

1. Purpose and outline

1.1 Introduction

The International Classification of Functioning, Disability and Health (ICF) provides a framework for the conceptualisation, classification and measurement of disability. It recognises disability as a multidimensional and universal experience. Within the ICF framework, a wide range of specific-purpose definitions and applications can be located, developed and related to each other.

Perspectives on disability may vary with environment, personal experience and professional training. The ICF provides an information framework – of concepts, terminology and classifications – that will help to establish a broadly shared understanding of disability at various life stages, in various settings and among people with varying experience and training. Widespread use of the ICF will lead to more integrated approaches to gathering and sharing information and to policy making.

The Australian Institute of Health and Welfare (AIHW) is now encouraging the use of the ICF in a broad range of fields in Australia.

1.2 Purposes of the User Guide

This Australian User Guide for the ICF is intended as a complement to the ICF, and to promote use of the ICF in Australia. The User Guide is consistent with the ICF which is the main reference source.

The guide provides:

- information on the content and usefulness of the ICF
- information on current and emerging applications of the ICF in Australia
- advice about ‘getting started’
- support for a consistent and constructive approach to using the ICF, particularly in those areas left to the user’s discretion.

The guide is designed to help users relate the ICF framework and classifications to their own measurement purposes and decide at what level to use the classifications.

Users are encouraged to record their experience in the templates provided on the AIHW web site so that Australian applications can, in time, assist in further development and clarification of the ICF.

1.3 For whom is the User Guide written?

The User Guide is designed for people who are:

- interested in finding out more about the ICF and its practical uses
- considering or planning a specific use of the ICF
- seeking more detail on some of the complex or discretionary areas of the classification.

Users could include people with disabilities; advocacy groups; policy makers in government or non-government organisations; health and allied health educators, practitioners and researchers; people designing data systems about services for people with disabilities; researchers in the fields of rehabilitation, human movement, social security or employment; and people designing surveys, clinical studies or assessment methods.

1.4 What are the uses of the ICF?

There are many ways in which the ICF and this User Guide can be used to improve policy and information on disability and human functioning.

Potential applications include:

- use of the broad ICF conceptual framework in advocacy, teaching, planning and education
- use of the classification at various levels in information systems, for instance, national data on disability or rehabilitation services
- reference to the classification in designing new assessment methods, or relating various methods to each other within a common framework
- use of the detailed codes in specific service, clinical or therapeutic settings.

Examples of these types of applications are discussed in the User Guide and actual or emerging applications are illustrated.

1.5 What is in this User Guide?

The following list indicates the questions that the various sections of the guide are designed to answer.

Where do I find an overview of the ICF?

Section 2 presents an overview of the main features of the classification.

Why should I think about using the ICF? Why classify at all?

Section 3 provides an overview of:

- potential applications
- past uses of the International Classification of Impairments, Disabilities and Handicaps (ICIDH), the forerunner of the ICF
- inquiries the Institute has received from people wishing to use the ICF.

How might I get started if I am thinking about using the ICF to structure information about functioning and disability?

Section 4 gives some brief practical and general advice on getting started as a user of the ICF.

How can I get a more detailed understanding of some of the newer concepts in the classification, and options for their use?

Section 5 discusses the concepts of Activities and Participation in the ICF, and suggests options for use in Australia, selecting from options provided in the ICF.

Section 6 discusses the concept of Environmental factors in the ICF. This is an important new component of the classification and there is little experience in its use. Users are strongly encouraged to use this component, and to document their experience and ideas.

If I am designing a data collection and want it to conform to the ICF and to other Australian disability data collections, what section should I read?

Section 7 contains information about national disability data elements (and refers readers to the National Community Services Data Dictionary). The section includes a discussion of the value of consistency in data concepts and collections in Australia.

What if I just want a single 'disability identifier' for a generic data collection—for instance, to monitor access to services by people with a disability?

Section 8 discusses disability identifiers and briefly looks at current international work on short question sets and census questions on disability.

What are the 'Personal factors' referred to in the ICF?

Section 9 identifies key sociodemographic items and refers readers to the Australian national data dictionaries for definitions.

