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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PLAIN LANGUAGE SUMMARY

What is intellectual disability?

When we try to think about this we need to divide our study into three parts:

- what name we use for intellectual disability
- how we describe what it is
- how we divide people with an intellectual disability into different groups.

Names

Many different names have been used for intellectual disability. Some of them would not be used today because they sound horrible.

Describing intellectual disability is hard. There are lots of different ways to say what intellectual disability is. We call these different ways – different **definitions.**

Dividing people into groups, or **classification,** is done for a lot of different reasons.

In this report we will mostly talk about names and definitions. The next report will look more at classification.

Early history

There have always been people with an intellectual disability. We do not really know much about what their lives were like in the olden days. Some people thought it was bad to have an intellectual disability. Sometimes people thought that people with an intellectual disability were special, like angels. Sometimes people were treated very badly, because others did not understand about intellectual disability.

People have often mixed up intellectual disability with mental illness. Even today some people still do this.

People's ideas about intellectual disability affect how people with an intellectual disability are treated. As time went on people realised that intellectual disability had something to do with how well people learn. They called this "intelligence".

Trying to measure intelligence

When scientists first tried to measure intelligence they measured the size of people's heads and how well they could see, or hear, or how quickly they reacted. This did not work.

The first intelligence test that seemed to work was developed by a Frenchman called Alfred Binet. He wanted to make a test to sort out which children needed special help at 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

- people must only be compared with other people the same age, and who are from the same background or culture.

This new definition was approved by some people with an intellectual disability in America. But they did not like the name that was used which was “mental retardation”. This name is not used in New Zealand. We say “intellectual disability”.

Not everyone agrees with the new definition. This is because intellectual disability is not a thing we can see or hold.

There are lots of other definitions around, and also lots of different names. In England people call it “learning disability” or “learning difficulty”.

What do people usually disagree about?

- What name to use.
- Where to put the cut-off point on an intelligence test. How low does your score have to be?
- Whether intellectual disability is permanent.
- Whether intellectual disability is always due to damage to your brain, or something you have inherited.
- Whether we should only use “intellectual disability” for people that we know have brain damage or some other condition that affects their learning.

What do people with an intellectual disability think?

Some people with an intellectual disability do not know or do not understand that they have an intellectual disability. Some parents never tell them, and pretend that they do not have any learning difficulties. They do not tell them because they think it might upset them, or hurt their feelings.

If people with an intellectual disability do not know about their disability, it might be hard for them to learn to be realistic, and to grow up to be responsible adults. If they are always treated as children and teenagers, it is also hard to grow up.

People with an intellectual disability need to feel good about themselves, and know that it is **not** bad to have an intellectual disability.

What people with an intellectual disability **do not** like is being called names, being teased, and not being helped to learn to be more independent. People with an intellectual disability want to be able to make their own decisions more often, and do what other people do.

Self-advocacy groups have helped lots of people with an intellectual disability to learn to be proud of what they can do. They have also taught people to speak out, for themselves, and for other people with an intellectual disability.

What does this report say we need to do?

1. We all need to learn more about what intellectual disability means.

2. We need to have up-to-date ideas about what people with an intellectual disability can achieve.

3. We need to understand people with an intellectual disability are all different in lots of different ways.

4. We should be very careful when we use definitions to make important decisions about people, like what they are allowed to do and whether they can get support provided.

5. People with an intellectual disability should be involved in deciding what name or definition they prefer.

WHAT IS INTELLECTUAL DISABILITY?

Introduction: Naming, defining, and classifying

Exploring the question “What is intellectual disability?” requires a separation among three distinct processes or considerations – naming, defining, and classifying (Luckasson and Reeve 2001). Controversies and difficulties sometimes arise from confusing these different aspects.

Naming

Naming is about the term used to refer to what is called “intellectual disability” in New Zealand. This particular term is not common in other countries but has gradually become the preferred term here over recent years, at least within policy, service provision, and among the people to whom the term is applied. However, it is probably **not** well understood outside of the sector, with many professionals, and the lay population showing unfamiliarity with the term. Older terms previously used in New Zealand, such as “intellectual handicap” or “mental retardation” may be more familiar to many people.

Many different names are still used for the same phenomenon. Names change over time, particularly when their connotations or stigma become so derogatory in common usage, that they are no longer acceptable. Table 1 illustrates this multiplicity of names that have been, or are still being used. With more consideration now being given to the views of people with an intellectual disability themselves, the issue of naming is now receiving considerable attention.

Table 1: Labels

Backward
Cretin
Educable
Educationally subnormal
Feeble-minded
Idiot
Imbecile
Intellectual disability
Intellectual disadvantage
Intellectual Handicap
Learning difficulty
Learning disability
Mental deficiency
Mental Handicap
Mental Retardation
Mental sub normality
Moron
Slow learner
Trainable

Luckasson and Reeve (2001) suggest that the following questions should be asked when names or terminology are considered.

1. Does this term name this, and nothing else?
2. Does this term provide consistent nomenclature?
3. Does this term facilitate communication?
4. Does this term incorporate current knowledge and is it likely to incorporate future knowledge?
5. Does this term meet the purposes for which it is being proposed?
6. Does this term contribute positively to the portrayal of the people with the disability? (p 48-9).

Defining

The second issue, that of **defining** the term, is a complex one, and is the subject of a major portion of this review. The definition of what we call "intellectual disability" can have major implications for **who** is included under it, and what can happen to them as a result. In the case of people with an intellectual disability, the definition may have legal consequences, consequences for their autonomy, for what type of education they receive, for their eligibility for support services, and many other aspects of their lives. As this review will show, enormous efforts have continued over the years to develop "better" definitions which are more in line with current knowledge and developments in the field. Luckasson and Reeve (2001) suggest the following questions should guide a consideration of defining intellectual disability.

1. Does this definition indicate the boundaries of the term, that is, who or what is inside the boundaries, and who or what is outside the boundaries?
2. Does this definition indicate the class of things to which it belongs?
3. Does this definition differentiate the term from other members of the class?
4. Does this definition use words that are no more complicated than the term itself?
5. Does the definition define what something is, not what it is not?
6. Does this definition allow some generalisations about characteristics of the individual or group named by the term?
7. Is this definition consistent with a desired theoretical framework?
8. Does this definition contribute positively to the portrayal of people included in the term? (p 49).

Classification

The third issue, classification, refers to dividing into groups what has been included under the name and its definition. This review will consider briefly some classification schemes which have been commonly used. Other systems of classification will be discussed in the next review.

In order to put the review into context, it is important to understand something of the history of how intellectual disability has been named and defined.

Early history

People with an intellectual disability have existed in all societies throughout recorded history, although **who** would be labelled as having an intellectual disability has varied over time. Our knowledge of the existence of people with an intellectual disability in ancient times is based on written records and archaeological evidence of people with particular conditions associated with intellectual disability. The earliest written record is probably the Papyrus of Thebes (1552 BC) which included discussion of the treatment of people with an intellectual disability (Ellis 1975, cited in Katims 2000). In addition to written references in records of societal history and religions, archaeology has also identified the remains of individuals with conditions such as microcephaly and Down syndrome.

