 18	3.99%	11
TOTAL		**276**

How Long Did You Think Your Child Might Have a Learning or Developmental Problem Before They Were Diagnosed?

This question drew emotional and detailed responses from families, illustrating how complex and uneven the path to diagnosis can be for children with intellectual or developmental disabilities (IDD). Some parents received immediate diagnoses at birth, while others endured years of uncertainty, misdirection, and medical dismissal before receiving answers. Families often reported that their instincts had flagged developmental concerns long before a diagnosis was confirmed. Many caregivers described attempts to get help rebuffed by professionals who minimized or dismissed early signs.

These missed windows underscore the need for immediate, streamlined referrals to ECI and developmental pediatricians when delays are suspected. Early intervention is a proven tool that leads to better developmental outcomes, reduces special education needs, and strengthens family resilience.

TABLE 10: **How long did you think your child might have a learning or developmental problem before they were diagnoed?**

Less than 6 months	33.26%	148
6 months to 1 year	19.55%	87
1 - 2 years	20.67%	92
More than 2 years	23.82%	106
We still are waiting for a diagnosis	1.12%	5
I've never tried to get a diagnosis	1.57%	7
TOTAL		**445**

Summary of Open-Ended Responses (n=85)

1. Early Diagnosis at or Before Birth

- Many respondents knew prenatally or immediately after birth that their child had a medical condition or genetic syndrome (e.g., Down Syndrome, Trisomy 21, cerebral palsy, Sturge-Weber, Beckwith-Weidemann).
- These families were often connected to early intervention services relatively quickly.

Key Quotes:

"Diagnosed at birth with Down Syndrome."

"We understood our son was in trouble by day 3 or 4."

"Diagnosed before birth due to ultrasound findings."

2. Parental Instincts Often Preceded Diagnosis

- Many caregivers said they suspected something was wrong early—often within the first year—but couldn't get providers to listen.
- Parents described delays in motor milestones, lack of speech, or unusual behaviors as early red flags.

Key Quotes:

"I could tell at 2.5 months that he wasn't meeting milestones."

"I somehow knew she had a problem."

3. Delays Due to Systemic and Provider Barriers

- Many families encountered dismissive doctors, insurance denials, or outdated protocols that delayed evaluations.
- Several were told their child was "too young" to diagnose, even when concerns were obvious.

Key Quotes:

"It was so hard to get an appointment or someone to just point us in the right direction."

"The medical establishment is not prepared for the influx of special needs children."

"In Texas, you can't tell if a child is delayed until they are 3—even if delays are obvious earlier."

"I received a formal diagnosis when my child was 8 years old. Private insurance denied genetic testing over and over."

"I was forced to quit my job to get her the medical attention needed."

4. Years-Long Diagnostic Journeys

- For children with subtler developmental issues (e.g., autism, apraxia, dyslexia), diagnoses often came well into elementary school.
- Some experienced misdiagnoses, such as ADHD or general "speech delay," before a full diagnosis was reached.

Key Quotes:

"He was originally diagnosed with ADHD at 5, then PDD-NOS at 14."

"A full diagnosis of all his disabilities took over 3 years."

"She was diagnosed with autism at age 9."

5. Regression and Late-Onset Challenges

- A few children developed typically but experienced developmental regression after medical events (e.g., seizures, head trauma, TBI) or unknown causes.

Key Quotes:

"He had normal development until seizures at 2, then he regressed."

"Car accident at 15 caused TBI."

"My daughter was typical until about age 2—then she began to regress."

Additional Quotes:

"No one would help or believe me about my son."

"They knew something was wrong at the hospital, but she wasn't diagnosed."

"We've known since year one of her life."

"My child was born with a diagnosis he'll never recover from."

> "The medical establishment is not prepared for the influx of special needs children."

Recommendations

1. Provider training on early warning signs of IDD and how to support families in pursuing evaluations without delay should be increased.
2. Launch a county-wide public awareness campaign on the benefits of ECI and how to access services.
3. Invest in ECI provider capacity to reduce wait times and expand bilingual and culturally relevant service delivery.
4. Streamline referrals for Early Childhood Intervention (ECI) and developmental pediatricians, particularly for parents who express concerns before their child's third birthday.
5. Require insurance coverage for genetic and developmental testing, particularly when red flags are present.
6. Create culturally and linguistically responsive education campaigns to help families recognize early signs and advocate effectively.
7. Enhance cross-agency communication to enable medical, early education, and social service providers to share concerns and expedite the provision of support.

> "A full diagnosis of all his disabilities took over 3 years."

Families often know something is wrong before anyone in the system says it aloud. Their stories reveal a landscape where persistence often supplants trust, and diagnosis is frequently delayed, not by science, but by access, disbelief, or outdated rules. Whether it's a parent who "just knew" or one who was ignored for years, the message is clear: we must do better, sooner, together.

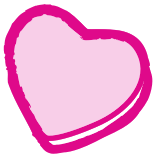
Accessing Services

When asked to identify their resources and referral networks, caregivers listed a diverse range of entities, including local nonprofits, schools, healthcare providers, social media, and informal community connections. Caregivers of children with intellectual and developmental disabilities (IDD) overwhelmingly describe a fragmented, inconsistent, and parent-driven system where meaningful coordination between schools, healthcare, case management, and community resources is the exception, not the norm. While a few families reported positive experiences (particularly through The MAC or AACOG), most shared deep frustration, emotional exhaustion, and a sense of being forced to act as full-time care coordinators themselves.

Timely identification of developmental disabilities is crucial, yet delays in diagnosis are a persistent problem. Children with autism or other developmental issues are often diagnosed later than ideal, which in turn delays the start of interventions.[1] One major factor is the shortage of specialized clinicians (such as developmental-behavioral pediatricians, child neurologists, and child psychologists) who can evaluate and diagnose IDD. Stakeholders report that Bexar County has a sufficient number of general pediatricians but a shortage of developmental specialists, resulting in long wait times for comprehensive evaluations. This mirrors national trends in the pediatric workforce.[2] It is not uncommon for families to wait months, even over a year, for an autism evaluation appointment. This shortage contributes to misdiagnosis or provisional diagnoses (like labeling a child with ADHD or behavioral problems) that don't fully explain the developmental challenges.[3] The COVID-19 pandemic exacerbated these issues – routine check-ups and evaluations were postponed, and early childhood services were disrupted.[4] According to the AACOG community needs assessment, the pandemic caused a "three-year setback" in timely diagnoses for children. In other words, many toddlers who might have been diagnosed at age 2 or 3 did not get identified until age 5 or 6, when they entered school, due to the pandemic's impact on healthcare access. This delay is especially concerning for autism spectrum disorder (ASD): data show rising prevalence of autism diagnoses in children, and research indicates that diagnosing and starting intervention by age 2-3 leads to better outcomes.[5] When children aren't diagnosed early, they miss the window for ECI services and may not receive any specialized help until they start school. Recent data indicate that the majority of children enrolled in ECI are identified in their second year of life (median age at enrollment is around 13–24 months) and most qualify due to developmental delays (about 86% of ECI children), rather than a specific medical diagnosis.[6]

> Timely identification of developmental disabilities is crucial, yet delays in diagnosis are a persistent problem.

The consequences of delayed diagnosis are significant. Without a diagnosis, children often cannot access certain therapy services, school supports, or Medicaid waiver programs that require documentation of an intellectual/developmental disability. In practical terms, a child who isn't diagnosed with autism until age 6 might only then be added to a waiver waiting list (which is over a decade long), meaning critical supports won't materialize until the teen or adult years.



Inconsistent referrals to ECI emerged as a major concern. Although some families were connected quickly following a diagnosis, others had to push persistently or were not referred at all. Several families described being told they had to wait until a child was "old enough" for services, even when delays were evident. These stories underscore the urgent need to demystify and de-stigmatize early intervention, and to remove procedural barriers that delay support. There are also efforts to streamline the school evaluation process when children "age out" of ECI at 3 – currently, families often find that "a doctor's diagnosis is not valid for the schools" and they must undergo another lengthy evaluation by the school district, which "could take up to two years to get a diagnosis" through the special education system.

Caregivers in San Antonio overwhelmingly describe the process of accessing services for individuals with IDD as complex, inconsistent, and dependent on luck, persistence, or personal connections. At the same time, a few respondents praised organizations, but most described a fragmented, under-resourced, and inaccessible system, especially after a child turns 18.

> **The consequences of delayed diagnosis are significant.**

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6 Zhang Y, Berns K, Handler K, Linton R, Menendez T, Mandell D, van den Berg AE, Hoelscher DM. UTHealth Houston School of Public Health, Michael & Susan Dell Center for Healthy Living. October 14, 2024. Early Childhood Intervention. A report of the Texas Research-to-Policy Collaboration Project.

TABLE 11: **When your child found out they had a learing or development problem, how fast did you get help?**

Immediately	47.88%	124
Within 1 month of diagnosis	15.83%	41
Within 3 months of diagnosis	11.97%	31
Within 6 months of diagnosis	8.11%	21
More than 6 months	16.22%	42
Other (please specify)		35
TOTAL		**259**

TABLE 12: **Have you contacted or used services from these referral networks? Please check all that apply.**

ANSWER CHOICES	**RESPONSES**	
The MAC (Morgan’s Multi-Assistance Center)	55.36%	253
AACOG	53.83%	246
Other (please specify)	19.47%	89
Autism Community Network	17.72%	81
211	14.00%	64
None of the above	11.82%	54
Autism Lifeline Links	8.53%	39
City of San Antonio	7.00%	32
311	3.28%	15
SACRD.org	2.63%	12
TOTAL		**457**

Survey respondents also identified a wide range of organizations in the " Other " category.

- Local Nonprofit Organizations: Caregivers frequently mentioned established nonprofits such as Any Baby Can, ARC of San Antonio, Brighton Center, Easter Seals, and the Down Syndrome Association of South Texas.
- Educational Systems and School Districts: Respondents highlighted school-based resources, including North East ISD (NEISD), local school districts, Region 20, and Head Start programs.
- Healthcare and Specialized Services: Families regularly accessed resources through healthcare providers, including the Children's Hospital of San Antonio, the Center for Health Care Services (YES Waiver), the Epilepsy Foundation, Camino Real, and Autism Treatment Centers.
- Government and Medicaid Waiver Programs: Several caregivers noted state-run programs, including CLASS Medicaid Waiver, the Texas Workforce Commission (TWC), MHDD, and Early Childhood Intervention (ECI).
- Informal Networks and Online Communities: Respondents often sought support through Facebook groups, Google searches, and direct connections with other caregivers (e.g., Parent 2 Parent).

TABLE 13: **How well do different service providers coordinate with each other to support your child?**

Very well	23.41%	103
Somewhat well	37.95%	167
Not well	24.77%	109
Not at all	13.86%	61
TOTAL		**440**

Summary of Open-Ended Responses (n=71)

1. Parents as Primary Coordinators

- A dominant theme is that families are left to "do all the coordination" between providers, specialists, and systems.
- There's little to no collaboration across agencies, and parents must repeatedly retell their child's story, chase down referrals, and manage appointments.

Quotes:

"I do all the coordination—it's too much work."

"You always have to repeat your child's story over and over."

"I'm smart and assertive, but that's the only reason my son gets what he needs."

2. Lack of Cross-System Communication

- Many families highlighted a disconnect between schools, medical providers, and community services, resulting in inconsistent care and redundant or delayed services.
- Some reported doctors not talking to each other, school services not aligning with outpatient therapy, and confusion over who manages what.

