Meeting the Mental Health Needs of People with Intellectual Disabilities

Developmental Disabilities Administration 2017

The Guidebook was developed by a team of professionals currently serving individuals with intellectual disabilities in the community. It originated out of the need to open the dialogue among providers and systems to better serve people experiencing co-occurring intellectual disabilities and mental health disorders. It is intended to be a resource for mental health providers who serve, or would like to serve individuals with intellectual disabilities and mental health disorders. It applies to all settings where mental health care is provided, from intake to crisis.

Intellectual Disability (ID) is categorized in the Diagnostic and Statistical Manual of Mental Disorders, 5th Ed. (DSM-5) as a Neurodevelopmental Disorder. Diagnoses in this group occur during the human developmental period. They generally become observable early in the person’s life, most prior to the child entering grade school. These disorders have in common effects that show themselves through the child failing to achieve developmental milestones within the customary timeframes for the larger population. The effects are seen in the person’s ability to gain skills and use them to function in the areas of life including: taking care of him or herself; recruiting, making and maintaining social relationships; learning new skills; and functioning in settings that expect consistent production of effort like learning in school or accomplishing job tasks.

ID is marked by deficits in general reasoning skills, problem solving, planning, thinking abstractly, exercising judgment, learning academic skills, and drawing conclusions from their personal life experiences. Difficulties in these general cognitive abilities are observed to affect the person’s ability to function independently and take care of responsibilities. This translates to significant delays in being able to take care of their person and personal care needs; communicating with others using language; developing and maintaining friendships; social judgment; managing their financial affairs; and learning and using practical knowledge. These tendencies are pervasive and seen in multiple contexts including the person’s home, the academic or work place, and in the community.

People with ID experience mental illness at an increased rate that is greater than the general population. It is estimated that 30-35% of those with ID have a co-occurring mental health disorder compared with 15-19% in the general population.

People with an ID are more vulnerable to mental health disorders. This is due to the complex interaction between the ID, biological, psychological and social factors.

Biological factors

Genetics

Some genetic disorders that cause ID can predispose a person to having specific mental health conditions. For example, someone who has fragile X syndrome is at increased risk for developing social anxiety, and someone with 22q11 deletion is at increased risk for developing schizophrenia.

Brain chemistry

Research indicates that chemical processes in the brain are involved in the development of mental health conditions. Recent research points to abnormalities in brain structure as a possible factor in the development of mental health conditions, particularly schizophrenia. People with ID may be predisposed to developing mental health disorders because people with ID have physical brain structures and chemical processes that differ from those in a neurotypically developing person.

Medical vulnerabilities

Individuals with ID have a higher incidence of medical conditions compared to the general population.
Medical problems are often missed because of communication differences or misattributed as "challenging behavior."

Seizures are more common among people who have ID. There is a complicated relationship between epilepsy and mental health conditions in people with ID that may reflect the underlying brain disorder causing the seizures rather than the epilepsy itself. Seizure disorders are important to consider because they may explain a person’s challenging behavior.

**Psychological factors**

The temperament a person is born with (e.g., a person’s tendency to internalize feelings) may increase the risk of developing mental health conditions. Psychological risk factors interact with life stressors, biological predispositions, and skill development resulting in a person’s often impacting a person’s ability to cope with stressors and remain resilient. Psychological risk factors include: poor social skills; poor coping and self-soothing skills; poor problem-solving skills; problems with communication; and low self-esteem.

**Stress**

Although stress does not cause mental health conditions, it can trigger or make them worse. People with ID experience a lot of stress in their lives and may have an even more difficult time coping with stress than do people in the general population.

**Social factors**

Negative life events have been tied to the development of mental health condition in individuals with ID. Research suggests that early childhood trauma and losses, such as the death or separation of parents, or adult events, such as the death of a family member or loss of a job or day activity, can be precursors to a mental health disorder. Conflicts with family members, residents or staff may be an important area of concern for individuals with co-occurring diagnosis.

Other environmental risk factors include poverty and lack of social support. People with ID are more likely to experience poverty and poorer housing conditions and live in high-crime areas compared to the general population.

**Physical, sexual and psychological abuse**

Individuals with ID are at increased risk for maltreatment and neglect. Those admitted to psychiatric hospitals, as well as those living in the community, should be screened for a history of maltreatment.

**Transition from adolescence to adulthood**

In the general population, the transition from adolescence to young adulthood (16–25 years) is a high-risk period for developing mental health conditions. This risk is higher in young adults with ID. Young adulthood is the most likely time for psychiatric hospitalization in individuals experiencing ID.

People with ID are affected by the stresses of puberty, as well as by the specific stresses associated with transitioning from the child to adult service system, which often means losing school supports and not getting sufficient services. This transition may also be a period of increased stress on family and parents.

**Barriers to Accessing Services**

Though the prevalence is high, individuals with ID face daily barriers to accessing necessary mental health services. Impediments to accessing services include:

- Provider capacity and a shortage of professional expertise.
  - Overshadowing, the presenting issues, often challenging behaviors are attributed to the individual’s disability, instead of considering underlying medical and mental health conditions.
Atypical presentation

Differences in communication styles, can make it difficult to assess, diagnose and treat both medical and mental conditions.

- Design and operation of the existing delivery systems and funding, often resulting in a lack of cross system collaboration.

Additional barriers to accessing mental health services may include stigma, lack of support in seeking services and a lack of awareness of symptoms one may be experiencing.

**Benefits of Mental Health Service**

As professionals who work in mental health, we know about the benefits of a therapeutic relationship. The goals and specific methodology can vary from psychodynamic to behavioral, you may be working on past trauma or teaching skills to manage anxiety, but the benefits of a supportive, empathetic counseling relationship are always beneficial. The same holds true for individuals with an intellectual disability.

As professionals in our field, we follow a code of ethics. We are tasked with reducing suffering, providing equal access to treatment without discrimination, and assisting our clients to improve and maintain their quality of life. Mental health professionals, more than other professions, recognize the importance of individual personhood and lived experience, because we see it every day in our clients’ lives.

Leaving aside all ethical and compassionate arguments, there are significant benefits of mental health services for individuals with ID. Individuals who receive appropriate treatment to manage their symptoms will be healthier, care for themselves better, manage their behaviors more appropriately, and maintain their functioning in the community. This will result in less incarceration, likely less medical care, and fewer episodes of crisis which can result in ambulance trips and admits to the ER. All of these things are costly and can be prevented with mental health care to help individuals maintain at baseline.

From a strictly practical standpoint, providing integrated mental health services for individuals receiving services for ID makes sense. When all the professionals involved can pool their knowledge and resources, effectively utilize specialists, and collaborate on treatment plans, the individual has a significantly better experience. Medical complications, deterioration, and changes in functioning and mood are noticed and caught before they become a significant problem. A collaborative team approach results in the best care.

Individuals are not a series of compartments, and are not neatly divided into the different factors in their lives. We cannot separate physical health from mental health any more than we can separate challenges related to substance use, housing, education, employment, relationships, or social interaction. A struggle in one area will affect other aspects of an individual’s life. Why would we compartmentalize treatment? Integration of mental health and ID services is more efficient, effective, compassionate, and respectful.

For the complete guidebook:

[www.dshs.wa.gov/sites/default/files/SESA/publications/documents/Meeting%20the%20mental%20health%20needs%20of%20people%20with%20intellectual%20disabilities.pdf](http://www.dshs.wa.gov/sites/default/files/SESA/publications/documents/Meeting%20the%20mental%20health%20needs%20of%20people%20with%20intellectual%20disabilities.pdf)