

Tips for Mental Health Providers Serving Adults with Intellectual and Developmental Disabilities

TIPS AND RESOURCES



Prevalence of mental health and developmental disabilities

Psychiatric disorders including major depressive disorder, bipolar disorder, psychotic disorder, and anxiety disorders have been shown to be three to four times higher among individuals with intellectual and developmental disabilities (IDD), compared with the general population (Pinals et al., 2021).

Research has found that 35.7% of people with cognitive disabilities reported mental distress compared to 7.2% of people without disabilities (Cree et al., 2018).

Suicide rates are higher among people with disabilities due to social isolation and lack of support, with 11.4% of adults with disabilities have serious thoughts of suicide. One study found autistic adults experience serious thoughts of suicide at nine times the rate of the general population (Cassidy et al., 2014).

Trauma and abuse are prevalent among individuals with disabilities, and particularly for those with IDD. Individuals with IDD are more likely to be victims of crime, sexual or financial abuse, physical restraint and seclusion, bullying, and neglect (Mevisen et al., 2020).

Barriers to Mental Health Service Access for Adults with IDD

Accessing appropriate mental health services is a major challenge for people with disabilities due to several factors including:

- Many mental health providers do not accept insurance, yet nearly 30% of adults with cognitive disabilities live in poverty (Thomas et al., 2024).
- Many mental health providers have offices that are not physically accessible.
- Psychiatric symptoms in individuals with IDD are often misattributed to their disability, rather than to a mental health condition, due to “diagnostic overshadowing.”
- Mental health practitioners often receive little or no training in addressing mental health needs of people with IDD (Pollack et al., 2024).
- People with IDD are often overmedicated, particularly with psychotropic medications, for distressing behaviors in the absence of a psychiatric disorder (Glover et al., 2015).

Such barriers are associated with serious harms for people with IDD, including heightened suicide risk, overreliance on antipsychotic medications, recurrent hospitalizations, criminal/legal system involvement, and early death (Kramer et al., 2019).

Who We Are and Who We Serve

The **Vanderbilt Kennedy Center** works with and for people with disabilities and their family members, educators and service providers, researchers, students, and policy makers. Faculty and staff engage in interdisciplinary research, training, service, and information dissemination and work in collaboration with local, state and national networks and partners. vkc.vumc.org



RESOURCES

Mental Health Resources for People with IDD

For those who would like to enhance their ability to provide appropriate care and medication management to individuals with IDD and mental health conditions, here are some useful resources.

IDD Toolkit, iddtoolkit.org

The IDD Toolkit website provides information for the primary care of adults with intellectual and developmental disabilities. The Toolkit offers health care providers best-practice tools and information regarding specific medical and mental and behavioral health concerns, including resources for patients and families.

IDD Toolkit Resources	Link
Initial Management of Behavioral Crises Behavioral crises arise from complex circumstances. This tool offers a systematic assessment of contributing factors, such as Health issues, Environment and supports, Lived experiences and emotional issues, and Psychiatric disorders (HELP).	https://bit.ly/4eiYD9b
Identifying symptoms and signs of mental distress in adults with intellectual and developmental disabilities Psychiatric diagnostic assessment of people with IDD is complex, especially in those who have limited communication. This tool can help in determining whether the patient's behaviors are likely caused by emotional distress from current or past life circumstances or by a psychiatric disorder.	https://bit.ly/3Tq2aut
HELP with Emotional and Behavioral Concerns This form to be completed can help primary care clinicians and others supporting adults with intellectual and developmental disabilities to understand contributing factors when these adults present with emotional distress and behavioral concerns.	https://bit.ly/3XD7wFb
Risk Assessment Tool for Adults with Developmental Disabilities in Behavioral Crisis This tool helps clinicians determine whether a patient who is experiencing an emotional or behavioral crisis can be managed safely in their current environment or should be referred to the emergency department or possible crisis care options.	https://bit.ly/3B06iLn
Psychotropic Medication Review This form assists clinicians in systematic and timely reviews of psychotropic medication prescribed to adults with IDD.	https://bit.ly/3TnOXIV
Mental Health Interventions This resource, although aimed at primary care clinicians, provides an overview of supports and interventions, including therapy, for adults with IDD presenting with emotional and behavioral concerns.	https://bit.ly/3XivxzX
My Coping Tool: How I Deal With Stress This form is for patients to complete: Sometimes you can feel very stressed, angry, or upset. My Coping Tool helps you and other people know what to do when you don't feel like your usual self.	https://bit.ly/4eenN8S



