

Definitions of intellectual disability

Review of the literature prepared for the
National Advisory Committee on Health and
Disability to inform its project on services for
adults with an intellectual disability

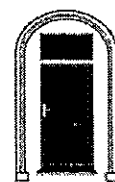
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NATIONAL ADVISORY COMMITTEE
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IHINGA KATITIRO I TE HIAKOROA O TE TANGATA

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for research & education
on intellectual disability

school. So he made a test that showed how much they had learned already. After this lots of other people developed tests like Binet's one. They were used for lots of things. One thing they are still used for today is to find out whether a person might have difficulty learning. If the person had a big enough problem with learning, then they might have what we call today – an intellectual disability.

Lots of people think that intelligence tests should be used very carefully. They should not be used to make life worse for people with an intellectual disability. They should be fair, and realise that some people might not have had the right experiences to learn.

Tests do not mean that people cannot learn. Our learning is affected by our opportunities and the help we get. Even if we are born with a disability we can still learn, with the right help.

Describing or defining intellectual disability

Older definitions said that intellectual disability was always due to some damage to the brain, and people could not really improve their learning very much.

We know much more about learning now and newer definitions do not say this. We know that all sorts of things affect how well people can learn. People's scores on intelligence tests can change too. People can learn new skills.

Most people agree now that we only call it intellectual disability when people had difficulty learning even when they were children.

Classification

People often talk about different degrees of intellectual disability, say "severe" or "mild". The latest definition says that it is much more useful to work out **how much support** a person with an intellectual disability might need. All people are different.

What a modern definition says

To have an intellectual disability, a person must have three things:

- a score on an intelligence test below about 75
- problems in at least two out of 10 areas; like daily living, school work, getting around independently
- learning difficulties as a child or teenager.

The definition also says:

- people's abilities must be assessed very carefully
- people have strengths as well as problems
- people can get better at learning with the right help

In terms of defining or understanding intellectual disability, therefore, it is critical that such simplistic beliefs about a central core of the concept, are not adhered to when it comes to understanding and supporting individuals who have what we call an "intellectual disability".

Apart from the conceptual and ideological critiques of intelligence tests and how they are used, there have also been criticism of "scientific" issues, such as reliability, validity, inappropriate norms, and using scores to **predict** future achievements or "potential" in individuals (eg, Ballard 1988).

The area of theorizing and measuring intelligence is an enormous area of research literature. For the purposes of this review, some basic understanding that intelligence and its measurement are **not** uncontroversial, and some of the issues, is all that can be covered here. How then has intellectual disability been defined in more recent times?

Definitions of intellectual disability in the twentieth century

Doll (1941) set out six essential criteria of intellectual disability, or as he called it, "mental deficiency":

- social incompetence
- due to mental subnormality
- which has been developmentally arrested
- which obtains at maturity
- is of constitutional origin
- is essentially incurable

This definition clearly reflected a medical model of intellectual disability, with its emphasis on biologically based causation and incurability, while acknowledging its expression in "social incompetence". There are also implications for policy and service provision which can be drawn from this conception. If intellectual disability is always of constitutional origin, then the whole focus of research efforts is likely to be on prevention at the level of biomedical research. There was little understanding at this time of environmental effects on intellectual and social functioning, such as poverty and lack of education. At a societal level, prevention at the level of reproduction would also be a logical implication from such a conception – people with an intellectual disability should not be allowed to have children. Eugenic beliefs resulted in widespread sterilisation, incarceration and segregation of people with an intellectual disability, in many Western countries, during the 1940s and up until the early 1970s.

Furthermore, if intellectual disability is essentially incurable, families and society should not waste their efforts and resources on training and education, which could only be expected to bring about minimal improvements in functioning. And, last but not least for the people so labelled once a "diagnosis" had been made, then the die was cast – it was virtually impossible to escape from the label and all the assumptions of incompetence that accompanied it. There was even an attempt to cope with contrary examples of later inexplicable achievement of people who had been diagnosed as having an intellectual disability, by coining the term "pseudo-retardation". In other words, someone must have simply made a wrong diagnosis in the first place.