The writings of great religious leaders over the centuries often mentioned people with an intellectual disability, and how they were to be regarded, in general or in reference to religious rituals. Some of these views were exceedingly negative, for example, Martin Luther, while others were very positive, such as Paracelsus, a Swiss doctor of the early sixteenth century (Ryan and Thomas 1987).

There are records of areas in which a particular condition leading to intellectual disability was common, such as cretinism in parts of Switzerland. While some writers refer to these people in extremely derogatory terms, apparently their families and communities regarded them as “angels from heaven, a blessing to their families and incapable of sin” (Ryan and Thomas 1987: p 89).

Provisions for the education and care of people with an intellectual disability, as a group rather than individually, were not apparent until the beginning of the nineteenth century. Early influential professionals, such as Itard, a French doctor, and Seguin, who had worked with Itard, were positive about the promises of education and training. Thus, the more recent histories tend to be the histories of legal or institutional provisions, or the stories of those who “made their mark” as great leaders or visionaries. As Ryan and Thomas (1987) put it, for people with an intellectual disability, “what history they do have is not so much theirs as the history of others acting either on their behalf, or against them” (p 85).

Assumptions are often made that people with an intellectual disability were invariably treated harshly until more recent times. Practices such as infanticide, banishment, or reliance on begging are often listed in historical accounts. However, recent critiques have pointed out that the historical evidence for such assumptions is very sparse and highly questionable, and the generalisations made are seldom based on reputable research undertaken by trained historians (Bragg 1997; Bredberg 1999; Gleeson 1997). Inevitably, the histories that have been written, present a story of unabated progress, from the misery and neglect of ancient history to the enlightened and effective treatment available in the present (Bredberg 1999). However, we actually know very little about the lived experiences of people with an intellectual disability in past eras and within different societies and communities, or how their families and communities perceived their impairments.

What is clear, is that how individuals and societal institutions define or understand intellectual disability, affects whether and how people with an intellectual disability are supported, and what roles they are ascribed by society. Concepts of intellectual disability are bound by the social contexts of time, place, and societal values, which may also differ among social groups within society.

> *The changing definitions of difference constitute the history of mentally handicapped people. These definitions have always been conceived of by others, never are they the expression of a group of people finding their own identity, their own history. The assertion of difference between people is seldom neutral; it almost always implies some kind of social distance or distinction. The differences between mentally handicapped people and others have mostly been seen negatively, making them a problem to themselves and to others. Only in a few instances has the 'otherness' of mentally handicapped people been valued positively or respected (Ryan and Thomas 1987: p 13).*

One of the earliest recorded misconceptions about intellectual disability – and one which persists today – is its confusion or equation with mental illness, (psychiatric disability). In the seventeenth century, Locke attempted to distinguish intellectual disability from mental illness:

> *Herein lies the difference between idiots and madmen, that madmen put wrong ideas together and reason from them, whereas idiots have few ideas and reason scarce at all (Source unknown).*

The early New Zealand legislation and provisions illustrate this combination of the two "conditions" together (Thomson 1995).

When society itself provides similar or the same services for both groups, this confusion is reinforced. For example, in New Zealand up until recently, many psychiatric hospitals continued to provide residential care for people with an intellectual disability. Public and political debate about issues of deinstitutionalisation frequently fail to distinguish between the two populations, and discussants cite irrelevant examples or evidence which relate to the other group. In fact, the histories and research evidence for deinstitutionalisation of each group is quite different and seldom acknowledged in such debates.

Changing conceptions of intellectual disability in more recent times can be seen by examining various definitions accepted by influential leaders in the field during the last century. These developments are also intertwined with changing views of "intelligence" and how it should be measured.

"Intelligence" and its measurement

The central construct in any conception of intellectual disability is of a degree of lack or restriction of "intelligence". Therefore an understanding of many of the controversies and dilemmas involved in defining, measuring, and "counting instances of" intellectual disability can only be gained from an examination of the concept of "intelligence" and the different attempts to measure it. The area of science devoted to the measurement of individual characteristics is known as "psychometrics". Far from an unchallenged march of scientific development, the field of psychometrics is the focus of extensive critical debate – theoretical, scientific, and political. Intelligence testing continues to draw extensive criticism, particularly the uses to which such testing is put.

As with our examination of historical conceptions of intellectual disabilities, it is helpful to look briefly at the history of intelligence or "mental" testing. The precursors of such measurement are in the 19th century, when measurements of human skull and brain sizes were believed to equate to differences in overall intellectual ability. One of the aims of this early work was to rank different races in terms of ability.

Francis Galton (who coined the term "eugenics") was also convinced of the inherited biological basis of intelligence, and the role of "natural selection" in producing apparent differences in intellectual ability between social classes and races. Galton's beliefs and scientific skills in measurement had a significant influence on the subsequent development of intelligence testing. Underlying his work, and those of other prominent scientists of the time, was a "desire to decrease fertility of the 'unfit' and promote that of the intelligent" (Olssen 1988: p 31). The focus of Galton's own measures were on characteristics of physical traits and sensory skills, which he believed would also reflect differences in intelligence.

These early tests were, however, a dismal failure. As Olssen notes, "On the sensorimotor skills Irish, blacks and 'other foreigners' persisted in outscoring the English" (p 32). These early measures were therefore abandoned, as the results did not match the scientists' views of who were "really intelligent".

However, even though Galton's early tests were a failure, he did leave two lasting legacies – the development of many statistical techniques and the idea that an intelligence test must confirm our beliefs as to who is "really intelligent", ie, a definition of intelligence is seen by some as simply "intelligence is whatever the tests measure". The major criterion for the measurement of intelligence is therefore to **rank** people in terms of their assumed abilities in what we call "intelligence".

The most significant development in intelligence testing occurred when Alfred Binet, a French psychologist, at the beginning of the twentieth century, developed some tests which **would** distinguish between children with typical abilities and those "dull" children who needed some compensatory form of education. So in devising this test, Binet focussed on including only items that gave him the results he wanted at different age levels – a pragmatic solution to the problem of defining intelligence. It was therefore possible to use "age standards" for "average" achievement, in what Binet saw as "general intelligence" rather than a grouping of different skills. Binet also tried to measure intelligence separate from school learning, as far as possible. He was very conscious of the danger of testing leading to a self-fulfilling prophecy, and disagreed with the notion that intelligence was a biological, fixed capacity (Simpson 1999).

The enormous range of "intelligence tests" developed during the twentieth century are mostly more sophisticated and updated versions of Binet's tests. There have been many and various models of intelligence proposed which favour concepts of different **types** of intelligence, rather than one global ability. For example, Greenspan and Granfield (1992) proposed a model which included social, practical, and conceptual intelligence. Tests of intelligence have been widely used for all sorts of purposes, particularly in education, but their assumptions and uses remain controversial. Lewis Terman, an American, played a significant role in introducing the concept of IQ (a standard score which reflected the ratio of “mental” to chronological age). He also introduced the notion that intelligence (or rather, intelligence test scores) are distributed normally in a bell-shaped curve. In actual fact, the tests are constructed to provide this distribution.