Quotes:

"None of her doctors like to communicate with each other. They just start fresh every time."

"School providers don't participate well with outpatient providers."

"There is a lack of continuity of care between schools and doctors."

3. Turnover and Inconsistent Information

- Frequent staff turnover in schools, case management, and community agencies was cited as a significant barrier to effective coordination.
- Inconsistent or outdated information often led to wrong referrals, unmet needs, or being bounced between systems.

Quotes:

> "Staff turnover is the biggest challenge."
>
> "Too many different people give different answers. You get referred in circles."
>
> "We've received referrals where the agency never even responded."

4. Families Caught in Bureaucratic Loops

- Many caregivers shared stories of being referred back and forth between providers, struggling with waitlists, and spending months trying to navigate eligibility.
- Systems appear to function more like silos than networks, leading to delays and burnout.

Quotes:

> "Sometimes one entity will refer me to another, and I go in circles."
>
> "I was told I'd only have to tell my child's story once... that's never been true."
>
> "Why do doctors stop seeing kids after age 3?! It just disrupts everything."

Recommendations

1. Establish a centralized care coordination hub for families, allowing parents to avoid being the primary coordinators.
2. Invest in cross-agency training and protocols to ensure that schools, healthcare, and social services communicate using a shared care plan.
3. Develop a shared digital platform or "child dashboard" where providers and families can track referrals, services, progress, and waitlist status.
4. Give navigators or care coordinators the authority to directly schedule appointments and follow up across systems, rather than just handing out phone numbers.
5. Help organizations retain talented staff to reduce turnover and improve consistency across provider relationships.

Families aren't asking for miracles—they're asking for connection, clarity, and continuity. This data shows that even the best services can fail without strong coordination. It's time to build a system where providers communicate with each other, families receive support, and no one is left to navigate alone.

TABLE 14: **How easy is it to find the right services at the right time when you need them for your loved one?**

Very easy	4.43%	20
Easy	19.96%	90
Difficult	49.89%	225
Very difficult	25.72%	116
TOTAL		**451**

Summary of Open-Ended Responses (n=95)

1. Waitlists and Delays Are the Norm

Long wait times are one of the most common barriers to accessing healthcare. Whether for ABA therapy, psychiatry, occupational therapy, or even dental care, families often wait six months to years to access appropriate services—if they can find them.

Quotes:

"The wait is always six months to a year for an appointment."

"It took 10 years to get into the CLASS program."

"Post-pandemic waitlists are longer, and services aren't readily available for older kids."

2. The System is Not Designed for Adults

Once individuals with IDD age out of pediatric systems or school-based supports, services become far more scarce, fragmented, and difficult to access. Many families reported feeling abandoned after their child turned 18.

Quotes:

"Turning 18, all help for my son dropped off the face of the earth."

"There are not enough services in San Antonio for IDD adults."

"If you're over 5 years old, it's nearly impossible."

3. Caregivers Must Be Their Case Managers

Nearly every caregiver described the need to independently research, advocate for, and coordinate services, often feeling isolated in navigating complex systems.

Quotes:

"I feel I do most of the investigating and digging to find information—not my caseworkers."

"We are good at problem solving and persistent caregivers—we find what we need by relying on our own resources."

"There's no one-stop place to go. It's scattered, confusing, and exhausting."

4. Insurance and Financial Barriers

Private insurance often doesn't cover necessary services or only covers a limited number of sessions per year. Medicaid is more comprehensive, but it is also harder to access. Cost is a barrier for many, especially for services like sedation dentistry, psychiatry, or specialized therapies.

Quotes:

"If you don't have Medicaid, insurance won't pay for services, or only covers 25 sessions a year."

"The right facilities exist—but they're too expensive."

"I pay out of pocket because I can't get anything approved."

5. Geography and Transportation Issues

Families outside Bexar County or in specific ZIP codes report even fewer options, especially due to providers' limited willingness to travel or serve rural clients.

Quotes:

"I live 40 minutes from Bexar County—no one will drive out here."

"Therapy is not an option because companies let therapists choose who they want to serve."

"There's a complete lack of resources around 78223."

Families were also asked, "Are there any services you need but cannot find in our community?" **When explicitly asked about unmet needs, parents highlighted several key themes: insufficient specialized healthcare options, a lack of accessible respite and caregiver support, gaps in transition services for adolescents and young adults, limited socialization opportunities, barriers to employment, transportation challenges, and financial strain.** Their responses reflect frustration and a desire for more comprehensive, accessible, and compassionate services tailored to the complex needs of individuals with IDD and their families.

1. Specialized Healthcare Services

Parents frequently expressed difficulties accessing critical medical and therapeutic services, emphasizing shortages and barriers related to Medicaid acceptance and sedation needs.

Quotes:

> "I dream about a place where I can get blood drawn, imaging completed, all while he is under anesthesia—but that doesn't exist, not even at the MAC."
>
> "Psychiatry; neurology; rheumatology; day programs for higher support needs adults; DSPs willing to work with adults daily (vs facility-based)."
>
> "Specialized physicians that accept Star Plus Medicaid that do not have a long waitlist to be seen."

2. Respite and Caregiver Support

Parents noted a critical lack of accessible and reliable respite services, especially for older children and adults, affecting their ability to maintain employment and manage personal well-being.

Quotes:

> "Respite for incontinent and G-tube fed teen."
>
> "We just need daytime respite on Saturday and Sunday. As well as more options during school breaks."
>
> "Finding respite care for a nonverbal person with very low intellect, where I can trust his care, is difficult."

3. Social Opportunities and Community Integration

Families cited limited opportunities for safe and inclusive social activities and community participation as a significant unmet need.

Quotes:

> "Social activities without needing waivers—dances, ballet, theater plays, sports specifically for IDD children."
>
> "Weekly Saturday social activities for teens—similar to day programs for adults during the week."
>
> "A social network for adults with IDD to do fun activities."

4. Transition and Independent Living

Concerns about future planning, transition from adolescence to adulthood, and a lack of independent living facilities were recurrent themes.

Quotes:

> "No appropriate dayhab, job opportunities, or life skills center for adults with autism with minor aggression."
>
> "Independent residential living facility that provides a safe, loving community. Current group homes are substandard."
>
> "I need to plan more after he turns 18...also plan for the future when we are gone."

5. Employment and Vocational Support

Families articulated substantial challenges in finding meaningful employment opportunities, including job training and long-term employment assistance.

Quotes:

> "Real training that is able to find my daughter a job."
>
> "YES—job training and driver training for adults with developmental disabilities."
>
> "Assistance in finding my daughter work."

"I need to plan more after he turns 18... also plan for the future when we are gone."

6. Transportation Barriers

Transportation emerged as a pervasive barrier, significantly limiting service accessibility and independence.

Quotes:

> "Safe and reliable transportation would be very much welcomed."
>
> "Transportation outside the ViaTrans zone."
>
> "Trustworthy transportation help (she's not able to use ViaTrans independently yet)."

7. Financial and Legal Support

Many caregivers highlighted financial hardship due to caregiving responsibilities and unmet legal needs, such as guardianship and special needs trusts.

Quotes:

> "Financial help. Having three kids with physical and mental diagnoses leaves me less time to work. This leaves us financially lacking."
>
> "Prep for adulthood at a reasonable cost—guardianship, special needs trust."
>
> "Long-term financial support without turning the family home into a government-run group home."

Caregivers clearly articulate the emotional, financial, and logistical burdens resulting from these unmet needs. Their insights provide a powerful call to action for community leaders and policymakers to prioritize expanding and improving service availability, reducing financial barriers, and ensuring more robust support systems to enhance the quality of life and well-being of individuals with IDD and their families.

Recommendations

1. Create a centralized resource hub for San Antonio and surrounding counties with up-to-date service listings, referral status, and eligibility tools.
2. Mandate better referral coordination between pediatricians, school staff, dentists, and mental health providers.
3. Increase funding and workforce development to reduce provider shortages, especially for adult services.
4. Advocate that philanthropy and funders consider clients' developmental age rather than their physical age. In this manner, many adult programs would qualify for funding typically reserved for children and youth.
5. Require therapy providers to serve rural and outlying areas, not just urban core ZIP codes.
6. Expand post-18 services and provide transition planning for youth with IDD starting at age 14.
7. Launch a service navigation training program for parents, offering one-on-one support for those without a healthcare or education background.

Finding services shouldn't feel like solving a puzzle without a picture. This data shows that families are willing to do the work—they just need systems that respect their time, reduce the chaos, and provide care when and where it's needed most. Without that, the result is what so many families describe: burnout, heartbreak, and loss of hope. It doesn't have to be this way.

> **Families are willing to do the work—they just need systems that respect their time, reduce the chaos, and provide care when and where it's needed most.**

Respite Care and Individualized Skills and Socialization Services

In Texas, an estimated 300,000+ individuals serve as family caregivers for a loved one with IDD. Strikingly, only about 7% of those families receive any support from a state IDD program or agency. In other words, over 90% of families supporting someone with IDD in Texas do so with no state-funded in-home services or respite. This aligns with the large interest list – many families are waiting for help. It also reflects Texas's historical underfunding of community services; families shoulder most of the care. (Texas's Medicaid "waiver" programs for IDD serve roughly 34,000 people, plus another ~5,000 in intermediate care facilities and ~2,800 in state institutions, totaling around 40,000–45,000 receiving robust services – well under 7% of the estimated IDD population.)

The survey responses reveal a broad spectrum of experiences with individualized skills and socialization services (ISS) and respite care programs for individuals with intellectual and developmental disabilities (IDD). The feedback includes families who have found meaningful connection and support through programs and others who report significant barriers or concerns.

TABLE 15: **Where does your loved one live?**

At home with me	88.11%	200
In a Group Home	5.29%	12
In a Care Facility	0.44%	1
In a Foster Home	1.76%	4
They live independently	1.32%	3
Other (please specify)	3.08%	7
TOTAL		**227**

TABLE 16: **Has your loved one attended a dayhab/adult daycare program?**

Yes, and currently attending	57.14%	120
No, have no interest	27.14%	57
No, but currently on a wait list	15.71%	23
TOTAL		**210**

Families shoulder most of the care.

Open-ended Responses (n=75)

1. Access and Awareness Gaps

- Many families were unaware of ISS options until recently, or had never heard of them.
- Several respondents are interested but aren't yet enrolled or on waiting lists, especially for young adults still in school or aging out of educational services.
- Some parents said they just learned about programs but don't know how to access them.

Quotes:

"He's never attended one because this the first that we are hearing of this.

"Would love to get more information."

"There is not enough information out there. I just recently found out about this."

2. Limited Availability and Long Waitlists

- Several families noted months- or years-long waitlists, especially for adult dayhab programs like The Arc or SA Life Academy.
- Access is often restricted due to behavioral or medical complexity, with many programs unwilling to accept individuals with incontinence, aggressive behavior, or higher support needs.
- Several caregivers mentioned needing more frequent days of care but only being able to access one or two days a week due to staffing or cost.

Quotes:

"It is difficult finding a facility that will take adults with incontinence. Most facilities require that the adult is potty trained."

"Only have been able to get one day a week."

3. Program Quality and Safety Concerns

- Some families reported excellent experiences, especially with programs that provided enriched environments
- However, others cited serious concerns, including:
    - o Lack of trained staff to support severe behavioral needs
    - o Fear of abuse or neglect, especially where staff are underpaid or overworked
    - o Negative past experiences, including clients being kicked out or mistreated

Quotes:

"They are amazing with him, and he loves attending their program."

