

Intellectual developmental disorders: towards a new name, definition and framework for “mental retardation/intellectual disability” in ICD-11

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Although “intellectual disability” has widely replaced the term “mental retardation”, the debate as to whether this entity should be conceptualized as a health condition or as a disability has intensified as the revision of the World Health Organization (WHO)’s International Classification of Diseases (ICD) advances. Defining intellectual disability as a health condition is central to retaining it in ICD, with significant implications for health policy and access to health services. This paper presents the consensus reached to date by the WHO ICD Working Group on the Classification of Intellectual Disabilities. Literature reviews were conducted and a mixed qualitative approach was followed in a series of meetings to produce consensus-based recommendations combining prior expert knowledge and available evidence. The Working Group proposes replacing mental retardation with intellectual developmental disorders, defined as “a group of developmental conditions characterized by significant impairment of cognitive functions, which are associated with limitations of learning, adaptive behaviour and skills”. The Working Group further advises that intellectual developmental disorders be incorporated in the larger grouping (parent category) of neurodevelopmental disorders, that current subcategories based on clinical severity (i.e., mild, moderate, severe, profound) be continued, and that problem behaviours be removed from the core classification structure of intellectual developmental disorders and instead described as associated features.

Key words: Intellectual disability, mental retardation, intellectual developmental disorders, health terminology, classification, mental disorders, ICD, ICF

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The health condition currently defined as “mental retardation” (MR) is a cluster of syndromes and disorders characterized by low intelligence and associated limitations in adaptive behaviour. Examination of the conceptual basis and terminology related to MR is relevant at present because the World Health Organization (WHO) is in the process of revising the International Classification of Diseases and Related Health Problems, Tenth Revision (ICD-10) (1). This paper describes the rationale and process for replacing the ICD-10 conceptualization of MR with the concept of *intellectual developmental disorders* (IDD) in ICD-11.

IDD have a long history within the taxonomy of mental disorders (2). Their prevalence is around 1% in high income countries and 2% in low and middle income (LAMI) countries (3,4). They have a major impact on functioning and disability throughout the life course, and high comorbidity with other mental disorders (5). They are frequently misdiagnosed, are associated with poor access to health care services, and involve very high costs for the health care system and for society as a whole (6-10). In spite of these facts, IDD are largely disregarded in the mental health sector, where

specific training on IDD and specialized services are limited to a few high income, primarily Western, countries (11,12).

During the past 15 years, an intense debate has taken place on how to properly name, define and assess IDD (13). In summary, the term “intellectual disability” (ID) has widely replaced MR for policy, administrative and legislative purposes in many developed countries and in an increasing number of LAMI countries. However, the question as to whether IDD are a disability or a health condition remains a hotly debated one, with two co-existing approaches used as a basis for new conceptualizations of this entity. Based on a health condition perspective, MR is currently coded as a disorder in ICD (category F.70). At the same time, impairments in intellectual functions that are central components of IDD can be classified within WHO’s International Classification of Functioning, Disability and Health (ICF) (14), and therefore seen as a part of disability.

Based on a disability perspective, the American Association on Intellectual and Developmental Disabilities (AAIDD) has assembled a comprehensive definition, classification, and system of supports that focus mainly on functioning, adaptive

behaviour and support needs and are consistent with the conceptual model proposed by the ICF (15,16). According to AAIDD, ID is a disability characterized by “significant limitations *both* in intellectual functioning and in adaptive behaviour as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18” (16).

In contrast, the WPA Section on Psychiatry of Intellectual Disability considers IDD to be a health condition: “a syndromic grouping or meta-syndrome analogous to the construct of dementia, which is characterized by a deficit in cognitive functioning prior to the acquisition of skills through learning. The intensity of the deficit is such that it interferes in a significant way with individual normal functioning as expressed in limitations in activities and restriction in participation (disabilities)” (17).

