Caregivers Caring for Young Adult and Adult Individuals with Developmental Disabilities

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What is a Developmental Disability?

- The Developmental Disabilities Act (2000) defines developmental disability as a severe, chronic disability of an individual that:
  - Is attributable to a mental or physical impairment or combination of mental and physical impairments;
  - Is manifested before the individual attains age 22;
  - Is likely to continue indefinitely;
  - Results in the substantial functional limitations in 3 or more of major life activities.

I/DD

Many individuals receiving services through DHHS DD services have a diagnosis of autism spectrum disorder, intellectual disability, or both and exhibit significant deficits in adaptive functioning (skills that involve ability to complete age-appropriate activities of daily living).

I/DD = Intellectual and/or developmental disability.

Intellectual Disability

- Intellectual Disability – deficits in intellectual functions, deficits in adaptive functioning, onset during developmental period.
  - Severity – Mild, moderate, severe, profound
  - Not contingent on specific IQ for clinical diagnosis.

Autism Spectrum Disorder

Autism Spectrum Disorder:

A. Persistent deficits in social communication and social interaction across multiple contexts

B. Restricted, repetitive patterns of behavior, interests, or activities.

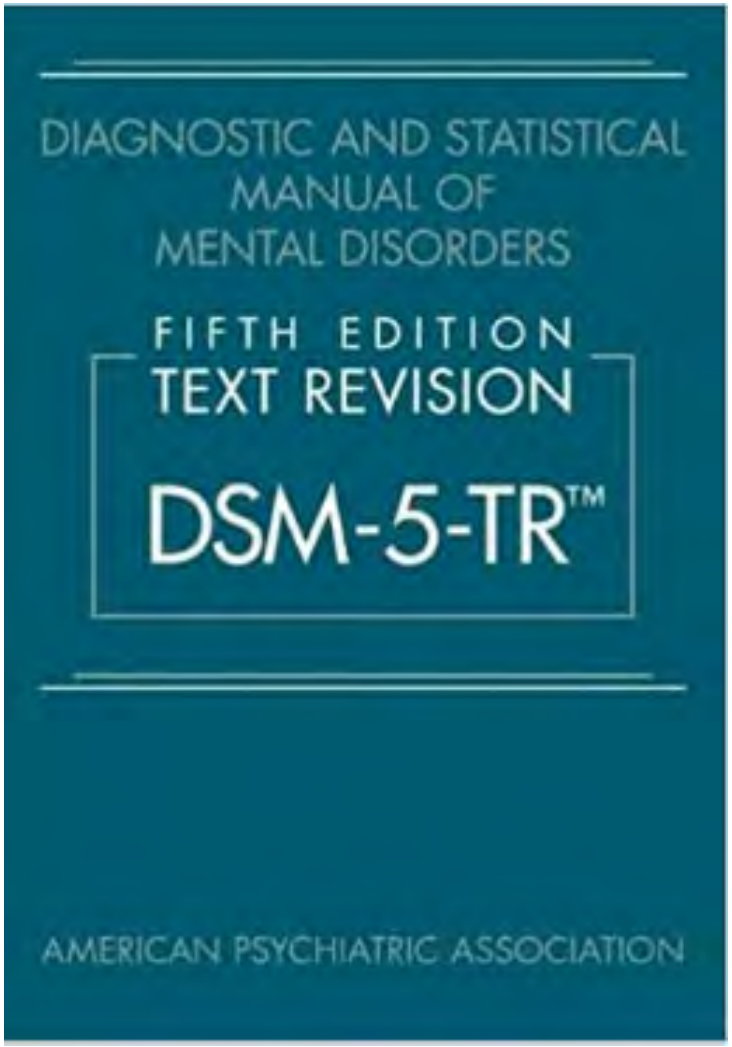
C. Symptoms must be present in early developmental period

D. Symptoms cause clinical impairment in social, occupational, or other areas of current functioning.

E. Disturbances are not better explained by an intellectual disability.

Mental Health Disorder

A mental disorder is a syndrome characterized by clinically significant disturbance in an individual's cognition, emotion regulation, or behavior that reflects a dysfunction in the psychological, biological, or development processes underlying mental functioning.



Dual Diagnosis

Dual Diagnosis - DD/MI dual diagnosis refers to individuals with an I/DD who concurrently experience a mental health condition. (https://thenadd.org/)

It is often difficult for clinicians to diagnose mental health conditions in individuals with I/DD.

