

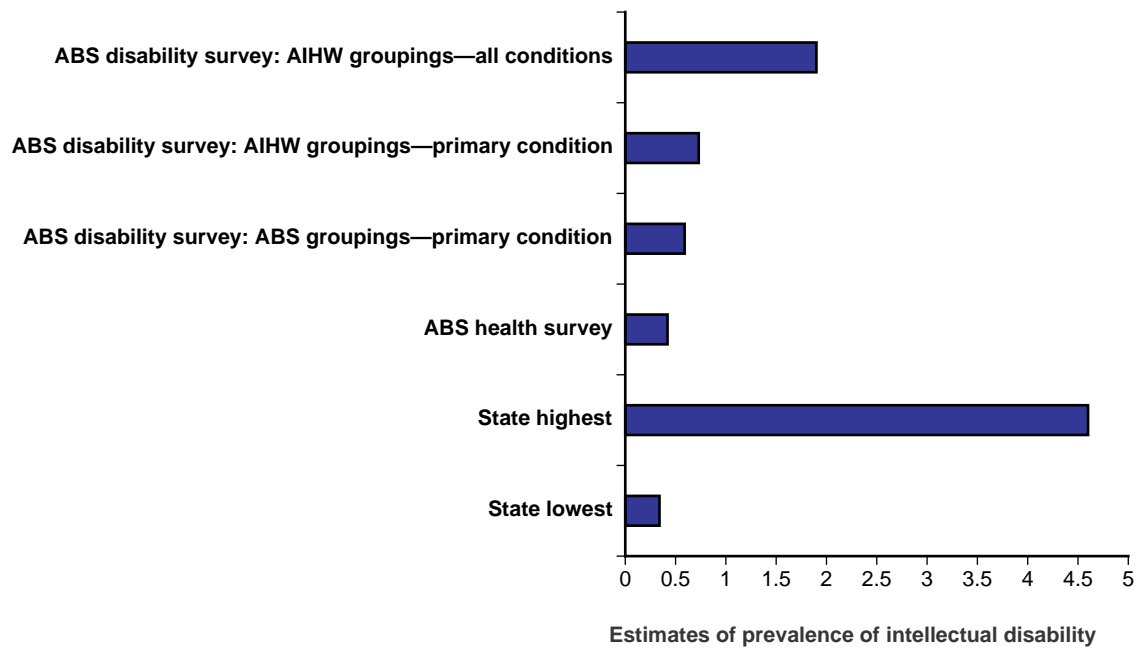
# 3 A review of existing estimates of prevalence

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:

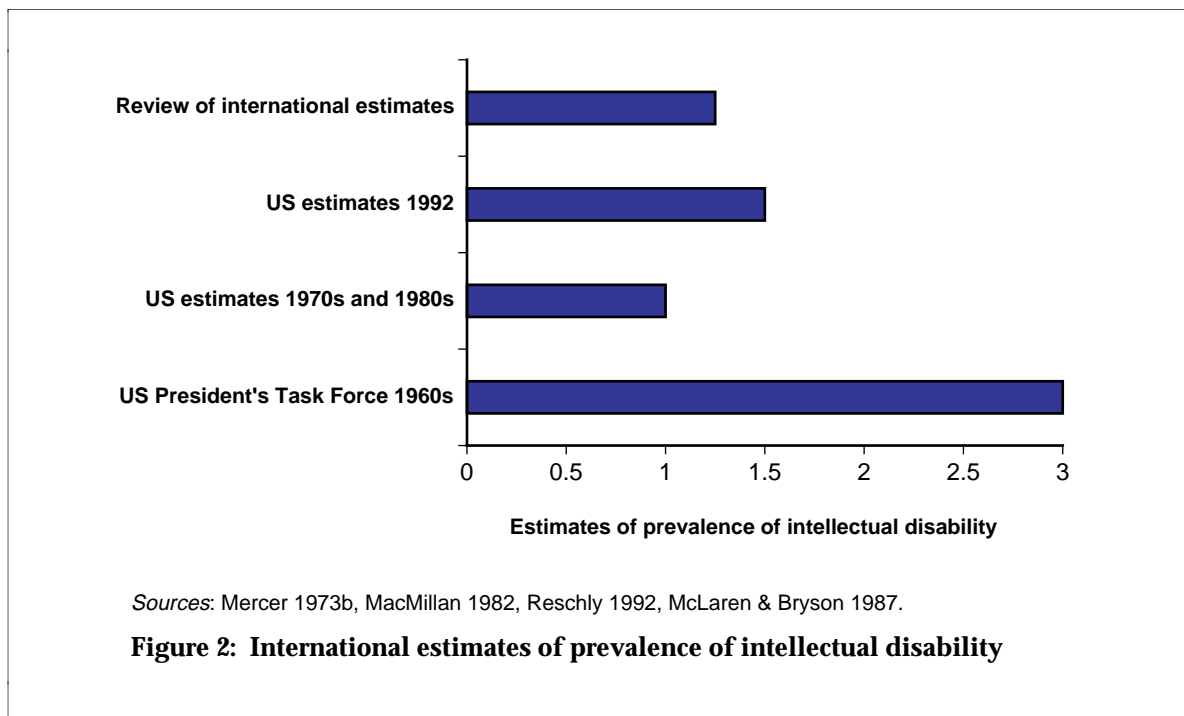
- the way responses to survey screening questions are categorised;
- the inclusion of different ‘disease’ codes (ICD codes); and
- the inclusion of **all** ‘disabling conditions’ or just the main one (see Section 3.2.2).