In terms of a concept of intellectual disability and ways of measuring it, the use of intelligence testing has remained central. The assumptions and uses which are of most concern have included:

- the use of IQ to support eugenics
- the assumed link between IQ and “moral character” during the first half of the twentieth century
- the use of IQ scores to segregate people in separate educational, residential, and vocational services
- the unwarranted assumption of stability of IQ scores over an individual’s lifetime
- the use of IQ scores for streaming in schools
- the use of differences in IQ scores to justify assumptions about racial inferiority and superiority.

Olssen summarises the history of intelligence testing as follows:

> *According to this view (a view shared by all major mental testers – Galton, Goddard, Terman, Spearman, Burt, Thurstone), intelligence is a homogeneous entity residing somewhere in the brain and is essentially similar to height or weight in that it can vary in amount or rate of growth or decline but remain stable in its nature throughout life (p 43).*

In USA, the use of intelligence testing has been challenged in a number of court cases (see, for example, Scheerenberger 1987: p 27-35), and the tests have been held to be culturally biased in some of these cases. Judge Peckham in 1979 went so far as to conclude that “the history of the IQ test is not a history of neutral scientific discoveries… but a history of racial prejudice, social darwinism, and the use of scientific ‘mystique’ to legitimate such prejudices (cited in Scheerenberger 1987: p 31). These court cases did result in more careful and constrained uses of such tests, at least with minority and disadvantaged children (Scheerenberger 1987: p 33). Stephen J. Gould (1981), who has provided an extremely critical review of intelligence theories and intelligence testing, concluded:

> *We pass through this world but once. Few tragedies can be more extensive than the stunting of life, few injustices deeper than the denial of an opportunity to strive or even to hope, by a limit imposed from without, but falsely identified as lying within (p 28-9).*

Although contemporary views of “intelligence” are far more complex and have a greater understanding of the critical influence of many environmental factors on human development, the lay population (and far too many professionals who should know better) often have simplistic and outdated beliefs about intelligence.

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.

The American Association on Mental Deficiency (now the American Association of Mental Retardation (AAMR)) has been the most influential body to develop and publish manuals on the definition and classification of intellectual disability. The first manual was published in 1921, followed by second and third editions in 1933 and 1941 respectively. A fourth edition, which provided a classification system based on etiology, was published in 1957. In 1959 and 1961 (reprinted) (Heber 1959; 1961) the AAMR produced a comprehensive manual on terminology and classification. The "Heber" definition, as it became known included two significant changes to earlier definitions:

- raising the IQ ceiling to one standard deviation below the mean, ie, an IQ of 85
- including an adaptive behaviour criterion.

The definition stated:

> *Mental retardation refers to subaverage general intellectual functioning which originates in the developmental period and is associated with impairment in adaptive behaviour.*

Every phrase in this definition has significance and was operationalised clearly. "Sub average general intellectual functioning" referred to a score on an intelligence test which was more than 1 standard deviation below the mean for a particular age group. In practice, this usually meant a score of approximately 85 or below, and could include 16 percent of the total population. This statistical model of measuring "intelligence" depended on an approximate "bell curve" distribution of test scores. In actual fact, the distribution of scores on the most commonly used intelligence tests is not a pure "bell" shape, but has a decided "bump" at the lower end of the curve, and a greater than expected number of scores within the range 50-70 IQ (Dingman and Tarjan 1960; Zigler 1967). The important issue here, however, is the very large proportion of the population who could be included under the label of "intellectual disability", using this 1961 definition.

This definition also introduced five levels of severity of intellectual disability, compared to the earlier categories of "moron, imbecile, and idiot". These categories, which had quickly become derogatory labels, were rejected, in favour of the more neutral ones of "borderline, mild, moderate, severe, and profound".

The second important aspect of this definition was its emphasis on the **dual** criteria to be met. No longer was an intelligence test score sufficient to be diagnosed as being mentally retarded (intellectually disabled), but the person must **also** show "impairment in adaptive behaviour". Such impairment was deemed to be shown in different ways, depending on the person's age:

- the rate at which the person develops basic motor and self-care skills (maturation) – particularly relevant to the infant and young child
- the ability of an individual to learn or gain knowledge from experiences
- the ability of an individual to show the level of independent functioning expected in a particular society.

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" (Scheerenberger 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*

> *mental retardation reflects years of work, research, contributions, and policy development by many persons in this field (Luckasson et al 1992: p ix).*

Belying its superficial resemblance to earlier definitions, the 1992 manual represented a major "paradigm shift" in thinking about intellectual disability (Coulter 1996; Luckasson and Spitalnik 1994; Schalock, Stark, Snell, Coulter, Polloway, Luckasson, Reiss and Spitalnik 1994). The paradigm shift in the new definition was a move to

> *… a conception of mental retardation not as an absolute trait expressed solely by the person, but as an expression of the functional impact of the interaction between the person with limited intellectual and adaptive skills and that person's environment… (Schalock et al 1994: p 181).*

The committee responsible for the 1992 manual not only considered theoretical and research developments in the field, but consulted with a range of stakeholders – including, most significantly, people with an intellectual disability themselves.

The 1992 AAMR definition of intellectual disability is as follows:

> *Mental retardation refers to substantial limitations in present functioning. It is characterized by significantly subaverage intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, and work. Mental retardation manifests before age 18. (Luckasson et al 1992, p 1).*

The definition itself reiterates some of the previous components of the 1983 definition, in that it:

- provides a description of **current** behaviour
- includes problems in adaptive behaviour as an essential requirement
- uses the same cut-off point in terms of intellectual functioning (ie, two standard deviations below the norm)
- requires manifestation before 18 years of age.

The most obvious difference in the definition itself is the replacement of a global view of adaptive behaviour with the delineation of 10 specific adaptive skill areas. To meet the definition's criteria, the individual must show limitations in two or more of these areas.

In addition, the definition's **application** rests on four essential assumptions:

> *The following four assumptions are essential to the application of the definition:*
>
> 1. *Valid assessment considers cultural and linguistic diversity as well as differences in communication and behavioural factors;*
>
> 2. *The existence of limitations in adaptive skills occurs within the context of community environments typical of the individual's age peers and is indexed to the person's individualized needs for support;*

> 3. *Specific adaptive limitations often coexist with strengths in other adaptive skills or other personal capabilities; and*
>
> 4. *With appropriate supports over a sustained period, the life functioning of the person with mental retardation will generally improve. (Luckasson et al 1992: p 1).*

These four assumptions have very clear implications for how the definition is to be applied, for example, in the diagnosis of intellectual disability in an individual. The first two assumptions have particular relevance to the assessment and diagnosis of a person from a culture or background which is different to the assessor, or different from the population on which the assessment tool was developed and normed.

The third assumption, a focus on individual strengths, reflects the wide use of "strength-based" approaches to intervention with a variety of individuals, families, or communities in a range of situations.

Finally, we are reminded of a critically important fact – that intellectual disability, as defined, is not necessarily lifelong, but its existence or degree will depend on the provision of appropriate supports. The need for supports will also vary over time for many individuals who meet the criteria of the definition.

Classification in the 1992 AAMR definition

The other major change accompanying the 1992 definition is its radically different classification system. Instead of "levels of intellectual disability" the manual sets out a system based on the individual's **needs for supports.** The intensity and pattern of supports systems are divided into four levels: intermittent, limited, extensive, and pervasive.

