

The definition and prevalence of intellectual disability in Australia

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Summary

People with intellectual disability represent a very significant client group of disability services, especially disability support services in Australia. This paper critically reviews some significant definitions of intellectual disability and attempts to quantify the size of this population group. It also aims to inform and stimulate discussion.

Definitions and classifications of intellectual disability

There is a diversity in the underlying concepts, definitions and classifications of intellectual disability adopted in Australia.

In the national population disability surveys, the Australian Bureau of Statistics (ABS) has adapted the concepts of the International Classification of Impairments, Disabilities, and Handicaps (ICIDH), and the classifications of the International Statistical Classification of Diseases and Related Health Problems Ninth Revision (ICD-9). The ABS national health surveys have used modified classification groups according to ICD-9.

Other Australian institutions, either in administration, legislation, or academic work at State and local levels, have adapted the definitions and classifications of the American Association on Mental Retardation (AAMR) to define intellectual disability. AAMR is a leading association in defining and classifying mental retardation. The key elements of the AAMR definition are: low general intellectual functioning as measured by IQ score, difficulties in adaptive behaviour and the conditions manifesting before age 18. The AAMR definition has been revised periodically to reflect the development in the field.

Australian operational definitions and estimates of prevalence of intellectual disability have been affected by the periodic revisions of the AAMR definitions and classifications, and by the variations in definitions and classifications between AAMR and other major classification systems. The mixed use of definitions of developmental disability and intellectual disability has also created inconsistency in data collections and estimates of prevalence.

The ICIDH and the AAMR systems are consistent conceptually. The ICIDH concepts of impairment and disability are reflected in the AAMR notion of 'low general intellectual functioning'. The concept of 'handicap', more socially defined in the 1980 ICIDH, is represented in the AAMR system in terms of 'difficulties in adaptive behaviour'.

The ICIDH is being revised and is likely to delineate the separation of three basic concepts: impairment as an effect at organic level; disability in terms of whole person functioning; and 'participation' which reflects the result of the interaction between disability and environmental factors. While the ICIDH is a broad classification system, its concepts are reflected in the more specific AAMR approach.

The AAMR definitions and classifications, like those of the ICIDH, are moving towards more emphasis on functional and environmental considerations, and less emphasis on an individual's 'deficiency'. The assessment of intensities and patterns of individuals' needed supports became an integral part of the new (ninth revision) AAMR definition and classification system.

These developments are in apparent harmony with disability policy in Australia, adopting a multidimensional approach and including assessment of the need for support as one of the components of definition and classification. This approach avoids reliance solely on IQ scores to classify severity of intellectual disability.

The limited availability and quality of data in Australia indicate that there is a need to improve the consistency of concepts and definitions in defining intellectual disability and to increase the comparability of different data collections.

Estimates of prevalence of intellectual disability

The existing estimates of prevalence show wide variations in operational definitions, measurements, survey approaches, data sources and geographic locations. In Australia, most estimates of prevalence have been confined to State level. The following table presents estimates from different data sources, methods and operational definitions, which are discussed in this paper.

Summary table: Comparison of estimates of intellectual disability

Estimates of prevalence (%)	Regions	Data sources and methods	Definitions
0.3–0.4	World	Agency records	Adapted definitions of AAMR/ ICD-9 etc.
0.4–0.5	Australian States	Agency records	Adapted definitions of AAMR
0.42	Australia	1989–90 ABS national health survey (excluded people in institutions) Mental retardation/specific delays in development as a long-term condition	Adapted ICD-9 classifications
0.65	Australia	1993 ABS disability survey, 'intellectual' as a primary disabling condition, identified before age 18	Adapted ICIDH concepts and ICD-9 classifications, AIHW groupings
0.73	Australia	1993 ABS disability survey, 'intellectual' as a primary disabling condition	Adapted ICIDH concepts and ICD-9 classifications, AIHW groupings
1–1.5	World	Epidemiological studies	AAMR/ICD etc.
1.7	Australia	1993 ABS disability survey, based on screening question of 'slow at learning or understanding'	All people reporting positively to the screening question of 'slow at learning or understanding'
1.86	Australia	1993 ABS disability survey, 'intellectual disability' including all relevant disabling conditions and disorders	Adapted ICIDH concepts and ICD-9 classifications, AIHW groupings
3.0	United States	US President's Task Force and President's Panel on Mental Retardation	This 'theoretical prevalence' rate is an extrapolation from statistical models based on IQ scores

Sources: References discussed in Chapter 3 of this paper.

Estimates based on statistical model of IQ scores

In the 1960s and 1970s, the US President's Task Force and the President's Panel on Mental Retardation estimated that about 6 million, or 3%, of Americans would be diagnosed as having mental retardation at some time in their lives. The 3% 'theoretical prevalence' estimate was criticised because it is an extrapolation from statistical models using IQ scores as a single arbitrary criterion rather than a result of empirical investigations.

In Australia, the highest prevalence rates of intellectual disability estimated from the 1993 ABS disability survey were 2.7%–2.8% among males of school ages, which were close to the 3% of the 'theoretical prevalence' rate.

There are a number of explanations for why the highest prevalence rate estimated among the population of school ages cannot be assumed as the 'true' prevalence rate of the general population. These reasons or factors include: difficulties in case identification in infancy, early childhood and post school period; some children with mild retardation in terms of IQ may achieve some level of adult independence after school years; the assessment applies only to present levels of functioning; when dual criteria (IQ tests and adaptive behaviour) are used, the prevalence will be reduced substantially; and mortality among people with severe mental retardation is higher than that of the general population.

It would be desirable to conduct some qualitative studies on these explanatory factors as well as studies on the possible impact of the new AAMR definition and classification on current or future data collections and prevalence estimation.

Australian estimates at national level

The ABS disability surveys are the only existing national data containing information about the prevalence of disability in the Australian population. The following estimates of prevalence of intellectual disability were derived from the 1993 Survey of Disability, Ageing and Carers:

- There were 328,000 people (1.86% of the total population) with intellectual disability, either as the primary disabling condition or an associated condition, of whom 174,000 people (0.99% of the total population) also reported the need for assistance with three basic daily living activities: self care, mobility, verbal communication. The figure of 174,000 may be the best estimate of population prevalence of intellectual disability based on available data, although some of the survey data limitations may contribute to an underestimation. These limitations include: not all adaptive skill areas of the AAMR definition are covered; the homeless people and people in prisons were not included in the collection; there are difficulties in case ascertainment of children under the age of 5 years; the survey questions on restrictions and limitations in activities are somewhat more focused on physical abilities of daily living, which may emphasise the presence of limitations from physical impairments.
- A recent ABS (1996) report on disability and disabling conditions estimated that 1.7% of the total population responded positively to the 1993 survey screening question of 'slow at learning or understanding'.

- According to reported primary disabling conditions, there were 128,900 people (0.73% of the total population) with intellectual disability, of whom 48,000 people (0.27% of the total population) also reported the need for assistance with the three basic daily living activities.
- There were 114,000 people (0.65% of the total population) with intellectual disability as a primary disabling condition identified before the age of 18 years.
- There were about 0.13% of people aged 55 and over with intellectual disability as a primary disabling condition identified before age 18.

Australian estimates at State level

Estimates of prevalence from administrative records in most Australian States were approximately 0.4%–0.5%.

National estimates of prevalence derived from the ABS population disability surveys, where the self-reported information might or might not be the result of professional assessment, were higher than those State estimates from administrative records, in which a majority of the cases were presumably verified by professional assessments. These records may tend to contain people with severe disabling conditions.

Pattern of intellectual disability

According to the 1993 disability survey, a great majority (86.6%) of people with an intellectual disability who lived in households reported having that disabling condition before age 18, and 38.3% reported an onset of their condition at birth or during infancy. This was in contrast to the pattern of all people with a disability, a majority (73.8%) of whose primary disabling conditions were identified at adult ages or older.

Both national and regional estimates showed that the age-specific prevalence rates increased with age until about age 10 to 14 years and then declined gradually. The rates were generally higher among children at school ages than among the adult population.

Consistently higher overall prevalence among males, as compared with females, was evident in the estimates at both State and national levels. The sex differences in prevalence were particularly significant among children and adolescents.

Of the people reporting intellectual disability as the primary disabling condition in the 1993 disability survey, 44% also reported associated impairments or disabilities in physical aspects and more than a quarter of people also presented with speech problems. A high proportion (22%) of people reported associated psychiatric disabilities.

Conclusion

The summary table provides an overview of a number of the most important estimates of intellectual disability in Australia and elsewhere.

In Australia, estimates of 0.4–0.5%, based on the number of people with intellectual disability known to the agencies, can be assumed to provide underestimates of prevalence of intellectual disability in the general population.

On the basis of the best available population data to date, there are 328,000 people (1.86% of the total population) with intellectual disability, either as the primary disabling condition or an associated condition, of whom 174,000 people (0.99% of the total population) need ongoing support. The figure of 174,000—or 0.99% of the population—is perhaps the best figure to use for an overall estimate of the prevalence of intellectual disability in Australia.

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1 Introduction

The two consecutive biennial reports of the Australian Institute of Health and Welfare (AIHW), *Australia's Welfare 1993* and *Australia's Welfare 1995*, provide an overview of population data on prevalence of disability in the Australian population. In addition, the AIHW conducted a study in 1995 (Madden et al. 1996) to inform the Commonwealth/State Disability Agreement (CSDA) Evaluation. The study examined available national data and made estimates of the demand (including unmet demand) for disability support services provided under the CSDA. These and other AIHW reports (Wen et al. 1995 and Madden et al. 1995) drew attention to the need for more work to be done on the dual issues of consistency of disability definitions and estimation of disability prevalence.

A number of other significant reports (Baume and Kay 1995, Yeatman 1996) have also highlighted the need to improve the consistency of disability definitions and the comparability of disability data collections. An Australian Disability Data Reference and Advisory Group (DDRAG) was established by the Institute in 1996 to examine these issues and provide a focus for work being done in this area.

Intellectual/learning disability is the most predominant primary disability type among the recipients of disability support services, accounting for about 70% of total clients (Black and Eckerman 1997). We need useable estimates of the prevalence of intellectual disability and a better understanding of the national picture of this population group in order to facilitate service planning and to inform the disability field and the community.

However, the existing estimates of intellectual disability show considerable variations, reflecting differences in operational definitions, measurements, survey methods, data sources and geographic locations. Most surveys and studies have been confined to State level.

This paper contains a critical review of existing definitions and estimates of prevalence from different data sources and studies, discusses the consequences of different purposes, operational definitions, measures and data collection methods, and presents estimates of the number of people with intellectual disability in Australia on the basis of the 1993 ABS disability survey. Estimates from this survey, which are based on self-reporting information, are compared with estimates from clinically oriented administration records.

The paper consists of four chapters, of which this brief introduction is the first. Chapter 2 provides an overview of existing definitions and classifications. Chapter 3 examines the existing published estimates of prevalence in Australia, refines the estimated number of people with intellectual disability, and analyses the pattern of intellectual disability in Australia, as revealed in the ABS disability surveys and other published studies. The discussion of prevalence is presented at both national and State levels, along with a comparison with international studies. Chapter 4 discusses issues relating to the definitions and estimates of prevalence of intellectual disability and presents some concluding remarks.

2 An overview of existing definitions and classifications

2.1 Definitions and classifications of intellectual disability

The terms 'intellectual impairment', 'intellectual disability', 'developmental disability' and 'mental retardation' are in common use. They are sometimes used interchangeably. In this section, the definition and use of these terms are discussed.

There are two broad approaches to the definition of intellectual disability and each approach has different assumptions. The traditional clinical approach (Heber 1959, 1961; Grossman 1973, 1983) considers intellectual disability as a characteristic of a person and a condition which is essentially within the individual and assumes that the source of the difficulty lies within the individual. The approach tends to define intellectual disability on the basis of either a medical model or a statistical model. The medical model focuses on pathology, which defines intellectual disability by the presence of pathological symptoms. The statistical model defines intellectual disability by identifying a certain group of the population as 'abnormal', using comparison of an individual's performance and the performance of a standardised norm group. The model measures the extent of disability by standardised tests, such as intelligence quotient (IQ) tests and social adaptation tests.

As an alternative, the social system approach assumes that an individual lives in a physical and social environment and that a disability is mainly the result of the interaction between the person and the environment. Mercer (1973a, 1973b) defines mental retardation as 'an achieved social status in a social system' so that individuals are labelled 'mentally retarded' as a function of their performance in a social environment. Mercer argues that the traditional approach is not adequate for identifying people with mild mental retardation. Gold (1980) suggested a concept which focused on the ability, or failure, of society to provide adequate training and education as the measure of mental retardation rather than on the failure of the individual (Patton et al. 1990).

It has been suggested that the traditional approach and the social system approach should not be viewed as alternatives, particularly in identifying people with mild mental retardation. Rather, the two approaches should complement each other, with the social system approach used first and followed by the traditional clinical approach (MacMillan 1982).

The latest (ninth) revision of the definition and classification by the American Association on Mental Retardation applied such a multidimensional approach. The new approach combined the traditional approach and the social system approach, and modified the classification system using descriptions which are more functional and oriented to service delivery (Luckasson et al. 1992).

2.1.1 The American Association on Mental Retardation (AAMR) definitions and classifications

The American Association on Mental Retardation (AAMR) definitions and classifications have wide, although not universal, endorsement in the United States. Most Australian institutions, either in administration records, legislation or studies at State or local levels, have adapted the AAMR definitions.

The latest (ninth) revision of the AAMR manual (1992) defines mental retardation as:

... substantial limitations in present functioning. It is characterised 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).

The definition requires the diagnosis of mental retardation before age 18. However, mental retardation may occur at any age beyond the developmental period through an acquired physical trauma or central nervous system deterioration. If this happens, the condition is more properly classified as dementia (Grossman 1983). For people under age 18, the diagnosis of dementia is generally made when the condition is not identified satisfactorily by the diagnosis of mental retardation. A diagnosis of dementia requires that the memory and other cognitive deficits represent a significant decline from a previously higher level of functioning (American Psychiatric Association 1994). People with mental retardation are more likely to suffer from other associated mental disorders as compared with people without mental retardation. The most common associated mental disorders are attention-deficit/hyperactivity disorder, mood disorder, pervasive developmental disorders, stereotypic movement disorder, and mental disorders due to a general medical condition (American Psychiatric Association 1994).

Modifications of the AAMR definitions and classifications

The first comprehensive AAMR manual on definition and classification was published in 1959 (fifth revision) and was reprinted with minor corrections in 1961. In the 1959 and 1961 revisions, adaptive behaviour was formally introduced as a criterion in defining mental retardation. Since 1961, the manual has been revised periodically to reflect current information and development in the field, while the key definitional elements have generally remained the same: low general intellectual functioning, difficulties in adaptation and chronological age 18 (or 16 for the 1961 Revision) as a cut-off point for the presence of the conditions (Table 1).

