

Mental Health Issues for Individuals with Intellectual & Developmental Disabilities: The Direct Service Perspective

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Learning Objectives

1. Understand risk factors for mental illness in individuals with IDD
2. Recognize common mental health challenges and their presentation in individuals with IDD
3. Identify strategies and resources to support individuals who are dually diagnosed

Why is it Important?

- Staff are the first line of defense and often the first to recognize signs and symptoms of mental illness. Early intervention can prevent symptom escalation and decompensation.
- Allows us to provide appropriate services, interventions, and supports. The solution must fit the problem!
- Fosters empathy and allows us to be more patient when a client is exhibiting challenging behaviors.
- Enables us to help our clients understand their experiences.
- Makes us better advocates for our clients with doctors, case managers, psychiatrists, behaviorists, etc.

People-First Language

“The language a society uses to refer to persons with disabilities shapes its beliefs and ideas about them. Words are powerful; Old, inaccurate, and inappropriate descriptors perpetuate negative stereotypes and attitudinal barriers. When we describe people by their labels of medical diagnoses, we devalue and disrespect them as individuals. In contrast, using thoughtful terminology can foster positive attitudes about persons with disabilities. One of the major improvements in communicating with and about people with disabilities is **People-First Language**. People-First Language emphasizes the person, not the disability. By placing the person first, the disability is no longer the primary, defining characteristic of an individual, but one of several aspects of the whole person. People-First Language is an objective way of acknowledging, communicating, and reporting on disabilities. It eliminates generalizations and stereotypes, by focusing on the person rather than the disability.”

True or False?

Individuals with IDD cannot have a mental health diagnosis.

FALSE

“The full range of psychopathology that exists in the general population also can co-exist in persons who have intellectual or developmental disabilities”

- National Association for the Dually Diagnosed (NADD)
www.thenadd.org

True or False?

Behavioral challenges in individuals with IDD occur because of their disability.

TRUE and FALSE


- ☀ Remember... **Behavior is communication of a legitimate need.** This need can be biological, social, or emotional.
- ☀ Behavioral challenges can be related to deficits in cognitive functioning, such as limited ability to problem-solve, communicate, or utilize coping skills. However, severe and pervasive behavioral challenges may be related to a deeper mental health issue.

Prevalence

“Estimates of the frequency of dual diagnosis vary widely, however, many professionals have adopted the estimate that 30-35% of all persons with intellectual or developmental disabilities have a psychiatric disorder.”

- National Association for the Dually Diagnosed (NADD)
www.thenadd.org

Risk Factors for Mental Illness in People with IDD

- 
1. What brings you joy and happiness? (at least 3)
 2. What cheers you up after a bad day? (at least 3)

Social Factors

- ☀️ Closest relationships are often paid staff
- ☀️ Friendships are few and/or unsatisfying
- ☀️ Lack of family involvement
- ☀️ Challenges with social interaction, especially nuanced skills like small talk and flirting
- ☀️ History of loss, including staff
- ☀️ Experience of marginalization, prejudice, and stigma
- ☀️ Discouraged from having romantic relationships
- ☀️ Experience of being taken advantage of
- ☀️ Lack of sexual contact and/or knowledge

Cognitive Factors

- ☀ Challenges with abstract thinking
- ☀ Difficulty with perspective-taking
- ☀ Reduced memory for learned coping skills
- ☀ Impaired reasoning and problem-solving
- ☀ Limited executive functioning (multi-tasking, planning, organizing)
- ☀ Receptive language deficit
- ☀ Difficulty identifying “why” they are experiencing an emotion

Environmental Factors

- History of multiple placements
- Institutionalization
- Unfulfilling job placements or day programs
- Limited access to enrichment activities
- Lack of financial independence
- Strict routines and lack of choice
- Service providers from different disciplines and agencies

Ability Factors

- ☀ Communication difficulties
- ☀ Reliance on others for care
- ☀ Level of independence
- ☀ Reduced sense of capability
- ☀ Conservatorship and case management

Psychological Factors

- Taught to be “compliant” and discouraged from doing tasks independently, leading to experience of helplessness
- Experience of shame around having a disability
- Fear of new environments or experiences due to feeling incapable
- Not having a “voice,” even if verbal, due to others not consulting them in decisions that impact them
- Being “bailed out” of challenging situations and not being given the opportunity to learn from mistakes
- History of abuse, bullying, and/or rejection
- Defense mechanisms may be primitive
- Impaired capacity for insight, resulting in an external focus for the cause of emotional distress

Group Discussion

What risk factors are present in
the clients you serve?