The pattern of supports needed, are based on a thorough assessment of an individual's strengths and weaknesses, and need for supports in the four broad dimensions of:

- intellectual functioning and adaptive skills
- psychological/emotional considerations
- physical/health/etiology considerations
- environmental considerations (Luckasson et al 1992, p 24).

The definition of the four levels of intensity of supports are as follows:

> ***Intermittent***
> *Supports on an "as needed basis." Characterized by episodic nature, person not always needing the support(s), or short-term supports needed during life-span transitions (eg, job loss or an acute medical crisis). Intermittent supports may be high or low intensity when provided.*

> ***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 deficit 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).*

But the "shifts" set out here have not taken place among all professionals, academics, law and policy makers, service providers and even families. They are major "shifts in progress" rather than universal achievements. In New Zealand, there are probably very few professionals who are even familiar with the manual, its conceptions, and guidelines for appropriate assessment and design of supports.

As well as being applauded by many, the 1992 AAMR definition has been strongly criticised by some American academics for a number of reasons. The major critiques have focussed on the following specific issues:

- theoretical and practical difficulties of applying the definition to children, particularly preschool children (eg, Vig and Jedrysek 1996)
- raising the IQ "cut-off" to 75, thus opening up the application of the label to a much larger potential group in the population (eg, MacMillan, Gresham and Siperstein 1993)
- exclusion of classification levels based on degree of intellectual disability, and replacing these with "levels of support" (eg, MacMillan et al 1993; Vig and Jedrysek 1996)
- lack of reliable assessment instruments for the ten adaptive skills (eg, MacMillan et al 1993)
- lack of specificity (in classifying by levels of supports rather than degrees of disability) affecting research and prevalence estimates (eg, MacMillan, Gresham and Siperstein 1995)
- ignoring the needs of people with "mild intellectual disability" (eg, MacMillan et al 1995)
- the perceived advocacy/political "bias" rather than a psycho-biological "precise" conception of intellectual disability (eg, Das 1998; MacMillan et al 1995)
- the age of onset criterion (eg, Borthwick 1994)
- the definition being too closely tied to a narrow conception of intelligence measured by test scores (Greenspan and Granfield 1992; McGrew, Bruininks and Johnson 1996).

These criticisms have all received vigorous responses and rebuttals (eg, Reiss 1994). Some of the criticisms appear to be based on a mistaken assumption that intellectual disability is an objective entity within the control and precise measurement of scientists. As Reiss (1994) points out:

> *The process of defining mental retardation is essentially an exercise in public policy. There is no single God-given definition that scientists can discover and present as the "true" definition. God has not created a universe in which an IQ of 35 to 50 must be classified by many as "moderate mental retardation". Prior to*

> *the new AAMR definition, scientists already had produced eight different AAMR definitions of mental retardation. None of these eight prior definitions can be regarded as the one "true" definition that "must" be used (p 5).*

Reiss goes on to describe the significant participation of consumers in the 1992 definition. He states that "the new AAMR definition was largely intended to facilitate the development of inclusionary services demanded by consumers (p 6). Unfortunately it appears that this has not happened to any significant degree, probably partly due to the failure of professionals to study the accompanying manual itself rather than merely note the definition itself.

There is little evidence that adoption of the 1992 definition and classification system has been widespread among American states' actual policy and service systems (Denning, Chamberlain and Polloway 2000) or by researchers in published research journals (Polloway, Smith, Chamberlain, Denning and Smith 1999). There is still apparently a strong adherence to the traditional classification system (ie, mild, moderate, severe, profound), rather than moving to classification by types and length of supports needed by individuals. Such changes, however, are likely to occur slowly. Luckasson and Reeve (2001) claim that "many community-based supports providers **have** adopted a supports-classification because it facilitates their agency's planning process and budgeting for supports" (p 51). The term "mental retardation" is also currently under serious consideration for change, due primarily to the concerns of those labelled and their families (Luckasson and Reeve 2001).
(Note: Since this review was compiled, AAMR has published a new definition, which is briefly outlined in Appendix 1).

Other definitions and classification systems

Intellectual disability (mental retardation) is not a medical disorder, but it is coded in a medical classification of diseases of the World Health Organization (WHO), (1992). Intellectual disability (mental retardation) is defined as

> *… a condition of arrested or incomplete development of the mind, which is especially characterised by impairment of skills manifested during the developmental period, skills which contribute to the overall level of intelligence, ie, cognitive, language, motor and social abilities. Retardation can occur with or without any other mental or physical condition (WHO 1992).*

This definition includes some very indefinite terms and phrases, and would be difficult to use in any definitive way, especially in situations in which a decision affecting an individual was to be made.

In another WHO classificatory system (Classification of Impairment, Disabilities and Handicaps (IDIDH), intellectual disability (mental retardation) is included as a sub-category under the heading "Impairments of intelligence", which also includes conditions such as dementia. This system also lists sub-categories of "profound", "severe", "moderate", and "other" intellectual disability with "other" referring to "mild" intellectual disability. The descriptions or definitions under these sub-categories reflect outdated and inaccurate beliefs about what people in those categories can learn.

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).*

Another definition which emphasises a teaching or training orientation was provided by Dever (1990).

> *Mental retardation refers to the need for specific training of skills that most people acquire incidentally and that enable individuals to live in the community without supervision.*

Although such definitions focus our attention on important issues of intervention, they have severe limitations when applied to decision-making and eligibility issues about individuals. The Bijou and Dever definitions could both conceivably include far more people than would normally be described as "intellectually disabled".

Understanding of both the sociocultural and behavioural emphases is evident in the 1992 AAMR definition which emphasises assessments relating to a person's culture and social group, **and** the basic importance of environmental interactions on learning and development.

Terminology also varies widely across the world. The term "developmental disabilities" is often used, particularly in USA and Canada, sometimes as a synonym for intellectual disability. While the term would **include** people with an intellectual disability, it also includes people with a variety of disabling conditions, such as cerebral palsy, which may or may not be associated with an intellectual disability. The major use of the term is in legislation, funding, and service planning, to refer to people with conditions arising before adulthood, which result in the need for ongoing long-term services (Scheerenberger 1987: p 15-6).

When communicating with the general public about intellectual disability, a simple, functional definition is usually more appropriate than a formal, professional definition such as the AAMR definition. In a study of definitions and prevalence of intellectual disability in Australia, for example, Wen (1997) found that many working definitions in use were more loosely defined, even though they were often based on the 1992 AAMR definition. For example, in a project in Tasmania, an intellectually disabled person was defined as

> *… someone with below average intellectual functioning which results in slower development of social and behavioural skills than other people of the same age (Wen 1997: p 15).*

Wen (1997) also points out that, in terms of need for services, using the three strict criteria of the AAMR definition when used as eligibility rules sometimes excluded people from services from which they could benefit. For example, they may meet only two of the three criteria (p 15). Wen concludes that a multidimensional approach is needed which includes assessment of intensities and types of support needs, as outlined in the 1992 AAMR Manual (Wen 1997: p 16).