Table 1: Comparison of different versions of A.AMR definitions of mental retardation

Term	Fifth revision (Heber 1961)	Sixth revision (Grossman 1973)	Eighth revision (Grossman 1983)	Ninth revision (Luckasson et al. 1992)
General definition	Subaverage general intellectual functioning which originates during the developmental period and is associated with impairment in adaptive behaviour.	Significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behaviour and manifested during the developmental period.	Significantly subaverage general intellectual functioning resulting in or associated with concurrent impairments in adaptive behaviour and manifested during the developmental period.	Substantial limitations in present functioning, it is characterised 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.
Subaverage	Greater than one standard deviation below the mean.	Significantly subaverage: two or more standard deviations below the mean.	Significantly subaverage: defined as an IQ of 70 or below on standardised measures of intelligence, could be extended upward through IQ 75 or more, depending on the reliability of the intelligence test used.	Significantly subaverage intellectual functioning: defined as an IQ standard score of approximately 70 to 75 or below.
Assessment procedure	General intellectual functioning: may be assessed by one or more of the standardised tests developed for the purpose.	Same as Heber.	Same as Heber for intellectual functioning. Adaptive behaviour assessed by clinical assessment and standardised scales.	Multidimensional approach including a three-step procedure for diagnosing, classifying and determining the needed supports.
Developmental period	Approximately 16 years.	Upper age limit of 18 years.	Between conception and the 18th birthday.	Manifesting before age 18.
Adaptive behaviour	Impairment in adaptive behaviour: refers to the effectiveness of the individual to adapt to the natural and social demands of his environment. May be reflected in: 1. maturation, 2. learning, 3. social adjustment.	Defined as effectiveness or degree with which the individual meets the standards of personal independence and social responsibility expected of his age and cultural group. May be reflected in the following areas: <i>During infancy and early childhood:</i> 1. sensory-motor skills development, 2. communication skills, 3. self-help skills, 4. socialisation <i>During childhood and early adolescence:</i> 5. application of basic academics in daily life activities, 6. application of appropriate reasoning and judgment in mastery of the environment, 7. social skills <i>During late adolescence and adult life:</i> 8. vocational and social responsibilities and performances.	Impairments in adaptive behaviour refers to significant limitations in an individual's effectiveness in meeting the standards of maturation, learning, personal independence, or social responsibility that are expected for his or her age level and cultural group. May be reflected in the same areas as 1973.	10 adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, and work. The relevant skills within each adaptive skill area may vary with chronological age, so that assessment of functioning must be referenced to the person's chronological age.
Levels of severity	Borderline retardation IQ 68–84 Mild retardation IQ 52–67 Moderate retardation IQ 36–51 Severe retardation IQ 20–35 Profound retardation IQ < 20	Mild retardation IQ 52–67 Moderate retardation IQ 36–51 Severe retardation IQ 20–35 Profound retardation IQ < 20	Mild retardation IQ 50–55 to approximately 70 Moderate retardation IQ 35–40 to 50–55 Severe retardation IQ 20–25 to 35–40 Profound retardation IQ below 20 or 25 Unspecified	Intensities of supports: Intermittent Limited Extensive Pervasive

Sources: Grossman 1983; Luckasson et al. 1992; Patton et al. 1990.

Intellectual functioning is measured by standard intelligence quotient (IQ) test scores. The IQ cut-off criterion for significantly subaverage intellectual functioning has been specified in terms of standard deviation (15) below the population mean (100) with a possible standard error -5 or +5. The cut-off scores were defined as greater than one standard deviation below the mean (Heber 1961), two standard deviations below the mean (Grossman 1973) and then in absolute IQ scores (Grossman 1983, Luckasson et al. 1992).

As can be seen in Table 1, the 1961 definition was broad, setting the upper IQ score limit up to 84 with 'borderline retardation' as an extra level of severity. However, the 1973 definition was more exclusive, by inserting the word 'significantly' before the term 'subaverage general intellectual functioning', and setting an IQ cut-off score close to 70. In the eighth revision (Grossman 1983), *significantly subaverage* is defined as an IQ of 70 or below on a standardised measure of intelligence. Yet the cut-off ceiling is a guideline and could be extended up to an IQ of 75 or more, 'depending on the reliability of the intelligence test used', provided that 'behaviour is impaired and it is clinically determined to be due to deficits in reasoning and judgment' (Grossman 1983:11). The latest (ninth) revision defines *significantly subaverage* as 'IQ standard scores of approximately 70 to 75 or below', which allows a range of 70-75 rather than an exact cut-off (Luckasson et al. 1992). These changes in IQ cut-off scores for defining intellectual functioning have resulted in great variations in Australia's definitions and classifications (for detailed discussion see particularly Sections 2.2 and 3.3).

The eighth (1983) revision was intended to make the AAMR definition consistent with the International Classification of Diseases, ninth revision, (ICD-9) of the WHO, particularly in terms of medical classification. However, because the purposes of the two systems are somewhat different, the two manuals are not identical. The AAMR manual was mainly for use by clinicians whose primary interest is in mental retardation, while the ICD-9 was designed for use in the context of the entire range of medical diseases and syndromes (Grossman 1983).

Changes in the latest (ninth) revision

Substantial changes occurred in the definitions and classifications of the ninth (1992) revision of the AAMR manual in contrast to earlier versions. One of the major changes is the 'shift from a deficiency-model to a support-model of mental retardation' (Reiss 1994, Schalock et al. 1994). The ninth revision considers mental retardation as substantial limitations in present functioning and broadens the concept of mental retardation by defining it as a *state*, rather than a *trait*, in which functioning is impaired in certain specific ways and occurs within the context of community environments (Luckasson et al. 1992). The new revision emphasises that mental retardation is a disabling condition resulting from the interaction between a person and the environment rather than a deficiency associated with individuals as it had been viewed in earlier revisions. The intention is not to change who is and who is not considered to have mental retardation but to change how people think about mental retardation. It 'shifts some responsibility for the consequences of disability from

the person to the environment' (Reiss 1994). One of the authors of the ninth revision has given the following example to illustrate the change:

Under the old AAMR definition, if a child had a low IQ and learned slowly in regular classrooms, the slow learning was attributed to 'mental retardation', and the teacher had an excuse for not producing better results in educating the child. The child was removed from regular classrooms and educated in 'special' places. In contrast, the new AAMR definition provides a basis for holding the school more responsible for the outcomes of education. For example, if a child with a low IQ learns slowly, the school is expected to provide the supports needed to educate the child in the regular education environment. When the new definition is more fully adopted, education in special classes no longer will be an option in many instances (Reiss 1994).

This shift from the old deficiency model to the new support model was supported by consumer organisations (Reiss 1994).

The second major change of the ninth revision is that the definition is based on a multidimensional (four dimensions) approach which provides a comprehensive description of a person with mental retardation (Luckasson et al. 1992). The approach aims to broaden conceptualisation of mental retardation, to avoid reliance on IQ scores to assign a level of disability, and to relate the individual's needs to the appropriate level of supports. The four dimensions are: intellectual functioning and adaptive skills, psychological/emotional considerations, physical/health/etiology considerations and environmental considerations.

A three-step procedure was introduced for diagnosing, classifying and determining the needed supports of a person with mental retardation. Step 1 is the diagnosis of mental retardation and determines eligibility for supports. Step 2 is classification and description, and identifies strengths and weaknesses and the need for supports. The person's strengths and weaknesses are evaluated in reference to all the four dimensions mentioned above. Step 3 is the profile and intensities of needed supports, and identifies needed supports.

As a result, the ninth revision excluded the previous classification of severity of mental retardation (i.e. mild, moderate, severe, or profound). Instead, it introduced a new concept of 'intensities of needed supports' on the basis of the assumption that a person's level of needed supports parallels the individual's limitations. The authors of the new revision concluded that such descriptions are more functional, relevant, and oriented to service delivery and outcomes than the labelling classification used in earlier revisions (Luckasson et al. 1992). Four levels of supports were specified: intermittent, limited, extensive and pervasive (for details of definition and examples see Appendix A). These levels of needed supports are to be identified in each of the four dimensions mentioned above.

Another major change is the expansion of the concept of adaptive behaviour. Under the new definition, ten applicable skill areas are specified (Table 1), which are considered as essential for service provisions in order to optimise the present functioning of the individual in the community. The definition also emphasises the degree of the skills since it is most closely linked to the need for services (Luckasson et al. 1992).

The modifications in the ninth revision can be mainly explained by the changes in its goals and philosophy. The purposes of the eighth revision, as the author stated, were to contribute toward an acceptable system to be used around the world, to facilitate communication for diagnostic, treatment, and research purposes, and to facilitate prevention efforts (Grossman 1983). However, the

new revision was chiefly intended to facilitate the development of inclusive services for people with a disability. The definition and classification provided the terminology needed to 'facilitate inclusive education, supported or competitive employment, and supported living' (Reiss 1994).

The authors of the new revision believe that the process of defining mental retardation is essentially an exercise of 'selecting from a range of possibilities the language and concepts that might serve as the cornerstone of today's public policy' (Reiss 1994).

Like any new initiatives, the new definition and classification of the ninth revision are still in a developing process. They need to be tested empirically, particularly in the classification of mental retardation and in the measurement of adaptive skills. The AAMR Classification and Terminology Committee (subsequently referred to as the Committee) admitted that further research is needed to develop measures of the ten adaptive behaviour skills and to evaluate the impact of the ninth revision on schools and service provision systems (Reiss 1994).

Main criticisms of the latest revision

One of the important issues is the consideration of how much weight to give to consumer versus professional opinions in developing the definition and classification. The authors of the ninth revision thought that 'consumers were entitled to have a substantial degree of influence over their own future' (Reiss 1994). Consequently, the consumers did play an important role in drafting the new definition. However, this has attracted criticism that the Committee has emphasised the values of advocacy and consumerism over those of scientific and empirical principles in drafting the ninth revision. The definition and classification seem to be a result of 'a sense of advocacy and concern with policy rather than being designed to meet the needs of researchers, clinicians, and practitioners' (MacMillan et al. 1993, 1995).

Replacing the former classification of severity of mental retardation with 'intensities of supports' in the ninth revision was criticised as neglecting the fact that people with mental retardation differ markedly in severity, etiology (organic and non-organic) and behavioural characteristics, and that the differences in characteristics and etiologies are substantial, if comparing people with mild mental retardation with those who have severe or profound mental retardation. The use of levels of supports instead of severity 'will result in classification that is less precise and less reliable than the one it replaces' (MacMillan et al. 1993, 1995). However, the Committee (Schalock et al. 1994) argued that the traditional distinction of the two broad groupings of etiology of mental retardation is probably no longer entirely valid. The epidemiological studies show that about 50% of individuals with mental retardation have more than one possible causal factor, sometimes reflecting cumulative or interactive effects of the factors (McLaren and Bryson 1987).

The issue of what should be the maximum IQ score to define subaverage general intellectual functioning is another controversy relating to the ninth revision. The Committee insisted that they did not intend to increase the IQ limits in defining mental retardation but to continue the past practice of

flexibility in the interpretation of IQ cut-off scores (Reiss 1994). However, MacMillan et al. (1993, 1995) raised serious concerns about the 'imprecision' of the definition that 'fails to provide clear guidelines and decision rules for eligibility of people in the upper IQ ranges of mental retardation'.

A small increase in the cut-off score will result in substantial change in the percentage of the population eligible to be diagnosed with mental retardation. In a normal distribution, twice as many people are eligible when the cut-off is IQ 75 and below (4.7%) as when it is IQ 70 and below (2.3%) (MacMillan et al. 1993, 1995). The 1961 version of the definition (Heber 1961) set the IQ upper limits score to 84. With that guideline in diagnosis, it was possible to identify statistically about 16% of the population in the United States as 'mentally retarded,' with an increase from about 6 million to 32 million (Patton et al. 1990; Evans 1991).

Conceptual and assessment concerns were also raised about the use of ten adaptive skills specified as defining criteria of mental retardation in the ninth revision. In the previous definitions, the authors acknowledged that the expectations of adaptive behaviour vary for different age groups and thus the deficits in adaptive behaviour will vary for people at different ages (Grossman 1983). The ninth revision appeared to neglect the strong relation between the degree of mental retardation and the age at which a person is diagnosed as having mental retardation. The ten adaptive skill areas adopted fail to consider developmental factors and cannot be assessed reliably (MacMillan et al. 1993). For instance, in examining a case of an infant suspected of having Down syndrome, virtually none of the skill areas could be assessed (MacMillan et al. 1993). The new revision does not identify any specific measures of adaptive behaviour skills, while the Committee provided some guidelines for the development of procedures and selection of instruments.

There are also general criticisms about the IQ tests. The rationale for setting the IQ cut-off score is based on a statistical model. The classification model based on IQ cannot account for the fact that two people with mental retardation having exactly the same IQ scores may differ considerably in everyday social competence (Zigler and Hodapp 1986). The tests have been found to lack reliability when applied to very young children or people with severe levels of impairment. Many of them cannot be given tests at all because of their extreme behavioural or physical disorders. The tests are considered to have a cultural bias when applied to various minority groups.

2.1.2 World Health Organization (WHO) definitions and classifications

International Statistical Classification of Diseases and Related Health Problems (ICD-10)

The WHO ICD-10 defines mental retardation 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, i.e. cognitive, language, motor, and social abilities. Retardation can occur with or without any other mental or physical condition (WHO 1992).

The classification points out that degrees of mental retardation are conventionally estimated by standardised intelligence tests, which can be supplemented by scales assessing social adaptation in a given environment. Intellectual abilities and social adaptation may change over time and may improve by training and rehabilitation, so diagnosis should be based on the current levels of functioning.

The category of mental retardation includes: mild mental retardation, moderate mental retardation, severe mental retardation, profound mental retardation, other mental retardation and unspecified mental retardation (for details of degrees of mental retardation according to the ICD-10 see Appendix B).

International Classification of Impairment, Disabilities and Handicaps (ICIDH)

The ICIDH is a manual of classification relating to the 'consequences of disease'. A disease or disorder may result in impairments. Disabilities reflect the possible consequences of impairments in terms of functional performance and activity by the individual. The term 'intellectual impairments' is used in the manual, which includes intelligence, memory and thought impairments (for details of classification of intellectual impairments according to the 1980 ICIDH see Appendix C). The ICIDH is currently undergoing a process of revision and is likely to delineate the separation of three basic concepts: impairment as an effect at organic level; disability in terms of whole person functioning; and 'participation' which reflects the result of the interaction between disability and environmental factors.

Comparison of ICD-10 and ICIDH

One of the common features of the two WHO manuals (ICD-10, ICIDH) is that neither has specified an age as a cut-off point for the developmental period, while the ICD-10 definition refers to the condition as 'especially characterised by impairment of skills manifested during the developmental period'. The definition of intellectual impairments in the 1980 ICIDH seems to refer to the population in general during their life time.

The second common feature of the two manuals is the use of the same range of IQ scores in classifying severity of mental retardation with a maximum IQ score of 70, which is similar to the classification used in the eighth revision of the AAMR manual.

There are also marked differences between the two WHO manuals. Intellectual impairments defined in the 1980 ICIDH cover a wider range of impairments and syndromes than those of ICD-10, involving impairments in intelligence, memory and thinking. Mental retardation is considered as one of the sub-categories of impairments of intelligence. The 1980 ICIDH definition of intellectual impairments excludes impairments of language and learning (Appendix C).

In the ICD-10 classification, apart from IQ scores and functional ability, need for support is one of the indicators differentiating mild mental retardation from moderate, severe or profound mental retardation, while in the 1980 ICIDH classification of intellectual impairments, only IQ scores and functional ability are considered.

2.1.3 The American Psychiatric Association definitions and classifications (DSM-III and IV)

The American Psychiatric Association (APA) has published four versions of *The Diagnostic and Statistical Manual of Mental Disorders* (DSM). The manual is used by clinicians, medical and health professionals, and researchers of many different disciplines. The sections relating to mental retardation in the third (DSM-III) and fourth editions (DSM-IV) have been written and modified to be compatible with the AAMR definitions and classifications (American Psychiatric Association 1980, 1994). The latest edition of the APA manual (DSM-IV) has incorporated the ten adaptive skill areas, which were specified in the latest definition of the AAMR manual, into its general definition of mental retardation.

Nevertheless, there are differences between the DSM-IV and the latest revision (ninth edition) of the AAMR manual. First, DSM-IV set the criterion for significantly subaverage intellectual functioning as an IQ standard score approximately 70 or below, while the ninth edition of AAMR set the score as approximately 70–75 or below. Second, DSM-IV retained the levels of severity of intellectual impairment (mild, moderate, severe, profound and unspecified), following the eighth edition of the AAMR manual. The ninth edition of the AAMR manual has replaced the levels of severity of retardation by ‘patterns and intensity of supports needed’.

2.1.4 Developmental disability and mental retardation

Definitions of developmental disability

The concept of developmental disability was not in general use until it was used in the US in a legal context—1970 *Developmental Disabilities Services and Facilities Construction Act* (PL 91–517).

Developmental disability has been defined as a broad term which includes mental retardation, cerebral palsy, autism, epilepsy, and other neurological impairments (Summers 1986). The term developmental disability is also used

in Australia to refer to severe chronic disabilities attributable to intellectual and/or physical impairment which occur before age 6 years.