(10 minutes)

Mental Health Diagnosis:

Signs, Symptoms, and Considerations

When to Consider a Mental Health Diagnosis

- ☀ New or unusual symptoms
- ☀ Behavioral strategies are ineffective
- ☀ Changes in biological functioning
- ☀ Behavioral challenges are more severe or excessive compared to others at a similar functioning level
- ☀ Decline in adaptive skills
- ☀ Increase or change in behavioral challenges
- ☀ Recent stressors
- ☀ Trauma
- ☀ Impaired functioning in multiple areas
- ☀ Self-injurious behaviors
- ☀ History of psychiatric hospitalization
- ☀ Family history of mental illness

Note: Any of the above factors alone is likely insufficient evidence of a mental health diagnosis.

When to Consider a Mental Health Diagnosis

- ☀ Symptoms are not the result of:
 - ☀ A medical condition
 - ☀ A substance (includes prescribed medications)
 - ☀ Another co-occurring psychiatric diagnosis
- ☀ Must cause marked impairment in functioning (social, occupational, educational, etc.)

Although you are not responsible for diagnosing, knowing signs and symptoms of mental illness will allow you to communicate effectively with diagnosing professionals.

Diagnostic Categories

As defined by the DSM-IV-TR, the major diagnostic categories include:

- Mood Disorders: characterized by disturbance of mood (e.g. depression, bipolar)
- Anxiety Disorders: characterized by nervousness, fear, or worry (e.g. PTSD, panic disorder, OCD)
- Psychotic Disorders: characterized by disturbances in perception of reality (e.g. hallucinations, delusions)

Diagnostic Categories

- ☀️ Adjustment Disorders: characterized by behavioral or emotional symptoms related to an identifiable stressor
- ☀️ Personality Disorders*: long-standing patterns of problematic behavior in relationships (e.g. borderline PD, OCPD)
- ☀️ Other Psychiatric Disorders* include: substance abuse-related disorders, sexual and gender identity disorders, impulse control disorders, eating & sleep disorders, etc.

Mood Disorders

Depression
Bipolar Disorder

Common Symptoms of Depression

- ☀ Sadness
- ☀ Irritability
- ☀ Loss of interest or pleasure
- ☀ Weight or appetite changes
- ☀ Insomnia or Hypersomnia
- ☀ Psychomotor agitation or retardation
- ☀ Fatigue or loss of energy
- ☀ Feelings of worthlessness
- ☀ Lack of concentration
- ☀ Thoughts of death
- ☀ Decreased interest in sexual activity
- ☀ Physical complaints
- ☀ Guilt or self-blame
- ☀ Hopelessness
- ☀ Not tending to personal hygiene
- ☀ Low self-esteem

Presentation of Depression in Individuals with IDD

- ☀ Aggression
- ☀ Irritability
- ☀ Self-injury
- ☀ No longer participates in favorite activities
- ☀ Reinforcements no longer effective
- ☀ Increase in activity refusal
- ☀ Food-seeking
- ☀ Meal refusals
- ☀ Disruptive behavior
- ☀ Seeking punishment
- ☀ Social isolation
- ☀ Need for frequent breaks
- ☀ Preoccupation with death or violence
- ☀ “I’m stupid”
- ☀ “I’ll never be able to do it.”

Bipolar Disorder

Bipolar disorder is characterized by significant mood swings. An individual with Bipolar Disorder experiences episodes of elevated mood (mania or hypomania) and depressed mood.