Examples of other functional definitions are:

> *Learning disability (ie, intellectual disability) includes the presence of:*

> - *a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with*
> - *a reduced ability to cope independently (impaired social functioning)*
> - *which started before adulthood, with a lasting effect on development. (Department of Health UK 2001).*

> *Intellectual disability is a learning difficulty that is characterized by limitations in various skill areas. These may include limitations in self-care, daily living, social interaction, judgement and self-direction. Intellectual disability usually becomes evident during the developmental years. The skill limitations due to the disability often exist alongside other abilities. With the appropriate support, people can learn skills to participate in their community (IHC Inc; Philosophy and Policy 1996: p 5).*

> *Intellectual disability (refers to) permanently impaired learning ability (usually from birth) which prevents or inhibits people from developing the range of physical and social skills usually found in a person of that age. (Ministry of Health, cited in Health Funding Authority and Ministry of Health 1998: p 17).*

This latter definition includes a number of assumptions, which differ from the conception and definition of intellectual disability embodied in 1992 AAMR manual, with a total focus on deficits in the person.

Different perspectives on defining intellectual disability

> *Mental retardation (intellectual disability) can be defined in many ways. We discuss the concept in terms of educability. We understand it in terms of causes (etiology). We particularize it in terms of the intelligence quotient (IQ). We examine it in terms of consequences. We do something about it in terms of treatments. Scientists study it, clinicians treat it, administrators deal with it, parents anguish over it, extended families contend with it, and many citizens ignore it (Blatt 1987: p 15).*

One of the most confusing aspects of intellectual disability is the multiplicity of terminology and perspectives focussed on the phenomenon (Holowinsky 1986; Sandieson 1998). Definitions are devised to suit the purpose of the user. For example, educational labels and classifications have been common in Western countries for many years. Traditionally referring to IQ-based definitions, these labels often carried stigmatising assumptions. In USA, for example, the three educational classifications referred to children with an intellectual disability as “educable”, “trainable”, or “custodial”. The three groups were thus placed into educational programmes which were based on these totally unwarranted assumptions about what each group could learn.

In New Zealand, our educational system used to have similar designations – “backward” and “intellectually handicapped”. As in USA, children went into different educational provisions depending on this classification – “backward” (mildly intellectually disabled) into special classes or, in special cases, to a special residential school, and “intellectually handicapped” (moderate intellectual disability) to special schools, previously called "occupation centres". Children with severe and profound disabilities were usually denied any education at all until 1990 (Wilton 1985).

Current provisions for students with an intellectual disability in New Zealand, as for other disabled students, are now based on a (supposedly) non-categorical approach, with resources based on individual students' difficulties in "accessing the curriculum", whether they are in regular or special classes or schools (see, for example, Ministry of Education 2000).

The United Kingdom has used various educational labels and categories, including "severely educationally subnormal", but like most other Western countries, with a move to including more disabled children in ordinary classes, these labels tend to disappear or change.

When it comes to eligibility for disability support services for adults, most countries opt for a functional definition with varying requirements for assessment or diagnosis. In New Zealand, the broad eligibility definition used by the Ministry of Health, for all people with disabilities is:

> *A person with a disability is a person who has been identified as having a physical, psychiatric, intellectual, sensory or age-related disability (or a combination of these) which is likely to continue for a minimum of six months and result in a reduction of independent functioning to the extent that ongoing support is required (Ministry of Health 1994: p 8).*

This definition clearly could exclude some people with an intellectual disability who may require intermittent rather than "ongoing support". Whether this criterion is always strictly applied may depend on other judgements.

Major controversies in defining intellectual disability

The major areas of controversy in defining and classifying intellectual disability are:

- where the "cut-off" between intellectual disability and "normal" functioning should be
- whether intellectual disability is permanent
- whether intellectual disability is always due to biological ie, organic or inherited factors, and environmental factors are of no or minimal influence
- whether we should conceive and define intellectual disability as one "disability", or as referring to two distinct groups of people, with people whose IQs are above 50 and have no identifiable cause for their disability being labelled and treated differently.

The "cut-off" point

As can be seen from previous examination of a number of definitions, the "IQ cut-off" point required as an essential criterion of intellectual disability, has been "moved" at various times. The implications for such changes are enormous, as it changes the proportion of the population who could potentially be deemed to be "intellectually disabled". Furthermore, a very small move in the boundary makes a big difference because the boundary resides in the portion of the (statistical) bell-shaped distribution of IQ scores which includes a lot of people. As MacMillan et al (1993) point out, moving the cut-off point from IQ 70 to IQ 75, means that **twice as many** people are eligible for a possible diagnosis of intellectual disability. The rationale provided by the 1992 Manual's authors is that the IQ 75 simply acknowledges the standard error of measurement on the most commonly used intelligence tests. It is not, therefore, a change from the previous definition.

There are significant implications for minority populations, who are already over-represented in the group of people labelled as having "mild intellectual disability" in all Western countries, if the upper "cut-off" IQ limit is raised at all.

The issue of permanence, or incurability

This issue is unlikely to go away in the foreseeable future. Adherents to this position fail to appreciate the difference between intellectual disability as a socially defined construct, and intellectual disability which is the outcome of a diagnosable biological impairment or medical condition.

Once again, the implications are most relevant to those people with an intellectual disability, who happen to fall closest to the "cut-off" or "boundary line". The critical fact is that while people may continue to have some degree of learning difficulties all their lives, this may not always be of sufficient degree to warrant a diagnosis of intellectual disability which refers to **current** functioning. The scores of an individual on an IQ test can change over time, and their adaptive skills can significantly increase. The presence of other stressors in their lives will also affect their current level of intellectual and adaptive functioning.

Biological/inherited or environmental?

Unfortunately the "nature-nurture" debate will not die a decent death. It is no longer scientifically sensible to conceive of nature and nurture (or biology and environment) as separate. Both are interacting from the moment of conception. Both are interdependent. In a recent influential review of empirical research on early childhood development, the USA National Academies concluded that

> *… nature and nurture are each sources of stability and malleability in human growth. More importantly, their coaction provides the impetus for development… (p 55).*
>
> *… despite a long historical tradition of dissociating the effects of nature and nurture on human character and development, their influences are, in the end, indissociable (National Research Council and Institute of Medicine 2000: p 56).*

These conclusions apply to all developing persons, whether they have impairments or not.

The “two-group” theory of intellectual disability

Allied to the nature-nurture controversy is the idea, long present in the field of intellectual disability, that there are essentially two groups of people with intellectual disability (eg, Zigler and Balla 1982). One group is deemed to have an intellectual disability due to some inherited or acquired neurological impairment – termed the “organic” group. This group supposedly consists of those people with at least “moderate” degrees of intellectual disability. Their development is conceived as following a different path to children without impairment.

The other group, typically those with a “mild” degree of intellectual disability has been termed the “cultural-familial” group. In this group, it is assumed that their intellectual disability is due to a combination of genetic inheritance and environmental deprivation. Their developmental path is seen to be the same as other children, but they develop at a slower rate and do not achieve the same end-point.

In fact, there is considerable overlap between these two groups and little empirical evidence to support the value of such a distinction for planning support services. For up to 50 percent of people with an intellectual disability, more than one causal factor is implicated (Schalock et al 1994). Furthermore, individuals with the same etiology often function at very different levels (Coulter 1996).

