

The background features a stylized globe with a grid of latitude and longitude lines. A compass rose is visible in the lower-left quadrant, showing the cardinal directions N, E, S, and W. The globe is partially obscured by a large, light-colored, curved shape that sweeps across the upper-left portion of the frame.

# **Participation in the Development of the ICD-11 Category for Intellectual Disability: Research, Policy, & Practice**

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American Association on Intellectual and Developmental Disabilities



American Association  
on Intellectual and  
Developmental Disabilities

# WHAT IS AAIDD?

# Founded in 1876, AAIDD is

- Multi-disciplinary professional society
- Membership organization
- Trusted source of information on intellectual and developmental disabilities
  - education, books, journals, positions, briefs
- Social change agent







# Mission and Goals

## Mission

- AAIDD promotes progressive policies, sound research, effective practices, and universal human rights for people with intellectual and developmental disabilities.

## Goals

- Enhance the capacity of professionals who work with individuals with intellectual and developmental disabilities.
- Participate in the development of a society that fully includes individuals with intellectual and developmental disabilities.
- Build an effective, responsive, well-managed, responsibly-governed, and sustainable organization.



# Major Functions

The major functions of the Association are to

- Support its members' leadership in activities that affect people with intellectual and developmental disabilities.
- Publish and promote cutting edge research, tools, and materials that inform policy and practice.
- Develop and implement educational opportunities for professionals, policy makers, and others; and
- Engage in activities that promote progressive public policy.



# Social Change Activities

- Communicate social change agenda
  - Release position statements
  - Endorse works of others
  - Utilize social and traditional media
  - Educate of policy makers and stakeholders
- Publish high quality materials
  - Books and journals promote progressive policies, sound research, effective practices, and universal human rights for people with intellectual and developmental disabilities
- Contribute to processes that influence public policy
  - Submit Amicus Curie briefs
  - Comment on draft federal legislation, regulations
  - Contribute to review and testing of DSM-5 & ICD-11

# Why is it important to have shared terminology and construct of ID?

- Maintaining a universal terminology and construct are crucial in ensuring fairness, accuracy, and consistency in and across countries in critical areas including clinical practice, teaching/training, research, population-based statistics reporting, and public health services.
- In addition, where diagnosis confers legal protections, minimizing ambiguity is crucial.







# A Major Challenge to Shared Understanding of the Condition: Dueling Manuals

## Timelines for Manual Revision

- Revision work begins years before manuals are actually published
- Actual (or anticipated) publication dates for the manuals:
  - AAIDD: 2010
  - APA: 2013
  - WHO: 2015