Common Symptoms of Mania

- Elevated, euphoric, or irritable mood
- High energy level
- Feeling of being invincible
- Decreased need for sleep
- Inflated self-esteem/grandiosity
- Racing thoughts
- Rapid/pressured speech
- Distractibility
- Agitation
- Increase in goal-directed behavior
- Risky behaviors (e.g. gambling, sexual promiscuity, excessive spending)
- Poor judgment
- Delusions about abilities

Presentation of Mania in Individuals with IDD

- Increased physical affection in non-favored individuals
- Boisterousness
- Disruptive behavior at bedtime
- Engaged in activities at night
- Making improbable claims
- Dressing provocatively
- Demanding rewards
- Increased singing or swearing
- Perseverative speech
- Interrupting
- Decrease in task performance
- Increase in masturbation
- Fidgeting
- Repetitive questions
- Delusional beliefs about self (consider developmental level)

Bipolar I vs. Bipolar II

There are two types of Bipolar Disorder:

☀️ **Bipolar I:**

- ☀️ at least 1 full manic episode or mixed (simultaneous depression and mania) episode
- ☀️ often individuals also experience depressive episodes

☀️ **Bipolar II:**

- ☀️ at least 1 depressive episode
- ☀️ at least 1 hypomanic (less intense manic) episode

Anxiety Disorders

Anxiety Overview

Obsessive-Compulsive Disorder

Post-Traumatic Stress Disorder

Typical Symptoms of Anxiety

- Excessive worry
- Restless, “keyed up,” on edge, fearful
- Fatigue
- Difficulty concentrating or mind going blank
- Irritability
- Muscle tension
- Sleep disturbance
- Heart palpitations and/or accelerated heart rate
- Sweating
- Trembling
- Symptoms present for at least 6 months
- Avoidance of triggering stimuli
- Panic attacks*
- Agoraphobia*

There is no adaptation for clients with IDD for generalized anxiety or panic disorders, however many of the symptoms may be observed rather than reported.

Obsessive Compulsive Disorder (OCD)

- ☀️ OCD is characterized by distressing thoughts or images (obsessions). Individuals with OCD must engage in certain behaviors (compulsions) to relieve the anxiety caused by these obsessive thoughts.
- ☀️ Repetitive or unusual behavior is not necessarily compulsive. To be considered a compulsion, it must cause ***marked distress***, be ***time-consuming***, or ***interrupt routine***.
- ☀️ Often individuals with OCD experience multiple types of compulsions.
- ☀️ Everyone has quirks. A compulsion is ***disruptive*** to daily life.

Presentation of OCD in Individuals with IDD

| Type of Compulsion | Examples |
|-------------------------------|--|
| Ordering Compulsions | Arranging, stacking, ordering, lining things up |
| Completeness/Incompleteness | Closing doors, dressing and undressing self, tying and untying shoes |
| Cleaning/Tidiness Compulsions | Unnecessary and excessive cleaning |
| Checking/Touching Compulsions | Checking faucet is off, Repeatedly turning doorknob |
| Grooming Compulsions | Checking self in mirror excessively, Washing hands repeatedly |

Post-Traumatic Stress Disorder (PTSD)

- ☀ PTSD is characterized by psychological and emotional distress in response to experiencing or witnessing a traumatic event.
- ☀ Traumatic events include:
 - ☀ Abuse
 - ☀ Violent crime
 - ☀ Rape or sexual assault
 - ☀ Natural disasters
 - ☀ Fires
 - ☀ Car accidents
- ☀ Individuals with IDD also experience less intense trauma, such as bullying, rejection, and multiple losses.