What are some current or planned applications in Australia?

Section 10 contains brief accounts of current Australian applications, in fields such as therapy outcomes, speech pathology, classification of athletes, insurance and disability services, along with details of where to find out more, including links where available.

How can I tell other users about my experience with the ICF?

Sections 5 and 6 include templates showing how to record and share information. This User Guide is designed to be an evolving resource that promotes the recording of Australian experience and links users to each other. If all users follow the requests to document their experience, they will learn from each other, be able to contact each other and contribute to the ongoing development of the ICF.

What are key references and resources on the ICF?

Section 11 lists web sites and references.

2. Overview of the ICF

This section identifies and explains the components of the ICF, discusses the classification scheme and qualifiers used and gives examples of ICF codes. It also discusses the relationship of the ICF to the World Health Organization (WHO) family of international classifications, outlines the history of the ICF and looks briefly at its potential and intended uses.

The value of using the ICF in Australia is that it:

- combines the major models of disability, recognising the role of environmental factors in the creation of disability and the importance of participation as a desired outcome, as well as the relevance of underlying health conditions and their effects; and
- provides a framework within which a wide variety of information relevant to disability and functioning can be developed, assembled and related.

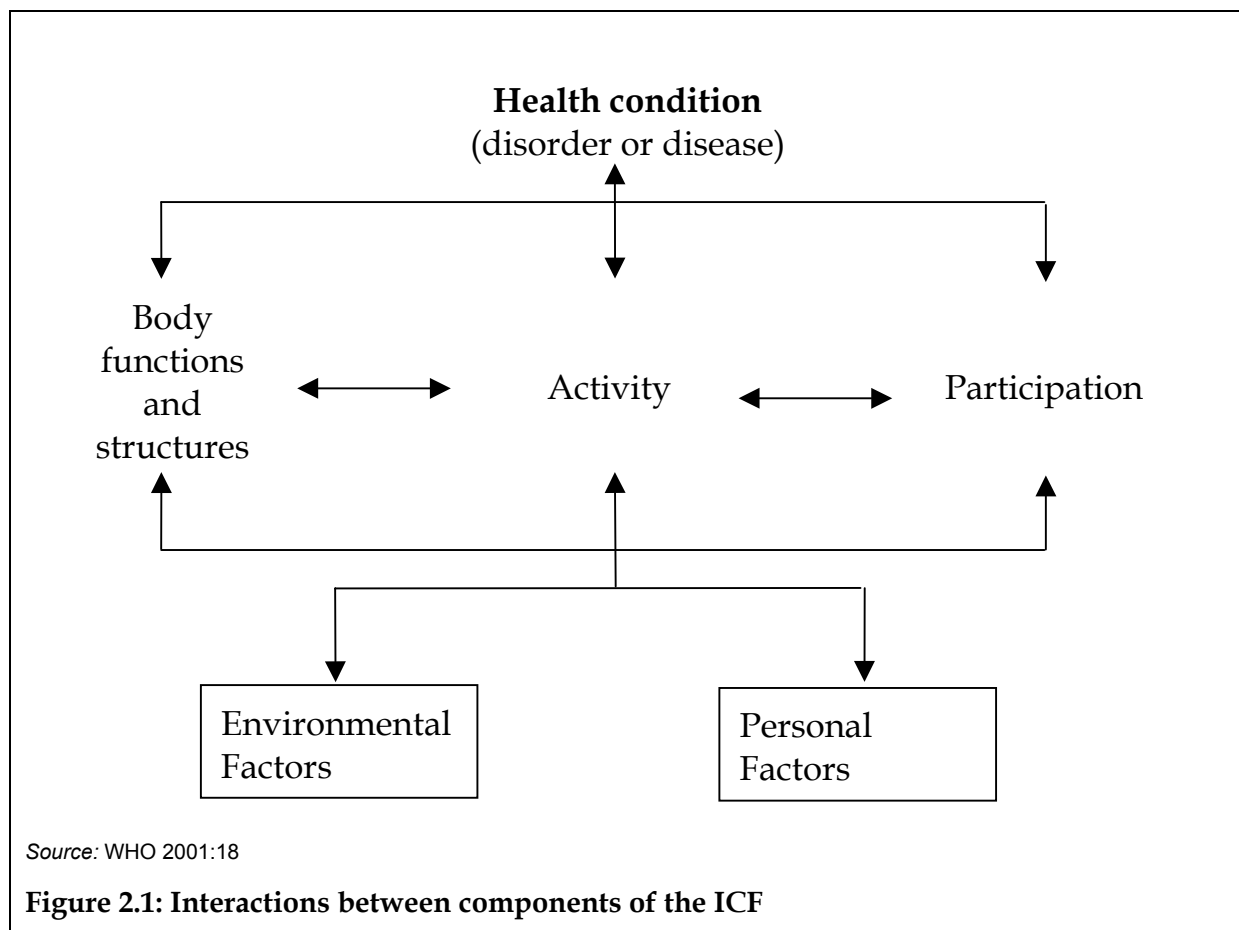
2.1 Components of the ICF

The ICF defines functioning and disability as multi-dimensional concepts, relating to:

- the body functions and structures of people
- the activities people do and the life areas in which they participate
- the factors in their environment which affect these experiences.

Each of these components is defined in the context of a health condition. Disability is the umbrella term for any or all of: an impairment of body structure or function, a limitation in activities, or a restriction in participation.