"I worry about the potential for abuse or neglect in day programs. I worry that positions might not be paid well, especially for the level of care and compassion that is needed."

4. Affordability and Funding Barriers

Many families rely on private pay due to limited state funding or long waits for Medicaid waiver services like HCS.

- Even when a dayhab is a good fit, cost limits access to just one day per week or prevents attendance entirely.
- Several respondents highlighted the need for greater state support, noting that Texas lags behind other states' funding and accessibility.

Quotes:

"Just found it. Private pay but worth it."

"She can only go one day of the week because the cost is far too high."

5. COVID Disruption and Transition Struggles

- Many individuals stopped attending dayhab during COVID and never returned due to safety concerns, shifting needs, or changes in program structure.
- Some families are now reconsidering dayhab as their loved one ages or as social opportunities dwindle post-pandemic.
- Others wait until their child finishes high school or an 18+ program before seeking adult care options.

Quotes:

"Attended a dayhab until Covid. Haven't gone back since."

"His Dayhabilitation closed during Covid and never reopened."

Standout Programs & Recommendations

- Some families advocated replicating integrated models from other states (like Washington) that blend arts, socialization, and broader community involvement, not just IDD-specific spaces.
- Families praised local program models that focus on community-based integration, structured programming, and experienced staff members
- Several respondents emphasized the need for more inclusive, flexible dayhabs that can handle complex behaviors, medical needs, and diverse levels of independence.

While some caregivers have found dayhab programs life-changing for their loved ones, many others face systemic barriers: lack of awareness, insufficient capacity, restrictive admission criteria, and unaffordable costs. There is strong interest in programs that offer social engagement, skill development, and compassionate care. Still, families consistently call for more flexibility, training, and state funding to ensure these programs can truly serve the full spectrum of people with IDD.

TABLE 17: **Do you have someone to help take care of your family member so you can take a break when you need it?**

Yes, I always have someone to help	18.48%	78
Yes, I sometimes have someone to help	47.16%	199
No, I do not have anyone to help	29.15%	123
I do not need a break	6.64%	28
TOTAL		**422**

Open-ended Responses (n=123)

The responses to this question provide a deeply personal and revealing look at the reality of caregiving for individuals with intellectual and developmental disabilities (IDD). They reflect a mix of resilience, burnout, gratitude, and systemic gaps in accessible support. Below are the major themes and key takeaways from the responses:

Major Themes

1. Reliance on Family Support

- Family members, including spouses, aging parents, siblings, and grandparents, are the most common sources of respite support.
- Many families alternate caregiving duties, with couples taking turns or older siblings helping when available.
- However, this support is often limited, inconsistent, or unreliable, and many caregivers expressed guilt or reluctance to ask for help due to others' life demands.

Quotes:

> "I do have a couple people who can help, but I don't feel 100% confident… especially when they aren't a medical professional."
>
> "Dad and I alternate."
>
> "We don't have family that is sober."
>
> "Only because of his group home. Otherwise, I would rarely have help."

2. Lack of Available or Appropriate Respite Providers

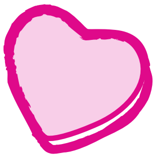
- Trained respite caregivers are challenging to find, especially for individuals with high behavioral or medical needs.
- Several respondents reported being denied services or forced to retrieve their loved one from a program due to behavior challenges.
- The current pay rate for respite care (around $10–11/hour) was frequently mentioned as a barrier to finding qualified, committed providers, especially when compared to less demanding jobs that pay more.

Quotes:

> "PROVIDER will say if any sort of aggression occurs, they'll call you to pick up. That's not appropriate nor safe respite care."
>
> "He's so physically abusive I'm scared he's going to really hurt one of us."
>
> "She has respite services approved but we don't have a qualified provider."
>
> "Chick-fil-A pays more than respite care, but respite has so much more responsibility."
>
> "I have a respite budget and can't find anyone to do the work."

3. Emotional and Physical Burnout

- Many caregivers expressed feeling overwhelmed, isolated, and physically exhausted, particularly those caring for individuals with severe behaviors or medical complexity.
- Some noted that they "rarely" get a break; when they do, it's too short or too infrequent to be restorative.
- Others voiced concern for the future, saying they don't know who will take over caregiving when they're too old or unwell.



Quotes:

> "I rarely go on vacation. If I do, I'm still available on the phone."
>
> "Most days feel overwhelming."
>
> "It's sometimes available… but the guilt of leaving him behind defeats the purpose."
>
> "It's just me and my husband and grandma. It's hard."

4. Systemic Barriers to Accessing Respite

- Even families with approved respite funding (e.g., CLASS, HCS) said they can't use it because no one is available to provide the care.
- Families often mentioned long waits, paperwork difficulties, and the burden of managing care even during supposed "breaks."
- Some programs were described as inflexible, with too many restrictions or inadequate hours to be truly helpful.

Quotes:

> "I waited 15 years to get CLASS respite."
>
> "Waiver respite doesn't even cover 50% of the cost."
>
> "We pay out of pocket, but it gets harder every year."

5. Pockets of Success & Community Support

- A few respondents found support through Respite Care of San Antonio, day, night, and weekend out services, and private caregivers (paid out of pocket).
- Others have benefited from dayhab programs, short-term camps, or Mother's Day out programs offered by local agencies or schools.
- Several respondents expressed deep gratitude for the limited support they receive and acknowledged that even small breaks can make a big difference.

Quotes:

> "Thanks to Respite Care my son can attend on weekends when needed so I am able to regroup and enjoy self-care."
>
> "We are thankfully very supported by close family. I don't know how we would do it without their support."

Respite care is a critical yet under-supported need for families caring for individuals with IDD. While some caregivers are supported by family or community programs, many are operating without any reliable help, leading to physical exhaustion, social isolation, and mental health challenges. Even when funding is available, the lack of qualified providers, inflexible systems, and low reimbursement rates make respite inaccessible to those who need it most.

Impact of Caregiving for Loved Ones with IDD on Employment

TABLE 18: **Has caring for your loved one made it hard for you to work or keep a job? (Select all that apply)**

It is hard to work and be a caregiver at the same time, but I still have my job	34.97%	135
I had to quit a job to care for my loved one	31.87%	123
I had to work fewer hours to take care of my loved one	23.32%	90
Taking care of my loved one has not changed my job	19.43%	75
Taking care of my loved one has made it harder to get a better job or promotion	17.10%	66
I said no to a new job because of caregiving	15.28%	59
TOTAL		**386**

Caring for a loved one with an intellectual or developmental disability (IDD) significantly impacts employment for many caregivers.[1] In Bexar County, families of individuals with IDD often face high out-of-pocket costs, reduced employment opportunities, and financial stress, especially given the long waits for public assistance programs. According to the AACOG needs assessment, disability-related health care costs in Texas total $56.7 billion per year, which averages to about $17,189 per person with a disability. Many of these costs eventually fall to families or caregivers, particularly while individuals are on waiting lists for Medicaid waivers or other supports. Medicaid waivers (such as the HCS or CLASS program in Texas) can cover expensive services like in-home attendants, therapies, and respite care – but as discussed below, the wait for these waivers is 10–15 years. In the meantime, even families with insurance often pay sizable expenses. For example, a parent might pay for private speech therapy or behavioral therapy because the child isn't yet receiving waiver services or school-based therapy is insufficient.[2] These costs can run hundreds or thousands of dollars per month, which is untenable for many.

Families without adequate resources sometimes must forgo recommended interventions, which can affect the child's progress. Additionally, many parents (often mothers) reduce work hours or leave the workforce to care for their child with IDD.[3] This loss of income compounds the economic strain. In Bexar County, the poverty statistics reflect this dynamic: households that include a person with a disability are more likely to have lower incomes.

According to survey data:

- Over one-third (34.97%) of respondents find balancing work and caregiving challenging, even though they remain employed.
- Nearly one-third (31.87%) had to quit a job entirely due to caregiving responsibilities, illustrating a substantial disruption to personal career paths.
- Approximately 23% have reduced their work hours to manage caregiving demands, reducing income and causing potential financial strain.
- 17.10% indicated that caregiving responsibilities hindered their career progression, making securing promotions or pursuing better job opportunities difficult.
- 15.28% have declined job offers explicitly because of caregiving obligations.

Only a small portion (19.43%) stated their job was unaffected by caregiving responsibilities, underscoring how prevalent employment disruptions are among caregivers.

Summary of Open-ended Responses (n=127)

Survey responses reveal the profound toll caregiving for a loved one with intellectual or developmental disabilities (IDD) takes on employment, careers, and financial stability. While a few respondents described fortunate flexibility or early retirement, most expressed deep frustration, exhaustion, and sacrifices made to prioritize care over career.

Major Themes

1. Quitting or Scaling Back Careers

- Many respondents quit their jobs entirely to care for their child or adult loved one, often after exhausting other options.
- Others took early retirement, shifted to part-time, or became stay-at-home caregivers due to their child's needs.
- Several people noted they had to leave careers they loved, delay professional goals, or abandon dreams of advancement.

Quotes:

"I had to halt my career or any plans to pursue a career to be at home for my son."

"I've been part time for a long time."

"I gave up my professional life to be a stay-at-home mother, and autism made it a full-time job."

2. Lack of Flexibility from Employers

- Families reported losing jobs when employers eliminated remote work or failed to accommodate their schedules.
- Those who kept jobs often felt trapped in positions with minimal flexibility because of the demands of caregiving.

Quotes:

> "My job has made it difficult for me to have flexible hours when I have to take him and pick him up from school."
>
> "Most employers seem to be quite rigid in scheduling. Minimal flexibility would drastically improve a parent's life."

3. Working Overnight, Freelance, or Self-Employment

- Some respondents found creative ways to stay employed by:
  - Working overnight shifts
  - Starting their own businesses
  - Taking low-paying, high-flexibility jobs
  - Becoming substitute teachers or gig workers for control over hours.

However, this often came at the cost of stability, benefits, and income.

Quotes:

> "I took low pay and high flexibility jobs."
>
> "Working from home through COVID gave me the flexibility I needed."

4. Financial Strain and One-Income Households

- Families frequently discussed the pressure of living on a single income, with one partner leaving the workforce.
- Several noted their inability to afford care or after-school support, further limiting work options.

Quotes:

> "We only have one income now; spouse stays home with child while I work."
>
> "More time off, sick days, or doctor appointments would help."

5. Systemic Gaps and Policy Recommendations

- Respondents called for better job protection, caregiver pay, and remote/hybrid work opportunities.
- There is strong interest in policy change that would allow parents to be paid caregivers, increase access to after-school care for teens, and provide more respite and flexible services.

Quotes:

> "You can't work and take care of your loved one. It's too hard."
>
> "It would be so much easier on families if parents could get paid to be caregivers."
>
> "This community needs case managers who help families proactively instead of waiting to be asked."

Recommendations

1. Expand paid family caregiving models to allow parents to remain financially stable while providing full-time care.
2. Promote remote and flexible job options, especially for caregivers.
3. Enhance after-school and adult day programs, particularly for teens and adults with complex needs.
4. Increase awareness of support programs—many families are unaware of what services exist or how to access them.
5. Improve employer training around caregiving challenges and the need for schedule flexibility.

These data underscore the profound economic and professional sacrifices caregivers regularly face, highlighting a critical need for policies and services, such as flexible working arrangements, respite care, and supportive employer practices, to alleviate these significant employment barriers.

