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# ICD-11 in Intellectual Disability:
## Disorders of Intellectual Development

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# Conflicts of Interest

- None to declare

# Principles for ICD-11 Guideline Development - I

- Incorporation of current scientific evidence to maximize **clinical utility** and **global applicability**
- For Disorders of Intellectual Development, guidelines developed:
  - To facilitate efficient and accurate identification of affected individuals
  - To determine the level of severity of the disorder accurately
  - To enhance appropriate matching to services in varied settings globally

# Principles for ICD-11 Guideline Development -II

- Consider contextual factors that facilitate or impede functioning or acquisition of skills
- Emphasize inclusiveness and participation in society
- Consistent with UN Convention on the Rights of Persons with Disabilities:
  - “the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community …” (UN General Assembly, 2006, A/RES/61/106)

# A New Name …

- ICD-11 Disorders of Intellectual Development replaces the label ICD-10 Mental Retardation
- “Intellectual Disability” not used because at odds with WHO Family of International Classifications that distinguishes health conditions (ICD) from their consequences (International Classification of Functioning, ICF)
- Reference to “development” reflects onset during the developmental period
- Reference to “intellect” is well understood by researchers, clinicians and policy-makers

# ICD-11 Disorders of Intellectual Development

- Heterogenous group of conditions with various medical aetiologies (prenatal, perinatal and postnatal) and affected individuals have varied needs
- *Core features* of Disorders of Intellectual Development are:
  1. Significant limitations in intellectual functioning
  2. Significant limitations in adaptive behaviour functioning
  3. With onset during the developmental period

# 1. Significant Limitations in Intellectual Functioning

- Limitations in general intellectual functioning, meaning across multiple domains of “g” (e.g., perceptual reasoning, working memory, processing speed, verbal comprehension)
- Emphasizes assessing intellectual functioning using normed, standardized tests
- Overall, results found approximately 2+ SD below mean scores on normed
- Relative strengths and weaknesses can occur across domains

# 2. Significant Limitations in Adaptive Behaviour - I

- Adaptive behaviours refers to set of *conceptual, social, and practical skills* learned and performed by people in their everyday lives:
  - *Conceptual skills* are those that involve the application of knowledge (e.g., reading, writing, calculating, solving problems, and making decisions) and communication;
  - *Social skills* include managing interpersonal interactions and relationships, social responsibility, following rules and obeying laws, avoiding victimization;
  - *Practical skills* are involved in areas such as self-care, health and safety, occupational skills, recreation, use of money, mobility and transportation, as well as use of home appliances and technological devices.

# 2. Significant Limitations in Adaptive Behaviour - II

- Adaptive functioning may change in response to environmental demands that change with age or with targeted interventions.
- Overall, results found approximately 2+ SD below mean scores.
- Adaptive skills learned during developmental period often improve the social and psychological functional capacities of affected individuals.
- A point in time assessment does not necessarily predict future functioning.

# 3. Onset During the Developmental Period

- Approximately before the age of 16
- It is possible to establish a Disorder of Intellectual Development through a person's history in adults who come to clinical attention without a previous diagnosis.
- If limitations are acquired after the developmental period (e.g., in adulthood) through disease (e.g., a brain tumour) or injury (e.g., a traumatic brain injury) the diagnosis is Secondary Neurocognitive Syndrome.

# Differentiation from Normality

- Borderline Intellectual Functioning (1 – 2 SD below the mean) is not a disorder in ICD-11
- Disorders of Intellectual Development must be differentiated from:
  - Communication, sensory, or motor impairments
  - Behavioural disturbances
  - Lack of mastery of the local language (e.g., new immigrants)
  - Low literacy levels
  - Other mental disorders
  - Effects of certain health treatments
  - Severe social or sensory deprivation

# Disorders of Intellectual Development - Severity

- Disorders of Intellectual Development are further characterized by one of four levels of severity:
  - Mild, Moderate, Severe and Profound
- Assigned according to intellectual **and** adaptive behaviour functioning (except for Severe and Profound, which are based on adaptive behaviour functioning only)
- Increasing severity is associated with a number of important support needs, including choice of living arrangements.
- A valid and reliable system of staging was identified as important to ensuring proper supports, particularly in LAMICs where mild severity is often seen as a “learning disability.”