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 <sup>(a)</sup>	1981 survey				
ABS groupings <sup>(b)</sup>	Males			0.62	0.57
	Females			0.42	0.40
	Persons	0.61	0.56	0.52	0.48
1988 screening questions <sup>(a)</sup>	1988 survey				
ABS groupings <sup>(b)</sup>	Males	0.82	0.79		
	Females	0.56	0.54		
	Persons	0.69	0.67	0.65	0.63
1988 screening questions <sup>(a)</sup>	1993 survey				
ABS groupings <sup>(b)</sup>	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 <sup>(b)</sup>	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
<b>AIHW groupings for 1993 survey data</b>		
305	299.0	Infantile autism
307	Search question <sup>(a)</sup>	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
<b>ABS groupings for 1981 and 1988 surveys</b>		
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<sup>(a)</sup> based on all reported disabling conditions, Australia, 1981, 1988 and 1993**

Categories of screening questions and groupings <sup>(b)</sup>	Year of survey	People with an intellectual disability (N)	Prevalence disability (%)
<b>1988 screening questions 1981 survey</b>			
ABS groupings	Persons	111,200	0.76
<b>1988 screening questions 1988 survey</b>			
ABS groupings	Males	89,400	1.10
	Females	66,000	0.80
	Persons	155,400	0.95
<b>1993 screening questions 1993 survey</b>			
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 (Krupinski 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).