Common Symptoms of PTSD

- Nightmares
- Recurring memories or flashbacks
- Physical complaints
- Hypervigilance
- Exaggerated startle response
- Depressive symptoms:
 - Lack of interest in activities
 - Insomnia
 - Difficulty concentrating
 - Feelings of sadness or hopelessness
 - Guilt over surviving trauma

Common Symptoms of PTSD in Individuals with IDD

- ☀ Reliving event through play or nightmares
- ☀ Intense or chaotic agitation
- ☀ Difficulty separating from caregivers or being alone
- ☀ Regressive behavior, including thumb sucking or bed wetting
- ☀ Unusual behavior in specific situations that resemble trauma
- ☀ Sense of being “on guard”
- ☀ Decreased task performance

Psychotic Disorders

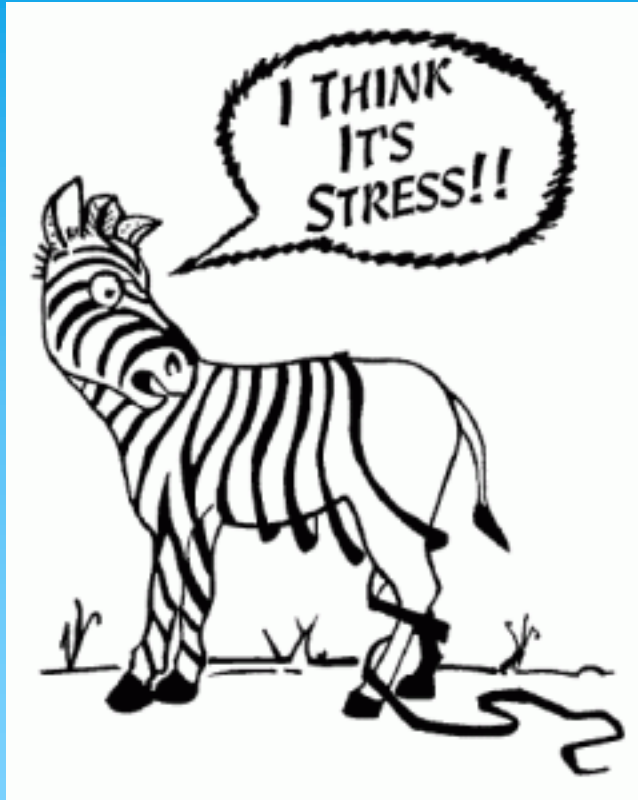
Schizophrenia
Schizoaffective Disorder

Schizophrenia

- ☀ Schizophrenia is characterized by disorganized thinking, emotional disturbance, and/or impaired perceptions of reality.
- ☀ Must consider developmental level – belief in fantasy worlds, imaginary friends, self-talk can all be appropriate.

Common Symptoms of Schizophrenia

- **Delusions:** strongly-held false beliefs (can be bizarre or non-bizarre)
- **Hallucinations:** perceiving things that aren't there (can impact all the senses)
- “Word salad” or disorganized speech
- Flight of ideas
- Catatonia
- Depressive symptoms



Adjustment Disorders

Characterized by behavioral or emotional symptoms related to an identifiable stressor

Adjustment Disorder

- ☀️ Adjustment disorders are characterized by a significant change in behavior or mood following an identifiable psychosocial stressor, such as a job change or move.
- ☀️ For clients with IDD, this can involve any change in their environment or placement that may require more independent functioning than they are comfortable with.
- ☀️ Symptoms may not be related to Bereavement.
- ☀️ Symptoms cannot persist for more than 6 months after the stressful event.

Adjustment Disorder Subtypes

- ✿ Adjustment Disorders can present with many different clusters of symptoms:
 - ✿ Anxiety
 - ✿ Depressed Mood
 - ✿ Disturbance of Conduct
 - ✿ ...or any combination of the above
- ✿ For some clients with IDD, they experience repeated, ongoing stressors (e.g. repeated hospitalizations, caregiver turnover, placement changes, etc.

Interventions, Strategies, and Supports



Challenges

Inconsistent Information

Medication

Intellectual Disability

Mental Illness

Direct Support Strategies

- ☀️ Work one step at a time, one concept at a time
- ☀️ Teach emotional vocabulary
- ☀️ Identify and encourage use of replacement behaviors (e.g. deep breathing)
- ☀️ Encourage clients who are irritable to examine what else they are feeling (e.g. shame, anxiety, fear, sadness)
- ☀️ Avoid abstract concepts
- ☀️ Help clients feel heard by summarizing what the client is communicating (either verbally or nonverbally)
- ☀️ Structure the environment for emotional regulation (e.g. lighting, noise, number of people)

Direct Support Strategies

- ☀️ Provide visual cues
- ☀️ Offer options/choices and avoid open-ended questions
- ☀️ Provide routines and structure, reduces need for executive functioning
- ☀️ Model appropriate boundaries and use of coping skills
- ☀️ Encourage natural and enduring relationships with friends, neighbors, family, etc.

