

## **3. Benefits and uses of the ICF for Australia**

Definition, classification and statistics may seem distant, academic exercises to those dealing with the day to day reality of disability. However, a broad, common understanding of disability, including common disability definitions, is crucial to the understanding and improvement of services and outcomes for people.

This section discusses some of the concerns raised about definition and classification and describes the benefits to be gained from having a common framework for work in the disability field. It also discusses past uses of the ICIDH, emerging uses of the ICF, and inquiries the AIHW has received on the ICF and its development.

### **3.1 Concerns about definition and classification**

Many people have reservations about the need to define, classify and measure disability, and there are perhaps two major areas of concern – labelling and assessment.

#### **Labelling**

Definition and classification can sometimes seem to involve labelling, and no-one likes to be labelled. People in the disability field can be very blunt when it comes to saying that the wrong terms are being used or that someone does not know enough about the field to classify the experiences of people in it. Many view labelling as an enemy of progress and are very sceptical about its value. These views are all valid. The ICF explicitly states that it does not classify people – its status and codes apply to body structures and functions, activities and areas of participation, and environmental factors (WHO 2001:8).

#### **Assessment**

The second area of concern arises because of the confusion which can occur between definition, classification and assessment.

The distinction is fundamental to the issue of definition. Definition should attempt to go to the core ideas of a phenomenon. Classification assigns things

to separate and distinct categories so as to group like with like. Definition and classification are descriptive and, ideally, represent part of a complete framework.

Assessment, on the other hand, is designed to serve a particular purpose, often administrative or clinical, and involves evaluation or measurement against specific criteria. In a disability context, assessment frequently involves taking a deliberately narrow view of one part of a person's life. Sometimes this is done with the aim of focusing on an aspect of disability where a particular profession has a relevant skill, for instance a physiotherapist seeking to diminish a specific impairment.

Assessment may also be done with the aim of restricting access to services to those most in 'need', where need is defined in relation to that service only. For instance, eligibility criteria for the Australian Disability Support Pension concentrate on the health condition (diagnosis) and the impairment aspects of disability. The only focus on activity limitation or participation restriction is in the assessment that someone is unlikely to work full-time at full award wages for the next two years. This assessment does not define disability; nor does it define a person. It merely reflects that the person has crossed over a certain line in the 'administrative sand' (in relation to their impairments and assessed likelihood of working) and so is eligible for a pension. Such an administrative definition does not define disability in the broad sense. It specifies that aspect of disability which Australian society has decided to respond to by the provision of a pension.

Assessment is thus a 'problem area' when it comes to promoting the value of definition and classification. People often associate the specificity and limitations of assessment with definition and classification; often they dislike the idea of being assessed even more than being labelled.

The ICF can help to overcome these problems and clarify the difference between assessment and definition and classification. It provides a broad framework that places assessment in context and clearly indicates its particular, and often narrow, purpose and focus in comparison to the broader processes of definition and classification.

## **3.2 Benefits of definition and classification**

Using a common framework of definitions and classifications can add value to many activities in the disability field and ultimately to the policies and services designed to meet the needs of people with a disability.

## Gathering meaningful information

The disability field, like any major policy field, needs information. In debates about policy, desirable outcomes, or resource allocation, information is essential for effective decision-making and reform. And *part* of the information we need is quantifiable data – numbers. Numbers can paint part of the picture, tell part of the story – not the whole story, but a potentially useful part of the story.

Once it is decided that numbers are needed, various questions arise – for example: what do we want to count? why do we want to count it? how can we go about getting reliable and valid data relating to what we want to count? These questions lead to important and complex conceptual challenges that must be dealt with effectively if we are to gather valid and useful information.

### An example: estimating unmet need

In 1995, 1997 and 2001 the AIHW was asked by Australian governments to make some estimates of unmet need for disability support services in Australia (AIHW 1997a, 2002b; Madden et al. 1996). Some of the key findings of the 1997 study were:

- In 1996 there were an estimated 13,400 people with an unmet demand for accommodation, accommodation support or respite services.
- There was an unmet demand for the equivalent of 12,000 full-time places for day programs.
- The estimated costs to Australian governments of providing these additional services totalled \$294 million annually, comprising \$178 million for accommodation services and \$116 million for day programs.
- Additional future pressure on disability services was expected as a result of population ageing and the ageing of carers.
- In 1993 there were an estimated 7,700 parents who were the principal carers of people with severe disabilities. About half of these parents had been providing this care for more than 30 years.

