Pediatric Mental Health Care Access Grant

Intellectual/Developmental Disability:

Etiology, Presentation, and Next Steps

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OBJECTIVES

1. Review the Diagnostic Criteria
2. Identify the Presentation and Challenges
3. Describe Accommodations and Next Steps

DIAGNOSTIC CRITERIA

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Diagnosed when children have:
"Impaired" Intellectual functioning
Defined as being in the 2nd percentile or below 70 on a standardized IQ test

AND (more importantly).....

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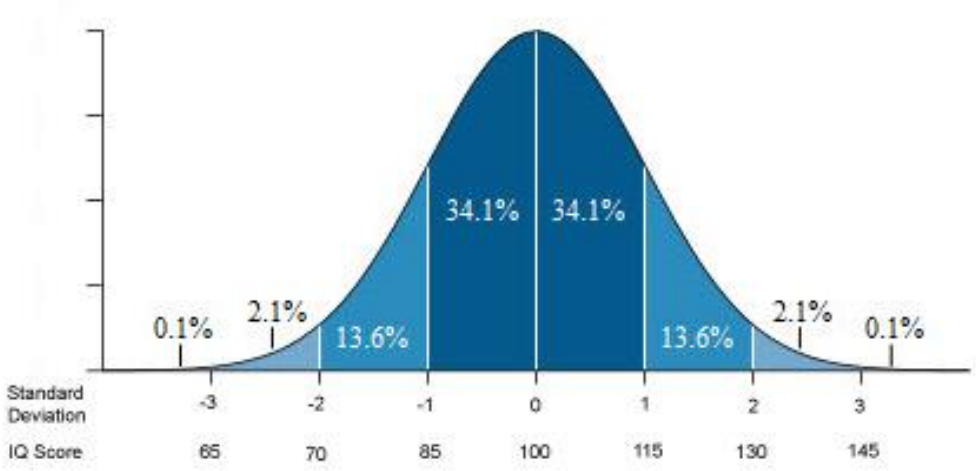
AND (more importantly)…..

"Impaired" ability to perform Activities of Daily Living (ADLs) also known as "Adaptive Functioning"

DIAGNOSTIC CRITERIA



THE CONTROVERSIAL IQ

- IQ is relatively stable over time
  - +- 3SEM after the age of 10
- IQ can change based on other variables:
  - Epigenetics - trauma
  - ADHD – Poor attention=Poor performance on testing
- The Flynn Effect: the phenomenon that IQ scores have risen about three points per decade
- Are IQ tests biased?

DIAGNOSTIC CRITERIA

(A) Deficits in intellectual functions, such as reasoning, problem-solving, planning, abstract thinking, judgment, academic learning and learning from experience, con-firmed by both clinical assessment and individualized, standardized intelligence 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.

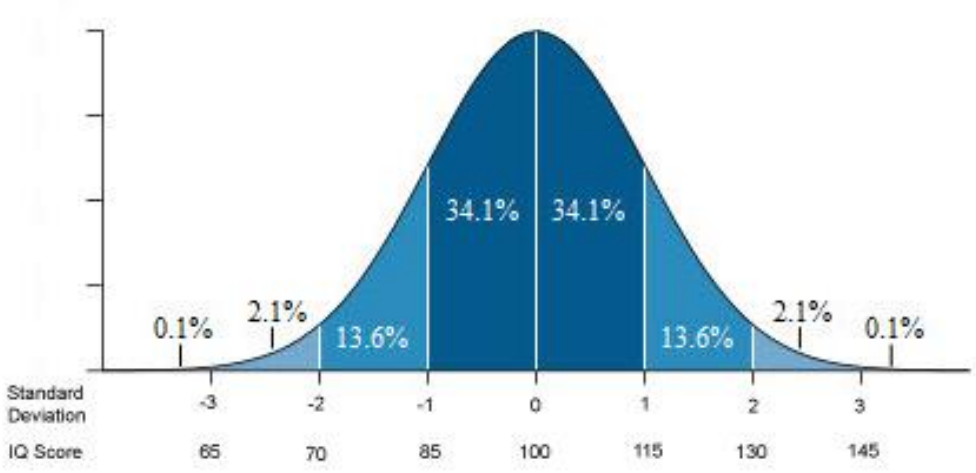
(C) Onset of intellectual and adaptive deficits during the developmental period.

DIAGNOSTIC CRITERIA

The DSM-5 categorizes different levels of intellectual disability according to degree of impairment and needed support.

- **These categories include**
  - **Mild**
  - **Moderate**
  - **Severe**
  - **Profound**

DIAGNOSTIC CRITERIA



PRESENTATION AND CHALLENGES

PRESENTATION AND CHALLENGES

MILD

- About 85% of persons with ID/DD
- Typically not identified until early elementary years
- Can/will develop social and communication skills

PRESENTATION AND CHALLENGES

MILD

Conceptual	Social	Practical
Difficulties with academics Concrete/literal thinking Impaired planning and organization	Communication, conversation, and language are more immature than the skills of peers. The child may have difficulty accurately understanding the social cues of others.	The child may function in an age-expected manner with regard to personal care. In adolescence, assistance may be needed to perform more complex daily living tasks like shopping, cooking, and managing money.

