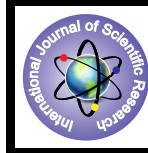


Mental Retardation Or Intellectual Disability (Does it really matter in clinical practice)



Medical Science

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ABSTRACT

Our purpose in this commentary is to clarify the shift to the term intellectual disability. At the heart of that shift is the understanding that this term covers the same population of individuals who were diagnosed previously with mental retardation in number, kind, level, type, and duration of the disability and the need of people with this disability for individualized services and supports. Furthermore, every individual who is or was eligible for a diagnosis of mental retardation is eligible for a diagnosis of intellectual disability. In addition, we explore why the field is shifting to the term intellectual disability. Increased understanding is based on a clear distinction among the construct used to describe a phenomenon, the term used to name the phenomenon, and the definition used to precisely explain the term and establish the term's meaning and boundaries.

INTRODUCTION

There is considerable and intense discussion in the field of Intellectual Disability and Mental Retardation about the construct of disability, how intellectual disability fits within the general construct of disability, and the use of the term intellectual disability [1-3]. This discussion is occurring within the context of competing world views of the philosophical and epistemological underpinnings of the conceptions of intellectual disability and mental retardation.

Increasingly, the term intellectual disability is being used instead of mental retardation. This transition in terminology is exemplified by organization names (e.g., the American Association on Intellectual and Developmental Disabilities—AAIDD, International Association for the Scientific Study of Intellectual Disabilities, President's Committee for People with Intellectual Disabilities), journal titles and published research [4]. A number of questions have emerged with the increased use of the term intellectual disability and must concerns clinicians today :

- Why is the term intellectual disability currently preferred to mental retardation
- How might the use of the term intellectual disability impact the current definition of mental retardation
- How might the use of the term intellectual disability affect persons diagnosed or eligible for a diagnosis of mental retardation
- Does a change in terminology actually reduce stigma
- Does our clinical understanding of mental retardation change with name changing.
- Does the management perspective of the disorder change
- Does the word disability bring new meaning to the problem
- Should clinicians really be concerned about the shift in name
- Does this name change the way parents perceive the problem

DEFINITION AND MEANING OF INTELLECTUAL DISABILITY

The current construct of disability is focused on the expression of limitations in individual functioning within a social context and represents a substantial disadvantage to the individual. Disability has its genesis in a health condition that gives rise to impairments in body functions and structures, activity limitations, and participation restrictions within the context of personal and environmental factors.

The construct of intellectual disability belongs within the general construct of disability. Intellectual disability has evolved to emphasize an ecological perspective that focuses on the person-environment interaction and recognizes that the systematic application of individualized supports can enhance human functioning.

The current construct of disability has emerged over the last 2 decades due primarily to an increased understanding of the

process of disablement and its amelioration. Major factors in this evolution include (a) the research on the social construction of illness and the extensive impact that societal attitudes, roles, and policies have on the ways that individuals experience health disorders [5]; (b) the blurring of the historical distinction between biological and social causes of disability [6]; and (c) the recognition of the multidimensionality of human functioning [7].

Because of these factors, the concept of disability has evolved from a person-centered trait or characteristic (often referred to as a "deficit") to a human phenomenon with its genesis in organic and/or social factors. These organic and social factors give rise to functional limitations that reflect an inability or constraint in both personal functioning and performing roles and tasks expected of an individual within a social environment [8]. This social-ecological conception of disability is reflected well in current publications of both the American Association on Mental Retardation (AAMR), now the AAIDD, and WHO. In the 2002 Manual, disability was defined as the expression of limitations in individual functioning within a social context and represents a substantial disadvantage to the individual. Similarly, in the World Health Organization's (2001) International Classification of Functioning, disability is described as having its genesis in a health condition (disorder or disease) that gives rise to impairments in body functions and structures, activity limitations, and participation restrictions within the context of personal and environmental factors. The importance of this evolutionary change in the construct of disability is that intellectual disability is no longer considered entirely an absolute, invariable trait of the person [9].

Rather, this social-ecological construct of disability, and intellectual disability, (a) exemplifies the interaction between the person and their environment; (b) focuses on the role that individualized supports can play in enhancing individual functioning; and (c) allows for the pursuit and understanding of "disability identity," whose principles include self-worth, subjective well-being, pride, common cause, policy alternatives, and engagement in political action [10].