Caring for a loved one with IDD doesn't end when the school day does—and for many, it means saying goodbye to professional goals, social life, and financial stability. This data powerfully illustrates why policies, workplace culture, and community systems must adapt to better support caregivers. Their labor is essential, yet often invisible, and it's time we change that.

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[1] Shahat, A. R. S., & Greco, G. (2021). The economic costs of childhood disability: a literature review. International journal of environmental research and public health, 18(7), 3531.

[2] Morris, Z. A., McGarity, S. V., Goodman, N., & Zaidi, A. (2022). The extra costs associated with living with a disability in the United States. Journal of Disability Policy Studies, 33(3), 158-167.

[3] Maestas, N., Messel, M., & Truskinovsky, Y. (2024). Caregiving and labor supply: New evidence from administrative data. Journal of Labor Economics, 42(S1), S183-S218.

Priorities for Loved Ones

"Which of the following is most important to you?"

This data reflects a ranked selection of the services or supports most important to caregivers and families of individuals with intellectual and developmental disabilities (IDD). Respondents were asked to rank nine service categories.

TABLE 19: **Which of the following is most important to you?**

	1	2	3	4	5	6	7	8	9	TOTAL
Qualified case management by a trained person helps someone with special needs get the services and support they need	48	18	36	22	31	22	18	19	12	**226**
Access to medical care for my loved one	44	23	26	25	24	24	23	19	18	**226**
Opportunities for social interaction for my loved one	33	40	34	40	20	18	16	16	9	**226**
Dayhab opportunities for my loved one	32	33	30	31	29	17	17	13	24	**226**
Job Opportunities for my loved one	22	21	11	17	25	21	24	35	50	**226**
Supportive Independent Housing for my loved one	15	22	24	28	23	30	23	31	30	**226**
Access to medical equipment and medication	11	26	22	18	28	24	24	38	35	**226**
Assistance with basic needs like clothing, food, and housing	11	23	21	21	18	33	48	24	27	**226**
Access to mental health support for my loved one	10	20	22	24	28	37	33	31	21	**226**

> **"I had to halt my career or any plans to pursue a career to be at home for my son."**

1. Qualified Case Management

- Most frequently selected as #1 priority (21.24% / 48 votes)
- Strong rankings across the board (15.93% selected it as their #3 choice)
- It reflects families' values regarding professional help in navigating systems, accessing benefits, and coordinating care.

Families are overwhelmed by fragmented systems and want expert guidance from someone who can connect them to the proper supports.

2. Access to Medical Care

- Second highest #1 ranking (19.47% / 44 votes)
- Frequently ranked in the top 3 (41.15% of all respondents placed it in their top 3)
- Medical needs remain a foundational concern, especially for families with medically fragile loved ones.
  Consistent access to primary and specialized healthcare is critical, particularly in navigating complex disability-related care.

3. Opportunities for Social Interaction

- Highly ranked across the board (17.70% each as a 2nd and 4th choice)
- More than 50% of respondents placed this in their top 4
- Signals concern for quality of life, isolation, and friendship, particularly as youth with IDD transition to adulthood.

Families want their loved ones to have meaningful relationships, community belonging, and engagement, not just care.

> Families want their loved ones to have meaningful relationships, community belonging, and engagement, not just care.

Other Notable Priorities

Dayhab Opportunities

- Consistently present in the top 5 for most respondents
- 32 people (14.16%) selected it as their top choice
- Reflects demand for structured daytime programs, especially post-high school

Job Opportunities

- Rises significantly in later rankings—most chosen 9th ranking
- 50 respondents placed it as their 9th choice (22.12%)
- Indicates long-term goals—important, but often takes a backseat to more urgent medical or daily care needs

Lower-Ranked but Still Significant Concerns

- Access to Mental Health Support: Ranked lower as a top priority but climbs in mid-level rankings (#6–#8)
- Medical Equipment & Medication: Few chose this as a top concern, but it becomes more important in later choices (possibly because it's already partially met for many)
- Basic Needs Support (Food, Clothing, Housing): High #7 priority (21.24%), signaling economic strain for some families, but not universally top of mind

Do You Have a Plan for Future Care or Services When Your Child Becomes an Adult?

The responses to this question reveal a widespread sense of uncertainty, frustration, and fear among caregivers planning for the future of their loved ones with intellectual and developmental disabilities (IDD). While a few families have formal plans or are connected to resources, most are either just beginning the process, stuck on waitlists, or overwhelmed by a lack of guidance and support.

TABLE 20: **Does your family have the following legal documents for your loved one...**		
Legal Guardianship	54.42%	123
Medical Power of Attorney	26.11%	59
None of the above	22.57%	51
Other (please specify)	12.83%	29
Healthcare Proxy	10.62%	24
TOTAL		**226**

TABLE 21: **Do you have a plan for future care services when your child becomes an adult?**		
Maybe. I have some ideas, but nothing concrete.	51.29%	139
No. No one has ever discussed with me what I need to do to prepare for my child becoming an adult.	32.47%	88
Yes, I've worked with service providers to put a plan in place for my child when they turn 18.	16.24%	44
TOTAL		**271**

Summary of Open-Ended Responses (n=40)

1. Waitlists Dominate the Planning Process

- Many caregivers mentioned being on long waitlists—some for Medicaid waivers (like CLASS or STAR+PLUS) and others for services like daycare or residential options.
- There is a strong sense of anxiety and helplessness as families wait years for services, often with no guarantee they'll be available when needed.

Quotes:

"Wait lists are so long... Children not even close to adulthood have to be placed on the list in hopes they can receive services."

"My son is registered with AACOG but is on a waitlist, so nothing is concrete."

"I am on waitlists, but can't recall what the names are."

2.Lack of Clear Guidance and Information

- Families consistently reported confusion about how and when to begin transition planning.
- Some rely on school Admission, Review, Dismissal, and Individualized Education Plan (ARD/IEP) meetings to initiate discussions, but others say they had to bring it up.
- Many don't know what steps to take or whether their child qualifies for services.

Quotes:

"No one has really told me what to expect or how to help him."

"We need more assistance with getting the word out about programs that can assist families."

"I'm really confused where to even start."

3.Families Anticipate Lifelong Caregiving

- Several respondents stated they expect their child to live with them permanently, either because of care needs or lack of other safe options.
- The emotional toll of not knowing what happens "after forever" was a recurring theme.

Quotes:

"My husband and I know he'll live with us forever, but we're just not sure what happens when forever ends."

"He will stay home with me."

"There are very few options for someone to live safely with only Social Security income."

4. Some Families Are Making Plans—but with Limits

- A handful of families mentioned pursuing power of attorney, enrolling in 18+ high school programs, or working with navigators to explore adult services.
- Others are taking creative steps, such as starting nonprofits or planning for college-based programs.

Quotes:

"The 18+ program at the high school is our plan for now."

"Starting a nonprofit to hopefully create a living community for our daughter and her friends."

"My son should be enrolled in a college program… to earn an associate's degree."

5.Overwhelmed Parents with Young Children

- For families of younger children, especially those under age 5, the idea of future planning feels daunting or premature, though many are still placed on waitlists early.

Quotes:

"My child is only 3."

"She is too young to have those things completely implemented."

"We are just too far away from that age right now."

Recommendations

1. Strengthen and expand transition support in schools, especially by age 14, and require ARD/IEP teams to initiate future planning conversations early.
2. Create centralized navigation hubs where families can get help understanding programs, applying for services, and developing long-term plans.
3. Expand waiver slots and simplify eligibility pathways so families aren't left navigating years-long waitlists in isolation.
4. Increase public awareness about future planning tools, such as power of attorney, supported decision-making, and adult guardianship.
5. Invest in family-led innovations, such as housing co-ops or community-based adult day programs, that give caregivers more control over their child's future.

For many families, planning for adulthood feels like entering a fog with no map. They want to do right by their loved ones, but they're forced to piece together a fragmented system on their own. This data is a call to action: families need better information, stronger systems, and the confidence that their child will not be forgotten once they age out of school-based services.

Training Needs

Families of individuals with IDD are navigating systems that are fragmented, confusing, and often unresponsive—yet they continue to show up with courage, resilience, and determination. In response to the question, "What training would help you navigate your family's situation?" caregivers overwhelmingly asked for more than just information—they asked for tools, connection, and empowerment. Their voices reveal a community that is ready to lead but urgently needs accessible, coordinated support. Families overwhelmingly requested training on navigating early intervention and understanding what supports exist for children under 3. A frequent theme was confusion around eligibility, rights, and what should trigger an ECI referral. This is not just a call for more resources but a call to action. We must listen to the lived experience of families, honor their expertise, and co-create solutions that are equitable, person-centered, and grounded in dignity.

Open Ended Responses (n=379)

1. Navigating Systems and Services

Families expressed deep frustration with the complexity, fragmentation, and opacity of systems meant to support individuals with disabilities. There is a strong desire for practical, step-by-step guidance on accessing services, understanding eligibility requirements, and communicating effectively with government bureaucracies.

Common Needs:

- How to apply for Medicaid, SSI/SSDI, and waiver programs
- Understanding insurance processes (HMO, PPO, CHIP)
- Knowing what to do at each life stage (birth to adulthood)
- "One-stop shop" training with all available resources in one place

Quotes:

"How to navigate the system and knowing where to begin."
"Training on how waiver programs work."
"What to apply for. First steps, follow-ups, trainings, events."
"How to navigate Medicaid and Social Security."

2. Planning for Adulthood and the Future

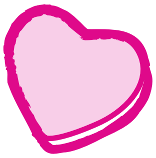
Many caregivers are anxious about the future, especially as their children transition to adulthood. They need guidance on housing, legal guardianship, financial planning, and independent living options.

Common Needs:

- Guardianship vs. alternatives like Power Of Attorney
- Special Needs Trusts, Achieving a Better Life Experience (ABLE) accounts
- Transition services post–high school
- Residential and day programs for adults

Quotes:

“What would happen to my daughter when I’m no longer here?”
“Planning for high school, adulthood.”
“Guardianship, setting up an ABLE account.”
“Understanding long-term housing for the future needs of our adult child.”



3. Behavioral and Emotional Support

Families want hands-on strategies for managing challenging behaviors, anxiety, and communication barriers, both for their children and themselves. They also emphasized the emotional toll of caregiving and the need for caregiver mental health support.

Common Needs:

- Behavior intervention strategies
- Managing meltdowns and aggressive behaviors
- Support groups and therapy for caregivers
- Coping tools beyond generic “self-care”

Quotes:

“Self-regulation skills for us caregivers… not just social media strategies of self-care.”
“Managing my daughter’s aggressiveness and anxiety.”
“How to cope with kids with IDD or Autism.”
“Therapy for my daughter and myself. Tips and tricks for everyday battles.”

4. Advocacy and Legal Training

Families feel unprepared to advocate effectively for their child’s school, healthcare, and government rights. They need training in legal rights, IEP processes, and how to engage with policymakers.

Common Needs:

- IEP/504 and education advocacy
- Legal planning and rights for adults with IDD
- Legislative advocacy and civic engagement
- Understanding protections under FAPE and ADA

Quotes:

“Breakdown of IEPs and how to advocate for your child.”
“Political engagement and activism.”
“How to successfully submit information to government officials who work on the Senate and House floor.”
“Legal advice for guardianship and setting up a special needs trust.”

5. Employment, Socialization, and Life Skills

There is a strong desire for training that supports real-world skills, such as job readiness, social engagement, and independent living, especially among teens and adults with disabilities.

