

1 Why are consistent definitions needed?

1.1 Introduction

'Disability' is a word used in daily conversation and holding different meanings for different people. Do these different meanings matter? What is there to be gained by trying to define disability more precisely and to attempt to use the word in consistent ways?

This paper attempts to explain why better national information on disability is important, and why it relies on consistent definitions to underpin the gathering of statistical data. The paper describes the current data situation in the disability field in Australia, and outlines national and international developments. A number of nationally significant service and survey definitions are related to key disability concepts. Suggestions are proposed as to how to progress towards the ultimate aim of greater consistency in data definitions, thereby enabling an improved picture of the need for and provision and use of disability services in Australia.

This is a discussion paper, designed to stimulate debate and thought, and to help inform the Institute about community views on terminology and data. The purpose of the paper is to work towards harmonising existing data definitions and to enable statistical collections to be related to each other; it is not designed to change administrative definitions or eligibility criteria. The paper will be revised and re-issued after discussion and comment. Information on how to comment on this paper is given in section 5.6.

1.2 Why define and measure disability?

The use of common terms and definitions provides individuals with a basis for a common understanding. In this way, communication is assisted, transparency in social programs is improved, and needs are better met through accurate identification and understanding of what people require.

It is important that the words we use are acceptable to the people who identify with those words. This principle is accepted in the search to refer appropriately to people from different racial backgrounds, women and older people as well as to people with a disability. Language may be in the forefront of the battles by individual groups to change social perceptions of the group and their situation.

If words are to be used in legislation and service definitions, it is important that their definitions clearly capture the essence of what is wanted or needed from that legislation or those services.

But there can be pitfalls associated with defining words or grouping people.

The drive towards administrative definitions can be perceived as degrading. People resist 'labels' or being slotted into an administrative 'box'. This process generally reduces a complex person and set of experiences to just one or two descriptors. This is a particular affront when the label summarises experiences of particular significance to the individual person—for instance the experience of disability.

Yet, the administrative task is to define programs and allocate resources in terms of people's needs. Fair programs generally must be open and clear about who is to receive benefit from them and why. This is why defining and categorising people's characteristics and experience becomes part of the task of identifying how much assistance is needed, who needs it and, in the longer run, whether the assistance given benefits the person. Thus, those of us who want or need some type of assistance from another person or from society may have to be prepared to express our situation in terms that the helper understands or which society has decided merits social assistance.

These two tendencies—the evolution of terminology to avoid labelling, and the apparent administrative need for stable definitions—can be apparently countervailing. Common terminology may leap ahead of administrative language and definitions, especially in a field in which community beliefs and philosophy appear to be developing faster than administrative change occurs.

1.3 Variation in administrative definitions

Even if it is accepted that definition and classification are useful, the debate is not over. Different purposes in defining or measuring may lead to different definitions and measures.

People with a disability, who may have lifelong experiences which require some type of social response, may require assistance from a number of programs and professional disciplines, each of which may develop different ways of perceiving disability. And within each of these programs, there can be a tension between the ways in which the person involved and the professionals perceive disability.

A multi-disciplinary workshop in 1994 revealed the wide diversity among purposes and approaches in defining and measuring disability (AIHW 1994b). Different viewpoints represented at the workshop were provided by:

- people representing people with a disability, whose purpose in measuring disability is often to indicate the level of need for services and to better match the individual's self-identified goals and abilities with the service offered;
- providers of support services, whose purposes in measuring disability include providing supports appropriate to the needs and abilities of services users, prioritising the use of resources, and comparing the resources and successes of their service with those of other services;
- funders and planners of broad disability programs, whose primary purposes in measuring disability are to assess the relative need for resources among groups of people with differing disability types and service needs, and to identify unmet needs;
- administrators of legislation outlining the rights of people with a disability, who may prefer to use broad definitions of disability to protect people who may be disadvantaged by exclusion;
- people responsible for income security policy, including the social security and compensation fields, who may prefer definitions and measures which clearly define the criteria for, and limit the number of people included in, their programs;
- clinicians, whose need may be to gauge the nature and severity of disability more precisely in order to devise the most appropriate intervention, or to compare the efficacy of various treatments;

- national and international statisticians, whose purpose in measuring disability is to be able to compare data across service types and across national and international boundaries; the measure of disability may then be an outcome measure of an intervention (often a health or community service intervention), an indicator of need for support or treatment, or a benchmark which enables the collation or comparison of data from several different sources.

The workshop reached no resolution, but there was a lively interest in achieving greater national consistency in Australia.

1.4 The context—disability services in Australia

The range of formal services and assistance to people with a disability are provided through disability-specific programs and also through generic programs. They may be broadly categorised as:

- disability-specific income support;
- disability support services; and
- generic services, some of which may contain components targeted towards people with a disability.

Table 1.1 outlines the scope of formal services in these broad categories, and how these services may be delivered or funded by non-government organisations and by Commonwealth and State Governments.