# Mental Retardation

Definition, Classification,  
and Systems of Supports

10th Edition  
AAMR

2010

# INTELLECTUAL DISABILITY

Definition, Classification, and Systems of Supports

THE 11TH EDITION OF THE AAIDD DEFINITION MANUAL

aaidd

AAIDD

# INTELLECTUAL DISABILITY Definition, Classification and Systems of Support

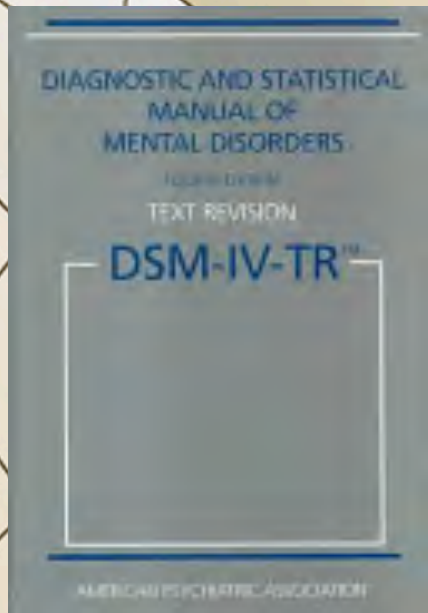


# AAIDD Definition of ID

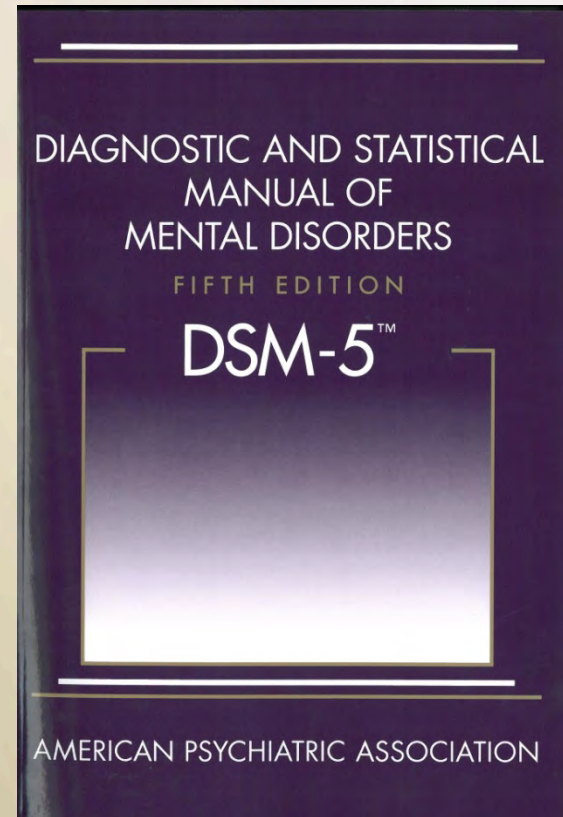
First edition of this manual published in 1910

## 3 pronged definition

- Significant limitation in intellectual functioning (approx  $2\text{ SD} < M$ )
- Significant limitation in adaptive behavior (approx  $2\text{ SD} < M$ )
- Onset during the developmental period (prior to age 18)



2013



American Psychiatric Association

**DSM-5**



# DSM

- Used in the US and to varying degrees around the world
- First edition in 1952, provides a criteria and terms for the classification of mental disorders.
- Evolved from several systems for collecting census and psychiatric hospital statistics and a US army manual.
- In the US, used by clinicians, researchers, **psychiatric drug regulation entities, health insurance, and policy makers**







# Concerns with DSM-5 Revision of “Mental Retardation”

- Research
  - Introduction of ambiguity in diagnostic criteria
  - Insufficient scientific evidence for criteria modifications
  - Failure to follow identified field testing protocols
- Practice
  - “Congruence” with ICD-11
  - Clear indication that modifications would not improve practice
- Policy
  - Clearly foreseeable harm with initially proposed label and criteria
  - Eligibility criteria for benefits
  - Legal protections
  - Consequences of confused policy makers



# Engagement with APA

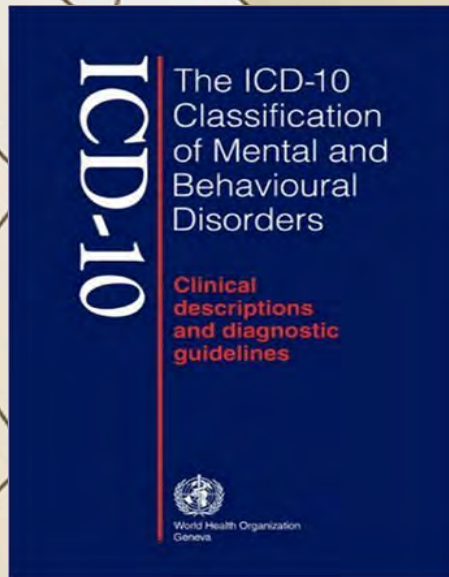
- Formal letter of concerns was submitted and made public
  - Press release
  - Partner organizations, *notably The Arc*
  - Articles in popular press
- Engaged in a series of back and forth communications
  - Some concerns addressed, some not
- Public policy vs. scientific outcomes