# Disorders of Intellectual Development - Severity

- The diagnosis and determination of severity may vary according to:
  - Nature and purpose of the assessment
  - Importance of the behavior in question in relation to the individual's overall functioning.
- For example, may be appropriate to place greater emphasis on one domain of adaptive behaviour skills if that skill is critical to determining eligibility of services for improving occupational functioning.

# Severity Levels

| Severity Level | Intellectual Functioning | Adaptive Behaviour |
|---|---|---|
| Mild | 0.1 – 2.3 percentile | 0.1 – 2.3 percentile |
| Moderate | 0.003 – 0.1 percentile | 0.003 – 0.1 percentile |
| Severe | <0.003 percentile | <0.003 percentile* |
| Profound | <0.003 percentile | <0.003 percentile* |

* Use of behavioural indicators can assist in differentiating Severe from Profound

- Level of severity assigned on the basis of the level at which the **majority** of the individual's intellectual ability and adaptive behaviour skills fall.

# Severity Levels - Example

| Severity Level / Domain | Intellectual | Conceptual | Practical | Social |
|---|---|---|---|---|
| Mild | | X | | |
| Moderate | X | | X | X |
| Severe | | | | |
| Profound | | | | |

Diagnosis: Moderate Disorder of Intellectual Development

# Disorder of Intellectual Development, Provisional

- Evidence of a Disorder of Intellectual Development but individual is an infant or child under the age of 4, making it difficult to ascertain whether the observed impairments represent a transient delay.
  - Disorder of Intellectual Development, Provisional in this context is sometimes referred to as Global Developmental Delay.
- Also used when evidence suggestive of a Disorder of Intellectual Development but not possible to conduct a valid assessment because of:
  - Sensory or physical impairments, motor or communication impairments, severe problem behaviours, or symptoms of another Mental, Behavioural, or Neurodevelopmental Disorder.

# Behavioural Indicators Tables

- Whenever possible normed, standardized measures of intellectual and adaptive behaviour functioning should be used.
- However, many settings worldwide, especially in LAMI countries, do not have appropriate measures.
- When not possible, separate tables divided by three age groups (early childhood, childhood and adolescence, and adulthood) can be used with clinical judgment to:
  - Determine severity level of intellectual functioning
  - Determine severity level of adaptive behaviour functioning

# Behavioural Indicators Tables – Example: Adaptive Behaviour

| SEVERITY LEVEL | *Conceptual* | *Social* | *Practical* |
|---|---|---|---|
| | *Reasoning, planning, organizing, reading, writing, memory, symbolic/internal representation, communication skills* | *Interpersonal competency (e.g., relationships), social judgment, emotion regulation* | *Self-care, recreation, employment (including domestic chores), health and safety, transportation* |
| MILD | • Most will need some help to sustain their attention for 30–minute period.<br>• Most can follow 3-step instructions.<br>• Most will acquire sufficient communication skills to use pronouns, possessives and regular tenses, as well as be able to ask "wh" question (e.g., who, what, where, when or why).<br>• Many will need support to tell a narrative story or to give someone simple directions. They also need assistance to explain their ideas using multiple examples, detail short-term goals and steps to achieve them, stay on the topic in group conversations and move from one topic to another.<br>*Literacy*<br>• Most will have reading and writing skills that are limited to approximately up to that expected of someone who has attended 4 to 5 years of schooling (i.e., several years of primary/elementary school). | • Some may have more concrete understanding of social situations and may need supports understanding some types of humor (i.e., teasing others), making plans and knowing to let others know about these plans as needed, control their emotions when faced with disappointment, knowing to avoid dangerous activities or situations that may not be in their best interest (e.g., taken advantage of or exploited).<br>• Some may need some supports initiating conversation, organizing social activities with others or talking about shared interests with peers/friends.<br>• Some may need substantial support to talk about personal things, emotions, or understanding social cues.<br>• Most are able to play outdoor sports or other social games in groups although they need help to play games with more complex rules (e.g., board games). | • Most will learn to perform independently most dressing, toileting, and eating skills.<br>• Most will continue to frequently need supports to attain independence for brushing teeth, bathing and showering, getting around the community and being safe (e.g., although they will know to stay to the side of routes with car traffic) may continue to need support to check for traffic before crossing a street.<br>• Many may be vulnerable to being taken advantage of in social situations. May continue to need some supports for telling time, identifying correct day/dates on calendar, making and checking the correct change at the store, being independent with basic health-maintaining behaviors.<br>• If available, many can learn to use computers for school and play.<br>• Will learn basic work skills at about the same pace as their same-age peers but will |

