

The definition and prevalence of physical disability in Australia

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The definition and prevalence of physical disability in Australia

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and
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1999

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Abbreviations

ABS	Australian Bureau of Statistics
ADA	Americans with Disabilities Act
ADL	activities of daily living; also Activities of Daily Living (scale)
AGPS	Australian Government Publishing Service
AIHW	Australian Institute of Health and Welfare
AMA	American Medical Association
CSDA	Commonwealth/State Disability Agreement
DISTAT	(United Nations) Disability Statistics Data Base
FAM	Functional Assessment Measure
FIM	Functional Independence Measure
IADL	Instrumental Activities of Daily Living (scale)
ICD	International Statistical Classification of Diseases and Related Health Problems
ICIDH	International Classification of Impairments, Disabilities and Handicaps
MDS	Minimum Data Set
SPR	standardised prevalence ratio
WHO	World Health Organization

Summary

'Physical disability' is commonly recognised as a disability group in the disability field, and in legislative and administrative contexts in Australia. People with physical disabilities represent a significant client group of disability services. However, the scope of this group is often not clearly defined. Consequently, existing estimates of physical disability prevalence vary. Consistent and useable estimates of disability prevalence are needed to facilitate service planning and to inform the community.

The main objectives of this report are:

- to conduct a critical review of existing definitions, data collections and estimates of prevalence relating to disability generally and physical disability in particular;
- to discuss some central issues in defining and measuring disability;
- to estimate the prevalence and demographic pattern of physical disability in Australia; and
- to promote discussion and the development of improved national data on the main disability groups.

Definitions and approaches to estimating disability prevalence

Definition and classification of disability

Defining disability entails providing a statement and/or a set of criteria that essentially describe what is meant by 'disability'. A classification system provides a structure within which information about different aspects of the disability experience can be organised. A classification approach can be used to delineate different disability groups (physical, intellectual, etc.) within disability generally.

The International Classification of Impairments, Disabilities and Handicaps (ICIDH) was published in 1980. It has been widely accepted as a model for conceptualising disability and has been used in a range of applications. The ICIDH is currently being revised to incorporate new developments and criticisms of the original ICIDH from a range of people active in the disability field.

The draft ICIDH-2 provides a basis for classifying the '**consequences** of health conditions', defined as 'any disturbance in terms of functional changes associated with health conditions at body, person and society level' (WHO 1997). This underlying concept distinguishes disability from diseases, disorders, injuries and health-related problems (commonly classified using the International Statistical Classification of Diseases and Related Health Problems (ICD)). It also distinguishes disability from social disadvantage unrelated to health conditions.

The conceptual framework of the draft ICIDH-2 consists of three dimensions plus contextual factors. Each dimension focuses on a particular aspect of the disability experience. 'Impairment' focuses on any loss or abnormality of body structure or function. 'Activity' (replacing the term 'disability' in the 1980 ICIDH) relates to the nature and extent

of functioning at the level of the person. 'Participation' (replacing the term 'handicap' in the 1980 ICIDH) reflects the nature and extent of a person's involvement in life situations at society level, and reflects the interplay between impairments, activities, health conditions and contextual factors (e.g. physical and social environmental factors) (WHO 1997). 'Activity limitation' and 'participation restriction' are the terms used to describe negative experience in the activity and participation dimensions, respectively. Within each dimension a classification structure is provided, which can be used to organise information on aspects of the disability experience.

The three dimensions are distinct but interrelated. On the one hand, negative experience related to any one dimension can be considered to constitute disability. On the other hand, disability can be viewed as a 'multidimensional' phenomenon (WHO 1997). Although the ICIDH does not describe the 'process' of disability (i.e. the causal links between health condition, impairment, activity limitation and participation restriction), it provides a means of exploring the connections between the different dimensions of disability.

Depending on the purpose of the data collection, operational definitions of disability may focus on different dimensions of the ICIDH. Different operational definitions can produce different data, and therefore result in different estimates of disability prevalence. The draft ICIDH-2 provides a useful framework for comparing, identifying gaps and moving towards consistency in Australia's statistical and administrative definitions and data collections (Madden & Hogan 1997).

