

3 Issues relating to operational definitions and approaches to estimating prevalence

Advocates for people with a disability, service providers, people responsible for policy and planning of disability programs, administrators of legislation on the rights of people with a disability, clinicians and statisticians are all interested in 'measuring' disability for different purposes (AIHW 1994). Operational definitions and approaches to measuring disability that are based on the ICD framework can vary substantially depending on the purpose for which they are developed. Operational definitions vary from broad, inclusive ones to narrow, specific ones (Chapter 1). As demonstrated in Chapter 2, variations in definition can affect estimates of prevalence.

Before calculating prevalence estimates it is necessary to examine some important conceptual and methodological factors. In this chapter these factors are divided into two groups. Section 3.1 discusses the issue of whether disability is defined in surveys on the basis of impairment or activity limitation. In practice, the operational definitions used in most disability surveys reflect a combination of impairment-focused and activity-focused approaches, with an emphasis on one or other component. Section 3.2 discusses other methodological factors affecting prevalence estimates. These include criteria for inclusion, such as minimum severity requirements, and data collection methods.

The final section of this chapter discusses the working definition of physical disability that is used in Chapter 4 as a basis for estimating prevalence.

3.1 Impairment-focused versus activity-focused approaches

Using an impairment-focused approach to identifying disability

As discussed previously (Table 2.1), using impairment-based screening questions in population surveys tends, in practice, to result in estimates of prevalence that are lower than those obtained using activity-based screening questions. This is probably because the number of impairments listed in survey screening questions is often limited. Also, in many cases, a person may have an activity limitation that is not obviously associated with an impairment.

If an impairment-focused approach is taken the particular impairments specified in the definition or screening questions may affect the prevalence rates estimated – a short list of specific impairments is likely to result in a lower estimate than a more comprehensive list. Another consideration is whether impairment is identified by medical examination or self-report. Impairment may be identified by a health professional, as the effect of a health condition on the structure or function of body parts and organ systems. More commonly in disability surveys, the presence of impairment is reported by survey respondents.

Respondents may report impairments that would not be confirmed by medical assessment, or may fail to report impairments that would be identified by medical assessment.

Assessment of impairment has been widely used as one of the main eligibility criteria for compensation, disability benefits and other entitlement programs in Australia. The eligibility criteria of the Department of Family and Community Services, the Department of Veterans' Affairs and Commonwealth Employees Rehabilitation and Compensation (COMCARE) reflect a strict medical basis for assessment of impairment.

Using an activity-focused approach to identify disability

As was discussed in Section 1.3, the functional assessment approach to measuring disability appeared almost two decades before the release of the first version of the ICIDH and has been developed over several decades. The approach focuses on the activity dimension of the draft ICIDH-2. A main feature of this approach is the measurement of a range of activity limitations without necessarily considering associated impairments or disabling conditions. In some cases the impairment causing an activity limitation may not be obvious. In population surveys people may report activity limitations without knowing what impairments or health conditions underlie them.

As can be seen from the international estimates of prevalence presented in Table 2.1, using broad disability (activity limitation) screening questions in surveys seems to result in higher prevalence estimates than those obtained using impairment-based questions.

As for impairment-based approaches, the scope of the list of activities used to identify disability can affect prevalence estimates. The same problem occurred in assessment of impairment. The number of people reporting activity limitations or impairments increases with the number of activities or impairments in a survey pick-list. Longer activity or impairment pick-lists tend to produce higher prevalence rates. Because of this it is often difficult to compare the results of different surveys and studies.

This problem can be demonstrated by the ABS disability surveys. The 1993 survey contained three new screening questions about activity limitations, restrictions and effects of long-term conditions, in addition to the 12 screening questions contained in the 1988 survey. The inclusion of these three questions resulted in an increase in the estimated disability prevalence rate of 256,000 people, or 1.5% of the population (AIHW analysis of ABS disability survey data).

Associations between impairment, activity limitation and participation

The associations between health conditions and the impairment, activity and participation dimensions of the draft ICIDH-2 are complex. A given health condition may result in a variety of impairments, and a single impairment may be caused by a combination of health conditions. An impairment or health condition may lead to a number of different activity limitations or participation restrictions, and an activity limitation or participation restriction could be associated with a number of different impairments or health conditions (Badley & Lee 1987a; WHO 1980).

The ICIDH is not a system for classifying people. Rather, its three dimensions are used to classify the 'attributes or experience' of disability and 'situations or circumstances' in which people with a disability find themselves (WHO 1997). An individual may have several impairments, activity limitations and participation restrictions, the associations between which may not be clear.

Some efforts have been made to investigate relationships between disorders, impairments and activity limitations. For example, Badley and her colleagues conducted a series of analyses looking at the relationship between underlying condition, impairment and activity limitations based on the British Survey of People with Physical Impairment and Disability in 1969 (Badley & Lee 1987a; Badley & Lee 1987b; Badley et al. 1987).