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# Developing behavioural indicators for intellectual functioning and adaptive behaviour for ICD-11 disorders of intellectual development

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# Preliminary Field Trial Results

- Evaluated inter-rater reliability and convergent validity of behavioural indicators tables with standardized measures (Leiter-3 & V-ABS) in 3 countries (India, Italy and Sri Lanka)

| Variables | Interrater Reliability (n) | Concurrent Validity - Raw (n) | Concurrent Validity - Adjusted (n) |
|---|---|---|---|
| **Intellectual** | 0.97 (175) | 0.71 (167) | 0.73 (167) |
| **Conceptual** | 0.91 (175) | 0.75 (172) | 0.77 (172) |
| **Social** | 0.93 (175) | 0.66 (172) | 0.68 (172) |
| **Practical** | 0.94 (175) | 0.68 (172) | 0.73 (172) |
| **Overall** | 0.97 (176) | 0.76 (166) | 0.82 (166) |

# Co-occurring Mental Disorders

- Identifying co-occurring conditions are often under-detected due to “overshadowing” but of vital importance in understanding the needs for, and developing, an appropriate treatment plan for affected individuals.
- Numerous mental disorders occur at the same, or higher, rates among individuals affected by Disorders of Intellectual Development, as compared to the general population (e.g., ADHD, Mood Disorders, Anxiety and Fear-Related Disorders, Impulse-Control Disorders, and Psychotic Disorders)
- Guidance provided on differentiating Disorders of Intellectual Development from other disorders (e.g., Developmental Learning Disorders)

# Co-occurring Mental Disorders

- ICD- 11 guidelines caution clinicians to ensure that assessments are conducted with methods that are appropriate to individuals' level of intellectual functioning
- This may require a greater reliance on signs in combination with collateral reports.
- Reporting of internal states is more difficult for affected individuals, particularly those with more severe forms of Disorders of Intellectual Development.

# Problem Behaviours

- Includes aggression, self-injurious behaviour, attention-seeking behaviour, oppositional defiant behaviour, and sexually inappropriate behaviour
- Co-occur in approximately 18% of adults with Disorder of Intellectual Development seeking services (Bowring et al 2019)
- Most common reason for referral to healthcare services with significant numbers without a diagnosed mental disorder being prescribed psychoactive medication to manage these behaviours (Cooray et al., 2015)
- Included as an Associated Clinical Feature because not present in all cases
- Stereotyped Movement Disorder with self-injury can be diagnosed with Disorders of Intellectual Development

# Limitations in Intellectual Functioning in Autism Spectrum Disorder – I

- In ICD-11, core features of ASD are:
  1. Persistent deficits in initiating and sustaining social communication and reciprocal social interactions, and
  2. Persistent restricted, repetitive, and inflexible patterns of behaviour, interests, or activities
  3. Onset is during the developmental period
- Can occur with or without impairment in intellectual functioning

# Limitations in Intellectual Functioning in Autism Spectrum Disorder – II

- In ICD-11, impairment in intellectual functioning is coded by adding a co-occurring diagnosis of Disorder of Intellectual Development (DID) and characterizing severity according to the system described in the Disorders of Intellectual Development guidelines (including BI tables)
- In ASD, when determining the level of severity of the accompanying Disorder of Intellectual Development, the **Social domain** of adaptive behaviour functioning is given less emphasis.

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# Questions?