Common Needs:

- Job training and placement support
- Social skills and community inclusion
- Daily living skills like budgeting, shopping, and transportation
- Flexible employment for caregivers

Quotes:

“Job training.”
“Options for after high school learning or job readiness, training for daily adult life.”
“How to teach skills like grocery shopping, etc.”
“Finding social opportunities and independent living skills.”

This feedback reveals clear priorities: simplify access to services, plan for the future with confidence, support the mental health and advocacy skills of families, and build meaningful pathways for adulthood. As a community, we can rise to meet these needs by investing in cross-sector collaboration, offering consistent and accessible training (including virtual and bilingual options), and establishing a centralized, family-friendly hub for information and navigation support. We must also build the capacity of schools, healthcare providers, employers, and community organizations to be true partners in this effort. The next step is to convene families, providers, and system leaders in shared problem-solving, ensuring that families are not just recipients of support but leaders in designing it. Together, we can shift from surviving the system to transforming it.

Highlights: Community Excellence

While there are many challenges with our current system, families were also equally passionate about the programs that work well and provided essential support. When caregivers were asked, "What is working well in our system? What organizations or people deserve a shout-out?", families repeatedly recognized organizations and individuals demonstrating outstanding commitment, compassion, and efficacy in supporting individuals with IDD and their families. Caregivers expressed deep gratitude for dedicated professionals, effective service coordination, impactful nonprofit organizations, and programs that foster inclusion and socialization.

1. Appreciation for Dedicated Organizations and Programs

Caregivers frequently praised local nonprofit organizations and specialized programs that consistently delivered critical support services and created inclusive, affirming spaces.

Quotes:

> “Respite care is such an amazing facility…This is the only place I trust with my son."
>
> "SA Life Academy is AMAZING and the best place that we have ever found!"
>
> "The MAC is fantastic! Took a long time to get an intake interview, but the resources are amazing."

2. Recognition of Exceptional Individual Professionals

Many respondents specifically acknowledged navigators, therapists, doctors, and educators who significantly impacted their family's experience through compassion and dedication.

Quotes:

> "Sandra Montoya at the MAC is wonderful, Dr. Svoboda has been amazing!"
>
> "Principal Lawrence Carranco from Hobby Middle School…requested staff training to mitigate miscommunication for neurodivergent students."
>
> "My navigator has been instrumental in helping me get things I need for my loved one."

3. Effective Resource Coordination and Navigation

Families valued organizations that effectively coordinated complex services and helped caregivers navigate the system more smoothly, specifically highlighting the Multi-Assistance Center (MAC), AACOG, and Any Baby Can.

Quotes:

> "AACOG has been helpful. The Arc on West Ave has been 'her place' for 14 years now and she loves it!"
>
> "The MAC Navigator has guided me to supports I did not know existed."
>
> "AACOG and Medicaid and HCS Medicaid waiver program."

4. Impactful Educational and School-Based Supports

Caregivers praised specific schools and educational programs that offered tailored, inclusive education and effective special education services.

Quotes:

> "Nellie Reddix Center, Brighton Center, Any Baby Can, MAC—amazing programs!"
>
> "All of the dyslexia and special Ed services at Roan Forrest Elementary in NEISD are outstanding."
>
> "Ed White Middle School special education department has been excellent."

5. Inclusive Recreational and Social Opportunities

Families greatly appreciated community efforts that created inclusive recreational and social activities, naming Kinetic Kids, Morgan’s Wonderland, Camp Camp, and Eva’s Heroes among others.

Quotes:

> "Special Reach, Eva’s Heroes, and Morgan’s Wonderland—amazing recreational programs!"
>
> "The people who organize Special Olympics…The people who work at the MAC."
>
> "Kinetic Kids! Action Behavior Centers! Morgan's Wonderland."

The responses underscore community gratitude toward several critical assets and individuals dedicated to improving the lives of people with IDD and their families. Organizations such as the Multi-Assistance Center (MAC), AACOG, San Antonio Life Academy, and The Arc of San Antonio, as well as various specialized recreational programs, repeatedly emerged as essential resources for support and advocacy. Additionally, numerous professionals were individually recognized for their exceptional service and dedication. These highlighted strengths illustrate that while gaps remain, substantial community resources and compassionate professionals provide foundational support and enhance families' quality of life, offering models for continued improvement and expansion of services.

Policy Implications

Several federal actions since 2022 have reduced or redirected funding for IDD services and special education, with downstream effects on state and local programs:

- Chronic Underfunding of IDEA and Proposed Cuts: The federal government has consistently failed to meet its commitment to fund 40% of the excess costs of special education under the IDEA. Current federal funding covers less than 13% of these costs, forcing states and school districts to absorb shortfalls. This chronic underfunding has led to gaps in services – students with disabilities lose access to therapies, face larger class sizes, and have limited assistive technology, harming educational outcomes. In 2023, concerns grew as Congress debated steep cuts for FY2024: a House proposal threatened an additional 20% reduction in IDEA funding, which advocacy groups warned would be a "severe disservice" to children with disabilities. Although final budgets averted the most drastic cuts, the climate of fiscal austerity at the federal level has constrained resources for special education. The new administration has also promised significant changes to both federal funding and the location of special education services within the federal government, proposing to relocate Special Education from the Department of Education to the Department of Health and Human Services.

- Stalled Federal Support for Newborn Screening: Federal funds that support state newborn screening programs – critical for early diagnosis of developmental disorders and rare conditions – have been delayed due to legislative gridlock. The Newborn Screening Saves Lives Reauthorization Act, which historically provided millions to state programs, has been held up in Congress.. As a result, a "huge chunk of funding" has been kept out of state hands, limiting states' ability to keep up with new tests. This occurs when more conditions are recommended for screening, placing a strain on state labs. Newborn screening programs, which test infants' blood spot cards for treatable conditions, are feeling the pinch – many state labs report staff shortages, outdated equipment, and inability to expand without the expected federal aid. On April 3, 2025, the Trump Administration eliminated the Advisory Committee on Heritable Disorders in Newborns and Children, which sets the standards for inclusion of screening for diseases in newborns. This recent development is very worrisome for the continued support of crucial newborn screening efforts.

- Expiration of COVID-19 Relief Measures: Temporary federal funding boosts during the COVID-19 emergency have lapsed, effectively reducing resources for disability services. Notably, the American Rescue Plan Act (ARPA) provided a 10-percentage-point increase in the federal Medicaid match for home- and community-based services (HCBS, including IDD waivers) from 2021 to 2022, with states required to reinvest savings into service improvements. Texas and other states used much of this one-time funding for workforce recruitment, retention, and training initiatives in IDD services. However, these ARPA funds are ending by 2025, removing over $37 billion nationally allocated to bolster HCBS. The most extensive use of these funds, which provided wage increases and bonuses, temporarily addressed staffing shortages. As the federal boost expires, states face difficulty sustaining enhanced caregiver pay and programs, raising concern that workforce shortages will worsen again. This could roll back gains in service capacity (e.g., fewer respite or dayhabilitation providers if supplemental payments vanish).

Disability-related health care costs in Texas total $56.7 billion per year, which averages to about $17,189 per person with a disability. Many of these costs eventually fall to families or caregivers, particularly while individuals are on waiting lists for Medicaid waivers or other supports.

Texas State Policy Actions Impacting IDD Services and Education

In Texas, a combination of executive decisions, budgetary allocations, and agency actions in recent years has significantly influenced the funding and capacity of IDD services and special education:

- Diversion of Health and Disability Funds to Other Priorities: In 2022, the state redirected substantial funds away from health and human services to support other initiatives. Governor Greg Abbott ordered over $200 million to be taken from the Texas Health and Human Services Commission (HHSC) budget (along with tens of millions from the Department of State Health Services) to finance "Operation Lone Star," a border security program. This mid-biennium reallocation reduced the resources available for HHSC programs, including Medicaid waiver services, mental health services, and public health services. While state leaders claimed this would not affect agency functions, advocates noted that such transfers delay or downsize planned program expansions. The diversion effectively reduced funding available for disability services, contributing to ongoing waitlist growth and under-resourced community programs.

- Limited Investment in Medicaid Waiver Slots (Waitlist Growth): Texas has long had the nation's largest waiting lists for IDD Medicaid waivers, and recent budgets have only marginally improved the situation. As of December 2022, about 160,000 individuals were on Texas interest lists for IDD community support waivers. The average wait for someone joining the list is estimated at 27 years at the current placement rate – essentially, a waiting period so long that many families see no relief. In 2021 and 2023, the Texas Legislature approved small increases in waiver slots (~1,500 to ~1,800 new slots each biennium). This represents less than a 1% annual reduction in the waiting list, far outpaced by new applicants yearly. Texas's funding for HCBS waivers has not kept up with demand, and the interest list continues to swell. This policy choice – funding only a fraction of needed services – directly contributes to the long delays families reported in the survey (e.g., 6–12+ month waits for therapy or day programs). Many are left waiting for years with no services or minimal state support until a waiver slot becomes available.

- Cuts to Special Education Medicaid Funds (SHARS Program): In 2023–2024, an administrative policy change dramatically reduced federal funding to Texas schools for special education services. The HHSC imposed stricter limits on reimbursements in the School Health and Related Services (SHARS) program, which provides Medicaid funds to school districts for therapy, nursing, and other services for students with disabilities. As a result, Texas is now slashing roughly $607 million per year from what schools typically receive for special education via SHARS. School officials report that this sudden cut in funding has worsened already-strained special education budgets, harming their ability to recruit and retain critical staff like speech therapists, counselors, and aides. The state has pointed to federal audit findings to justify tighter billing rules. Still, the scale of the reduction (over half a billion dollars annually) far exceeds the small portion identified as problematic. This redirection of funds away from local districts effectively leaves schools to either cover the gap with their limited resources or reduce services for students with disabilities. The timing (2024) means many districts are now facing tough choices potentially increasing caseloads, delaying services, or cutting positions, directly impacting the support kids receive in special education.

- Early Childhood Intervention (ECI) Funding Struggles: Texas's ECI program (serving infants and toddlers with developmental delays) has experienced persistent underfunding. Even as need grows, state funding has been inconsistent. Advocates note that maintaining ECI funding levels is "always a struggle" in the Texas budget. The Texas Legislature's 2025 session brought renewed attention to ECI's funding and structure. In the state budget process, lawmakers acknowledged the need to bolster ECI resources. The introduced House budget (HB 1) included an additional $18 million (Exceptional Item #5 in HHSC's request) to fund projected ECI caseload growth of ~3.5% over the next two years. This $18 million appropriation is essential to keep up with rising enrollment, ensuring that per-child funding does not erode further. (Without it, due to growing enrollment, the average state funding per child would have dropped from about $452 in FY2025 to $424 in the 2026–27 biennium, according to Texans Care for Children. While this funding is a positive step, it is considered only a first step. Advocates note that even with the caseload adjustment, Texas ECI funding has not been restored to its earlier levels, adjusted for inflation. They have called for additional investments, such as a 6% rate increase for ECI therapy services (to begin catching up on the decade of stagnant reimbursement rates) and a boost in base funding per child. These recommendations were prominent in committee testimony in early 2025, where experts warned that "chronic underfunding threatens the quality and availability" of ECI services if not addressed. On the policy side, the 2025 Legislature also considered structural improvements to integrate ECI with other early childhood programs better. House Bill 2310 (89th Legislature) directs state agencies to create a strategic plan for improving early learning opportunities for young children with disabilities.[1] HB 2310 addresses long-standing coordination gaps: currently, three separate agencies serve overlapping populations (ECI under the Health and Human Services agency, public pre-K and Early Childhood Special Education under the Education Agency, and subsidized childcare under the Workforce Commission). These siloed systems often fail to communicate, causing difficulties for families as their child transitions from ECI to school services at age 3 or attempts to access inclusive childcare. The bill would require a multi-agency strategic plan to identify barriers to inclusion and coordinate efforts across ECI, preschool special education, and childcare. For example, it calls for strategies to ensure children with disabilities can participate in regular pre-K or daycare, and to smooth the hand-off when toddlers "age out" of ECI at 36 months. Advocates like The Arc of Texas have praised HB 2310, stating that a coordinated plan will be "a significant step forward in ensuring that all children in Texas have access to a strong early educational foundation" and that it will help remove systemic barriers to inclusion.[2] As of May 2025, HB 2310 was moving through the legislative process, reflecting a broader legislative recognition that ECI cannot operate in isolation; it must be linked with broader early childhood and disability policy. Additionally, the Legislature has been examining ECI eligibility rules; while no major eligibility expansion has passed yet in 2025, there is awareness that prior cuts (e.g., narrowing the developmental delay criteria in 2011) excluded some children who could benefit. Any future changes will likely aim to balance reaching more children earlier versus the program's resource constraints.