One of the problems with actually applying this definition was that there were no scientifically valid ways of measuring differences in “adaptive behaviour” at different ages. In practice, therefore, the IQ usually “reigned supreme” in diagnosis and the decisions that went along with that.

Two other major differences to earlier definitions, such as Doll’s, are also very important, and represent a significant advance in knowledge about human development. The AAMD 1961 definition made no assumptions about etiology, and also did not assume incurability. This was an apparently small, but significant move away from the purely medical model of intellectual disability. This is not to say that the definition was accepted by all those influential in the field; many in the medical profession were often unconvinced that much could be done to improve a person’s level of functioning.

The next major revision of the influential AAMD definition occurred in 1973 (Grossman 1973). With a stroke of a pen, thousands of people with an intellectual disability were “cured” overnight – by the removal of the category of “borderline” and the move of the “fence” down to two standard deviations below the mean (IQ of approximately below 70). This single action illustrates how intellectual disability is a social construct. Society (in the form of a group of experts) decides who is to be “normal” and who is to be “intellectually disabled”. The concept is a moveable one – a new definition redefines who it applies to. The new, revised definition read as follows:

Mental retardation refers to significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behaviour, and manifested during the developmental period.

Further revisions incorporating minor changes occurred in 1977 and 1983 (Grossman 1983). Once again, the Association emphasised that the definition carried “no connotation of chronicity or irreversibility and, on the contrary, applies only to levels of functioning” (Schacter 1987: p 13).

Why is it necessary to continually re-examine, rename, and redefine what we call “intellectual disability”? Luckasson and Spitalnik (1994) have explained this very simply:

*If mental retardation were a thing, it could be named once, and defined once, for all time, like, for example, a thistle, or a rock formation...
Because mental retardation is not a thing, but a relationship, a status, it must continually be renamed and redefined. Societies are not static, and relationships in a nonstatic world evolve (p 81).*

A contemporary definition

Four years of work by a prestigious Committee resulted in the latest 1992 manual of the AAMR, the ninth edition focussing on definition and classification. The manual (“Mental Retardation: Definition, Classification, and Systems of Support”) was based on

... an evolving understanding of the concept of mental retardation and how it can be best defined and classified in our times. The present status of understanding

Limited

An intensity of supports characterized by consistency over time, time-limited but not of an intermittent nature, may require fewer staff members and less cost than more intense levels of support (eg, time-limited employment training or transitional supports during the school to adult provided period).

Extensive

Supports characterized by regular involvement (eg, daily) in at least some environments (such as work or home) and not time-limited (eg, long-term support and long-term home living support).

Pervasive

Supports characterized by their constancy, high intensity; provided across environments; potential life-sustaining nature. Pervasive supports typically involve more staff members and intrusiveness than do extensive or time-limited supports (Luckasson et al 1992: p 26).

For the purpose of planning and providing services, the new classification system provides a far more functional and relevant approach than the old one. However, its application relies on comprehensive assessments and an individualised approach to the design and provision of support services.

The AAMR 1992 manual set out to reflect and promote a changing view of intellectual disability, and the major trends taking place in service provision. Luckasson and Spitalnik (1994) set out the shifts in thinking and practice, leading to the 1992 manual.

What mental retardation is

*From trait to interaction between person and environments
From defect model to functional interpretation and assessment
From a statistic to a functional interaction*

Interaction between mental retardation and environments

*From control and coercion to empowerment
From dependence to self-definition, personal autonomy, and choice
From being a burden to being a person with challenges
From an eternal child and helpless to transitions to adult status
From fear of a person to understanding of a person's full humanness*

Resulting changes in services and habilitation

*From ineffectual teaching to good teaching and learning
From no schools to separate schools to inclusive schools
From residential segregation to neighbourhoods
From custodial care and maintenance to teaching functional skills
From institutions to group homes to supported living
From risk to family to acceptance to affirmation and supports
From denial of medical care to universal access to health care
From idleness to adult day program to segregated workshop to jobs
From job discrimination to antidiscrimination to supported employment
From IQ = restrictiveness to individualized determination of supports
(Luckasson and Spitalnik 1994: p 84).*

Neither of the two WHO manuals specify an age cut-off point for the developmental period (Wen 1997).

