

The definition and prevalence of intellectual disability in Australia

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January 1997

Australian Institute of Health and Welfare
Canberra

AIHW Catalogue Number DIS 2

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ISBN 0 642 24720 X

Suggested citation

Wen X 1997. The definition and prevalence of intellectual disability in Australia. AIHW Catalogue no. DIS 2. Canberra: AIHW.

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Published by the Australian Institute of Health and Welfare

Printed by Panther Publishing and Printing

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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.

Acknowledgements

I am very grateful to Ros Madden, Head of the Disability Services Unit at the Australian Institute of Health and Welfare, for her invaluable guidance, stimulation, constructive comments and editorial suggestions throughout the preparation of this paper.

I would like to acknowledge with gratitude the helpful comments and suggestions from Dr Ching Choi, Head of the Welfare Division of the Institute, and my colleagues, Ken Black, Tracie Hogan, Kim Wisener, Phil Anderson and Judith Clark.

Expertise and comments from two external referees, Mr Mark Pattison, Executive Director, National Council of Intellectual Disability and Professor Trevor Parmenter, Macquarie University, are gratefully acknowledged.