In the ICF, a person's functioning or disability is conceived as a dynamic interaction between health conditions and environmental and personal factors (WHO 2001:6) (see Figure 2.1). Environmental Factors – an important new component of the ICF – are included in recognition of their influence on functioning and disability. Although Personal Factors are recognised in the interactive model shown in Figure 2.1, they are not classified in, and are beyond the scope of, the ICF. Such factors might include age, sex, and Indigenous status and would be selected by users according to the application.



Definitions

The following are definitions of the components:

- **Body functions** are the physiological functions of body systems (including psychological functions).
- **Body structures** are anatomical parts of the body such as organs, limbs and their components.
- **Impairments** are problems in body function and structure such as significant deviation or loss.
- **Activity** is the execution of a task or action by an individual.
- **Participation** is involvement in a life situation.
- **Activity limitations** are difficulties an individual may have in executing activities.
- **Participation restrictions** are problems an individual may experience in involvement in life situations.
- **Environmental factors** make up the physical, social and attitudinal environment in which people live and conduct their lives. These are either barriers to or facilitators of the person's functioning.

Domains within components

Each component is composed of various domains; these are sets of related physiological functions, anatomical structures, actions, tasks, areas of life, and external influences. The ICF has a separate chapter for each of the domains. Table 2.1 lists ICF components and domains, with examples of some of the contents of each domain.

2.2 Classifications and codes

The ICF contains a hierarchy of classifications and codes for each of the components – Body Functions and Structures, Activities and Participation, and Environmental Factors. Measures can be recorded against each of the neutral codes, to indicate the extent of ‘problem’ with any of these aspects of functioning. Environmental factors can be recorded as being either barriers to, or facilitators of, a person’s functioning.

Figure 2.2 outlines the hierarchy of classification in the ICF. Domains are at chapter level (e.g. mental functions) and consist of facets or blocks (e.g. specific mental functions) within which are nested groups of second-level, third-level, and sometimes fourth-level categories. These categories are the units of classification. Each successive level can be used to further refine the code, or level of detail recorded; the user chooses the level appropriate to the classification.