RESOURCES

Books

- Diagnostic Manual—Intellectual Disability 2 (DM-ID): A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability Second edition by Jarrett Barnhill, Sally-Ann Cooper, Robert Fletcher
- Trauma and Healing in the Lives of People with Intellectual Disability by Karyn Harvey
- Intellectual Disability: Definition, Diagnosis, Classification, and Systems of Supports, 12th Ed

Additional websites with information and training

- **The Link Center: Bridging IDD and Mental Health Systems**, <https://acl.gov/TheLinkCenter>
The Link Center works to improve supports available to children and adults with IDD, brain injuries, and other cognitive disabilities with co-occurring mental health conditions. The Link Center provides training and technical assistance and advances systems change that will increase access to effective services and supports for people with co-occurring conditions.
- **NADD**, <https://thenadd.org/>
NADD is an association for persons with intellectual disabilities and mental health needs, made up of individuals, families, and support professionals dedicated to enhancing the understanding and treatment of people with co-occurring IDD and mental health conditions. NADD provides training, certification, and resources to enhance the mental health care of people with IDD.
- **The National Center for START Services**, <https://centerforstartservices.org/>
The National Center for START Services aims to improve the lives of persons with IDD and mental health needs and their families through the START model, a crisis prevention and intervention model, with services and supports that emphasize local, person-centered, positive, multidisciplinary, cost-effective and evidence-informed practices. The center provides online training to clinicians, direct support staff, and care coordinators.

References

- Pinals, D. A., Hovermale, L., Mauch, D., & Anacker, L. (2022). Persons With Intellectual and Developmental Disabilities in the Mental Health System: Part 1. Clinical Considerations. *Psychiatric Services*, 73(3), 313–320.
- Cree RA, Okoro CA, Zack MM, Carbone E. Frequent Mental Distress Among Adults, by Disability Status, Disability Type, and Selected Characteristics - United States, 2018. *MMWR Morb Mortal Wkly Rep*. 2020 Sep 11;69(36):1238-1243. doi: 10.15585/mmwr.mm6936a2. PMID: 32914770; PMCID: PMC7499832.
- Cassidy S, Bradley P, Robinson J, Allison C, McHugh M, Baron-Cohen S. Suicidal ideation and suicide plans or attempts in adults with Asperger's syndrome attending a specialist diagnostic clinic: a clinical cohort study. *Lancet Psychiatry*. 2014 Jul;1(2):142-7. doi: 10.1016/S2215-0366(14)70248-2. Epub 2014 Jun 25. PMID: 26360578.
- Mevissen, L., Didden, R., de Jongh, A., & Korzilius, H. (2020). Assessing Posttraumatic Stress Disorder in Adults with Mild Intellectual Disabilities or Borderline Intellectual Functioning. *Journal of Mental Health Research in Intellectual Disabilities*, 13(2), 110–126.
- Thomas, N., Paul, S., Bach, S., & Houtenville, A. (2024). Annual Disability Statistics Compendium: 2024 (Table 6.7). Durham, NH: University of New Hampshire, Institute on Disability.
- Glover, G., Williams, R., With, D., Branford, D., Avery, R., Chauhan, U., Hoghton, M., & Bernard, S. (2015). Prescribing of psychotropic drugs to people with learning disabilities and/or autism by general practitioners in England. Technical Report. Public Health England (PHE).
- Pollack HA, Berg KL. Meeting the Mental Health Needs of Americans Who Live With Intellectual and Developmental Disabilities. *Milbank Quarterly Opinion*. March 12, 2024.
- Kramer JM, Schwartz AE, et al. Improving Research and Practice: Priorities for Young Adults with Intellectual/Developmental Disabilities and Mental Health Needs. *Journal of Mental Health Research in Intellectual Disabilities* 2019 Aug. doi: 10.1080/19315864.2019.1636910

