The Other dual diagnosis. Working with and providing mental health services to the DD/ID (IDD) population and their family

Presented by: Jackie Scarborough, Ph.D., LPC, ACS, BCPC
Director of Mental Health at Bost, Inc.
Counseling and Relationship Enrichment Services (C.A.R.E.S.)

"It is really hard for people in direct care to see their power. They often see themselves as the least powerful person in the organization so they forget that they are often the most powerful person in the life of somebody with a disability." - Dave Hingsburger

What is dual diagnosis?

- Dual Diagnosis is a term applied to the co-existence of the symptoms of both intellectual or developmental disabilities and mental health problems.
- The American Psychiatric Association defined intellectual disabilities as significantly below average intellectual and adaptive functioning with onset before age 18 years (DSM-V, 2013).
- Significantly sub average functioning is defined as an IQ score of 70 or below.
- Adaptive behavior refers to the effectiveness with which an individual meets society's demands of daily living for individuals of his/her age and cultural group. The measurement of adaptive behavior may include an evaluation of an individual's skills in such areas as eating and dressing, communication, socialization and responsibility.

3

WHY IS THIS IMPORTANT?

- Staff, friends and family members are the first line of defense and are 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, school personnel, etc.

4

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

5

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.

6

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

7

Risk Factors for Mental Illness in People with IDD

- What do you think are some risk factors?

8

Social Risk Factors

- Closest relationships can often be paid staff
- Friendships may be 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
- Experience of being taken advantage of
- Discouraged from having romantic relationships
- Lack of sexual contact and/or knowledge

9

Cognitive risk 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

10

Environmental risk factors

- History of multiple placements
- Institutionalization (FINALLY ON THE WAY OUT!)
- Unfulfilling job placements or day programs
- Limited access to enrichment activities
- Lack of financial independence
- Lack of privacy
- Strict routines and lack of choice
- Service providers from different disciplines and agencies

11

Ability risk factors

- Communication difficulties
- Reliance on others for care
- Level of independence
- Reduced sense of capability
- Conservatorship

12

Psychological Risk 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 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

13

Stress Risk Factors

- Stress – mental or emotional tension due to any event perceived by the individual to be demanding, straining, or challenging
- Stress can be a good thing, however, chronic stress can impact physical and mental health
- Fewer resources or coping skills to deal with stress
- Each additional stressor increases odds of poor mental health by 20% (Scott & Havercamp, 2014)

14

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

15

When to Consider a Mental Health Diagnosis (cont.)

- 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. Adapted from Solutions Building Community Collaborative www.solutionsbuilding.org
  - People with IDD often increase or decrease already-existing behavior anomalies (e.g., hand flapping, making loud noises, pacing). These baseline exaggerations are routinely mistaken for learned behaviors that are part of the developmental delays and not assessed as possible symptoms of an emerging mental illness, according to Silka and Hauser.

16

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

17

Presentation of Depression in Individuals with IDD (cont.)

- 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."

18

Presentation of Mania in Individuals with IDD

- Increased physical affection in non-favored individuals
- Boisterousness
- Disruptive behavior at bedtime
- Engaged in activities at night
- Dressing provocatively
- Demanding rewards
- Increased singing or swearing
- Perseverative speech (repetition of a particular response (such as a word, phrase, or gesture) regardless of the absence or cessation of a stimulus)

19

Presentation of Mania in Individuals with IDD (cont.)

- Interrupting
- Decrease in task performance
- Increase in masturbation
- Fidgeting
- Repetitive questions
- Delusional beliefs about self (consider developmental level)

20

Typical Symptoms of Anxiety

- Excessive worry
- Restless, "keyed up," on edge, fearful
- Fatigue
- Difficulty concentrating or mind going blank
- Irritability
- Muscle tension
- Sleep disturbance

21

Typical Symptoms of Anxiety (cont.)

- 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.

22

Presentation of OCD in Individuals with IDD

TYPE OF COMPULSION	EXAMPLE
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

23

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

24

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.

25

Adjustment Disorders

- Having emotional or behavioral symptoms within three months of a specific stressor occurring in your life
- Experiencing more stress than would normally be expected in response to a stressful life event and/or having stress that causes significant problems in your relationships, at work or at school
  - 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.
  - For some clients with IDD, they experience repeated, ongoing stressors (e.g. repeated hospitalizations, caregiver turnover, placement changes, etc.)
- Symptoms are not the result of another mental health disorder or part of normal grieving

26

Direct Support Strategies

- Work one step at a time, one concept at a time
- Teach emotional vocabulary
- Identify and encourage use of coping skills to replace unhealthy behaviors (e.g. deep breathing, taking a break)
- 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)

27

Direct Support Strategies (cont.)

- 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.

28

Direct Support Strategies (cont.)

- 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 (feeling blue, driving me up the wall)
- Acknowledge and celebrate success. Be your client's cheerleader and validate!

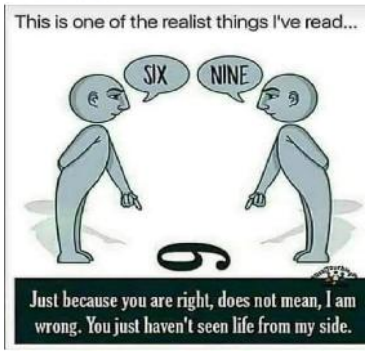
29

Direct Support Strategies (cont.)

- Validate…
- Validate…
- Validate!!
  - Empathy vs. Sympathy
    - Empathy means **experiencing** someone else's feelings. It requires an emotional component of really feeling what the other person is feeling. Sympathy, on the other hand, means **understanding** someone else's suffering. It's more cognitive in nature and keeps a certain distance.
      - "But" or "at least" is NOT a sign of empathy!
    - Empathy put you on the same team, with shared feelings. Instead of trying to fix it by offering a different perspective, the fix is to assure the other person that those feelings are valid and that they are not alone.

30

First seek to understand. Then be understood…



31

REFERENCES

- Diagnostic and Statistical Manual of Mental Disorders: DSM-5 by the American Psychiatric Association
- 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)
- Hartley, S.L., & MacLean , W.E. Jr. (2009). Stressful social interactions experienced by adults with mild intellectual disability. American journal on intellectual and developmental disabilities, 114(2), 71-84
- Scott, H.M. (2016). Social support, physical activity, and stress as determinants of wellbeing in adults with intellectual disability.
- Scott, H.M., & Havercamp S.M. (2014). Mental health for people with intellectual disability: the impact of stress and social support. American journal on intellectual and developmental disabilities, 119(6), 552-564
- Developmental Disabilities Assistance and Bill of Rights Act of 2000. Public Law 106-402. October 30, 2000.

32