There are continuing calls to remove those with “mild” intellectual disability from the definition, and the resulting labelling (MacMillan, Siperstein and Gresham 1996). The concerns centre on the stigmatisation of the label, the over-representation of cultural minorities in this subgroup, and the lack of appropriate services for this group (MacMillan et al 1996). These authors also point out how more and more American states are choosing to label children who have an intellectual disability as “learning disabled” or “ADHD”. These terms appear to have become the “labels of choice”.

How do people with an intellectual disability see themselves?

The previous examination of different theories, definitions, and ways of categorising intellectual disability presented only one side of the picture. This side is that of the “experts” – the public figures, professionals, and academics – all of those who have the power to name and describe.

But what about the people to whom the label is given? Do they share the same picture of themselves? Do they acknowledge their “difference”? If so, how do **they** describe it?

The social model of disability, as promoted in the New Zealand Disability Strategy, has rarely been applied in disability theory and research to understanding the lives of people with an intellectual disability (Nunkoosing 2000). In terms of the construction of knowledge about intellectual disability

> *… both our ways of knowing and what we know … have privileged the knowledge of professionals and academics. One consequence of this is that the knowledge that men and women with learning disabilities (intellectual disability) possess about their experiences has been largely ignored (Nunkoosing 2000: p 50).*

The conception of intellectual disability embodied in definitions, such as the 1992 AAMR definition, are based on a positivist view of deficits which then imply a need for services which remedy such deficits, often by seeking to change the person (Nunkoosing 2000). We also use different language to refer to people with an intellectual disability – clients, consumers, tenants, patients – which constructs them in particular ways, often reinforcing their "otherness", or difference to "us". It is important that the supposed "objectivity" of the definitions and classifications accepted by academics and professionals, are recognised as bound to specific historical and social contexts, and not "value-free".

The first important proviso to remember in considering research in this area is the heterogeneity among people who are labelled as "intellectually disabled". The range of experiences and understandings is far greater than among people regarded as "intellectually normal". Their conceptions of the label and how it applies to them will therefore be very diverse as well.

Secondly, there have been relatively few research studies in this area, and few published narratives by people with an intellectual disability. It is also impossible to separate the label itself from the **experiences** that people with an intellectual disability have undergone because of the label. This section will examine empirical research, followed by an outline of some of the narratives provided by people with an intellectual disability themselves.

Research on the views of people with an intellectual disability

Intellectual disability is seen primarily as a difficulty in **learning.** It is not surprising, therefore, that many of our support systems focus on this primary characteristic. Practices such as "needs assessments" and "individual programme planning" can place the person with an intellectual disability in the position of a **"perpetual learner".** Williams and Robinson (2000) studied the views of 51 carers and the people with an intellectual disability they cared for, about their community care assessments and individual service reviews. Very few of the people with an intellectual disability understood what these processes were about. Many of them thought such meetings were about monitoring their progress, rather than helping them to plan for a future that they wished to achieve. As Williams and Robinson explain:

> *People with learning disabilities (intellectual disability) are constantly surrounded by others who are judging them, and their whole life can seem to them like an educational journey, with intermittent progress reports sent to their parents (p 298).*

With this type of conception of themselves, acquiring a view of themselves as "adult", with its notions of autonomy and responsibility, is likely to be very difficult.

Are people with an intellectual disability aware of the label and do they apply this to themselves? Is the label part of their self-identity? A UK study of 60 young people with a range of abilities and communication skills (Davies and Jenkins 1997) sought answers to these questions. The two areas of research focus were the participants' views of being an adult, and their understanding and self-application of the terms "learning difficulties" and "mental handicap". The responses of the 53 young people with sufficient communication skills to discuss their understanding of these terms fell into five categories. The largest category (42%) showed complete incomprehension of the terms, but showed no discomfort or embarrassment as to the questions. The second most frequent response (30%) provided a definition but one that excluded themselves. Most of these definitions focused on a physical impairment or a specific disability. Only 28 percent included themselves in their understanding of the terms "mental handicap" or "learning difficulties".

Those adults who explained their own disability referred to explanations given to them by their parents, referring to the origins of their disability in infancy eg, meningitis, reaction to whooping cough injection. However, most of their parents had avoided discussing their disability with them. Some of the adults identified employment as a critical criterion of **not** being "handicapped". Thus their self-identity was related to their experience of sheltered employment or attendance at a day activities centre.

Comparisons with non-disabled siblings were also a source of some understanding of their learning difficulties, as were experiences with physical limitations which affected their daily functioning.

The effects of their label with which the majority were familiar were the power and control exercised over them by other people in virtually every part of their lives. Thus while they often could not explain what a particular label meant or how it might apply to them, they had a view of themselves as dependent and lacking in a say in most of the areas in their lives, including very simple decisions. It is important to note, however, that the participants in this study were drawn from vocational disability support services, and were therefore unlikely to include people who did not need, or chose not to use these services.

The role of parents in controlling their offspring's understanding of intellectual disability was also explored by Todd and Shearn (1997). Parents of 33 adults with an intellectual disability (who still lived at home) were interviewed on three or four occasions. This research found that while parents had had to deal with the stigma of intellectual disability themselves, they deliberately tried to prevent their sons or daughters from having to deal with similar problems. The parents acted as mediators between their offspring and the outside world "filtering out" the stigma of the label, and minimising the effects of the label of intellectual disability on their offspring's self-identities. Parents clearly have a major role to play in shaping the self-identities of their adult sons and daughters.

Todd and Shearn (1997) also identified the problems experienced by parents and their adult offspring with the notion of an "adult identity." While parents did not deny the reality of adulthood in terms of age and physical development, they felt that the perceived dependency of their offspring meant that they viewed them generally as "non-adults". As neither adults nor children, therefore, "adolescent status" was accepted by many parents as the most accurate description of their offspring's identity. As the assumption of an adult status is often a contested one for adolescents, so "their sons and daughters were seen as stuck at an adolescent stage of resistance to parental authority" (Todd and Shearn 1997: p 349). Parents often described them as "living in a fantasy world", with which they often colluded, rather than providing their sons and daughters with accurate information about their disabilities and the demands of the real world. Thus parents were "keepers of secrets" about their offspring's intellectual disability, to protect them from the perceived pain and negative impact of "telling" on their offspring's sense of self. These researchers conclude that "many people with learning (intellectual) disabilities may be invisible to themselves" (p 363). This conclusion has, however, been challenged by other researchers.

Rapley, Kiernan and Antaki (1998) reviewed some of the data from Todd and Shearn (1997), and additional data of their own, to challenge the notion that people with an intellectual disability have little awareness of their own disability and ascribed social identity. All of the participants in the Rapley et al research were described as having a "mild or moderate intellectual disability", and able to communicate verbally. Rapley et al argue that the conversations show many examples of the recognition and rejection of the identity of an "intellectually disabled person". They also point out that social identity is far more dynamic and fluid than is often portrayed. In numerous social interactions, most people spend a lot of time "doing being ordinary" (Sacks 1984), and many people with an intellectual disability do this too. Rapley et al provide a number of extracts which support their interpretation that

> *While they may not have offered their interviewers a textbook diagnostic definition of the term 'intellectual disability', close examination of what is said reveals clear understandings of the interactional and social realities of their lives (p 824).*

There is considerable evidence that some people with an intellectual disability are only too well aware of the derogatory stereotypes, connotations and stigma of the label of intellectual disability or one of its synonyms. The early work of Robert Edgerton (1967) described how people who had moved out of institutions in the early 1970s put strenuous efforts into denying the label and their personal history and "passing" as "normal". The label itself, even today, acts as a "social identifier", placing the individual in the category of "abnormal", and often calls forth fear reactions (Danforth and Navarro 1998), such as the NIMBY (Not in my Backyard) Syndrome.