Direct Support Strategies

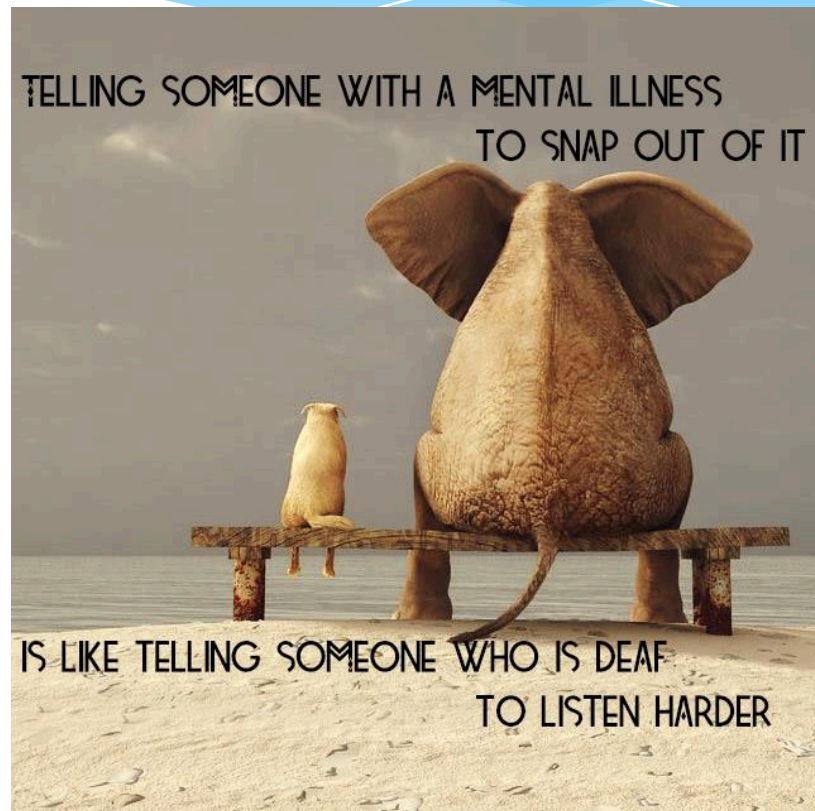
- ☀ Focus more on a client's emotional experience than the accuracy of their information
- ☀ Be aware of your body language and nonverbal communication. Individuals with IDD are very receptive and can “read” what you want them to do/say.
- ☀ Help build self-esteem and confidence by working on adaptive skills
- ☀ If you use figures of speech, make sure you provide a concrete explanation
- ☀ Acknowledge and celebrate success. Be your client's cheerleader!

Direct Support Strategies

☀️ Validate...

☀️ Validate...

☀️ Validate!!



Treatments and Interventions

- Adapted Psychotherapy
- Guided Relaxation
- Skills-Focused Groups
- Creative Therapies
- Volunteering or Vocational Training
- Sensory Integration
- Psychotropic Medications

Scenarios

As a group, read the scenario and answer the following questions:

- ☀️ Name at least 3 specific risk factors (e.g. psychological, social, cognitive, etc.) for mental illness.
- ☀️ What mental health diagnoses would you consider for this client?
- ☀️ Name at least 3 strategies/resources you would try to support this client.

Resources

- ☀ DM-ID: A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability, edited by Robert Fletcher
- ☀ The Psychopharmacology Primer by Edward E. Hughes and Jerry McKee
- ☀ The Solutions Building Community Collaborative Certificate of Excellence in Dual Diagnosis (www.solutionsbuilding.org)
- ☀ National Association for the Dually-Diagnosed (www.nadd.org)