These estimates informed multilateral negotiations resulting in the provision by governments of an additional \$519 million over the 2 years 2000–01 and 2001–02. The preparation of these estimates relied on a small number of common concepts present in both the Commonwealth/State Disability Agreement (CSDA) and in the main disability survey, now conducted every six years by the Australian Bureau of Statistics (ABS). In the Agreement, the target group for CSDA services was defined in terms of specific impairments, reduced capacity for communication, learning or mobility, and the need for

ongoing support<sup>1</sup>. The concepts on which these definitions were based were similar to those used for gathering population data in the ABS survey.

While several data sources were used, the foundation stone of the AIHW estimates of unmet need was the use of similar concepts and terms in the ABS survey and the CSDA itself – in particular, the focus on the need for assistance with activities of daily living. This commonality arose from the fact that elements of the ABS survey and the CSDA eligibility criteria could be readily mapped to a common framework – the internationally recognised concepts of the ICIDH for the 1997 study, and the ICF for the 2002 study (e.g. AIHW 2002b:24).

The use of a common framework, with its common definitions and classifications, thus helps to produce meaningful information for decision making and policy development – and increases the likelihood of improved outcomes for people with disabilities.

## **The value of consistency**

A number of significant national reports have called for common data frameworks and definitions in the disability field. Why does consistency matter so much?

The effects of disability may be experienced in any aspect of the lives of people with a disability and their families. This means that definitions underlying data collections need to be not only clear and meaningful, but also holistic and consistent across all areas of life and all services. Otherwise, data cannot be used efficiently. Studies relying on the combined use of several data sets cannot produce the kind of detailed, authoritative findings that were possible in the study of unmet need discussed earlier in this section.

In a broader sense, consistent concepts and definitions would also lead to succinct, nationally consistent disability questions, identifiers and descriptors that could be used for generic services as well as for disability-specific services. We would then be able to, for instance:

- estimate how many people with disabilities worked in various industries

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1 The CSDA target group was people with a disability attributable to an intellectual, psychiatric, sensory, physical or neurological impairment or acquired brain injury (or some combination of these) which is likely to (a) be permanent and (b) result in substantially reduced capacity in at least one of the following: self-care/management, mobility or communication; and requiring ongoing or episodic support.

- estimate what use people with various kinds of disabilities make of health services
- say how many children with various support needs were attending regular schools, or special schools or classes, in each state and territory
- compare outcomes for people with similar disabilities and needs in different service types
- compare access to facilities and services many people take for granted, for instance sporting clubs, radiology services (e.g. mammograms)
- compare health outcomes for people with various disabilities and for people with no disability.

## Identifying and evaluating outcomes

In any field, people need to identify and evaluate outcomes in order to achieve improvement. Having a common framework for analysing outcomes helps to provide a clearer picture of those outcomes across the entire field and indicate areas where improvement may be needed.

The concept of participation presented in the ICF has been used in Australia for this purpose. (AIHW 1997b:334–42; AIHW 1999:255–63). Population survey data were analysed to look at participation of people with a disability in relation to living arrangements and self-care; housing and homelessness; self-perceived health; mobility and transport; communication; social relationships and community life; time use and leisure; education; employment; and economic life. Findings included:

- A decline in the proportion of people aged under 65 with a ‘profound or severe core activity restriction’<sup>2</sup> living in ‘cared accommodation’, from 9.9% in 1981 to 2.6% in 1998 (AIHW 1999:256). This trend, in line with Australian governments’ explicit policy of de-institutionalisation, was accompanied by a large rise in the number and percentage of such people living in households, usually with families.
- People aged 15 years and over with a disability tended to report lower levels of health than the general population. ‘Poor health’ was reported by 11.0% of people with a disability and ‘excellent health’ by 8.6%. In comparison, 4.0% of the general population reported ‘poor health’ and 19.5% reported ‘excellent health’.

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2 People with a ‘profound or severe core activity restriction’, according to the ABS survey, always or sometimes need assistance with self-care, mobility or communication (ABS 1999). ‘Cared accommodation’ includes hospitals, aged care homes and children’s homes.