The debate regarding these differing conceptualizations of IDD has gained momentum and importance in the context of the current revision of the two major classifications of mental disorders: the ICD-10 and the American Psychiatric Association (APA)’s Diagnostic and Statistical Manual of Mental Disorders (DSM) (18). An extreme position in this debate suggests that if IDD are defined solely as disabilities and not as a health condition, they should be deleted from the ICD and classified using only codes from the ICF. Regardless of whether there is conceptual validity to this position, it is the ICD – not the ICF – that is widely used by the 194 WHO member countries to define the responsibilities of governments to provide health care and other services to their citizens. ICD categories, including categories related to IDD, are used throughout the world to specify which people are eligible for what health care, educational and social services under what conditions. Therefore, removing IDD from the list of health conditions would have a major impact on the visibility of IDD, on national and global health statistics, on health policy, and on the services available to this vulnerable population.

Conversely, if IDD are considered solely as a health condition, then the term “disability” should not be used to refer to them. But this would be at odds with the position already adopted by many governments and international organizations. Such a solution might be judged as a reductionist, biomedical approach and rejected by many key international stakeholders, users and experts in the field. Additionally, there are major unresolved questions in the definition of IDD as a health condition, including in what part of a health classification IDD should be placed, the age cut-off for onset, and the nature of the association between cognitive impairments and behavioural skills.

Collective experience related to terminology and ontology in the IDD field may help to clarify the conceptualization of the disease and disability components in ICD-11 and ICF; that is, where the health condition component of IDD can be appropriately placed within a classification of diseases and disorders, and how their functional consequences can be conceptualized using a classification of functioning and disability (6). Such an approach may provide alternative solutions to similar problems related to other mental disorders

that may be associated with disability.

The work described in this article has been conducted in the context of the revision of the classification of mental and behavioural disorders within the ICD-10, led by the WHO Department of Mental Health and Substance Abuse, which has been described elsewhere (19,20). In the area of IDD, an important purpose of the ICD-11 will be to provide tools to enable more widespread, efficient, and accurate identification and prioritization of persons with IDD who need services. In most countries, service eligibility and treatment selection for persons with IDD are heavily influenced by diagnostic classification. Persons with IDD are more likely to receive the services they need if health workers in the settings where they are most likely to be seen have a diagnostic system that is reliable, valid, clinically useful and feasible. It is very unlikely that such front-line personnel will be psychiatrists and, in LAMI countries, they are unlikely to be specialist mental health professionals of any kind, and are often not physicians. These factors have strongly influenced the conceptualization of the tasks and workflow for the revision of the ICD-10, as well as the composition of ICD revision Working Groups, including the one on IDD. The revision process is also influenced by the newly created Content Model for the overall ICD-11, which determines the structure and nature of the information to be provided for each diagnostic category, integrating the category within much larger informational infrastructure (21).

A mixed qualitative approach was used by the Working Group on IDD to combine available evidence with prior expert knowledge (22). This approach was applied in three face-to-face meetings, seven teleconferences, and electronic exchanges to generate consensus on the proposals submitted to the ICD International Advisory Group. This paper focuses on the proposals agreed upon by the Working Group related to the parent or supra-ordinal category for IDD, the name of the entity, its definition, and its subtypes.

OUTCOME OF THE WORKING GROUP’S DISCUSSIONS

Placement in the classification

There was consensus among the Working Group on the need to relocate IDD in the larger grouping (supraordinal or parent category) of neurodevelopmental disorders. In ontological terminology, subcategories are called children categories, and the supraordinal category is called the parent category. This position recognizes IDD as a health condition, and not solely as a constellation of disabilities.

Terminology

The term “intellectual” was favoured because in most countries it is well understood and widely used, and is broadly acceptable in the context of clinical and policy ap-

plications. In parallel with current definitions of intelligence (23), it does not refer to a unitary characteristic but rather is an umbrella term that includes cognitive functioning, adaptive behaviour, and learning that is age-appropriate and meets the standards of culture-appropriate demands of daily life. Even though “cognitive” may be seen as a more precise term that more closely reflects underlying phenomena of IDD, it also has a broader meaning in psychology. The use of the term “cognitive” in connection with dementia and schizophrenia may also cause confusion.

General support was expressed for adopting the term “developmental”, in that it refers to a period of time during which the brain and its functions are developing. The term “developmental” implies a process and a lifespan perspective and emphasizes the dynamic nature of IDD.