Badley and Lee (1987a) used the survey data on impairment (or 'functional limitation' – derived from tests of motor capacity) and activity limitation (or 'disability' – derived from questions about performance of self-care activities) to explore relationships between impairment and activity limitation. Using factor analysis to explore groupings of variables they concluded that impairments could be considered in four groups – three to do with upper extremity function (manipulative functions, movements of the arm, and the ability to lift objects) and one concerning lower extremity function. Results of the analysis suggested that these impairment groups were correlated with limitations in specific self-care activities (disabilities), with particular associations reflecting the parts of the body involved.

Further, Badley et al. (1987) investigated the relationship between underlying health condition and impairment profile (again using the four impairment groups). Three groups of conditions, expected to result in different impairment profiles, were used in the analysis: conditions affecting control (e.g. stroke, multiple sclerosis), mechanical performance (e.g. arthritis), and energy levels (e.g. cardio-respiratory conditions). There was a greater similarity of impairment profile between conditions within groups than between groups. This was interpreted as supporting the proposition that, for people with physical disability, there are three general patterns of impairment profile, reflecting these three groups of underlying conditions.

However, activity limitation profiles did not closely reflect the grouping of underlying conditions as impairment profile did. A suggested explanation for this was that it may be the effect of an impairment on overall body functioning, rather than its physical location or biochemical nature, that determines the activity limitation profile. Also, not only individual impairments, but also the combinations in which they occur, may affect the nature of activity limitation experienced (Badley & Lee 1987b).

The authors suggest that these relationships between underlying condition, impairment and activity limitation may have implications for developing simpler approaches to describing the consequences of disease. A large number of different conditions may give rise to a relatively few impairments, and these relatively few impairments may lead to limitation in a wide variety of activities. Thus, impairment mediates between the underlying disease and the resultant activity limitation.

3.2 Other factors affecting estimates of prevalence

Self-reported versus observed disability

Data on disability in the general population are usually derived from self-reported information collected through population surveys that use a set of screening questions about impairments and/or activity limitations to identify disability. There has been growing acceptance of self-reported measures of health as a valid way of obtaining health status data. Such measures have been found to be a good predictor of relative mortality risks among older Australians (McCallum et al. 1994).

However, estimates of disability based on self-report data may vary because respondents interpret survey questions differently. People of different age or sex, or with different cultural, language and educational backgrounds, can have different perceptions of disability. Self-reported disability measures do not provide comparable measures for populations that do not share common standards and assumptions about good health (Mathers 1997). Nevertheless, most of the variation in self-reported disability that is due to changing perceptions and standards affects reporting at the very mild end of the disability spectrum (Mathers 1991, 1996). People appear to have interpreted the survey questions relating to assistance with activities of daily living in a similar way over the three ABS disability surveys (AIHW 1997).

Prevalence estimates may also be affected by the actual questions asked, the wording of questions and the procedure by which information is collected (e.g. personal interview, phone interview, questionnaire).

In some cases the results of self-reporting may be affected by the purpose of the reporting. For instance, a person who is seeking to establish entitlement to benefits or services may tend to over-state his or her condition(s). However, as information provided in the context of population surveys does not have a direct outcome for the individual, respondents are less likely to over- or under-state their health conditions.

Registration data and service provision data collected by administrators often contain information on disability obtained by professional assessment. However, this information usually only covers people known to the administrators or service providers. Hence, these data provide information on those people using services, rather than the prevalence of disability in the general population.

Minimum severity requirement and other criteria

Variations in prevalence estimates may reflect factors such as whether the level of difficulty experienced or need for assistance was assessed, and whether there was a minimum requirement for 'severity' or duration of disability.

For instance, the broad definition of disability in the Commonwealth *Disability Discrimination Act 1992* contains no minimum requirement for severity or duration of disability. Rather, the Act covers people who presently have a disability, who had a disability that no longer exists, or to whom a disability is imputed.

In the ABS disability surveys, a minimum duration requirement of 6 months applies to the impairments, conditions, limitations and restrictions listed in the screening questions if they are to be considered to constitute 'disability'.

In contrast, the narrower definition used in the Commonwealth *Social Security Act 1991* requires, among other criteria, a minimum severity of 20% impairment which must be permanent or expected to last for more than two years. Prevalence estimates derived from data based on such an exclusive definition will represent a subset of the people with a disability who would be identified using broader, more inclusive definitions.

Using impairment or disabling conditions to describe underlying cause of disability

Either impairment or disabling condition can be used as the primary variable for explaining the underlying cause of disability. The distinction between the two approaches is subtle and complex. The United Nations DISTAT database shows that most international disability

surveys use disabling condition rather than impairment (Chamie 1995). In many cases a person may have an activity limitation that is not obviously associated with an impairment, but the disease or disorder underlying the activity limitation may be more easily identified. Thus, in population surveys, people may be unable to specify a particular impairment, but may describe a disabling condition, disorder or injury.