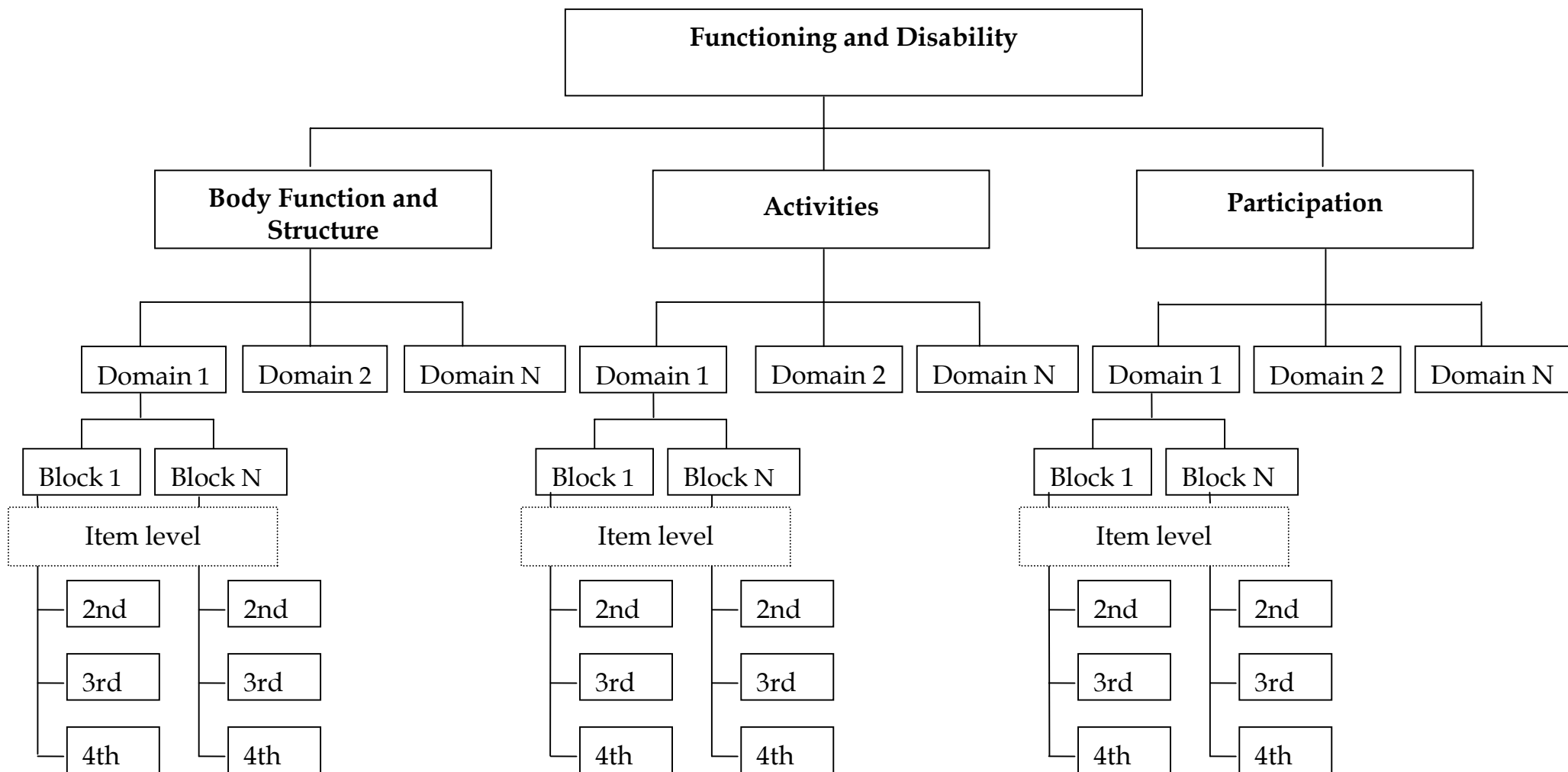


Figure 2.2: Hierarchy of classification in the ICF

Qualifiers

Qualifiers are numeric measures coded after the relevant category code. Qualifiers are recognised as essential to the meaningful use of the classification because the domains and codes are expressed in neutral language. Without qualifiers, the codes have no inherent meaning (WHO 2001:222).

A uniform or 'generic' qualifier is provided to record the extent of the 'problem' in relation to impairment, activity limitation, participation restriction and environmental barrier. The extent of the problem is denoted using the following scale:

Generic qualifier:

0	No problem
1	Mild problem
2	Moderate problem
3	Severe problem
4	Complete problem
8	Not specified
9	Not applicable

The Environmental factors qualifier uses both a positive and a negative scale, to indicate the extent to which an environmental factor acts as either a facilitator or barrier.