PRESENTATION AND CHALLENGES

MODERATE

- **About 10% of those with ID/DD**
- **Usually identified during preschool years**

PRESENTATION AND CHALLENGES

MODERATE

Conceptual	Social	Practical
Preschoolers' language and preacademic skills develop slowly. Adolescents' academic skills are usually at the elementary school level.	The child shows marked differences in social skills compared to peers. Language is simple/concrete Social judgment and decision-making are limited. Friendships with peers are often affected by social deficits.	The child needs more time and practice than peers to learn self-care skills, such as eating, dressing, toileting, and hygiene. Household skills can be acquired by adolescents with ample practice.

PRESENTATION AND CHALLENGES

SEVERE

- **About 3-4% of those with ID/DD**
- **Usually identified at a very young age**
  - **Delays in developmental milestones and visible physical features are usually seen**
- **May have mobility or other health problems**
  - **May need special assistance throughout their lives**

PRESENTATION AND CHALLENGES

SEVERE

Conceptual	Social	Practical
The child generally has little understanding of written language or numbers. Caretakers must provide extensive support for problem-solving throughout life.	Spoken language is very limited with simplistic vocabulary and grammar. The child understands simple speech and gestures. Relationships are with family members and other familiar people.	The child needs ongoing support for all activities of daily living: eating, dressing, bathing, elimination. Caregivers must supervise children at all times. Some youths show challenging behaviors, such as self-injury.

PRESENTATION AND CHALLENGES

PROFOUD

- About 1-2% of persons with ID/DD
- Identified in infancy due to marked delays in development and biological anomalies
- Learn only the rudimentary communication skills
- Require intensive training for:
  - Eating, grooming, toileting, and dressing behaviors
- Require lifelong care and assistance

PRESENTATION AND CHALLENGES

PROFOUND

Conceptual	Social	Practical
Conceptual skills generally involve (letters, numbers, etc.) Some visual–spatial skills, such as matching and sorting, may be acquired with practice. Co-occurring physical problems may greatly limit functioning.	May understand some simple instructions and gestures. Communication is usually through nonverbal means. Relationships usually with family members and other familiar people.	The child is dependent on others for all aspects of physical care, health, and safety, although he or she may participate in some aspects of self-care. Some youths show challenging behaviors, such as self-injury.

PRESENTATION AND CHALLENGES

- **Down syndrome is the result of failure of the 21st pair of the mother's chromosomes to separate during meiosis, causes an additional chromosome**
- **Fragile-X syndrome is the most common cause of inherited ID**
- **Williams Syndrome**
- **Prader-Willi and Angelman syndromes**
  - **Both are associated with abnormality of chromosome 15**
- **Phenylketonuria results in lack of liver enzymes necessary to metabolize phenylalanine**

PRESENTATION AND CHALLENGES

- Maternal Illness
  - Toxoplasmosis, Zoster Virus, Syphilis, Hepatitis B, HIV/AIDS, Rubella, Cytomegalovirus, Herpes Simplex Virus Type 2
- Lead Exposure
- Intrauterine Polysubstance Exposure
- *Fetal Alcohol Spectrum Disorder* (FASD)
  - #1 Preventable cause of ID/DD
  - NOFAS – 1:100
    - Closer to 1:40 in ND

PRESENTATION AND CHALLENGES

- Adverse biological conditions
  - Examples: infections, traumas, and accidental poisonings during infancy and childhood
- *Fetal Alcohol Spectrum Disorder* (FASD)
  - #1 Preventable cause of ID/DD
  - Estimated to occur in one-half to two per 1000 live births
  - NOFAS – 1:100
    - Closer to 1:40 in ND

PRESENTATION AND CHALLENGES

Emotional/Behavioral Problems

- Rate is three to seven times greater than in typically developing children
  - Largely due to limited communication skills, additional stressors, and neurological deficits
- Most common psychiatric diagnoses:
  - Impulse control disorders, anxiety disorders, and mood disorders
- ADHD-related symptoms are common

PRESENTATION AND CHALLENGES

Emotional/Behavioral Problems

- Pica is seen in serious form among children with ID
- Self-injurious behavior (SIB)
  - Can be life-threatening
  - Affects about 8% of persons across all ages and levels of ID/DD
- Internalizing problems and mood disorders in adolescence are common

PRESENTATION AND CHALLENGES

Health and development can be affected

- Degree of intellectual impairment is a factor
- Prevalence of chronic health conditions in ID population is much higher than in the general population

ACCOMMODATIONS AND NEXT STEPS

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- American Association on Intellectual and Developmental Disabilities (AAIDA)
- Americans with Disabilities Act (ADA)

ACCOMMODATIONS AND NEXT STEPS

- Head Start and Preschool Prevention
- Mainstreaming and Academic Inclusion (IDEA)
- Universal Design in the Classroom
- Applied Behavior Analysis
- Positive Reinforcement
- Medication

ACCOMMODATIONS AND NEXT STEPS

- Treatment involves a multi-component, integrated strategy
- Considers children's needs within the:
  - Context of their individual development
  - Family and institutional setting
  - Community

ACCOMMODATIONS AND NEXT STEPS

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