ICD-11 and Intellectual Disability

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Purpose of this Presentation

• Describe the function of the World Health Organization’s International Classification of Diseases (WHO ICD)
• Explain why it is important
• Review the contributions of AAIDD to the process of ICD-11
• Anticipate next steps
Review of Major Functions Relevant in Terminology and Classification

- Naming
- Defining
- Diagnosing
- Classifying
- Planning Supports

What is the essential question in each function, and what is at stake?
<table>
<thead>
<tr>
<th>Function</th>
<th>Essential questions</th>
<th>What is at stake?</th>
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</thead>
<tbody>
<tr>
<td>Naming</td>
<td>How will the status be known?</td>
<td>Personal identity</td>
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<td></td>
<td>What words will attach to the individual and people close?</td>
<td>Stigma or valuation for individuals and their families</td>
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<td>Separation or inclusion</td>
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<tr>
<td>Defining</td>
<td>What group will be “in” the category for protections and benefits, and what group</td>
<td>Eligibility (operational definition)</td>
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<td>will be “out” of the category?</td>
<td>Government and economic commitment</td>
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<td></td>
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<td>Distinguishing the operational definition from the constitutive definition</td>
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<td>Diagnosing</td>
<td>What assessment steps are required for identifying individuals?</td>
<td>Fairness and accuracy</td>
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<td>Individualized decision-making</td>
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<td></td>
<td></td>
<td>Efficiency</td>
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<tr>
<td>Classifying</td>
<td>How is the total group that was defined as “in” the category now subdivided based</td>
<td>Improved understanding of the person</td>
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<td></td>
<td>on criteria that are relevant to a specified purpose of subdividing?</td>
<td>Rationally linking subgroup characteristics to important actions,</td>
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<td></td>
<td></td>
<td>(e.g., research, funding, supports planning, outcomes evaluation, and societal</td>
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<td></td>
<td></td>
<td>priorities)</td>
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<td></td>
<td></td>
<td>Fairness</td>
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<td></td>
<td></td>
<td>Equitable distribution of resources</td>
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<tr>
<td>Planning</td>
<td>What approach does one take to enhancing human functioning?</td>
<td>The functioning of a citizen and family</td>
</tr>
<tr>
<td>supports</td>
<td></td>
<td>Responsibilities of a society to enhance the personal well-being of its</td>
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<td></td>
<td></td>
<td>citizenry</td>
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<tr>
<td></td>
<td></td>
<td>Addressing personal goals and assessing support needs</td>
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<td></td>
<td></td>
<td>Deliberated alignment of needs, resources, and desired outcomes</td>
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</tbody>
</table>

Description of WHO’s ICD

- The World Health Organization was established in 1948 in the United Nations
- ICD is a classification of all health conditions (more than 10,000 disease and disorder codes)
- Revised approximately every 10 years; the last was ICD-10 (1992)
- ICD is part of the WHO “family” of classifications, including ICF and ICHI
- Purposes: worldwide leadership in health; “consensual, meaningful and useful framework which governments, providers and consumers can use as a common language” (http://www.who.int/classifications/en/)
The Process for Development of ICD 11

• Expected publication of ICD-11 in 2015
• Complex process overseen by WHO Dept. of Mental Health and Substance Abuse
• “Mental Retardation” (ICD-10) is included within the classification of Mental and Behavioral Disorders
• An appointed international Working Group of experts in ID presented proposed changes to WHO Secretariat
Process, cont.

- WHO Secretariat prepares a version for public review and comment
- WHO encourages consultation with and input from stakeholders from the 193 member countries (this is where AAIDD made its comments and recommendations in Jan. 2013)
- Revisions
- Clinical field testing
- Finalization for May 2015
Why is this Important?

There are critical advantages to having a unified, aligned, consistent effort regarding the name, definition & diagnosis, and classification system globally

• Scientific
• Psychosocial
• Policy
AAIDD’s Process

• AAIDD President Tasse convened a small and diverse group of experts in January 2012 for 1 ½ day meeting
• Prepared recommendations on naming, defining and classifying, and field testing
• Prepared suggested revisions of the “Content Forms for Mental and Behavioral Disorders” previously submitted by the ICD Working Group
• Submitted, as a stakeholder, the material to WHO
Content of AAIDD’s Recommendations

- “Disorders of ID” (not “Intellectual Developmental Disorders”)

- “condition characterized by significant limitations in intellectual functioning and adaptive behavior, originating during the developmental period.”

- Diagnostic guidelines: “significant limitations in intellectual functioning, significant limitations in adaptive behavior, and onset during the developmental period.”
AAIDD Recommendations, cont.

• Recommended “Constituent Categories” (levels):
  – Disorder of ID, Marked
  – Disorder of ID, Extensive
  – Disorder of ID, Pervasive
  – Disorder of ID, Other

Recommendation: Determine categories (levels) based on functioning, more than IQ
AAIDD Recommendations, cont.

• Field testing: AAIDD offered to participate in field testing, especially given that AAIDD has members across North America and more than 50 countries
Current Status of ICD-11 regarding ID

• **Development of ICD-11 is underway:** The 11th version, ICD-11, is now being prepared. The development phase will continue for three years and ICD-11 is expected to be finalized in 2015.
# Comparison of Recommended Changes to ICD-11 and AAIDD’s T&C 11th Edition (2010)

<table>
<thead>
<tr>
<th></th>
<th>AAIDD</th>
<th>Recommended to ICD-11</th>
<th>2015 ICD-11</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Name</strong></td>
<td>Intellectual Disability (ID)</td>
<td>Disorders of Intellectual Disability (Disorders of ID)</td>
<td>?</td>
</tr>
<tr>
<td><strong>Definition/ Diagnosis</strong></td>
<td>characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18.</td>
<td>characterized by significant limitations in intellectual functioning and adaptive behavior, originating during the developmental period</td>
<td>?</td>
</tr>
<tr>
<td><strong>Classification</strong></td>
<td>Select a multidimensional system that fulfills an important purpose, e.g. intensity of needed supports (depends on jurisdiction: intermittent, limited, extensive, pervasive)</td>
<td>Disorder of ID, Marked Disorder of ID, Extensive Disorder of ID, Pervasive Disorder of ID, Other (Based on functioning)</td>
<td>?</td>
</tr>
</tbody>
</table>
Conclusion

- These issues are important – there is a great deal at stake.
- Given AAIDD’s historical contributions in terminology and classification (11 editions!) and expert resources, the comments of AAIDD are respected and we have much to offer.
- Vigilance and attention globally are required. [http://www.who.int/classifications/icd/revision/en/](http://www.who.int/classifications/icd/revision/en/)
Resources

• April 2013 Special Issue of *Intellectual and Developmental Disabilities, 51(2).*


• [http://www.who.int/classifications/icd/revision/en/](http://www.who.int/classifications/icd/revision/en/)
Resources, cont.


Thank you

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