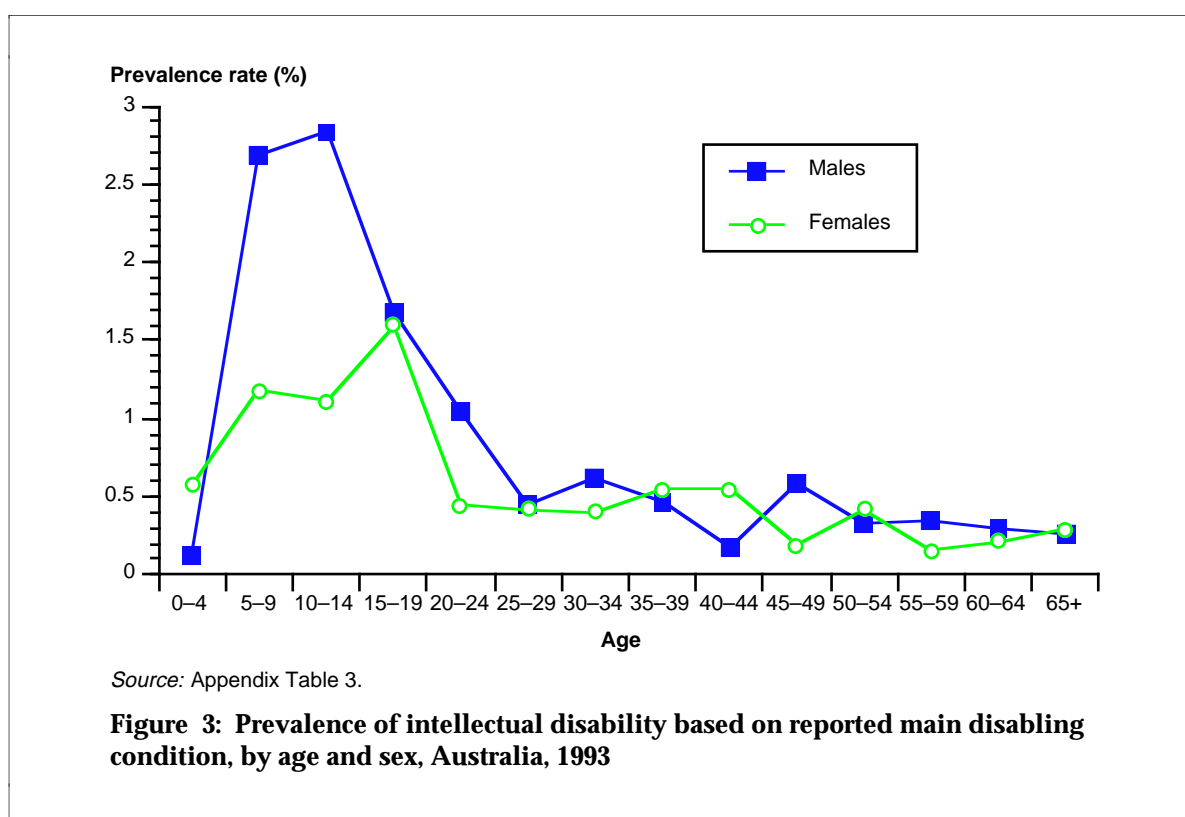
The study found that the overall prevalence rate among people aged 20 to 50 years in 1988 was 0.33%, or 0.34% if including those who were ascertained with an IQ score above 70 but whose level of functioning and adaptive skills qualified them for obtaining special services (Table 6 continued). Prevalence 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 <sup>(a)</sup>
	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
<b>Total</b>	<b>0.68</b>	<b>6.17</b>	<b>0.88</b>	<b>0.58</b>	<b>0.73</b>	<b>128,900</b>

(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).

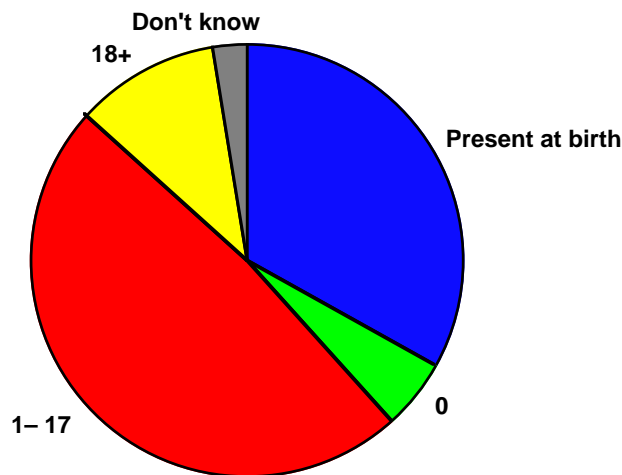
**Table 8: People with a disability in households, age when main disabling condition happened, Australia, 1993**

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
<b>Total</b>	<b>3,018,400</b>	<b>100.00</b>	<b>118,600</b>	<b>100.00</b>
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
<b>Total disability rate</b>		<b>17.30</b>		<b>0.68</b>

(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.

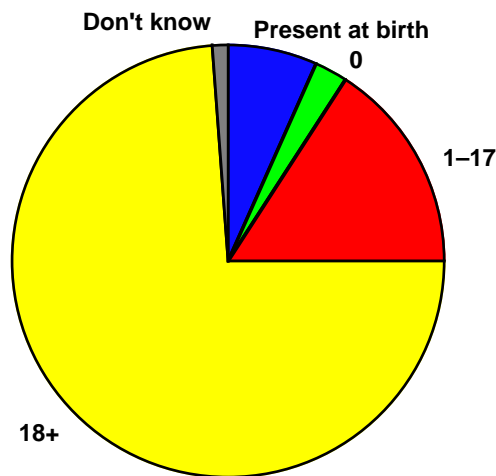
(b) Question on age when main disabling condition happened was only asked among people in households.

