

The definition of disability in Australia

Moving towards national consistency

**Ros Madden
and
Tracie Hogan**

1997

**Australian Institute of Health and Welfare
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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.

2 National developments

2.1 An important time ...

Several current national developments affect the move towards national consistency of disability data. Major initiatives of relevance are the renegotiation of Commonwealth–State responsibilities in the community services field, the report on the evaluation of the CSDA (Yeatman 1996), and the initiation by the Council of Australian Governments (COAG), of work on performance indicators for government service provision, including disability services. Data initiatives such as the development of the National Community Services Information Agreement and National Community Services Data Dictionary will ultimately have significant effects on data collection in the disability field.

Internationally, the current development and testing of the new draft International Classification of Impairments, Disabilities and Handicaps (ICIDH) could contribute to the achievement of national as well as international consistency.

This chapter describes current developments of national significance which relate to the aim of disability data harmonisation. Relevant national policy developments are outlined, as well as national and international statistical developments in the field. Two new pieces of statistical infrastructure to promote harmonisation are described—the new National Community Services Information Agreement and, in the specific area of disability, the Disability Data Reference and Advisory Group established by the Institute.

The challenge over the following months is to keep abreast of these activities, and to attempt to interweave data developments as constructively and efficiently as possible. Otherwise, uneven progress may be made, and consistency gains will be offset by unconnected developments.

2.2 National policy and administrative developments

Disability policy and the profile of disability services have undergone continual change in Australia over the past two decades (see AIHW 1993 and 1995). These changes create new demands for relevant statistics. National policy in disability and related services in Australia in recent years has been typified by:

- action to make important generic or ‘mainstream’ services accessible by all the community, including people with a disability;
- initiatives to remove discrimination, most recently by the introduction of the *Disability Discrimination Act 1992*;
- the redefinition and greater provision of disability support services designed to enable people with disabilities to achieve increased independence, employment opportunities and integration in the community.

There has been emphasis on the rights of people with a disability to receive the services necessary for them to achieve their maximum potential. Significant change also occurred in 1996 and 1997. Some relevant developments are outlined below.

Reduced government role in service delivery: purchaser/provider split

Most Australian governments are seeking to reduce their role in direct service provision, and to become funders and/or purchasers of services, with an involvement in standard setting, quality assurance, planning and policy development. This direction is as strong in the field of disability services as in other community services. The creation of Centrelink, the new Commonwealth services delivery agency, for example, represented a major change in the way government services are to be delivered and a major step towards the purchaser/provider split in the delivery of welfare services.

Commonwealth–State arrangements for disability support services

The CSDA was signed by Australian heads of government in July 1991. The Agreement outlines how responsibilities are shared between the Commonwealth and State Governments, and sets out the types of disability support services to be provided or funded by governments.

Broadly, the Commonwealth takes responsibility for employment services, and the States and Territories assume responsibility for accommodation and other support services. Both levels of government retain some responsibility for advocacy and research. Governments share responsibility for planning and funding advocacy services, and agree to share information about them.

The CSDA is being renegotiated in 1997, taking into account an independent review (Yeatman 1996). Scheduled to expire on 30 June 1997, the agreement is being extended on a month-by-month basis until February 1998.

National performance indicators: COAG working group

In February 1994 COAG agreed that ‘in clarifying the roles and responsibilities of Governments in the delivery of services, the overriding objective should be to improve outcomes for clients and value for money for taxpayers’ (quoted in Steering Committee for the Review of Commonwealth/State services provision 1995:2). A process of ‘performance monitoring’ was begun, and now operates under the auspices of COAG.

In 1996 a working group was established to begin work on performance indicators for disability services. The working group comprises representatives of all Australian jurisdictions, the Industry Commission (which coordinates the work) and the AIHW.

This work also, in documenting the goals of the national service framework and attempting to indicate progress towards achieving these goals, will interact with national data definitions and collections, by using data from them, and by playing a part in refining key concepts used to define services.

National Disability Advisory Council

In 1996, the then Minister for Family Services, Judi Moylan announced the establishment of the National Disability Advisory Council (NDAC):

The [NDA] Council’s work program will include consideration of future Commonwealth/State disability arrangements, how to best ensure people with a disability are involved in mainstream issues such as Federal policy development,

programs and services, and liaising with State advisory bodies and national disability organisations. (media release, 16 August 1996)

This council replaces the Australian Disability Consultative Council.

Disability Discrimination Act (DDA) Standards Development

The development of standards under the Commonwealth *Disability Discrimination Act 1992* has been progressing in five key areas: building codes, employment, public transport, information, and communication.

The recently established NDAC has made a commitment to this work, with members involved on the following working groups: DDA Standards, Public Transport and the Building Access Technical Committee.

2.3 Revision of the International Classification of Impairments, Disabilities and Handicaps (ICIDH)

Perhaps the most widely accepted international definitions are those provided by the World Health Organization's (WHO) International Classification of Impairments, Disabilities and Handicaps. These international definitions provide a useful starting point for a framework in which to locate the Australian definitions now in use, because the three concepts of the 1980 ICIDH—impairment, disability and handicap—have been quite widely recognised in Australia (for example, AIHW 1994b).

There is considerable critical literature on the ICIDH, and the World Health Organization and its collaborating centres (including the Institute) are working to refine the existing draft classifications. This work is designed to provide a more coherent and widely applicable set of classifications in the next version of the ICIDH, due to be published in 1999.

The new revised ICIDH has the potential to become the single most used classification system for disability in the world. The opportunity it presents for harmonisation of data and classification is significant—not only within Australia but on the international front as well. If the ICIDH is to become a useful and accepted tool in the Australian context, then it is necessary to ensure, as far as possible, that Australian views shape this revision.

A revised draft of the ICIDH (the 'Beta' draft ICIDH-2) is now available (internet site <http://www.who.ch/icidh>) for public discussion and field testing. Given its potential influence on disability classification in Australia, chapter 3 of this paper describes the development of the ICIDH in some detail.

2.4 ABS Survey of Disability, Ageing and Carers

The ABS Survey of Disability, Ageing and Carers is conducted every five years and is an important source of national population data on disability, covering both rural and urban areas in all States and Territories. The 1993 survey gathered information from a sample of 15,957 households and 378 'special dwellings' (representing some 42,215 people) as well as from 593 establishments (representing 4,816 people). Information obtained by personal interview included 'disabling condition', disability and presence, area and severity of 'handicap'. There were also questions on assistance needed and received for specific activities, and informal and formal main providers of assistance.

The concepts underpinning the ABS disability survey are those of the 1980 ICIDH, and this relationship has been pivotal to data analysis, for such reports as the AIHW's demand study (Madden et al. 1996).

The 1998 disability survey was first piloted in November 1996. A full 'dress rehearsal' of the survey is scheduled for November 1997, with the actual survey taking place in March and May 1998. Suggestions for the 1998 survey have focused on the need to examine the individual's situation in the context of their usual environment, including support from unpaid carers. This is in line with the emerging information needs of the policy makers, service providers and care givers for people with a disability—changes also reflected in the ICIDH revision process.

2.5 Australian Disability Data Reference and Advisory Group

The developments outlined above demonstrate the importance and complexity of the need for greater national consistency in disability definitions, acknowledged in chapter 1.

The Institute's national role in developing data on disability services is set out in its legislation, and recognised in recent reports and current developments. The Director of the Institute therefore decided to establish a broad-based advisory group in March 1996, to provide a mechanism for concentrating the efforts of the Institute and the bodies with which it cooperates.

The Disability Data Reference and Advisory Group (see appendix 1 for a list of members) was established in March 1996. Broadly, the purposes of the Group are to:

1. promote the improvement and harmonisation of disability data collections in Australia at the national level;
2. further the work on consistency of definitions recommended by the Commonwealth Disability Strategy and the Baume report; and
3. promote the effectiveness of Australia's participation in the revision of the ICIDH, and to ensure, as far as possible, that Australian views shape the revision, and that the revised ICIDH becomes a useful and accepted tool in the Australian context.

The Group has agreed to focus on two separate, yet related, strands of work: international and national.

Strand 1: International

The international strand aims to achieve the third objective above. Figure 2.1 shows the agreed strategies and key outputs for this strand of work. A more detailed account of this work is presented in chapter 3.

Figure 2.1: International strand—strategies and key activities

Strategies	Outputs
1.1 Promote and provide a forum for the exchange of information and comment among people with an interest and/or responsibility for definitions of disability and in particular the ICIDH.	1.1 Interested and relevant individuals and organisations given the opportunity to provide input to the ICIDH revision process.
1.2 Develop an understanding of Australian views.	1.2 Disability services model/framework, informed by understanding and comment on the ICIDH.
1.3 Develop a framework to describe the delivery of services to people with a disability in Australia.	1.3 Discussion paper prepared by AIHW, with the advice of the DDRAG.
1.4 Develop an understanding of the relationship between Australian views and the ICIDH.	1.4 Comment and input to the ICIDH revision process.
1.5 Provide timely and quality input to the ICIDH revision process.	
1.6 Promote the use of the ICIDH in the Australian context.	

Strand 2: National

The national strand aims to promote the improvement and harmonisation of disability data collections in Australia at both the State and Commonwealth level. Figure 2.2 shows the objectives and key outputs for this strand.

At present the work in this strand focuses on two key tasks: the development of a disability services information model (see section 2.6 and 5.5), and the preparation and discussion of this paper. These steps will hopefully provide some clarity with respect to the concepts relating to disability, and a framework for the further work of the Group.

Figure 2.2: National strand—strategies and key activities

Strategies	Outputs
2.1 Promote a forum for discussion and cooperation among people working on disability data collections of national significance.	2.1 Disability services model/framework.
2.2 Cooperative work among members of the Group, developing and agreeing on standard or relatable definitions, classifications and codes for use in disability data collection.	2.2 Operation of the DDRAG as a major gateway for provision of input to the national disability data debate.
2.3 Facilitate consultation among people with a disability, service providers, clinicians, program administrators and people involved in research and data collection.	2.3 Discussion paper prepared by AIHW, with the advice of the Group.
2.4 Provide comment and advice as requested to people working in fields related to the purposes of the Group.	2.4 Wide ranging comment sought on the above paper.
	2.5 DDRAG input to ABS survey.
	2.6 DDRAG opportunity to comment on other major data collections and guidelines for example, NIMS and the CSDA MDS.
	2.7 Modules of key data items for disability service and population collections.
	2.8 Consideration of the development of a data dictionary for use in disability service and population collections.

A desired long-term output of this strand would be input to the National Community Services Data Dictionary, for use in population and administrative data collections of relevance to people with a disability. The data dictionary, ideally, will promote the harmonisation of data collected, simplify the task of data providers, and enable policy analysts and researchers to relate data from different sources. It should also accommodate the necessary and inevitable differences in the target populations of the wide variety of services—both specialist and mainstream—which are of relevance to people with a disability.

2.6 National community services information agreement, development plan and model

The need for effort to enhance and harmonise national data has been recognised throughout the community services field, not just within the area of disability services.

The Standing Committee of Community Services and Income Security Administrators (SCCSISA) agreed in February 1996 that the AIHW would take carriage of the formulation of a National Community Services Information Agreement and Development Plan, and in early 1997 the National Community Services Information Agreement was signed by SCCSISA. This Agreement is between community service government authorities and statistical agencies. Essentially the agreement sets out to:

- provide a framework to facilitate, coordinate and manage national information developments;
- provide structure and standards for defining uniform data definitions and classifications; and
- improve access to information.

A National Community Services Information Management Group has been established to oversee the development of an Information Development Plan and a Work Program. This group also oversees a data committee responsible for developing processes and guidelines for data standards, disseminating data and data definitions, and preparing a national community services data dictionary. The management group will make recommendations to SCCSISA on national community services information priorities, work programs, funding implications and other information policy issues. The inaugural meeting of the National Community Services Data Committee (which works to the management group) was held in February 1997. At this meeting they agreed to establish a working group to oversee the development of a National Community Services Information Model and to commence work on the development of a National Community Services Data Dictionary (on both of which the AIHW is now working).

Work initiated by the Disability Data Reference and Advisory Group, in the development of a Disability Data Information Model, has been expanded and refined to form Version 0.5 of the National Community Services Information Model (see appendix 2).¹ Development of the first draft National Community Services Data

¹ The Australian Health Information Model was developed in 1996 under the sanction of the Australian Health Ministers' Advisory Council. The model now has broad acceptance within the health sector and provides the framework for restructure of the National Health Data Dictionary. It is also proving capable of providing a consistent conceptual underpinning for data systems developed across the health sector.

Dictionary has also begun, via a process of collecting, comparing, assessing and collating existing definitions.

In undertaking this task the Data Committee has agreed to identify and establish working relationships with key groups currently working on data development in the community services sector, such as the DDRAG.

Another relevant development is the National Community Services Classification, to be published by the AIHW in September 1997, which classifies community services according to their activities, target groups and settings. This classification should contribute to the framework for the other national data developments described; it has already been used by the ABS in the first national Community Services Industry Survey.

2.7 Conclusion

All these developments, nationally and internationally, mean that 1997 is a useful and important time for the Australian disability field to work together towards greater clarity and consistency in the way we collect and exchange information about disability and disability services.

3 International Classification of Impairments, Disabilities and Handicaps (ICIDH)

3.1 Introduction

The 1980 ICIDH was published by the WHO as a manual of classification relating to the consequences of disease. It is undergoing a process of review—an international effort coordinated by the WHO. A publicly available draft Beta ICIDH-2 has recently been released (internet site <http://www.who.ch/icidh>), with the final revised version scheduled for release in 1999.

This chapter briefly describes the 1980 ICIDH, and indicates some criticisms. It then describes the process of revision of the 1980 ICIDH, including in Australia, and outlines the newly released draft 'Beta-1' ICIDH-2. The chapter focuses on the new third dimension of the ICIDH-2, Participation (formerly Handicap), and the various approaches suggested for its measurement.

3.2 1980 ICIDH and directions for change

The 1980 ICIDH provides a conceptual framework for disability which is described in three dimensions—Impairment, Disability and Handicap:

Impairment: In the context of health experience an impairment is any loss or abnormality of psychological, physiological or anatomical structure or function.

Disability: In the context of health experience a disability is 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 handicap is 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. (WHO 1980)

Impairment is considered to occur at the level of organ or system function. Assessment of impairment requires judgement of mental and physical functioning of the body and its component parts according to accepted standards. The classification of impairment is hierarchical, allowing considerable specificity for those needing to record such detail.

Disability is concerned with functional performance or activity, and limitations therein, affecting the whole person. The disability codes attempt to encompass those activities considered important in daily life. Like impairment, the classification of disability is hierarchical but allows for an additional parameter to record the severity of disability.

Handicap focuses on the person as a social being and reflects the interaction with and adaptation to the person's surroundings. The handicap codes attempt to classify those consequences which place that individual at a disadvantage in relation to their peers. The classification system for handicap is not hierarchical, but comprises a group of 'survival roles', with each survival role having an associated scaling factor to indicate impact on the individual's life.

The ability of the ICIDH not only to classify an individual's circumstance but to provide a theoretical framework to interrelate impairment, disability and handicap has made it a powerful tool for a range of applications including:

clinical diagnosis and rehabilitation assessment, record keeping in health and rehabilitation settings, the development of medical and rehabilitation monitoring systems, program evaluation and development, the promotion of linguistic agreement, debate and conceptual development in the interdisciplinary field of disablement studies, development of research programs, the formulation of disability policy and the planning measures for equalisation of opportunity, data collection in survey research and database development. (Badley 1993)

There is, nevertheless, a considerable critical literature relating to the ICIDH (for instance, WCC and Dutch Classification and Terminology Committee for Health 1994) and an associated recognition of the need to revise the classifications. A fairly wide recognition in Australia of the concepts of impairment, disability and handicap, and an interest in the ICIDH revision were indicated at a 1994 AIHW workshop on the measurement of disability, when people from a wide range of disciplines discussed the need for more reliable terms, definitions and measuring instruments (AIHW 1994b).

The workshop also discussed the possible further development of the ICIDH and participants made a number of observations which are characteristic of the criticisms made of the current ICIDH:

- There are overlaps in the way impairment, disability and handicap are operationalised in the classification. These boundary problems and other structural problems (a suggested lack of cohesiveness or coherence) mean that the 1980 ICIDH is not yet considered by some to be a true classification system.
- Handicap in particular needs further development, in terms of its definition, classification and rating. It is a social construct by definition, so there is difficulty in establishing an international standard enabling comparison among different societies and cultures. The concept of 'handicap' has encountered great difficulty in translation to various languages.
- The environmental influence on handicap needs specific recognition, for instance in the identification of barriers, of appropriate interventions and of the outcomes of interventions.
- There is a need for a fourth dimension in (or perhaps adjunct to) the ICIDH, relating to the environment and to the barriers (including discrimination) contributing to the individual's experience of disability and handicap.
- Despite the understanding of the social context which defines handicap—and the recognition that environment not only affects handicap but can also affect disability—the ICIDH concepts are defined specifically 'in the context of health experience'. A number of participants pointed out the importance not only of recognising that the ICIDH is set out 'in the context of health experience' but also of retaining the notion of impairment as underlying or accompanying disability and handicap. Otherwise, according to one workshop participant, disability is

purely socially constructed and ‘becomes a matter of choice’; then there is no accompanying basis for constructing the desired indicators of severity and need.

- If the ICIDH is to be an international standard it needs to provide replicable measurements. If it is too specific to context and culture it becomes too difficult to make comparisons across contexts.

It was generally thought by workshop participants that the ICIDH needs greater promotion in Australia, in order to foster the search for a national and international standard.

3.3 Revision of the 1980 ICIDH

In 1993, the WHO agreed to begin a revision process of the 1980 ICIDH, across all three dimensions—Impairment, Disability and Handicap. The aim of this work is to provide a more coherent and widely applicable set of classifications, which will be conceptually valid and useful.

Revision process

The revision process is coordinated by the WHO. In the early stages, various collaborating centres throughout the world concentrated on a specific content or classification area. The French and Dutch Centres worked on Impairment, the Dutch Centre worked on Disability, and the North American Centre (US and Canada) worked on Handicap and the newly proposed annexe of Environmental/Contextual Factors. In addition, specialist task forces worked on the applicability of the classification in the areas of: mental health, children, social policy and the aged.

In 1994 the AIHW was asked to extend its terms of reference as a WHO Collaborating Centre for the International Classification of Diseases (ICD), to participate in the revision of the ICIDH. The AIHW considered that it could best contribute to the third dimension of the classification (Handicap), and agreed to focus on this dimension, the development of which was being led by the North American Collaborating Centre.

An ‘Alpha’ draft of the revised ICIDH was collated in May 1996, incorporating the work of all collaborating centres. At this point, it was agreed that collaborating centres would concentrate on the draft as a whole. From then until February 1997 the collaborating centres and task forces provided comment on the Alpha draft. Basic questions confronting major issues were also discussed.

At the April 1997 international meeting of collaborating centres, a preliminary Beta draft was distributed to participants. This draft integrated suggestions made in the previous year. After discussion at the meeting, the current Beta-1 draft (ICIDH-2) was prepared and released into the public arena for field trials. The timeline for further development is outlined in table 3.1.

Table 3.1: Timeline for development of the new ICIDH

Date	Milestone
December 1997	End of stage 1 of Beta testing
May 1998	Release of revised Beta draft for second stage testing
December 1998	Completion of second stage Beta testing
1999	Release of new ICIDH-2

The first stage of field trials is underway. Trials are being undertaken in several countries, including Australia. The Australian Collaborating Centre plans to undertake stage 1 Beta testing of the ICIDH-2 in the following areas:

- *People with intellectual disabilities.* This is a joint project involving the Institute and the new Centre for Developmental Disability Studies in Sydney. The testing will examine both the concepts and classifications of the ICIDH-2;
- *Disability among Aboriginal and Torres Strait Islander communities.* This project will examine relevance of the concepts of disability to Indigenous people, using the ICIDH-2 as a possible framework. The addition of the Contextual Factors annexe to the ICIDH-2 may be particularly significant to understanding disability in these communities, given the importance of environmental and cultural factors among them;
- *National discussions of the ICIDH.* These will be undertaken in tandem with national discussions of this paper; and
- *Other opportunities to obtain comment on ICIDH-2.* For example, the Institute was invited to present the Beta version to an expert group convened to discuss rehabilitation coding.

3.4 Incorporating Australia's perspective

For the ICIDH to become a useful and accepted tool in the Australian context, it is necessary to ensure that Australian views shape this revision as far as possible. The AIHW as the Australian Collaborating Centre has worked to achieve this through:

- holding meetings with the Disability Data Reference and Advisory Group. The Group agreed at its first meeting, to serve as the Australian Reference Group (to the Australian Collaborating Centre) for the revision of the ICIDH. It provides the Collaborating Centre with an invaluable source of understanding and knowledge of the Australian disability field;
- developing suggestions to WHO about the conceptualisation and qualification of the third dimension (Participation in the ICIDH-2). A discussion of Australia's input into the revision process is found in section 3.6;
- coordinating testing in Australia, and collating comments for transmission to WHO;
- coordinating and promoting testing of the ICIDH-2 in the Australian context; and
- holding discussions of this paper and the ICIDH-2 to enable wide input.

3.5 Beta-1 draft of the ICIDH-2

The introduction to the new draft ICIDH-2 states that the aim of the classification is to provide a unified and standard language to serve as a frame of reference for the 'consequences of health conditions'. The classification covers any disturbances in terms of functional changes associated with health conditions at body, person and society levels. The ICIDH does not classify diseases, disorders or injuries, which is the aim of the ICD (International Classification of Diseases).