During the discussion, three words emerged as possible descriptors of the entity in question: “impairment”, “difficulties”, “disorder”. The term “impairment” is specifically used in the ICF to refer to problems in body functions and body structures that may be associated with a wide variety of health conditions. The term “difficulties” was proposed to avoid medical connotations and because it is less likely to be rejected by consumers, family groups and care providers. It may imply that the person can overcome his/her problems with some help or support, but it may also be confusing because for many people these difficulties are long-standing and will not be overcome completely. The term “spectrum” was also discussed, but it was discarded due to its low taxonomical value within a categorical classification.

WHO’s Clinical Descriptions and Diagnostic Guidelines for ICD-10 Mental and Behavioural Disorders (24) define a “disorder” as “clinically recognizable set of symptoms or behaviour” that is usually associated with interference with personal functions or with distress. The term “disorder” was seen as having utility, because it places intellectual disability at the same level of other major disorders such as dementia or schizophrenia. The term implies that it is not just a question of intelligence, and it fits with the existence of multiple etiologies and comorbidities and with the variability of IDD.

Definition

It was agreed that the definition of IDD should include terms related to the developmental origin of the brain impairment, manifestations in cognitive functioning and adaptive deficits, aetiology, course and outcomes. The Working Group’s proposed definition and its main descriptors are shown in Table 1.

Subcategories

The Working Group reached a consensus to maintain the subcategories (children categories) corresponding to the four clinical severity levels of mild, moderate, severe and

Table 1 Definition and main descriptors of intellectual developmental disorders (IDD) agreed by the ICD Working Group

Definition

A group of developmental conditions characterized by significant impairment of cognitive functions, which are associated with limitations of learning, adaptive behaviour and skills.

Main descriptors

- IDD is characterized by a marked impairment of core cognitive functions necessary for the development of knowledge, reasoning, and symbolic representation of the level expected of one’s age peers, cultural and community environment. Nevertheless, very different patterns of cognitive impairments appear for particular conditions of IDD.
 - In general, persons with IDD have difficulties with verbal comprehension, perceptual reasoning, working memory and processing speed.
 - The cognitive impairment in persons with IDD is associated to difficulties in different domains of learning, including academic and practical knowledge.
 - Persons with IDD typically manifest difficulties in adaptive behaviour; that is, meeting the demands of daily life expected for one’s age peers, cultural, and community environment. These difficulties include limitations in relevant conceptual, social, and practical skills.
 - Persons with IDD often have difficulties in managing their behaviour, emotions, and interpersonal relationships, and maintaining motivation in the learning process.
 - IDD is a life span condition requiring consideration of developmental stages and life transitions.
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profound IDD, in addition to the provisional categories of other and unspecified IDD.

A number of important organizations in the field have called for a discontinuation of children categories based solely on IQ. The AAIDD, for example, proposes a multidimensional system for classification and considers IQ ranges insufficient to be the sole determinant of cognitive functioning or clinical severity level (16). The Working Group argued that the determination of clinical severity levels for IDD should rely on a clinical description of the characteristics of each subcategory, and that the IQ score should be considered as one clinical descriptor among others also considered important in determining severity level.

The Working Group decided against discontinuing clinical severity levels, due to their current diagnostic and clinical utility (25). For example, increasing severity of IDD has been shown to be associated with lower levels of self-determination in choosing living arrangements, including where and with whom to live (26). Those with profound IDD are much more likely to live in a long-term care facility than those with mild IDD, and are less often able to determine their living arrangement. In addition, severity levels are already in wide use in many public health systems, determining the level of services and benefits provided. They may be helpful for communication between professionals in different disciplines, families, and users.

The subcategorization by clinical severity levels does not contradict the use of other approaches to subclassification, including multidimensional approaches aimed at connecting the IDD diagnosis to needed supports including intervention and planning (23). In the future, subcategorization based on clinical severity levels should be complemented by

subcategorization based on functional and personal characteristics and/or supports needed (ICF). A number of tools have been developed for classifying support needs and relevant characteristics of persons with IDD (27,28), but this field is still in its infancy and has not progressed to the point that such measures are available for worldwide use.