- Workforce Crisis in Community Services: A less explicit but profoundly important policy factor is the state's low reimbursement rates for IDD services, which have contributed to a workforce crisis. Provider agencies in Texas struggle to hire and retain direct support professionals (DSPs) – the caregivers who staff dayhabilitation programs, respite care, and group homes – because wages funded by Medicaid rates are very low. Even after a modest rate increase in late 2023 (bringing base pay to roughly $10.60/hour for many community DSPs), nearly one-third of frontline positions remain vacant. Since 2021, vacancy rates for group home staff have climbed from 30% to 33–34% by 2024. These shortages have forced providers to take drastic measures: 43% of Texas community-based group home providers reported permanently closing some homes, and nearly half are not accepting new referrals. Many agencies frequently cannot offer respite or day program slots because they lack the staff to serve more individuals. This trend results from policy choices – stagnant provider rates that do not match market wages, and no state-funded programs to supplement caregiver pay – and it directly causes the "severely under-resourced" respite and dayhab landscape families described. In practice, the workforce gap means even authorized services go unused: families eligible for respite or day programs often sit on internal waitlists or are turned away due to a lack of capacity. The state's recent moves to raise rates slightly and consider new managed care models for IDD (scheduled for future years) acknowledge the issue. Still, from 2022 to 2025, the crisis has only deepened, jeopardizing the availability of community-based care.

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[1] tcdd.texas.govtcdd.texas.gov

[2] Texas Council for Developmental Disabilities

"I want to make sure she is taken care of. And I don't know how to make that happen."

Impacts on Access to Care and Resources for Individuals with IDD

The cumulative impact of these federal and state policy actions has been to strain the IDD service system, reinforcing many challenges identified by the Community Champions survey:

- Reduced Service Capacity: Funding shortfalls and workforce crises have translated to fewer service options. Providers facing budget cuts (e.g., school programs losing SHARS funds, or Medicaid providers unable to pay competitive wages) have scaled back offerings. Families report that even when they become eligible for a service, it may not exist in practice. For example, a dayhabilitation program might nominally be available but has no open slots or cannot handle higher-need individuals due to staffing limitations. The survey found that one-third of caregivers have no one to help them take a break, and even those with theoretical respite benefits often cannot utilize them. This aligns with statewide trends: dozens of community group homes and respite facilities have closed or capped admissions in the past two years because they cannot hire enough staff. Service capacity has not kept pace with need, especially in adult services and rural areas, leaving families with dwindling respite or day program options.

- Longer Waitlists and Delays: Both federal and Texas policy choices have contributed to growing wait times for support. In Texas, the minimal growth in waiver slots amid surging demand means interest list wait times have only increased, now measured in decades for many. Federally, the end of extra HCBS funds and uncertainty around future funding mean states are cautious to expand programs. The result for families is prolonged waiting at every stage: waiting for diagnosis (if ECI or screening programs were slow to respond due to under-resourcing), waiting for school supports (as districts triage limited special ed staff), and waiting for adult services (as waiver lists and provider backlogs grow). Our finding that waits of 6–12 months or more are the norm for therapies and medical care likely reflects provider scheduling issues and systemic backlogs exacerbated by funding constraints. Notably, early diagnosis programs have been affected, with newborn screening expansion stalled; some infants in Texas may not be screened for newer conditions that other states catch, potentially delaying critical early interventions. Likewise, capacity issues in ECI can delay evaluations; several respondents in open-ended answers described knowing something was wrong but having to push for months to get services. These delays can worsen outcomes, as developmental therapies are most effective when begun early.

- Diminished Access to Special Education Resources: The squeeze on funding for special education at both federal and state levels has immediate consequences in the classroom. Texas school districts, dealing with the $600+ million annual cut in Medicaid reimbursements, are warning of having to cut staff or programs for students with disabilities. This comes on top of federal underfunding that already left a $1.7 billion gap for Texas schools (the amount state/local funds must cover due to federal IDEA shortfall). The Texas legislature recently passed, and Governor Abbott signed into law, school vouchers. It is unclear how vouchers will impact schools, but there is little doubt they will continue exacerbating the existing budget crisis. These abstract budget issues are very real limitations for students and families: fewer paraprofessionals to provide inclusion support, longer waits for evaluations or therapy services in school, and limited availability of specialized placements. The survey's indication that coordination between service providers is often "not at all" effective may be aggravated by schools being understaffed and unable to participate fully in inter-agency coordination. Access to appropriate education for IDD students becomes a postcode lottery – families with means might supplement with private services. In contrast, others must make do with whatever the under-resourced public system can offer.

- Strain on Families (Caregiver Burnout and Economic Impact): All these policy-driven gaps ultimately push more responsibility onto families, who become the safety net of last resort. When formal services are cut or waitlisted, parents and caregivers must fill the void. The survey documented that "families are the system," coordinating care independently and often sacrificing employment. Reduced public funding deepens this dynamic: for instance, if a school can't provide adequate therapy, a parent might reduce work hours to transport their child to outside appointments; if respite care isn't available, the family never gets a break, increasing burnout. Several recent national studies have quantified the economic toll – caregivers of people with disabilities have higher rates of job loss and financial strain, which the survey echoed (32% quit a job due to caregiving). Policy lapses like failing to reauthorize caregiver support programs or not expanding family support grants mean families receive little relief. The mental and physical health of caregivers is thus impacted: many are operating with chronic stress and exhaustion, which in turn can affect the stability of care for the IDD individual. In short, the policy environment often forced families to carry an even heavier load, precisely at a time when pandemic recovery funds and innovative strategies could have been used to lighten it.

- Geographic and Demographic Disparities: The effects of funding cuts and policy inaction are not felt evenly. Typically, those in rural areas or those needing specialized services (e.g., severe behavioral support) suffer the most when resources are scarce. These programs often cut first or last to be expanded. For example, if a state doesn't fund enough waiver slots, rural regions might get very few of them, meaning virtually no services outside metro areas. Texas's choices have likely widened disparities: specific communities (like Bexar County, as highlighted in this report) are trying to compensate through local collaboration, but others may lack such capacity. Federally, the delay in uniform newborn screening recommendations means a baby's chance at early detection of an IDD-related condition can depend on their state of birth. Without robust federal support, state-by-state variability increases. All of this reinforces inequitable access to care – a theme the survey respondents noted, with services highly "dependent on privilege" (those with time, money, or knowledge can navigate the maze better). Recent policy shifts have unfortunately not yet reversed that inequity; in some cases, they intensified it by requiring families to fend for themselves when public systems contract.

Caregivers of people with disabilities have higher rates of job loss and financial strain, which the survey echoed (32% quit a job due to caregiving). Policy lapses like failing to reauthorize caregiver support programs or not expanding family support grants mean families receive little relief.

The recent policy landscape has often undermined the IDD service infrastructure when demand and costs are rising. The impacts – waitlists, provider shortages, caregiver burnout, and lost opportunities for early help – are acutely felt by individuals with IDD and their families in Texas. These challenges form the backdrop for the community's priorities and serve as a call to action. They also highlight areas where strategic changes and advocacy could make a difference. For example:

1. Advocate for the Restoration and Expansion of Funding: Policymakers at both the state and federal levels should work to increase investment in IDD services. Plugging funding gaps must be a top priority. For example, the community should support efforts like the IDEA Full Funding Act (to raise federal special education support from ~13% toward the promised 40%) and call on Congress to fully reauthorize and fund the newborn screening programs, allowing Texas to implement the latest tests without delay. At the state level, advocacy should focus on substantially reducing waiver waitlists by funding more slots. Rather than incremental increases of <2,000 slots (which yield <1% annual impact), Texas should allocate a larger sum (e.g., tens of thousands of slots) to cut the 27-year wait meaningfully. Texas HHSC and the legislature should work to reverse harmful funding decisions – for instance, reevaluating the SHARS policy so that school districts are not left without $600M for special education services. Collaboratively, local IDD champions, school officials, and families can present a unified case that demonstrates how these funds directly impact children's daily support and long-term outcomes. In summary, assertive advocacy for funding restoration (in education, ECI, Medicaid waivers, and other programs) is necessary to ensure that families are not left to bear an unfair burden.

2. Strengthen the Direct Care Workforce through Policy and Partnerships: To address the severe provider shortage, pursue strategies that improve workforce recruitment, retention, and compensation. National best practices suggest adequate wages and training for direct support professionals (DSPs) are key to service quality. All caregivers should be paid a living wage. Texas can leverage the new CMS "Access Rule," which will require states to set transparent rate floors for HCBS and direct more funding to worker pay, as an opportunity to raise DSP wages significantly (e.g., aiming for $15/hour or higher instead of $10–11). Locally, we can explore partnerships with workforce development boards or community colleges to create DSP training pipelines, making attracting workers into the IDD field easier.

Locally, The Arc of San Antonio actively advocates for increased reimbursement rates for Direct Support Professionals (DSPs), recognizing that a stable, compensated workforce is essential to a strong foundation for IDD services. We have met with numerous elected officials across both chambers of the Texas Legislature to elevate awareness of the unique needs of individuals with intellectual and developmental disabilities (IDD) and the critical role DSPs play in their daily lives. Our advocacy has included oral testimony at the Senate Finance Committee and written testimony to the House of Representatives, urging the state to raise the Medicaid reimbursement rate to a sustainable $17.50 per hour. At the current rate of $10.60, Texas is undercutting the workforce that supports some of our state's most vulnerable citizens, leading to high vacancy rates, facility closures, and caregiver burnout.

Recognizing that systems change takes time, The Arc understands this work is a marathon, not a sprint. In collaboration with The Arc of Texas, The Arc of San Antonio has hosted two "Tours of Texas." offering legislators, staffers, and community leaders a firsthand look at the vital services provided to adults with IDD through Individualized Skills and Socialization (ISS) programs. These tours and conversations have helped humanize the data, showing how appropriate funding allows adults with IDD to thrive and family caregivers to remain in the workforce. Supported by strong data from a study from Dr. Steven R. Nivin, Chair of the Economics Department at St. Mary's University and our operations, the message is clear: investing in DSP wages is not only a moral obligation but an economic necessity that delivers a 106% return on investment to the State of Texas. Through these efforts, The Arc continues to push for the policy changes necessary to build a more sustainable, equitable system for Texans with IDD and their families.