The new draft ICIDH-2 proposes three dimensions, Impairment, Activity, and Participation, and a supplementary annexe, Contextual Factors. The title of the classification has been changed from *ICIDH: International Classification of Impairments, Disabilities and Handicaps*, to *ICIDH-2: International Classification of Impairments, Activities, and Participation*.

In the draft ICIDH-2, the second dimension (previously Disabilities), has been renamed Activities. The third dimension (previously Handicap) has been expanded and renamed as Participation. The ICIDH-2 states:

Thus the term 'disability' has been replaced by a neutral term 'activity' and negative circumstances in this dimension are described as 'activity limitation'. Similarly, 'handicap' has been replaced by 'participation', and negative circumstances in this dimension are described as 'participation restriction'. The term 'disablements' has been included as an umbrella term to cover all the negative dimensions of the ICIDH-2 (ie: impairments, activity limitations and participation restrictions), either together or separately.

A brief description of each of the dimensions of the draft ICIDH-2 are included in boxes 3.1, 3.2, and 3.3. Appendix 3 contains a list of the one- and two-digit codes, with some examples, of each dimension.

Box 3.1: Impairment dimension of ICIDH-2

Definition

In the context of health condition, Impairment is a loss or abnormality of body structure or of a physiological or psychological function.

Operationalisation of Impairment

The classification of Impairment relates primarily to loss or abnormalities at the level of the body, body part or organ. It does not include problems at the level of tissues or cells, or at the subcellular or molecular level. Impairments are not the same as the underlying pathology, but are the manifestations of that pathology. Impairments may be temporary or permanent, progressive or regressive, intermittent or continuous, and may contribute to disablement and/or other health conditions and influence the extent of the person's participation.

Qualifiers of Impairment

Impairment is coded in two complementary sections: Impairments in function and Impairments in structure. Where appropriate, individual chapters in the first section contain additional codes to qualify the impairment of function.

The second section, Impairments of structure, is qualified using two additional digits:

Structural impairment code

- 0 more than one type of structural impairment*
- 1 absence—total*
- 2 absence—partial*
- 3 additional part*
- 4 aberrant dimensions*
- 5 discontinuity*
- 6 deviating position*
- 7 qualitative changes in structure, including accumulation of fluid*
- 8 pain*
- 9 not stated*

Region code

- 0 more than one region of structural impairment*
- 1 right*
- 2 left*
- 3 both sides*
- 4 front*
- 5 back*
- 6 proximal*
- 7 distal*
- 8 not applicable*
- 9 not stated*

Source: Beta-1 draft ICIDH-2, WHO.

Box 3.2: Activity dimension of ICDH-2

Definition

In the context of health condition, Activity is the nature and extent of functioning at the level of the person. Activities may be limited in nature, duration and quality.

Operationalisation of Activity limitations

Difficulties with activities can arise when there is a qualitative or quantitative alteration in the way in which these activities are carried out. Limitations in activities were formerly referred to as disabilities. Limitations in the ability to carry out an activity may be temporary or permanent, reversible or irreversible, and progressive or regressive. Limitations in activities, therefore, relate to the individual's difficulties in performing, or the impossibility to perform an activity or set of activities.

Qualifiers of Activity limitations

For most people the ability to carry out an activity is not an 'all or nothing' phenomenon. Activities may be carried out with varying degrees of ease or difficulty, or as components of different types of behaviour. Activities may also be carried out using technical or other aids, or with the help of another person. This classification is therefore designed to be used in conjunction with two qualifiers that indicate the manner of accomplishment of the activity.

The first qualifier rates degree of difficulty of accomplishment of the activity and is rated as follows:

- 0 no difficulty*
- 1 slight difficulty*
- 2 moderate difficulty*
- 3 severe difficulty*
- 4 unable to carry out the activity*
- 9 level of difficulty unknown*

The second qualifier is optional and describes any personal or non-personal assistance used in accomplishment of the task. Assistance is rated as follows:

- 0 no assistance needed*
- 1 non-personal assistance (including the use of assistive devices, technical aids, adaptations, prosthesis, wheelchair, cane and other material help)*
- 2 personal assistance (where the task is carried out with the 'help' of another person, where 'help' includes supervision as well as cuing and/or physical help)*
- 3 both non-personal and personal assistance*
- 9 level of assistance unknown*

Source: Beta-1 draft ICDH-2, WHO.

Box 3.3: Participation dimension of ICIDH-2

Definition

In the context of health condition, Participation is the nature and extent of a person's involvement in life situations in relation to impairments, activities, health conditions and contextual factors.

Operationalisation of Participation

Participation may be restricted in nature, duration and quality (a restriction in participation was formerly called a handicap). Participation is characterised as the outcome or result of a complex relationship between, on the one hand, a person's health condition, and in particular the impairments or limitations of activities he or she has, and on the other, features of the context that represent the circumstances in which the person lives and conducts his or her life.

Unlike the notion of handicap in the original 1980 version of the ICIDH, the notion of participation is neutral, if not positive. Undoubtedly, the primary and most appropriate use of the ICIDH-2 is to identify situations of limitation or restriction of function, activity or participation—that is, negative situations. The classification of Participation is available to identify areas of life in which a person with impairments or limitations of activities is restricted in some way.

The classification of Participation explicitly incorporates the principle of 'equalization of opportunities' from the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities. This establishes an international norm that requires that the levels of participation for persons with disablement be classified in the light of the expected levels of participation for persons without disablement.

Qualifiers of Participation

There are two qualifiers for the classification of Participation. The first records on a seven-point scale the extent of participation. The second, used when the recorded level of participation is less than full, records which area of the context is responsible for the recorded level of participation. It can also be used to record contextual facilitators of participation.

Extent of Participation

- 0 Full participation under all usual circumstances. Without reliance on any contextual facilitators.*
- 1 At risk full participation. The person fully participates, but is at risk for reduced participation if contextual facilitators are lost, removed or made inoperative.*
- 2 Participation with restrictions. The person has full participation in some situations but has minor or major restrictions in participation in other situations.*
- 3 No participation*
- 7 Not expected*
- 8 Not determined*
- 9 Not applicable*

Contextual facilitator/barrier

- 0 Product, tools and consumables*
- 1 Personal support and assistance*
- 2 Social and political institutions, associations and organizations*
- 3 Education and training systems*
- 4 Economic institutions*
- 5 Other public infrastructure*
- 6 Sociocultural structures, norms and rules*
- 7 Human-made physical environment*
- 8 Natural environment*
- 9 Other or unknown*

Source: Beta-1 draft ICIDH-2, WHO.

Participation—the new third dimension

A significant change since the 1980 version has occurred in the third dimension, where Handicap has been renamed and re-conceptualised as Participation. Whereas the 1980 definition of handicap focused on the disadvantage experienced by an individual when trying to fulfil a life role, the new draft version states much more explicitly that participation is a consequence of the interaction between a person and their environment.

This shift at the third level reflects the growing emphasis on the rights and needs of people with a disability. It is grounded in the philosophy that people with a disability are entitled to the same opportunities and choices as the rest of the community, and generally desire participation in all areas of human and social life. It recognises that individuals experience a participation outcome as a consequence not only of their impairment but also of their interaction with the world around them.

The introduction of the ICIDH-2 makes the following point regarding Participation:

Handicap, as formerly used, focused on seven dimensions which were defined as the most important dimensions of disadvantageous experience. It gave a summary measure of one's disadvantage in relation to peers in accordance with the norms of society. The structure of the P code has also evolved further to a nominal classification instead of summarising only the most important domains. The new third dimension identifies the domains of social interactions between the person and society/environment.

Table 3.2 provides a comparison of the 1980 Handicap dimension's six survival roles, and the seven domains of participation in the ICIDH-2.

Table 3.2 Third dimensions of the 1980 ICIDH and 1997 ICIDH-2

1980 Handicap—six survival roles	1997 ICIDH-2 Participation—seven domains of Participation
Orientation handicap	Participation in personal maintenance
Physical independence handicap	Participation in mobility
Mobility handicap	Participation in exchange of information
Occupation handicap	Participation in social relationships
Social integration handicap	Participation in the areas of education work, leisure and spirituality
Economic self-sufficiency handicap	Participation in economic life
Other handicap	Participation in civic and community life

The 1980 survival roles are coded with a single digit, so are very broad groupings. Participation contains seven domains of interactions which are further divided to the three-digit coding level, so are more detailed.

Contextual factors annexe

Contextual factors are defined as 'the features, aspects and attributes of, or objects, structures, human-made organizations, service provision, and agencies in, the

physical, social and attitudinal environment in which people live and conduct their lives’.

The objective of the annexe is to present a list of potential objects, structures and organisations, or features, aspects or attributes of these things, which might help a person with impairments or activity limitations to increase their level of participation in some domain, or alternatively which might be responsible for decreasing the level of participation.

There are no qualifiers for this annexe, because it is developed with the classification of participation in mind, and is explicitly incorporated as the second qualifier of participation.

The Contextual factors listing is coded using three digits. The single-digit groupings are:

- products, tools and consumables;
- personal support and assistance;
- social, economic and political institutions;
- sociocultural structures, norms and rules;
- human-made physical environment; and
- natural environment.

Appendix 3 provides the two-digit detail for these codes.

3.6 Development of qualifiers for the participation dimension: a key area of Australian input

New qualifiers for participation

The movement from the six ‘survival roles’ of the 1980 ICIDH to the seven domains of Participation in the draft ICIDH-2 meant that the six individual severity scales of Handicap needed rethinking. Critical to the development of the new qualifiers was the notion that some relatability be retained between the old scales and those proposed in the draft ICIDH-2.

A range of qualifiers for participation have been suggested during the revision process, chiefly by the North American and Australian Collaborating Centres. The final drafting team for the draft ICIDH-2 also suggested a qualifier: ‘extent of participation’.

Proposals of the Australian centre

At the May 1996 meeting of ICIDH centres, the Australian Collaborating Centre commented that the qualifier then proposed for the third dimension—satisfaction with participation—was useful for monitoring the extent of participation in society, but still inadequate. Missing were some of the underlying, useful ideas in the ‘handicap’ dimension of the 1980 ICIDH.

It was also noted that it is important to be clear about the policy purpose for measuring this third dimension. The purposes of measuring impairment and disability include

monitoring the outcomes of health conditions and health interventions, and indicating the need for and success of medical and rehabilitation interventions. The purposes of measuring participation are more oriented towards social policies and services.

It was argued that the new notion of participation needed an indication of where the help or intervention is needed, and the amount of help or response needed. This concept was present in a rudimentary form in the 1993 ABS disability survey, and was crucial in being able to quantify unmet demand for certain types of services and assistance (see chapter 4).

Australia also suggested a need for a second qualifier—an improved and environmentally conscious version of the previous ‘handicap’ notion which not only indicates the *type* of assistance needed (falling broadly into person-focused assistance or environmental/systemic modification), but also the *level* or amount.

Australia was asked at the May 1996 ICIDH meeting to draft its ideas on a set of ‘enabling response’ qualifiers for the third level. Two drafts were sent during 1996, developed in discussion with Australian experts. A third draft was sent in December 1996, attached to the Australian Centre’s comments on the Alpha draft ICIDH as a whole. The proposals are outlined in appendix 4.

‘Options testing’

The published draft ICIDH-2 contains two qualifiers for participation—‘extent of participation’ and ‘contextual enabler/facilitator’ (Box 3.3). These qualifiers represent the new work of the Beta drafting team and a modified version of the ‘environment focused enabling response’ of the Australian Centre.

At the April 1997 meeting, the Australian Centre made a brief critical analysis of all the qualifiers suggested so far for the participation dimension. It argued that there were five key ideas, which were all worthy of inclusion in the testing of the draft ICIDH-2. A paper outlining these ideas was submitted by the Australian Centre to WHO, shortly followed by an ‘options testing’ document for testing these qualifiers against those proposed in the draft ICIDH-2. An abridged version of the Australian Centre’s submission follows.

Australian submission on qualifiers of participation (May 1997)

There is some overlap among many of the qualifiers suggested to WHO during 1996 and 1997. However, if we attempt to extract the key ideas reflected in these qualifiers, five emerge:

- satisfaction of the person
- (contextual) facilitator or barrier
- personal support needed
- difficulty experienced by the person
- extent of participation.

There are good reasons for the inclusion of all these key ideas in the Beta test. Some have had more operationalisation and application than others, but all these ideas are recognisable in the field.

Ideas included in the description of the participation dimension also point to the need for a range of qualifiers. The text contains repeated use of the phrases: the ‘quality and

extent of', 'manner and extent of', 'nature and degree of', 'quality, extent and character of' and so forth. These words provide an indication of important aspects of participation.

When the variously proposed qualifiers and the key phrases of the Beta version are compared, the following relationships emerge:

- quality: implicit in the 'satisfaction' qualifier;
- extent and degree: found in the 'extent' qualifier (which would understandably be difficult to develop, but the frequent use of this terminology in the document indicates a need for such an instrument);
- nature and manner: implicit in the 'personal support' and 'contextual facilitator/barrier' qualifiers.

This only leaves the 'difficulty' qualifier not directly relating to these key phrases in the Beta text. However, 'difficulty' can be a significant factor in 'satisfaction'—depending on whether you are measuring satisfaction with the *process* of participation, or satisfaction with the *outcome* of participation. Difficulty is very much about process. The inclusion of two satisfaction qualifiers, one focused on process and the other on outcome, would then be valuable.

Five qualifiers were then proposed by the Australian centre for Beta testing.

1. Satisfaction with *manner* of participation

Key Beta words: quality

Advantages

- One of the main goals of the disability field appears to be to empower the person to set their own goals and make their own decisions.
- It is clear who is making the judgement.
- 'Difficulty' is implied—this needs to be clarified in the text, and possibly in the codes.

Use the North American Collaborating Centre's (NACC) draft of June 1996:

1. Very satisfied
2. Satisfied
3. More or less satisfied
4. Dissatisfied
5. Extremely dissatisfied
6. Indifferent

2. Satisfaction with *outcome* of participation

Key Beta words: quality/quantity, extent of participation

Advantages

- One of the main goals of the disability field appears to be to empower the person to set their own goals and make their own decisions.
- It is clear who is making the judgement.

Use the NACC draft of June 1996 (1–6 as for 'manner' above), changing the focus to outcome, for example, by asking 'Are you satisfied with your participation outcome?'

3. (Contextual) facilitator or barrier

Key Beta words: nature and manner

Advantages

- This provides important recognition that the environment/context may need to change.
- This concept is capable of highlighting areas requiring attention.

Use existing Beta ICIDH-2 draft (see box 3.3).

4. Personal support or assistance

Key Beta words: nature and manner

Advantages

- ‘Support needed’ is a well recognised concept in disability support services, and a key factor included in the ninth revision of the American Association on Mental Retardation (AAMR) definitions (see Luckasson et al. 1992).
- This concept has been operationalised in Australian population surveys and used to estimate unmet demand for disability support services.

Use Australian Collaborating Centre’s draft (December 1996) minus the difficulty element:

- 0 No response needed in usual environment
- 1 Equipment and/or financial assistance
- 2 Occasional assistance to participate to desired level
- 3 Needs regular personal assistance (most days)
- 4 Needs significant daily support

5. Extent of Participation

Key Beta words: extent and degree

This may be the most complex qualifier. Whoever judges the extent of participation could take into account a number of things including the person’s goals, the person’s activity limitations, cultural expectations, UN rules, and other aspects of the environment.

All these factors are relevant, not only in determining the actual level of participation, but also for anyone judging what this ‘level of participation’ actually means.

Depending on which of these factors are taken into account, this qualifier could overlap to some extent with ‘satisfaction with outcome’ above.

Use existing Beta ICIDH-2 draft (see box 3.3)

3.7 Where to from here?

It is difficult to predict what influence the new ICIDH will have in Australia, because it will depend on a number of factors:

- results of the two stages of Beta testing and the contents of the final classification;
- relevance of the new ICIDH to the Australian context—which it is hoped will be maximised by Australia’s participating in and commenting on the draft;

- relatability of the new ICIDH to the previous version and existing classifications and collections in place in Australia; and
- commitment of key players to the promotion and integration of the new ICIDH.

It is fair to say that there has been fairly broad acceptance in Australia of the utility of three 'dimensions of disablement' to support the provision of information relevant to the very wide range of purposes of interest and value in the disability field. The ICIDH conceptualisation thus potentially provides a useful starting point for a framework in which to locate the Australian definitions now in use. Chapter 4 of this paper explores this idea further by mapping current definitions and terminology to the new draft ICIDH-2.

4 Current concepts, terminology and definitions in use in Australia

4.1 Introduction

The approach to describing, naming and measuring disability in legislation or service programs may vary according to:

- the purpose and/or target group of the service or program;
- the model of service delivery; and
- the philosophy of disability and the appropriate social response to it.

Some of these sources of variation have been described briefly in chapter 1. The ways in which service and target group definitions affect disability definitions are explored more fully in this chapter, which discusses some of the main concepts, terminology and definitions in place in Australia. The purpose of the chapter is to indicate the variation in approaches to naming and defining disability concepts used by some of the main services of relevance to people with a disability in Australia. This 'catalogue' cannot be exhaustive, but aims to be nationally representative and is a first step in an attempt to find common elements in these approaches, and perhaps a common framework. The administrative definitions are compared to the emerging new ICIDH approach, to explore the possibility that the ICIDH may provide a useful national framework—and perhaps to influence its development for that purpose.

There is no search for 'uniform definitions'. It is accepted that administrative definitions must vary, as different services attempt to meet different needs, provide different supports or promote different abilities. Instead, a framework is sought, providing some common language, common reference points and, for statistical purposes, data items which can be related to each other.

Concepts, terminology and definitions

Terminology provides a name to a concept—an idea or a way of thinking about a particular entity, relationship or situation—and the description of the concept may be formalised into a definition.

Terminology is subject to change as the disability field develops, and as certain words become pejorative. It has become unclear in some instances, with some terms being used to label a range of definitions. The word 'disability', while often used according to its definition within the 1980 ICIDH, is also used as a substitute word for the now less-favoured 'handicap'. A single word may also be used to describe more than one concept. Commonly, for instance, a reference to 'intellectual disability' refers to both

‘disability’ and ‘handicap’ (in the 1980 ICIDH sense) arising from any of a range of intellectual impairments.

In this chapter, the three dimensions of the ICIDH-2—Impairments, Activity [limitations], and Participation [restrictions]—are mapped against current Australian definitions and terminology. As well, the related Contextual factors are discussed in terms of how well this aspect of the ICIDH-2 fits Australian definitions and terminology.

Definitions in use in Australia

This chapter outlines some of the major administrative definitions in use in Australia. It attempts to relate these definitions to the current and emerging concepts and definitions of the ICIDH.

For the purposes of this comparison, Australian definitions are grouped into four main categories :

- broad inclusive definitions for population research and anti-discrimination measures (discussed in section 4.2);
- definitions for generic or ‘mainstream’ services (discussed in section 4.3);
- definitions for income support: insurance and social security (discussed in section 4.4); and
- definitions for disability support services (discussed in section 4.5).

Health outcome and health status measures are considered briefly in section 4.6, to investigate the extent of their consistency, overlap or complementarity with the broad notion of ‘disability’.

Definitions related to acute health care services are not within the scope of this paper. Health services play a part in the prevention or creation of impairment, and ‘disability’ may be considered as an outcome of health services and processes, but these services should not drive the definition of disability.

4.2 Broad, inclusive definitions

Commonwealth Disability Discrimination Act

Section 4 of the Commonwealth *Disability Discrimination Act 1992* (DDA) defines disability as:

- (a) total or partial loss of the person’s bodily or mental functions; or
- (b) total or partial loss of a part of the body; or
- (c) the presence in the body of organisms causing disease or illness; or
- (d) the presence in the body of organisms capable of causing disease or illness; or
- (e) the malfunction, malformation or disfigurement of a part of the person’s body; or
- (f) a disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction; or

- (g) a disorder, illness or disease that affects a person’s thought processes, perception of reality, emotions or judgement or that results in disturbed behaviour; and includes a disability that:
- (h) presently exists; or
- (i) previously existed but no longer exists; or
- (j) is imputed to a person.

The Act provides for disability standards to be made by the Attorney-General, with parliamentary approval. Areas in which standards may be made include administration of Commonwealth laws and programs. Working groups have been established to develop standards in the following five areas: access to premises; employment; public transport; education; commonwealth information and communication.

The Act’s definition is geared to including as many people as possible within its operation, and is wider in scope than definitions which focus on establishing and possibly limiting rights to support services. This definition uses an unstructured mixture of the ICIDH and the International Classification of Diseases ideas, in order to cast its net wide in the existing field of disability and related conditions.

