

## Mental Health in Intellectual and Developmental Disabilities

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### Introduction

Research on the unmet mental health needs of people with intellectual and developmental disabilities (IDD) are often constricted by a limited understanding of the population and lack of training for practitioners and caregivers (National Council on Disability, 2024; Pinals et al., 2022). In addition, doctors and other professionals usually make decisions about treatment with little direct input from patients (Camm-Crosbie et al., 2019). The result is ineffective, restrictive, and harmful care (Rich, DiGregorio, & Strassle, 2021).

### Recommendations for the Future of Mental Health in IDD

Targeted resources must be provided to promote effective change. Research is required to develop, disseminate, standardize, and implement best practices throughout all mental health services for people with IDD.

The following recommendations specify key areas to address and provide examples of efforts currently underway:

1. **Terminology:** To better address stigma and diagnostic overshadowing, we suggest the phrase “mental health in intellectual and developmental disabilities” to describe the mental health aspects of IDD and to overcome a unidimensional approach associated with the use of the term “dual diagnosis” (McLennan, 2018).
2. **Person-Centered Mental Health Approaches:** Direct patient self-reporting is needed to determine if treatment models, services, and supports are effective. The Person Experience Interview Survey (Kramer et al., 2023) is an example of an accessible patient-reported mental health service

### Plain Language Summary

People with intellectual and developmental disabilities (IDD) often struggle to get good mental health care. Doctors and others don't always understand the best ways to help them. This means many people with IDD don't get the kind of mental health support they need.

Here are some ideas to make things better:

1. Use the phrase “mental health in intellectual and developmental disabilities” to reduce blame and diagnostic mistakes.
2. Ask people with IDD what they think about their own mental health care.
3. Include people with IDD in research to learn how to make mental health care better.
4. Train doctors and others to better understand mental health in IDD.
5. Support different groups to work together to share information on what works.
6. Create better ways to help people before they have serious problems.

People with IDD deserve good mental health care where people listen to them and help them feel better. The system isn't working well right now, but it can be improved by making changes to the way doctors and others provide mental health care.

experiences measure for people with IDD ages 12 and older, used to evaluate their experiences with mental health services and providers.

3. **Evidence-Based Practices:** Inclusive, accessible, and meaningful research is needed. While federal grant funding is in some measure available, there is a dearth of qualified researchers and limited research engagement with people with IDD. One project to expand capacity, the National Research Consortium on Mental Health in Intellectual and Developmental Disabilities (Institute on Disability, n.d.) provides mentoring and innovation grants for new researchers.
4. **Ongoing Capacity Building:** Evidence-based standardization of best practices must be incorporated into professional and paraprofessional development. Professional development, training, ongoing education, credentialing, and quality assurance are integral. Examples of peer-reviewed resources developed for treatment providers of people with IDD include mental health prescriber guidelines (Beasley et al., 2021; Caoili et al., 2022) and outpatient counseling guidelines (Witwer et al., 2022; 2024).
5. **Cross-Systems Dialogue and Partnerships on a National Level:** One notable effort toward cross-systems collaboration between people with IDD, mental health service systems, and IDD service systems is the Link Center (Administration for Community Living, n.d.).
6. **System-Wide Resources to Improve Mental Healthcare for People with IDD:** Funding to allow for IDD mental health services should include reasonable accommodations in integrated clinical settings and proactive strategies to prevent and intervene in times of crisis. Two successful models of care are the Developmental Disabilities Health Home model in Colorado, which integrates mental health into ongoing healthcare (Colorado Department of Health Care Policy & Financing, n.d.), and the Systemic, Therapeutic,

Assessment, Resources, and Treatment (START) model, a well-researched, evidence-based crisis prevention and intervention model used in many U.S. states (Beasley & Kroll, 2002; Kalb et al., 2019).

### Conclusion

The absence of effective mental health care for people with IDD leads to restrictive, costly, and harmful interventions that have undermined mental health, emotional wellbeing, and quality of life in this population. While some efforts to address policy and practice gaps are underway, this is not yet a national trend. Better standards of training and care for proactive, comprehensive, integrated, and evidence-based practices—along with policies to provide needed resources—are required. Coordinated dissemination of peer-reviewed evidence-based best practices aimed at the standardization of effective treatment approaches is needed.

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