

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.