Table 4.1: Disability Discrimination Act

Purpose/philosophy	To eliminate discrimination on the grounds of disability in a range of specified areas of ‘participation’.
Eligibility/coverage	A person comes under operation of the Act if, because of their disability, a ‘discriminator’ treats or proposes to treat them (the ‘aggrieved person’) less favourably than the discriminator treats or would treat a person without the disability. The definition appears to be framed to ensure that a very wide group of people are potentially included.
ICIDH-2 dimensions	
• Impairment (I)	Concept present in definition of ‘disability’ (section 4 of the Act), for instance, in terms of loss of organ or body part.
• Activity (A) [limitation]	Concept present in definition of ‘disability’ (section 4 of the Act), in terms of loss of functions, or learning or thought processes ‘resulting’ from a disorder or malfunction. Term ‘disability’ present and defined, but definition is broader than that provided by the ICIDH.
• Participation (P) [restriction]	Concept present in section 3 of the Act, outlining the domains of participation (work, accommodation, education, access, etc.) from which it is the object of the Act to eliminate discrimination.
• Contextual factors	Concept present in provision for standards (section 31) in relation to employment, education, accommodation, public transport, Commonwealth laws and programs. The sociocultural environment is recognised via its interaction with ‘imputed disability’.

Australian Bureau of Statistics Survey of Disability, Ageing and Carers

The ABS Survey of Disability, Ageing and Carers uses screening criteria which range over impairment, disability and even handicap and health condition. For the purpose of this survey:

- ‘impairment’ is defined by the WHO 1980 ICIDH definition;
- ‘disability’ is defined, by the screening criteria, as the presence of one or more of 15 limitations, restrictions or impairments (see box 4.1) which had lasted, or were likely to last, for a period of six months or more. A criterion such as ‘disfigurement’

suggests impairment and an effect on participation, so ‘disability’ is imputed in a sense;

- ‘handicap’ is identified as a limitation in performing certain tasks associated with daily living. The limitation must be due to a disability and in relation to one or more of the areas: self-care; mobility; verbal communication; schooling; or employment. Persons aged less than 5 years with one or more disabilities are all regarded as having a handicap, but are not classified by areas or severity of handicap.

The ABS considers that it is established that people identified by one or more of these screening questions are within the concept of disability as commonly accepted by data users.

Box 4.1: Areas of limitation, restriction or impairment identified by the ABS

Affirmative responses to any of the following categories ‘screen’ the person into the ABS survey:

- *loss of sight, not corrected by glasses or contact lenses*
- *loss of hearing*
- *speech difficulties in native languages*
- *blackouts, fits, or loss of consciousness*
- *slowness at learning or understanding*
- *incomplete use of arms or fingers*
- *difficulty gripping or holding small objects*
- *incomplete use of feet or legs*
- *treatment for nerves or an emotional condition*
- *restriction in physical activities or in doing physical work*
- *disfigurement or deformity*
- *long-term effects of head injury, stroke or any other brain damage*
- *a mental illness requiring help or supervision*
- *treatment or medication for a long-term condition or ailment and still restricted*
- *any other long-term condition resulting in a restriction.*

This list creates the definition of disability for the survey.

In developing the survey questions, the ABS attempted to relate the survey concepts as closely as possible to the 1980 ICIDH concepts and definitions.

Although it is a broad definition, the ABS survey is not designed to ‘pick up’ all people entitled to protection under the Disability Discrimination Act—for instance, those with ‘imputed’ disability (section 4j) would not be included.

The draft ICIDH-2 categories of impairment and activity concord quite well with ABS screening questions (for example, mental functions, sight, hearing, mobility and communication). The ABS concept of activity limitation or difficulty in performing tasks relates directly to the ICIDH-2 concept of Activity limitation. The need for personal help or reliance on technical aids relates both to the ‘assistance’ qualifier of the activity dimension of the ICIDH-2, and to the ‘personal support and assistance’ code of the ‘contextual facilitator’ qualifier of the participation dimension of the ICIDH-2.

However, some of the later screening questions are harder to map to ICIDH-2—for instance, unspecified ‘long term conditions’. When trying to map the ICIDH-2 to the screening questions, it can be seen that the screening questions do not include large

categories—they omit specific mention of cardiovascular and respiratory ‘impairments’ even though these are significant disabling conditions (although, when asking people to consider ‘any other condition’, surveyors show a prompt card listing five general conditions including ‘heart disease’ and ‘asthma’). Some of the more complex activities in the ICDH-2, such as ‘domestic activities’ or ‘dealing with particular situations’, are dealt with later in the ABS survey, but not specifically used to screen people.

Nevertheless, the screening questions focus on impairments and activity limitations, even if not covering them perfectly, and are thereby used to define disability for the purposes of the survey. This ensures that later detail on Participation is related to disability rather than any other socially defined or influential characteristic (for instance, race or sex).

Table 4.2: ABS Survey of Disability, Ageing and Carers

Purpose/ philosophy	To provide information about people with a disability and their carers.
Eligibility or coverage	Persons included are those that respond positively to one or more of the screening questions. The screening questions use a mixture of Impairment, Activity and Participation, and also ICD (health) concepts which can assist with identifying persons with a disability. These questions are designed to ensure inclusion, and possibly extend beyond the concepts below by incorporating of such questions as ‘is anyone having treatments or medication for a long term condition or ailment?’ Severity of handicap decided only on self-care, mobility, verbal communication
ICIDH-2 dimensions	
• Impairment	Concept present in areas of limitation, restriction or impairment included in the screening questions e.g.: ‘loss of sight’, ‘loss of hearing’.
• Activity [limitation]	Concept present in areas of limitation, restriction or impairment included in the screening questions e.g.: ‘difficulty gripping or holding small objects’, ‘restriction in physical activities or in doing physical work’. Term ‘disability’ present and defined as above by the screening criteria (box 4.1).
• Participation [restriction]	Concept present in screening questions and in questions relating to restrictions and the need for assistance in particular domains of participation, e.g.: ‘a mental illness requiring help or supervision’.
• Contextual factors	Concept acknowledged in questions on access to assistance, housing modifications, public transport, income support.

4.3 Generic services

Commonwealth Employment Service

Until recently the Commonwealth Employment Service (CES) has assisted people to enter the workforce by providing labour market programs for unemployed people and job search assistance.

The CES used JOBSYSTEM codes to classify clients. These codes included a set of ‘disability codes’ which include ‘amputation’, ‘arthritis’, ‘intellectual learning’, alcohol dependence’, ‘speech or voice disorders’ and ‘disorders of the immune system’. Examination of these items show they are a mixed collection of condition, impairment and disability codes. Notification of disability with the CES did not automatically entitle the client to additional or specific services.

From May 1998, most labour market assistance administered by DEETYA will be 'cashed out' to fund employment services in the new employment services market.

Table 4.3: Commonwealth Employment Service

Purpose/philosophy	To assist people to enter the workforce.
Eligibility or coverage	All Australian citizens and citizens of other countries with a valid work permit are eligible for assistance from the CES. To be included as a person with a disability, one or more of the disability codes must be marked.
ICIDH-2 dimensions	
• Impairment	Concept present in codes such as: amputation, visual impairment. Concept possibly implied in systemic codes such as respiratory system, circulatory system.
• Activity [limitations]	Concept present in codes such as: specific learning disability. Concept possibly implied in codes such as musculoskeletal & intellectual disability.
• Participation [restrictions]	Concept not considered in codes.
• Contextual factors	Concept not considered in codes.

Commonwealth Higher Education Programs

Students with disabilities have the opportunity to self-identify at the time of enrolment in Commonwealth higher education programs. Identification opens the gateway to certain types of assistance such as adaptive technology, tutors, signers and interpreters, and flexible assessment procedures.

Table 4.4: Higher education admissions

Purpose/philosophy	To identify students needing special assistance while studying.
Eligibility or coverage	Students with disabilities are defined as those responding in the affirmative to both the first and third of these three questions asked of them at the time of their enrolment or re-enrolment by the institutions. Q1. Do you have a disability, impairment or long-term medical condition which may affect your studies? Q2. If 'yes' to Q1, please indicate the area/s of impairment: () hearing () learning () mobility () vision () medical () other. Q3. If 'yes' to Q1, would you like to receive advice on support services, equipment and facilities which may assist you?
ICIDH-2 dimensions	
• Impairment	Concept possibly present in the list of disability types the student is asked to identify. Term not used.
• Activity [limitations]	Concept implicit in the questions on need for assistance with hearing, vision, mobility. Possibly assumed in the self-identification question. Term present in the self-identification question. The word 'disability' is used in the questions as well as to name the 'class of clients', where it includes the ICIDH concepts of impairment, disability and participation.
• Participation [restriction]	Concept implicit in the questions on: – effect on studies; – need for assistance with hearing, learning, mobility, vision.
• Contextual factors	Concept present in the notion of support services, equipment and facilities which are provided in response to the identified disability.

Other training institutions

Data are collected by all training organisations except on those programs which fall within the higher education and schools collection (described above), and includes programs delivered by state training authorities (apprenticeships and traineeships), State TAFE systems, adult migrant education service and, more recently, Adult and Community Education and private providers of vocational education. The data are collected in a format compliant with the national standard, called the Australian Vocational Education and Training Management Information Statistical Standard (AVETMISS).

AVETMISS classifies disability which an individual may have where ‘the disability is both significant and permanent; and for a specific enrolment, the disability may affect performance in the course or module’.

The draft Operations Guide being developed by the Australian Committee on VET Statistics defines disability as ‘any restriction or inability (resulting from impairment) to perform an activity in the manner or within the range considered normal for a human being’.

Table 4.5: Other training institutions

Purpose/philosophy	To collect data on the client group undertaking vocational education and training. Also used to identify students needing special assistance while studying.
Eligibility or coverage	AVETMISS classifies disability which an individual may have where: ‘the disability is both significant and permanent; and for a specific enrolment, the disability may affect performance in the course or module’. Those who self identify via the following questions: Q1. Do you consider yourself to have a permanent and significant disability? If Yes, then tick applicable boxes: () visual/sight () physical () chronic illness () hearing () intellectual () other Q2. Do you require special assistance because of the disability?
ICIDH-2 dimensions	
• Impairment	Concept possibly present in the list of disability types. Word not used.
• Activity [limitation]	Concept implicit in the questions on need for assistance with hearing, vision, mobility. Term ‘disability’ present in the self-identification question. The term ‘disability’ is used in the questions as well as to name the ‘class of clients’, where it includes the ICIDH concepts of impairment, activity limitation and participation restriction.
• Participation [restriction]	Concept present in the criteria ‘and for a specific enrolment, the disability may affect performance in the course or module’. Concept implicit in the questions on – effect on studies; – need for assistance with hearing, learning, mobility, vision.
• Contextual factors	Concept possibly present in the concept of requiring special assistance because of the disability.

AUSTUDY and the Assistance for Isolated Children’s Schemes

These schemes provide concessions for students with disabilities, primarily in the area of the academic eligibility rules (workload and duration of assistance). While Assistance for Isolated Children (AIC) is primarily targeted to geographically isolated students, assistance is also available to students who cannot attend their local school daily because of disability.

AUSTUDY and AIC do not prescribe definitions of disability. In the main, statements from medical practitioners are accepted where a student's disability is a determinant of scheme eligibility and/or the amount of assistance provided.

Students normally need to study full time to be eligible for AUSTUDY. However, students with a physical, intellectual or psychological disability which substantially affects their ability to study can obtain AUSTUDY assistance for part-time study. To claim, students need to include a letter with their application describing their situation, and a certificate from a specialist practitioner. Students on the Disability Support Pension do not need to provide extra documentation, and may receive the AUSTUDY Pensioner Education Supplement.

Similarly, general access to Assistance for Isolated Children by students with disabilities is granted where students board at a special institution which caters specifically for their condition. A statement from a medical practitioner is sought if doubt exists.

Table 4.6: AUSTUDY and the Assistance for Isolated Children Schemes

Purpose/ philosophy	To provide financial assistance to eligible people to enable them to obtain an education. AUSTUDY provides some concessions for people with a disability, and the AIC Scheme provides funds for people who are isolated due to their disability.
Eligibility or coverage	AUSTUDY: Students with disabilities can access assistance for part-time study where their disability precludes full-time study. Eligibility is proven by: (1) a medical assessment of the impact of a disability (confined to a physical, intellectual or psychological disability) on students' ability to study full-time; or (2) the person being on the Disability Services Pension. AIC: Students who are boarding at a special institution which caters specifically for the condition, or provision of a medical certificate.
ICIDH-2 dimensions	
• Impairment	Concept possibly present in the notion of 'condition' for AIC funding. Concept not apparent in AUSTUDY criteria.
• Activity [limitation]	Concept possibly present in AUSTUDY criteria in '(1) a medical assessment of the impact of the disability (confined to a physical, intellectual or psychological disability)'. Term 'disability' present in AUSTUDY eligibility criteria but not defined.
• Participation [restriction]	Concept present in 'precluding full time study' in AUSTUDY criteria. Also implied in AIC criteria in 'boarding at a special institution which caters specifically for the condition'
• Contextual factors	Concept present in a limited way in AIC criteria in 'boarding at a special institution which caters specifically for the condition'.

Commonwealth Rehabilitation Service

The provision of services by the Commonwealth Rehabilitation Service (CRS) is governed by Section 3 of the Commonwealth *Disability Services Act 1986*. The objective of the CRS is to achieve positive outcomes, such as increased independence, employment opportunities and integration in the community, for persons with disabilities who are of working age, by providing comprehensive rehabilitation services.

CRS staff case manage client programs, providing discipline-specific input and purchasing other specialist services as needed to achieve clients' vocational and independent living goals.

Table 4.7: Commonwealth Rehabilitation Service

Purpose/philosophy	To reduce the personal, social and financial cost of disability to the individual and the community. Their philosophy is one of minimising the impact of functional limitations on social and vocational roles.
Eligibility or coverage	<p>People with a disability attributable to certain impairments, where there is a reduced capacity for paid employment or independent living.</p> <p>The Act defined the target group as persons who:</p> <p>(a) have attained 14 years of age but have not attained 65 years of age; and</p> <p>(b) have a disability that:</p> <p>(i) is attributable to an intellectual, psychiatric, sensory or physical impairment or a combination of such impairments; and</p> <p>(ii) results in a substantially reduced capacity of the person:</p> <p>(A) to obtain or retain unsupported paid employment; or</p> <p>(B) to live independently.</p>
ICIDH-2 dimensions	
• Impairment	<p>Concept present as ‘gateway’ to eligibility: ‘disabilities that ... are attributable to an intellectual, psychiatric, sensory or a physical impairment or a combination of such impairments’.</p> <p>Term present in definition of target group, but undefined in the Act.</p>
• Activity [limitation]	<p>Concept implied in definition of target group. The work of the CRS is aimed at minimising the impact that functional limitations have on the social and vocational roles of an individual, and thus the concept of activity limitation is considered in practice.</p> <p>Term ‘disability’ present in definition of target group, but undefined in the Act.</p>
• Participation [restriction]	<p>Concept present in definition of target group in the notion of reduced capacity for paid employment or independent living. Concept also represented in the objective ‘to achieve positive outcomes, such as increased independence, employment opportunities and integration into the community’.</p>
• Contextual factors	<p>Concept possibly present in the notion of assisting people back ‘into the workplace’.</p>

4.4 Income support: social security and insurance

Social Security Act 1991

Income security is a Commonwealth responsibility administered by the Department of Social Security (DSS). The Department operates under the *Social Security Act 1991*. Key disability-related terms and definitions from this Act are set out below.

- ‘Care’ includes attention and supervision
- A person has ‘a continuing inability to work because of an impairment’ if the secretary is satisfied that:
 - (a) the impairment is of itself sufficient to prevent the person from doing any work within the next two years; and
 - (b) either (i) the impairment is of itself sufficient to prevent the person from undertaking educational or vocational training or on-the-job training during the next two years; or (ii) even if the impairment does not prevent the person from undertaking educational or vocational training or on-the-job training, such training is unlikely (because of impairment) to enable the person to do any work within the next two years.

- A 'handicapped person' means a person who:
 - (a) has a physical or mental disability; and
 - (b) has turned 16.
- A 'severely handicapped person' means a person who:
 - (a) has a physical, intellectual or psychiatric disability; and
 - (b) because of that disability: (i) requires frequent care in connection with the person's bodily functions; or (ii) requires constant supervision to prevent injury to the person or to another person permanently or for an extended period.
- A person is 'severely disabled' if:
 - (a) a physical impairment, a psychiatric impairment, an intellectual impairment, or two or all of such impairments, of the person make the person, without taking into account any other factor, totally unable: (i) to work for at least the next two years; and (ii) unable to benefit within the next two years from participation in a program of assistance or a rehabilitation program; or
 - (b) the person is permanently blind.
- A young person is a 'disabled child' if:
 - (a) the young person has a physical, intellectual or psychiatric disability; and
 - (b) because of that disability: (i) the young person needs care and attention from another person on a daily basis; and (ii) the care and attention needed by the young person is substantially more than that needed by a young person of the same age who does not have a physical, intellectual or psychiatric disability; and
 - (c) the young person is likely to need that care and attention permanently or for an extended period.

The main pensions and allowances administered by the DSS and of relevance to people with a disability are described in this subsection.

Disability Support Pension

The purpose of the Disability Support Pension is to ensure an adequate level of income for people whose physical, intellectual or psychiatric impairment prevents them from working for at least thirty hours per week at award wages, or for people who are permanently blind.

The person claiming the pension is asked to provide a report on their impairment and work capacity from their own doctor. In addition, there may be an examination by an Australian Government Health Service Medical Officer.

If a claim is granted, the person may be invited to meet a disability panel to discuss their needs and preferences, and to develop an 'activity plan'. The panel comprises representatives from the Department of Health and Family Services (usually the CRS), DEETYA, and the DSS.

Table 4.8: Disability Support Pension

Purpose/philosophy	To provide income support to people who, because of disability, are not able to work in paid employment
Eligibility or coverage	To be eligible a claimant must: (a) have a physical, intellectual or psychiatric impairment of at least 2%; and (b) be prevented by that impairment from working at least 30 hours per week at award wages at the person's usual work, or be unable to be retrained for work, within the next two years; or (c) be permanently blind.
ICIDH-2 dimensions	
• Impairment	Concept used as a screening device or gateway: 20% 'whole person impairment' must be established before further consideration. The assessment of 'whole person impairment' goes further than the ICIDH, which provides no rules for assessing and combining multiple impairments. Concept implied in the criteria that 'blindness' creates automatic eligibility. Term used in definitions i.e.: a person is severely disabled if: (a) a physical impairment, a psychiatric impairment, and intellectual impairment, or 2 or all of such impairments, of the person, make the person'.
• Activity [limitation]	Term 'disability' present but more consistent with the I and P levels of the new ICIDH. The Social Security Act defines a person as 'severely disabled' if: (a) a physical impairment, a psychiatric impairment, an intellectual impairment, or 2 or all of such impairments, of the person, make the person, without taking into account any other factor, totally unable: (i) to work for at least the next two years; and (ii) unable to benefit within the next 2 years from participation in a program of assistance or a rehabilitation program; or (b) the person is permanently blind.
• Participation [restriction]	Concept present in the notion of 'being prevented from working' for the next two years.
• Contextual factors	Concept possibly implied in the idea of a 'program of assistance' to help the person back to work.

Child Disability Allowance

The Child Disability Allowance gives financial help to parents or guardians who care for a child with a disability at home. Qualification for the allowance currently depends on the amount of extra care and attention needed by the child every day, and not the type of disability, or the costs involved.

A new assessment tool for new claimants will be introduced in July 1998. It will measure functional ability of the child in the areas of communication, self-care, feeding and mealtime skills, social/community skills, and motor skills/mobility. In addition it will take into account the child's behaviour, emotional state and additional special care needs. The focus of the new assessment is therefore not just on the needs of the child, but takes into account the child's impact on the family.

Table 4.9: Child Disability Allowance

Purpose/ philosophy	To provide financial help for parents or guardians who care for a child with a disability at home.
Eligibility or coverage	Requirements of the <i>Social Security Act 1991</i> are that: (a) the child has a physical, intellectual or psychiatric disability; (b) because of a disability the child requires care and attention from another person on a daily basis which is substantially more than that required by a child of the same age who is not disabled; (c) the child is likely to need that care and attention permanently or for an extended period; and (d) the child receives care and attention from the claimant on a daily basis in the claimant and child's home.
ICIDH-2 dimensions	
• Impairment	Concept not apparent, although implied by usual interpretation of terms such as 'intellectual disability'. Term not used.
• Activity [limitation]	Concept present in eligibility criteria. Term 'disability' present in the eligibility criteria and defined in the Act—a young person is a 'disabled child' if: (a) the young person has a physical, intellectual or psychiatric disability; and (b) because of that disability; (i) the young person needs care and attention from another person on a daily basis; and (ii) the care and attention needed by the young person is substantially more than that needed by a young person of the same age who does not have a physical, intellectual or psychiatric disability; and (c) the young person is likely to need that care and attention permanently or for an extended period. This definition extends beyond the ICIDH definition of Activity and includes some Participation. The new assessment tool explicitly assess functional ability in five areas: communication, self-care, feeding and mealtime skills, social/community skills, and motor skills/mobility.
• Participation [restriction]	Concept present for two people: the child, who needs support for daily activities; and the carer, who is providing more than usual support and has other activities curtailed.
• Contextual factors	Concept not apparent. Possibly present in the eligibility criteria '(c) the child is likely to need that care and attention permanently or for an extended period', i.e.: the child needs to be in a constantly supporting environment. Concept present in the new assessment tool in the consideration of the impact of the child on the family.

Carer Payment

The Carer Payment is made under the Social Security Act to eligible people who personally provide a 'severely handicapped' person with constant care and/or constant supervision on a daily basis. 'Personal care and attention' refers specifically to the assistance required with routine bodily functions, such as eating, dressing, hygiene and mobility, but not assistance with everyday domestic tasks such as housekeeping, gardening, shopping etc. The application form for receipt of the carer pension states that 'it follows that a person caring for that person [the 'severely handicapped' person] will generally be unable to undertake employment of a full-time or substantial nature'.

