

## What's New in Research and Practice for Intellectual and Developmental Disabilities (IDD)

(Based on research provided by GPT 5.2)

Researchers and people who provide services for people with intellectual and developmental disabilities are shifting from “fixing problems” to helping people live full lives. That means more focus on rights, participation, and supports that help people make their own choices. At the same time, there are big advances in genetics and technology, new ways to deliver care (like telehealth), and growing effort to make services work better in the real world. However, serious challenges remain – especially around access, workforce shortages, equity, and using new tools in an ethical way.

### Major Themes

**A rights - and person-centered approach** - More emphasis on supporting people with dignity, independence, and centering what people themselves want. Success is frequently measured by quality of life and community participation.

**Genetics and “precision” diagnosis – with hard decisions** - Genetic tests are used more often. While they can explain why a person has IDD, these tests raise tough questions about consent, privacy, cost, eugenics, and access.

**Thinking about the whole life, not just childhood** - There's more work on identifying and helping children early, which can improve outcomes. Researchers are also paying more attention to teens, adults, and older people with IDD – especially supports for jobs, housing, health care, and dementia risk.

**Mental health and trauma matter a lot** - People with IDD often have mental health problems (depression, anxiety, behavior challenges). The field is learning how to adapt therapies and services so they work for people with IDD and how to provide trauma-informed care when people have experienced abuse or neglect.

### **What works in behavior and education – and how to deliver it -**

Evidence-based approaches (like positive behavior support and communication-focused therapies) remain the backbone of services. There's more focus on supporting teachers, families, and local programs to deliver these practices efficiently and effectively.

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**Technology is both useful and tricky** - Telehealth, speech apps and devices (AAC), wearables, and mobile tools have expanded rapidly. While they can increase access, they also raise issues around privacy, reliability, and unequal access to devices or internet.

**Services and workforce problems** - There aren't enough trained people (therapists, special educators, behavior analysts) to meet demand. Researchers are testing ways to train paraprofessionals, use remote supervision, and redesign services to be more integrated and efficient.

**Better research methods and involving people with lived experience** - More studies now involve self-advocates and families in designing research. Big datasets and longer-term studies are improving our understanding of outcomes over time. There is also a shift toward measuring things that really matter to people in daily life (participation, well-being).

### **Big gaps that need attention**

- Inequality: race, income, and geography affect who gets diagnosed and who gets help.
- Not enough research on adults, especially older adults.
- Ethics and privacy: genetic data and digital tools create new concerns.
- Too much good evidence doesn't reach communities because of money, workforce, or policy barriers.

### **Bottom-line priorities**

- Make services centered on the person's goals and rights.
- Scale evidence-based supports by investing in workforce and systems that can deliver them with fidelity.
- Reduce disparities so innovations reach all communities.
- Continue to involve people with IDD and families in research and program design.
- Evaluate and regulate new technologies and genetic testing so they're safe, useful, and fair.

### **Sample of Journals used to compile this brief:**

- Journal of Intellectual Disability Research
- American Journal on Intellectual and Developmental Disabilities
- Journal of Applied Research in Intellectual Disabilities
- Research in Developmental Disabilities
- Intellectual and Developmental Disabilities
- Journal of Autism and Developmental Disorders
- Developmental Medicine & Child Neurology
- Pediatrics and journals in psychiatry, genetics, education, and rehabilitation (for cross-disciplinary findings)