- A total of 723,100 people of all ages with a disability needed assistance with mobility in 1998. Of these, 89.9% received assistance from informal care providers, 17.7% received assistance from formal services, and 7.9% did not receive the assistance they needed.
- People with a disability had lower labour force participation rates (53.2%) than the general population (75.6%), and generally higher rates of unemployment (AIHW 1999: 261-2).

## **Achieving potential benefits of the ICF**

So far in this section it has been said:

- definition and classification in the ICF are not about labelling and assessment
- to the extent that consistent disability definitions in Australia have been available, they have been put to good analytical use, in ways that can improve services for people with disabilities.

The goals of the ICF are broad and the aim is to make the classification meaningful to people with a disability, to those involved in making relevant social policy, and to a range of service providers and health-care workers. These broad goals have been set in recognition of the very wide interest in disability and the wide variety of potential uses and users. The more a conceptual framework is meaningful to a wide variety of people, the more 'validity' it may be supposed to have, and the more these different users will be talking the same language and working towards the same goals.

WHO and the Collaborating Centres have listened and responded to past criticisms of the ICIDH and have brought the ICF into line with newer visions, for instance, the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities and the social model of disability.

If it is desirable to see people with a disability, policy makers, therapists, physicians, employment agencies and others exchanging ideas in a more common framework, then it is worth spending some time trying to use the ICF as a common framework.

Rachel Hurst of Disabled Peoples International (1998) writes of her reasons for participating in the drafting of the ICF, despite the inherent challenges:

In a perfect world we would prefer to have no classification at all...However, for the purposes of statistics, assessment for services and programs and above all for non-discrimination legislation, we do need to have a definition of who we are and of our situation and we reluctantly accept that this means some sort of classification or analysis of disablement.

Good data are needed in the disability field. The potential reward of good data is better policy. Policy clearly drives data collection, and so it should, but relevant data inevitably inform policy development and evidence-based approaches to service and treatment development. Good data require well-defined data items, which are part of a meaningful, holistic framework. Otherwise there will only be bits and pieces of unrelated data.

### **3.3 Past and emerging uses**

The past uses of the ICF's predecessor, the ICIDH, provide some examples of the likely applications of the ICF. These include:

- statistical applications – specification, collection and recording of data (e.g. in population surveys, studies, management information systems)
- research – to support the measurement of outcomes, quality of life, and environmental factors
- clinical use – to shape needs assessment (e.g. vocational, rehabilitation) and evaluate outcomes
- social policy analysis – in general policy design and implementation, social security, planning, and compensation systems
- educational applications – in curriculum design, and to raise awareness of the multidimensional nature of disability and undertake social action (WHO 2001:5).

Badley (1993) highlighted the inherent usefulness of the ICIDH to the fields of health and health care, social care, social security, employment, education and training, survey research and statistics, listing the following general applications:

- clinical diagnosis and rehabilitation assessment
- record keeping in health and rehabilitation settings
- development of medical and health monitoring systems
- program evaluation and development
- promotion of linguistic agreement
- concept development in field of disablement studies
- development of research programs
- formation of disability policy
- data collection in survey research and database development.

The Collaborating Centre for the WHO Family of International Classifications in the Netherlands publishes a regular newsletter which, over the years, has

documented a vast range of uses of the ICF and its predecessor the ICIDH (for instance, WHO-FIC Collaborating Centre in the Netherlands 2002).

Specific examples of application in the United States by different disciplines are described in Nieuwenhuijsen (1995). These examples reflect the diverse use of the ICF as a framework in areas such as:

- outcome-based approaches to education
- measurement of functional gains in elderly blind people, resulting from rehabilitation services
- the development of the Craig Handicap Assessment and Reporting Technique (CHART) to measure the degree to which impairments may limit activities and restrict participation
- the collection of data to enhance strategies preventing work-related back disabilities among nurses
- back-coding of national datasets to review and enhance equal opportunities for, and full participation of, students in special education.

In a discussion on ICF applications, Stucki et al. (2002) stated that the ICF is 'likely to become the generally accepted framework to describe functioning in rehabilitation'.