# Final DSM-5 Definition of the Condition

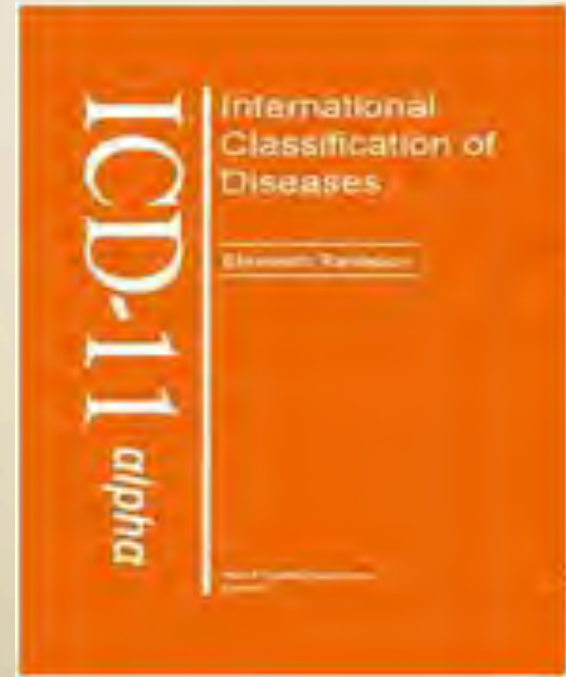
## **319. Intellectual Disability**

(Intellectual Developmental Disorder) is a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social, and practical domains.





2015



World Health Organization

**ICD-11**





# ICD

WHO member countries agree to use ICD as standard for health information and reporting

## **Basis for:**

- Assessment and monitoring of mortality, morbidity, injuries, external causes, other health parameters
- Tracking epidemics and disease burden
- Identifying appropriate targets of health care resources
- Accountability of WHO member countries for public health

WHO reticence to revise the *International Classification of Functioning (ICF)* with emphasis on context and supports increases the importance of the ICD as tool for describing conditions

# Concerns with the ICD-11 Revision of “Mental Retardation”

- English-language term
  - Disorder vs. Disability
  - WHO conceptualization of “disability” as an emergent property of underlying condition
- Introduction of ambiguity in the definition
- Substantial modification of diagnostic criteria without scientific support
- Forseeably result in
  - Diagnostic inaccuracy
  - Collection of inaccurate data
  - Confusion among policy makers





# Definition and Term

## Definition

- Original proposal:

*A group of developmental conditions characterized by significant impairment in cognitive functions across a number of core domains, which are associated with limitations in learning, adaptive behavior and skills*

- AAIDD proposal:

*A disorder of **intellectual disability** is a condition characterized by significant limitations in intellectual functioning and adaptive behaviour, originating during the developmental period*

## Term (in English)

- Original: Intellectual Developmental Disorders
- AAIDD Proposed: Disorders of Intellectual Disability (ID)
- Final: Disorders of Intellectual Development (ID)