Table 4.10: Carer Payment

Purpose/philosophy	To provide financial assistance to people who personally provide a 'severely handicapped' person with constant care. It is acknowledged that these carers are usually limited from participating in the workplace.
Eligibility or coverage	A 'severely handicapped person' means a person who: (a) has a physical, intellectual or psychiatric disability; and (b) because of that disability (i) requires frequent care in connection with the person's bodily functions; or (ii) requires constant supervision to prevent injury to the person or to another person permanently or for an extended period. 'Personal care and attention' refers specifically to the assistance required with routine bodily functions, such as eating, dressing, hygiene, mobility, but not assistance with everyday tasks.
ICIDH-2 dimensions	
• Impairment	Concept not apparent although implied by terms such as 'intellectual disability'. Term not present.
• Activity [limitation]	Concept implied in the [severely handicapped] person's inability to perform personal care and attention functions such as eating, dressing, hygiene etc. Term 'severely disabled' defined in the Act.
• Participation [restriction]	Concept possibly implied for the person with a 'severe handicap' in their need for assistance with personal care and attention. Does not include assistance with everyday tasks like housekeeping, gardening, shopping etc. Concept present for carer in their restrictions to participate in the workplace.
• Contextual factors	Concept not apparent. Possibly present in the eligibility criteria (b)(ii) 'requires constant supervision... permanently or for an extended assistance' i.e.: the child needs to be in a constantly supporting environment'.

Mobility Allowance

Under the Social Security Act a successful applicant for Mobility Allowance must meet certain qualifying criteria. One qualification is that the person's physical, intellectual or psychiatric disability precludes the use of public transport without substantial assistance, either permanently or for an extended period (one year or more). This does not just mean local public transport the client may have to use, but their ability to use public transport in general in any location at any time and at any place. 'Substantial' means the degree of assistance required to do certain activities with no difficulty.

The examining doctor's assessment provides the basis for determining whether the client requires substantial assistance.

Table 4.11: Mobility Allowance

Purpose/philosophy	Mobility Allowance is payable to persons who are unable to use public transport without substantial assistance because they have a physical, intellectual or psychiatric disability. They must also be spending at least 8 hours per week in employment and/or vocational training.
Eligibility or coverage	<p>The person's physical, intellectual or psychiatric disability precludes the use of public transport without substantial assistance, either permanently or for an extended period (one year or more). The person must be working or undertaking vocational training.</p> <p>The person must be a 'handicapped person', which means a person who: (a) has a physical or mental disability; and (b) has turned 16 years of age.</p>
ICIDH-2 dimensions	
• Impairment	<p>Concept not apparent.</p> <p>Term not used.</p>
• Activity [limitation]	<p>Concept implied in person's difficulty with mobility..</p> <p>Concept explicit in the examining doctor's report which assesses the person's level of activity with specific activities such as 'sitting in public transport' and 'personal survival skills'.</p> <p>Term 'disability' used in the definition of a 'handicapped person', but not defined.</p>
• Participation [restriction]	<p>Concept present in a limited way in the notion of assistance with mobility. Also present in the eligibility criteria which states '...This does not just mean local public transport the client may have to use, but their ability to use public transport in general in any location at any time and at any place.</p> <p>The Act uses the phrase 'handicapped person' as part of the eligibility criteria.</p>
• Contextual factors	<p>Considered in the use of '...not just any transport the client may have to use, but their ability to use public transport in general in any location at any time and at any place'.</p>

Veterans' Affairs Disability Pension

The Veterans' Entitlements Act provides compensation for disability which is caused by diseases or injuries resulting from war or other eligible service. Once a disease or injury is found to be service related, it is called an accepted disability. Medical treatment is provided for these disabilities. If the accepted disability (or combination of accepted disabilities) causes a measurable amount of 'incapacity', a disability pension may also be granted.

Incapacity is defined in the Act as 'the effects of the injury or disease and not a reference to the injury or disease itself'. It is determined by combining a medical impairment rating and a lifestyle rating. These are described below.

- 'Impairment' consists of two components: physical loss of, or alteration to, any body part or system; and the functional loss to which this may give rise. The Department uses the concept of whole person impairment, that is, impairment scores are expressed as a percentage impairment of the whole person. Whole person impairment by complete loss of sight, for example, is rated at 85%. Impairment is assessed using system-specific tables. In cases of non-specific loss of function, or where the system-specific tables do not apply, additional tables provide an assessment of impairment based on 'activities of daily living' and 'pain and suffering'. Impairment ratings are made by a Departmental medical officer after a purpose-specific medical examination has been made.
- The 'lifestyle rating' examines the impact of the impairment on the person's capacity to function in society and enjoy life. Four areas are considered: relationships; mobility; recreational and community activities; and employment and domestic activities. Lifestyle assessments can either be self-assessed using one of two assessment instruments, or the applicant can opt to have an average score allocated according to their level of medical impairment.

Appendix 7 of the Guide to Assessment of Rates of Veterans' Pensions provides a table for combining the impairment and lifestyle ratings to derive the overall incapacity rating. The derived rating is then used to allocate the rate of pension payable to the veteran.

The basic disability pension is the General rate and is paid in multiples of 10% up to a 100% pension. Additional pension is available to veterans who:

- (a) are unable to undertake remunerative work for more than 50% of the time ordinarily worked on a full-time basis, or 20 hours per week; and as a result, are suffering a loss of salary or wages, or earnings on their own account that they would not otherwise be suffering; or
- (b) are totally and permanently incapacitated i.e.: are incapable of undertaking remunerative work for periods in excess of eight hours per week; and as a result of accepted disabilities alone, are prevented from continuing to do the work the person was doing, and are, as a result, suffering a loss of salary or wages, or of earnings on their own account, that they would not be suffering if free of that incapacity.

An Extreme Disablement Adjustment payment is also available to those veterans over the age of 65 years who are severely disabled by their accepted disabilities but able to work.

Table 4.12: Veterans' Affairs Disability Pension

Purpose/philosophy	To provide compensation for incapacity which is caused by diseases or injuries resulting from war or other eligible service.
Eligibility or coverage	Available to Australian veterans who have been assessed as having an accepted disability— defined as 'a war-caused injury or war-caused disease, or both, or a defence-caused injury or defence-caused disease, or both'.
ICIDH-2 dimensions	
• Impairment	Concept present as a fundamental component in determination of incapacity. Measured by the system-specific impairment tables. Term present, and defined in terms of two components: (a) physical loss of, or alteration to, any body part or system; and (b) the functional loss to which this may give rise. Part B of this definition may also include the concept of activity limitation.
• Activity [limitation]	Concept present in the 'other' impairments table which assesses ability to undertake simple activities of daily living (ADLs). Concept also present in the 'Whole person impairment' approach which considers the impact of the condition on the ability of the whole person to function. Term not present.
• Participation [restriction]	Concept present in the 'lifestyle rating', which is combined with the impairment rating to derive an incapacity rating, examines the impact of the impairment on the person's capacity to function in society and enjoy life. Four domains are considered: relationships; mobility; recreational and community activities; and employment and domestic activities. Concept also present in availability of additional pension if the person is limited in participating in the workplace.
• Contextual factors	Concept present in the need for participation in a 'military environment' as a criterion for eligibility.

Insurance and compensation schemes

A number of insurance and compensation schemes exist in Australia. Generally, these schemes provide compensation in three areas:

- income replacement,
- general damages—non-economic loss, pain and suffering; and
- long-term care components.

This paper will consider four schemes that could be considered under this broad heading:

- Commonwealth employees rehabilitation and compensation (Comcare);
- Private accident and injury insurance;
- Victorian Workcover; and
- the Victorian Transport Accidents Commission.

Commonwealth employees rehabilitation and compensation (Comcare)

Comcare operates under the *Commonwealth Employees Rehabilitation and Compensation Act 1988*. It provides insurance for full-time, part-time, temporary and probationary employees of an organisation insured with Comcare. Compensation is available for

impairment of any body part, system or function, caused by or contributed to in a material degree by a work-related injury. Compensation can be provided as:

- weekly payments;
- the covering of medical expenses; and
- the payment of a return to work plan and essential needs.

In addition, the Act provides for the payment of compensation in a lump sum for permanent impairment and other non-economic loss resulting from a work related injury. Non-lump-sum payments are based on the loss of income for the person as a result of the injury. The degree of injury or impairment is not measured. Approval of a claim for compensation is based on the claimant's anecdotal and medical evidence, and support from the employing organisation.

The degree of impairment and the degree of non-economic loss are determined using the Guide to Assessment of the Degree of Permanent Impairment. The Guide states that 'impairment' means 'the loss, loss of use, damage or malfunction, of any part of the body, bodily system or function or part of such system or function'. It relates to the health status of an individual and includes anatomical loss, anatomical abnormality, physiological abnormality and psychological abnormality.

Impairment is measured against its effect on personal efficiency in the 'activities of daily living' compared with a normal healthy person. The measure of 'activities of daily living' is a measure of primary biological and psychological function and includes: ability to receive and respond to incoming stimuli; standing; moving; feeding; control of bladder and bowel; self-care; and sexual function.

The impairment tables are based on the concept of 'whole person impairment' which is drawn from the American Medical Association's Guide to Physical Impairment. Evaluation of the whole person impairment is a medical appraisal of the nature and extent of the effect of an injury or disease on a person's functional capacity and on the activities of daily living (ADLs). The guides are structured by assembling detailed descriptions of impairments into groups according to body system and expressing the extent of each impairment as a percentage value of the functional capacity of a 'normal healthy person'. Thus, a percentage value can be assigned to an employee's impairment by reference to the relevant description in this guide.

'Non-economic loss' is a subjective concept of the effects of the impairment of the employee's life. It includes pain and suffering, loss of amenities of life, loss of expectation of life, and any other real inconveniences caused by the impairment. Non-economic loss is determined by examination of the 'lifestyle effects' of the impairment.

'Lifestyle effects' are a measure of an individual's mobility in, enjoyment of, and participation in, recreation, leisure activities and social relationships. It is emphasised that the employee must be aware of the losses suffered. Employees may have equal ratings of impairment but it would not be unusual for them to receive different ratings for non-economic loss because of their different lifestyles.

Section 29, part 3, of the Act allows for some payment of the costs of attendant care as a result of an injury. However, no allowance is provided for possible loss of income by a family member as a result of performing a caring role.

Table 4.13: Comcare

Purpose/philosophy	Comcare helps employees who are unable to work because of work-related injuries and illnesses return to safe, productive work at the earliest opportunity. For people permanently unable to return to work it provides financial compensation for economic and non-economic loss for work-related injury and illness.
Eligibility or coverage	Employees are eligible if they incur income loss, expenses or certain non-economic losses from a work-related injury, illness or impairment.
ICIDH-2 dimensions	
• Impairment	Concept present as basis for eligibility. Level of impairment is assessed using the 'guide to the assessment of the degree of permanent impairment'. Permanent 'impairment' is an essential prerequisite for consideration for lump sum payment for non-economic loss.
• Activity [limitation]	Concept is present in the determination of 'Impairment' which is 'measured against its effect of personal efficiency in the activities of daily living in comparison with a normal healthy person'. This is similar to the whole person impairment concept in other schemes.
• Participation [restriction]	Concept present in the assessment of non-economic loss in terms of 'lifestyle effects', which are a measure of an individual's mobility and enjoyment of, and participation in, recreation, leisure activities and social relationships. Also present in the notion of economic loss, in terms of paid employment. The term 'participation' is used in the definition of lifestyle effects.
• Contextual factors	Concept present in payment for 'return to work plan' and 'essential needs'.

Private accident and injury insurance

This type of policy is available from most life insurance companies. As an example, AMP provides an 'income continuation and business overheads insurance' policy, which insures a individual against the loss of income due to illness or injury.

This policy provides a monthly benefit to people suffering illness or injury causing them to be unable to carry out their usual occupation and lasting beyond the selected waiting period. Depending on the occupation and the benefit payment period, the 'usual occupation' provision may only apply to the first two or five years of disablement. Subsequently, there may be a benefit only if the person is unable to do any work for which they are 'reasonably suited' by training, education or experience.

Table 4.14: Example of a private accident and injury insurance policy (AMP)

Purpose/philosophy	To insure against loss of income if the person is unable to work due to illness or injury.
Eligibility or coverage	Under this policy, disablement means an inability, due to illness or injury, to carry out usual business. The claimant is required to remain under the ongoing care of their doctor and not undertake any remunerative work.
ICIDH-2 dimensions	
• Impairment	Concept not apparent. Implied in determination of eligibility i.e.: the presence of illness or injury.
• Activity [limitation]	Concept not apparent. The term 'disablement' is used, but is defined in terms of Participation i.e.: the person's inability to work due to illness or injury.
• Participation [restriction]	Concept a key determinant of eligibility i.e.: the inability to participate in the workplace is the single criterion for receipt of benefit.
• Contextual factors	Concept present in the notion that the person is paid for not being able to participate <i>in the workplace</i> .

Victorian Workcover

Victorian Workcover's objectives are to prevent work injuries, to assist individuals with their return to work after injury, and to provide compensation for injury and impairment.² Workcover operates under the *Accident Compensation Act 1985* of Victoria. The Act defines the following terms:

- 'Disease' includes (a) any physical or mental ailment, disorder, defect or morbid condition whether of sudden or gradual development; and (b) the aggravation, acceleration, exacerbation or recurrence of any pre-existing disease.
- 'Incapacity' includes (a) in relation to industrial deafness, inability to engage in the worker's own or other suitable employment because of an immediate and substantial risk of increasing the industrial deafness to a level of material disability; and (b) a disfigurement that is sufficient to affect the earning capacity of a worker's opportunities for employment.
- 'Partial incapacity' in relation to a worker, means an inability arising from an injury such that the worker is not able to return to his or her pre-injury employment but is able to return to work in suitable employment.
- 'Total incapacity' in relation to a worker means an inability arising from an injury such that the worker is not able to return to work, either in the worker's pre-injury employment or in suitable employment.
- 'Injury' means any physical or mental injury and without limiting the generality of the foregoing includes (a) industrial deafness; (b) a disease contracted by a worker in the course of the worker's employment whether at or away from the place of employment and to which the employment was a significant contributing factor; and (c) the recurrence, aggravation, acceleration, exacerbation or deterioration of any pre-existing injury or disease where the worker's employment was a significant contributing factor to that recurrence, aggravation, acceleration, exacerbation, or deterioration.

Compensation is paid for permanent injury. The Act sets out a 'table of maims' which provides a whole person percentage injury rating for a range of 'losses' such as loss of an eye, and impairments such as impairment of the back. Medical assessors must use the American Medical Association's Guide for Physical Impairment.

In addition, a person with an impairment rating of 30% or greater is deemed to have a substantial impairment and is entitled to sue under common law for costs and damages. People with an impairment rating of less than 30% can sue under common law if they are assessed as eligible. Eligibility in these cases is determined by an oral disability assessment.

Once permanent injury is established, a claim for 'pain and suffering' can be made. No guidance is provided for the measurement of pain and suffering, except that due regard must be given to the duration of pain and suffering and the severity of any injuries.

² Other similar schemes exist in other States. This example is used as an illustration.

Table 4.15: Victorian Workcover

Purpose/ philosophy	To improve the health and safety of persons at work and reduce the social and economic costs to the Victorian community of accident compensation.
Eligibility or coverage	Persons eligible for compensation must have injuries which arise out of or in the course of employment.
ICIDH-2 dimensions	
• Impairment	<p>The concept is present in the payment of compensation for permanent injury. The Act sets out a 'table of maims' which provides a whole person percentage injury rating for a range of 'losses' such as loss of an eye, and impairments such as impairment of the back.</p> <p>Concept may be implied in definition of 'disease' as (a) any physical or mental ailment, disorder, defect or morbid condition whether of sudden or gradual development; and (b) the aggravation, acceleration, exacerbation or recurrence of any pre-existing disease.</p> <p>Term 'impairment' is not defined in the Act.</p>
• Activity [limitation]	<p>Concept not apparent.</p> <p>Term 'disability' not present.</p>
• Participation [restriction]	<p>Concept implied in 'incapacity' where the ability of the person to operate in the workplace is a criterion for eligibility.</p> <p>Concept also present in the development of a 'return to work' plan as a key factor in the rehabilitation process.</p>
• Contextual factors	<p>Concept present in the provision for costs incurred in returning the person to the workplace, including aids, workplace modification and medical care.</p> <p>Concept also present in the occupational health and safety and injury prevention roles of Workcover.</p>

Victorian Transport Accidents Commission

The Victorian Transport Accidents Commission performs accident prevention activities, provides rehabilitation for people injured in a transport accident, and provides compensation for people who are injured or die in a transport accident. The Commission operates under the *Victorian Transport Accident Act 1986*, which defines 'injury' as 'physical or mental injury and includes nervous shock'.

Depending on their age, status before the accident, and needs and degree of impairment, injured persons are able to claim for:

- rehabilitation costs including aids, treatment and assistance;
- a weekly payment or lump sum compensation;
- a weekly payment to compensate for total loss of earning capacity; and/or
- a weekly payment to compensate for partial loss of earning capacity.

To be eligible for rehabilitation or compensation, the degree of impairment of the applicant must be determined. The assessment of degree of impairment is undertaken using the American Medical Association's Guide to Physical Impairment (second edition). Assessment cannot be undertaken until 18 months after the accident, or until the injury stabilises, whichever occurs last, that is, the scheme is compensating for permanent impairment.

In addition, a person with an impairment rating of 30% or greater is deemed to have a substantial impairment and is entitled to sue under common law for costs and damages. People with an impairment rating of less than 30% can sue under common law if they are assessed as eligible. Eligibility in these cases is determined by an oral disability assessment.

The legislation was amended in 1996 so that secondary or consequential impairments as a result of a transport accident are not eligible for compensation.

Table 4.16: Victorian Transport Accidents Commission

Purpose/ philosophy	To undertake accident prevention activities, to rehabilitate people injured in a transport accident, and to provide compensation for people who are injured or die in a transport accident.
Eligibility or coverage	A permanent impairment of 10% or greater as a result of a transport accident that occurred in Victoria or in a Victorian registered motor vehicle.
ICIDH-2 dimensions	
• Impairment	Concept used as the basis of determining entitlement to rehabilitation. The assessment of degree of impairment is undertaken using the American Medical Association's Guide to Physical Impairment (second ed.). Term present but not defined.
• Activity [limitation]	Concept not apparent. Term not present.
• Participation [restriction]	Concept present in notion of reduced income (usually as a result of reduced participation in the workplace) which is compensated for. No other domains of participation are considered.
• Contextual factors	Concept present in determining eligibility for compensation i.e.: legal status of motor vehicle at time of accident. Concept also present in provision of funding for rehabilitation which includes the provision of appliances and apparatus, and modifications to a home or a motor vehicle.

4.5 Disability support services

Commonwealth, State and Territory disability-specific legislation

In July 1991, the CSDA was signed by Australian heads of government. This Agreement outlined how responsibilities are shared between the Commonwealth and the State and Territory Governments, and sets out the types of disability support services to be provided or funded by governments.

It was a requirement of the CSDA that all jurisdictions develop legislation for provision of disability services. Thus the CSDA definitions have provided a reference point for the development of State disability services legislation, and a common approach can be seen when comparing the various State legislation.

Discussed below are:

- the Commonwealth *Disability Services Act 1986*
- the Commonwealth/State Disability Agreement
- the *Disability Services Act 1993*, South Australia
- the *Disability Services Act 1992*, Queensland
- the *Disability Services Act 1991*, Victoria
- the *Intellectually Disabled Persons' Services Act 1986*, Victoria
- the *Disability Services Act 1993*, New South Wales

Commonwealth *Disability Services Act 1986*

The Act covers all disability support services provided by the Commonwealth and the services of the CRS.

Table 4.17: Commonwealth *Disability Services Act 1986*

Purpose/ philosophy	To assist persons with disabilities to receive services necessary to enable them to work towards full participation as members of the community.
Eligibility or coverage	Persons with a disability that: (a) is attributable to an intellectual, psychiatric, sensory or physical impairment or a combination of such impairments; (b) is permanent or likely to be permanent; and (c) results in: (i) a substantially reduced capacity of the person for communication, learning or mobility; and (ii) the need for ongoing support services.
ICIDH-2 dimensions	
• Impairment	Concept present as 'gateway' to eligibility: 'disabilities that ... are attributable to an intellectual, psychiatric, sensory or a physical impairment or a combination of such impairments'. Term present but undefined.
• Activity [limitation]	Concept present in eligibility criteria which include 'disabilities which ... are permanent or likely to be permanent; and result in: (a) a substantially reduced capacity of the person or persons for communication, learning or mobility; and (b) the need for ongoing support services. Term present but undefined.
• Participation [restriction]	Concept implied in eligibility criteria by the notion of 'need for ongoing support services'. Also implied in: 'disabilities which are permanent or likely to be permanent; and result in: (a) a substantially reduced capacity of the person or persons for communication, learning or mobility; and (b) the need for ongoing support services. Concept of participation present in objectives of the Act which are: ' (b) to ensure that persons with disabilities receive the services necessary to enable them to achieve their maximum potential as members of the community, (c) to ensure the further integration of persons with disabilities in the community..., (d) ... to achieve positive outcomes, such as increased independence, employment opportunities and integration in the community' etc.
• Contextual factors	Concept present in Act purpose: 'to promote services provided to persons with disabilities that (iii) are provided on ways that promote in the community a positive image of persons with disabilities'.