Most of the definitions of developmental disability used in Australia are modified versions based on the US *Developmental Disabilities Services and Facilities Construction Act (PL 95-602)* which defined it as:

A severe, chronic disability of a person which

- (a) is attributable to a mental or physical impairment or combination of mental and physical impairments;
- (b) is manifested before the person attains age 22;
- (c) is likely to continue indefinitely;
- (d) results in substantial functional limitations in three or more of the following areas of major life activity:
 - (i) self-care,
 - (ii) receptive and expressive language,
 - (iii) learning,
 - (iv) mobility,
 - (v) self-direction,
 - (vi) capacity for independent living, and
 - (vii) economic self sufficiency; and
- (e) reflects the person's need for a combination and sequence of special, inter-disciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and individually planned and coordinated (Summers 1986: 3-4).

The establishment of the age of 22 as the cut-off point for the developmental period is arbitrary (the previous version of the Act set the age at 18). The main intent of using the age of 22 (or 18) as the cut-off point for manifestation of the disability is that the disability must be present in a visible form during a person's formative years (Summers 1986).

In Australia, Victorian legislation defines the development period as 'before the child attains the age of 6 years' (*Intellectually Disabled Persons Services Act 1986*).

The US legislative definition has several main features. First, it is a broad term which encompasses a very heterogeneous population group ranging from people who are intellectually sound but who have severe physical impairments, to those who are physically fit but have severe intellectual impairments.

Second, the definition relies on broad categories of impairments: mental or physical impairment or both, rather than clinical diagnosis. The focus of the definition is on functional limitations (what a person can or cannot do) which then results in substantial limitations in a set of major life activities.

Third, this revised version of the definition emphasises the severity and chronicity of the impairment (to be 'likely to continue indefinitely') and the need for special and generic services. The definition's requirement for substantial functional limitation in three or more major life activities was intended to ensure provision of services to people with more severe impairments.

According to Seltzer (1983), the revision of the legislative definition (PL 95-602) resulted in a functionally oriented definition which considered that people living on their own and not needing services would no longer be classified as 'developmentally disabled' (cited from Evans 1991). The revision, with particular emphasis on severity of the impairments, has resulted in a 27%

reduction in numbers of the target population by exclusion of people with mild developmental disabilities (Henney 1980). This change demonstrated the great sensitivities of estimates of prevalence to the amendment of the definition as well as the impacts on accessibility and provisions of services.

Difference between developmental disability and mental retardation

Mental retardation is a particular state of functioning which begins in childhood and in which limitations in intelligence coexist with related limitations in adaptive behaviours. In this sense, it is a more specific term than developmental disability (Luckasson et al. 1992). The AAMR definition of mental retardation overlaps in many aspects with the US legislative definition of developmental disability but there are also marked differences.

Both definitions are developmental in origin and emphasise multiple areas of functional limitations and the need for a wide range of services from a multiplicity of service providers. Thus, both of the definitions are intended to link service planning, provision, and eligibility determination to the individual's capability (Luckasson et al. 1992). Most clinical types of mental retardation contain central nervous system pathology and IQ scores below approximately 55, which meet both the physical and mental criteria of the developmental disability definition. This subgroup of mental retardation is defined as having permanent impairments and 'substantial' functioning limitations (Grossman 1983).

The main difference between the two definitions of developmental disability and mental retardation occurs in describing the upper range of IQs. The AAMR definition of mental retardation does not emphasise chronicity or irreversibility of the condition; on the contrary, it applies only to present levels of functioning. Those children with mild mental retardation often are 'functionally impaired' in the school years only. They have no visible neurological disorders and achieve some level of adult independence after school years. Therefore, they fall outside the definition of developmental disabilities (Grossman 1983).

2.1.5 Learning disability and mental retardation

In the United States, the federal *Education for All Handicapped Children Act* (PL 94-142) defined learning disability as:

... a disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, which may manifest itself in an imperfect ability to listen, speak, read, write, spell, or do mathematical calculations (Batshaw and Perret 1992).

The definition includes conditions which have been referred to as perceptual handicaps, brain injury, minimal brain dysfunction, dyslexia, developmental aphasia, etc. It excludes learning problems which are due primarily to visual, hearing, or motor handicap, to mental retardation, emotional disturbance, or to environmental disadvantage (Grossman 1983). The definition fails to clarify what the 'basic psychological processes' are and how to measure the 'imperfect ability' (Batshaw and Perret 1992).

By the legislative definition, an important difference between learning disability and mental retardation is the level of measured intelligence. In learning disability, there are impairments in specific areas (e.g. reading, expressive language) but there is no general impairment in intellectual development and adaptive functioning. Therefore, learning disability should exclude mental retardation and, presumably, include people of at least average intelligence. People who have mental retardation can have learning difficulties, which correspond to general impairment in intellectual functioning (Grossman 1983).

There has been much debate relating to the definition and identification of learning disabilities. A particular issue is whether learning disability can occur concurrently with other disabilities. To address this issue, the US National Joint Committee on Learning Disabilities published a revised definition:

Learning disability is a generic term that refers to a heterogeneous group of disorders manifested by significant difficulties in the acquisition and use of listening, speaking, reading, writing, reasoning, or mathematical abilities. These disorders are intrinsic to the individual and are presumed to be due to central nervous system dysfunction. Even though a learning disability may occur concomitantly with other disabling conditions (e.g. sensory impairment, mental retardation, social and emotional disturbance) or environmental influences (e.g. cultural differences or insufficient/inappropriate instruction), it is not the direct result of those conditions or influences (Hammill 1990, cited from Batshaw and Perret 1992).

This definition admitted the possibilities of co-existence of learning disability and mental retardation. But learning disability is not considered as a direct consequence of mental retardation.

Gething (1992) suggested that learning disability is a more specific term than intellectual impairment. It refers to limitation in a specific area and can occur in people with all levels of intellectual functioning, including those classified as above average.

The American Psychiatric Association manual DSM-IV pointed out that in learning disorders, development in a specific area (e.g. reading, expressive language) is impaired but there is no generalised impairment in intellectual development and adaptive functioning. However, DSM-IV also suggests that, while in mental retardation learning difficulties correspond to general impairment in intellectual functioning, in some cases of mild mental retardation the level of achievement in academic skills (reading, mathematics or written expression) is significantly below expected levels given the person's schooling and severity of mental retardation. In such cases, an additional learning disorder diagnosis should be made (American Psychiatric Association 1994).

2.2 Australian administrative definitions of intellectual disability

2.2.1 Legislative definitions

Many of the Australian administrative or legislative definitions of intellectual disability have adapted the AAMR definitions. For instance, the *Western Australian Authority for Intellectually Handicapped Persons Act 1985* adopted the

AAMR definition and classification. The Authority for Intellectually Handicapped Persons was a State government agency where all people with an IQ score less than 70 were eligible for registration (Wellesley et al. 1992).¹

The *Victorian Intellectually Disabled Persons Services Act 1986* defines intellectual disability as:

... intellectual disability, in relation to a person over the age of 5 years, means the concurrent existence of (a) significant sub-average general intellectual functioning; (b) significant deficits in adaptive behaviour; each of which became manifest before the age of 18 years (Intellectually Disabled Persons Services Act 1986, Reprinted 3 August 1995 incorporating amendments up to Act No. 48/1995).

The major difference between the Victorian Act and the AAMR definition of mental retardation is that the former excludes people under age 6. This is related to the modification of the definition of developmental delay in the Victorian Act, which specified that the developmental delay must be manifested before the age of 6.

The *Social Security Act 1991* provided tables for assessment of impairment as part of the assessment for eligibility for the Disability Support Pension. Intellectual impairment is assessed using three key criteria shown in Table 2. The scores of all the three assessment criteria are added, and weighted, to convert to a whole person impairment score using a specified table. The table contains the weights for conversion to whole person impairment scores with a starting point of 10% for a total score of 3. Each increase in the total score of the key criteria by one unit will result in an increase of 5% in the whole person impairment score. The Act specified an impairment score of 20% or more as one of the eligibility criteria for the Disability Support Pension (Department of Social Security 1993).

The assessment criteria set the cut-off IQ scores between 70 and 80 rather than below 70 or 75. People with IQ scores of 50 and less and with severe behaviour problems will be considered as 'totally dependent' in terms of capacity for independent living (Department of Social Security 1993).

Table 2: Classification of intellectual impairment

Score	Intellectual	Behaviour	Capacity for independent living
0	Normal	Normal	Self-sufficient
3	Borderline (IQ 70–80)	Slight problem	Needs minor help
4	—	Moderate problem	Needs regular help
5	Mildly impaired or worse (IQ 50–70)	Moderate to severe problem	Needs major help
6	Moderately impaired (IQ 30–50)	Severe problem	Totally dependent
8	Moderately to severely impaired (IQ 20–30)	—	—
10	Severely impaired (IQ < 20)	—	—

Source: Department of Social Security 1993.

¹ The *Western Australian Authority for Intellectually Handicapped Persons Act 1985* was repealed by the *Western Australian Disability Services Act 1993* and the Disability Services Commission was established in 1993 through amalgamation of the former Authority for Intellectually Handicapped Persons and the former Bureau for Disability Services.

2.2.2 Definitions in national data on disability support services

The Commonwealth/State Disability Agreement (CSDA) Minimum Data Set (MDS) provides data items and definitions which are used to compile nationally consistent data on disability support services provided or funded under the CSDA (Black and Madden 1995).

Disability type, one of the data items of consumer profile in MDS, is used for a broad categorisation of disabilities in terms of the underlying impairment, condition or cause. In the 1995 national collection, the category of intellectual/learning disability generally refers to conditions identified during the developmental period (age 0–18) with concurrent learning difficulties and the need for more support in daily life-skills compared to others of the same age (Black and Madden 1995). The category of developmental delay is applicable to children aged 0–5 only and refers to conditions appearing in the early developmental period, with no specific diagnosis (Black and Eckerman 1997).

The MDS is being progressively developed and the 1996 collection has separated the learning disability from the former category of 'intellectual/learning'. Learning disability generally refers to a group of disorders, presumed due to central nervous system dysfunction rather than an intellectual disability, covering significant difficulties in the acquisition and use of listening, speaking, reading, writing, reasoning or mathematical skills (Black and Eckerman 1997).

2.2.3 Working definitions

In some working documents in Australia intellectual disability was more loosely defined even though the definitions were adapted from the AAMR definition. The following working definition, for example, was used by the joint Commonwealth and State review into the needs of people with intellectual disability in Tasmania:

... an intellectually disabled person is someone with below average intellectual functioning which results in slower development of social and behavioural skills than other people of the same age (Foster et al. 1984).

The imprecise working definition might be the result of limitations in data source and quality. The review's survey was able to identify only 1,089 service recipients with intellectual disability in Tasmania and for nearly 30% of the 1,089 clients there was no information about their severity of retardation at the time of the survey (Foster et al. 1984).

A project on patterns of service for people with an intellectual disability conducted by the South Australian Health Commission (1981) adopted the AAMR definition. The project team found that although the AAMR definition was the most satisfactory definition available, there were limitations when it was used as an operational definition. As previously mentioned, the AAMR definition consists of three key criteria: low general intellectual functioning, difficulties in adaptation, and chronological age 18 as a cut-off point for the presence of the disabling condition. Some people had one or two but not all the three criteria but they needed or benefited from services similar to those provided for people with an intellectual disability.

The following five groups of people were identified by the project team (South Australian Health Commission 1981):

- *Adults with borderline or low normal intelligence who have psychotic behaviour disorders.* As a result of the interaction of the two conditions, they may require services similar to those for people with more severe mental retardation.
- *People with borderline intelligence and multiple disabilities.* While the severity of retardation of those people may be only in the borderline category, their other physical or sensory disabilities often mean they have similar needs for services and benefits.
- *Children with borderline intelligence and their only adaptive behaviour deficit is incapable to cope with normal schooling.* This group could include people with autism. These children would face similar problems and need similar services to those with mild retardation during their adolescence or young adulthood.
- *Children too young for accurate assessment.* Children with mild to moderate retardation who are too young for accurate assessment may or may not eventually be identified as having intellectual disability. They share the need for early intervention programs with children having more severe retardation.
- *Adults with brain injury.* Adults with brain injury who have all the characteristics of intellectual disability but would be excluded from the AAMR definition because of the late age of onset of their disabling conditions.

These practical issues arising from field experiences suggest that it is necessary to adopt a multidimensional approach, and to include assessment of intensities and patterns of need for support as one of the components of the definition and classification. This is the direction which the new AAMR definitions and classifications are moving towards.

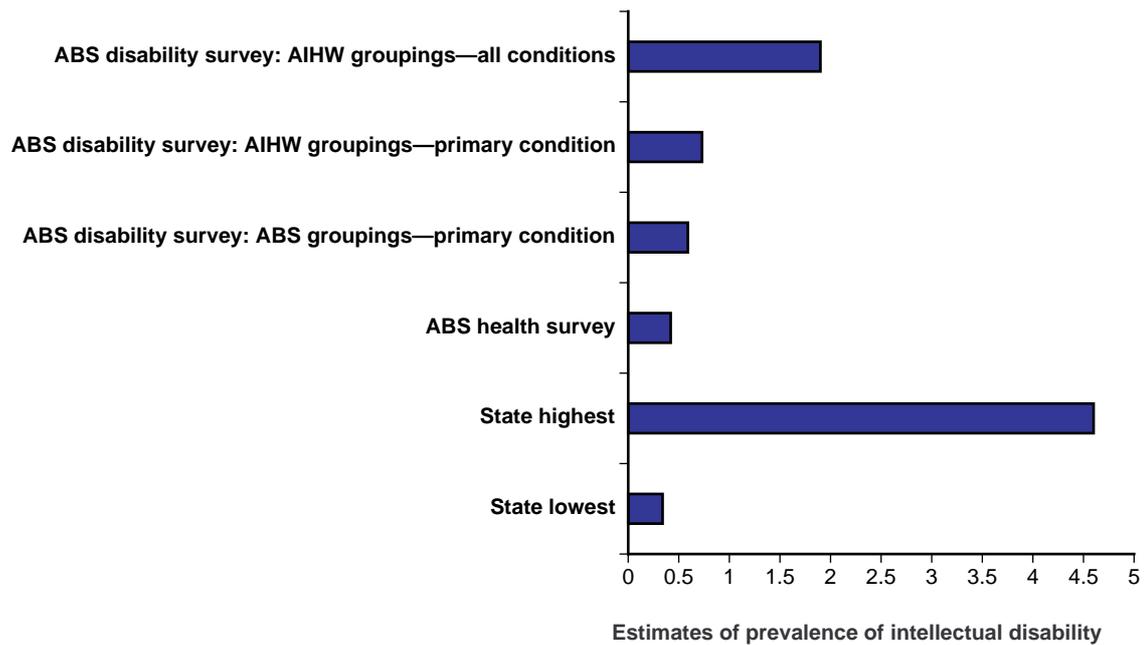
3 A review of existing estimates of prevalence

Although a number of epidemiological studies have estimated the prevalence of intellectual disability in Australia, there have been wide variations in definitions, measurements, survey methods and geographic locations. Most studies have been confined to local areas. Little analysis has been performed on the basis of national comprehensive survey data.

Figure 1 shows the striking differences in estimates of prevalence of intellectual disability in Australia, particularly the estimates at State levels. The lowest estimates at State level were about 0.3% while the highest was over 4%. At the national level, an estimate derived from the ABS 1989–90 National Health Survey was about 0.4%.

