DOUBLE TAKE: WHEN ID/D AND MH COLLIDE

CONSIDERATIONS FOR SUPPORTING DUALLY-DIAGNOSED INDIVIDUALS

Priscila Norris, MS, MSW, LCSW
RHA Heath Services
Clinical Director, NC START East
priscila.norris@rhanet.org

Morgan Futrell, MS, MSW
RHA Heath Services
Team Leader, NC START East
morgan.futrell@rhanet.org

Presentation Outline

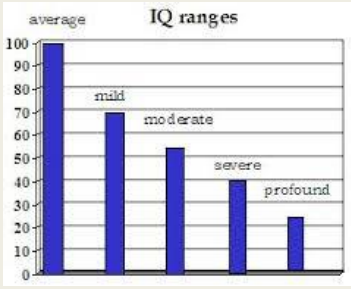
- Review of Intellectual and Developmental Disabilities
- IDD and MH comorbidity
- Special vulnerabilities
- Clinical presentations of common psychiatric conditions in people with IDD
- Clinical Interviews: Obtaining meaningful information through a biopsychosocial approach
- Case studies

What Is an Intellectual Disability?

- Intellectual Disability (Intellectual Developmental Disorder per DSM 5) is a life-long and complex developmental condition
- Associated with significant impairment in intellectual functioning and adaptive behaviors, negatively effecting a person's ability to learn and function independently
- Characterized by significant subaverage intellectual functioning and deficits in conceptual, social, and practice skills.
- Varied etiology and course
- Diagnosed by assessing three factors
  - *Intellectual Functioning - IQ Testing*
  - *Adaptive Functioning – Comparative Rating Scales*
  - *Onset of intellectual and adaptive deficits during the developmental period*

Four Levels of ID by IQ

- Mild – 70 to 50/55
  - *(85% of all ID)*
- Moderate – 50 /55 to 35 /40
  - *(10% of all ID)*
- Severe – 35 /40 to 20 /25
  - *(3 – 4% of all ID)*
- Profound – Below 20 /25
  - *(1 – 2% of all ID)*



- Intellectually disabled but not developmentally disabled – Moderate to Severe TBI in adulthood
- Developmentally disabled but not intellectually disabled - ASD with no intellectual impairment
- Global Developmental Delay- Clinical severity and diagnosis of ID not reliable in children under age 5

Prevalence in general population

- Prevalence of ID ~ 1% of gen pop
- Higher in males:
  - *Mild ID 1.6:1 male-to-female ratio*
  - *Serve ID 1.2:1 male-to-female ratio*
- Highly associated with Down syndrome and Fragile x syndromes
- Higher prevalence among lower income countries and those under US poverty level
- Aprox. 38-41% of individuals with ASD have co-occurring ID

American Psychiatric Association, 2013
National Association for the Dually Diagnosed, 2016

Mental Health Conditions and IDD

Though Intellectual and Developmental Disabilities and Mental Health conditions are classified under DSM 5 as *Mental Disorders*, it is important to remember the differences.

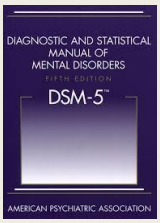
MH	ID/D
• impairment in behavior, mood, thought processes and/or interpersonal relationships to a degree causing significant disruption in that person's typical functioning. • Diagnostic methods vary, but often involve an interview with the individual who describes his/her symptoms. • Broad range of MH Dx grouped by categories like depressive disorders, schizophrenia spectrum, anxiety disorders, etc. • Onset: 75% begin at age 24 • Treatment responsive • Can remiss	• Affects both intellectual functioning and adaptive abilities • Adaptive abilities may increase, but cognitive decline is expected with age • May have onset at any time during development, including gestation • Diagnostic methods reliant upon psychometrically sound measures, along with collateral and interviews • Life-long • Increases medical and psychiatric vulnerabilities

Prevalence of co-morbidity

- Between 20-70% of individuals with ID/DD experience significant behavioral problems- though may not meet Dx criteria
- Rate of diagnosable mental disorder in gen pop: I in 5 adults
- Rate of diagnosable mental disorders in ID pop: 3-4 x higher
- Higher prevalence rates have been linked to:
  - *severity of ID*
  - *level of impairment in adaptability*
  - *coexisting neurological or medical conditions*
  - *history of abuse and neglect*
- Acute Stress: early life stressors may cause changes to brain structure and chemistry
  - *Baseline atypical brain structures (e.g., smaller hippocampus) may predict risk of heightened effects of stress*

American Psychiatric Association, 2013
Nezu, Nezu and Gilll-Weiss, 1992.