The American Psychiatric Association also includes intellectual disability in its classification of psychiatric or "mental" disorders (American Psychiatric Association, DSM-IV 1994). The definition provided in DSM-IV is essentially the same as the 1992 AAMR definition. However, it retains the traditional four "degrees of severity" – mild, moderate, severe, and profound, related to IQ levels. The manual acknowledges that these four levels of severity are **not** directly comparable with the AAMR "levels of support".

At various times, other definitions have been promoted by individuals or groups which have made a significant contribution to knowledge but have not received such widespread support as those developed by the American Association on Mental Retardation. Continuing concern about the cultural bias of most measures of intelligence and adaptive behaviour, with minority populations being more likely to be labelled, led to definitions with greater emphasis on culture and the environment. For example, Masland (cited in Scheerenberger 1987) proposed the following definition:

Mental retardation (refers) to a condition of intellectual inadequacy which renders an individual incapable of performing at the level required for acceptable adjustment within his cultural environment (p 14).

During the 1960s and 1970s, Jane Mercer, a sociologist, stressed the critical importance of sociocultural context in assessing functioning. She asserted that people's functioning within their own cultural group should be the point of reference, rather than national norms or expectations of the majority culture (Scheerenberger: p 17). Mercer (1970) wrote:

...mental retardation is not viewed as individual pathology but as a status which an individual holds in a particular social system and a role which he plays as an occupant of that status. In this context, mental retardation is not a characteristic of the individual, but rather a description of an individual's location in a social system, the role he is expected to play in the system, and the expectations which others in the system will have for his behavior. Mental retardation is an achieved status (p 383).

Mercer also pointed out that an individual may not be "retarded" in one system, but will be in another. Her views supported the finding in Western countries that far more individuals are classified as intellectually disabled during their school years than at any other times, due to the academic demands of that system. This phenomenon became known as "the six-hour retarded child".

Behaviourism, a very influential development in psychology, beginning in the 1960s, led to a definition which was couched in terms of operant learning. A person who is intellectually disabled is one

who has a limited repertory of behavior evolving from interactions of the individual with his environmental contacts which constitute his history (Bijou 1963: p 101).

APPENDIX 1

Update of AAMR Definition

Since this Review was compiled, the American Association on Mental Retardation has published a new definition and manual (AAMR 2002).

The 2002 definition is:

Mental retardation is a disability 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.

This new definition continues to promote the primary assumptions in the earlier definition. It provides a more concise description of adaptive behaviour, "as expressed in conceptual, social, and practical adaptive skills", rather than listing the previous ten adaptive skill areas. Assessment of these skills is to relate to typical rather than maximum performance.

The multiple dimensions of intelligence and adaptive behaviour are stressed in assessment, which should focus on strengths and limitations, and provide information that is useful in supporting the person to learn.

A further emphasis in the new definition is the need to analyse the individual's environment in terms of the opportunities available for personal growth, meaningful participation, and social interactions.

The model of individual functioning in the latest definition sees "supports" as an essential mediator of the effects in five aspects: intellectual abilities; adaptive behaviour; participation in education and social roles; health; and context.

Classification of "levels" of intellectual disability continue to be based on the intensity of needed supports. The manual provides extensive discussion of the implications of this "supports model" for policy and individualised service planning.

The new definition and model of intellectual disability also challenges many legal conceptions of intellectual disability and suggests the need for legal accommodation to redress the injustices often faced by people with an intellectual disability.

Reference

American Association on Mental Retardation (AAMR). 2002. (Luckasson R, Borthwick-Duff S, Buntinx Wil HE, Coulter DL, Ellis M(Pat)C, Reeve A, Schalock RL, Snell ME, AAMR Ad Hoc Committee on Terminology and Classification). *Mental Retardation: Definition, Classification, and Systems of supports*, 10th ed. Washington D.C: American Association on Mental Retardation.