CHOICE OF A TERM – FACTORS

Luckasson and Reeve [11] discussed five important factors that need to be considered when selecting a term. First, the term should be specific, refer to a single entity, permit differentiation from other entities, and enhance communication. Second, it must be used consistently by different stakeholder groups (e.g., individuals, families, schools, clinicians, lawyers, physicians, professional organizations, researchers, and policy makers). Third, the term must adequately represent current knowledge and be able to incorporate new knowledge as scientific advances occur. Fourth, it should be robust enough in its operationalization to permit its use for multiple purposes, including defining, diagnosing, classifying, and planning supports. Fifth, it should reflect an essential component of naming a group of

people, which is to communicate important values, especially towards the group. This aspect of the naming process (i.e., communicating important values) has generated a great deal of discussion, with many individuals asserting that the term mental retardation does not communicate dignity or respect and, in fact, frequently results in the devaluation of such persons [12].

There is an emerging consensus that not only does the term intellectual disability meet these five criteria, but that the term is preferable for a number of reasons. Chief among these are that the term intellectual disability (a) reflects the changed construct of disability described by the AAIDD and WHO, (b) aligns better with current professional practices that focus on functional behaviors and contextual factors, (c) provides a logical basis for individualized supports provision due to its basis in a social-ecological framework, (d) is less offensive to persons with the disability, and (e) is more consistent with international terminology.

DEFINITION OF INTELLECTUAL DISABILITY

Defining refers to explaining precisely the term and establishing the term's meaning and boundaries. The authoritative definition of intellectual disability is that of the AAIDD (previously the AAMR). The definition in the 2002 AAMR Manual remains in effect now and for the foreseeable future. This definition is shown here with a minor edit that substitutes the term intellectual disability for mental retardation:

Intellectual disability is 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.

The following five assumptions are essential to the application of the definition of intellectual disability i.e.

1. Limitations in present functioning must be considered within the context of community environments typical of the individual's age peers and culture.
2. Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor, and behavioral factors.
3. Within an individual, limitations often coexist with strengths.
4. An important purpose of describing limitations is to develop a profile of needed supports.
5. With appropriate personalized supports over a sustained period, the life functioning of the person with intellectual disability generally will improve.

A definition can make someone (a) eligible or ineligible for services; (b) subjected to something or not subjected to it (e.g., involuntary commitment); (c) exempted from something or not exempted (e.g., from the death penalty); (d) included or not included (as to protections against discrimination and equal opportunity); and/or (e) entitled or not entitled (e.g., as to Social Security benefits).

CONCLUSIONS

Intellectual disability is the currently preferred term for the disability historically referred to as mental retardation, and the authoritative definition and assumptions promulgated by the AAIDD (previously the AAMR) remain the same. The term intellectual disability covers the same population of individuals who were diagnosed previously with mental retardation in number, kind, level, type, and duration of the disability, and the need of people with this disability for individualized services and supports. Furthermore, every individual who is or was eligible for a diagnosis of mental retardation is eligible for a diagnosis of intellectual disability. The fact that the construct of intellectual disability belongs within the general construct of disability helps one understand why the term intellectual disability has emerged as a preferred term to replace mental retardation. The term intellectual disability (a) reflects the changed construct of disability proposed by AAIDD and WHO; (b) aligns better with current professional practices that are focused on functional behaviors and contextual factors; (c) provides a logical basis for individualized supports provision due to its basis in a social-ecological framework; (d) is less offensive to persons with disabilities; and (e) is more consistent with international terminology.

We anticipate that discussions will continue in an attempt to further refine the construct of intellectual disability, improve the reliability of diagnosis, and better understand these aspects of human functioning: the nature of intelligence, adaptive behavior, and disablement. In addition, the field will continue to examine the relationships between people with intellectual disability and other defined groups (such as those with learning disability, developmental disability, and traumatic brain injury); the provision of individualized supports to enhance individual functioning; the impact of the consumer and reform movements on the field; the effects of terminology upon peoples' lives; and the impact of an increased understanding of the biomedical, genetic, and behavioral aspects of the condition. At this time and for the foreseeable future, the definition and assumptions of intellectual disability/mental retardation remain those promulgated by AAMR in 2002; the term, however, is changed to intellectual disability.

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