Clinical Presentations



Schizophrenia and other psychotic disorders

- Research has shown that up to 4% of people who have ID have schizophrenia (compared with about <1% gen pop)
- Delusions and Hallucinations are identified by self-report, which can be difficult for a person with ID.
  - Developmental profile (Magical thinking, imaginary friends, self-talk, wishful thinking, and fantasy)
  - Attempting to mask ID
  - Ability to describe and report internal states and medical symptoms; Vocabulary array and verbal comprehension deficits
  - Previous institutionalizations, including inpatient hospitalizations
- Concrete thoughts and low perceptual reasoning- speech appears to be jumbled, which could be misattributed as disorganized thinking
- Concern about what other people think – often because they have been treated unkindly, rejected or discriminated against in the past. This could be misinterpreted as paranoid thinking
- Diagnostic clarity more difficult in severe ID
- Socially inappropriate or disturbed behavior that is out of character could be an early sign of psychosis. Must know the baseline.

Post-Traumatic Stress Disorder

- In the general adult population, the most common symptoms reported include nightmares, trouble sleeping, and "jumpiness"
  - Intellectual and communication deficits may interfere with the individual's capacity to give a coherent and reliable narrative disclosing trauma experience
  - Heavy reliance on collateral informants, who may not know the individual's history
- Events not commonly viewed as traumatic such as loss of caregiver or a car accident, can be experienced as such in individuals with ID, and elicit post-traumatic symptoms
- The lower the developmental level, the greater the likelihood of behavioral rather than verbal expression of distress
  - Flashbacks may be mistaken for hallucinations
  - Emotional numbing may be confused with depression or task refusal
  - Lack of motivation or confusion is associated with the negative symptoms of psychosis
- Brain physiology is affected by trauma: cortex should be biggest part but in individuals with PTSD it is smaller, and the amygdala is larger
- Alarmingly, one of the most frequent diagnoses preceding PTSD in individuals with IDD is either no diagnosis or schizophrenia

Depression

- Depression is easily missed in people with greater cognitive impairment and communication deficits, but depression is more common in people with ID
- DSM 5 included DMDD to address over-diagnosis of Bipolar D/o in children- youth with chronic irritable mood are more likely to have anxiety or depressive disorder.
- Depression and anxiety gave similar and overlapping developmental pathways
- Diagnosis of depression is heavily dependent upon expression of internal states- reliance on informant reports
- Co-occurring aggression and motor restlessness are often mistaken for mania
- Due to deficits in communicating one's feelings, it is important to be able to describe and monitor any behaviors which may reflect any underlying depression
- Phenomenology of depression in people with ID follows mental age, not chronological
  - Irritable mood, motor restlessness, conduct disturbances
  - In general, behavioral changes, such as screaming, agitation, self-injury, sleep disturbance and reduced communication are common
  - Aggression is not diagnostically specific though occur at high rates

Anxiety

- Affects about 18% of gen pop; same or higher in the IDD pop
- All DSM 5 anxiety disorders use the terms “fear”, “anxiety”, or “worry” . These are concepts that require some introspection and cognitive ability to assess and report
- A study investigating depression (n=85), anxiety (n=70) , and bipolar disorder (n=70) in individuals with ID
  - Fearful, irritable, anxious distress were the highest reported symptoms
  - Show fearfulness was higher than in the other groups
  - Ritualized behaviors were the highest behavioral symptoms reported followed by tantrums
- Anxiety is frequently part of depressive illnesses- similar and overlapping neuropathways
  - Behaviors might include constant seeking for reassurance, restlessness, and increased agitation
- Individuals with ID are often sifted among providers, residential placements, and have little control over their own lives- creating anxiety and worry
- Most with anxiety present with somatic complaints leading to fruitless medical evaluations and missed psychiatric diagnosis.

Hurley, 2008
National Association of Dually Diagnosed, 2016

Grief

- DSM 5 recognizes that bereavement is a severe psychosocial stressor that can precipitate major depressive episode in a vulnerable individual and can begin soon after loss
- Early psychodynamic theories of grief suggest that only those who are capable of understanding the finality of death, and who are able to perform the arduous psychological task of withdrawing, grieve. Even without a cognitive understanding of death, however, it is possible to notice the absence of a loved one and to react emotionally to that loss. (Brickell & Munir)
- Cognitive limitations may limit ability to successfully discover meaning in loss and determine developmentally-equivalent explanations of death and loss (e.g. “she is now an angel”, “I talk to her in my mind”)
- Grief may be experienced across a full spectrum of symptoms
- Hollins & Esterguyzen studied 50 bereaved adults with ID, matched for age and disability with 50 controls, using the Aberrant Behaviour Checklist (ABC) and the Psychopathology Instrument for Mentally Retarded Adults (PIMRA).
  - The bereaved group was significantly more irritable, lethargic, and hyperactive, and had significantly more inappropriate speech.