The Australian Law Reform Commission recently undertook a review of this legislation. This review made three recommendations relating to the definition of disability (box 4.2).

Box 4.2 Australian Law Reform Commission recommendations regarding CSDA definitions

- *Recommendation 14: 'The Commission recommends that the new legislation contain a broad definition of disability based on the definition in the Commonwealth Disability Discrimination Act 1992'.*
- *Recommendation 15: 'The Commission recommends that people included within this definition should also have to demonstrate they have a need for the services being provided and meet the eligibility criteria'.*
- *Recommendation 20 proposes that the new legislation broadly base eligibility for the CRS and other services funded by the Commonwealth on need for the service rather than on whether the person has a particular type of disability or a disability attributable to a specified cause.*

The Commission is recommending a broad, inclusive definition—based on a mixture of concepts—with individual services and programs left to define their specific subgroup of people. According to Recommendation 20, eligibility for Commonwealth services would be established by looking at activity limitation and participation restriction rather than impairment. No decisions have been taken on these recommendations.

Commonwealth/State Disability Agreement (CSDA)

Services covered by the Agreement include employment services, accommodation and other support services such as independent living training, respite care, recreation, information, print disability and advocacy support services. The Commonwealth takes administrative responsibility for employment services, with the States and Territories assuming responsibility for accommodation and other support services. Both levels of government retain some responsibility for advocacy and research.

The range of services provided by each jurisdiction is largely similar, with the exception of early intervention and psychiatric services which are funded outside the CSDA in some States.

Table 4.18: CSDA

Purpose/ philosophy	Set out in Part III of the Agreement (principles and objectives) including: a. Services should have as their focus the achievement of positive outcomes for persons with disabilities, such as increased independence, employment opportunities and integration into the community. g. 'Programs and services should be designed and administered so as to promote the participation of persons with disabilities in the life of the local community through maximum physical and social integration in that community'
Eligibility or coverage	The Agreement specifies its target group as people with disabilities that: 1 are attributable to an intellectual, psychiatric, sensory or a physical impairment or a combination of such impairments; 2. are permanent or likely to be permanent, and result in: (a) a substantially reduced capacity of the person or persons for communication, learning or mobility; and (b) the need for ongoing support services. 3. This includes a person or persons with a disability of a chronic episodic nature.
ICIDH-2 dimensions	
• Impairment	Concept present as 'gateway' to eligibility i.e.: 'disabilities that ... are attributable to an intellectual, psychiatric, sensory or a physical impairment or a combination of such impairments'. Term present in the Agreement but not defined.
• Activity [limitation]	Concept implied in eligibility criteria i.e.: 'disabilities which ... are permanent or likely to be permanent; and result in: (a) a substantially reduced capacity of the person or persons for communication, learning or mobility'. Term 'disability' present in Agreement, but not defined.
• Participation [restriction]	Concept implied in eligibility criteria by the notion of 'need for ongoing support services' i.e.: 'disabilities which ... are permanent or likely to be permanent; and result in: (a) a substantially reduced capacity of the person or persons for communication, learning or mobility; and (b) the need for ongoing support services'. Concept also present in the principles and objectives (Part III) (a) independence, employment opportunities, integration and (g). participation (see above under purpose).
• Contextual factors	Concept recognised in the notion of assistance to achieve greater participation, as well as in the principles and objectives (Part III), for instance (b) ensuring the conditions and patterns of everyday life are ... as close as possible to norms and patterns which are valued in the general community.

All jurisdictions have cooperated with the AIHW in the formulation of a Minimum Data Set for the national collation of data on services provided under the CSDA. This data set attempts as far as possible to use commonly accepted terminology to group disability into the following categories: developmental delay, intellectual, specific learning, autism, physical, acquired brain injury, deaf-blind, vision, hearing, speech, psychiatric and neurological.

These disability groupings make extensive use of the impairment and activity concepts, although there is by no means a perfect concordance in the coverage. While it is quite easy to map the disability groupings to the ICIDH-2 impairment and activity dimensions, mapping in the reverse direction shows some gaps. The CSDA MDS disability groupings largely omit specific recognition of the impairments of function set out in chapters 6, 7, 8, 9 and 11 of the draft ICIDH-2, and the complex activities (chapters 6, 7, 8, 9 and 10). Appendix 3 provides details of these ICIDH-2 chapters.

A major use of the first two dimensions of ICIDH-2 is in the defining and naming of disability groupings referred to in common terminology.

Box 4.3: CSDA evaluation recommendations

- *Recommendation 33: The Disability Services Sub Committee (or the National Disability Management Agency as recommended in Rec 44.) establish a Taskforce which includes Australian Institute of Health and Welfare and relevant professional expertise associated with the full range of impairment types to:
 - (e) consider the implications of a broad, more inclusive classification for how disability and handicap are to be defined.*
- *Recommendation 34: As advised by the recommendations of the Taskforce (see Rec. 33) the State, Territory and Commonwealth Governments continue to work with the Australian Institute of Health and Welfare to adopt a common definition of disability-related need for services which can be incorporated into all relevant legislation, policy and program objectives, eligibility criteria etc.*
- *Recommendation 36: The Taskforce (referred to in Rec. 33) also be asked to consider whether permanency should be made a defining feature of disability for the purposes of designing a disability service system, and whether there is a more appropriate definitional criterion than that of 'permanency'.*
- *Recommendation 37: For the purposes of negotiating with the next CSDA, and as subject to review, the eligible target group for CSDA services to be defined as follows:
 - 'A person with a disability attributable to an intellectual, developmental, psychiatric, sensory, physical, cognitive or neurological impairment (or a combination of these) which is permanent or likely to be permanent and results in:
 - (i) a substantially reduced capacity of the person for: self-care and management, mobility, communication, learning, employment, social interaction; and
 - (ii) the need for disability-related support services, including needs which are of a chronic and episodic nature, and including services which result in the enhancement or increase of the capacities of persons with disabilities, and their carers.*

South Australian *Disability Services Act 1993*

In determining eligibility for and priority of access to services, the provider of the service is also required to take the following into account:

- (a) the person's wishes;
- (b) the level of disability and its impact on the person;
- (c) the needs and capabilities of any carers;
- (d) the extent of support and assistance (if any) provided or available to the person from all other sources;
- (e) the implications of any decision for carers and members of the person's family;
and
- (f) such other matters as may be considered relevant.

Table 4.19: South Australian *Disability Services Act 1993*

Purpose/ philosophy	To describe the principles to be applied to people with disabilities, to set out the objectives for providers of disability services and researchers, and to provide funding for these activities.
Eligibility or coverage	People with a disability: (a) that is attributable to intellectual, psychiatric, cognitive, neurological, sensory or physical impairment, or a combination or any of those impairments; and (b) that is, or is likely to be, permanent; and (c) is the result of the person having (i) a reduced capacity for social interaction, communication, learning, mobility, decision making or self-care; and (ii) a need for continuing support services.
ICIDH-2 dimensions	
• Impairment	Concept possibly present in definition of disability, which states that impairment is a prerequisite for disability i.e.: 'a disability that is attributable to intellectual, psychiatric, cognitive, neurological, sensory or physical impairment, or a combination or any of those impairments'. Term present but not defined.
• Activity [limitation]	Concept implied in definition of disability i.e.: 'a disability ... that is attributable to intellectual, psychiatric, cognitive, neurological, sensory or physical impairment, or a combination or any of those impairments'. Concept also present in definition i.e.: 'and is the result of the person having (i) a reduced capacity for social interaction, communication, learning, mobility, decision making or self-care'. Term 'disability' present in the act and defined (see eligibility above) in terms of Impairment, Activity and Participation.
• Participation [restriction]	Concept possibly present in the notion of 'reduced capacity' and 'need for ongoing support services' in the definition of eligible persons. Concept also present in Schedule 2 of the Act which states that 'Disability Services are to be administered and designed so as (a) to achieve positive outcomes for persons with disabilities, such as enhanced image and level of competence, increased independence, increased education, training and employment opportunities and integration into, and participation in the life of the community, and (b) to ensure that the conditions of the day-to-day life of persons with disabilities are as close as possible to those of other members of the community.
• Contextual factors	Schedule 1 of the Act states that 'in receiving the services ... persons with disabilities (a) have the right to choose between those services, and to choose between the options available within a particular service, so as to provide assistance and support that best meets their individual needs'. Schedule 2 also states that in assessing the person's eligibility and priority of access the following must be taken into consideration: (c) the needs and capabilities of any carers, (d) the extent of support and assistance (if any) provided or available to the person from all other sources, and (e) the implications of any decision for carers and members of the person's family.

Queensland's *Disability Services Act 1992*

This Act is based on the philosophy that people with disabilities have the same human rights as others, and these principles are stated in part 3 of the Act.

Table 4.20: Queensland's *Disability Services Act 1992*

Purpose/ philosophy	To affirm the rights of people with disabilities, to set out the objectives of programs and services for people with disabilities, and to establish a funding mechanism.
Eligibility or coverage	A person with a disability: (a) that is attributable to an intellectual, psychiatric, cognitive, neurological, sensory or physical impairment or a combination of impairments; and (b) that results in (i) a substantial reduction of the person's capacity for communication, social interaction, learning or mobility; and (ii) the person needing support. The disability must be permanent or likely to be permanent. The disability may be, or may not be, of a chronic episodic nature.
ICIDH-2 dimensions	
• Impairment	Concept implied in definition of target group as a 'prerequisite' to disability i.e.: 'a disability:(a) that is attributable to an intellectual, psychiatric, cognitive, neurological, sensory or physical impairment or a combination of impairments'. Term present but not defined.
• Activity [limitation]	Concept implied in definition of target group i.e.: 'a disability ... that is attributable to intellectual, psychiatric, cognitive, neurological, sensory or physical impairment, or a combination of impairments.' Concept also partially present in definition i.e.: 'and is the result of the person having (i) a reduced capacity for social interaction, communication, learning, mobility, decision making or self-care'. Term 'disability' present in the act as a descriptor of the target group and defined (see eligibility above).
• Participation [restriction]	Concept partially present in eligibility criteria i.e.: ' that results in substantial reduction of the person's capacity for communication, social integration, learning or mobility'. Term and concept also present in part (3) of the Act i.e.: 'People with disabilities have the right to: (c) services that support their attaining a reasonable quality of life in a way that supports their family unit and their full participation in society: (d) participate actively in the decisions that affect their lives, including the development of disability policies, programs and services; and (e) any necessary support, and access to information, to enable them to participate in decisions that affect their lives'.
• Contextual factors	Concept present in part (3) which states 'People with disabilities have the right to: (a) respect for their human worth and dignity as individuals; and (f) receive services in a way that results in the minimum restriction of their rights and opportunities'.

Victoria's *Disability Services Act 1991*

There are two relevant Acts in Victoria—an older Act, relating to services for people with intellectual disability, and a newer Act relating generally to disability support services, introduced after the CSDA commenced.

Table 4.21: Victoria's *Disability Services Act 1991*

Purpose/ philosophy	To set out the principles with respect to persons with disabilities, and the objectives and funding provisions for providers of services and researchers.
Eligibility or coverage	The Act states that 'disability' in respect of a person, means a disability (a) which is attributable to an intellectual, psychiatric, sensory or physical impairment or a combination of those impairments; and (b) which is permanent or likely to be permanent; and (c) which results in (i) a substantially reduced capacity of the person for communication, learning or mobility; and (ii) the need for continuing support services; and (d) which may or may not be of a chronic episodic nature.
ICIDH-2 dimensions	
• Impairment	The concept of Impairment is implied as a prerequisite for disability i.e.: 'means a disability (a) which is attributable to an intellectual, psychiatric, sensory or physical impairment or a combination of those impairments and (b) which is permanent or likely to be permanent'. Term present but not defined.
• Activity [limitation]	Concept implied in definition of disability i.e.: 'a disability ... that is attributable to intellectual, psychiatric, sensory or physical impairment, or a combination of impairments'. Concept also partially present in definition i.e.: 'which results in (a) a substantially reduced capacity for communication, learning or mobility'. Term 'disability' present in the act and defined (see eligibility above).
• Participation [restriction]	Concept partially represented in eligibility criteria i.e.: 'which results in (i) a substantially reduced capacity of the person for communication, learning and mobility and (ii) the need for continuing support services'. Concept and word present in schedules 1 & 2 which include: 1(b) 'to ensure that services provided to persons with disabilities (i) further the integration of persons with disabilities in the community ... (ii) enable persons with disabilities to achieve positive outcomes, such as increased independence, employment opportunities, and integration into the community'. 2 'The principles which are to be furthered with respect to persons with disabilities are that (e) persons with disabilities have the same right as other members of Australian society to participate in decisions which affect their lives'.
• Contextual factors	Concept present in schedules 1 & 2 which include: 1(b) 'to ensure that services provided to persons with disabilities (iii) are provided in ways that promote in the community a positive self image of persons with disabilities' and (d) to encourage innovation in the provision of services for persons with disabilities'. 2(b) 'persons with disabilities, whatever the origin, nature, type and degree of disability, have the same basic human rights as other members of Australian society', and (d) 'persons with disabilities have the same right as other members of Australian society to services which will support their attaining a reasonable quality of life' and (f) 'to receive those services in a manner which results in the least restriction of their rights and opportunities'.

Victoria's *Intellectually Disabled Persons' Services Act 1986*

The objectives of this Act are to outline the principles and objectives of programs for intellectually disabled persons, and to establish the Intellectual Disability Review Panel.

Table 4.22: Victoria's *Intellectually Disabled Persons' Services Act 1986*

Purpose/ philosophy	The objectives of this Act are to outline the principles and objectives of programs for intellectually disabled persons, and to establish the Intellectual Disability Review Panel.
Eligibility or coverage	<p>People with 'intellectual disability', that is, over the age of 5 years, and with the concurrent existence of:</p> <p>(a) significant sub-average general intellectual functioning; and</p> <p>(b) significant deficits in adaptive behaviour each of which became manifest before the age of 18 years.</p> <p>People with 'developmental delay', that is a delay in the development of a child which:</p> <p>(a) is attributable to a mental or physical impairment or a combination of mental and physical impairments; and</p> <p>(b) is manifested before the child attains the age of 6 years; and</p> <p>(c) results in substantial functional limitations in one or more of the following areas of major life activity: self-care, receptive and expressive language, cognitive development, motor development; and</p> <p>(d) reflects the child's need for a combination and sequence of special, interdisciplinary, or generic care, treatment or other services which are of extended duration and are individually planned and coordinated.</p>
ICIDH-2 dimensions	
<ul style="list-style-type: none"> • Impairment 	<p>Concept present in the use of IQ as an indication of subaverage intellectual functioning. Also implied as a 'prerequisite' to developmental delay in the definition i.e.: 'delay in the development of a child which (a) is attributable to a mental or physical impairment or a combination of mental and physical impairments'.</p> <p>Term present but not defined.</p>
<ul style="list-style-type: none"> • Activity [limitation] 	Concept present in the notion of 'general intellectual functioning' and 'developmental delay' resulting in 'substantial functional limitations' in self-care, language, cognitive or motor development.
<ul style="list-style-type: none"> • Participation [restriction] 	<p>Concept present in the notion of 'adaptive behaviour' and in the need for ongoing care or service.</p> <p>Concept and term included in 'Statement of Principles' including (e) Services should promote maximum physical and social integration through the participation of intellectually disabled persons in the life of the community.</p> <p>Concept and term also present in 'Aims and objectives of the Department' including : '(m) to put into effect policies in relation to services provided by government and non-government organisations to ensure that intellectually disabled persons are able to participate in decisions about the provision of services'.</p>
<ul style="list-style-type: none"> • Contextual factors 	<p>Concept present in the consideration of developmental delay which is in part culturally determined, and also in the need for ongoing care or service.</p> <p>Concept present in 'Statement of Principles' including (f) Services generally available to all members of the community should be adapted to ensure access by intellectually disabled persons and specialised supplementary services should be provided to the extent required to meet individual needs, (g) Services to intellectually disabled persons should be provided in such a manner that an individual need not move out of his or her local community or travel inordinately long distances to receive the services needed.</p> <p>Concept also present in 'Aims and objectives of the Department' including: '(b) To ensure access by intellectually disabled persons to a range of services ..., and (q) to promote actively through education programs ... positive and enhancing social images of intellectually disabled persons'.</p>

New South Wales' *Disability Services Act 1993*

Table 4.23: New South Wales' *Disability Services Act 1993*

Purpose/ philosophy	To outline the goals of services for people with a disability, to provide the mechanism for funding disability services, and to determine eligibility for CSDA State-funded services.
Eligibility or coverage	For the purposes of this Act, a person is in the target group if the person has a disability (however arising and whether or not of a chronic episodic nature): (a) that is attributable to an intellectual, psychiatric, sensory, physical or like impairment or to a combination of such impairments; and (b) that is permanent or is likely to be permanent; and (c) that results in (i) a significantly reduced capacity in one or more major life activities, such as communication, learning, mobility, decision making or self-care; and (ii) the need for support, whether or not of an ongoing nature.
ICIDH-2 dimensions	
• Impairment	Concept implied in definition of target group as a 'prerequisite' for disability i.e.: 'means a disability (a) which is attributable to an intellectual, psychiatric, sensory, physical or like impairment or a combination of such impairments and (b) which is permanent or likely to be permanent'. Term present but not defined.
• Activity [limitation]	Concept present in definition i.e.: 'that results in (i) a significantly reduced capacity in one or more major life activities, such as communication, learning, mobility, decision making or self-care'. Concept implied in definition of target group i.e.: 'a disability ... that is attributable to intellectual, psychiatric, sensory, physical or like impairments, or a combination of such impairments'. Term 'disability' present but not defined.
• Participation [restriction]	Concept implied in eligibility criteria 1(c)(i) and possibly (ii). Concept and Term present in 'Principles' and 'Applications of Principles' in the Act including: 'Persons with disabilities have the same basic rights ... include the following (b) Persons with disabilities have the same right to live in and be part of the community'. 'Services and programs of services must apply the principles ... to achieve the following (a) to have as their focus the achievement of positive outcomes for people with disabilities, such as increased independence, employment opportunities and integration into the community, and (g) to promote the participation of persons with disabilities in the life of the local community through maximum physical and social integration in that community'.
• Contextual factors	Concept possibly implied in eligibility criteria 1(c)(ii) re: the need for support being ongoing or short term. Concept present in 'Principles' and 'Application of Principles' including 'Services and Programs of services must apply the principles ... to achieve the following (b) to contribute to ensuring that the conditions of the everyday life of persons with disabilities are the same as, or as close as possible to, norms and patterns which are valued in the general community'.

Home and Community Care (HACC) Services

The HACC program is a cost shared program between the Commonwealth Government and State and Territory Governments. Through the program, financial assistance is provided for services which support people living at home who are at risk of inappropriate institutionalisation. The objective of the HACC program is to provide an integrated range of support services for frail aged and other people with a disability and their carers to enable them to be more independent at home and in the community.

The program is administered in accordance with the *Home and Community Care Act 1985*. This legislation states that 'the program shall be directed towards assisting

- (a) persons living in the community who, in the absence of basic maintenance and support services provided or to be provided within the scope of the program, are at risk of premature or inappropriate long-term residential care including:
 - (i) frail or at-risk aged persons, being elderly persons with moderate or severe disabilities;

- (ii) younger disabled persons, being people with moderate or severe disabilities;
- (iii) such other classes of persons as are agreed upon by the Commonwealth Minister and the State Minister; and

(b) the carers of those persons’.

The HACC National Guidelines further describe the eligible group as people ‘having a functional disability which makes it difficult for them to perform the tasks of daily living, such as dressing, preparing meals, house cleaning, home maintenance or using public transport, without personal assistance or supervision’.

The Client Information, Assessment and Referral Record Form asks questions regarding:

- any health problems or difficulties the applicant may have (such as hearing, allergies, incontinence) and their possible effect on service delivery;
- the applicant’s ability to undertake tasks of daily living (such as shopping/banking, house work, transport) and tasks of self-care (such as bathe/shower, grooming, eating, foot care) and equipment needed to maintain independence;
- the person’s physical and social environment (such as home safety and carer needs); and
- specific service needs (such as GP/hospital, food services and respite)

Table 4.24: HACC definitions

Purpose/philosophy	The objective of the HACC program is ‘to enhance the quality of life of the frail aged and younger people with disabilities and their carers’, by the provision of support services, and to avoid inappropriate admission to residential care.
Eligibility or coverage	Persons must have ‘moderate or severe disabilities’, be living in the community, and be ‘at risk’ if services not provided (need help with any of a series of tasks).
ICIDH-2 dimensions	
• Impairment	Concept not present. Concept may be considered in questions on health problems/difficulties which may affect service delivery. Term not present.
• Activity [limitation]	Concept represented in guidelines i.e.: ‘having a functional disability which makes it difficult for them to perform the tasks of daily living, such as dressing, preparing meals, house cleaning, home maintenance or using public transport without personal assistance or supervision’. Concept also represented in the application form in questions on tasks in self-care. The terms ‘moderate’ and ‘severe’ disability are used but not defined.
• Participation [restriction]	Concept partially represented in guidelines which consider the need for personal assistance or supervision’. Objective of program is to ‘enhance the quality of life ... by the provision of support services, and to avoid inappropriate admission to residential care’.
• Contextual factors	Concept present in eligibility criteria i.e.: persons must be living in the community, and at risk of inappropriately being shifted to a long term residential situation. Concept also present in questions asked in application form i.e.: questions on social supports and environmental safety.