The three top bars in Figure 1 show the three different estimates based on the ABS 1993 disability survey. The methods for deriving those three estimates are described in Section 3.2.2, but the source of their variation lies in:

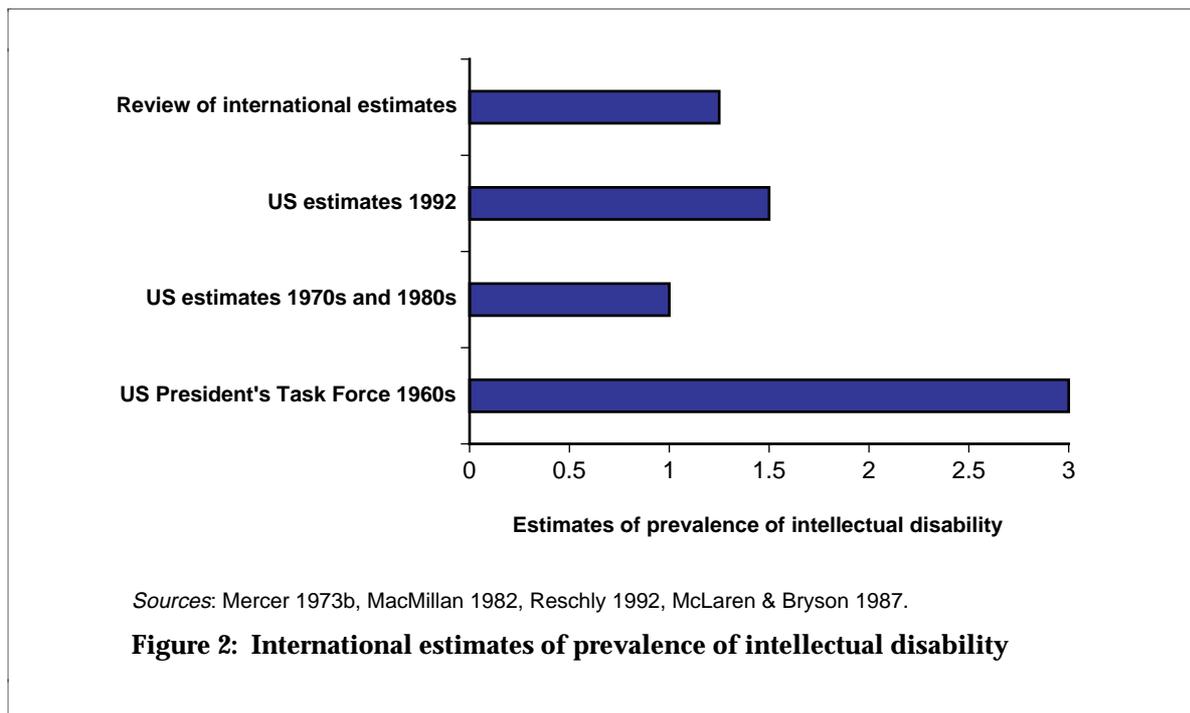
- the way responses to survey screening questions are categorised;
- the inclusion of different ‘disease’ codes (ICD codes); and
- the inclusion of **all** ‘disabling conditions’ or just the main one (see Section 3.2.2).



Sources: Tables 3, 5, 6 and Section 3.2.2.

Figure 1: Differences in estimates of prevalence of intellectual disability in Australia

The great discrepancies in estimates of prevalence in Australia are not unique. Figure 2 illustrates some examples of the wide variations in international estimates of prevalence. The US President’s Task Force stated in the late 1960s that about 6 million or 3% of Americans would be diagnosed as having mental retardation at some time in their lives (Mercer 1973b, MacMillan 1982). The estimates in the 1970s and 1980s were generally agreed at about 1% (Heber 1970, Mercer 1973b, MacMillan 1982, Summers 1986). However, more recent estimates indicated the prevalence rates of mental retardation in the US were around 1.5% (Reschly 1992). A review of many international estimates found that an average prevalence rate of mental retardation is at least 1.25% (McLaren and Bryson 1987).



This chapter will examine the existing estimates, refine the national estimates and analyse the pattern of intellectual disability in Australia. Before going to detailed discussion, some issues on estimates of prevalence are clarified in Section 3.1.

3.1 Some issues on estimates of prevalence

The AAMR definition requires that both 'IQ score 70 and below' and 'deficit in adaptive behaviour' should be used to define mental retardation. In practice, exclusive reliance on IQ scores to define mental retardation is quite common. Many studies use IQ scores as the sole criterion to estimate prevalence of mental retardation. This is partly because there are no totally objective measures of social adaptive behaviour, particularly in different socioeconomic and cultural environments. In many studies (for Australian examples see Table 6), the IQ scores were grouped into two categories, namely 'mild' and 'severe' retardation. The term 'severe mental retardation' includes AAMR categories of moderate, severe, and profound mental retardation. Although there are doubts about the comparability of IQ tests, it has generally been the only basis of epidemiological comparison available.

This paper focuses on prevalence, rather than incidence, as the preferred measure for intellectual disability in the population. Incidence refers to the number of new cases of a disease or condition over a certain time period. Prevalence refers to the total number of cases of a particular condition or disease at a specified point in time, which includes all previously existing cases plus any newly identified cases of the disease or condition in question. Prevalence also takes into account factors of population survival and migration. Prevalence is important for estimating current and future needs for disability services.

It is important to mention that some studies have also estimated the 'life-time prevalence' of mental retardation or proportion of 'ever-retarded' people based on a theoretical model. These estimates are neither incidence nor prevalence. Rather, they are projections of the proportion of the population that may be considered as having mental retardation at some point in their lives. Typical examples are the estimates conducted by the US President's Task Force and the President's Panel on Mental Retardation in the 1960s and 1970s (Figure 2), which stated that about 6 million, or 3%, of Americans would be diagnosed as having mental retardation at some time in their lives (Mercer 1973b, MacMillan 1982).

The 3% 'theoretical' prevalence rate was criticised because it is an extrapolation from the statistical normal distribution curve using IQ scores below 70 as a single arbitrary criterion rather than a result of empirical investigations (Mercer 1973b). The empirical estimate of prevalence rate of mental retardation was generally agreed to be about 1%–1.5% of the US population (Figure 2, Heber 1970, Mercer 1973b, MacMillan 1982, Reschly 1992, Summers 1986).

There are a number of explanations for the differences between the theoretical prevalence rate of 3% and the empirical estimates of around 1%. First, it is difficult to identify mental retardation in infancy, early childhood and the post school period. A large proportion of people with mental retardation were not identified until school entrance. Second, many school age children who were identified as having mental retardation were 're-absorbed' in the general population when they became adults (Mercer 1973b). Third, mortality among people with severe mental retardation is higher than that of the general population (Tarjan et al. 1973). Fourth, when dual criteria (IQ tests and adaptive behaviour) are used, the prevalence rates will be cut substantially. Mercer (1973b) suggested that the reduction was about 50%, and people with mild mental retardation made up a large proportion of the reduction.

3.2 Australian estimates at national level

3.2.1 The ABS national disability surveys

The ABS disability surveys provide the only available data based on a comprehensive national population survey on disability. The surveys covered both rural and urban areas in all States and Territories and gathered data from both household and establishment samples. In the 1993 Survey of Disability, Ageing and Carers, the household sample included about 17,800 private dwellings and 1,600 special dwellings units, while the establishment sample included approximately 700 establishments. The effective sample resulted in about 42,000 persons for the household component and 4,800 persons for the establishment component, with a maximum of 14 disabling conditions able to be recorded for each respondent (ABS 1993a).

The three ABS disability surveys collected cross-sectional data at three different points in time (1981, 1988 and 1993) over a period of 12 years. Unlike the data obtained from administrative agency records, the ABS disability surveys collected data on the basis of the respondents' self-reporting information which may or may not be a result of professional assessments.

The operational definitions used in the surveys were based on a set of survey screening questions on impairments and restrictions. These definitions adapted the conceptual definition of ICIDH. The survey definitions tend to be inclusive and aim at ensuring that all eligible people in the Australian population are included in the survey.

Disability is defined as the presence of one or more of a list of limitations, restrictions or impairments which had lasted, or were likely to last, for 6 months or more. Handicap is identified where a person with a disability also has limitation or restriction in performing certain specific tasks associated with daily living, due to their disability (ABS 1993a). The limitation must be due to a disability and related to one or more of five activity areas (self care, mobility, verbal communication, schooling and employment).

In the 1981 and 1988 surveys, three levels of severity of handicap (mild, moderate and severe) were determined on the basis of the person's ability to perform tasks relevant to three areas (self care, mobility and verbal communication) and on the amount of assistance required. In the 1993 survey the severe handicap category was further divided into severe handicap and profound handicap (ABS 1993a).

The ABS definition of severity of handicap does not directly relate to any particular category or level of impairment. Rather it is measured by the need for, and the intensity of, personal support in three of the five activity areas which define the handicap. The surveys did not collect information about IQ scores from the respondents to define intellectual disability.

The measurement of severity in ABS surveys is similar to those specified in the ninth edition of AAMR manual, which is a measure of needs for assistance. However, the survey questions on restrictions and limitations in the activities are somewhat more focused on physical abilities of daily living, which may emphasise the presence of handicap arising from physical impairment (Madden et al. 1995). In this paper, the number of people who reported intellectual disability and also reported severe or profound handicap was estimated. However, the estimates of severity may not be directly comparable to those estimates based on IQ test scores. Caution needs to be exercised in interpreting these estimates.

3.2.2 Estimates based on the three ABS disability surveys

Table 3 shows the estimated prevalence of intellectual disability based on reported main disabling conditions in the three surveys. People responding positively to one or more of the ABS survey screening questions were asked to indicate specific disabling conditions. A main disabling condition is the condition identified by the respondent with multiple conditions as the one causing the most problems. Where only one condition is recorded, this is coded as the main disabling condition (ABS 1993a).

Table 3: Prevalence of intellectual disability based on reported main disabling conditions, Australia, 1981, 1988 and 1993

Categories of screening questions and groupings	Year of survey	Prevalence disability (%)	Age adjusted rate (%)	Prevalence handicap (%)	Age adjusted rate (%)
1988 screening questions ^(a)	1981 survey				
ABS groupings ^(b)	Males			0.62	0.57
	Females			0.42	0.40
	Persons	0.61	0.56	0.52	0.48
1988 screening questions ^(a)	1988 survey				
ABS groupings ^(b)	Males	0.82	0.79		
	Females	0.56	0.54		
	Persons	0.69	0.67	0.65	0.63
1988 screening questions ^(a)	1993 survey				
ABS groupings ^(b)	Males	0.77	0.77	0.71	0.71
	Females	0.42	0.42	0.38	0.38
	Persons	0.59	0.59	0.54	0.54
1993 screening questions	1993 survey				
AIHW groupings ^(b)	Males	0.88		0.82	
	Females	0.58		0.55	
	Persons	0.73		0.68	

(a) These adjusted rates are calculated as the basis for comparisons using the definitions consistent with the 1981 and 1988 screening questions, as being more comparable with 1981 and 1988 data.

(b) For detailed categories of ABS or AIHW groupings see Table 4.

Sources: ABS 1982, 1989, 1990a, 1990b; ABS unpublished data; Mathers 1991; AIHW analysis of ABS 1993 Survey of Disability, Ageing and Carers data.

The first three categories of groupings of Table 3 present estimates from the three surveys (1981, 1988, 1993) using screening questions consistent with the 1981 and 1988 surveys. For a comparison of the three consecutive surveys, the 1993 survey data were re-derived using 1988 survey screening questions. The ABS groupings of disabling condition were used in estimation.

The ABS 1993 survey is more inclusive because of the addition of three more screening questions. Figures in the bottom panel of Table 3 present estimates based on the 1993 survey actual data. The AIHW groupings of disabling conditions were applied.

In estimation of prevalence, the AIHW approach differs from the ABS approach in two aspects: the specific groupings of disabling conditions and the methods of estimation (Madden et al. 1995). The difference between the ABS groupings and the AIHW groupings of disabling conditions is illustrated in Table 4. The ABS groupings included only four categories of conditions, while the AIHW groupings contained nine categories, which include the three ABS components but exclude mental degeneration due to brain damage.

Apart from the difference in the groupings of different disabling conditions, there is also a difference in using the survey information on relevant disabling conditions. In the estimation, the ABS approach contains only people who responded positively to the survey screening question on being 'slow at learning or understanding things', and who may or may not have a relevant

ICD code assigned for a specific disabling condition. The AIHW approach uses not only information from the responses to screening questions but also the ICD codes allocated to the reported disabling conditions. Some of the screening questions are fairly non-specific, for example, the question relating to long-term treatment or medication. Hence, it is necessary to avoid reliance solely on one screening question to define intellectual disability. Using the AIHW approach, people with a disability would have the disability classified as 'intellectual' if:

- a positive response was made by or for them to the screening question on being 'slow at learning or understanding things'; and/or
- their reported conditions were coded with any of the relevant ICD/ABS codes in the AIHW groupings (Table 4); ICD codes are recorded for disabling conditions reported by people responding positively to *any* of the screening questions (Madden et al. 1995).

Table 4: Comparison of groupings of intellectual disability for ABS Survey of Disability, Ageing and Carers data

ABS code	ICD code	Diseases, impairments and conditions
AIHW groupings for 1993 survey data		
305	299.0	Infantile autism
307	Search question ^(a)	Slow at learning or understanding things
309	317–319	Mental or intellectual retardation/disability
316	315.02	Developmental dyslexia
316	315.0	Reading disorder
316	315	Specific delays in development
317		Behaviour changes
318		Memory loss
703	758.0	Down syndrome
ABS groupings for 1981 and 1988 surveys		
309		Mental retardation
308		Mental degeneration due to brain damage
307		Slow at learning or understanding things
316		Specific delay in development

(a) The codes for search questions refer to the survey search questions only, no corresponding ICD code appropriate.

Sources: ABS unpublished disabling condition codes; Madden et al. 1995.

Although it would be desirable to separate the learning disability from intellectual disability in the calculation of prevalence, it is difficult to do so because of the survey data limitations. The AIHW groupings also include the categories of 'slow at learning or understanding things' and 'reading disorder', because these conditions may be an integral part of all disabling conditions reported by people with an intellectual disability. People with an intellectual disability are more likely to have learning difficulties, and intellectual disability and learning disability may occur concurrently while the latter may not be the direct consequence of the former.

It should be noted that the criterion of age 18 as the cut-off point for manifestation of intellectual disability was not introduced in the calculation of the prevalence rates shown in this section. This criterion will be taken into account in Section 3.4.

Figures in the first three categories of groupings of Table 3 show that, with the ABS categories consistent with the 1981 and 1988 survey screening questions, the prevalence rates of intellectual disability reported as a main disabling condition varied between 0.56% and 0.67% over the three surveys, after removing the age effect of the population changes. The variations in handicap rates were between 0.48% and 0.63% (Table 3).

Figures in the bottom panel of Table 3 show that, using AIHW groupings and 1993 survey screening questions will yield a prevalence rate of 0.73%, which is much higher than the rate of 0.59% derived using the ABS 1988 survey categories and screening questions (Table 4). Among those who reported an intellectual disability, 48,000 people (0.27% of total Australians) also reported a severe or profound handicap (Appendix Table 1).

The prevalence of intellectual disability may be underestimated if only main disabling conditions are considered, particularly those with a mild intellectual disability. Table 5 presents the estimates of prevalence derived from all reported disabling conditions by the survey respondents, irrespective of main or non-main disabling conditions. On the basis of all reported disabling conditions, the use of the AIHW approach and the 1993 survey screening questions yielded a prevalence rate of 1.86% for 1993 which was more than twice those of the 1981 and 1988 surveys estimated by ABS. The 1993 survey indicated that 174,000 people (0.99% of total Australians) reported an intellectual disability (based on all conditions) and had also reported a severe or profound handicap (Appendix Table 2). Apart from the impact of the AIHW groupings which include more disabling conditions in the categories (Table 4), Table 5 also shows the effect of the AIHW approach, which uses the ICD codes to pick up more information about disability types, in particular, people experiencing multiple disabilities.

Table 5: Prevalence of intellectual disability^(a) based on all reported disabling conditions, Australia, 1981, 1988 and 1993

Categories of screening questions and groupings ^(b)	Year of survey	People with an intellectual disability (N)	Prevalence disability (%)
1988 screening questions 1981 survey			
ABS groupings	Persons	111,200	0.76
1988 screening questions 1988 survey			
ABS groupings	Males	89,400	1.10
	Females	66,000	0.80
	Persons	155,400	0.95
1993 screening questions 1993 survey			
AIHW groupings	Males	174,800	1.99
	Females	153,200	1.73
	Persons	328,000	1.86

(a) Estimates of 1,900 or less have a relative standard error (RSE) of 50% or more. Estimates of 8,000 or less have an RSE of 25% or more.