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**



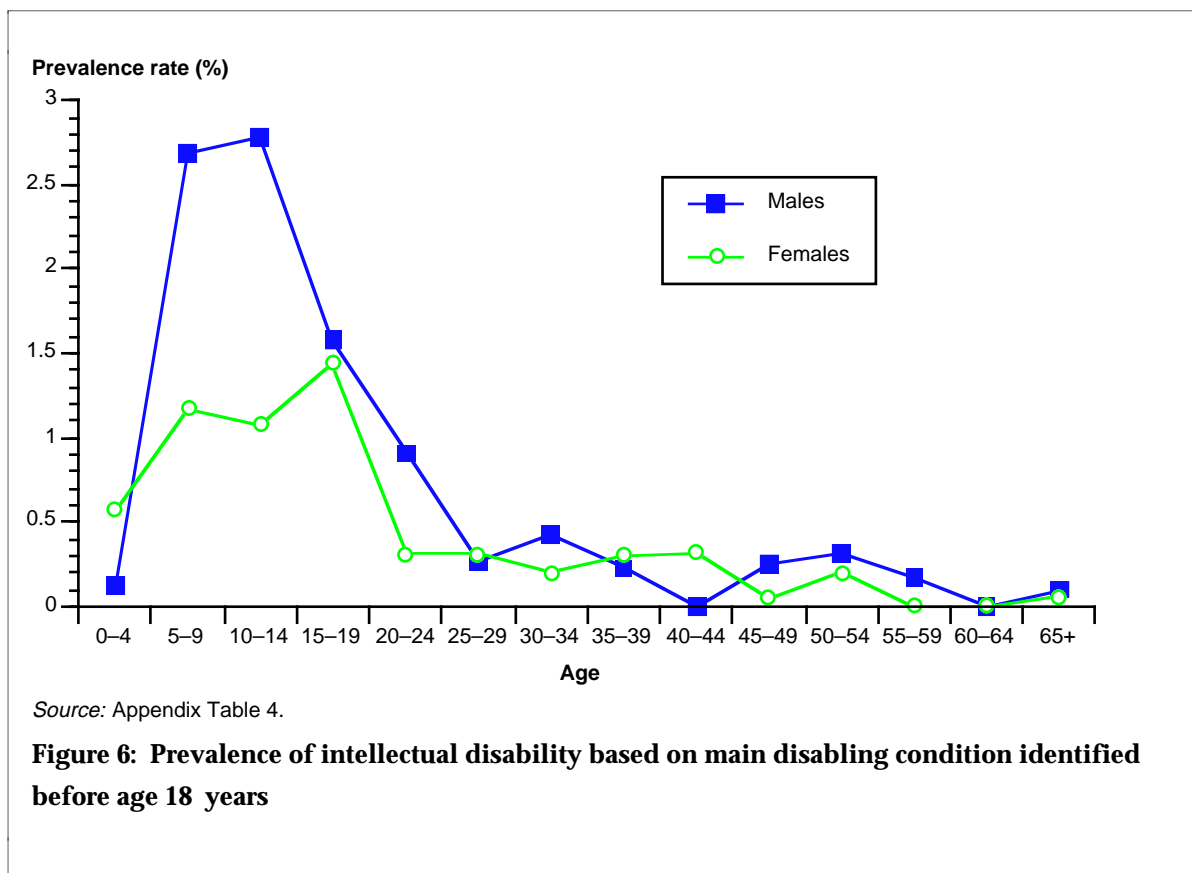
Source: Table 8.

**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<sup>(a)</sup> 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' <sup>(b)</sup>	% 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
<b>Total people with intellectual disability<sup>(c)</sup></b>	<b>102,700</b>	<b>86.6</b>	<b>13,000</b>	<b>11.0</b>	<b>2,927</b>	<b>2.5</b>	<b>118,600</b>	<b>100.0</b>

(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.