Prevalence Rates

- While the exact prevalence is unknown, most professionals accept that roughly 35% of people with intellectual disabilities also experience mental health challenges. (https://thenadd.org/)

Common Mental Health Conditions

- Depressive disorders
- Anxiety disorders
- Schizophrenia spectrum disorder and other psychotic disorders
- Bipolar and related disorders
- Obsessive-compulsive and related disorders
- Trauma- and stressor-related disorders

Common Mental Health Conditions

Schizophrenia – Delusions, hallucinations, disorganized speech, disorganized or catatonic, diminished emotional expression	OCD – Presence of obsessions, compulsions, or both.	Bipolar – Combination of manic episodes and depressed mood
• Different than symptoms of ID • Individuals may have lack of insight • Symptoms may be under-reported	• May not have complex obsessive thoughts or ability to communicate thoughts. • Not the same as repetitive behaviors found in ASD	• Bipolar 1 – Severe mania and often depression • Bipolar 2- Hypomanic and major depressive episode • Aggression may be a result of irritable mood • Pressured speech may appear as increased vocalization.

Anxiety

- Anxiety disorders are common in individuals with developmental disabilities (I/DDs), they may not be diagnosed and treated as often as they are in patients without DDs (Davis, Saeed, & Antonacci, 2008).
  - May be made more difficult by communication deficits, behavior problems, and lack of assessment tools for the I/DD population.
- Individuals with I/DD may exhibit symptoms of anxiety disorder at much higher rates than the general population.
- High rates of anxiety have been consistently reported for individuals meeting criteria for autism or autism spectrum disorders (Montazeri, Bildt, Dekker, & Anderson, (2019).
  - Can have an impact on functioning and qualify of life.

Anxiety

Individuals with an I/DD may not report anxiety in the same way as people without an I/DD.

People with an I/DD may report more physical aspects of anxiety

- “I feel like I’m having a heart attack”
- Complaints of an aching chest
- Complaints of a sore throat
- Reports that their body is “falling apart”
- Reporting lack of sleep

Perseveration

Inability to move on from a specific topic or idea.

Intervention

Visual Schedule
Write out answer
Use of a timer
Planned Ignoring
Differential Attention

Depression

Social and cognitive factors that contribute to depression in individuals without an intellectual disability, also contribute to individuals with an intellectual disability.

Depression in individuals with a mild intellectual disability is associated with low levels of social support (Reiss & Benson, 1985).

Depression is correlated with negative automatic thoughts and feelings of hopelessness in individuals with mild intellectual disability (Nezu et al., 1995).

Depression and ASD

Lifetime prevalence is 14.4%

Current prevalence is 12.3%

Rates were higher in studies that included individuals with higher intelligence.

Compared to typically developing adults, individuals with ASD are 4 times more likely to experience depression in their lifetime (Hudson, Hall, & Harkness, 2019).

Depression Treatment

- Behavioral Activation
  - Exercise
  - Social activities
  - Engaging in hobbies or activities
- Reframe negative thoughts
- Minimize attention to depressive comments

I/DD Vulnerabilities

- Individuals with ID/DD are at an increased risk for experiencing victimization across the lifespan (Fisher, Corr, & Morin, 2016).
  - Child abuse
  - Bullying
  - Criminal victimization (adulthood)
- Lifetime prevalence rates of 26%-90% among women with disabilities and 29%-87% among men with disabilities (Hughes, Lund, Powers, & Curry, 2011).
- Childhood victimization is also linked with greater risk of re-victimization in adulthood (Renner & Slack, 2006).

I/DD Vulnerabilities

Biological

- Genetic and medical difficulties

Sociocultural

- Lack of social support
- Bullying
- Difficulties finding and maintaining friendships

Cognitive

- Deficits in learning, processing information, understanding social cues, communication

Systemic

- Services after school
- Obtaining services and finding providers that work within the I/DD community

Psychodynamic

- Less likely to access therapy or to find a therapist.

Habilitative Programming

Data-based decision making

- Set reasonable and realistic goals
- Track progress by collection of data
- Utilize data in meaningful manner

Meaningful habilitative programming

- Are goals relevant to increased independence and least restrictive environment?

Accurate measurement (not all based on level of prompts).

Measurement

If tracking problem behavior you would like to reduce, collect data on the frequency of behavior

If you are teaching a skill the individual has not mastered, collect data on level of prompting

Determine “Can’t Do” vs “Won’t Do.”