Definition of terms used in this paper

Disability terminology is in a transitional phase, partly because the terms used in the draft ICIDH-2 are beginning to replace those used in the 1980 ICIDH. Summary Table 1 sets out definitions for terms that are used frequently throughout this paper. Definitions of the dimensions of the 1980 ICIDH and draft ICIDH-2 are also given. We will be using the terminology of the draft ICIDH-2 in this publication.

The word 'disability' can be particularly confusing, as it has tended to be used in two quite different ways. The 1980 ICIDH used 'disability' to denote the second dimension of the classification—'any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being'. This usage of the word is still encountered in the literature. However, 'disability' has long been used in a looser sense as an umbrella term, and that is how it will be used in this paper.

Table S1: Working definitions of terms relating to disability, as used in this paper

Term	Working definition
Disability	An umbrella term meaning negative experience in any one or more of the draft ICIDH–2 dimensions (i.e. an impairment, activity limitation or participation restriction).
Health condition	A disease, disorder or injury, regardless of its exterior manifestation.
Disabling condition	A disease, disorder or event that leads to impairment, activity limitation or participation restriction. In the context of the 1993 ABS Survey of Disability, Ageing and Carers, a disabling condition is a disease, disorder or event that had lasted or was likely to last for six months or more, or had produced a long-term effect, resulting in one or more of the limitations, restrictions or impairments used to identify disability (ABS 1996).
Functional (ability or limitation)	Relating to functioning at the body, the person or the society level (depending on the context in which it is used). In the context of functional assessment measures, ‘functional limitation’ generally means a limitation of functioning at the person level (i.e. equivalent to activity limitation). It is also commonly used at the body level to mean impairment of body parts and organ systems.
Draft ICIDH–2 dimensions	
Impairment	(In the context of health condition) A loss or abnormality of body structure or of a physiological or psychological function.
Activity	(In the context of health condition) The nature and extent of functioning at the level of the person. Activities may be limited in nature, duration and quality.
Participation	(In the context of health condition) The extent of a person’s involvement in life situations in relationship to impairments, activities, health conditions and contextual factors. Participation may be restricted in nature, duration and quality.
Context	Includes the features, aspects, attributes of, or objects, structures, human-made organisations, service provision, and agencies in, the physical, social and attitudinal environment in which people live and conduct their lives.
1980 ICIDH dimensions	
Impairment	(In the context of health experience) Any loss or abnormality of psychological, physiological or anatomical structure or function.
Disability	(In the context of health experience) Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.
Handicap	(In the context of health experience) A disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual.

Source: Adapted from literature cited in Chapters 1 and 2.

Operational definitions and estimation

Disability can be identified and assessed at the level of the body (impairment), person (activity) or society (participation). The level or levels at which information is collected should reflect the purpose of collection and the operational definition of disability being used. However, within any one dimension different information can be gathered. For instance, impairment is often identified using a non-comprehensive list of selected impairments. The identification of activity limitation may focus on certain types of activities (e.g. basic activities of daily living (ADL)), and the identification of participation restriction may be restricted to certain realms of participation (e.g. paid employment). The type of information collected should reflect the purpose for which it is being collected.

Approaches to assessment and prevalence estimation can also vary in terms of the minimum severity and duration criteria used to identify disability. Variations across data collections can occur due to differences in the wording of questions, and how the data are collected (e.g. interviewer-administered versus self-administered questionnaires).

In disability surveys or administrative data collections, screening devices play a crucial role in identifying disability. A screening device is generally a set of questions or measurement instruments designed on the basis of the operational definition being used. The screening questions are used to identify the existence of 'disability', and the dimension on which they are focused – usually impairment or activity limitation – can substantially affect estimates of disability prevalence. Therefore, in moving towards consistency in disability data, the design of consistent screening questions is a crucial element (Madden & Hogan 1997).