Residential aged care services

Residential aged care services are provided under two Acts, *the Aged or Disabled Persons Care Act 1954* and the *National Health Act 1953*. It is anticipated that new legislation will be implemented by 1 January 1998 to replace both these Acts. Although the Aged or Disabled Persons Care Act contains definitions of ‘aged person’, ‘disabled

person' and 'eligible person', these are not used to define the target group of Aged Care Services.

Currently, clients receiving government-subsidised residential aged care services are first assessed by an Aged Care Assessment Team (ACAT). These teams were introduced to ensure that only those most in need of intensive levels of care entered nursing homes. However, their function is now much broader, and the ACATs operate as an interface between the health and aged care systems. They are multi-disciplinary teams, specially trained to perform a holistic assessment of the person's care needs. In response to these needs, a range of services may be provided, including both residential-based (nursing homes and hostels) and community-based (HACC) services. The teams also assess some younger people with disabilities.

Age Care Assessment Teams use a wide variety of assessment measures and no standard assessment procedure is prescribed. A national minimum data set was established in 1994 which collects data on 23 items including 'primary diagnosis' and severity ratings in the areas of 'mobility', 'continence' and 'orientation'.

Hostel care services

Hostel care is for people who can no longer maintain, without support, a satisfactory standard of personal care, health or nutrition or social wellbeing in their own home.

The *Aged or Disabled Persons Homes Act 1974* defines a 'disabled person' as a person who has attained the age of 16 years and who is (a) permanently blind or (b) permanently incapacitated for work.

In making their assessment, assessment teams must consider the following criteria (DCSH 1991).

- An eligible person shall be assessed as requiring hostel care services if that person's physical, mental or social functioning is affected to such a degree that the person cannot maintain himself or herself independently without support.
- Evidence of loss of physical functioning should be established by tests of capacity to perform daily living tasks such as reading, using public transport, laundering, cooking meals, writing, dressing, toileting, cleaning, using the telephone, following a special diet or taking medication.
- Evidence of loss of social functioning shall be established by an investigation of the extent of a person's social contact with relatives, friends, other persons and general community services.

Table 4.25: Hostel care services

Purpose/ philosophy	Hostel care is for people who can no longer maintain without support, a satisfactory standard of personal care, health or nutrition or social wellbeing in their own home.
Eligibility or coverage	An eligible person shall be assessed as requiring hostel care services if that person's physical, mental or social functioning is affected to such a degree that the person cannot maintain himself or herself independently without support. A 'disabled person' means a person who has attained the age of 16 years and who is: (a) permanently blind; or (b) permanently incapacitated for work.
ICIDH-2 dimensions	
• Impairment	Concept only apparent in terms of being 'permanently blind' in the definition of 'disabled person'. Term not present.
• Activity [limitation]	Concept present in the need to provide evidence of loss of physical functioning by tests of capacity to perform daily living tasks such as reading, using public transport, laundering, cooking meals, writing, dressing, toileting, cleaning, using the telephone, following a special diet or taking medication.
• Participation [restriction]	Concept present in need to provide evidence of loss of social functioning by an investigation of the extent of a person's social contact with relatives, friends, other persons and general community services. Concept present in definition of disability i.e.: 'a person that is ... permanently incapacitated for work'.
• Contextual factors	Concept present in the notion that hostel care is for people who can no longer maintain without support ... wellbeing <i>in their own home</i> .

Nursing homes

Information required for an application to nursing home admission is provided by the ACAT and a registered medical practitioner. Key aspects of the assessment process for entry into nursing homes are:

- accurate medical diagnosis and provision of appropriate medical management of disabling conditions (includes service use);
- accurate description of the person's disabilities (including mobility, falls, continence, orientation and behaviours), as well as their capability to perform activities of daily living (including bathing/washing, eating, transferring to/from bed/chair/walking aid) and provision of appropriate retraining/rehabilitation; and
- accurate description of the family, social and community supports available to the person.

In terms of 'functional disability', a nursing home resident should be someone requiring care by a registered nurse, or under the supervision of a registered nurse on a continuing (24 hour) basis. It is also expected that approval would be given where it is no longer possible to support the person at home or with carers, with support from a full range of community services.

A Domiciliary Nursing Care Benefit is a payment for carers who live with and provide care to relatives or friends who have been assessed as needing the level of care provided in a nursing home. The assessment of the care recipient's care needs is based on his or her need for nursing and personal care and whether he or she needs complete or almost complete assistance with activities of daily living such as mobility, toileting, eating, washing and dressing.

In general, nursing homes are not appropriately staffed or equipped to provide care for people with psychiatric disorders or intellectual disability. However, some younger people with 'psychiatric illness' or 'intellectual handicap' are admitted to

nursing homes where ‘... they need the nursing home care for reasons not related to these conditions and where the overall needs of the applicant can be most suitably met in a nursing home’.

Table 4.26: Nursing homes

Purpose/philosophy	To provide care for people requiring care by a registered nurse, or supervision of a registered nurse on a continuing (24 hour) basis.
Eligibility or coverage	For people who can no longer be supported at home or with carers, with support from a full range of community services. Key aspects of the assessment process for entry into nursing homes are: (a) accurate medical diagnosis and provision of appropriate medical management of disabling conditions; (b) accurate description of the person’s disabilities, as well as their capability to perform activities of daily living, and provision of appropriate retraining/rehabilitation; and (c) accurate description of the family, social and community supports available to the person. Some younger people with ‘psychiatric illness’ or ‘intellectual handicap’ are admitted to nursing homes where ‘they meet need the nursing home care for reasons not related to these conditions and where the overall needs of the applicant can be most suitably met in a nursing home’.
ICIDH-2 dimensions	
• Impairment	Concept implied in need to provide ‘accurate medical diagnosis and provision of appropriate medical management of disabling conditions’. Term not present.
• Activity [limitation]	Concept present in the need for an ‘accurate description of the person’s disabilities, as well as their capability to perform activities of daily living such as eating, toileting and showering’. Term ‘disability’ present, but not defined.
• Participation [restriction]	Concept present as eligibility to nursing homes is determined somewhat by an inability to participate i.e.: ‘It is also expected that approval would be given where it is no longer possible to support the person at home or with carers, with support from a full range of community services’.
• Contextual factors	Concept present in the assessment criteria with respect to the inability to remain in the home environment. Assessment criteria also include consideration of the family, social and community supports available to the person.

4.6 Quality of life and health status measures

The ICIDH was first developed as a classification of health outcome measures, recognising the inadequacies of existing measures to describe the longer term effect of some conditions and events. Health outcome measures have now proliferated, with many measures and scales being devised for specific purposes and specific client groups. The same instruments can be used for both health outcome and health status measurement purposes, but the attribution of ‘outcome’ is generally more complex than simply describing ‘status’. Disability free life expectancy and disability adjusted life years (DALYs) are used to measure the success of health policies and actions, the burden of disease and to guide resource allocation. These uses of the term ‘disability’ are beyond the scope of the present paper, but comment is invited on whether the ICIDH definitions are relevant for use in the health field, and what issues might arise from such an extended use of the term.

The ICIDH, as a classification system, can perhaps only provide a framework for these more detailed measures. But, in considering whether the ICIDH provides a useful conceptual framework for Australian disability definitions, it seems worthwhile to examine the following questions: Are the ICIDH concepts present in some outcome

measures? Are there elements of some important outcome measures which are not present in the ICIDH? Are they inconsistent and, if so, does it matter?

To examine these questions briefly, we look at two common measures of health status or health outcome, and one quality of life measure developed specifically for people with an intellectual disability.

SF-36

The SF-36 is a set of 36 questions which have been developed for use—as either a health status or health outcome measure—in clinical practice and research, health policy evaluations and population surveys (Ware & Sherbourne 1992). The questions can be self-administered by people aged 14 years or older; obtaining the ‘patient’s view’ was an aim of the development. The SF-36 includes one multi-item scale which assesses eight health concepts:

1. limitations in physical activities because of health problems;
2. limitations in social activities because of physical or emotional problems;
3. limitations in usual role activities because of physical health problems;
4. bodily pain;
5. general mental health (psychological distress and wellbeing);
6. limitations in usual role activities because of emotional problems;
7. vitality (energy and fatigue);
8. general health perceptions.

The SF-36 approach is compatible with some of the ICIDH concepts, but there are some notable differences in the approach. Probably the most significant is the attribution of cause, and the associated exclusion of some effects from some ‘causes’. Question 3, for example, states: ‘The following questions are about activities you might do during a typical day. Does your health now limit you in these activities?’ The SF-36 does not explore the possibility that usual roles can be limited by other than ‘physical health problems’ (group 3 above), and makes no reference to environmental factors—the only ‘diagnosis’ relates to the person.

Table 4.27: SF-36

Purpose/ philosophy	To measure health-related quality of life, general health and depression.
ICIDH-2 dimensions	
• Impairment	Concept implied in the attribution of cause to ‘health problems’. Concept possibly implied in the question ‘How much did pain interfere with your normal work?’.
• Activity [limitation]	Concept implied in the following questions: ‘Does your health now limit you in these [list of activities] activities?’ and ‘As a result of physical health/emotional problems, have you had difficulty in performing work or other activities?’.
• Participation [restriction]	Concept present in the questions ‘As a result of your physical health/emotional problems, have you cut down on the amount of time on work or other activities?’ and ‘As a result ... have you accomplished less than you would like?’ and ‘... how much has.. health.. interfered with your social activities?’.
• Contextual factors	Concept not present.

Generally, the SF-36, while focusing on the person's 'usual roles' makes limited use of the broader disability framework, and is firmly based in a narrower health framework.

London handicap scale

This scale was developed using the 1980 ICIDH concepts fairly directly (Harwood et al. 1994). People are asked whether their 'health':

- stops them from getting around;
- stops them from looking after themselves;
- limits work or leisure;
- stops them from getting on with other people;
- stops them from understanding the world around;

and asks whether they can afford the things they need.

A six-point gradation, generally from 'not at all' to 'completely' is used for the answers. The scale is based on the six handicap 'survival roles' of the 1980 ICIDH, and focuses solely on the notion of handicap or participation restriction. The words 'disability' and 'impairment' are not used in the questionnaire, only the more general and undefined 'health'.

Table 4.28: London handicap scale

Purpose/ philosophy	To measure effect of health on 'everyday life'.
ICIDH-2 dimensions	
• Impairment	Concept possibly implied in the attribution of cause to 'health problems'.
• Activity [limitation]	Concept appears present in questions such as: 'does your health limit your work or leisure activities', but on further examination of response categories it is clear the question is aimed more at the concept of Participation [restriction] as an example, one response for this question is 'you do almost all the things you want to do'.
• Participation [restriction]	The six questions of the scale are based on the six 'survival role' categories of the Handicap dimension of the 1980 ICIDH.
• Contextual factors	Concept not present explicitly, but is present in response categories to questions, for example, the question 'Does your health stop you from getting around?' has responses including 'You get out of the house but not far away from it' and 'You go most places you want, but not all'.

ComQol

The ComQol scale (Cummins 1993) is designed as a comprehensive quality of life scale, which incorporates a contemporary understanding of the quality of life construct. ComQol defines life quality in terms of seven domains which together are intended to be inclusive of all quality of life components. These are: material wellbeing, health, productivity, intimacy, safety, place in community, and emotional wellbeing. There is an adult version of the ComQol, with two parallel versions also developed: ComQol-AD for adolescents, and ComQol-ID for people who have an intellectual disability or cognitive impairment.

In scoring against this scale, objective and subjective measures are considered independently. The measurement of each subjective quality of life domain is achieved by obtaining a satisfaction score for that domain which is weighted by the perceived importance of the domain for the individual. The measurement of each objective

quality of life domain is achieved by obtaining an aggregate score based on the measurement of objective indices relevant to that domain. ‘Material wellbeing’ for example, is measured by an aggregate score of income, type of accommodation and personal possessions.

Table 4.29: ComQol

Purpose/ philosophy	To provide an aggregate score for the quality of life of an individual, combining objective and subjective measures.
ICIDH-2 dimensions	
• Impairment	Implied in the questions: Do you have any disabilities or medical conditions (e.g. visual, hearing, physical, health etc.)?
• Activity [limitation]	Implied in above question.
• Participation [restriction]	Frequency of participation in social and recreational domains, such as clubs and societies, chatting with neighbours, movies etc. Satisfaction with and importance of different domains is explored (domains similar but not identical to ICIDH-2 domains).
• Contextual factors	Questions on environment mainly relate to home and living arrangements.

4.7 Conclusion

The framework provided by the draft ICIDH-2 appears useful in describing and relating the various administrative definitions of disability and disability services in Australia.

Mapping the various definitions and concepts has highlighted some patterns in services for, and legislation relating to, people with a disability. Broad, inclusive definitions—such as those used in the Commonwealth Disability Discrimination Act, and those used by the ABS in its Survey on Disability Ageing and Carers—focus on all dimensions as well as contextual factors.

Generic or ‘mainstream’ services tend to use impairment and activity limitation as screens to bring people under consideration, and then may use participation and contextual factors to determine eligibility, if the assistance offered is directed to these effects (for instance, the effects of impairment on education, and the possibility that equipment may be of assistance).

Income support schemes—social security or insurance based schemes—frequently use the concept of impairment (sometimes including a concept of ‘whole person impairment’) as a gateway to eligibility, and then use participation restrictions (usually relating to employment) to establish entitlement to income replacement.

Specialist services for people with a disability appear to focus principally on participation, both in terms of eligibility for and purpose of the services. Impairment again is a gateway to eligibility (and to categorising ‘disability groups’) although it does not establish eligibility on its own.

Specific definitions or use of the concepts of activity limitation or disability are relatively rare, as is acknowledgment of environmental or contextual factors.

5 Issues for discussion

In this chapter we bring together some conclusions from the developmental and investigative work outlined in the first four chapters. The purpose is to draw out issues for discussion in the disability field in Australia, particularly during 1997 while evaluating the draft revised ICIDH and contributing to the development of the first National Community Services Data Dictionary.

5.1 Terminology and definition: the yin and yang of policy and data

Terminology has played a crucial role in achieving changed policy and perceptions in the disability field. Good terminology unearths and crystallises basic concepts. Ideally it is also stable and consistent enough to help people communicate.

Data definitions at best reflect the ‘true’ underlying concepts and are consistent with current terminology. Good definitions clarify key ideas and are capable of underpinning a range of complex data collections.

When terminology changes fast, data definitions tend to lag behind. When terminology is being used as an instrument of policy change, data definitions—by nature slower moving and frequently aligned to the policy status quo—may be seen to be part of a system needing reform.

Both roles are important: terminology as the flag bearer of vision and sometimes change; data definitions as the monitoring instruments. Ideally the roles are complementary but consistent, rather than competitive. Terminology which is flexible and data definitions which are more stable both make important contributions to our understanding of disability and the effects of disability policy.

Thus, data definitions should:

- reflect as far as possible the ‘true’ underlying concepts, but not necessarily change as frequently as terminology changes;
- be meaningful and acceptable to people with a disability; and
- relate to the way in which services are defined, so that service use can be monitored and related to needs and outcomes for people.

Population data collections and administrative data collections must develop in concert. If they develop separately, the needs of people (as evidenced in population surveys), cannot be related to data on services received. An obvious corollary is that administrative definitions should be able to be related to each other, as well as to population data.

Ideally, then:

- basic concepts are agreed;
- terminology and data relate to the same basic concepts; and
- data also relate to the policy and administrative framework.

However:

- terminology may evolve faster than do data definitions, which are (and probably should be) more stable (or conservative) than terminology;
- we use terminology to explore common ideas about basic concepts—which we have to hope are relatively stable.

Thus, the interrelationships between concepts, terminology and data can be complex and fluid. Differences among them—and the different pulls each may exert on the other—may be inevitable and may reflect a healthy, evolving system.

However, a fruitful evolution of data definitions should not leave too wide a distance from terminology on the one hand and service definitions on the other.

5.2 Key concepts and terminology

This section briefly discusses some issues about disability terminology in use in Australia, partly to lay them on the table for the public discussion of this paper, but also to suggest language for the discussion which follows in the next section. Promoting public discussion of terminology is one of the main purposes of this paper. Terminology should be as acceptable and meaningful as possible to the people involved, and enhance the debate about the basic concepts.

If the four key concepts of the draft revised ICIDH-2—impairment, activity, participation and environmental or contextual factors—are basic concepts which are recognised and used in Australia (and in section 5.3 we suggest that they are), then how well and how clearly are these concepts reflected in common terminology in Australia?³

Disability

Perhaps the most notable feature about disability terminology in Australia is the number of different meanings apparently attached to the word ‘disability’ itself. In many ways the word ‘disability’ has taken on an overarching meaning.

The term ‘people with a disability’, in the context of disability support services, actually often means people who are experiencing a participation outcome which requires intervention either in terms of personal assistance or environmental modification. In this sense, the term for the second dimension of the 1980 ICIDH—disability—has often been used when referring primarily to the third dimension—handicap.

‘Disability’ is also sometimes used in a shorthand allusion to both impairment and disability. Most of the Australian disability-specific legislation follows the CSDA in referring to something like ‘people with a disability that is attributable to an intellectual, psychiatric, sensory or physical impairment or combination of such impairments’. But in common terminology the two ideas are collapsed—the notion of a

³ Deciding the order of sections 5.2 and 5.3 vividly illustrated the interconnections between concepts, terminology and data (and administrative) definitions. It is hard to discuss a topic without agreeing on terminology first, but it is hard to agree on terminology until the topic and concepts are tested against a range of common usage.

'disability attributable to a physical impairment' becomes condensed into the term 'physical disability'.

These two uses or connotations mean that 'disability' as a term brings in three of the dimensions of the 1980 ICIDH—impairment, disability and handicap—and at times may be even more blurred. Perhaps reflecting these difficulties, 'disability' is seldom defined in Australian legislation.

Activity and activity limitation

The second dimension of the ICIDH now classifies a range of activities (which could possibly be carried out by any human being) and replaces the term 'disability' with the notion of 'activity limitation', which is classified in terms of the difficulty the person experiences with the activity and/or the assistance they need in performing the activity (see box 3.2).

Issues for discussion

- Are these new terms and ideas useful? Are they preferable to the 1980 disability classification? Are they in fact new or is the change simply a renaming and expansion?
- Is it accurate to say that it is now 'activities' which are classified? Is the definition accurate, or should it be phrased as 'area of functioning' rather than 'nature and extent of functioning'?
- Should the 'activity' classification be brought into line with more generic activity classifications such as those used in the time use surveys (which have an internationally agreed activity classification)?

Disablement

In the draft ICIDH-2 the word 'disablement' is used in two ways. First, it is used in the singular, as an overarching concept, much as 'disability' is now. Effectively, 'disablement' seems to replace 'disability' as a generic term in the ICIDH-2 draft. The word also still carries the notion of a 'process', as used previously.

Second, it is used as a term which is exchangeable with any of the three dimensions; thus a reference to 'disablements' could mean any of a number of effects relating to impairment, activity or participation. Used in this way it refers to the person affected, and appears to be used in the draft ICIDH-2 to dispense with the general term 'disability'.

Issues for discussion

- Are both these uses of the term 'disablement' in the ICIDH-2 clear and acceptable?
- Or do we prefer to accept disablement mainly in its current use, as a term for an overarching process?
- Is the effective replacement of the word 'disability' acceptable in Australia? Or do we prefer to retain the word 'disability' as the general personal descriptor—that is, use 'person with a disability' to refer to someone who has an impairment, activity limitation or participation restriction?

Handicap or participation restriction?

The word 'handicap' is widely perceived to be no longer an acceptable term among people with a disability and their advocates. It is understood that the term has fallen from favour largely because of the use of the word 'handicapped' to label people, and to see them only in term of this label—to fail to describe them as people first, with many capabilities as well as some disability.⁴

The draft revised ICIDH-2 proposes the ideas of 'participation' and 'participation restriction' as more accurately reflecting the key outcomes desired (see chapter 3).

It was reported at the ICIDH meeting in May 1996 that there is a view in some developing countries that a change in terminology (from impairment, disability and handicap) will be confusing in countries who are only just beginning to recognise the concepts and to separate disability policy from a more medical approach. There may be some international pressure to retain the word 'handicap'.

There appear to be mixed views in the United States. There has been a strong view in favour of replacing the word 'handicap', expressed for instance by North American participants at WHO meetings of ICIDH collaborating centres, who state that the word 'handicap' cannot be used in the United States or Canada. A more recent view, put in correspondence to WHO from members of a task force working on children's disability, has nevertheless been that the 1980 word 'handicap' and related concepts should be tested in the Beta phase.

Issues for discussion

- What is the preferred word in Australia—'handicap' or 'participation restriction'?
- How does the preferred word relate to the desired concept for the third dimension?
- Is the definition of 'participation' clear (see box 3.3)? Should it be preceded by 'in the context of disablement' or would this make the definition circular?
- Does the phrase 'in relation to impairments, activities, health conditions and contextual factors' clarify that the classification does refer to participation restrictions associated with 'disability'?
- Should the definition of 'participation refer' to 'activity limitations' rather than 'activities'?
- Are the participation domains or the handicap 'survival roles' preferred and why (see table 3.2 and appendix 3)?
- If the revised ICIDH adopts the word 'participation', is it satisfactory for Australian purposes? And should it be widely adopted into official data collections?