Understanding Behavioral Concerns

Not all I/DD individuals are dually diagnosed or have a co-existing mental health condition

Several factors contribute to behavioral concerns

- Cognitive deficits (lack of understanding)
- Difficulties with communication
- Environment
- Mental Health conditions

Functions of Behavior

Functions typically include the following:

Peer/staff attention	**Escape from an unwanted task or activity**	**Access to tangibles**	**Automatic (sensory, not maintained by environment)**

Response (intervention) should always be based on function.

Determining ABCs

Antecedent (what happens right before behavior)

- Setting event

Behavior (What exactly happens during behavior)

- Be as specific as possible

Consequence (not punishment)

- What happens directly after behavior
- ABCs should be summarized in GER documentation.

Setting Event

External or internal conditions that increase the likelihood that the behavior will occur.

Events that “set the stage.”

Examples of setting events

- **Underlying mental health concerns**
- Missing breakfast
- Not taking morning medications
- Substitute staff
- Physical problem such as headache or stomachache

Attention Maintained Behavior

Planned ignoring

- Refraining from providing attention to inappropriate behavior
- May result in an extinction burst

Differential attention

- Provide positive attention to appropriate behaviors
- Utilize planned ignoring for behaviors you would like to see less of.

Escape Maintained Behavior

Offer opportunity to take a short break

Break large tasks into smaller tasks

Utilize “if, then” statements.

Access to Tangibles

Reinforce appropriate requests

If you can’t honor request, remind individual when they may have access to the item.

If possible, refrain from providing item if problem behavior is occurring.

Sensory

Block response if possible

Provide alternative sensory stimulation

If overstimulated, move to a quiet location

Teach Replacement Behaviors

Obtain object/activity: Teach how to ask for the item (using words, signs, pictures, or gestures)

Obtain Attention: Teach how to request attention (e.g. raise hand, tap your shoulder, etc.)

Avoidance/Escape Difficult Tasks: Teach how to ask for a short break or ask for assistance with a difficult task

Always positively reinforce (reward) use of appropriate replacement behaviors!!!

Responding to Problem Behaviors

Behaviors to not occur “out of the blue.” First determine the function of the behavior.

While an individual may be struggling with mental health concerns, we do not want to teach the individual inappropriate responses to difficult emotions/feelings.

Refrain from discussing the problem while the individual is upset. It is not that we do not value the individual’s thoughts and feelings, but we do not want to positively reinforce problem behavior.

Set clear expectations and consequences for problem behavior.

Provide opportunity for individual to utilize a replacement behavior and positively reinforce the use of a replacement behavior.

Self-Care and Coping

Behavior change is difficult

- If working to reduce problem behavior, expect behavior to get worse before it improves.

Some of the most effective behavioral interventions include not responding.

- Remove yourself to a safe location if possible.
- Utilize strategies to make planned ignoring easier to implement (e.g. distraction, calming techniques).

Diaphragmatic Breathing

Lie on your back on a flat surface or in bed, with your knees bent and your head supported. You can use a pillow under your knees to support your legs.

Place one hand on your upper chest and the other just below your rib cage. This will allow you to feel your diaphragm move as you breathe.

Breathe in slowly through your nose so that your stomach moves out, causing your hand to rise. The hand on your chest should remain as still as possible.

Tighten your stomach muscles, so that your stomach moves in, causing your hand to lower as you exhale through pursed lips. The hand on your upper chest should remain as still as possible.

https://my.clevelandclinic.org

Depersonalization

"They know better"

"They should be able to, they have before"

Remember the needs of the individual and why they are in your care.

- Mental health
- Setting event
- Behavioral ABCs

Always attempt to determine the function of the behavior.

Questions??

Resources

- https://thenadd.org/
  - An association for persons with intellectual disability and mental health needs.
- Diaphragmatic breathing
  - https://www.youtube.com/watch?v=Mg2ar-7_HfA

References

- https://thenadd.org/
- Hudson, C.C., Hall, L., Harkness K.L. 2019. Prevalence of depressive disorders in individuals with autism spectrum disorder: A Meta-Analysis. *Journal of Abnormal Child Psychology,* 47, 165-175
- Montazeri, F., de Bildt, A., Dekker, V. et al. J Autism Dev Disord (2019) 49: 2219. https://doi-org.library1.unmc.edu/10.1007/s10803-018-3474-4
- Nezu, C. M., Nezu, A. M., Rotherburg, J. L., DelliCarpini, L., Groag, I. 1995 Depression in adults with mild mental retardation: are cognitive variables involved? *Cognitive Therapy and Research*, **19**, 227 39.

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