In the ABS disability surveys people with a disability, as defined by the survey, were asked to specify their disabling conditions. The conditions were recorded using codes adapted from the ICD-9 (see Section 2.2). As well as the ABS disability survey, major administrative disability data sources in Australia, such as the client data of CentreLink, Department of Employment, Education, Training and Youth Affairs and the Commonwealth Rehabilitation Service, have also used a classification of health conditions as a basis for so-called 'disability groupings'.

The current impairment dimension of the ICIDH does not accommodate the experience of disease, disorder and injury, though they are implied in the definition of impairment by the words 'in the context of health condition'. This feature causes some practical problems when classifying disability data. Information about disease or disorder associated with activity limitations or participation restrictions cannot be readily classified within the current ICIDH. This may explain why the ICD classification is more commonly used for classifying underlying conditions associated with disability.

The mixed use of the two classifications (ICIDH and ICD) in classifying impairment has resulted in some difficulties in disability data classifications and groupings. For example, the ABS grouping of disabling conditions (ABS 1996) uses two types of classification: impairment groups and disabling condition groups. The two types of classification overlap, both conceptually and in terms of data items. As mentioned in Chapter 2, the broad impairment grouping is based on information from the survey screening questions that are a mixed set of impairment, disorder, disabling condition and activity limitation.

3.3 An operational definition of physical disability

Earlier sections of this report have critically reviewed existing definitions and estimates of physical disability. This section discusses the desirable features of an operational definition. Table 3.1 provides working definitions for a number of terms that have appeared in the first three chapters of this paper. While the terms may be used differently by some authors, it is important to clarify the sense in which they will be used in the remainder of this report.

Table 3.1: 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 disability survey, 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.

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

The terms physical impairment, physical activity limitation, and physical disability are concepts that are not clearly defined in the literature.

As discussed previously (Section 1.3), there is substantial variation in the definition and scope of the terms 'physical impairment' and 'physical disability' as used in some international documents. In Australian legislation and administrative documents these terms are not generally defined. However, it is important to develop a clear operational definition of physical disability as a basis for prevalence estimations.

In Australia, disability groups tend to reflect a broad categorisation of disability on the basis of underlying impairment, disabling condition or cause. The concept of a disability group also implies similar activity limitations and common needs related to underlying impairments or disabling conditions. When defining disability groups for the purpose of prevalence estimation the issue is whether the grouping of information about disability experience should be based primarily on impairment, activity limitation or participation

restriction, or a combination. The classifications used in current data collections often start with, or focus on, impairments and disabling conditions. Hence, the classification of disability groups reflects a mainly impairment-focused approach.

This approach to defining disability groups is consistent with the provision of information that can be used to tailor service provision. This is because, to provide appropriate services it is relevant to know not just what activities people have difficulty with, but also why and how. If somebody has difficulty moving about outside the house because of a physical impairment (e.g. paraplegia) they are likely to need different support to someone who has difficulty moving around outside the house because of a sensory, intellectual or psychiatric impairment.

We classify our functions or activities as physical, intellectual or sensory based on what parts of ourselves we use to do the activity (e.g. if we use parts of our body the activity is physical, if we use our mind/cognitive abilities the activity is intellectual, etc.). There is no other obvious way to label an activity as 'physical' or otherwise. For this reason complex activities (e.g. driving) are difficult to label – because we use many different parts of ourselves, many different abilities, in combination. 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).

However, if such an approach is taken, some means of identifying a 'physical impairment' must be developed. Looking at classifications in common use (e.g. in existing data collections) there seem to be no unifying characteristics that can form the basis of an operational definition. The difficulty of defining 'physical impairment' has tended to be solved by simply compiling lists of impairments deemed to be 'physical' (e.g. United Nations DISTAT database and expert report recommendation).

If an activity-based approach, rather than an impairment-based approach, was to be used to define disability groups, a division based on types of activities (e.g. 'communication', 'mobility') might be more appropriate than the current body-centred groups ('physical', 'intellectual', etc.).

Participation, the third dimension of the draft ICIDH-2, is to do with functioning at society level. It seems unlikely that information on participation restrictions could be used to identify disability as 'physical' or otherwise. There is also the practical consideration that, in Australia, information collected on participation restrictions is generally less comprehensive than information collected on impairments and activity limitations. Therefore, the participation dimension probably does not currently provide a good basis for defining disability groups.

Further research is needed to investigate the associations between the three dimensions of disability experience. A better understanding of the associations might lead to the development of an approach to defining disability groups that combines elements of the three ICIDH-2 dimensions (Section 3.1).

It seems, at this stage, most feasible to define physical disability as 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.

The operational definition of physical disability developed in Section 4.1 and used for prevalence estimation is based largely on a list of physical impairments (and disabling conditions) that is in line with significant international and Australian classifications. However, although an impairment-based approach is used to delimit the physical disability group, a person is only counted as having a physical disability if they have reported an

activity limitation or participation restriction, as well as a physical impairment or disabling condition. In this way the estimation procedure incorporates information on all three draft ICDH-2 dimensions.