

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.