People attending a 1994 Australian workshop on the ICIDH and the measurement of disability identified a wide range of areas that would benefit from national consistency in disability concepts and measurement (AIHW 1994):

- consumers interested in ways of better relating data on needs for services and the provision of services
- service providers and planners interested in relating needs, eligibility criteria and resource allocation
- people and policy makers interested in equity and wanting agreed broad definitions of disability in order to define and monitor exclusion and inclusion
- clinicians of many disciplines who wished to relate disability outcomes and the 'severity' of functioning to appropriate interventions, and to relate their clinical practice to experience in the wider population
- national and international statisticians interested in being able to estimate prevalence (the proportion of the population with a disability), needs for support and outcomes in informative and comparable ways (it was noted that the ICIDH had already been widely used to develop national surveys in Australia and elsewhere)

- policy makers in a wide range of fields (e.g. aged care, insurance, compensation and income security) who wished to improve their data and to be able to relate it to data collected in other fields.

## **The ICF—inquiries made**

Since 1994, the AIHW has received inquiries about the ICF and its predecessor, the ICIDH, from a wide range of disciplines. Although some of these inquiries have simply been requests for information about the classification, others have indicated the potential or proposed use of the ICF as a framework for a specific undertaking (Table 3.1).

Health and health care have been among the main disciplines investigating the use of the ICF. Researchers and practitioners in the fields of ageing research, speech pathology and geriatric medicine have proposed an examination of the ICF's suitability as a framework for outcomes measurement (e.g. rehabilitation, sub-acute care), service prioritisation, clinical practice and medical teaching. Assessment tools based on the ICF, or some of its components, have also been discussed, specifically to describe health conditions and their effects, to recognise conditions of care essential to people with long-term illnesses, and to measure participation.

Outside the health field, information on the ICF has been requested from people with particular interests in social work, housing, physical activity and education. The definition and/or classification of disability has been a particular focus, e.g. to describe the potential consequences of domestic violence (on women and unborn children) and to classify athletes competing in disabled games. Support needs for students with disabilities was another area where ICF was being evaluated as a framework for 'assessment for support' procedures in education.

Further information about major current uses is provided in Section 10, which will be a regularly updated feature of this guide.

## **3.4 The future**

People in the fields listed in Table 3.1 are likely to continue to be interested in and use the ICF, and there are advantages in their doing so. If it is desirable to see people with a disability, policy makers, therapists, physicians, employment agencies and others exchanging ideas in a shared framework, then it is worth spending some time trying to use the ICF as a common framework.

The AIHW, with its responsibilities for national data development and in its role as a WHO Collaborating Centre for the WHO Family of International Classifications, will continue to use the ICF and take a keen interest in its use.

**Table 3.1: Some current and potential uses of the ICF as identified in inquiries and discussions**

<b>Discipline</b>	<b>Use of ICF</b>
Nursing	Tool to develop understanding of care for people with a long-term illness
Geriatric medicine	Framework for clinical practice and teaching of geriatric medicine
Children's health	Assessment of specific health conditions, e.g. Rett syndrome
Women's health	Assessment of participation
Dental health	Impact on oral health
Disability advocacy group	Definition of disability and the importance of functional aspects of definition
Ageing research	Framework for outcomes measurement in rehabilitation and sub-acute care
Speech pathology	Framework for measuring outcomes and prioritising services
Social work	Framework for describing disability in relation to consequences of domestic violence in pregnancy
Education	Support in schools for students with disabilities
Employment opportunities	Development of a database that monitors the success of an organisation in employing people with disabilities
Housing	Definition(s) of disability
Human movement	Classification of athletes for disability athletics; use of physical activity as a health indicator for people with disabilities
Disability advocacy group	Definition of disability and delineation between medical aspects of mental health and functioning and disability
Disability services	Corporate planning for non-government agency
Aged care services	Mapping and harmonising tools for assessing aged care 'dependency'
Community services (government)	Input into data structures for new system

This User Guide represents the AIHW's approach to:

- explaining the ICF content to potential users and to people with a general interest in disability definition
- explaining how the AIHW is using the classification
- outlining and keeping an up-to-date picture of some of the key uses of the ICF in Australia
- promoting interchange among current users, including the AIHW.

Section 10 contains more detailed information on some new applications.