(b) For detailed categories of ABS or AIHW groupings see Table 4.

Sources: ABS 1982, 1989, 1990a, 1990b; ABS unpublished data; Mathers 1991; AIHW analysis of ABS 1993 Survey of Disability, Ageing and Carers data.

3.2.3 Estimates based on the National Health Survey

The 1989–90 National Health Survey was conducted during the period October 1989 to September 1990. It obtained health status information by personal interview from residents of a sample of 22,202 private and non-private dwellings. Long-term conditions were defined as those medical conditions (illness, injury or disability) which had lasted at least six months, or which the respondent expected to last for six months or more (ABS 1992). The classification of medical conditions was based on ICD-9. Fairly broad classification groups were used and the classification was modified to ensure that the types and quality of information were likely to be reported in the survey (ABS 1992).

Estimates from the 1989–90 National Health Survey show that 72,200 people or 0.42% of total Australians reported long-term conditions of mental retardation and/or specific delays in development (ABS 1992). This is lower as compared with 0.73% using AIHW groupings on the basis of the 1993 ABS disability survey. The National Health Survey excluded people in hospitals, nursing homes and other institutions and, if more than seven conditions were reported by a respondent, only the first seven were recorded. These factors may contribute to an underestimation of the prevalence of the conditions in the general population. The long-term conditions recorded in the National Health Survey were not necessarily associated with disabilities.

3.2.4 Estimates based on a national collection of service provision data

The Commonwealth/State Disability Agreement (CSDA) Minimum Data Set (MDS) is a significant source of data on the disability support services under the CSDA. The MDS consists of an agreed set of data items, and for each data item an agreed definition. Some of the data items for consumers are designed to be related to the ABS disability survey data. Data are collected by separate jurisdictions and collated nationally by the AIHW (for details of the CSDA MDS development and collection see Black and Madden 1995).

In 1995 the first full-scale national collection gathered data from 4,588 service providers on the selected snapshot day. The data on consumers show that intellectual/learning disability was the most predominant primary disability type, which was reported by 68.4% (41,272 people) of the total 60,374 service recipients. There were also 907 people or 2.2% of the total clients reporting a primary disability type of developmental delay. The data also show that the reported primary disability type of intellectual/learning accounted for 70% of those clients aged under 60 years and 40% of those aged 60 and over (Black and Eckerman 1997).

Because the data related only to people receiving disability support services under the CSDA, they do not include, for example, children with an intellectual/learning disability attending special schools or receiving special education assistance.

3.3 Australian estimates at State and local level

This section reviews nine published studies on the prevalence of intellectual disability in Australia at State or local level. These studies were conducted in six States, including five studies of the general population, three studies on children under the age of 17 years, and one of adults aged 20–50 years.

3.3.1 Five studies on the general population

Five studies (Table 6) reported estimates of the prevalence of intellectual disability in the general population in NSW, Victoria, WA, SA and Tasmania (Kraus 1973, Cocks and Ng 1983, South Australian Health Commission 1981, Henderson et al. 1972 respectively). The dates of these surveys varied from July, 1969 in Tasmania to January 1983 in Victoria. At first glance, the estimates of the overall prevalence in five States exhibited striking differences from a high rate of 4.6% for NSW to a low rate of 0.34% for Victoria (Table 6). A close examination found that these differences were largely attributable to the different definitions, measurements and survey methods applied in the studies. The overall prevalence seemed to be approximately between 0.4% to 0.5%, if the exceptional high estimate from the NSW study is excluded (see reasons in following discussion) and the low estimate of the Victorian study was adjusted according to the study authors' suggestion.

Differences in definition and measurement

In defining the population of interest, the NSW study set an IQ score up to 75, while SA and Tasmanian studies set a cut-off IQ score at 70 or below (Table 6). Victorian and WA studies included an additional category of severity coded as 'borderline', which could include IQ scores up to 84 (Cocks and Ng 1983). Even in studies using the same IQ cut-off score there were variations in the way of obtaining the scores. The Tasmanian study also included persons recognised as having mental retardation by the State Department of Social Welfare on the basis of severe 'social inefficiency'. However, the SA study had excluded people with mental retardation in normal schools from the eligible population.

Table 6: Comparison of the studies on prevalence of intellectual disability in Australia

Study area	Population	Survey method and data source	Definition	Severity and prevalence (%)				Sex difference in prevalence (%)		
				Mild	Moderate	Severe	Profound	Total	Males	Females
NSW (Kraus 1973)	Total population (n=3,948,400)	Data published by the Department of Education of NSW and the Department of Health of NSW	IQ score 75 or less mild 56-75 moderate 36-55 severe 20-35 profound 0-19 All data are based on age groups in which the prevalence of a given grade of severity was maximum.	4.135	0.390	0.019	0.014	4.558	60%	40%
Victoria (Cocks and Ng 1983)	Total population (n=3,948,400)	Survey on client data of Mental Retardation Division of the Health Commission of Victoria and Education Department of Victoria	Number of clients registered. Severity includes: borderline, mild, moderate, severe, profound. Details of IQ scores for each level were not stated.					0.342		Males over females and the approximate proportion was 54.0% to 45.4% with 0.6% unknown.
WA (Cocks and Ng 1983)	Total population (n=1,290,000)	Survey on agency records	Number of clients registered. Severity includes: borderline, mild, moderate, severe, profound. Details of IQ scores for each level were not stated.			0.21 (including all but mild)		0.44		Males over females and the approximate proportion was 59% to 41%.
SA (South Australian Health Commission 1981)	Total population (n=1,294,000)	Survey on number of people with an intellectual disability known to the main (41) service agencies. People with an intellectual disability currently in the normal school system were excluded.	Use AAMR definition and include people who often require services. mild 55-70 moderate 40-55 severe 25-40 profound < 25 Upper age limit of 18 years for developmental period.			0.29 (including all but mild)		0.44		Males over females and the approximate proportion was 55% to 43% with 0.2% unknown.
Tasmania (Henderson et al. 1972)	Total population (n=371,435)	Survey on records held by the Mental Health Services Commission and its Guardianship Board, the Mental Retardation Division of the Royal Derwent Hospital, the State Departments of Health Services, Education and Social Welfare, and other medical, social and educational agencies in the State.	The criteria used for case identification are: • the clinical diagnosis of retardation, with or without objective measurement of intelligence; • a measured IQ of below 70 in the school tests conducted at the age of 10 years; and • persons recognised as retarded by the State Department of Social Welfare on the basis of severe social inefficiency. mild 50-69 moderate 30-49 severe 0-20	0.363	0.093	0.075		0.541 (including 0.008 with an unknown IQ)		The overall male to female ratio was 1.47:1.

(continued)

Table 6 (continued): Comparison of the studies on prevalence of intellectual disability in Australia

Study area	Population	Survey method and data source	Definition	Severity and prevalence (%)				Sex difference in prevalence (%)		
				Mild	Moderate	Severe	Profound	Total	Males	Females
Northern Suburbs of Sydney, NSW (Beange and Taplin, in press)	Adult population aged 20-50 years (n=104,584)	Survey on records from government agencies, hospitals, local mental health professionals, child and family health services, general practitioners and medical specialists	IQ score below 70 and all those ascertained were interviewed and psychometrically assessed. mild 56-70 < 55 severe	0.112		0.219		0.331	0.344	0.318
Victoria (Krupinsk 1966)	Population aged 0-16 years	Survey on records from health, education and social agencies	IQ score below 70 and had been referred to a special health, educational or social agency because of their mental retardation	0.223	0.125	0.057		0.467	0.455	0.352
Queensland (Reynolds 1976)	Population aged 5-16 years (n=396,200)	Survey on records from Qld Sub-Normal Children's Welfare Association and Central Assessment Clinic of the State Health Department	Two factors: • IQ test score below 3 standard deviations (under 55); • to be judged unable to cope in a primary school, opportunity school or special class.					0.341	0.382	0.298
WA (Wellesley et al. 1992)	Population aged 6-16 years	Survey on records from Authority for Intellectually Handicapped Persons, Support Branch of the Education Department and all agencies, public and private schools	The assessment is based on an IQ test (below 70) and the classification of the American Association on Mental Retardation (AAMR): mild 55-69 moderate 35-54 severe 20-34 profound < 20	0.30	0.24	0.10	0.06	0.76 (including 0.08 with an unknown IQ)	0.89	0.63

The higher cut-off IQ score had probably contributed to most of the exceptionally high overall prevalence rate (4.6%) in NSW, particularly the 4.1% for mild intellectual disability (Table 6). As mentioned in Section 2.1.1, in a normal distribution, twice as many people are eligible when the cut-off is IQ 75 and below (4.7%) as when it is IQ 70 and below (2.3%). In the NSW study, the calculation of prevalence rates was based on age groups in which the prevalence of a given level of retardation was maximum: mild age 10; moderate age 14; severe and profound age 15 to 24 (Kraus 1973). The approach relied on the assumption that, for example, the general population at all ages would have the same prevalence rate of mild retardation as that of people aged 10 years. This assumption had also, to some extent, inflated both the age-specific rates and the overall prevalence rate (4.6%) which was even higher than the 'theoretical' prevalence rate of 3%.

The IQ test was standardised for the Tasmanian school population at age 10, and thus one of the criteria used in case identification in the Tasmanian study was a measured IQ of below 70 in the school test. Children younger than the test age of 10 who had not been diagnosed by other methods would be missed out from the records, possibly resulting in an underestimate of the prevalence (Henderson et al. 1972).

It is notable that, except for the SA study, all the studies did not set a clear upper age limit for the developmental period which is one of the components of the AAMR definition for mental retardation. Although the Tasmanian study used IQ testing scores at age of 10 years as a criterion, this was certainly not the case in other studies. The lack of age limit for the developmental period in the definition might inflate the prevalence rate by the inclusion of people with an intellectual disability because of injury or diseases occurring after their adolescence.

Data limitations

The lowest prevalence rate of 0.34% from the Victorian study, appears to be the result of poor registration data, while the definition had included an extra level of severity (borderline) which contained IQ scores above 70 and probably up to 84 (Table 6). The level of intellectual disability had not been formally assessed for about 57% of the registered clients in Victoria and there was no information for another 16.5% of the clients. Some clients might have been in receipt of services by other agencies and not been registered in State services records. Compared with other States, in Victoria people with a mild level of mental retardation and children in the preschool age group were considerably under-represented. Information was also not available on a large proportion of the Victorian population. Therefore, the authors of the study believed that a reasonable estimate of the prevalence in Victoria was 0.50% (Cocks and Ng 1983).

The 1983 Victorian study identified a total number of 13,493 people with an intellectual disability, including 10,378 registered with the then Health Commission and 3,115 special school attendants registered with the Victorian Education Department. A recent (1994) report reviewing day programs for people with an intellectual disability stated that over 13,000 people are currently registered as clients of intellectual disability services in Victoria (Victorian Department of Health and Community Services 1994). It appears that

the number of registered clients of disability services increased by about 25% or 2,600 people over ten years.

As the authors of the SA and Tasmanian studies admitted, the use of agency records is likely to lead to underestimation, particularly for adults with mild intellectual disability. A reverse U shape of the age-specific prevalence rates for both males and females with mild intellectual disability was found in the Tasmanian study. This pattern might not indicate a genuine decline in prevalence after mid adolescence. Rather, it may indicate failures in case identification after the school leaving age (Henderson et al. 1972).

The WA study (Cocks and Ng 1983) reported a prevalence rate of 0.44%, while the definition also included those with IQ scores in the range of 'borderline', which would generally be expected to yield a higher prevalence rate.

Estimates based on substantial surveys

The studies conducted in SA and Tasmania yielded prevalence rates of 0.44% and 0.54% respectively, which were estimated from two substantial surveys with clear statements of definitions, classifications and methods. The slightly lower rate in SA might be partly because of the exclusion of people with an intellectual disability who were currently in the normal school. If people with 'borderline' intelligence were also included in the calculation, the prevalence rate in SA would be 0.5% (South Australian Health Commission 1981). A more recent source suggested that the Intellectual Disability Services Council in South Australia had 6,300 registered clients and the estimated number of South Australians with an intellectual disability was about 7,500 or 0.44% of the general population (South Australian Health Commission, Disability Services Office, 1994).

3.3.2 Three studies on children and adolescents

Three studies of children and adolescents were conducted in Victoria (Krupinski 1966), Queensland (Reynolds 1976) and WA (Wellesley et al. 1992) between the late 1960s and the early 1990s (Table 6 continued).

The Queensland study focused on school age (5–16) children with moderate, severe or profound intellectual disability, which excluded those with mild intellectual disability. Two criteria were used in defining the target population: having an IQ score under 55, and being judged unable to cope in primary school, opportunity school or special class. The estimated prevalence rate (for all but mild) was 0.34% in Queensland.

While the studies in Victoria and WA both set an IQ score of below 70 as the criterion to identify intellectual disability among children under age 17, the prevalence rate of 0.47% in Victoria was much lower than the rate of 0.76% in WA. The difference between the two estimates may be partly attributable to the different selection of the baseline populations at risk. The WA study excluded the 0–5 age group, while the Victorian study included all children under the age of 17 years. For case ascertainment, the population aged 0–5 is particularly difficult to ascertain since the reliable assessment of the children's condition cannot often be made in their first few years of life. The age-specific prevalence rates for Victoria indicated a clear underestimation in the under-6 age groups (Krupinski 1966).

Other factors affecting the estimates may include the time gap between the two studies. The comprehensive study in WA was conducted in 1992, which may reflect the impact on data collections of the more advanced administrative information systems and service provisions than those in Victoria of 1966.

Nevertheless, in WA the data were collected for each child from their records on the basis of the tests done as close as possible to 6, 10 or 16 years of age. In other words, the children who were aged 6 years at the time of the survey would have one test record, while the children who were age 16 would have test records for each of the three ages. It was expected that some children born in the latter years of the survey cohort would continue to be identified as having an intellectual disability because of the time lag to diagnosis (Wellesley et al. 1992). The survey method excluded people with non-congenital intellectual impairments or conditions caused by injury, accidents or other disabilities.

3.3.3 One study on Northern Sydney adults aged 20–50 years

A study (Beange and Taplin 1996) on adults was undertaken in the Low North Shore of Sydney, NSW, among over 100,000 people aged between 20 and 50 years, using the AAMR 1983 definition and classification to define intellectual disability with a cut-off IQ score of 70 (Table 6 continued). In the study the term 'severe' is used collectively for those with an IQ score below 55, including people with moderate, severe or profound retardation. All those eligible persons known by agencies or professionals were contacted and interviewed by clinical psychologists, and ascertained cases were verified by information about either previous or current psychological assessments (Beange and Taplin 1996).