Offering credentialing programs, career ladders, or tuition support for DSPs can professionalize the field and reduce turnover (several states have done this via apprenticeships or Medicaid-funded training stipends). A stable workforce directly correlates with reduced waitlists and better care (as evidenced by the closures and crises in the report). The bottom line is that improving pay, training, and career support for those who care for individuals with IDD will increase provider capacity and allow families to use the respite, dayhab, and other services they desperately need.

Expand Access to Respite and Dayhabilitation Services (Implement Lifespan Respite Models): Caregivers identified respite and day programs as severely under-resourced areas. To improve this, Bexar County can look to best-practice models from other states that have successfully broadened respite access. One recommendation is to develop a "lifespan respite" program in Bexar County or Texas-wide. This coordinated system pools funding streams to provide respite vouchers or services across age groups and disability types. Federal grants via the Lifespan Respite Care Program (administered by the Administration for Community Living, ACL) exist, and Texas can pursue these to jump-start local respite coalitions. However, it is unclear how recent federal shifts in priority will impact these programs. Innovative respite models – such as paid family caregiving (offering stipends to family members or trusted friends to provide respite care), or rotating cooperative respite (families banding together to relieve each other with support from professionals) – could be explored with or without federal funding. Bexar County could look to pilot inclusive community-based programs that follow models like those in Washington state (blending arts, social, and vocational activities in an integrated setting. It is crucial to increase respite and dayhab availability through creative use of funds (grants, Medicaid waivers, state general revenue) and adoption of proven program models, thereby giving caregivers the relief and individuals the enrichment these services provide.

Enhance Early Identification and Intervention Efforts: Early diagnosis and intervention are critical for better outcomes, so policies that strengthen these systems are critical. Texas must safeguard and expand newborn and early childhood screening programs. For instance, Texas should ensure it implements any newly recommended screenings (such as those for conditions like Krabbe disease)– this may require state funding if federal dollars lag. The community can lobby the state to cover the costs of adding all Recommended Uniform Screening Panel (RUSP) conditions to Texas's newborn screen as a standard of care, ending the "death by ZIP code" disparity where Texas babies might not be tested for conditions detectable elsewhere. Moreover, Texas must boost the outreach of the Early Childhood Intervention (ECI) program and its capacity to address delays in recognizing developmental issues. This could involve increasing the per-child funding rate to hire more therapists and raising provider reimbursement so that no regions go without ECI services. According to testimony from Texans Care for Children, state funding per child for ECI has dropped 38% since 2010 (inflation-adjusted).[1]

The survey data showing many parents had "vague ideas" or no plan for adult care also signals a need for earlier planning support. National best practices suggest empowering families immediately after diagnosis with information and case management, which yields better long-term engagement. Texas may take inspiration from states with no waiting lists for ECI services and ensure that every referred infant is evaluated within the required timeline and receives the necessary support. This may mean allocating emergency funds if any area has a waitlist for ECI. In summary, by reinforcing newborn screening and Early Childhood Intervention (ECI), Texas can identify issues earlier and connect families to supports when they matter most.

If the IDD System within Bexar County can ensure that families of special needs children can access the $1 billion in education savings accounts, or ESA, they have an opportunity to augment their financial safety net and utilize the funds for a variety of needs. Eligible expenses include early childhood education, tuition, transportation, therapy and other education-related items.

Build Coordinated Local Systems and Statewide Accountability: The fragmentation of services was a core theme in the survey. To combat this, the community should pursue system-level solutions alongside funding, including the development of a Bexar County IDD Coordination Council that involves all relevant entities – schools, health care providers, LIDDAs (Local IDD Authorities), state agency reps, and family advocates. This council can work on real-time problems like creating a centralized waitlist dashboard (so families and providers know where openings exist – an idea already endorsed in the community priorities). Texas HHSC should be urged to implement the new federal requirement by 2027 to report waiting list data consistently publicly, and even go further by updating local stakeholders quarterly on progress (or regression) in reducing waits. Additionally, state accountability mechanisms must be strengthened. Texas must clear targets (e.g., "reduce the IDD waiver interest list by 10% each year" or "increase special education funding per student by $X") and track them. Public reports or scorecards could be issued to keep these issues visible. On the coordination front, adopting a No Wrong Door approach in the county or region would ease navigation: families should be able to call a single hotline or visit a one-stop resource center (like The MAC or SACRD IDD portal in development) and get connected to all available supports, rather than making dozens of calls. Some states (e.g., Virginia or Wisconsin) have implemented No Wrong Door systems for long-term services. Texas HHSC can invest in similar navigation infrastructure. Lastly, legal and advocacy support for families should not be overlooked: ensuring parents know their education rights (especially as special ed funding tightens) and how to appeal or seek mediation can help maintain services for children despite systemic cuts. Equipping the community with this knowledge, perhaps via workshops led by disability rights attorneys, is a best practice to empower families in the interim while policy fixes are underway.

Utilize School Vouchers (now called Education Savings Accounts) to Help Vulnerable Families Access Funds: Now that school vouchers have passed in the State of Texas, therein lies a potential opportunity for a coordinated response. If the IDD System within Bexar County can ensure that families of special needs children can access the $1 billion in education savings accounts, or ESA, they have an opportunity to augment their financial safety net and utilize the funds for a variety of needs. Eligible expenses include early childhood education, tuition, transportation, therapy and other education-related items. The ESA program will prioritize families making less than five times the federal poverty line or about $160,000. Households making more than that can still take up to 20% of available slots. Families with special needs students would receive 100% of their school district's student allotment, up to $30,000. A coordinated effort, particularly for early childhood education when public schools are not an option, may be the targeted outreach that can help a family to access critically needed funds. This would require case management support in a coordinated fashion to ensure local families access these funds, targeting pre-schoolers where school choice is not an option, and secondarily for families who prefer private schools over public schools. The ESA is only available if the family of a school-age child withdraws from their public school, hence targeting pre-school children in the beginning. A coordinated response is needed, as evidenced by how many families in this survey are overwhelmed by applications and processes. Applications are expected to open in the fall of 2025, notice of acceptance in the Spring of 2026, in time for 2026-2027 school year.

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[1] Mendoza, Alec, Texans Care for Children. HB 1 Funds Enrollment Growth for ECI for Toddlers with Disabilities, But Reimbursement Rates and Per-Child Funding Are Lagging Testimony to the House Appropriations Subcommittee on Article II on Early Childhood Intervention (ECI) Funding Available here.

Dreams for Our Children: Voices of Parents in Bexar County

In the quiet moments between therapy sessions, school meetings, and daily care routines, parents of children with intellectual and developmental disabilities (IDD) hold dreams for their children's futures—dreams filled with hope, love, and a vision for lives of dignity and purpose. These dreams may evolve over time, as one parent beautifully expressed: "The dream I had for my son when he was little isn't the same one as today." Yet they share common threads that weave together a tapestry of aspiration and possibility.

When we asked parents in Bexar County about their dreams for their children with IDD, their responses revealed not only the depth of their love but also their unwavering commitment to creating a world where their children can thrive. Their voices offer profound insights into what truly matters: safety, independence, connection, and meaning.

Major Themes from Parent Voices

1. **Safety and Security After Parents Are Gone**

   Perhaps the most prevalent concern expressed by parents was ensuring their children would be safe, supported, and well-cared for when they are no longer able to provide care themselves.

   - "Beyond safety, enabling my son to have a meaningful life with the support of his waiver staff long after his parents have passed on—this is a huge fear that it will not happen."
   - "Not to worry how she will be taken care of after I no longer can."
   - "My dream for my son is to be living in a home where he is loved, not in an institution."
   - "I want to make sure she is taken care of. And I don't know how to make that happen."

   Parents consistently expressed the need for more quality group homes, better training for support staff, and clearer pathways to establish long-term care plans.

2. **Independence with Appropriate Support**

   Many parents dream of their children achieving levels of independence appropriate to their abilities, while recognizing that independence looks different for each individual.

   - "Independence for her will always include assistance needed. But I hope she will always have the resources she needs when her parents are no longer alive."
   - "To be as independent as possible, not sure."
   - "I would like for my child to be able to live independently, even if that means living in her own apartment within my home or on my property."
   - "To be independent or to have access to resources that can help my child when they become an adult."

   Parents see independence not as complete self-sufficiency but as the ability to exercise choice, dignity, and self-determination with the right supports in place.

3. **Meaningful Community Connection and Friendship**

   The desire for their children to experience genuine belonging and friendship emerged as another central theme among parents' dreams.

   - "To have a meaningful life with natural peer support; we need to advocate for more community opportunities such as work, school, socialization opportunities, and it doesn't need to be traditional."
   - "For my littles—I would love for all four to be able to transition into either college or a trade program some day."
   - "I'd love her to have a fulfilling job she enjoys and friends who love her and eventually be able to live independently with support."
   - "I want him to have friends and continue learning with his peers."

   These responses highlight the universal human need for connection and the importance of creating inclusive communities where meaningful relationships can flourish.

> **“My dream is for my child to live a life up to their potential, in a community that understands and supports their needs and values their strengths and contributions to the community.”**

4. Purposeful Employment and Contribution

Many parents expressed dreams of their children finding meaningful work that allows them to contribute to society and experience the dignity of purposeful activity.

- "That Daniel never stops Hugging People, Bringing Joy to their Lives, and that he finds a Job where that he is excited to go to every day and to make a difference in other people's lives..."
- "I would love for my son to be able to work or volunteer."
- "Working part time at a place that can accommodate her special needs, keep her safe but feel like she is contributing to society, socializing and growing."
- "I want my daughter to be able to find a career path that is stable and will make her happy."

Parents emphasized that employment should not just be about productivity but about finding opportunities that match their children's interests, abilities, and potential for contribution.

5. Improved Services and System Navigation

Parents frequently mentioned the need for better services, clearer information, and simplified navigation of complex support systems.

- "To know what resources we need at certain times. Or what our options would be/expected cost. It's overwhelming trying to plan for forever."
- "Have a network a book/manual for the parents of special needs community that provides a list of services and a network of doctors that provide services for this population."
- "Someone following through and actually assisting with some of the leg work."
- "We need to develop more resources in San Antonio to meet the needs of the diverse IDD community here so parents don't feel that they have to leave their community to seek quality care."

Parents expressed that navigating the maze of services often feels like a full-time job, and they dream of systems that work with them rather than against them.

A Community of Belonging for All

The dreams shared by caregivers of loved ones with IDD in Bexar County are not extraordinary—they are the same hopes that all parents hold: safety, happiness, purpose, and connection. What differs is the path to achieving these dreams and the support needed along the way.

Building a truly inclusive Bexar County means recognizing that all of us—neighbors, employers, educators, healthcare providers, and community leaders—have roles to play in transforming these dreams into reality. When we create neighborhoods where differences are celebrated, workplaces that value diverse abilities, and systems that respond with flexibility and compassion, we build a stronger community for everyone.

Each person with IDD brings unique gifts, perspectives, and contributions that enrich our collective experience. By working together to remove barriers, increase understanding, and develop comprehensive supports, we create pathways for these dreams to flourish. The journey toward full inclusion doesn't happen overnight, but it begins with listening to these parental voices, honoring their dreams, and committing ourselves to actions that bring these visions closer to reality.

In Bexar County, let us move forward with the understanding that a community that works for its most vulnerable members works better for all of us. Let's build that community together—one where every person, regardless of ability, can live with dignity, purpose, and belonging.

“My dream is for my child to live a life up to their potential, in a community that understands and supports their needs and values their strengths and contributions to the community.”

That dream belongs to all of us now.