Hollins & Esterguyzen, 1997
Brickel & Munir, 2008

Personality Disorders

- Prevalence estimates in the literature range from 1.4% to 91% across settings
- Personality variables are concepts without sharp boundaries, making them imperfect measures of functioning or of any other concept.
- Personality is reflected in patterns of behavior and experience that occur consistently across a variety of settings, and across lifetime.
- There are currently 10 personality disorders, and PD NOS.
- Exposure to complex trauma such as abuse and neglect impact development of secure attachment, brain biology, behavioral control, cognition, affective regulation, self-concept
- The PDs characterized by "patterns" similar to those of individuals with a history of complex trauma are Borderline, Histrionic, Avoidant, and Dependent.
  - habitual rigidity, inflexibility, develop rituals, try to control others and their environment, quickly shutdown, become angry, focus on personal interests/obsessions
- Individuals with IDD are likely to experience delays in development that may result in immature personality, which will likely have these traits.
- In addition, many of these "patterns" can be seen as symptoms of early and/or prolonged exposure to trauma, development of attachment difficulties, and from common experiences of individuals with IDD that may have had protected upbringing and relative restricted exposure to some cultural experiences that would facilitate learning social norms and community skills

Personality Disorders cont.

- Borderline : instability of interpersonal relationships and significant impulsivity. Might feature anger toward caregivers if they are seen as neglectful or abandoning. Impulsivity in at least 2 areas: spending, sex, SU, reckless driving, and binge eating
- Histrionic: excessive emotionality and attention-seeking. Can be sexually provocative and theatrical, display shallow and shifting emotions, are suggestible.
- Avoidant: social avoidance and inhibition, preoccupation with rejection, and hypersensitivity
- Dependent: characterized by a fear of separation or loss of support, need for reassurance, and need for others to assume responsibility

Clinical Interviews and assessment: a biopsychosocial approach

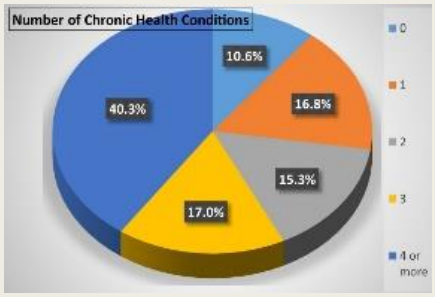
Biomedical vulnerabilities

- Have a High Rate of Unmet Health Needs
  - Often lack access to appropriate and effective health care
  - Previously missed problems are found at high rates when screens and health checks are completed
- Are at higher risk to a variety of medical conditions such as cardiovascular disease, seizure d/o, neurological abnormalities, seizures, gastrointestinal issues, etc.
- People with ID have few ways to express distress and are poor at reporting their internal states
- Most people with ID are referred for psychiatric care due to problem behaviors i.e. aggression, SIB, disruptive behaviors
  - Pain or physical discomfort may act as a “setting event” lowering the threshold for challenging behaviors
  - higher odds of displaying aggressive behavior than those with fewer and less severe physical health problems.”
- Aggression can be a sign of physical distress. "It's like a Fever”

Sobsey & Varnhagen, 1992
Crocker, A. G., Prokić, A., Morin, D., & Reyes, A. 2014

Biomedical vulnerabilities

- A 2012 study of 983 individuals with IDD revealed that 2/3 had 3 or more chronic conditions, and 40.3% had 4 or more



Hsieh K, Rimmer J, Heller T, 2012

Biomedical vulnerabilities: Rule out medical issues

Gather information on medical and pharmacological history and rule out medical or biological issues

- Changes in eating or fluid intake
- Changes in vital signs
- Falls
- New, worsening, or unusual movements
- Lethargy
- Sleep problems
- Changes in bowel or bladder behavior
- Changes in mental status
- Know the individual's usual behavior
- Know the individual's ability to describe pain

Psychological vulnerabilities

Four confounding factors that often present during clinical interviews w/ persons w/ ID (Sovner, 1986)

- Baseline Exaggeration – Problem behavior is present in most daily activity, but increase in frequency/intensity during periods of distress
- Intellectual Distortion – Individual not understanding questions and/or cannot mentally assemble correct response
- Psychosocial Masking – Presenting symptoms within a developmental framework. (e.g. individual experiencing a manic episode may believe he/she can drive a car – not often seen as grandiose w/ typically developing person)
- Cognitive Disintegration – Effects of MH symptoms like MDD, GAD may require too much "psychic energy" for individual w/ ID. As such they may appear delusional or psychotic.