# Engagement with WHO

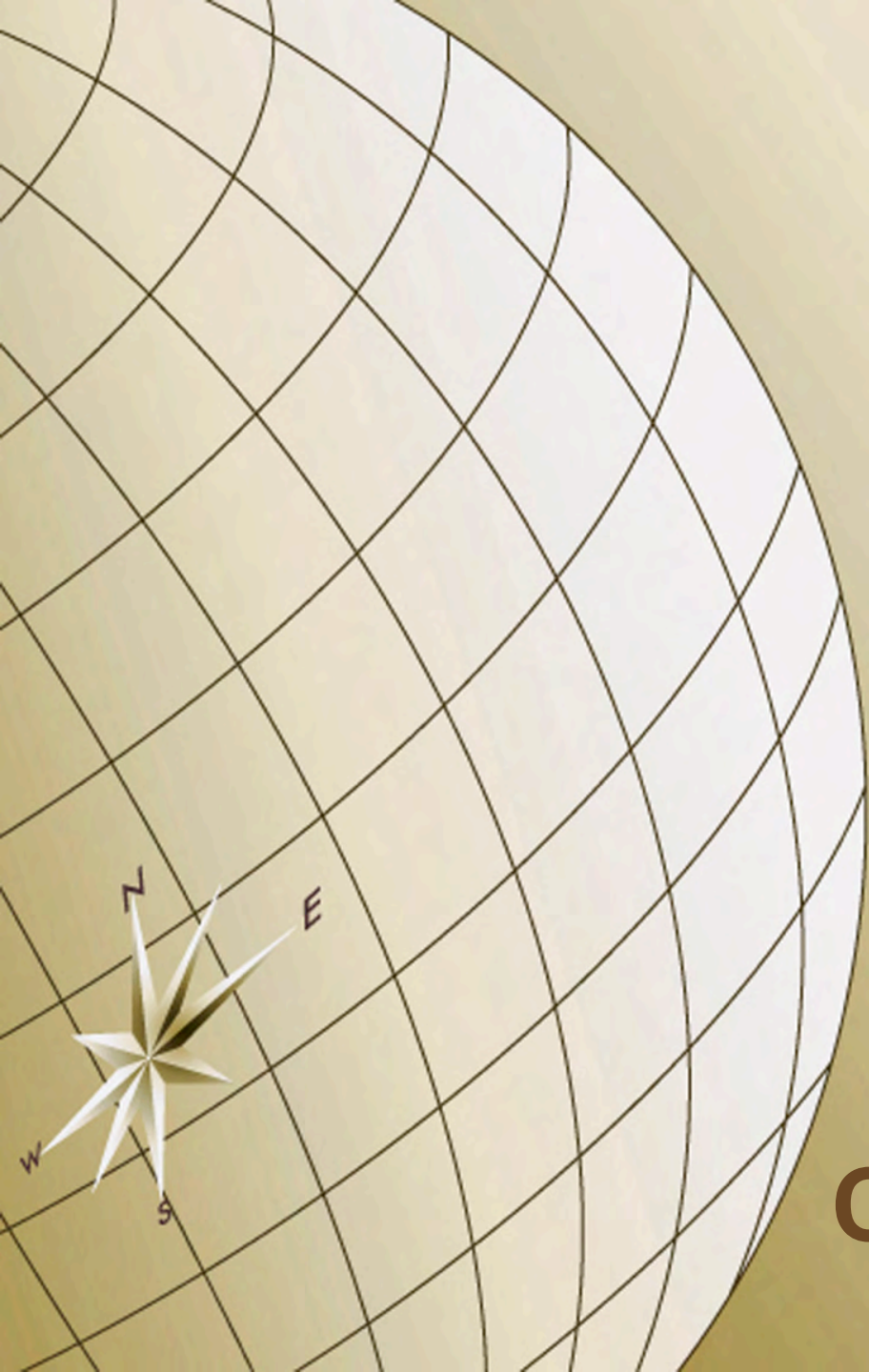
- Direct approach to WHO staff through a member of the relevant workgroup
- Invitation to host a “North American Experts Panel” to provide comments
- Submission of comments
  - version available in the April issue of *IDD*
- Ongoing communications with WHO
- Planned support of field testing later this year



# Field Testing

- 3 Levels of Interest
  - National/international epidemiology and policy
  - Clinical, diagnostic, research
  - Individuals with condition(s) and their families
- Electronic Portal
  - 6 languages





# **IMPLICATIONS & CONSIDERATIONS**

# Parallel definitions until the next editions of the manuals

- What's important in systems change (both in manuals and public policy)
  - Processes for reasoned discourse
  - Decision makers understand policy implications
  - Coalitions to raise awareness, engage in advocacy
  - Credibility



# Parallel Definitions

AAIDD	APA	WHO
Significant limitations in <b>intellectual functioning</b>	Includes both <b>intellectual and adaptive functioning deficits</b> in conceptual, social, and practical domains.	Significant limitations in <b>intellectual functioning</b>
Significant limitations in <b>adaptive behavior</b>		Significant limitations in <b>adaptive behaviour</b>
Onset during the <b>developmental period</b>	Onset during the <b>developmental period</b>	Originating during the <b>developmental period</b>