First qualifier for Environmental factors:

.0	No barrier	+0	No facilitator
.1	Mild barrier	+1	Mild facilitator
.2	Moderate barrier	+2	Moderate facilitator
.3	Severe barrier	+3	Substantial facilitator
.4	Complete barrier	+4	Complete facilitator
.8	Barrier, not specified	+8	Facilitator, not specified
.9	Not applicable	+9	Not applicable

It is recognised that these qualifiers need calibration to relate them to existing measurement and assessment instruments in the field.

In addition to the generic qualifier, qualifiers for specific components are included:

- a 2nd qualifier for Body structure, which measures the change in body structure

- a suggested 3rd qualifier for Body structure to record the localisation of the impairment.

Performance and capacity

Two constructs – ‘performance’ and ‘capacity’ – can also be used with the generic qualifiers for the Activities and Participation domains. These constructs indicate the environment in which measurement is taking place.

According to the ICF (WHO 2001:15):

performance...describes what an individual does in his or her current environment;

capacity...describes an individual’s ability to execute a task or an action...(and) aims to indicate the highest probable level of functioning that a person may reach in a given domain at a given moment. To assess the full ability of the individual, one needs a ‘standardised’ environment to neutralise the varying impact of different environments on the ability of the individual. This ‘standardised’ environment may be (a) an actual environment commonly used for capacity assessment in test settings; or (b) in cases where this is not possible, an assumed environment which can be thought to have a uniform impact.

The ICF also states:

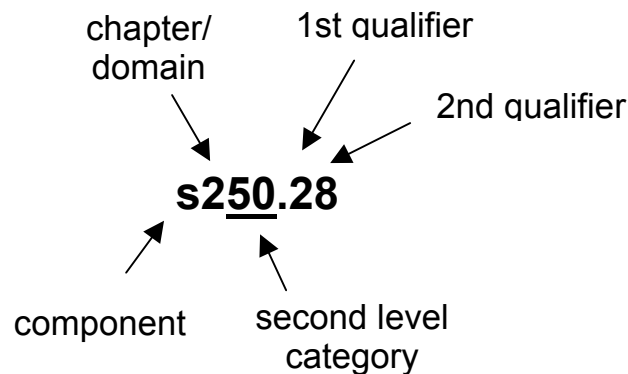
The gap between capacity and performance reflects the difference between the impacts of current and uniform environments, and thus provides a useful guide as to what can be done to the environment of the individual to improve performance (WHO 2001: 15).

Thus the notion of ‘capacity’ also relates to the identification of what is needed to enhance a person’s opportunities to ‘perform’ to their ‘highest probable level of functioning’. In this sense, the ‘assumed’ environment may be thought of as, in some sense, optimum. This aspect of the concept of ‘capacity’ appears to accord with Australian policy goals, focusing on people’s abilities. In comparison, the notion of a ‘standardised environment’ may be more difficult to operationalise widely, except within particular disciplines e.g. clinically based physiotherapy.

The ICF is intended to be grounded in a human rights philosophy, and its relationship to the UN Standard Rules on Equalization of Opportunities for Persons with Disabilities is acknowledged. Operationalising these rules appears to relate primarily to performance, i.e. the *actual* participation experience of people with disabilities.

Applying ICF codes

The general format of an ICF code is as follows.



In this example, the code s250.28 is recorded for a person experiencing a moderate problem with the structure of the middle ear, where:

- s denotes the component, in this case Body structures
- the first digit (2) denotes the chapter or domain, i.e. The eye, ear and related structures
- the second and third digits (50) denote the second-level category, i.e. structure of middle ear
- the first digit after the decimal point (2) denotes the generic qualifier, indicating, in this case, a moderate impairment with the middle ear
- the second digit after the decimal point (8) indicates, in this case, that the nature of the impairment is not specified.

Box 2.1 gives more detailed examples of codes.

Box 2.1: Examples of applying ICF codes to case studies

Note: These examples do not generally contain enough information to code the severity of impairment, but codes are included to illustrate aspects of the text.