The ICIDH does not provide assessment or measurement tools. However, there exist several measurement tools that are widely used and can be related to the ICIDH framework. For instance, the American Medical Association's Guides to the Evaluation of Permanent Impairment (the Guides) provide a widely used method for assessing the presence and severity of impairment. The Activities of Daily Living (ADL) scale and Instrumental Activities of Daily Living (IADL) scale, are measures of functional ability that have been widely used in clinical settings and population surveys to define disability and to assess need for services. They correspond to the activity dimension of the draft ICIDH-2 framework.

In summary, the diversity of efforts to describe disability experience reflects variation in the definition of disability and approaches to assessment and prevalence estimation. As we work towards consistency, we should aim to develop reliable operational definitions to enable the collection of comparable disability data, and a consistent module of screening devices to be used in identifying disability.

Delineating 'physical disability'

In Australia, disabilities are often divided into 'disability groups'. A 'disability group' is generally a broad categorisation of disabilities on the basis of underlying impairment, disabling condition or cause. The concept also implies similar activity limitations and common needs related to the underlying cause.

To estimate the prevalence of physical disability it is necessary to develop a basis for identifying physical disability. While disability is a multidimensional phenomenon, the delineation of individual groups within disability generally may be based on more limited information, corresponding to one or two ICIDH-2 dimensions only.

If we attempt to delineate 'physical disability' primarily on the basis of activity limitation some problems are encountered. Simple activities (e.g. gripping an object) can be readily identified as physical or otherwise. However, complex activities (e.g. driving) are more difficult to label because we use many different parts of ourselves, many different abilities, in combination.

Indeed, it seems that we identify an activity as physical, intellectual or sensory based on what parts of ourselves we use to do the activity. Therefore, to identify 'physical disability' it may be more appropriate to take an approach based largely on factors operating at the body level (i.e. corresponding to the impairment dimension of the ICIDH-2). A physical disability may then be identified as a disability associated with a physical impairment. Physical activity limitations may also be used to identify physical disability, but should be

defined as limitations in performing simple activities that are clearly associated with physical (rather than intellectual, sensory, etc.) abilities.

If such an approach is taken some means of identifying a 'physical impairment' must first be developed. The difficulty of defining physical impairment has tended to be solved by compiling lists of physical impairments (e.g. United Nations Disability Statistics Data Base (DISTAT) and expert report recommendation; Table 1.2).

In this paper we develop a primarily impairment-based operational definition of physical disability (described in Section 4.1). However, while information corresponding to the impairment dimension of the ICDH-2 is used to delineate the physical disability group, information corresponding to the impairment, activity and participation dimensions is used to define disability. The list of physical impairments (and disabling conditions) that we use to identify physical disability as a basis for prevalence estimation is in line with significant international and Australian classifications (for the full list of codes used to identify physical impairments and disabling conditions see Appendix A).

Existing estimates of prevalence of physical disability

Prevalence of disability generally

Comparisons using the United Nations Disability Statistics Data Base (DISTAT) data show that estimates of disability prevalence range from 0.2% to 20.9% among the 55 countries studied. This large variation is mainly due to differences in operational definitions and approaches to measurement and estimation. Surveys using impairment-focused screening questions produced the lowest prevalence rates, ranging from about 0.3% to 5.0% of the general population. In contrast, surveys using activity-focused screening questions yielded the highest prevalence rates, ranging from about 7.1% to 20.9% (Chamie 1989, 1995; WHO 1990).

Using data from the 1993 Survey of Disability, Ageing and Carers, the Australian Bureau of Statistics (ABS) estimated that 18% of Australians had a 'disability' (ABS 1993b:1). Disability was defined by the ABS as the presence of one or more of a list of limitations, restrictions or impairments that had lasted, or were likely to last, for a period of 6 months or more.

Existing estimates of physical disability prevalence in Australia

Few overseas estimates of the prevalence of physical disability have been published. Estimates of the prevalence of physical disability in Australia vary, reflecting differences in operational definitions, measurement instruments, survey methodology and geographic location. Most existing estimates of physical disability are based on the 1993 ABS disability survey data. However, the operational definitions used to obtain estimates from the survey data vary (Summary Table 2). The estimates for South Australia are based on a State-wide telephone survey of disability prevalence.

