INTELLECTUAL/DEVELOPMENTAL DISABILITY

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TERMINOLOGY

Intellectual Disability
Mental Retardation
Developmental Disability
Intellectual Impairment
Learning Disability (UK)

Dual Diagnosis
Dual Disability
Co-Occurring MI-IDD
Co-Existing Disorders
HISTORICAL SYSTEM SEPARATION:

MH---------------------------------------IDD

- Medical model
- Episodic treatment
- Strong individual rights
- Embraces use of psychopharmacology
- Provides treatment
- Governmental structure

- Educational model
- Life span philosophy
- Strong family rights
- Reticent use of psychopharmacology
- Provides supports
- Governmental structure
I/DD TERMINOLOGY

- Person Centered-Planning
  - Essential Lifestyle Planning
  - Personal Futures Planning
- Inclusion
- Positive Approaches
- Positive Behavioral Supports (PBS)
- Self advocacy or self determination
MH TERMINOLOGY

- Strengths-based approaches
- Consumer-centered/Consumer Empowered
- Culturally Competent
- Community Based/Natural Supports
- Accountable
- Recovery-oriented
WHO ARE THESE INDIVIDUALS?

• Capable of significant skill development
• More like us than not.
• Experience the full range of emotions.
• Most medicated persons in society.

(Aman & Singh, 1998)
INCIDENCE AND PREVALENCE: ADULTS

- Persons with ID/D are 3-4x more susceptible to psychiatric disorders as per DM-ID and DSM 5;
- Persons with I/DD can display a wide range of psychopathology;
- Capable of significant skill development
- Persons with ID/D receive less attention in the health care system;
- Minority cultures experience poorer health and more difficulty with access and funding.
- Most medicated persons in society.

(Aman & Singh, 1998)
AAIDD DEFINITION

- Communication
- Home living
- Community use
- Health & safety
- Leisure

- Self-care
- Social skills
- Self-direction
- Functional academics
- Work

IDD manifests before age 18
AAIDD DEFINITION

- Substantial limitations in present functioning
- Significantly sub-average intellectual functioning, existing concurrently with:
- Related limitations in 2 or more of the applicable adaptive skill areas
PROBLEM WITH IDD DEFINITION

- Not a unifying concept—more correctly stated as intellectual/developmental disabilities
- Not clinically helpful
- Must be diagnosed before age 18
- High level of medical co-morbidity
- IDD has >1300 causes
- 2 standard deviations from the norm
- Programmatic, social, legal, practical implications of IDD diagnosis
DSM 5 INTELLECTUAL DISABILITY

- Onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social, and practical domains. Following 3 criteria must be met:
  
  A. Deficits in intellectual functioning such as reasoning, problem solving, planning, abstract thinking, academic learning and learning from experience, confirmed by both clinical assessment and individualized standardized testing;
  
  B. Deficits in adaptive functioning that result in failure to meet developmental and sociocultural standards for personal independence and social responsibility. Without ongoing support, the adaptive deficits limit functioning in one or more activities of daily life, such as communication, social participation and independent living, across multiple environments such as home, school, work and community.
  
  C. Onset of intellectual and adaptive deficits during the developmental period.

Specifiers of Mild, Moderate, Severe, Profound
DSM 5 NEURODEVELOPMENTAL DISORDERS

- Intellectual Disabilities 319
  - (F70) Mild
  - (F71) Moderate
  - (F72) Severe
  - (F73) Profound
  - (F79) Unspecified IDD

- Communication Disorders
  - 315.39  (F80.9) Language Disorder
  - 315.39  (F80.0) Speech Sound Disorder
  - 315.35  (F80.81) Childhood onset Fluency Disorder (stuttering)
  - 315.39  (F80.89) Social Communication Disorder
  - 307.9   (F80.9) Unspecified Communication Disorder
A. Autism Spectrum Disorder

- Persistent deficits in social communication and social interaction across multiple contexts
- Restricted, repetitive patterns of behavior, interests, or activities
- Symptoms are present in early developmental period
- Symptoms must cause clinically significant impairment in social, occupational or other important area of functioning
- Disturbances not better explained by ID or global developmental delay
CONCEPT OF DUAL DIAGNOSIS  FLETCHER 2005

• Co-existence of two disabilities:
  Intellectual Disability and Mental Illness

• Both Intellectual Disability and Mental Health disorders should be assessed and diagnosed