Example 1

Mr B has a high-level spinal cord injury, as a result of a severe neck injury, and cannot perform the basic movements required to drive a standard car. However, with a suitably modified vehicle, he can drive safely. Unfortunately, there is a law in his state that prohibits him from driving. The following codes might be used to describe Mr B.

b730.3 Muscle power functions – severe impairment

a475.1 Driving – mild difficulty (in performance of activity in modified vehicle)

e120+4 Products for personal mobility and transportation – complete facilitator

e540-4 Transportation services, systems and policies – complete barrier

Example 2

A couple have been married for several years and have always wanted to have children. They both have intellectual impairment. There are no medical reasons why they cannot have children, and they believe that they will not have any problems in the day-to-day care of a child. Yet they have decided not to have a child because they believe that people will think they are unsuitable parents and their child will be shunned by other children and made fun of. The following codes might be used to describe the main aspects relating to this couple's life and current situation.

b117.1 Intellectual functions – mild impairment

b660.0 Procreation functions – no impairment

a660.08 Assisting others – no difficulty with performance (capacity not specified)

p760.38 Family relationships – severe difficulty with performance (capacity not specified)

e460+3 Societal attitudes and beliefs – severe barrier

Example 3

Mr C has cerebral palsy. He cannot speak clearly, but his speech has improved with the help of a speech therapist. Around friends or close colleagues at work he has no difficulty with conversations. However, most strangers do not take the time to listen carefully to understand him. So, Mr C does not always get what he wants in shops and restaurants. The following codes might be applied in describing Mr C.

b320.2 Articulation functions – moderate impairment

d330.1 Producing spoken messages – mild difficulty

d350.0 Conversation – no difficulty

d355.0 Discussion – no difficulty

d620.1 Acquisition of goods and services – mild difficulty

d730.1 Relating with strangers – mild difficulty

d750.0 Informal social relationships – no difficulty

e580+3 Health services, systems and policies – 'severe' (strong) facilitator

e345-1 Strangers – mild barrier

Source: WHO Assessment Classification and Epidemiology Group 2000

2.3 The ICF and the WHO family of international classifications

The ICF has been developed for use in describing functioning and disability. It is now recognised as a reference member of the WHO family of international classifications (WHO-FIC), and complementary to the International Classification of Diseases and Related Health Problems (ICD). The WHO family of international classifications provides a framework and language for information about health and functioning so that people can communicate about health and health care in common terms, across various disciplines and between countries (WHO 2001:3).

Health conditions (diseases, disorders, injuries etc.) are generally classified using the ICD (the most current version is the ICD-10), which provides diagnosis codes for diseases, disorders or other health conditions. Functioning and disability associated with health conditions are classified using the ICF. The ICD-10 and the ICF enable consistent collection of information about diagnosis as well as human functioning. The use of both classifications together is considered to provide a more meaningful and complete picture of the health needs of people and populations (WHO 2001:4).

There is some overlap between the two classifications. Both classifications refer to body systems, and the ICF concept of 'impairment' is also used in the ICD-10. However, 'the ICD-10 uses impairments (as signs and symptoms) as parts of a constellation that forms a 'disease', or sometimes as reasons for contact with health services, whereas the ICF system uses impairments as problems of body functions and structures associated with health conditions' (WHO 2001:4).

See Section 11 for web sites on the Australian 'family' of health and related classifications.

2.4 History and development of the ICF

In May 2001, the World Health Assembly endorsed the ICF (WHO 2001). This marked the finalisation of revision of the ICF's predecessor, the International Classification of Impairments, Disabilities and Handicaps (ICIDH) (WHO 1980), a process that involved several years of redevelopment and testing by WHO and its Collaborating Centres, including the AIHW.

The ICIDH was originally proposed to describe the effects of chronic conditions such as arthritis and the long-term effects of rehabilitation. In 1980 the ICIDH was published by the WHO as a 'manual of classification relating

to the consequences of disease' (and injuries and other 'disorders') and as a 'conceptual framework for information' (WHO 1980).