Studies of self-concept or self-esteem among people labelled as having a "mild" intellectual disability have found that most were aware of the stigma attached to them (eg, Jahoda, Markova and Cattermole 1988) but saw themselves as "essentially the same" as non-disabled people. Social identity theory suggests that a person's self-identity is derived from their group membership

How can people with an intellectual disability develop a positive, self-identity which is based on an understanding and acceptance of their difficulties, rather than a denial of them, and a distancing of themselves from the labelled group? For other disabled people, the development of a group identity based on pride in their differences, has given the strength to recognise and challenge discrimination and disabling social and physical environments. However, if these identities are based on very limited or ambiguous information, adults with an intellectual disability are likely to find it very difficult to develop a shared group identity from which to challenge their negative experiences, as other groups of disabled people have done. Despite these challenges, however, some people with an intellectual disability have begun to develop a group identity through their involvement in the "Self-advocacy Movement". The "Self-advocacy Movement" among people with an intellectual disability in many countries, illustrates their efforts to establish a positive group identity, and to speak for themselves about matters that vitally affect them.

The beginning of this civil rights movement was located in Sweden in 1970, when a group of 50 young adults (who had an intellectual disability) reviewed their lives, unmet needs, and aspirations (Blatt 1987: p 99-102). The movement grew significantly since then, from the establishment of the first “People First” organisation in Oregon, USA in 1974 to over 505 such groups in USA by 1994 (Ward 1996). People with an intellectual disability in New Zealand have been an active part of this movement since the mid 1980s, although the development has not been all “plain sailing” (Gosling and Gerzon 1994). Most groups call themselves “People First”, reflecting a strong assertion that their individuality and similarity to all people is more important than their disability label.

What do “People First” groups do?

A 1994 survey of 505 self-advocacy groups in USA found that their activities focussed on individual advocacy (38.2%), social and recreational activities (24.4%), group advocacy (15.1%), and self-related topics (14.75%) (Longhurst 1994). A UK survey of self-advocacy groups in service settings, (Crawley 1988) found that achievements of the groups surveyed, were evident in two areas: bringing about positive changes in local services, and the individual gains in skills and confidence of group members. Topics of activities were similar to the USA survey, but also showed that 28 percent of the issues discussed related to intellectual disability itself eg, labelling, attitudes, rights, what is intellectual disability (Crawley 1988: p 16).

What do people with an intellectual disability themselves say?

Published stories and oral presentations by people with an intellectual disability are relatively recent, but are increasingly available. Published autobiographies and life reflections include, for example:

Seagoe MV. 1964. *Yesterday was Tuesday, all day and all night: The story of a unique education.* Boston: Little, Brown. This book is the edited diary of Paul Scott, a young man who has Down syndrome.

Bogdan R, Taylor S. 1982. *Inside Out: The Social Meaning of Mental Retardation.* Toronto: University of Toronto Press. This book contains two life stories, as told by people who had been labelled as mentally retarded (intellectually disabled) by everyone in their lives. Ed Murphy, one of these narrators says:

> *There is discrimination against the retarded. There are people out of ignorance who have hurt retarded children. It really doesn’t help a person’s character the way the system treats you. One thing that’s hard is that once you’re in it, you can’t convince them how smart you are. And you’re so weak you can’t convince them how smart you are. And you’re so weak you can’t really fight back…*

> *… I'm talking like an expert. I had to live it. Shit, I'm just another person out there. I have to pay taxes. I'm not really different. I only had different experiences in my life than you… (p 29-30).*

Some of the stories reveal the appalling experiences of people with an intellectual disability who spent many years living in large institutions:

White Marion Rose. Quoted in B Blatt. 1987. *The Conquest of Mental Retardation.* p 107-10. USA: ProEd.

Burkig TO, Edwards SA. 1979. *On the Inside – Looking Out.* Texas, USA: Grunwald Printing Co.

Bolnik JP. 1985. *Winnie: "My Life in the Institution": A Memoir of a Special Woman.* N.Y: St Martin's/Marek.

Hunter A. 1996. *My Life.* Dunedin: Donald Beasley Institute.

Other published stories reflect a more ordinary life growing up in a family and community:

Kingsley J, Levitz M. 1994. *Count us In: Growing Up with Down Syndrome.* USA: Harcourt Brace.

In order to present the voices of people with an intellectual disability themselves, the following quotations come from the Third International People First Conference in 1993 (People First of Canada 1993). The stories from which these excerpts come are from conference participants from 30 countries who dictated or wrote their stories at the Conference.

> *The most important time in my life was when I came out of the institution and started living like everyone else in the community. I have now lived in the community since I was 21 (p 7). Carol Pein, Sydney.*
>
> *I hope we have more meetings like this. It brings people together. We are like brothers and sisters. Even if you are born yellow or green, intellectually or physically disabled it is all the same. Everyone has the right to be treated like everyone else. We should all feel at home in our community (p 9). Jean-Claude Jalbert, Canada.*
>
> *I work at "Speaking for Ourselves" which is a self-help group for people with mental and physical disabilities. We prefer the name handicapable rather than handicapped (p 15). Steve Dorsey, USA.*
>
> *Although I speak well, I am a slower learner than other people. The only way I can learn is first-hand experience. One way I learn is to write songs (p 25). David Cooper, USA.*

> *My proudest moment was getting a job and earning money. Not being looked down upon by others. Living harmoniously with my colleagues (p 30). Sin Wing Chi, Hong Kong.*
>
> *I am not a disabled person because I have Down Syndrome. I am just like everyone else. You should look at the person first and their disability second. You should not judge them by their disability but as a person (p 39). Mike Anderson, USA.*
>
> *Do you know about the mythical bird the Phoenix? This bird grew out of the ashes and came back to life. That is how I feel now as a President of People First in Ajax (p 46). John Daniel Brown, Canada.*
>
> *I wrote a poem which I use sometimes when I speak to people:*
>
> *Some people call me retarded but I don't think they are being honest with themselves*
> *They look at me and say things behind my back such as mentally retarded.*
> *Well if you have a defect, they will pick on it and make it into something it isn't*
> *I feel very strongly and suggest to them, they should look at their own labels and adjust to mine (p 61). Brian Beaudet, Canada.*

In an early leadership training manual written for People First groups in Canada, (Worrell 1988) two leading self advocates said:

> *I was labelled mentally retarded and I still am. I work in the community, I live in the community, but I'm still labelled mentally retarded. That label has been hanging over my head for a long time…*
> *… I would say that People First, for me as an individual has made me a stronger individual because it has given me a purpose, it has given me a reason to live each and every day. It has given me encouragement, it has given me the fight or the strength that I need to go on every day and to face new challenges, to become aware of situations that we have to deal with as individuals in the so-called average life… … We have a handicap but we are not the handicap (Pat Worth: p 5).*
>
> *People First helps all labelled people figure themselves out. Through my involvement in People First I have learned to speak up for myself and the rights of others. People First is a place for us to share our feelings and support each other. I have met many friends through People First. One of the many friends that I made through People First is my wife. She is more than a friend (Peter Park: p 19).*

These excerpts from members of self-advocacy groups show their awareness of being labelled along with a strong rejection of the stereotyping and different treatment that went with the label. Involvement in a group movement can also be experienced as inspiring, motivating, and a source of pride, helping individuals to achieve and challenge individual experiences of rejection, stigma, or stereotyping. This group involvement, which is by personal choice, can contribute positively to self-concept, through a shared sense of identity (Harris 1995). There is evidence that, as a group, self-advocates are more positive about themselves than other people with an intellectual disability who are not involved in a self-advocacy group (Simons 1992, cited in Harris 1995).