• All needed treatments and supports should be available, effective and accessible

• Diagnostic Overshadowing must be considered.
  • (Reiss, Levitan & Szyko, 1982)
IDD CAUSES

• Genetic abnormalities (>50%)
  • 1995 285 causes of I/DD
  • 2015 1300+ Genetic Causes of I/DD

• Infections

• Metabolic

• Nutritional

• Toxic

• Trauma (Prenatal and perinatal)

• Unknown
GENOTYPES AND PHENOTYPES

- Genotype: genetic constitution
- Phenotype: behavioral manifestation and characteristics associated with genetic disorders
  - Demonstrate the interaction between genes, brain structure and organization and complex behaviors
GENOTYPES AND PHENOTYPES

- Behavioral phenotypes
  - Are not set in stone
  - Look at syndromes rather than set diagnoses
  - Behavioral manifestations arise from the interaction of genes and environment
  - Present a wide range of symptoms
  - Used as clues not as expectations
ETIOLOGY VERSUS DESCRIPTION (DSM 5, AAIDD)

- Anticipates medical needs
- Allows insight
  - Vulnerabilities
  - Behaviors
  - Learning Styles
- Life span approach
GENETIC SYNDROMES

- Down Syndrome
- Fragile X Syndrome
- Smith-Magenis Syndrome
- Prader-Willi Syndrome
- Smith-Lemli-Optiz Syndrome
- Williams Syndrome
- Lesch-Nyhan Syndrome
- Angelman Syndrome
GENETIC SYNDROMES

• Down Syndrome
  • Most Common & Well Known

• Fragile X Syndrome
  • Most Inherited Form of ID

• Smith-Magenis Syndrome
  • Believed Rare?
DOWN SYNDROME: TRISOMY 21
DOWN SYNDROME

- 1/800 births worldwide, 1/1600 US
- Trisomy 21, extra chromosome 21
  - 92% Trisomy 21
  - 3%-5% Mosaic (Subsequent to first cell division)
  - 3%-5% Robertsonian Translocation 21st on 14th (Transmittable)
- Prevalence
  - Significant Increase > 45 years old (1:32)
  - 80% Moms < 35 years old.
DOWN SYNDROME: PHYSICAL CHARACTERISTICS

Microcephaly and abnormally shaped head

Prominent facial features

Flattened nose, protruding tongue, upward slanting eyes with rounded inner eye fold

Broad short hands, short fingers, with single palm crease

Short stature
MALADAPTIVE VULNERABILITIES WITH GENETIC SYNDROMES

- Down Syndrome
- Noncompliance, stubbornness, inattention, overactivity, argumentative, withdrawn (depression and dementia among adults)
DOWN SYNDROME: STRENGTHS

High Visual Memory

Sequential Processing Intact

Language reception excellent

Good at Breaking down tasks

High sociability

Increased Life Expectancy 75+
Fragile X

- Social anxiety, shyness, gaze aversion, perseveration, autism/PDD, inattention, hyperactivity, sadness or depression (primarily females)
MALADAPTIVE VULNERABILITIES WITH CERTAIN GENETIC SYNDROMES

- Williams Syndrome
  - Anxiety, fears, phobias, inattention, hyperactivity, social disinhibition, overly friendly, indiscriminate relating, sensitive

DYKENS 2000
WILLIAMS SYNDROME
MALADAPTIVE VULNERABILITIES WITH GENETIC SYNDROMES

- Prader-Willi

- Hyperphagia, non-food obsessions & compulsions, skin-picking, temper tantrums, perseveration, stubbornness, underactivity

DYKENS 2000
PRADER-WILLI
MALADAPTIVE VULNERABILITIES WITH CERTAIN GENETIC SYNDROMES

- Smith-Magenis

- Inattention, hyperactivity, aggression, attention-seeking, self-injury, stereotypies (often with mouth), sleep disturbance, self-hugging
MALADAPTIVE VULNERABILITIES WITH CERTAIN GENETIC SYNDROMES

- 5p- or Cri du chat
- Infantile high-pitched cat-like cry, hyperactivity, inattention, stereotypies, self-injury, social, interests in communicating
BIOLOGICAL FACTORS

- Self-injurious behavior is seen in 4% to 16%
- Recent studies integrate behavioral triggers with abnormalities in the endogenous opioid and serotonin systems
- 17% with ID have deafness
- 30% with ID have visual impairments