⁴ For similar reasons people in Australia are no longer usually referred to as 'disabled' because the label characterises the person solely in terms of one characteristic of many; the more acceptable term is now 'person with a disability'. Nevertheless, in the United Kingdom the term 'disabled' appears to be preferred, signifying that the person has been disabled by society rather than having an attribute of 'disability'.

Health

The 1980 ICIDH definitions have a standard preamble ‘in the context of health experience’ (section 3.2). Health interventions usually focus on individuals, and on shorter term medical interventions, so health-related terminology has perhaps been seen as irrelevant or even inimical to the development of disability services and the enhancement of rights and life opportunities for people with a permanent disability. Further, a concentration on clinical diagnosis (or grouping) rather than on needs is sometimes believed to lead to inappropriate resource allocation. Social and environmental improvements as well as services providing people with ongoing support have been sought instead, to enable participation and autonomy of the person involved.

Health is defined by the WHO as ‘a state of complete physical, mental and social well-being’ (WHO 1946). This holistic definition may soften the perceived ‘clinical’ focus of health, but does not clarify the scope of the ICIDH classification.

ICIDH-2 retains the preamble ‘in the context of health condition’ (section 3.5). This preamble may be considered desirable, for example, in widening the ambit of disability in Australia beyond ‘impairment’ and ‘activity limitation’ to include the HIV virus under the Disability Discrimination Act.

Issues for discussion

- Does the inclusion of the preamble ‘in the context of health condition’ widen or narrow the scope of ICIDH-2?
- Is widening or narrowing the effect desired?

Level of support needed—‘severity’ concepts

The notion of ‘support needs’ appears to be a familiar one in Australia, especially when considering access to disability support services, and the type of assistance needed. The ABS disability survey collects national data on support needs in activities of daily living (self-care, mobility and communication). A wider variety of supports than just activities of daily living is envisaged in the ‘participation’ domains of the revised ICIDH-2, which also include social relationships, education work and leisure, economic life and civic and community life (table 3.2).

Measures of support needs may be used to ‘assess’ people’s need for services or assistance. Such measures, if not validated by all parties, can be seen as inappropriate and even oppressive. Where measurement methods change over time, or vary among related services, they may be seen as arbitrary. But without publicly transparent eligibility criteria and ranking criteria, rationing (which exists in the provision of most public services) becomes informal and unaccountable. Thus, some indicator of support needed is a tool for monitoring equitable access to disability support services.

The use of undefined terms such as ‘substantial’ and ‘significant’ in many Australian services definitions (chapter 4) allows administrative discretion on ‘relative need’, that is, informal rationing. A measure of support needed, if not defined, is likely to creep in undefined, thereby limiting public accountability.

Need

The word and concept of ‘need’ is present in a number of service definitions in Australia (and in some of the proposed qualifiers for ICIDH). Its presence in the main

population disability survey in Australia enabled the estimation of unmet demand for disability support services (Madden et al. 1996).

All people have needs, and much has been written about the nature of human need (see, for instance, Bradshaw 1972; Doyal & Gough 1991). People are often obliged to express these needs or take other action to satisfy them. One of these actions may be to seek help or a service. People seeking a service to satisfy their needs are generally required to express their need in terms of the service definition, and to provide some information to the service giver (see chapter 1). If the person does not need the service, no information is given.

It is understood that some people object to the use of the word 'need' as implying some 'deficit' in the person expressing the need. Again, this is an issue for public discussion. However, if the word is unacceptable, views should also be expressed on the implications of rejecting the idea of 'need'.

Issues for discussion

- Are the notions of 'need' and 'support needs' acceptable in Australia?
- If they are unacceptable, what concept or idea should replace the idea of 'need'? Or can we do without one?
- If there is a view that the idea is not required, how can we describe the rationale and process by which services are requested and supplied (and related information collected)?

Qualifiers for 'participation'

Five key concepts have been suggested in the course of developing qualifiers for the new third dimension of the ICIDH: satisfaction with manner of participation (difficulty), satisfaction with outcome of participation, contextual facilitator (or barrier), personal support needed, difficulty experienced by the person, and extent of participation. These proposals are described in section 3.6.

'Satisfaction with participation' seems a particularly useful concept, reflecting the key notions of empowerment and autonomy—satisfaction should be in relation to the person's own goals.

Issues for discussion

- Is the 'satisfaction with participation' metric a useful qualifier of participation dimension?
- Which are the two or three least useful of the five qualifiers set out in Section 3.6 and why?
- How can the 'extent of participation' in relation to norms be judged for any one person?
- Does it matter that the concepts of 'difficulty' and 'assistance' are suggested as qualifiers for both 'activity limitation' and 'participation'? Is there a distinction or does this lead to confusion?

Combining a number of impairment scores

A single, global measure of impairment for a person has become an important measure for social security payments in Australia.

Issues for discussion

- Is a method for combining individual impairments, activity limitations or participation restrictions needed in the ICIDH?
- Are Australian methods used by the DSS and DVA worth placing into the international arena for review in this context?

5.3 Key concepts and data definitions: is the ICIDH a possible cornerstone for Australian data definitions?

Terminology was related to key concepts in section 5.2. In this section, data definitions are related to key concepts, by reflecting on how the definitions discussed in chapter 4 relate to the proposed ICIDH. The approach is to see if the draft ICIDH-2 works in the Australian data context and, if not, what would be better. The purpose of the section is to attempt to draw out issues for public discussion.

There are a wide range of services in Australia, both specific and generic, of relevance to people with a disability. Many of these services use apparently different definitions of disability and related concepts for their own purposes, usually via eligibility criteria for the service. The administrative definitions generally define a subset of people with a disability for whom a service is provided, rather than defining disability. These various administrative definitions dictate the way with which services are administered and described, and the data emanating from them. However, the larger the reach of service, the more the administrative definition is likely to influence perceptions of disability.

Australian statistical and administrative definitions were mapped onto the ICIDH-2 framework in chapter 4. Not only were the four basic ICIDH-2 concepts frequently present and distinguishable, but the gaps in the definitions became apparent—for instance the infrequent reference to environmental or contextual factors as well as the general absence of definition of ‘disability’.

The separation of the broad notion of ‘disability’ (or ‘disablement’?) into four concepts appears useful for understanding and analysing processes which are occurring. Disability service information must necessarily include the notion of ‘participation’, which is affected by the environment and society at large, and is also a prime purpose of disability support services. It also seems essential to separate this concept from the more personal measures of impairment or activity limitation. Using this approach, we might be able to comment that, with certain changes to services, a certain percentage of people with impairment or activity limitation have improved their participation outcome. A number of disability initiatives are aimed at social and environmental effects. To the extent that the Australian environment becomes more appropriate to people with a disability, there should be a lowering of the apparent need for support services. The success of these approaches needs to be evident from the statistics, otherwise there is a risk of not knowing what has worked and efforts in important areas may be relaxed.

The revision of the ICIDH has strived to make the classification more relevant and acceptable to people in the field, in particular by responding to criticism that the 1980 version did not adequately reflect the importance of environmental factors.

The role of carers has gained increasing public recognition in recent years. Informal care, provided by family and friends, provides the majority of the assistance received

by people with a disability (ABS 1995; AIHW 1995a). This contribution is recognised by governments which provide some support to carers, chiefly in the form of financial support or respite. Thus, collecting information on informal care as well as formal services is also an important part of providing a national picture of assistance to people with a disability.

Chapter 4 tests the ICIDH-2 concepts in the administrative context. It is also vital to test them in the wider community. Do these concepts reflect the way in which people in the field think about disability? Does the ICIDH provide a framework which helps relate key questions in the field to data definitions which might help answer these questions?

Issues for discussion

- What are the key questions that people in the disability field would like to see answered by the provision of quantitative data? Does the ICIDH help us frame these questions?
- Do the four new draft ICIDH-2 dimensions—Impairment, Activity (limitation) and Participation (restriction)—work in the disability field at large, particularly among people with a disability?
- Is the conclusion of chapter 4 reasonable—that the four new ICIDH concepts do provide a useful framework into which to fit Australian statistical and administrative definitions?
- Do the participation qualifiers enable improvements in participation to be monitored at a personal and also a socially aggregated level?
- Do the concepts of the ICIDH-2 support collecting data about carers?

5.4 Core questions for disability data?

This section further explores the possibility that the ICIDH-2 concepts provide a workable framework on which to build some key questions and output for disability data in Australia. The ultimate aim is to draft a range of related or consistent data items and questions, as options for use or reference, to promote national consistency of disability data. These suggestions are formulated in response to the high demand for nationally consistent disability data (see chapter 1) and to ensure that key disability data items are reflected in the National Community Services Data Dictionary now being developed (see chapter 2).

Core output: the first digit of ICIDH-2 dimensions?

If the ICIDH-2 is a reasonable framework for key disability definitions and classifications, then core output from data collections should provide information on the first digit classifications of the three main dimensions—Impairments, Activities, and Participation.

These dimensions are defined in boxes 3.1, 3.2, 3.3. The first digit codes are given in appendix 3. The five possible qualifiers for participation are set out in section 3.6.

Purposes and nature of collection

Before considering draft questions capable of producing this output, it is useful to review the types of purposes of each ICIDH-2 dimension in various current collections (see chapter 4).

Broadly, the ICIDH-2 concepts of impairments and activities (or activity limitations) are currently used in Australia to:

- screen people into population surveys or the ambit of services, that is, to define the broad group of ‘people with a disability’;
- define and name specific disability groupings in legislation and related service collections and in common terminology; and
- enable the collection of data on impairments and activity limitations.

Thus, impairments and activity limitations are:

- the key to screening questions in the major services and in the ABS survey;
- also a screen for ICIDH, so that a participation restriction is not picked up unless associated with impairment or activity limitation;
- the key to the CSDA MDS ‘disability groups’ (for instance ‘physical disability’);
- the basis of a possible census question;
- located in ‘person characteristics’ in the AIHW information model (see appendix 2).

Data on the participation dimension are usually collected to present a fuller picture of the person’s situation (in some detail as in the ABS survey) or as a central part of service provision (in focused detail). Specific services concentrate on different aspects of participation, for instance, the person’s likelihood of participation in work (as in assessment for the Disability Support Pension) or the person’s need for living assistance (as provided by a disability support service).

How the ICIDH-2 output could be produced

This subsection sets out a number of questions, in increasing detail, which could be used in various types of data collections—the more disability-specific collections enabling the greatest level of detail, and the large, more general collections demanding a shorter set of questions.

A minimum solution—questions for the census and some generic service collections

In late 1996 the ABS convened a meeting in Canberra, of interested stakeholders to discuss a possible census question relating to disability. There is great interest in this possibility, so as to be able to refine estimates of disability prevalence for small areas (for planning purposes) and for small population groups (especially Indigenous peoples).

An ABS draft, based on the New Zealand census question, was further refined during the meeting to (among other things) make it align to the complete activities dimension of the ICIDH-2:

CQ1. Do you find it difficult or impossible, or do you need or receive help:

- seeing, hearing or recognising things?
- to do everyday activities such as eating, dressing or moving around?
- to communicate or socialise with others?
- to do activities that people your age usually do (work, school, leisure, handling money)?
- to learn, understand or remember things?

CQ2. Is this because of your (or the person's):

- long-term health condition?
- short-term health condition?
- age?
- disability? OR impairment or injury of body part or function?⁵

These questions, or something similar, are being tested and further developed by the ABS and discussed with ABS user groups to examine their possible use in the next census.

Their brevity means that they could also be used in generic service collections aiming to identify people with a disability, in a manner consistent with the census. If it were important to focus on one particular activity area, for instance, education, this could be split from its grouping with other areas.

Issues for discussion

- Are these questions likely to lead to meaningful data?
- Could these questions also be used for generic service data collections wishing to identify people with a disability?
- How can these questions be made clearer to people responding?

Questions for population surveys and disability specific data collections

Questions for population surveys and disability specific data collections would be similar to the minimalist census questions, but would:

- allow more specificity by providing lists (or prompt cards) showing all activities for CQ1 and all 'conditions' and 'impairments' for CQ2; and
- allow for information on participation and contextual factors.

Thus, CQ1 and CQ2 could be supplemented by similar questions based on the Participation dimension of ICIDH-2:

DQ3. Are you restricted in your participation in the area of:

- work, education, leisure?
- social relationships?
- financial transactions and economic life?
- communication, including writing?
- eating, dressing or moving around?

⁵ The response options for CQ2 are not mutually exclusive, and will hopefully be refined in ABS testing.

(This draft has not been refined to make it clear to survey respondents; it is simply framed to reflect the full participation dimension.)

DQ4. For any area where your answer was yes:

- what assistance do you need (insert personal support categories)?
- what changes do you need in the people or things around you (insert contextual facilitator/barrier categories) to make it easier for you to participate in this area?
- how satisfied are you with your level of participation (insert categories for satisfaction with outcome of participation)?
- how satisfied are you with the process, how difficult is your participation (insert 'process/manner' categories)?

Further work by the AIHW is planned, to map these questions on to the definitions and collections outlined in chapter 4 (and map in the reverse direction) so as to check the viability of these proposals. Work with the CSDA minimum data set network could result in the tighter use of CQ1 and CQ2 in naming the 'disability groups' in that collection; some information relating to DQ3 and DQ4 is already in the collection.

Discussion of the proposal could help to formulate firm proposals for adoption in administrative data collections.

ABS disability survey

The importance of the ABS disability survey as a national data source is such that it will remain a key focus of conceptual development of data on disability in Australia.

The operationalisation of new ICIDH-2 concepts—if practical and acceptable—into the disability population survey will be largely the responsibility of the ABS. If their developmental and consultative work proceeds in parallel with the work flowing from this paper, consistency can be achieved. The ABS survey has influenced this work and its ongoing development will continue to do so.

It is vital that population data be able to be related to service data and that census questions on disability produce estimates compatible with population survey questions.

How to produce consistency once questions are drafted

The National Community Services Data Dictionary (discussed briefly in chapter 2) will be a major vehicle for promoting consistency of disability data. It is hoped that the first draft of this Data Dictionary will be released in 1997, but work such as suggested in this paper will take longer to develop and agree (and can be included at a later time). The definitions in the national data dictionary might be accompanied by different illustrative questions designed to show (as suggested above) how relevant questions would look in:

- a lengthy population survey;
- a population census;
- an administrative data collection relating to disability support services; and
- an administrative data collection relating to generic services, where the main purpose may simply be to identify the person with a disability.

The shortest set of questions will be required for use in the census and in some generic service collections (administrative and population surveys other than the specialist disability survey). This short 'identification module' should be consistent with ABS screening questions for the disability survey.

5.5 How to move towards consistency in Australia

This discussion paper has been prepared on the assumption that it is desirable to move towards greater consistency of disability data in Australia. Calls for greater consistency in definitions have been made over a number of years, and the greater usefulness and power of more reliable national data sets appears to be widely acknowledged.

The paper also, in reviewing nationally significant definitions and collections, has tended towards the conclusion that the draft ICIDH-2 may provide a useful framework for more consistent administrative and data definitions. The ICIDH-2 concepts appear to reflect the general approach of Australian service definitions, and have attempted to embrace ideas and criticism put forward by the wider disability field. In chapter 4 it was found to provide a useful framework for comparison and identifying gaps.

An attempt has been made in section 5.4 to use the draft classification to move on to the next step, and to draft some basic common questions which might be used in Australian data collections. Are these draft questions usable? acceptable? Will they help answer the key questions identified (by discussants) in section 5.3? It is unrealistic to expect that differences among administrative definitions can be eliminated, but the gradual evaluation and adoption of such questions, based on an international classification system, may minimise differences in data collections.

The National Community Services Data Dictionary and Information Model

Moves towards greater consistency of data definitions are occurring across the community services field (see chapter 2). The development of a National Community Services Data Dictionary is a high priority in the national work plan established, reflecting the need across the whole community services sector for greater consistency in data definitions and rationalisation of data collections. Potentially this greater consistency will have benefits not only within a diverse field such as the disability services field, but also for organisations and people working across a number of different community services (for instance non-government organisations acquitting funding from several different government programs). The parallel development of both an information model and a data dictionary is planned for 1997 and 1998.

Recognising the value of information models in clarifying ideas, aiding communication and setting priorities for data development—as well as the complexity of developing a much needed data dictionary for disability services—the AIHW began in 1996 to develop a draft Disability Information Model. The first draft resulted from a workshop with the Disability Data Reference and Advisory Group, who have maintained a watching brief over its subsequent development. Further work has now produced a

first draft of a Community Services Information Model (included and described in appendix 2). The four draft ICIDH-2 concepts informed the development of the model. Recommendations arising from the discussion of this paper will inform these national developments.

Issues for discussion

- Is there reason not to work towards greater national consistency in disability data?
- Does the draft Community Services Information Model include concepts which reflect the main issues in the field (in particular, provide a framework for answering the key questions which discussants identify in section 5.3)?
- Are the draft questions in section 5.4 relevant to the key issues in the field? Can they be used to underpin key data collections relating to the population needing services and those receiving services? Are they worded in an acceptable way? Are they relatable to important current collections? Could they be useful elements in a National Community Services Data Dictionary?

5.6 What next?

This paper is to be available in the following additional formats:

- Full version and plain English version available at the AIHW Home Page (<http://www.aihw.gov.au>);
- Full version and plain English version available on diskette, on request to the authors;
- A plain English version will be available on audio cassette, probably after being read on Print Handicap Radio.

You are invited to respond to the issues raised in this paper in a number of ways:

- by responding to the questionnaire on the website (<http://www.aihw.gov.au>);
- by responding to the enclosed questionnaire;
- by writing to the authors at the AIHW.

In addition nominees of DDRAG will be invited to a specific discussion. Other people interested in attending a discussion can indicate their interest in the questionnaire.

Following this feedback, a final paper of conclusions will be published. These conclusions will be used to inform the Australian response to WHO on the draft ICIDH-2, and the work of the Institute in formulating a National Community Services Data Dictionary.

Abbreviations

ABS	Australian Bureau of Statistics
ACAT	Aged Care Assessment Team
ACROD	Peak organisation of service providers for people with a disability
ADL	Activity of daily living
AHS	Australian Hearing Services
AIHW	Australian Institute of Health and Welfare
ATSIC	Aboriginal and Torres Strait Islander Commission
CES	Commonwealth Employment Service
COAG	Council of Australian Governments
CRS	Commonwealth Rehabilitation Program
CSDA	Commonwealth/State Disability Agreement
CSDA MDS	CSDA Minimum Data Set
DCSH	Department of Community Services and Health
DEETYA	Commonwealth Department of Employment, Education, Training and Youth Affairs
DHFS	Commonwealth Department of Health and Family Services
DHSH	Department of Human Services and Health
DSS	Commonwealth Department of Social Security
DSSC	Disability Services Sub Committee
DVA	Commonwealth Department of Veterans' Affairs
HACC	Home and Community Care Program
ICIDH	International Classification of Impairments, Disabilities and Handicaps
NDAC	National Disability Advisory Committee
SCCSISA	Standing Committee of Community Services and Income Security Administrators
WHO	World Health Organization

References

- Accident Compensation Act 1985. No. 101191. Victoria.
- Aged or Disabled Persons Care Act 1954. Commonwealth.
- Aged or Disabled Persons Homes Act 1974. No. 115. Commonwealth.
- AMP Financial Services 1996. Income continuation and business overheads insurance brochure, January 1996. Australian Mutual Provident Society.
- Australian Bureau of Statistics (ABS) 1993. Disability, ageing and carers, data reference package. Cat. no. 4432.0. Canberra: AGPS.
- Australian Bureau of Statistics (ABS) 1995. Focus on families: caring in families—support for persons who are older or have disabilities. Cat. No. 4423.0. Canberra: ABS.
- Australian Institute of Health and Welfare (AIHW) 1992. Australia's health. Canberra: AGPS.
- Australian Institute of Health and Welfare (AIHW) 1993. Australia's welfare 1993: services and assistance. Canberra: AGPS.
- Australian Institute of Health and Welfare (AIHW) 1994a. Australia's health. Canberra: AGPS.
- Australian Institute of Health and Welfare (AIHW) 1994b. Measurement of disability: workshop proceedings, Canberra, Australia, 21–22 February 1994. Canberra: AGPS.
- Australian Institute of Health and Welfare (AIHW) 1995a. Australia's welfare 1995: services and assistance. Canberra: AGPS.
- Australian Institute of Health and Welfare (AIHW) 1995b. Data briefing for open employment services, No. 1, Quarter 1.
- Australian Institute of Health and Welfare (AIHW) 1996a. National community services information agreement and development plan. Canberra: AIHW.
- Australian Institute of Health and Welfare (AIHW) 1996b. National data for aged care services: an overview of current collections, 2nd edition. May 1996. Canberra: AIHW.
- Badley EM 1993. An introduction to the concepts and classifications of the International Classification of Impairments, Disabilities, and Handicaps. *Disability and Rehabilitation* 15(4):161–78.
- Baume P & Kay K 1995. Working solution: report of the strategic review of the Commonwealth Disability Services Program. Canberra: AGPS.
- Bradshaw J 1972. The concept of social need. *New Society* 30:640–3.
- Castles I 1993. Disability ageing and carers: data reference package. ABS Cat. No. 4430.0. Canberra: ABS.
- Canberra Institute of Technology 1997. Enrolment form.
- Comcare Australia 1989. Guide to the assessment of the degree of permanent impairment. Canberra: AGPS.
- Comcare Australia 1993. How it works brochure. Canberra.
- Commonwealth Department of Community Services and Health (DCSH) 1991. Interim commonwealth guidelines for hostel assessment, January. Canberra.