Conclusion

This study was born out of a growing recognition that families navigating intellectual and developmental disabilities (IDD) in Bexar County were facing systemic challenges that too often left them isolated, overburdened, and underserved. In Fall 2024, two pivotal events sparked a wave of collective action: the Texas Cavaliers asked what systemic change the IDD community most needed, and a state-based foundation expressed interest in funding policy efforts to address those needs. In response, a coalition of committed nonprofits—including Any Baby Can, Brighton Center, The MAC, Respite Care of San Antonio, The Arc of San Antonio, and SA Life Academy—came together to design a hyperlocal, community-led study to both inform programmatic improvement and shape systemic solutions.

The resulting IDD Community Survey, launched in early 2025, gathered over 800 responses from caregivers, educators, and stakeholders. It reflects a deep well of community experience and knowledge, and a shared call for action. Informed by community-based participatory research and utilization-focused evaluation principles, the study aimed to ensure that every step—from design to data analysis—was grounded in the voices of those most directly affected. The collaborative has already taken tangible steps forward: the first endorsed action, the creation of a guided, IDD-specific resource directory through SACRD, is underway with two-thirds funding secured and community input already shaping its design. This tool will be free, anonymous, and accessible for families and frontline providers.

The data underscore what families have known for years: the system is fragmented, exhausting, and inequitable. Parents are left to act as full-time care coordinators, navigating confusing eligibility processes, years-long waitlists, and underfunded programs. While some have found support through trusted programs, many report burnout, financial strain, and fear for the future. The transition to adulthood is particularly fraught, with families often feeling “dumped” by systems that provided some support during childhood but offer few paths forward once a loved one turns 18. Employment challenges, lack of respite, difficulty accessing care, and poor service coordination are recurring themes. These challenges are not the result of caregiver failures—they are symptoms of system design.

And yet, this report is not just a catalogue of what’s broken. It is a roadmap of what could be built. Families are not asking for miracles—they are asking for connection, clarity, and continuity. They are asking for systems that recognize the complexity of caregiving and provide the flexibility, resources, and dignity that every family deserves.

This report is a call to action. It affirms what families have long known: we must start earlier. Early intervention through ECI is one of the most effective, evidence-based strategies for improving outcomes in children with intellectual and developmental disabilities. When families have access to timely, compassionate, and coordinated supports, children thrive. The opportunity is clear—and the time to act is now.

The IDD nonprofit ecosystem has already begun to align around shared priorities, with regular stakeholder meetings, a commitment to the SACRD project, and a community pledge to continue the work through the summer and fall of 2025.

Bexar County has long been known for collaboration and compassion. With this report as a foundation, we now have the opportunity—and the responsibility—to build something better. The insights here clearly mandate that families must no longer navigate this system alone. Together, we can transform isolated frustration into coordinated action and patchwork programs into a cohesive network of care.

This report is not just a catalogue of what’s broken. It is a roadmap of what could be built.

Top 10 Concerns of Caregivers: Under 18

Raising a child with intellectual and developmental disabilities (IDD) requires deep strength, fierce advocacy, and unwavering hope. In Bexar County, families are doing all of this—and more—every single day. Through this survey, we listened to hundreds of caregivers whose words illuminate both the heartache and the resilience of their journeys. Their stories point to real, solvable gaps in care, but they also offer a blueprint for change. They speak not just about what's missing—but what's possible. With their wisdom, we can create a community that meets families with open doors, real solutions, and the promise of inclusion for every child. This summary captures the top 10 themes across all questions, illustrated with direct quotes, and concludes with a call to collective action for a more inclusive Bexar County.

Top 10 Themes

1. Access to Autism and Mental Health Providers

Many families shared stories about delayed diagnoses, long waits for specialists, and difficulty finding appropriate mental health or autism-related care.

"Had to wait for my daughter to be tested for dyslexia."

"I had to get outside help because the school couldn't test. It took until age 8 for an official diagnosis."

2. Independent Living and Life Skills

Families emphasized the importance of teaching daily living skills and creating pathways to independence.

"I dream he can attend all day ABA and then all day school in the same location so he can be independent and happy."

"I hope my child can live independently one day."

3. Community Services for Families of Children with IDD

Respondents frequently mentioned the need for more accessible, affordable community-based services tailored for children with IDD.

"Limited resources, insurance help, limited awareness in the community."

"Hard to find good therapists. Mac was the only place we could get into."

4. School Inclusion and Special Education Support

Parents described difficulty with public schools, lack of staff training, and the need for individualized education supports.

"He was 18 months and we didn't understand symptoms initially."

"There was a process of evaluations, paperwork, staff meetings, and doctors."

5. Parent Education and Awareness of Services

Families want better access to training and guidance to understand available programs, how to qualify, and how to advocate effectively.

> "I know he will probably need a Medicaid waiver but I don't know how to get it."
>
> "Nobody teaches you how to find the right services. You have to learn on your own."

6. Childcare and Balancing Work and Caregiving

Caregivers often struggle to maintain employment while managing care responsibilities, citing a lack of flexible childcare.

> "I can't work full-time because I have to be there for therapy appointments."
>
> "We don't qualify for respite and daycare won't take him because of his behaviors."

7. Navigating Systems and Finding the Right Fit

Many families find systems—such as Medicaid, schools, and nonprofits—confusing and poorly coordinated, making it difficult to find programs that meet their child's specific needs.

> "I've been bounced between different agencies and no one seems to know who can help us."
>
> "We need help navigating all the services and understanding what's best."

8. Access to Therapy and Insurance Barriers

Affording and accessing therapies like ABA, occupational, and speech is a consistent struggle. Insurance denials and provider shortages are common.

> "My insurance doesn't cover ABA and the waitlist is too long for the ones that do."
>
> "We had to pay out of pocket for therapy for two years."

9. Long Waitlists and Limited Availability of Services

Whether it's a waiver program, therapy provider, or support group—many services are oversubscribed with years-long waits.

> "We've been on the CLASS waitlist for six years."
>
> "We finally got into MAC after calling every month for a year."

10. Need for Respite and In-Home Support

Caregivers expressed exhaustion and isolation, with many calling for reliable, trained respite providers.

> "We don't want to ever be dependent on a state system, but we need a break sometimes."
>
> "There's no one we trust to care for him so we never get a break."

These responses reveal both a resilient caregiving community and a system in need of serious investment and coordination. Parents are asking for a roadmap—services that are easier to find, staffed by well-trained professionals, and designed to meet their child's unique needs. As a county, we have the opportunity to build a more inclusive, responsive infrastructure that meets these families where they are.

Top 10 Concerns of Caregivers: Over 18

Across Bexar County, families of adults with intellectual and developmental disabilities (IDD) are navigating a fragmented system of care with persistence, ingenuity, and hope. Their voices—captured through this community survey—reveal both the promise and the pain of aging out of childhood services into a system that is not yet fully equipped to support adulthood with dignity. From housing insecurity to mental health needs, these families articulate clear priorities and offer powerful insight into what must change. This summary captures the top 10 themes across all questions, illustrated with direct quotes, and concludes with a call to collective action for a more inclusive Bexar County.

Top 10 Themes

1. Diagnosis and Early Intervention Still Matter in Adulthood

Many families highlighted the lifelong impact of delayed or inaccessible diagnoses. Despite being past school age, diagnostic clarity remains foundational to accessing services and supports.

> "I received a formal diagnosis when my child was 18 years old. We had been trying for years, but kept hitting walls."
>
> "The school always said he was 'just slow'—he didn't get evaluated until after graduation."
>
> "It's hard to plan a life without knowing exactly what your child is facing."

2. Health and Mental Health Access Is Inadequate

Families expressed urgent needs for mental health services, often noting that co-occurring conditions like anxiety, trauma, or depression are left unaddressed in adulthood.

> "Mental health is still health—why are we told to call the police instead of being offered therapy?"
>
> "There are no psychiatrists trained in both IDD and adult care. It's terrifying."
>
> "My adult child has epilepsy and autism, but doctors don't talk to each other."

3. Group Homes and Staffing Concerns

The quality and safety of group homes is a major concern. Families cited undertrained staff, high turnover, and environments that fail to meet even basic standards of care.

> "Staff needs Safety Care training to ensure safety and dignity. We've had too many dangerous incidents."
>
> "She came home from her group home with bruises. No one could explain why."
>
> "There's no oversight. The agencies just check boxes and move on."

4. Waiver Services and Provider Gaps

Despite qualifying for HCS or TxHML waivers, families report long waitlists, inconsistent provider quality, and bureaucratic barriers that delay or prevent access.

> "We were approved for HCS two years ago. Still no provider."
>
> "The waiver system is broken. It feels like a full-time job just managing it."
>
> "Why are there so few providers for those with high needs?"

5. Local Programs and Community Anchors

Certain programs and agencies—like the Arc of San Antonio and SA Life Academy—were highlighted as bright spots. Families expressed gratitude but also concern that access is limited.

> "SA Life Academy is AMAZING and the best place we've ever found."
>
> "The Arc has been our lifeline. But there's only so many spots."
>
> "We need more like MAC and The Arc—places that 'get' our kids."

6. Independent Living and Employment Desires

Families dream of safe, supported independence for their adult children, but lack resources and options for job training, supported housing, or even basic life skills coaching.

> "He wants to work. No one will hire him, even with support."
>
> "There should be apartments with built-in supports—not just group homes."
>
> "She's capable, but needs someone to teach her the basics—budgeting, cooking, etc."

7. Service Navigation and Case Management Challenges

Many caregivers shared frustration about not knowing where to start, who to call, or how to access available services. Even those with case managers felt lost.

> "Every agency tells you to call someone else. It's a circle."
>
> "I don't even know what we qualify for. No one explains it clearly."
>
> "Case management shouldn't be a guessing game."

8. Dayhabilitation Gaps and Quality Issues

Dayhab programs—often the main daytime option for adults with IDD—were criticized for low engagement, poor staffing, and a lack of meaningful activities.

> "They just sit and watch movies all day. That's not habilitation."
>
> "Staff turnover is constant. My son doesn't even know who his worker is anymore."
>
> "We need dayhabs that build skills, not babysit."

9. School Transition and Housing Instability

Families noted the abrupt drop in support after high school and the absence of clear pathways to adulthood. Housing, in particular, remains an unresolved fear for many.

> "After 22, everything just stops. It's like falling off a cliff."
>
> "I worry about where he'll live when I'm gone. That keeps me up at night."
>
> "No one talks to you about adulthood until it's already here."

10. Respite Care and Caregiver Burnout

Respite options are minimal, especially for adults with behavioral or medical complexity. Parents expressed exhaustion and the need for structured relief.

> "I haven't had a break in 12 years."
>
> "Serenity House won't take him because of his behaviors. So what are we supposed to do?"
>
> "Even just one weekend a quarter would make a huge difference."

These powerful insights from families of adults with IDD are not just reflections—they are a roadmap. A roadmap toward a community where every person, regardless of ability, is supported to live a full life with dignity and purpose. We must respond with urgency and empathy, designing systems that offer continuity, choice, and connection. Bexar County is filled with committed families and strong programs. Now is the time to align leadership, funding, and advocacy so that these voices lead to real change. Let us rise together to ensure that adulthood for individuals with IDD is not an afterthought—but a time of growth, belonging, and hope.

IDD Champions

Collaborating for Inclusive Solutions

The Arc of San Antonio

Brighton Center
Here there are only Abilities.

ABC of Southwest Texas

Respite Care
Caring for children with special needs

Morgan's MAC
Multi-Assistance Center

SALife Academy
Doing Life Together