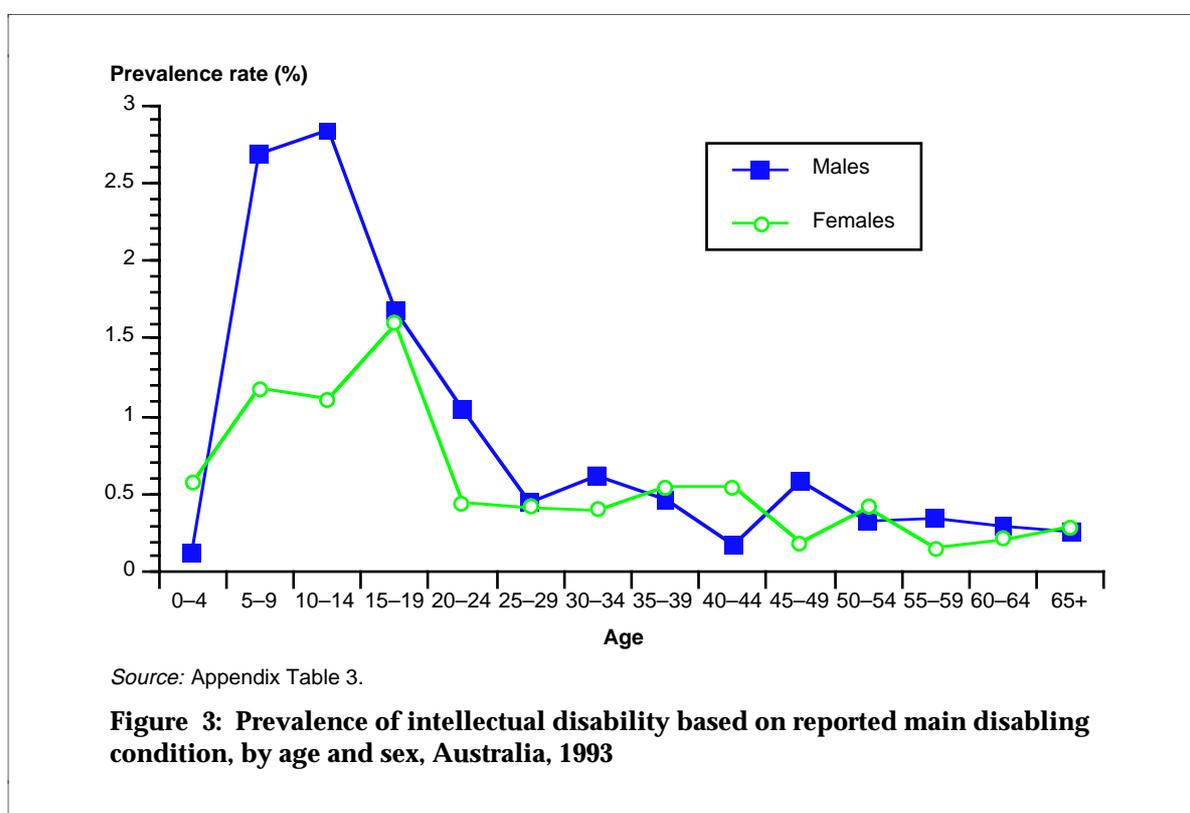
The study found that the overall prevalence rate among people aged 20 to 50 years in 1988 was 0.33%, or 0.34% if including those who were ascertained with an IQ score above 70 but whose level of functioning and adaptive skills qualified them for obtaining special services (Table 6 continued). Prevalence of severe intellectual disability did not vary significantly with age. However, prevalence of mild intellectual disability was lower than other comparable studies and declined significantly with age (Beange and Taplin 1996).

Case ascertainment of intellectual disability is more difficult among the adult population than among children at school ages, particularly among adults with mild retardation. The low prevalence rates of mild disability of this study may be also associated with the favourable socioeconomic conditions in the study area where the levels of income and education were above the Sydney average (Beange and Taplin 1996).

3.4 Pattern of intellectual disability in Australia

3.4.1 Age distribution of prevalence

Figure 3 (Appendix Table 3) and Table 7 show the pattern of age-specific prevalence rates of intellectual disability based on reported main disabling conditions in the 1993 ABS disability survey. The estimates of prevalence tended to increase with age until about age 10–14 (by five-year age groupings) or age 7–12 (by special age groupings), with the highest rates between 2% and 2.2%. After the peak, the rates then declined slightly among adolescents, with a prevalence rate around 1.6%.



Children under age 5 reported a very low prevalence, which probably reflected the underestimation because of the difficulties in case identification among children at preschool ages. As was illustrated in Table 7, the exclusion of children under age 6 from the baseline population to calculate the prevalence would increase the overall prevalence rate by more than 0.5 percentage point for children under age 17, from 1.43% for children aged 0–16 years to 1.97% for children aged 6–16 years. The age-specific prevalence rates among the adult population, particularly people aged 40 and over, were considerably lower than the rates of population under age 18 (Figure 3, Table 7 and Appendix Table 3).

Table 7: Prevalence of intellectual disability based on reported main disabling condition, by age and sex, by place of residence, Australia 1993

Age	Residence		Sex		Total (%)	Total people with intellectual disability ^(a)
	Households (%)	Establishments (%)	Male (%)	Female (%)		
0–4	0.34	0.00	0.12	0.57	0.34	4,400
5	0.99	0.00	1.66	0.28	0.99	2,400
6	1.99	14.00	3.60	0.47	2.00	5,400
7–12	2.14	52.97	2.84	1.46	2.17	33,700
13–16	1.62	19.52	2.20	1.04	1.63	16,100
17–18	1.64	12.53	1.64	1.65	1.65	8,800
19+	0.39	5.83	0.50	0.42	0.46	58,300
Total 0–16	1.41	28.91	1.86	0.97	1.43	61,800
Total 5–16	1.87	30.41	2.61	1.14	1.89	57,500
Total 6–16	1.94	31.69	2.69	1.21	1.97	55,100
Total	0.68	6.17	0.88	0.58	0.73	128,900

(a) Estimates of 1,900 or less have a relative standard error (RSE) of 50% or more. Estimates of 8,000 or less have an RSE of 25% or more.

Source: AIHW analysis of ABS 1993 Survey of Disability, Ageing and Carers data.

State-based studies containing information about age differences in prevalence also confirmed the similar pattern of age variations. The estimates from Tasmania and SA demonstrated that the highest prevalence in the general population was reported among people of school age, and the ages of maximum prevalence were age groups of 10–14 for Tasmania and 15–19 for SA (Henderson et al. 1972, South Australian Health Commission 1981). The age-specific prevalence rates among Victorian children steadily increased up to the age of 12 years, and maintained an even level up to age 16 (Krupinski 1966). The age pattern in Tasmania also indicated that the prevalence rates for moderate or more severe retardation were relatively stable while the rate for mild retardation showed a sharp increase during the school age with its peak at age 10–14 years. The maximum prevalence rates were in the 10–14 year age groups with 2.2% for males and 1.1% for females (Henderson et al. 1972).

3.4.2 Male and female difference

The studies in the States and the estimates from the ABS disability survey suggested that there was a consistently higher overall prevalence rate among males, as compared with females (Figure 3, Tables 6 and 7). However, further analysis of age-specific prevalence rates revealed that although the sex difference increased with age up to 15 years, after that the difference then reduced substantially. Among people aged 40 and over, there was no consistent pattern of sex difference in prevalence across age groups according to the ABS 1993 disability survey (Figure 3 and Appendix Table 3). The explanation may be the high standard errors as a result of smaller sample numbers involved among the adult population with an intellectual disability.

The study on Northern Sydney adults (Beange and Taplin 1996) found no significant sex difference among adults with an intellectual disability.

Fishbach and Hull (1982) also reported that marked sex differences among Canadian children, apparent prior to 12 years, became insignificant after that age (McLaren and Bryson 1987).

The study on children aged 6–16 years in Western Australia found that the sex disparity occurred only among people with mild or moderate intellectual disability but not among the severe or profound categories (Wellesley et al. 1992).

The lower prevalence rate for males under age 5, as compared with females, probably indicated the failure of ascertainment or under-reporting among that age group in the ABS 1993 disability survey (Figure 3).

3.4.3 Age at onset of main disabling conditions

In the ABS surveys, a question on the age when conditions first appeared was only asked among people living in households, and was related to their main disabling conditions. The ABS 1993 survey shows that a great majority (86.6%) of people with an intellectual disability, in households, reported having that disability before age 18; 38.3% reported an onset of their condition at birth or during infancy; 41.2% reported an onset between age 1 and 11, and 7.1% at age 12–17 (Figure 4 and Table 8). This was in contrast to the pattern of all people with a disability, which indicated a majority (73.8%) of people with a disability whose main disabling conditions were identified at adult ages or older (Figure 5 and Table 8).

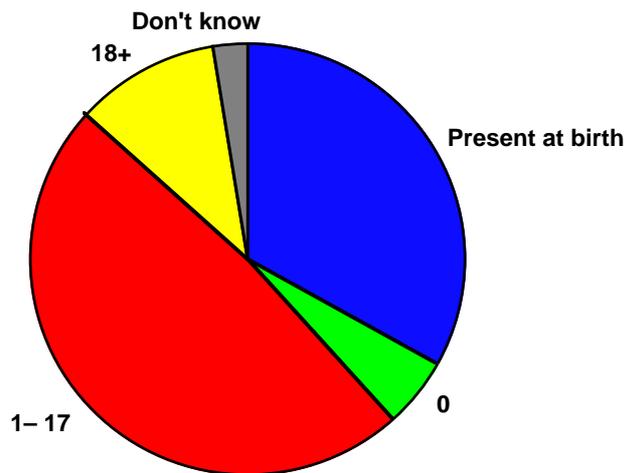
Table 8: People with a disability in households, age when main disabling condition happened, Australia, 1993

Age when condition happened	People in households with a disability (a)(b)		People in households with an intellectual disability (a)(b)	
		% of total		% of total
Present at birth	204,100	6.76	39,000	32.89
0	69,100	2.29	6,400	5.38
1–5	194,000	6.43	28,900	24.35
6–11	142,900	4.73	20,000	16.83
12–17	143,700	4.76	8,400	7.10
18–19	66,200	2.19	1,200	0.97
20–21	79,000	2.62	1,500	1.23
22+	2,083,400	69.02	10,400	8.51
'Do not know'	36,100	1.20	2,900	2.47
Total	3,018,400	100.00	118,600	100.00
Total before age 18	753,800	24.97	102,700	86.56
Total age 18 and over	2,228,500	73.83	13,000	10.97
Total disability rate		17.30		0.68

(a) Estimates of 1,900 or less have a relative standard error (RSE) of 50% or more. Estimates of 8,000 or less have an RSE of 25% or more.

(b) Question on age when main disabling condition happened was only asked among people in households.

Source: AIHW analysis of ABS 1993 Survey of Disability, Ageing and Carers data.



Source: Table 8.

Figure 4: People with an intellectual disability in households, age when primary disabling condition identified



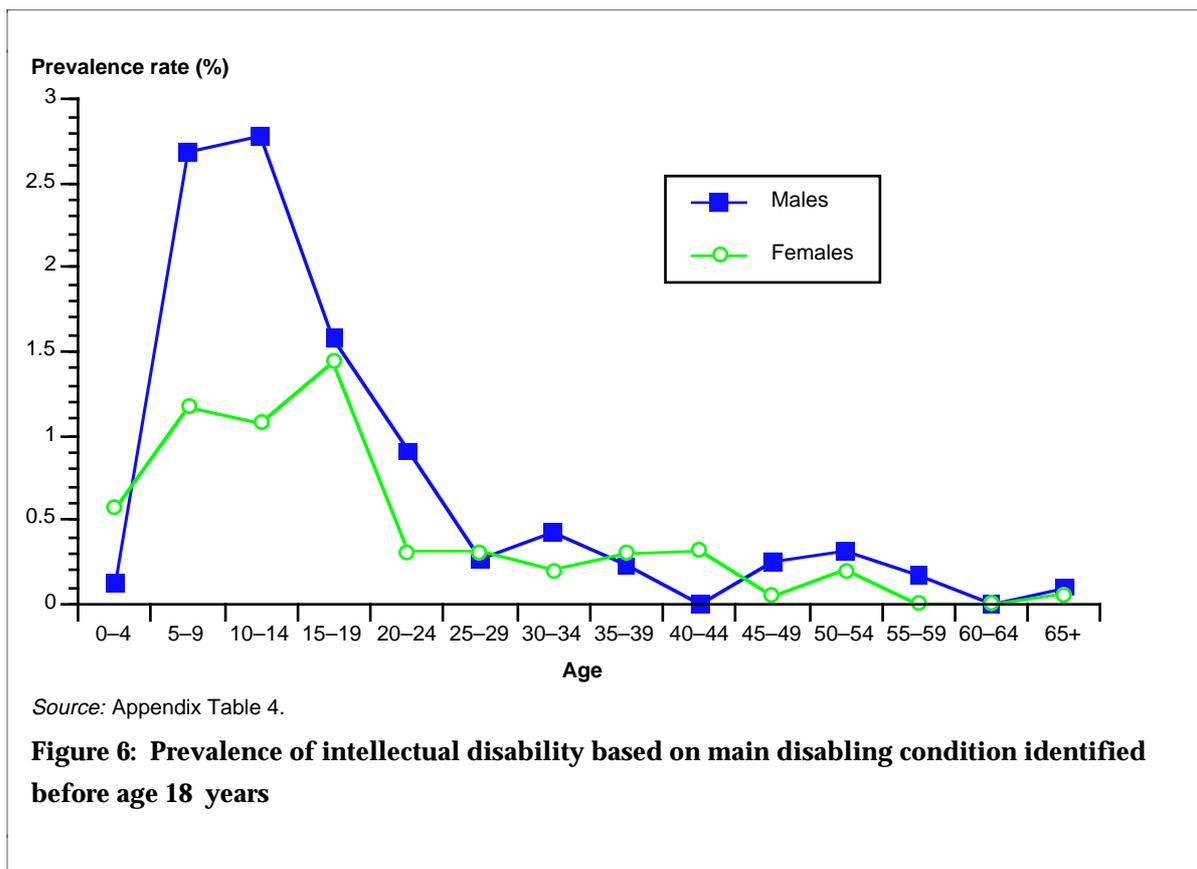
Source: Table 8.

Figure 5: People with a disability in households, age when primary disabling condition identified, Australia, 1993

The prevalence of intellectual disability among the general population in households, irrespective of age at onset of their condition, was 0.68% or 118,600 people (Table 8). If the age 18 cut-off criterion was introduced for identification, the rate was 0.60% or 102,600 people, excluding 2,900 people who did not know the age when their main conditions happened (Table 8). The prevalence among people living in establishments was 6.2% or 10,300 people. If

we assume that the proportion (86.6%) of people in households whose main condition occurred before age 18 could be applied to people with an intellectual disability but who did not know when their condition occurred and to those who were living in establishments, then the age cut-off criterion can be introduced to calculate prevalence for the total population. The prevalence in the total population would be 0.65% or 114,000 people. This reflected an 11% (14,800 people) reduction from the prevalence rate of 0.73% (128,900 people) in the general population irrespective of age when condition happened.

Figure 6 shows that when the age 18 cut-off criterion was used in computing prevalence, the general age and sex patterns were the same as compared with the total people with an intellectual disability (Appendix Table 4).



3.4.4 Associated impairments or disabilities

Evidence from many international studies found that a large proportion of people with intellectual disability suffered from associated disabilities (McLaren and Bryson 1987). Table 9 presents data on associated impairments or disabilities reported by people with intellectual disability as the main disabling conditions in the ABS 1993 Survey. Many people with an intellectual disability in Australia had multiple impairments or disabilities.

Among people with an intellectual disability who lived in households and whose disabling conditions occurred before the age of 18 years, the most commonly associated impairments or disabilities were physical (37.6%). More than a quarter of people also presented with speech problems.

Table 9: People with an intellectual disability in households^(a) based on reported main disabling condition, by reported other disabilities or impairments, by age when condition happened, Australia, 1993

Reported other disabilities or impairments	Age when accident or condition happened						Total	% of total people with intellectual disability
	Before age 18	% of total before age 18	Age 18+	% of total 18+	'Do not know' ^(b)	% of total not known		
Psychiatric	19,800	19.3	4,100	31.5	—	—	23,900	20.1
Acquired brain injury	12,800	12.5	2,100	16.5	—	—	14,900	12.6
Vision	700	0.7	600	4.7	—	—	1,300	1.1
Hearing	6,500	6.3	1,500	11.7	—	—	8,000	6.7
Speech	27,000	26.2	300	2.2	—	—	27,300	23.0
Physical	38,600	37.6	8,700	66.6	799	27.3	48,300	40.7
Neurological	3,400	3.3	1,100	8.2	—	—	4,400	3.7
Other	15,100	14.7	9,800	75.2	368	12.6	25,900	21.9
Total people with intellectual disability^(c)	102,700	86.6	13,000	11.0	2,927	2.5	118,600	100.0

(a) Estimates of 1,900 or less have a relative standard error (RSE) of 50% or more. Estimates of 8,000 or less have an RSE of 25% or more.

(b) People do not know when accident or condition happened.

(c) Total numbers of people with an intellectual disability are less than the sum of the components of all other reported disabilities or impairments since a person may have more than one disability or impairment.