Table 1.1: Formal services in Australia relevant to people with a disability—broad service categories and sector roles (in funding and/or provision)

	Commonwealth role	State role	Local government role	Non-government role
Income support	Income security programs of DSS, DVA and DHFS	Injury compensation schemes and related services	Rate concessions	Emergency relief (non-specific)
	Concessions, fringe benefits	Concessions, fringe benefits		Disability insurance Superannuation
Disability support	Employment and other services under CSDA, including funding to States	Accommodation and other support services under CSDA and State schemes	HACC services	CSDA services and HACC services
	HACC services	HACC services		Other support services, including information and advocacy
	Nursing homes and hostels—funding	Nursing homes and hostels—funding and provision		Nursing homes and hostels—funding and provision
	Commonwealth Rehabilitation Service Australian Hearing Service	Various equipment schemes		
Relevant generic	Employment programs, including disability-specific programs	Education, both special and integrated	Physical access, parking	Emergency relief (non-specific)
	Public housing and crisis accommodation, including disability-specific	Public housing, including disability-specific housing		
	Child care services, including disability-specific	Child care services, including disability-specific	Provision and coordination of child care services	Provision of child care services
	Funding of health services	Funding and provision of health services		
	Other, e.g. sport, library and information	Other, e.g. sport, library and information Transport, including disability-specific	Other, e.g. sport, library	

Note: No distinction is made between for-profit and not-for-profit sectors.
Source: Adapted from AIHW (1995a: 259).

This table illustrates the types of services in Australia for which more consistent data might be collected.

1.5 The drive towards consistency and reliability in Australia

A number of reports of national significance have suggested the need for greater consistency of concepts and definitions in the disability field. The Commonwealth/State Disability Agreement (CSDA) of 1991 was set out in the context of the need to exchange data among the Commonwealth and the States. A report of the Senate Standing Committee on Community Affairs (1992)—*Employment of People with*

Disabilities—recommended the use of the same terminology, definitions and measures of disability by relevant departments and by the Australian Bureau of Statistics. The first biennial report of the AIHW on the welfare area, *Australia's Welfare 1993*, discussed the need for greater consensus on concepts, as a precursor to being able to relate disability definitions and to relate and improve administrative data collections (AIHW 1993). The 1994 interim report by Professor Peter Baume, reviewing the Commonwealth's Disability Services Program, recommended work to standardise definitions across Commonwealth government departments (Baume & Kay 1995). The Commonwealth Disability Strategy recommended that the Disability Task Force, in consultation with the AIHW and the ABS, should develop a framework for ensuring that consistent core disability definitions and data collection methods are used in all Commonwealth government collections (Office of Disability 1994). The independent evaluation of the CSDA also made recommendations concerning the definition of disability (Yeatman 1996).

The goals enunciated by some of these reports mention 'consistent core definitions', 'comparability', 'relating and reconciling standard definitions'. It is not generally suggested that the goal should be a single, standard definition, but rather that the definitions and data items used in different service collections should be able to be related to each other. Organisations providing services collect only those data needed for the administration of the service. In the case of mainstream services, such as those provided by the Commonwealth Department of Employment, Education, Training and Youth Affairs, self-identification of disability is voluntary.

Thus sources of variation will remain, for instance, as to the scope of services and the level of support needed by client groups. What should become clearer, if the goals of this paper are met, are the ways in which the data relate. It may be possible to describe the clients of Department of Employment, Education, Training and Youth Affairs (DEETYA) employment services and social security recipients, for instance, in terms which enable the differences between the groups to be defined and quantitatively described.

Most recently the report on the evaluation of the CSDA (Yeatman 1996) documents similar concerns about disability definitions. The demand study carried out by the AIHW to support the evaluation suggested several steps to move towards a solution (Madden et al. 1996), outlining four areas for improvement:

- increased effort to move towards more consistent definitions of key terms and data items, including disability itself, so that the main relevant data collections become more relatable. Such work should include working on data at the 'borders' of disability to make health, epidemiology and disability more consistent and mutually relevant. This area of improvement underpins the other three;
- enhancements to the next ABS survey on disability in the Australian population;
- enhancements to State and Commonwealth administrative information systems for disability support services, accounting for emerging administrative changes; and
- enhancements to administrative data systems for relevant mainstream services, perhaps by the development of 'modules' or small packages of data items which would clarify the relationships among disability service collections.

The need for better data and for better infrastructure, including common or at least relatable definitions, is thus widely recognised in the disability field in Australia. Such

improvement is essential to enable the better estimation of levels of people's need for, use of and outcomes from disability services in Australia.

1.6 Outline of the paper

The following chapter of this paper describes national developments relevant to the collection of consistent disability data, reinforcing the timeliness of the attempt to promote greater national consistency in data collections.

Chapter 3 outlines the features of the main international classification system for the disability field, and the current revision process.

An exploration and comparison of definitions of disability now used in the main data collections in Australia are provided in chapter 4. For instance, definitions used in populations surveys, income support and disability support service definitions and data systems were examined. These definitions are mapped broadly to the draft international classification as a common reference point.

Finally, chapter 5 draws the discussion together, outlining issues which emerge from the paper and on which the Institute would like to receive comment.