Dykens2000, King1993
NEUROLOGICAL PROBLEMS

- Not homogenous
  - Sydenham’s Chorea
  - Cerebral palsy
    - Spastic (70% cases) 25% with seizures
    - Athetoid (20% cases)
    - Ataxic (10% cases)
    - Mixed
  - Migraine headaches
  - Seizure disorders
  - Muscular dystrophies
PSYCHOSOCIAL CONSIDERATIONS

• Being different from peers
• Losses rather than gains
• Social isolation although mainstreamed
• Rejected by peers
• Failure experiences dominate school histories
• Low social status
PSYCHOSOCIAL CONSIDERATIONS  ZIGLER, 1999

- Outer directed personality orientation
  - look to others rather than selves for problem solution
- Aberrant social styles
  - Too wary or too disinhibited
  - Low expectancy or enjoyment of success
- Low self-esteem
- Distrust of self
- Sadness, depression, dependency & withdrawal
- Helplessness
- Impulsivity
PSYCHOSOCIAL CONSIDERATIONS

• Adolescents with ID are at a higher risk for developing depression
• Children & adolescents with ID are at heightened risk for exploitation & physical or sexual abuse
• Friendships with non-disabled peers show lack of shared play, decision-making & laughter
INDIVIDUAL AND FAMILY PREDICTORS OF PSYCHOPATHOLOGY  DEKKER ET AL, 2003

- Inadequate daily living skills
- Social incompetence
- Chronic physical condition
- High physical symptoms
- Negative life events
- Psychopathology of caregiver
VULNERABILITIES

- VULNERABILITIES commonly seen in people with IDD include challenges to learning and communication that can have a large influence on behavior
  - Also known as “risk factors”
  - Communication deficits
  - Learning challenges and teaching Implications
LEARNING CHARACTERISTICS OF PEOPLE WITH IDD

• Learning occurs more slowly
  • Slower “information processing”

• Difficulty remembering information, especially recently learned materials
  • Might repeat back when calm, then cannot remember when upset

• Difficulty in working memory
  • Has huge impact on problem solving

• Difficulty in executive functions
  • Planning, control over our emotions and behavior…using what we learned when we need it
LEARNING CHARACTERISTICS

- Attention difficulties, both focus and span
  - Yet may “perseverate” on some things
  - Much harder to focus on things that are too difficult
- Problems in learning abstract concepts
- Problems with cognitive rigidity
  - Difficulty changing from one task to another
  - Accepting alternative solutions or explanations
  - Shifting focus of attention
- This BRAIN BASED not being stubborn, or oppositional
LEARNING CHARACTERISTICS

• Difficulty in generalizing skills acquired in one situation/at one time to other conditions/circumstances
  • Especially when there is stress or anxiety
• Difficulty planning - implementing complex behavioral chains/sequences of actions.
  • SEQUENCING deficits are common
  • May not understand time concepts well so it's hard to wait for things
LEARNING CHARACTERISTICS  CHARLOT, 2011

• Demonstrates an outer-directedness and passive learning style (seeks cues/directions from others)

• Low expectations for being a successful learner due to excessive failure history ⇒ generalized learned helplessness
NUANCES OF ASSESSMENT

Unique Differences and Commonalities
DM–ID: Two Manuals

- Diagnostic Manual – Intellectual Disability: A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability
MEDICAL CONDITIONS

The Bio-medical Culprit
OVERVIEW OF I/DD AND PSYCHIATRIC DIAGNOSES

- Always consider medical causes of behavior first

- Co-occurring medical disorders—importance of integrating medical conditions

- Chronic Pain
  - Pain is complex-CNS reaction

- Acute Pain
  - Sinusitis, Dental Pain, Orthopedic, Arthritis, Spastically, Headache, Back pain

- Sleep Disturbances and Disorders
  - High incidents of apnea, aggression and sedation, sleep architecture
COMMON MEDICAL CONDITIONS (McGilvery & Sweeland, 2011)

• Gastrointestinal conditions
  • Dysphagia
  • GERD
  • Constipation

• Urological Conditions

• Asthma

• Seizure Disorders
  • 21% higher prevalence vs. 1% in I/DD
  • Generalized seizures
  • Partial seizures
  • Pseudoseizures