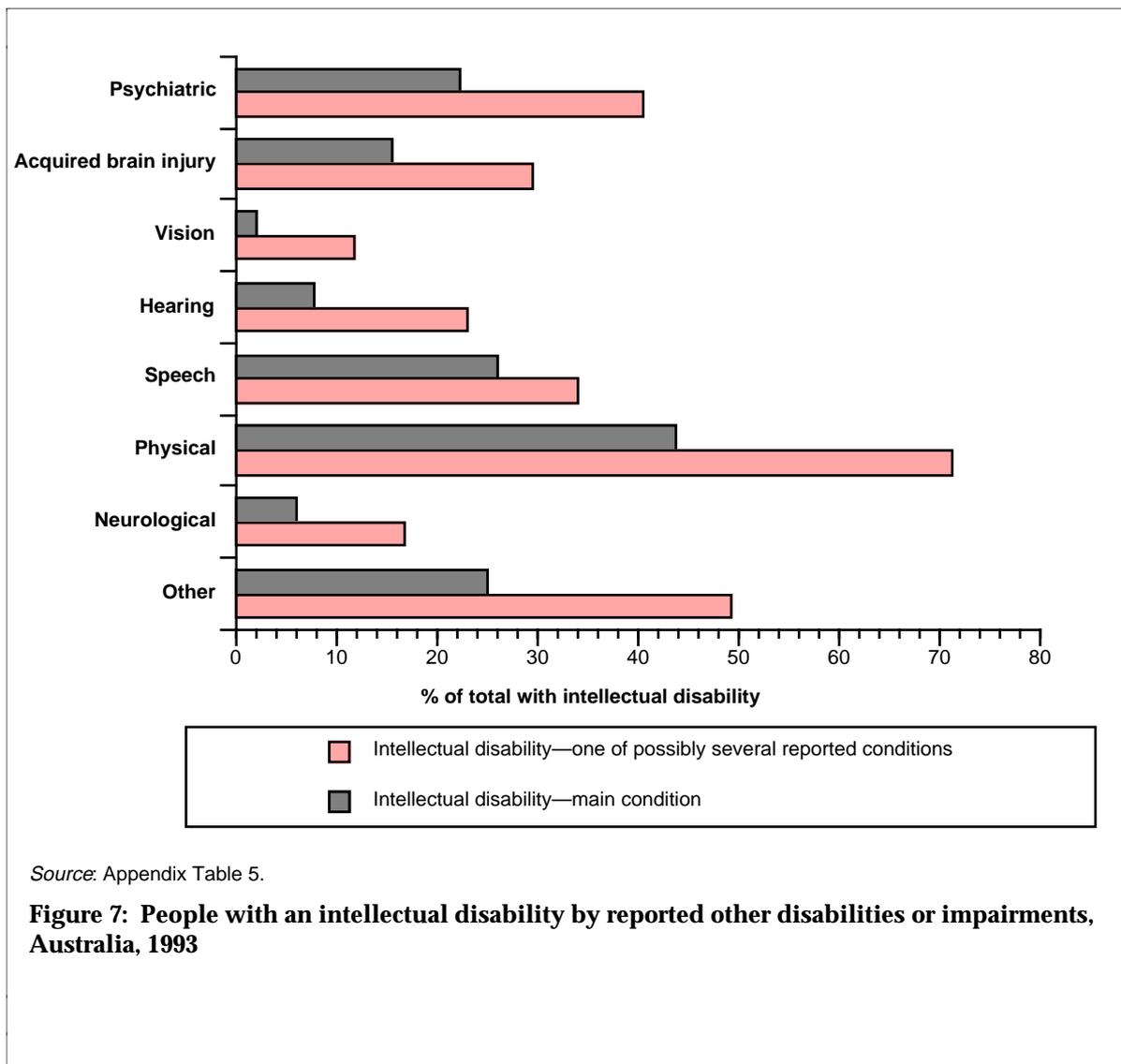
Source: AIHW analysis of ABS 1993 Survey of Disability, Ageing and Carers data.

A substantially high proportion (19.3%) of people reported associated psychiatric disabilities, which was likely to include many people who were suffering from behavioural disorders. A recent survey (Sigafos et al. 1994) on aggressive behaviour within a population of 2,412 people with intellectual disability in Queensland shows that 80% of the sample cases engaged in three or more forms of aggression, and two-thirds received medication for their challenging behaviour. Many of the sample cases also displayed self injury (34%) or property destruction (30%). These aggressive behaviours were attributed to syndromes such as autism and schizophrenia in about 21% of the sample cases, and to some relatively vague causes such as frustration (21%) and boredom (14%).

A study, derived from a population survey of 24,498 children in Sweden, suggested that 64% of children with severe retardation and 57% of children with mild retardation were suffering from a psychiatric condition (Gillberg et al. 1986). The study also found that the disorders grouped in the 'psychotic behaviour' category were the most common, affecting 50% of all children with a severe mental retardation and 14% of children with mild mental retardation (Gillberg et al. 1986).

Figure 7 (Appendix Table 5) presents data on other associated disabilities or impairments reported by people with an intellectual disability as one of several

disabling conditions compared with those for people whose intellectual disability was the main disabling condition, irrespective of the age when conditions happened. The data suggest that 40.5% or 132,900 people with an intellectual disability, defined by all reported disabling conditions, also had psychiatric disabilities, and 71.1% or 233,000 people also had physical impairments or disabilities. As a comparison, there were 28,600 people (22%) with intellectual disability as the main disabling condition who also reported psychiatric disorders and 56,400 (44%) suffering physical disorders.



3.4.5 Estimates of older people with intellectual disability (Australia and New Zealand)

A New Zealand study (Hand 1994) attempted to find people who had been regarded as having mental retardation since childhood and who had become old. The definition used in the survey was 'all individuals in New Zealand born before 1940, who had been judged before the age of 20 to be in need of care, or

eligible for a particular service or benefit on the grounds of intellectual disability of a longstanding or developmental nature, or excluded from normal education or participation in other usual-for-age activities' (Hand 1994: 276). The survey found that prevalence of intellectual handicap among all people aged 55 years and over was 0.14%, with wide regional variations.

Estimates from the ABS 1993 Survey of Disability, Ageing and Carers show that the prevalence of intellectual disability as the main disabling condition among Australians aged 55 and over in households was 0.08%, with their main conditions happening before the age of 20. Assuming that the distribution of age at the onset of the condition before 20 among people in establishments was the same as that for people in households, the overall prevalence rates for Australians aged 55 and over would be 0.13% with an age of onset before 20, a prevalence level similar to the estimate (0.14%) for New Zealand in 1990.

A national survey on older Australians with an intellectual disability was conducted to identify people aged 55 years and over whose primary disability was intellectual, in order to provide a database for service planning (Ashman et al. 1994). The survey produced a national database of 2,543 people 55 years of age and over with an intellectual disability after extensive enquiries made through disability and generic services in all States and Territories of Australia. The number is substantially lower than those of the ABS 1993 disability survey which yielded a number of 9,237 people in the total population (5,693 people in households and 3,544 in establishments).

The difference between the two estimates suggests that the estimates of prevalence from a national population survey, based on self-reported information, tend to be higher than those derived from administration records.

4 Discussion

This paper has critically reviewed the existing definitions and estimates of prevalence of intellectual disability with special reference to Australia. Refined estimates of prevalence from national population surveys were compared with the estimates from agency records. A preliminary analysis of patterns of intellectual disability in Australia was also presented. This chapter discusses main issues relating to the definitions and estimates of prevalence of intellectual disability, and summarises the major findings.

4.1 Issues relating to underlying concepts and definitions

Most Australian institutions have adapted the AAMR definitions and classifications to define intellectual disability. The ABS national disability surveys and health surveys have adapted the WHO ICIDH and ICD-9 concepts and definitions, using fairly broad classification groups.

Neither of the two WHO manuals (ICD-10, ICIDH) has specified an age as a cut-off point for the developmental period to define intellectual disability, while the ICD-10 definition refers to the condition as 'especially characterised by impairment of skills manifested during the developmental period'. The definition of intellectual impairments in ICIDH seems to refer to the general population.

The intellectual impairments defined in ICIDH cover a wider range of impairments and syndromes than those of ICD-10, involving impairments in intelligence, memory and thinking. Mental retardation is considered as one of the sub-categories of intelligence impairments. The ICIDH definition of intellectual impairments excludes impairments of language and learning.

The mental retardation section of DSM-IV has been written and modified to be compatible with the AAMR definition and has incorporated the ten adaptive skill areas of the AAMR definition into its general definition. However, DSM-IV set the cut-off IQ score for intellectual functioning as approximately 70 or below, while the new AAMR definition set the score as approximately 70–75 or below. The DSM-IV has also retained the classification of severity of retardation corresponding to the eighth edition rather than the new (ninth) edition of the AAMR manual.

The substantial changes in the latest (ninth) revision of the AAMR manual, in contrast to earlier versions, can be mainly explained by changes in its goals and philosophy. The ninth revision appears to have taken significant steps moving away from a clinically oriented perspective towards a multidimensional approach in defining mental retardation. It put more emphasis on functional and environmental considerations, and less emphasis on an individual's deficiency. The evaluation of intensities and patterns of individuals' needed supports became an integral part of the definition and classification system.

The shift from assessing the level of an individual's deficiency (mild, moderate, severe, profound) to assessing the intensities of needed supports (intermittent, limited, extensive, pervasive) was aiming to address the issue that eligibility for services should be based more on functional criteria which demonstrate need for support rather than solely on formal, traditional tests of performance (Schalock et al. 1994). However, it might be more appropriate to incorporate the 'intensities of support' as a complementary measure to the former classification of severity of mental retardation rather than replacing it completely, while further effort is needed to study the nature and causes of mild versus more severe levels of intellectual disabilities.

Comparability might be another issue which needs to be considered, in relation to the substantial departure of the new AAMR definition from other major classification systems such as WHO ICD-10 and the American Psychiatric Association's (1980) Diagnostic and Statistical Manual of Mental Disorders (DSM-IV). The Australian operational definitions and estimates of prevalence have been affected by the periodic revisions of the AAMR definitions and classifications, and by the variations in definitions and classifications between AAMR and other major classification systems. There are, so far, no published study, survey or administrative documents which have applied the ninth revision of the AAMR definition and classification in Australia. The possible impact of the new definition and classification on current or future data collections and service provisions also need to be examined.

Trends in the disability field support the appropriateness of the AAMR multidimensional approach, to include assessment of intensities and patterns of need for support as one of the components of the definition and classification. This broadens the conceptualisation of intellectual disability and avoids reliance solely on IQ scores to classify severity of intellectual disability and relate the individual's needs to appropriate level of supports.

The existing variety of data suggests a need to improve the consistency of concepts and definitions for intellectual disability and to increase the comparability of data collections for different purposes.

4.2 Issues relating to operational definitions and estimates of prevalence

4.2.1 National perspectives

The empirical estimate of the prevalence rate of mental retardation was generally agreed around 1%–1.5% of the US population (Figure 2, Heber 1970, Mercer 1973b, MacMillan 1982, Reschly 1992, Summers 1986). Other international estimates derived from total population screening indicated that the prevalence rate was at least 1.25% (0.7% of severe and 0.55% of mild), in contrast to the rates from 0.3% to 0.4% which were estimated from agency administration records (McLaren and Bryson 1987).

Morbidity data from the ABS 1989–90 National Health Survey suggested that 0.42% or 720,000 people reported long-term conditions as having mental retardation and/or specific delays in development (ABS 1992). However, the survey was not specifically designed to obtain disability information. The relatively low prevalence was partly due to the exclusion of people living in establishments and students at boarding schools.

The ABS disability surveys are the only existing national data containing valid and reliable information about the population with disability. This paper has presented a number of estimates of national prevalence of intellectual disability derived from the ABS three disability surveys (1981, 1988, 1993), depending on the methods and assumptions used in estimation.

The results show that national estimates of prevalence derived from ABS population disability surveys, of which the self-reported information might or might not be the results of professional assessment, were higher than those State estimates from administrative records, of which a majority of the cases were presumably verified by professional assessments. This is consistent with findings reported in other reviews of international studies, which found that the estimates on the basis of agency records were about 0.3%–0.4% (McLaren and Bryson 1987).

The difference between national and State estimates may also be attributable to the fact that State estimates were limited to the cases known to the agencies, which are more likely to contain people with severe disabling conditions. In contrast, national population disability surveys, which are based on samples of the entire population, are more likely to include people with both severe and mild disabling conditions.

Estimates without an age criterion for the ‘developmental period’

When the criterion of age 18 as the cut-off point for manifestation of the disability was not introduced in estimation, the following different estimates were obtained:

- Using the ABS definitions and categories consistent with the 1981 and 1988 survey screening questions, the national overall prevalence rate of intellectual disability was 0.59% in 1993, as a reported main disabling condition. The rates varied between 0.56% and 0.67% over the three ABS disability surveys, after removing the age effect of population changes.
- Using the 1993 survey screening questions (adding three additional screening questions) and applying AIHW groupings, the 1993 survey produced a prevalence rate of 0.73% (128,900 people) for intellectual as a main disabling condition. There were 48,000 people or 0.27% of total Australians who reported both an intellectual disability and severe or profound handicap (according to the ABS definition of severity of handicap).
- When the prevalence was derived from **all** reported disabling conditions, the use of the AIHW approach and the 1993 survey screening questions yielded a prevalence rate of 1.86% (328,000 people). There were 174,000 people or 0.99% of total Australians reporting both an intellectual disability and severe or profound handicap.

- A recent ABS (1996) report on disability and disabling conditions estimated that 1.7% of the total population responded positively to the 1993 survey screening question of 'slow at learning or understanding'.

Estimates including an age criterion for the 'developmental period'

When the age criterion of the developmental period was applied in estimation, different estimates were re-calculated on the basis of reported main disabling condition. The prevalence of intellectual disability of the total population in 1993 was 0.65% or 114,100 people with their conditions identified before age 18. This reflected an 11% (14,800 people) reduction from the prevalence of 0.73% (128,900 people) in the general population irrespective of age when their condition happened.

The overall prevalence rate of Australians aged 55 and over was 0.13% with their conditions occurring before age 20.

4.2.2 Regional perspectives

All the Australian published studies on prevalence at state or local level obtained information from administration records held by governments or by medical, social and educational agencies. These studies revealed considerable variations in estimates of prevalence across States. The variations were attributable to the diversity in survey operational definitions, methodological factors and other non-methodological factors.

The methodological factors include:

- use of single (using IQ test only) versus dual criteria (using both IQ test and adaptive behaviour assessment) in survey definitions;
- use of different IQ cut-off scores to define the eligible people (even if the same IQ cut-off score was used, there were variations in approaches to obtaining an IQ score);
- selection of different population groups at risk (children, adults, the aged or general population, including or excluding children under age 6).

The non-methodological factors include differences—both within and across States—in the characteristics of the population at risk, such as social, economic, cultural, ethnic and regional differences, and other environmental differences.

Because of the confounding effects of the methodological and non-methodological factors on prevalence estimated in these studies, there is no way to separate the effects of the two groups of factors on the basis of available published studies.

Estimates of overall prevalence from administration records in most Australian States were approximately 0.4%–0.5%, if the exceptionally high estimate from the NSW study is excluded. The estimated prevalence rates of severe (including moderate, severe or profound) intellectual disability were between 0.2% and 0.3%.

Many international epidemiological studies suggested that approximately 0.3% to 0.5% of the general population were identified as having moderate, severe, or profound intellectual disability (Reschly 1992). This pattern has been found since an early study (Lewis 1929) and in both developing and industrial countries (Kiely 1987).

A review of 15 international community studies of children with severe mental retardation suggested an overall estimate of the prevalence rate of severe intellectual disability of approximately 0.4% (Starza-Smith 1989).

Estimates of severe (including moderate, severe or profound) intellectual disability from the three Australian regional studies on children under the age of 17 years yielded prevalence rates of 0.2% for Victoria, 0.3% for Queensland and 0.4% for WA. The slightly lower rate for Queensland was probably due to the dual criteria used in the study which excluded children with a measured IQ score below 55 but who did cope with the school system either in regular or special classes. The lower rate for Victoria may be mainly attributable to the inclusion of children under age 6 as the baseline population at risk, and the age-specific prevalence rates indicated a clear underestimation in that age group (Krupinski 1966).