Psychological vulnerabilities

Diagnostic overshadowing

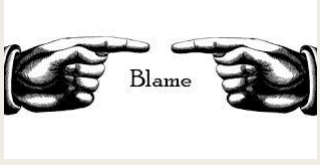
- Diagnostic overshadowing refers to the process of over-attributing an individual's symptoms to a particular condition
- It was originally described in people with developmental disabilities, where their psychiatric symptoms and behaviors were falsely attributed to their disability, leaving any comorbid psychiatric illness undiagnosed
- Research has shown that comorbid medical conditions are often "diagnostically overshadowed" by the presence of a prior psychiatric disorder or developmental disability diagnosis

Psychosocial vulnerabilities: Acute Stress and Trauma

- Institutional trauma
  - Continuous changes in residential placements, lack of stability, hospitalizations, incarceration, etc
- Physical abuse
- Sexual abuse
  - 8 out of 10 females and 6 out of 10 males with IDD
- Social trauma
  - Bullying, limited social interactions, lack of natural supports
- Death or sudden losses of loved ones
- Medical procedures and treatment of acute illness
- Individuals with ID/D are more likely to have experienced abuse, neglect and exploitation (especially as children)
  - They are also less likely to report this type of maltreatment

Social vulnerabilities: displacement

- Children with ID/DD are more likely than their typically developing peers to enter the child welfare system and be placed in out-of-home care
- Individuals with Dual Diagnosis (IDD/MI) are often shifted between the community mental health and developmental disabilities systems.
  - Confusion as to which system bears responsibility, which condition is the "primary" problem leading to disorganized and uncoordinated care.



Obtaining meaningful information: Suggestions for Interviewing the individual w/ ID/D

- When assessing an individual w/ ID for MH symptoms, know the limits of verbal dialogue.
- Consider their ability to understand abstract concepts (e.g. guilt, delusions, hallucinations, etc.)?
  - Mild ID – Probably
  - Moderate ID – Maybe
  - Severe ID – Highly Unlikely
  - Profound ID – No
- Attempting to mask ID
- Verbal ability does not equate verbal comprehension, but may respond anyway (e.g. "Can I go home so I can cut myself, then?")
- Responding in a way that they have been praised for previously (e.g. "yes", "hearing voices")

Obtaining meaningful information: Suggestions for Interviewing the individual w/ ID/DD

- Keep the questions simple and avoid overuse of abstract concepts- think concretely (i.e. "Do you hear voices?")
- Try to avoid using questions that can be answered as "yes" or "no" , but check and check again
- Try questions like "What did you do after you woke up?" and "Who did you go to the store with?"
- *Additionally – be mindful of problems w/ labeling emotions. Individuals w/ ID may report they are "angry" when really "frightened" – observe body language and mood congruence.*

Treatment

- Early intervention is key to helping address mental health needs and prevent individuals from developing chronic and persistent mental illness
- Community MH Service agencies and providers often shy away from supporting individuals with ID due to perceived lack of skills
  - *Though community mental health services are not fully equipped to deal with mental illness in people with IDD… neither are the people with IDD*
- Evidence-based practices such as CBT and DBT, can be used to treat a variety of conditions in individual's with ID, when interventions are adapted to individual's cognitive levels
  - *Success rate for outpatient mental health treatment is higher among those with milder levels of ID.*
- Some individuals may benefit from Applied Behavioral Analysis and developmental therapy
- Social skills training is an effective intervention and when coupled with positive behavioral interventions can be very successful in increasing self-esteem, self-efficacy, and improving mood while also improving independence and community integration
- Families of individuals with IDD are especially vulnerable to caregiver burn-out and development of mental health conditions and should be referred to services and linked to resources whenever appropriate
- Use of pharmacology should be judicious and carefully monitored

Sturney, P, & Rdidden, R, 2016

Case studies

- Martin, ADD/ADHD
- Regina, PTSD/schizophrenia
- Kerri, Trauma/Borderline
- Vivian, medical/delirium/psychosis
- Max, ASD and ODD

IDD and ADHD Case Study

- Martin is a 12 year-old male who has a diagnosis of Moderate ID and ADHD
- Upon meeting Martin he is fidgety, very active, has difficulty sitting in one spot for any length of time, constantly running and jumping around the room