- Do not underestimate the effect of chronic pain on behavior
- Observe for any pain-related behavior in non-verbal persons
- Look for:
  - Facial expressions
  - Moving in unusual ways
  - Not using part of body
  - Vocalizations such as moaning/ crying
- Assess for sleep, ambulation and sitting changes
- Add pain management strategies to the treatment plan
I/DD AND PSYCHIATRIC DIAGNOSES IN ADULTS

- Most Frequent DSM 5 mental illnesses in persons with ID/D
  - Depressive disorders
    - Major depressive disorder
      - With psychotic features
  - Bipolar disorder
  - Anxiety disorders
    - Generalized anxiety disorder
  - Obsessive compulsive and related disorders
  - Trauma and stressor related disorders
  - Personality disorders in persons with ID/DD
  - Major psychotic disorders
ASSESSMENT

- Multi-method, multi-informant approach
- Maladaptive behaviors are best understood through interview with the individual and caregivers
- Assessment must be ongoing and use a strengths-based perspective
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<tr>
<th>DSM Criteria</th>
<th>Observable Criteria</th>
<th>Objective Measure</th>
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<tbody>
<tr>
<td>Depressed mood, irritable in children</td>
<td>Apathetic facial expression with lack of emotional reactivity</td>
<td>Measure rates of smiling, responses to preferred activities, crying</td>
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<tr>
<td>Decrease in interest or pleasure by self-report or observed apathy</td>
<td>Withdrawal, lack of reinforcers</td>
<td>Measure time spent tin room, alone</td>
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<tr>
<td>Insomnia or hypersomnia</td>
<td>Change in total sleep time</td>
<td>Use sleep chart to record sleep</td>
</tr>
<tr>
<td>Feelings of worthlessness or guilt</td>
<td>Statements such as “I’m retarded”</td>
<td>Requires expressive language to determine if symptom is present</td>
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### DSM Diagnostic Criteria for Mania and Behavioral Equivalents

SOVNTER & HURLEY, 1986

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<td>Euphoric/elevated/irritable mood</td>
<td>Boisterousness or excitement. Self injury connected to irritability</td>
<td>Measure rates of smiling</td>
</tr>
<tr>
<td>Inflated self esteem, grandiosity</td>
<td>Thought content centers around mastery of daily living</td>
<td>Measure inappropriate remarks</td>
</tr>
<tr>
<td>Decreased need for sleep</td>
<td>Increased maladaptive behavior at bedtime or early morning</td>
<td>Monitor sleep patterns using 30 minute intervals</td>
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<tr>
<td>More talkative, pressured speech</td>
<td>Increase frequency of vocalization</td>
<td>Measure rates of swearing, singing, screaming</td>
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COMMUNICATION (MCGILVERY & SWEELAND, 2011)

• Receptive language skills
• Expressive language skills
• Methods of communication
  • May need to modify language
    • Keep language simple
    • Explain what you are doing
  • Be sensitive to impact of medication on processing
  • Use adult communication
ENHANCING PERSON TO PERSON COMMUNICATION
(MCGILVERY & SWEELAND, 2011)

- Developing therapeutic relationship
  - Active listening
  - Empathetic responses
  - Non-judgmental attitude
  - Avoid power struggles
  - Be aware of body language and position
  - Validate the person’s feelings
  - Offer choices and alternatives
What influences how we behave?

“Multimodalities of Influence” Lots of different things will affect person’s tendency to become aggressive

Biomedical
- Medical – Neurological – People with IDD have problems and don’t self-report well
- Psychiatric – Depression, anxiety etc impact on how we behave when stressed and vice versa
- Genetic - we are born with some areas of strength and weakness, temperament etc

Psychological-
- Cognitive (How we process information and our beliefs)
- Emotional (feelings and how we manage our emotional states)
- Motivational, behavioral (what we learn and what matters most to us)

Environmental
- Physical, social, interpersonal, program-related
FOCUS OF TREATMENT

• **(Re)-Habilitation**--to restore person to level prior to illness episode, e.g., pre-illness level of functioning ⇒ depressive episode ⇒ inappropriate self-harm ⇒ treatment of depression ⇒ return to pre-illness level of functioning+ absence of self-harm behaviors

• **Habilitation**-- to teach new or improved ways of successfully coping with a range of personal, interpersonal, and social expectations, demands, or requirements. No assumption that person with ID initially had skills but lost them due to illness.