In the years following its release, a number of review articles described the potential applications and uses of the ICIDH, including:

- conceptual development in interdisciplinary fields related to disability
- medical and rehabilitation monitoring systems
- survey research
- data base development
- clinical diagnosis and rehabilitation assessment
- program evaluation.

By 1994 the ICIDH had been translated into 13 languages. However, some strong criticism was levelled at the ICIDH, particularly from people with disabilities and many professionals who were critical of the inadequate recognition given to the role of the environment in the creation of disability. Seven years of revision and testing ensued. A review of the overall development of the ICIDH is discussed in Bickenbach et al. (1999).

The development process—research, advice, and the role of people with disabilities

Organisations representing people with disabilities played an active role in ICF development at national and international levels. The advisory group for the AIHW's work as the Australian Collaborating Centre included such representation, and people with disabilities participated in the research carried out during the ICIDH development process. The involvement of disability organisations in the revision is a significant achievement of the ICF and has vastly improved its validity.

The ICF provides a framework for the description of human functioning, on a continuum – not just at the extremes. This point is explicitly stated in the classification. Because of the efforts taken to involve a wide range of disciplines and people in development and testing, the ICF should be able to be used in an even wider range of applications than its predecessor, the ICIDH.

A summary of the ICF development process, focusing on the contribution of the Australian Collaborating Centre, is outlined in Disability Data Briefing 21 (AIHW 2002a: Table 1). The web version of the data briefing contains links to related reports prepared during the course of the revision, including reports on Australian research and testing.

2.5 Overview of potential and intended uses

The ICF is a multipurpose classification designed to serve various disciplines and sectors across different countries and cultures. The stated aims of the ICF (WHO 2001:5) are to:

- provide a scientific basis for understanding and studying health and health-related states, outcomes and determinants;
- establish a common language for describing health and health-related states in order to improve communication between different users, such as health care workers, researchers, policy-makers and the public, including people with disabilities;
- permit comparison of data across countries, health care disciplines, services and time; and
- provide a systematic coding scheme for health information systems.

Thus there is a broad range of intended and potential uses to which the ICF will be put. Importantly, the ICF is not just used by people who describe themselves as working in the disability or health sector. People may use it across other broad sectors including insurance, social security, employment, education, economics, social policy, legislation and environmental modification. Furthermore, the ICF is accepted as one of the United Nations social classifications, and is referred to in and incorporates *The Standard Rules on the Equalization of Opportunities for People with Disabilities* (WHO 2001:5).

The ICF as a ‘framework’ as well as a classification

Australia has broad policies on disability, encompassing approaches to both generic and specialist services relevant to people with disabilities. A wide range of data is therefore needed to describe the status of people with disabilities in the population and their access to services. It is important that information collected embraces or considers all components of disability and relates to other information collected, both in service settings and at the population level. A broad, common understanding of disability, including common or relatable disability definitions, is crucial to understanding and improving outcomes for people with disabilities.

This User Guide includes a number of practical illustrations of the ways the ICF has been applied as a ‘framework’ for developing such common understanding:

- Section 3 discusses the value of a common conceptualisation of disability and outlines applications that illustrate this point.

- Section 7 provides background about the reasons for adopting the ICF as a framework for national disability data before outlining the main tools used to promote national data consistency – national information agreements and the Australian data dictionaries.
- Section 10 provides a practical example of how the ICF was applied as a framework and classification in redeveloping the major national administrative data collection in the disability services sector, the Commonwealth/State Disability Agreement Minimum Data Set (CSDA MDS).

Relationship to assessment and measurement

The ICF is not an assessment or measurement tool, but rather a framework and set of classifications on which assessment and measurement tools may be based and to which they can be mapped. This distinction can be misunderstood, with people sometimes referring to the ICF itself as an assessment tool or a data set. The broad framework of the ICF puts assessment in context and shows how narrow the focus of assessment often is. Methods of assessing particular aspects of disability should be able to be located within the ICF framework, thereby clarifying which aspects they do, and do not, attempt to measure. For further information see Section 3, which includes a detailed discussion of the differences between definition and classification, labelling and assessment, Section 8 on disability identifiers and measurement, and Section 10 on examples of current uses.