The subcategories of other and unspecified IDD will be maintained in the ICD-11, as they are standard components of the ICD-11 taxonomical system. However, they will be used as provisional diagnoses for specific age-defined populations. In children less than 4 years of age, there are well-known difficulties in diagnosing IDD or severity level due to the lack of reliable cognitive assessment tools and the temporal instability of measured cognitive impairments (29-31). For these reasons, it has been agreed that the provisional diagnosis of "unspecified IDD" should be used for all infants and children less than 4 years of age, where evidence exists of significant cognitive impairment. While a subset of these children will not go on to meet criteria for IDD, the ability to make this transitional diagnosis allows for the provision of early intervention services and clinical evaluation that are critical to improving developmental outcome.

The subcategory of "other IDD" is a provisional diagnosis to be used when IDD can be diagnosed, but where clinical severity level cannot be determined due to barriers in assessment, such as those presented by certain problem behaviours, psychiatric disorders, sensory or physical impairments. However, this provisional diagnosis is reserved for persons over the age of 4 years of age, so that the subcategories of unspecified and other IDD are mutually exclusive.

Problem behaviours

The Working Group agreed that problem behaviours, though very relevant to treatment and service usage, are not a core component of the linear structure of IDD as in ICD-10, and therefore they may be considered associated features rather than being subcategories or specifiers for IDD.

DISCUSSION

To the best of our knowledge, this is the widest international effort undertaken to date to reach a consensus on the name and definition of IDD. It has involved 30 experts from 13 countries, representing the different WHO regions, and experts from both high income and developing countries. This process has taken place in the context of an intense social and scientific debate on how to properly name and define IDD, which may have broad implications for users and families, and for eligibility and care provision in the future.

One of the major changes recommended by the Working Group is the integration of IDD with neurodevelopmental disorders. In ICD-9 (32), IDD were separated into a different large grouping from other neurodevelopmental disorders, an

action intended to provide greater visibility to these disorders and to underscore their common co-occurrence with other developmental disorders. Subsequently, the APA's DSM-III (33), which was multiaxial, excluded MR from Axis I, while analogous meta-syndromic categories more characteristic of adults (e.g., dementia) were retained as part of the main axis of mental disorders. Unfortunately, the separation of IDD diagnoses from other developmental disorders does not seem to have spurred the development of more specifically targeted services in most countries, as may be deduced from WHO's Global Atlas on Intellectual Disabilities (34). The incorporation of IDD in the large grouping of neurodevelopmental disorders will have significant implications for this supraordinal or parent category, and it may require a re-analysis of the hierarchy and the conceptual map of neurodevelopmental disorders to avoid double coding (e.g., in the case of Rett's and fragile X syndromes).

The recommended name and definition of IDD clearly identify them as a health condition. These recommendations are consistent with the 2008 position paper by the WPA Section on Psychiatry of Intellectual Disability (17), which recommended a polysemic-polynomial approach for complex entities such as IDD, allowing for the use of more than one name and meaning for different audiences and purposes so long as their relationship and semantic similarity is unambiguous and formally defined (35). It is important to have a clear description of the different meanings and uses of these terms in the scientific, social and policy arenas.

Disabilities should be seen as potential consequences of IDD health conditions. This is consistent with the approach promoted by the WHO within the Family of International Classifications, in which conceptually separate, though clinically overlapping, disease entities and functional impacts are coded using the ICD and the ICF. The position adopted by the Working Group on IDD may provide an example on how to formulate the hierarchy and the operationalization of the disease and disability components in ICD and ICF, which would also apply to other neurodevelopmental disorders (e.g., autism, specific developmental disorders), and more broadly to other mental disorders (e.g., dementia, schizophrenia).

The name and definition of IDD proposed by the Working Group do not conflict with the use of the terminology of ID, the functional definition approved by AAIDD, or a functional definition based on the ICF model. The proposed model preserves the distinction made in the WHO Family of International Classifications, and therefore in international health policy, between disease and disorder on the one hand, and the functional impacts of health conditions (i.e., disability) on the other (14).

In conclusion, the Working Group conceptualized IDD as a meta-syndromic health condition, parallel to other meta-syndromic conditions such as dementia, which may be related to a variety of specific etiologies. The Working Group endorses a polysemic-polynomial approach to the classification of IDD. This approach distinguishes between IDD (a

clinical meta-syndrome) and ID (the functioning/disability counterpart), which have different scientific, social and policy applications. The Working Group believes that this approach best supports the public health mission of WHO and the provision of appropriate services and opportunities to persons with IDD.

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