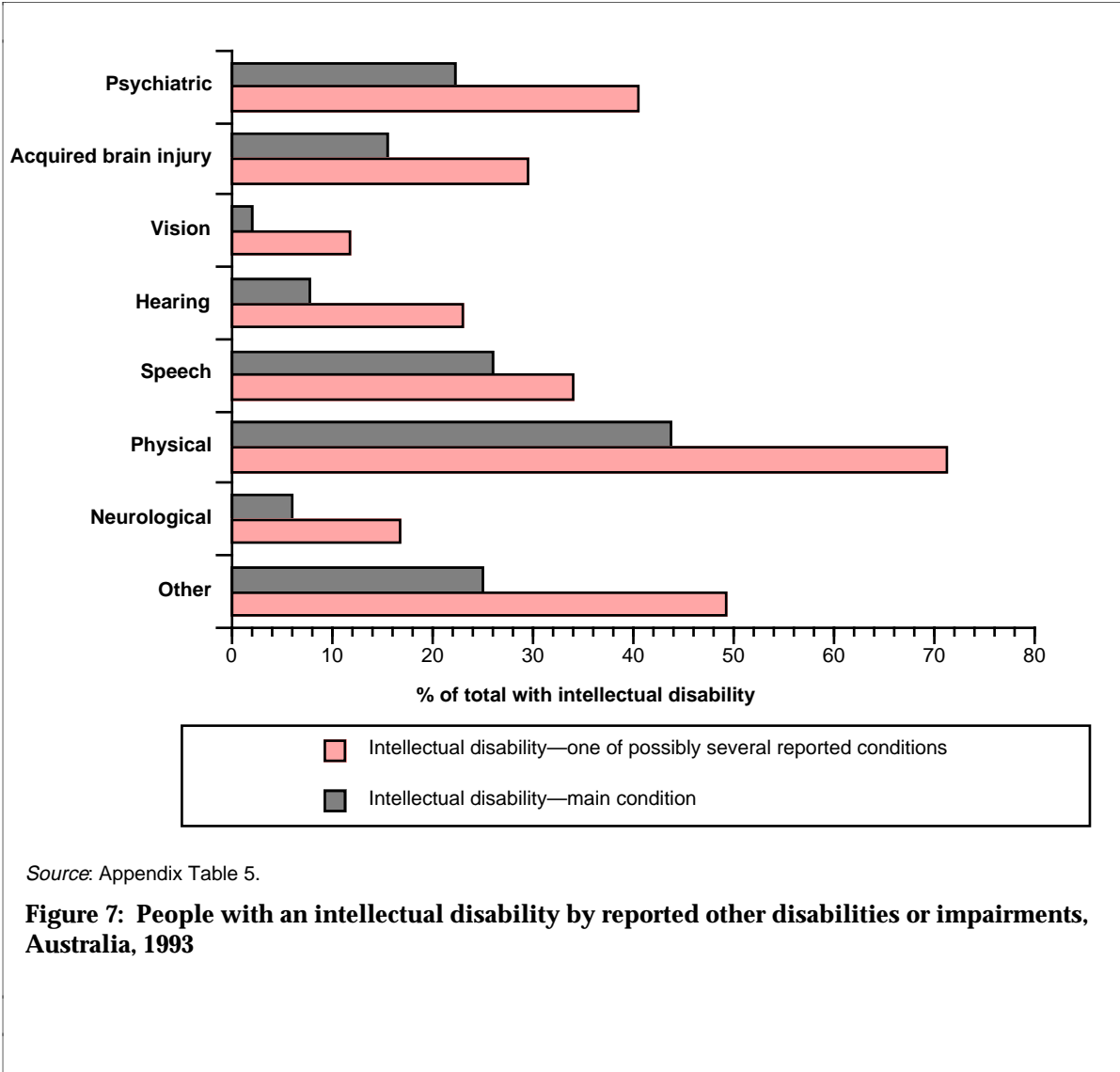
Source: AIHW analysis of ABS 1993 Survey of Disability, Ageing and Carers data.

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.