



IDD Champions

Collaborating for Inclusive Solutions

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B E X A R C O U N T Y

IDD Champions Community Survey

— June 2025 —



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

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.



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.