Two studies have provided overall prevalence estimated among children under the age of 17 years. The prevalence rate of 0.76 in WA was much higher than the rate of 0.47 in Victoria. The WA study had excluded children under the age of 6 years and conducted a more vigorous and comprehensive survey which collected information about IQ scores at up to three consecutive assessments of a person; other factors affecting the estimates could include the time gap between the two studies. The WA study was conducted in 1992, which might reflect more advanced administrative information systems and service provisions than those of Victoria in 1966.

4.2.3 Pattern of intellectual disability

Both national and regional estimates showed that the age-specific prevalence rates increased with age until about age 10 to 14 years and then declined slightly among adolescents. The rates were markedly higher among children at school ages than among the adult population. This general pattern is consistent with the findings from other international studies (Kiely 1987, McLaren and Bryson 1987). The dramatic increase and the marked fall of the reported age-specific prevalence rates across age groups may not necessarily mirror the variations in actual prevalence among the population. Rather, it probably mainly reflects the limitations and the different efforts in case ascertainment.

The variations may be also due to the ability of adults with mild intellectual disability to adapt to the demands of society with the passage of time (Beange and Taplin 1996). After discharge from school, many people with intellectual disability lost contact with service agencies because they did not need further assistance (South Australian Health Commission 1981). The differentials in mortality between people with an intellectual or learning disability and the general population may also account for, to some extent, the lower prevalence among the adult population. A recent study in the UK found that the death rate in the adult population with learning disability exceeded that of the general population (McGuigan et al. 1995). The high and stable prevalence rates among

children at school age demonstrated the great impact of the education system on case identification of intellectual disability.

The ABS 1993 disability survey data showed that among people living in households, 86.6% of those who reported a main disabling condition as intellectual, had the condition identified before age 18, and 38.3% reported an onset of their conditions at birth or during infancy.

Consistently higher overall prevalence among males, as compared with females, was evident in the estimates at both State and national levels. The sex differences in prevalence were particularly significant among children and adolescents.

According to the ABS 1993 disability survey, of people reporting intellectual as their main disabling condition, 44% also reported associated physical impairments or disabilities and more than a quarter of people also presented with speech problems. A high proportion (22%) of people were suffering associated psychiatric disabilities.

It is also notable that 40.5% of people with an intellectual disability, reported as either a main disabling condition or as an associated condition, were also suffering from psychiatric disabilities.

4.2.4 Trends in prevalence of intellectual disability

There are no published data or studies which examine the current or future trends in prevalence of intellectual disability in the general population of Australia. The regional studies conducted at different times showed disparities in prevalence but no information about trends in the overall prevalence. Other work, reviewed briefly elsewhere (Madden et al. 1996: 30–33), should, in time, inform work on likely trends in prevalence. Such work includes that of the Institute's Perinatal Statistics Unit and National Injury Surveillance Unit, as well as the work of the Institute for Child Health Research and organisations monitoring condition-specific registers.

The three ABS disability surveys collected cross-sectional data at three different points in time over a period of 12 years. The estimates of prevalence from the three ABS national surveys may be used as a proxy indicating the changes in the 1980s and the early 1990s. As mentioned in Section 3.2.2, using the ABS definitions and categories consistent with the 1981 and 1988 survey screening questions, the prevalence rates varied between 0.56% and 0.67% over the three consecutive surveys, if the age at onset of the main condition was not taken into account. Nevertheless, no firm conclusion on future perspective of the prevalence can be reached on the basis of studies and data available to date.

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Appendix A

Definition and examples of 'intensities of supports'

Intermittent

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

Limited

An intensity of supports characterised 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 (e.g. time-limited employment training or transitional supports during the school to adult provided period).

Extensive

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

Pervasive

Supports characterised 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.

Source: Luckasson et al. 1992, 26.

Appendix B

WHO ICD-10 Classification of mental retardation

Mild mental retardation

Approximate IQ range of 50–69 (in adults, mental age from 9 to under 12 years). Likely to result in some learning difficulties in school. Many adults will be able to work and maintain good social relationships and contribute to society.

Includes: feeble-mindedness, mild mental subnormality.

Moderate mental retardation

Approximate IQ range of 35 to 49 (in adults, mental age from 6 to under 9 years). Likely to result in marked developmental delays in childhood but most can learn to develop some degree of independence in self-care and acquired adequate communication and academic skills. Adults will need varying degrees of support to live and work in the community.

Includes: Moderate mental subnormality.

Severe mental retardation

Approximate IQ range of 20 to 34 (in adults, mental age from 3 to under 6 years). likely to result in continuous need of support.

Includes: severe mental subnormality.

Profound mental retardation

IQ under 20 (in adults, mental age below 3 years). Results in severe limitation in self-care, continence, communication and mobility.

Includes: profound mental subnormality.

Other mental retardation

Unspecified mental retardation

Includes: mental:

- deficiency non otherwise specified;
- subnormality non otherwise specified.

Source: WHO 1992. International statistical classification of diseases and related health problems: tenth revision (ICD-10), 369–370.

Appendix C

WHO ICIDH Classification of Intellectual Impairments

Intellectual impairments include those of intelligence, memory and thought, and exclude impairments of language and learning.

Impairments of intelligence

Includes: disturbances of the rate and degree of development of cognitive functions, such as perception, attention, memory and thinking, and their deterioration as a result of pathological processes.

Profound mental retardation

IQ under 20

Individuals who may respond to skill training in the use of legs, hands, and jaws.

Severe mental retardation

IQ 20–34

Individuals who can profit from systematic habit training.

Moderate mental retardation

IQ 35–49

Individuals who can learn simple communication, elementary health and safety habits, and simple manual skills, but do not progress in functional reading or arithmetic.

Other mental retardation

Mild mental retardation

IQ 50–70

Individuals who can acquire practical skills and functional reading and arithmetic abilities with special education, and who can be guided towards social conformity.

Other

Unspecified

Other impairments of intelligence

Global dementia

Dementia affecting all cognitive functions and skills

Includes: deterioration of cognitive functioning as a result of cerebral disease or trauma.

Lacunar or patchy dementia

With partial preservation of some cognitive functions and skills

Other and unspecified dementia

Loss of learned skills

Other

Unspecified

Impairments of memory

Amnesia

Includes: partial or complete loss of memory for past events, and inability to register, retain, or retrieve new information.

Retrograde amnesia

Impaired memory for happenings prior to some well-identified event

Impairment of long term memory

Impairment of recent memory

Includes: congrate amnesia, impaired ability to acquire new information.

Psychogenic amnesia

Irregularity of pattern of memory loss

Impairment of memory for shapes

Impairment of memory for words

Impairment of memory for figures

Other

Unspecified

Other impairments of memory

Memory includes the capacity to register, retain, and reproduce information

Includes: false memories and distortions of memory content.

Confabulation

Memory illusions

Paramnesia

Cryptomnesia

Recall of facts or events without recognising them as memories

Other distortion of memory content

Forgetfulness

Other

Unspecified

Impairment of thinking

Impairment of flow and form of thought processes

Includes: disturbances affecting the speed and organisation of thought processes, and the ability to form logical sequences of ideas.

Impairment of conceptualisation or abstraction

Relates to the ability to interpret the meaning of what is perceived, to integrate perceptions, to form meaningful relations among perceptions, and to abstract.

Impairment of logical thinking

Relates to the ability to relate ideas hierarchically

Slowness of thought

Acceleration of thought

Perseveration

Includes: 'getting stuck', repeating phrases, and constantly returning to same topic.

Circumstantial thinking

Obsessional ideas

Flight of ideas

Includes: association of words by sound or rhyme.

Other

Includes: incoherence of thought processes.

Unspecified

Impairment of thought content

Includes: restriction of thought content, excessive or unrealistic emphasis on and preoccupation with a particular set of ideas to the exclusion of critical examination of the ideas, and false beliefs not amenable to correction through logical argument and reality testing.

Poverty of thought content

Overvalued ideas

Paranoid delusions

A delusion is a false belief, impervious to the force of reason, and not shared by others of similar education and cultural background. A paranoid delusion or idea of reference is a delusion in which the individual considers that things in his surroundings are happening especially in connection with him.

Depressive delusions

Includes: delusions of guilt and impoverishment.

Delusional jealousy

Delusions of grandeur

Fantastic delusions

Hypochondriacal and nihilistic delusions

Other delusions

Other and unspecified

Other intellectual impairments

Other intellectual impairment

Includes: impairments of gnosis and praxis functions, where there is disturbance of higher cortical functions underlying the recognition and purposeful manipulation of objects.

Agnosia

Disturbed ability to recognise objects in the absence of impairments of consciousness, memory, and thinking

Apraxia

Disturbed ability to perform learned purposeful movements in the absence of impairments of consciousness, memory, thinking, and motor capacity

Acalculia

Disturbed ability to count and operate with numbers in the absence of impairments of consciousness, memory, and thinking

Impairment of openness to new ideas

Misinterpretation

A misinterpretation is a false construction put by the individual on an occurrence

Other

Unspecified

Source: WHO 1980. International classification of impairments, disabilities, and handicaps: a manual of classification relating to the consequences of disease, 53–56.

Appendix D

Appendix tables

Appendix Table 1: People with severe or profound handicap and reporting an intellectual disability based on reported main disabling condition by age, sex and residence as a percentage of Australian population of that age, sex and residence, Australia, 1993

Age	Residence		Sex		Total (%)
	Households (%)	Establishments (%)	Male (%)	Female (%)	
0–4 ^(a)	—	—	—	—	—
5–9	0.68	12.61	1.02	0.35	0.69
10–14	0.68	25.72	0.97	0.42	0.70
15–19	0.44	8.87	0.37	0.53	0.45
20–24	0.41	25.18	0.68	0.19	0.44
25–29	0.08	37.99	0.07	0.19	0.13
30–34	0.16	42.62	0.23	0.29	0.26
35–39	0.15	37.10	0.14	0.33	0.24
40–44	0.13	23.82	0.07	0.28	0.17
45–49	0.09	21.20	0.16	0.08	0.12
50–54	0.11	12.65	0.16	0.11	0.14
55–59	0.01	12.77	0.06	0.06	0.06
60–64	0.00	5.95	0.01	0.08	0.04
65+	0.07	1.66	0.18	0.18	0.18
<i>Total</i>	<i>0.23</i>	<i>5.07</i>	<i>0.31</i>	<i>0.23</i>	<i>0.27</i>
Total number	39,516	8,448	27,442	20,522	47,964

(a) Severity of handicap was not defined among children under age of 5 years.

Source: AIHW analysis of ABS 1993 Survey of Disability, Ageing and Carers data.

Appendix Table 2: People with severe or profound handicap and reporting intellectual disability based on reported all disabling conditions by age, sex and residence as a percentage of Australian population of that age, sex and residence, Australia, 1993

Age	Residence		Sex		Total (%)
	Households (%)	Establishments (%)	Male (%)	Female (%)	
0-4 ^(a)	—	—	—	—	—
5-9	1.30	83.67	1.87	0.81	1.35
10-14	1.24	42.49	1.60	0.92	1.27
15-19	0.85	22.87	0.71	1.03	0.87
20-24	0.72	51.38	0.84	0.75	0.79
25-29	0.49	64.20	0.56	0.59	0.57
30-34	0.35	65.02	0.52	0.49	0.50
35-39	0.24	69.10	0.21	0.57	0.39
40-44	0.30	57.76	0.33	0.47	0.40
45-49	0.51	70.36	0.62	0.61	0.62
50-54	0.22	55.12	0.35	0.36	0.35
55-59	0.22	57.22	0.59	0.31	0.45
60-64	0.19	54.44	0.51	0.67	0.59
65+	0.81	42.46	2.62	4.40	3.63
<i>Total</i>	<i>0.57</i>	<i>45.07</i>	<i>0.88</i>	<i>1.10</i>	<i>0.99</i>
Total number	98,820	75,038	76,977	96,882	173,858

(a) Severity of handicap was not defined among children under age of 5 years.

Source: AIHW analysis of ABS 1993 Survey of Disability, Ageing and Carers data.

Appendix Table 3: Prevalence of intellectual disability based on reported main disabling condition, by age and sex, by place of residence, Australia 1993

Age	Residence		Sex		Total (%)
	Households (%)	Establishments (%)	Male (%)	Female (%)	
0-4	0.34	0.00	0.12	0.57	0.34
5-9	1.95	17.48	2.69	1.18	1.96
10-14	1.96	42.84	2.83	1.11	1.99
15-19	1.62	18.09	1.68	1.60	1.64
20-24	0.71	33.38	1.05	0.44	0.75
25-29	0.38	45.34	0.45	0.42	0.44
30-34	0.39	50.63	0.62	0.40	0.51
35-39	0.41	41.63	0.46	0.55	0.50
40-44	0.31	31.67	0.18	0.55	0.37
45-49	0.36	22.66	0.59	0.19	0.40
50-54	0.34	14.55	0.33	0.42	0.38
55-59	0.19	13.44	0.34	0.15	0.25
60-64	0.19	8.33	0.29	0.21	0.25
65+	0.15	1.95	0.26	0.29	0.27
<i>Total</i>	<i>0.68</i>	<i>6.17</i>	<i>0.88</i>	<i>0.58</i>	<i>0.73</i>
Total number	118,593	10,280	77,135	51,738	128,873

Source: AIHW analysis of ABS 1993 Survey of Disability, Ageing and Carers data.

Appendix Table 4: Prevalence of people with an intellectual disability in households, based on reported main disabling condition which occurred before age 18, Australia, 1993

Age	Prevalence rate (%)			Number ^(b)		
	Male	Females	Persons	Male	Females	Persons
0–4	0.12	0.57	0.34	800	3,600	4,400
5–9	2.69	1.17	1.95	17,600	7,300	24,900
10–14	2.78	1.08	1.96	18,000	6,600	24,600
15–19	1.58	1.44	1.51	10,600	9,200	19,700
20–24	0.91	0.31	0.61	6,700	2,200	8,900
25–29	0.26	0.31	0.28	1,700	2,100	3,900
30–34	0.42	0.20	0.31	3,000	1,500	4,500
35–39	0.23	0.30	0.26	1,600	2,000	3,600
40–44	—	0.32	0.16	—	2,000	2,000
45–49	0.25	0.05	0.15	1,500	300	1,800
50–54	0.31	0.20	0.26	1,400	900	2,300
55–59	0.17	—	0.09	700	—	700
60–64	—	—	—	—	—	—
65+	0.10	0.06	0.08	800	600	1,500
Not known ^(a)	—	—	—	1,800	800	2,500
Total	0.76	0.45	0.60	66,100	39,100	105,200

(a) 2927 people did not know age when main condition happened. The numbers in this row were calculated assuming that the distribution of age at onset of main condition was the same as that of those who knew.

(b) Estimates of 1,900 or less have a relative standard error (RSE) of 50% or more. Estimates of 8,000 or less have an RSE of 25% or more.

Source: AIHW analysis of ABS 1993 Survey of Disability, Ageing and Carers data.

Appendix Table 5: People with an intellectual disability^(a) by reported other disabilities or impairments, Australia, 1993

Reported other disabilities or impairments	People with intellectual disability based on main disabling condition (N)	% of total with intellectual disability (%)	People with intellectual disability based on all disabling conditions (N)	% of total with intellectual disability (%)
Psychiatric	28,600	22.2	132,900	40.5
Acquired brain injury	19,700	15.3	96,100	29.3
Vision	2,500	1.9	38,300	11.7
Hearing	9,800	7.6	75,500	23.0
Speech	33,500	26.0	111,300	33.9
Physical	56,400	43.8	233,100	71.1
Neurological	7,600	6.0	54,600	16.7
Other	32,200	25.0	161,700	49.3
Total people with intellectual disability^(b)	128,900		328,000	

(a) Estimates of 1,900 or less have a relative standard error (RSE) of 50% or more. Estimates of 8,000 or less have an RSE of 25% or more.

(b) Total numbers of people with an intellectual disability are less than the sum of the components of all other reported disabilities or impairments since a person may have more than one disability or impairment.

Source: AIHW analysis of ABS 1993 Survey of Disability, Ageing and Carers data.