Table S2: Existing estimates of the prevalence of physical disabling conditions and physical disability in Australia

Region	Prevalence	Definition	Data sources	Source
Australia	16.0%	Main disabling condition, physical—ABS broad grouping, including sensory conditions	1993 ABS Disability Survey	ABS 1993
Australia	10.3%	Impairment, physical—ABS grouping of survey screening questions	1993 ABS Disability Survey	ABS 1996
NSW	5.0%	'Single impairment group', physical	1993 ABS Disability Survey	Kennedy 1996
NSW	13.9%	Main disabling condition, physical—ABS broad grouping, including sensory conditions	1988 ABS Disability Survey	New South Wales Department of Family and Community Services 1990
Qld	16.0%	Main disabling condition, physical—ABS broad grouping, including sensory conditions	1993 ABS Disability Survey	Queensland Department of Families, Youth and Community Care 1997
WA	12.6%	Main disabling condition, physical (excluding sensory conditions)	1993 ABS Disability Survey	Alessandri et al. 1996
SA	11.9%	Musculoskeletal disability	South Australia Survey of Disability Prevalence, November 1996–February 1997	South Australian Health Commission 1998
	4.2%	Musculoskeletal disability (main condition)		
	0.7%	Neurological disability		
	0.4%	Limiting neurological disability		
ACT	16.8% ^(a)	Main disabling condition, physical—ABS broad grouping, including sensory conditions	1993 ABS Disability Survey (standardised rate)	Gilbert 1997

(a) The figure of 16.8 per 1,000 given on page 20 of Gilbert (1997) is a typographical error. The correct figure, as confirmed by the author, is 168 per 1,000.

AIHW estimates of the prevalence of physical disability in Australia

Estimates of disability prevalence published by the ABS are based on a fairly broad and inclusive definition of disability. In the 1993 disability survey, a person was identified as having a disability if they answered positively to one or more of the screening questions – a mixed list on limitations, restrictions or impairments. The ABS has published estimates of the proportion of people with a disability identified as having a physical impairment, via their response to the screening questions, and the proportion of people with a disability who reported a physical 'main disabling condition' (Table 2.2; ABS 1993b, 1996). However, the ABS has not specifically produced prevalence estimates for different disability groups based on the survey data.

In this paper we develop an approach for estimating the number of people with a physical disability (the 'AIHW method') based on data from the 1993 Survey of Disability, Ageing and Carers. The ABS broad definition of disability (based on response to screening questions) is used as a starting point. People with a physical disability are then identified using combined information from the screening questions, reported disabling conditions, and questions about limitations, restrictions and the need for assistance.

The AIHW method consists of two steps. Step one selects people who reported one or more physical impairments or disabling conditions, either through the screening device or through subsequent questions on disabling conditions (for the full list of physical impairments and disabling conditions see Appendix A). This group is then narrowed down in step two by applying a 'filter' – only people who have reported limitations or restrictions in one or more activities of daily or social life are retained in the group (for the full list of questions on limitations and restrictions see Appendix B). In effect, step one uses a primarily impairment-based approach to delineate the physical group, and step two is a means of standardising the definition of disability across disability groups, so that prevalence estimates are readily comparable. Physical disability is further divided into the subcategories circulatory, respiratory, arthritis, other musculoskeletal, neurological, and 'other physical'.

The measures of prevalence presented in this report include unstandardised estimates of prevalence rate, standardised prevalence ratio (SPR) and indirectly standardised rates. Indirectly standardised rates are calculated by multiplying the SPR for a particular sub-population by the national prevalence rate. The SPR is used to compare prevalence rates between populations with different age and/or sex structures. In this report SPR is used to compare prevalence in different jurisdictions, and between sub-populations defined by country of birth and Indigenous status.