Commonwealth Employees Rehabilitation and Compensation Act 1988. No. 75.

Council of Australian Governments (COAG) 1995. Council of Australian Governments meeting, 11 April 1995. Communique. Canberra.

Council of Australian Governments (COAG) 1996. Council of Australian Governments meeting, 14 June 1996. Communique. Canberra.

Cummins RA 1993. Comprehensive quality of life scale for adults, 4th edition (ComQol-4). Melbourne: School of Psychology, Deakin University.

Department of Employment, Education, Training and Youth Affairs (DEETYA) 1997. AUSTUDY Information Book. Canberra.

Department of Employment, Education, Training and Youth Affairs (DEETYA) 1996. Commonwealth programs for schools 1996: administrative guidelines. Canberra: AGPS.

Department of Veterans' Affairs (DVA). Claims for Disability Pensions: information for veterans and members of the defence forces brochure. Canberra.

Department of Veterans' Affairs (DVA) 1994. Guide to the assessment of rates of Veterans' Pensions, 4th edition. Canberra: AGPS.

Department of Social Security (DSS) 1996. Claim for Carer Pension form SA002.9607.

Department of Social Security (DSS) 1995. Claim for Child Disability Allowance form SC005.9510.

Department of Social Security (DSS) 1995. Claim for Disability Support Pension form SA002.9510.

Department of Social Security (DSS) 1995. Claim for Mobility Allowance form MA001.9511.

Department of Social Security (DSS) 1995. More opportunities for people with disabilities brochure, July. Canberra.

Disability Discrimination Act 1992. No. 135. Commonwealth.

Disability Services Act 1986. No. 129. Commonwealth.

Disability Services Act 1992. Queensland.

Disability Services Act 1993. No. 36. Western Australia.

Disability Services Act 1993. No. 18. South Australia.

Disability Services Act 1991. No. 80. Victoria.

Doyal L & Gough I 1991. A theory of human need. London: Macmillan Press.

Gillett S & Katauskas E 1993. Waiting lists—a look at the literature. Canberra: AIHW.

Harwood RH, Rogers A, Dickinson E, Ebragim S 1994. Measuring handicap: the London handicap scale, a new outcome measure for chronic disease. *Quality in Health Care* 3:53-57.

World Health Organization (WHO) 1997. ICDH-2: International Classification of Impairments, Activities and Participation. A Manual of Dimensions of Disablement and Functioning. Beta-1 draft for field trials. Geneva: WHO.

Luckasson R, Coulter D, Polloway E, Reiss S, Schalock R, Snell M, Spitalnik D & Stark J 1992. Mental retardation: definition, classification, and systems of supports. Washington DC: American Association on Mental Retardation.

- Madden R, Black K & Wen X 1995. The definition and categorisation of disability in Australia. Canberra: AGPS.
- Madden R, Wen X, Black K, Malam K & Mallise S 1996. The demand for disability support services in Australia: a study to inform the Commonwealth/State Disability Agreement evaluation. Canberra: AGPS
- Martin LM 1994. Equity and general performance indicators in higher education: volume 1 equity indicators. Canberra: AGPS.
- North American Proposal for the Social Participation Level of the International Classification of Impairments, Disabilities and Handicaps 1996. Unpublished communication with the WHO, June.
- Office of Disability 1994. Commonwealth Disability Strategy: a ten-year framework for Commonwealth departments and agencies. Canberra: AGPS.
- Senate Standing Committee on Community Affairs 1992. Employment of people with disabilities. Canberra: Senate Printing Unit.
- Social Security Act 1991. No. 46. Commonwealth.
- Steering Committee for the Review of Commonwealth/State Service Provision 1995. Report on government service provision. Melbourne: Industry Commission.
- Steering Committee for the Review of Commonwealth/State Service Provision 1997. Report on government service provision. Melbourne: Industry Commission.
- University of Canberra 1977. New student unit registration form 1997. Form No. SA68.07B. Canberra.
- Victorian Workcover Authority 1996. 1995–1996 Annual Report. Melbourne.
- Ware JE & Sherbourne CD 1992. The MOS 36-Item Short-Form Survey (SF-36) 1, Conceptual framework and item selection. *Medical Care* 30(6):473–83
- WCC & Dutch Classification and Terminology Committee for Health 1994. A survey of criticism about the classification of impairments and the classification of disabilities of the International Classification of Impairments, Disabilities and Handicaps. Zoetermeer: ICIDH.
- World Health Organization (WHO) 1946. Constitution of the WHO. Reprinted in *Basic Documents*, 37th ed. Geneva: WHO.
- World Health Organization (WHO) 1980. *International Classification of Impairments, Disabilities, and Handicaps: a manual of classification relating to the consequences of disease*. Geneva: WHO.
- Yeatman A 1996. *Getting real: The final report of the review of the Commonwealth/State Disability Agreement*. July 1996. Canberra: AGPS.

Appendix 1: Disability Data Reference and Advisory Group

Organisation	Representative
National Caucus of Disability Consumer Organisations	Dianne Temby Mark Pattison
Carers Association of Australia	Rose Ross (to mid 1997) David Fisher (mid 1997)
ACROD	Helen McAuley
Federation of Ethnic Community Councils of Australia	Kin Win May
ABS	Jennie Widdowson
DSS	Trevor Hughes
DHFS	Angela Hewson
DEETYA	Monica McMahon
DSSC	Karl Mortimer (SA) Sharyn Campbell (NSW)
Person expert in Aboriginal and Torres Strait Islander statistics	Tony Barnes
Independent experts	Maree Dyson Bill Jolley (to mid 1997) Trevor Parmenter John Taplin John Walsh
AIHW	Ching Choi (Chair) Ros Madden Tracie Hogan

Appendix 2: National Community Services Information Model

The Australian Institute of Health and Welfare is undertaking the development of a National Community Services Information Model in consultation with the National Community Services Data Committee. The Institute has considerable experience in information modelling having published the *National Health Information Model Version 1.0* in January 1996. (This publication extensively describes the concepts, techniques and rules for developing an information model.)

Development of the model has occurred via four workshops held between June and September 1997. Units from the Welfare Division of the Institute (Children and Family Services, Disability, Aged Care, SAAP and Welfare Expenditure) participated in the workshops as well people working on mental health within the Institute's Health Division. The Institute has not been resourced to undertake extensive national consultation on this project. National consultation will be facilitated by the Data Committee and the jurisdictions they represent. Representation on the Data Committee includes members from Commonwealth and State Governments as well three representatives from non-government organisations.

The overall objective of the model is to provide a framework for community services information development culminating in the publication of the inaugural National Community Services Data Dictionary. The existence, endorsement and use of a framework will ensure that the Data Dictionary is not driven by individual data collections and their associated data development activities. Other objectives of the model are to:

- identify a commonly agreed information base to enable research and policy development of national community services information;
- assist in minimising duplication of effort in community services information development;
- assist in promoting a common language and the identification of commonality in information requirements across community service sectors;
- inform and facilitate record linkage via improving data comparability; and
- provide a management tool to assist the ongoing development and communication of national community services information, and a coordinating mechanism for this work.

Version 0.5 of the model is shown on the following page. Version 1.0 of the model will be published as part of the Data Dictionary in early 1998. Comment on the current stage of development of the model is welcomed. Feedback can be provided to Joe Christenson (Head, National Information Development Unit, AIHW) by telephone 02 6244 1148 or by mail at GPO Box 570, Canberra, ACT, 2601.

Please note the NCS Information Model (and Data Dictionary) are undergoing development, and changes will be made continually. If using the Model (or Dictionary) for development or presentation in another context, please be advised of their developmental status. If you have any comments or queries on the latest versions of the Model or Dictionary please contact Joe Christenson.

**National Community Services Information Model
Version 0.5**
Prepared by the National Information Development Unit
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PARTY

PERSON	PARTY GROUP
	FAMILY
	HOUSEHOLD
AGENCY	TARGET GROUP
	OTHER PARTY GROUP

LOCATION

ADDRESS
SETTING
SERVICE DELIVERY SETTING
OTHER SETTING

Party characteristics

PERSON CHARACTERISTIC	PARTY GROUP CHARACTERISTIC
DEMOGRAPHIC CHARACTERISTIC	FAMILY CHARACTERISTIC
SOCIO-CULTURAL CHARACTERISTIC	FAMILY INCOME CHARACTERISTIC
EDUCATIONAL CHARACTERISTIC	OTHER FAMILY CHARACTERISTIC
LABOUR CHARACTERISTIC	HOUSEHOLD CHARACTERISTIC
ACCOMMODATION / LIVING CHARACTERISTIC	HOUSEHOLD INCOME CHARACTERISTIC
INCOME CHARACTERISTIC	OTHER HOUSEHOLD CHARACTERISTIC
LEGAL CHARACTERISTIC	AGENCY CHARACTERISTIC
IMPAIRMENT CHARACTERISTIC	STATE OF WELLBEING
DISABILITY CHARACTERISTIC	PERSON VIEW
FUNCTIONAL CHARACTERISTIC	
OTHER PERSON CHARACTERISTIC	

NEED

PERSON PARTICIPATION / INDEPENDENCE

EVENT

PERSON EVENT	HEALTH AND WELFARE SERVICE EVENT
BIRTH EVENT	REFERRAL EVENT
LIFE EVENT	ASSESSMENT OF ELIGIBILITY FOR SERVICE EVENT
DEATH EVENT	ENTRY INTO SERVICE EVENT
	ASSESSMENT EVENT
ENVIRONMENTAL EVENT	SERVICE PROVISION EVENT
ENVIRONMENTAL MODIFICATION EVENT	CASE MANAGEMENT EVENT
	LEAVE FROM SERVICE EVENT
ECONOMIC TRANSACTION EVENT	EXIT / DISCHARGE FROM SERVICE EVENT
EXPENDITURE	DETERMINATION OF LEGAL STATUS EVENT
TRANSFERS/SUBSIDY	OTHER HEALTH AND WELFARE SERVICE EVENT
REVENUE/RECEIPT	OTHER EVENT
COMMUNITY / FAMILY EVENT	
INFORMAL CARER ASSISTANCE EVENT	
INFORMAL CARE EVENT	

ENVIRONMENT

TOOLS AND EQUIPMENT
PERSONAL SUPPORT
SOCIAL AND CULTURAL ENVIRONMENT
ECONOMIC AND POLITICAL ENVIRONMENT
HUMAN MADE PHYSICAL ENVIRONMENT
NATURAL ENVIRONMENT

PARTY ROLE

PERSON ROLE	AGENCY ROLE
CITIZEN ROLE	SERVICE PROVIDER ROLE (Agency)
FAMILY RELATIONSHIP ROLE	SERVICE FUNDER ROLE
CARER ROLE	SERVICE PURCHASER ROLE
RECIPIENT ROLE	OTHER ROLE
SERVICE PROVIDER ROLE (Person)	

Enabling factors

RESOURCE
KNOWLEDGE FACTOR
AVAILABILITY FACTOR
ACCESSIBILITY FACTOR

OUTCOME

HEALTH AND WELFARE PROGRAM

SERVICE

FEE STRUCTURE
ACTIVITY

Appendix 3: One- and two-digit codes of the draft ICDH-2

Classification of impairment

Classification of impairments of function

Chapter 1	Mental functions
Chapter 2	Voice, speech, hearing and vestibular functions
Chapter 3	Seeing functions
Chapter 4	Other sensory functions
Chapter 5	Cardiovascular and respiratory functions
Chapter 6	Digestive, nutritional and metabolic functions
Chapter 7	Immunological and endocrinological functions
Chapter 8	Genitourinary functions
Chapter 9	Neuromusculoskeletal and movement related functions
Chapter 10	Functions of the skin and related organs

Classification of impairments of structure

Chapter 1	Brain, spinal cord and related structures
Chapter 2	Structures involved in voice and speech
Chapter 3	Structures of the ear and vestibular system
Chapter 4	The eye and related structures
Chapter 5	Structures of the circulatory and respiratory systems
Chapter 6	Structures related to the digestive system and metabolism
Chapter 7	Structures related to the immunological endocrinological systems
Chapter 8	Structures related to the urogenital system, continence and reproduction
Chapter 9	Structures related to movement
Chapter 10	Skin and related structures

Classification of activities

Chapter 1 Seeing, hearing and recognising

seeing
hearing
recognising by sensory input
recognising relationships in space and time

Chapter 2 Learning, applying knowledge, and performing tasks

remembering
acquiring and applying knowledge
problem solving
learning a task
performing tasks
managing different kinds of tasks
sustaining performance
managing general psychological demands
other activities relating to knowledge acquisition and use

Chapter 3 Communication activities

understanding messages in speech and formal sign language
understanding non-verbal messages (other than sign language)
understanding written language
producing messages in speech or formal sign language
communicating messages
producing non-verbal messages other than formal sign language
producing written language
using communication devices/techniques

Chapter 4 Movement activities

maintaining a body position
shifting the weight of the body
changing a body position
walking and related activities
transferring oneself while sitting or lying
activities involving fine hand use
activities aimed at making objects move

Chapter 5 Moving around

moving around in the general environment
climbing
moving around in specified environments
moving around in traffic situations as a pedestrian
using transportation
moving around in traffic situations as a driver

Chapter 6 Daily life activities

washing oneself
care of body parts, teeth, nails, hair
activities related to excretion
dressing
eating and drinking
caring for own wellbeing
dealing with everyday objects and appliances

Chapter 7 Care of necessities and domestic activities

procuring and taking care of daily necessities
procuring and taking care of shelter
taking care of meals
laundry and caring for clothes and footwear
taking care of dwelling
taking care of other household or family members
looking after possessions, plants and animals

Chapter 8 Interpersonal behaviours

general interactive skills
other interpersonal skills
managing own personal behaviour
maintaining close personal relationships
maintaining relationships with friends and peers

Chapter 9 Responding to and dealing with particular situations

managing in a specific climate or temperature
managing in other environmental circumstances
managing in a dangerous environment
work- and school-related behaviours
work acquisition and retentions skills
personal social activities
economic skills

Chapter 10 Use of assistive devices, technical aids and other related activities

using aids for therapy and training
using orthoses and prosthesis
using aids for personal care and protection
using aids for personal mobility
using aids for housekeeping
using furnishings and adaptations to homes and other premises
using aids for communication, information and signalling
using aids for handling products and goods
using aids and equipment for environmental improvement, tools and machines
using aids for recreation

Classification of participation

Chapter 1 Participation in personal maintenance

participation in personal care
participation in health maintenance
participation in nourishment
participation in housing and shelter

Chapter 2 Participation in mobility

participation in home environment mobility
participation in mobility outside the home
participation in transportation

Chapter 3 Participation in exchange of information

participation in spoken and non-spoken exchange of information
participation in written exchange of information
participation in exchange of information by symbols and signs
participation in exchange of information by public symbols
participation in exchange of information by means of telecommunication

Chapter 4 Participation in social relationships

participation in family relationships
participation in intimate relationships
participation in relationships with friends and acquaintances
participation in relationships with peers
participation in relationships with strangers
participation in other social relationships

Chapter 5 Participation in the areas of work, education, leisure and spirituality

participation in education
participation in work
participation in play, recreation and leisure
participation in spirituality

Chapter 6 Participation in economic life

participation in economic transactions
participation in economic security

Chapter 7 Participation in civic and community life

participation in citizenship
participation in community

List of contextual factors

Chapter 1 Products, tools and consumables

products or substances for personal consumption
money and other assets
assistive technology
products for personal use in daily living
products for commercial, industrial or employment use
educational products and equipment
cultural or religious objects

Chapter 2 Personal support and assistance

family members
friends
acquaintances, peers and colleagues
personal assistants and other care providers
health service providers
animals

Chapter 3 Social, economic and political institutions

social security system
social assistance and health system
education and training system
associations and organisations
economic institutions
political institutions
other public infrastructure

Chapter 4 Sociocultural structures, norms and rules

sociocultural structures
informal social attitudes
formal social rules
population composition, variation and movement

Chapter 5 Human-made physical environment

architecture
land use

Chapter 6 Natural environment

geography
flora and fauna
weather and air quality
time-related changes
sound
light

Appendix 4: Australian proposals about participation qualifiers (December 1996)—excerpt and adaptation

'Enabling response' is the response, from supports or factors external to the person, needed by the person to enable their desired level of participation in a particular domain. Because participation reflects an interaction between the person with an impairment and/or activity limitation and the environment, the enabling response may be provided in the form of assistance to the person or modification of the environment.

Enabling responses may be, broadly:

- person-focused enabling response—assistance to the person (employment support, equipment, carer etc.); and/or
- environmental-focused enabling response—systemic or environmental modification (ramps, toilets, parking spaces, large print or plain English publications, legislative reforms, attitudinal change, etc.)

'Enabling response' identifies what the person needs in order to achieve the desired level of participation. They may or may not be receiving this response. Information gathered on this variable gauges the ongoing need for various responses (e.g. equipment, personal assistance in various areas). Further questions, for instance, in population surveys or service-related interviews, would elicit what the current level of unmet need is, either on a personal or population basis.

The information or rating should be provided, as far as possible, by the person concerned.

The proposed 'qualifier' is related to the rest of the draft classification in the following way:

- it complements the other originally proposed qualifier of the third dimension (level of satisfaction); whereas that indicates the level of individual satisfaction with participation in various areas, this qualifier indicates the individual's analysis of what external 'response' will enhance their level of participation;
- whereas the 'environmental factors' as presently classified, provide a framework in which an environment can be evaluated, the 'enabling response' indicator shows the specific factors which, for a particular individual in a particular area of participation, need to change or respond in order to enhance participation in a given domain by that individual.

Table A4.1: Person-focused enabling response

Suggested code	Suggested interpretation
0	No response needed in usual environment to participate to desired level.
1	No response generally needed if person is in a suitable community environment (of a standard it is reasonable to expect)—or may experience minor difficulty in a suitable environment. (May imply need for environmental response — eg workplace modification.— but no person-focussed response)
2	Needs equipment and/or financial assistance only—and then experiences at most only minor or occasional difficulty to participate at desired level.
3	Needs no assistance (other than perhaps aids and/or financial assistance), but is experiencing moderate to significant difficulty, or experiencing some curtailment in participation.
4	Is not participating to desired level, is experiencing significant financial hardship (as a result of their disability?), and chiefly requires financial assistance rather than personal assistance with particular activities
5	Needs occasional or infrequent help to participate to desired level, even with equipment or financial assistance. Includes use of signing translator for deaf people Includes when social interaction is difficult beyond friends, colleagues and family?
6	Needs regular support with particular tasks eg 1-4 times per week, but manages many tasks independently on a daily basis. Includes when person does not participate in relationships beyond spouse or immediate family, or can obtain employment only under special circumstances. Includes curtailed participation without support.
7	Needs regular support most days with particular tasks, to participate to desired level. Includes: <ul style="list-style-type: none"> • total dependence on external economic supports; or • difficulty with sustaining employment, education or leisure activities under most favourable circumstances.
8	Needs significant daily support by a carer but can be left alone safely for at least an hour.
9	Needs substantial support by a carer on a daily basis and cannot be left alone safely. Includes someone who is totally economically reliant on others, including government assistance. Generally signifies extremely low levels of participation in the domain.

Source: Australian Collaborating Centre comments on Alpha draft ICIDH, December 1996.

The Australian proposal represents a change of focus from ‘degree of difficulty’ in the 1980 ‘handicap’ and in the June 1996 US proposals on ‘level of satisfaction’, to the idea of ‘response needed’. The gain is a shift from a static view or assessment of difficulty to an emphasis on enabling the person to achieve their desired level of participation.

Similarly there is a shift from the consideration of norms to the consideration of the person’s own goals. ‘Restricted occupation’ (p. 196 of 1980 ICIDH) is measured against some norm. The Australian proposal relates to the person’s own goals, i.e. what is needed to help them achieve their potential—thus focusing on avoidable disadvantage rather than some objective ‘extent of disadvantage’ against social norms.

This qualifier indicated the individual’s analysis of what external response will enhance their participation. The ‘severity of handicap’ scale of the 1980 ‘handicap’ classification can be mapped fairly well onto the ‘person-focused enabling response’ — thus affording some continuity of the old and new versions of the ICIDH.

The environment-focused response (box A4.2) explicitly incorporates the impact of the environment into the third level by describing the particular factors of the

environment that need to change or respond in order to enhance participation in the area by that individual.

Table A4.2: Environment-focused enabling response

Suggested code	Suggested interpretation: Environmental factor needed to respond
0	No environmental response needed to enhance participation
1	Physical factors
2	Technological change, equipment(Comment: not just support needed—see above—but change in the mix of services etc)
3	Social, psychological climate, culture Includes informal support, from family, friends, community Organizations (Comment: not just support needed—see above—but change in the mix of services etc)
4	Legal factors and other administrative policy, practice ('politico economic' factors)
5	Economic system including labour market
6	Health and social services (Comment: not just support needed—see above—but change in the mix of services, eligibility etc)
7	Education and training system response
8	Public infrastructure including public transport
9	

Source: Australian Collaborating Centre comments on Alpha draft ICIDH 1996.

The specific types of response would probably have to be culture-specific and modified by individual countries. In Australia such responses could include: formal disability support services, informal assistance, environmental modification, other improved access to mainstream services, assistive equipment, ongoing medication, or 'self-help'.