Schizophrenia and IDD Case Study

- Regina is a 13-year-old AA female diagnosed with Mild ID and was given a diagnosis of schizophrenia after reporting that she was hearing voices and "seeing things"
- She also has a significant trauma history and these "hallucinations" were often similar to a sexual assault that occurred
  - *Talking in different voices, screaming, throwing things, etc.*

IDD and "attention seeking behaviors"

- Kerri is a 32-year-old female diagnosed with Major Depressive Disorder, recurrent episode, moderate; Mild Intellectual Disability, and Borderline Personality Disorder
- She called 911 and or went to the local emergency department over 15 times in one week. During an inpatient stay she overheard a nurse discussing her case with another nurse and engaged in an altercation with him. Things continued to escalate which led to an assault charge and forty-five days of incarceration.

IDD and unspecified psychosis

- Vivian is a 28-year-old Caucasian female diagnosed with moderate ID
- who presented at the local emergency department expressing that she needed help, that her skin felt like there were bugs on it and she was crawling out of her skin
- Telepsych saw the individual and admitted her to an inpatient unit for medication adjustment and treatment of psychotic symptoms
  - *After bloodwork was completed it was identified that this individual was lithium toxic and her kidneys were shutting down*

ASD and ODD

- Max is a 12-year-old AA male diagnosed with Autism Spectrum Disorder and Oppositional Defiant Disorder.
- He had 8 emergency department visits in 10 months. Due to his repeated refusal to follow rules, his frequent verbal aggression (including threats) and arguments with his grandfather and mother, and physical aggression towards peers and siblings, he was diagnosed with Oppositional Defiant Disorder.

References

American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5th ed.). Washington, DC: American Psychiatric Publishing.

Carr E., Smith C., Giacin T., Whelan B. & Pancari J. (2003) Menstrual discomfort as a biological setting event for severe problem behavior: assessment and intervention. *American Journal on Mental Retardation* 2, 117-133.

Charlot, L., et al. . (2016).. In Fletcher, R.; Barnhill, J., Cooper, S., (Eds.), *Diagnostic Manual- Intellectual Disability 2 (DM-ID): A textbook of diagnosis of mental disorders in persons with intellectual disability* (pp 265-302) Kingston NY: NADD

Cooray, S., et al. . (2016).. In Fletcher, R.; Barnhill, J., Cooper, S., (Eds.), *Diagnostic Manual- Intellectual Disability 2 (DM-ID): A textbook of diagnosis of mental disorders in persons with intellectual disability* (pp 303-328) Kingston NY: NADD

Crocker, A. G., Prokić, A., Morin, D., & Reyes, A. (2014). Intellectual disability and co-occurring mental health and physical disorders in aggressive behaviour. *Journal of Intellectual Disability Research, 58(11)*, 1032-1044.

Courtois, C. (2008).Complex Trauma. Complex Reactions: Assessment and Treatment. Psychological Trauma: Theory, Research, Practice, and Policy. Vol. S, N.1, 86-100.

Gardner W. & Whalen J. (1996) Discussion: a multimodal analytic model for evaluating the effects of medical problems on nonspecific behavioral symptoms in persons with developmental disabilities. *Behavioral Interventions* 11, 147-161.

Hollins, S. & Esterguyzen, A. (1997) Bereavement and grief in adults with learning disabilities. The British journal of psychiatry: the journal of mental science, 170, 497-501

Hsieh K, Rimmer J, Heller T. Prevalence of falls and risk factors in adults with intellectual disability. American Journal of Intellectual Developmental Disabilities (2012) 117:442–5410.1352/1944-7558-117.6.442

Hurley, A (2008). Depression I adults with intellectual disability: symptoms and challenging behavior. Journal of intellectual Disability Research 52(11), 905-916

Lindsay, W., Dana, L., Alexander, R., Griffiths, D., Wilkinson, S. (2016).. In Fletcher, R.; Barnhill, J., Cooper, S., (Eds.), *Diagnostic Manual- Intellectual Disability 2 (DM-ID): A textbook of diagnosis of mental disorders in persons with intellectual disability* (pp 599-636) Kingston NY: NADD

Nezu, A., Nezu, C., & Gill-Weiss, M. (1992) Psychpathology in Domestic Violence Against Women with Mental Retardation. Champaign, IL: Research Press.

Sturmey, P. & Didden, R. (2016). Evidence-Based Practice and Intellectual Disabilities. West Sussex UK: Wiley & Sons

Thank you.