Estimates at national level

In the 1993 ABS disability survey, people with a disability were asked to indicate their specific disabling conditions. The condition reported to cause the most problems was identified as the person's main disabling condition.

Main disabling condition

In 1993, there were 1,726,200 people, or 9.8% of the Australian population, with a disability (using the ABS broad definition) who reported a physical main disabling condition (Summary Table 3). Of these, 423,100 people, or 2.6% of the Australian population aged 5 years and over, also had a severe or profound handicap, meaning that they always or sometimes needed personal assistance or supervision with activities of daily living (self-care, mobility or verbal communication).

Arthritis (2.9% of Australians) was the most commonly reported physical main disabling condition, followed by other musculoskeletal disorders (2.0%).

All disabling conditions

About 2,350,300 people, or 13.3% of Australians, reported one or more physical impairments or disabling conditions in 1993 (Summary Table 3). Of these, 620,400 people, or 3.8% of Australians, also had a severe or profound handicap. The figure of 3.8% (620,400 people) is comparable with the AIHW estimate of intellectual disability prevalence – 178,000 or 1.0% of the Australian population – which included only those people with a severe or profound handicap (Wen 1997).

Using the AIHW method (i.e. selecting people who reported one or more physical impairments or disabling conditions and one or more activity limitations), the prevalence of physical disability in 1993 was 11.9%, or 2,099,600 people. Arthritis was the most frequently reported condition (5.1% of the total population).

Table S3: People with a disability: physical disability by method of calculation, Australia 1993^(a)

	Circulatory	Respiratory	Arthritis	Other musculo-skeletal	Neuro-logical	Other physical	Total physical
Main disabling condition plus severe or profound handicap^(a)							
('000)	56.9	47.6	118.1	83.6	41.8	75.1	423.1
%	0.3	0.3	0.7	0.5	0.3	0.5	2.6
Main disabling condition							
('000)	276.7	290.4	504.3	359.0	111.0	184.9	1,726.2
%	1.6	1.6	2.9	2.0	0.6	1.0	9.8
All disabling conditions plus severe or profound handicap^{(a) (b)}							
('000)	225.6	121.9	259.8	143.6	90.7	387.1	620.4
%	1.4	0.7	1.6	0.9	0.6	2.4	3.8
All disabling conditions							
('000)	826.7	524.1	974.2	516.5	205.2	925.4	2,350.3
%	4.7	3.0	5.5	2.9	1.2	5.3	13.3
AIHW method (all disabling conditions plus activity limitation)							
('000)	765.6	464.8	891.8	474.8	177.9	864.1	2,099.6
%	4.3	2.6	5.1	2.7	1.0	4.9	11.9

- (a) Severity of handicap was not determined for children aged 0–4 years with a disability—these estimates apply to people aged 5 and over.
(b) Prevalence estimates based on all disabling conditions plus severe or profound handicap are comparable with the AIHW estimate of the prevalence of intellectual disability (Wen 1997).

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

Demographic pattern of physical disability

Country of birth

People born overseas accounted for 25.4% of people with a physical disability, whereas they made up only 22.2% of the total Australian population.

Unstandardised estimates using the AIHW method show that the overall physical disability prevalence rate for people born in Australia (11.4%) was lower than for people born overseas – 14.5% for people born in other English-speaking countries and 13.0% for people born in non-English-speaking countries.

In contrast to the unstandardised estimates, the standardised prevalence ratios (SPRs) that take account of different age and sex structures within sub-populations show that people born in Australia were more likely to report physical disability than those born overseas. The SPR for the Australian-born population was 1.04, higher than for people born overseas – 0.90 for people born in non-English-speaking countries and 0.92 for people born in other English-speaking countries.

The contrast between the unstandardised estimates and the SPR can be mainly attributed to marked differences in age structure between the three population groups. The overseas-born populations are more concentrated in the later age groups, in which rates of physical disability are higher. Therefore, unstandardised estimates suggest that overall prevalence rates are higher for the overseas-born than for the Australian-born population, when age-specific rates are in fact lower in the overseas-born population. People aged 65 and over made up much higher proportions of the population for people born in other English-speaking countries (16.9%) and non-English-speaking countries (13.5%) than for people born in Australia (10.7%). The most striking contrasts in population age structure, however,

were in the 20–64 age group. In the two overseas-born populations, the proportion of people in this age group was about 75%, as compared with 55% in the Australian-born population.

