The Lasting Effects of Fragmented Care: A Call to Action for Medical Professionals Serving Individuals with IDD

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Executive Summary

Fragmented care systems disproportionately impact individuals with intellectual and developmental disabilities (IDD), leading to delayed diagnoses, inadequate access to services, caregiver burnout, and poor long-term outcomes. In Bexar County, the IDD Champions Community Survey of over 800 stakeholders revealed that families are often forced to act as full-time care coordinators, navigating disconnected systems with little support.

This white paper presents the clinical consequences of fragmented care, real-life examples, and data-driven recommendations for medical professionals to improve coordination, access, and outcomes.

Key Numbers at a Glance

The survey findings are clear: fragmented care is not an isolated frustration - it is a system-level barrier affecting diagnosis, access, family stability, and long-term health outcomes.

47% Families waited over a year for a diagnosis	**75%** Families reported difficulty finding services when needed	**Nearly 50%** Families said coordination between providers was ineffective
32% Caregivers quit jobs due to care demands	**311K+** Texans on IDD waiver waitlists	**10-15 yrs** Typical waits for Medicaid waiver services

Bottom Line for Medical Professionals

Fragmented care is not just an administrative challenge. It is a clinical risk that delays diagnosis, increases caregiver strain, and leaves families without clear pathways to coordinated support. Medical professionals can help close those gaps by identifying needs early, making warm referrals, and treating follow-through as part of the care plan.

Understanding Fragmented Care in the IDD Ecosystem

Fragmented care refers to the lack of coordination among healthcare providers, social services, educational systems, and community programs. For individuals with IDD, this fragmentation results in delayed diagnoses, limited access to services, poor provider communication, and significant economic strain on families.

- **Delayed diagnoses:** 47% of families waited over a year for a diagnosis.
- **Limited access to services:** 75% of families reported difficulty finding services when needed.
- **Poor provider communication:** Nearly 50% said coordination between providers was ineffective.
- **Economic strain:** 32% of caregivers quit their jobs due to care demands.

Real-Life Examples of Fragmented Care

The following examples illustrate how fragmented systems turn routine needs into high-risk barriers for individuals with IDD and their caregivers.

INSURANCE BARRIERS

"We have struggled to find the right doctors that take our insurance."

Why it matters: Limited provider networks can delay or prevent access to needed care.

EQUIPMENT ACCESS & SAFETY RISK

"I had to buy a wheelchair and walker from Amazon despite having a prescription because all durable medical equipment companies I contacted did not take Medicaid."

Why it matters: DME access gaps can become immediate safety risks after surgery or during seizure-related episodes.

LOSS OF DAY PROGRAM SUPPORT

"After a post-seizure complication, my daughter's local day program discharged her. Now she sits at home all day, every day."

Why it matters: When programs cannot support complex medical needs, adults with IDD and their families can lose critical daily structure and respite.

Clinical Impacts of Fragmented Care

Clinical Risk Snapshot

33%	88%	2x
Families suspected a problem within 6 months of birth	Adults with IDD live at home with family caregivers	Adults with disabilities are nearly twice as likely to report unmet healthcare needs

Delayed Diagnosis and Missed Early Intervention

- 33% of families suspected a problem within 6 months of birth, but many waited years for a diagnosis.
- Delays in diagnosis prevent timely access to Early Childhood Intervention (ECI), which is proven to improve developmental outcomes.

Inadequate Access to Specialists

- Families report long waitlists for neurologists, psychiatrists, sedated eye exams, and sedation dentistry.
- Adults with IDD face even greater barriers, with few providers trained in dual diagnosis (IDD + mental health).
- Adults with disabilities are nearly twice as likely to report unmet healthcare needs.

Caregiver Burnout and Economic Fallout

- 88% of adults with IDD live at home, placing long-term strain on families.
- 23% of caregivers reduced work hours; 15% declined job offers due to caregiving demands.

Why This Matters Clinically

When diagnosis, referrals, therapy, equipment, and family supports are disconnected, patients are more likely to experience preventable delays, caregiver strain, and avoidable crisis care. Medical professionals can reduce these risks by treating care coordination as part of the clinical plan, not an afterthought.

Policy Context: Why Medical Professionals Must Engage

Medical professionals are trusted voices in conversations about access, safety, quality, and prevention. Their engagement is especially important because fragmented care is not only a family burden; it is a clinical risk and a system-design issue.

System Pressure Snapshot

311K+	10-15 yrs	97K
Texans on IDD waiver waitlists	Estimated wait for some waiver services	Of an estimated 485K Texans with IDD receive long-term services

Texas Medicaid Waiver Waitlists

- Over 311,000 Texans are on IDD waiver waitlists, with waits of 10-15 years.
- Only 97,000 of the estimated 485,000 Texans with IDD receive long-term services.

Underfunded Systems

- Texas ranks among the lowest per-capita spending on IDD services.
- Cuts to special education Medicaid reimbursements (SHARS) have reduced school-based therapy access by $600M annually.

Recommendations for Medical Professionals

Why It Matters

Medical professionals often see the consequences of fragmented care before other systems do. When clinicians identify gaps, coordinate referrals, and document unmet needs, they can help prevent delayed treatment, avoidable crises, and family burnout.

1

Improve Care Coordination

- Implement shared care plans across specialties and settings.
- Designate a care coordinator or navigator for patients with complex needs.
- Use interoperable Electronic Medical Records (EMRs) to ensure continuity across providers and reduce redundant assessments.

2

Prioritize Early Diagnosis

- Train pediatricians and family physicians to recognize early signs of IDD.
- Streamline referrals to ECI and developmental pediatricians.

Recommendations for Medical Professionals

3

Advocate for Systemic Change

- Support policy efforts to expand Medicaid waiver slots.
- Engage local IDD councils to align healthcare with community needs.
- Champion funding for respite care, day programs, and adult services through professional associations and legislative outreach.

4

Educate and Empower Families

- Refer families to trusted community resources.
- Provide clear, written guidance on navigating Medicaid, Supplemental Security Income (SSI), and waiver programs.
- Host or participate in training sessions for caregivers on future planning, legal tools, and service navigation.

5

Create Inclusive Clinical Environments

- Offer sensory-friendly spaces and trauma-informed care.
- Ensure staff are trained in IDD-specific communication and behavioral support.
- Plan accessibility for patients with mobility, sensory, or cognitive challenges.

6

Track and Improve Outcomes

- Collect and analyze data on access, wait times, disability status, non-medical drivers of health, and patient satisfaction for IDD populations.
- Use quality improvement methods to reduce delays and improve coordination.
- Share best practices with peers and contribute to a culture of continuous improvement.

Call to Action: What Medical Professionals Can Do

Call to Action

Medical professionals are uniquely positioned to reduce harm caused by fragmented care for individuals with IDD. By improving coordination, advocating systemic reform, and embracing inclusive practices, clinicians can help build a responsive, compassionate system that honors the dignity and potential of every individual with IDD.

The data is clear: fragmented systems harm patients and families. But with intentional action, clinicians can help build a more coordinated, compassionate, and effective system. Let this be the moment medical professionals step forward - not just as providers, but as partners in building a system that works for every individual with IDD.

Coalition Statement

The IDD Champions Coalition includes Brighton Center, The MAC, Respite Care of San Antonio, The Arc of San Antonio, and SA Life Academy.

References

1. IDD Champions Community Needs Assessment - Bexar County (June 2025).
2. Improving Health Care for Adults with Disabilities; An Overview of Federal Data Sources - Centers for Medicare and Medicaid Services (CMS) (December 2020).