Finlay and Lyons (1998) investigated the importance of the intellectual disability label, to people's self-descriptions and the strength of their identification with the group (ie, people with that label). By identifying with the group, persons with an intellectual disability are more likely to perceive their disadvantages in socio-structural terms rather than as individual misfortune or fault. In this study, 28 people classified as having "mild or moderate learning difficulties" were interviewed to establish measures of: understanding terminology, self-descriptions, self-esteem, group evaluation, and group identification. Contrary to expectations, this study found that "those who evaluated the group negatively did not feel any worse about themselves, even when they admitted the label applied to themselves, and those that admitted the label did not evaluate it more positively than those that denied the label" (p 44). This study shows that there is no simple direct link between group identity and self-concept. However, in this group of participants it is interesting that only two attended People First groups. In an on-going study reported by the researchers, involving interviews with 38 similar participants, very few of them mentioned intellectual disability in self-descriptions. Is this simply a matter of denying the label's applicability to oneself?

Finlay and Lyons (1998) point out that researchers should not assume that a disabled identity is central to the concept of self. As the quotations from people with an intellectual disability show, they have many other experiences, in family, work, and with friends, which may be far more important than the disability label. Knowledge of stigma is not the same as its internalisation. People with an intellectual disability may not perceive why they share the same label as other people, who may be quite different to them in many ways. Simply because our culture treats people with an intellectual disability as an identified group, does not mean that members of that group will do the same. Finlay and Lyons conclude that some of the difficulties that self-advocacy groups have encountered may be due to the fact that many people with an intellectual disability may not identify with the group, an essential pre-requisite for collective advocacy actions.

How can we summarise the messages from people with an intellectual disability themselves? Burton Blatt (1987) provides a summary for us, (in the language of his culture and times):

> *Mentally retarded people have viewpoints about their condition and also about the world in general. We are not mentally retarded and, consequently, can't present those viewpoints with any authority. For that you have to go directly to these people themselves – or to their published words which are beginning to amount to quite a body of literature. What we have learned confirms a few generalizations: (a) People do not regard themselves as hopeless and terminal; (b) people do not regard themselves as anything but human; and (c) people do not regard themselves as deserving to be alone, unwanted, and without friends. And those beliefs are exactly correct. We are all equal as human beings, and to live well we must believe that about everyone, especially ourselves (p 111).*

More recent contributions have argued for abandoning the classification of "intellectual disability" rather than continuing to seek for terms with less stigma or more "scientific" definitions. Smith and Mitchell (2001) argue that we need to weigh up the issue of need vs the issue of stigma, by asking ourselves the following questions:

> *… is the aggregation of people into this diagnostic category truly necessary to meet their needs? Are services in the name of mental retardation (intellectual disability) justified given the risk of stigma associated with the label? How can we achieve a balance between the need for assistance and the risk of diminished individuality? (p 146, 'intellectual disability' added).*

Conclusions and implications

The issues involved in defining what we, in New Zealand refer to as "intellectual disability" are complex and always changing, as can be seen from an examination of some of these developments. What is critical is that we understand that intellectual disability is **not** a condition or disorder, although some conditions or damage to the central nervous system can result in intellectual disability. Intellectual disability is merely a description of society's current judgement on an individual's functioning. However scientific and objective we may strive to be, however useful we find the idea, we must recognise that intellectual disability is a socially defined phenomenon, a metaphor, a social construction (Biklen 2000). As Biklen explains, the important issue about the social construction of intellectual disability was "not that it is a social construction, but that it was so often and so universally taken up as real and immutable and that, in the main its reification is dangerous to people so labelled" (p 454).

People with a more severe intellectual disability are usually recognised as disabled in any time or culture, and will need lifelong support to varying degrees. The most controversial issues about naming and defining usually relate to people who are seen as "less different", particularly those who are closer to society's "boundary" between "normality" and "intellectual disability". Does it make sense to include such a wide range of individual differences under one label? Some would argue that it does not make sense, and is, in fact, damaging to those so labelled (eg, Baroff 1999). The largest group of people who could meet the criteria for intellectual disability often do not use disability support services and would reject the label of intellectual disability.

Developing **one** definition of intellectual disability that would meet the six criteria set out by Luckasson and Reeve (2001) (see Introduction) is probably impossible. Definitions are developed and used for different purposes, and any definition must be appropriate for that purpose. Furthermore, definitions will inevitably change over time to reflect changing knowledge and societal responses to people with an intellectual disability. Definitions are also **never** value-free, however "scientifically" they may be developed and detailed in "objective" terms.

Definitions of intellectual disability, and the names we invent, are, after all, applied to real people, and used as the basis for significant decisions about people's lives.

While a consideration of the complex issues involved in naming, defining, and classifying intellectual disability, may be confusing, some important implications can be identified.

A contemporary understanding of how intellectual disability is conceived and defined is critical to inform service planning and development. The label "intellectual disability" typically conjures up a lay perception of a severe degree of impairment, which is far from accurate for the majority of adults with an intellectual disability.

When a definition is to be used to make significant decisions about a person's rights or to secure eligibility to scarce resources, it is critical that definitions and their application are well-informed.

Service planners should not ignore the needs of those people who do not use the label "intellectual disability" to refer to themselves and usually do not use disability support services. Traditionally referred to as "people with mild disabilities", this group of adults may have significant needs for appropriate support on an intermittent basis, in areas such as employment, parenting, mental health, prevention of exploitation and abuse, prevention of offending.

People with an intellectual disability should be involved in considerations of terminology (names), defining and classifying intellectual disability, and the uses to which these definitions are put.

The research suggests that many people with an intellectual disability are **not** given information about their learning difficulties. This can limit their own development and ability to challenge discrimination, unnecessary overprotection and limitations, and to deal effectively with the hurtful attitudes of other people.

> *There is no simple solution to the fundamental problem of difference. We cannot deny that important differences amongst people exist, nor suppose that they are only a matter of arbitrary social labels. But this does not mean that we should exaggerate and reinforce these differences, as we do, nor see them as entirely due to the deficient nature of the individuals concerned. What is needed, but seems so hard to achieve, is a recognition of difference amongst people that allows for special needs and unusual behaviour, but which doesn't thereby disqualify anyone from full acceptance as a human being (Ryan and Thomas 1987: p 29).*

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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 funding in the latest definition sees "supports" as an essential mediator of the effects of five aspects: intellectual abilities; adaptive behaviour; participation, interaction 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.

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