Age and sex pattern of prevalence

Total Australians

The overall prevalence of physical disability was higher for females than for males. This pattern was more marked for people with a severe or profound handicap and people aged 65 and over. Females had higher rates of arthritis than males across all age groups.

Country of birth

Overall unstandardised prevalence rates of physical disability were higher for females than for males among people born in Australia. There were no significant sex differences in prevalence rates among people born in overseas countries, either for physical disability generally or within particular subgroups.

Australian-born females had higher prevalence rates than Australian-born males in three of the six sub-categories of physical disability (circulatory, arthritis and other physical). Males had higher rates of other musculoskeletal disorders.

Associated disabilities

Some people with a physical disability also reported other types of disability. Hearing impairment was the most commonly associated disability for people with physical disability of all ages. Psychiatric disorders and acquired brain injury were the second most commonly reported conditions, each accounting for 14% of people with physical disability.

Estimates at State and Territory level

All disabling conditions using AIHW method

The unstandardised prevalence rates estimated using the AIHW method show that South Australia had the highest rate (13.9%) of all the jurisdictions while the Northern Territory had the lowest rate (7.7%). The Australian Capital Territory (10%) and New South Wales (11.2%) also had rates below the national average (11.9%). Rates for the other States were close to the national average (Summary Table 4).

In contrast to the unstandardised rates, age-standardised rates in the Australian Capital Territory and the Northern Territory were close to the national average. Both Territory populations have younger age structures than the Australian population as a whole – notably, the proportion of people aged 65 and over is much lower than the national average. Thus the low unstandardised rates for the Australian Capital Territory and the Northern Territory can be attributed largely to their younger population structure.

In South Australia the proportion of people aged 65 and over is higher than for all Australians. But even when the effect of age structure was removed, the prevalence of physical disability in South Australia was still higher than the national average. Thus, the higher unstandardised rate in South Australia may reflect a combination of high age-specific prevalence and a high proportion of people aged 65 years and over.

Only New South Wales had prevalence rates lower than the national average using both standardised and unstandardised measures, despite the fact that the proportion of people aged 65 and over in New South Wales (12.2%) was slightly higher than the national average

(11.6%). This suggests that, overall, the effect of lower age-specific prevalence rates in New South Wales outweighed the effect of an older population age structure. The low prevalence rates were particularly evident among people under the age of 65 years.

Standardised prevalence rates for the population aged under 65 provided a slightly different picture for some States and Territories. Queensland had a significantly higher rate (8.5%) than the national average (7.6%). New South Wales had a very low rate of 6.6%, significantly below the national average.

Table S4: People with a disability: physical disability calculated using the AIHW method, by State or Territory, by age, unstandardised prevalence rate, standardised prevalence ratio (SPR), and standardised prevalence rate^(a), Australia 1993

	States and Territories								Australia
	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	
Under 65 years									
Unstandardised rate	6.7	7.9	8.4	8.2	8.5	7.4	7.4	6.3	7.6
SPR	0.87	1.03	1.12	1.10	1.08	0.97	1.05	0.98	1.00
Standardised rate	†6.6	7.8	†8.5	8.4	8.2	7.4	8.0	7.4	7.6
All ages									
Unstandardised rate	†11.2	12.4	12.2	11.6	†13.9	12.3	†10.0	†7.7	11.9
SPR	0.92	1.03	1.05	1.04	1.09	1.01	1.06	1.04	1.00
Standardised rate	†10.9	12.3	12.5	12.4	†13.0	12.0	12.6	12.4	11.9

† Rates are significantly different from the national rate.

(a) Standardised prevalence rate was calculated by multiplying the standardised prevalence ratio for a particular State or Territory by the national prevalence rate.

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