Intellectual/Developmental Disability: Etiology, Presentation, and Next Steps

Dr. Justin J. Boseck, Ph.D., L.P., ABPdN, CBIS, NCSP
Licensed Psychologist (ND 490),
Board-Certified Pediatric Neuropsychologist,
Fellow of the American Board of Pediatric Neuropsychology,
Certified Brain Injury Specialist, and
Nationally Certified School Psychologist

OBJECTIVES

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

Diagnosed when children have:
“Impaired” Intellectual functioning
Defined as being in the 2\textsuperscript{nd} percentile or below 70 on a standardized IQ test

AND (more importantly)…..
DIAGNOSTIC CRITERIA

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).....

“Impaired” ability to perform Activities of Daily Living (ADLs) also known as “Adaptive Functioning”
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, confirmed 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.
The DSM-5 categorizes different levels of intellectual disability according to degree of impairment and needed support.

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

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

### PRESENTATION AND CHALLENGES

**MODERATE**

- About 10% of those with ID/DD
- Usually identified during preschool years
PRESENTATION AND CHALLENGES

MODERATE

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

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

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

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

<table>
<thead>
<tr>
<th>Conceptual</th>
<th>Social</th>
<th>Practical</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conceptual skills generally involve (letters, numbers, etc.)</td>
<td>May understand some simple instructions and gestures.</td>
<td>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.</td>
</tr>
<tr>
<td>Some visual–spatial skills, such as matching and sorting, may be acquired with practice.</td>
<td>Communication is usually through nonverbal means. Relationships usually with family members and other familiar people.</td>
<td>Some youths show challenging behaviors, such as self-injury.</td>
</tr>
<tr>
<td>Co-occurring physical problems may greatly limit functioning.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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
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

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
ACCOMMODATIONS AND NEXT STEPS

• 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

MILD

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


### ACCOMMODATIONS AND NEXT STEPS

#### MODERATE

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

### ACCOMMODATIONS AND NEXT STEPS

#### SEVERE

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

#### PROFOUND

<table>
<thead>
<tr>
<th>Conceptual</th>
<th>Social</th>
<th>Practical</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conceptual skills generally involve (letters, numbers, etc.)</td>
<td>May understand some simple instructions and gestures.</td>
<td>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.</td>
</tr>
<tr>
<td>Some visual–spatial skills, such as matching and sorting, may be acquired with practice.</td>
<td>Communication is usually through nonverbal means. Relationships usually with family members and other familiar people.</td>
<td>Some youths show challenging behaviors, such as self-injury.</td>
</tr>
<tr>
<td>Co-occurring physical problems may greatly limit functioning.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

---

**Pediatric Mental Health Care Access Grant**

---

**Intellectual/Developmental Disability:**

**Etiology, Presentation, and Next Steps**

Dr. Justin J. Boseck, Ph.D., L.P., ABPdN, CBIS, NCSP  
Licensed Psychologist (ND 490),  
Board-Certified Pediatric Neuropsychologist,  
Fellow of the American Board of Pediatric Neuropsychology,  
Certified Brain Injury Specialist, and  
Nationally Certified School Psychologist