

ICF Australian User Guide

Version 1.0

The Australian Institute of Health and Welfare is Australia's national health and welfare statistics and information agency. The Institute's mission is better health and wellbeing for Australians through better health and welfare statistics and information.

DISABILITY SERIES

ICF Australian User Guide

Version 1.0

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Abbreviations

ABS	Australian Bureau of Statistics
ACAIDD	Advisory Committee on Australian and International Disability Data
ACC	Australian Collaborating Centre
AIHW	Australian Institute of Health and Welfare
CDDS	Centre for Developmental Disabilities Studies
CSDA	Commonwealth/State Disability Agreement
CSTDA	Commonwealth State/Territory Disability Agreement
CSDA MDS	Commonwealth/State Disability Agreement Minimum Data Set
CSTDA NMDS	Commonwealth State/Territory Disability Agreement National Minimum Data Set
HACC	Home and Community Care
ICD	International Classification of Diseases and Related Health Problems
ICD-10	International Classification of Diseases and Related Health Problems-10th edition
ICF	International Classification of Functioning, Disability and Health
ICIDH	International Classification of Impairment, Disability and Handicap
ISO	International Organization for Standardisation
NCSDD	National Community Services Data Dictionary
NDA	National Disability Administrators
UN	United Nations
WHO	World Health Organization
WHO-FIC	WHO Family of International Classifications

ICF Australian User Guide

Version 1.0

The ICF Australian User Guide has been developed by the AIHW as the Australian Collaborating Centre for the WHO Family of International Classifications to promote the use of the ICF in Australia. The User Guide is intended to be a complement to the ICF classification, to assist Australian users to understand the classification, to inform them about current and potential applications and to provide advice on 'getting started'. It is aimed at those wanting to find out more about the practical use of the ICF in Australia or planning to use the ICF.

The User Guide has been designed to be fully consistent with the ICF. At various points the ICF presents optional approaches. This User Guide aims to guide Australian users in their approach to the ICF, including the selection and application of these options.

The Australian ICF User Guide is available in printed form and on the AIHW web site (<http://www.aihw.gov.au/disability/icf_ug/index.html>).

Translations and adaptations of this User Guide are being developed by both the French (<<http://perso.club-internet.fr/ctnerhi/cih.htm>>) and Nordic Collaborating Centres (<<http://www.nordclass.uu.se>>). Other Centres are in the process of requesting to do so.

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.

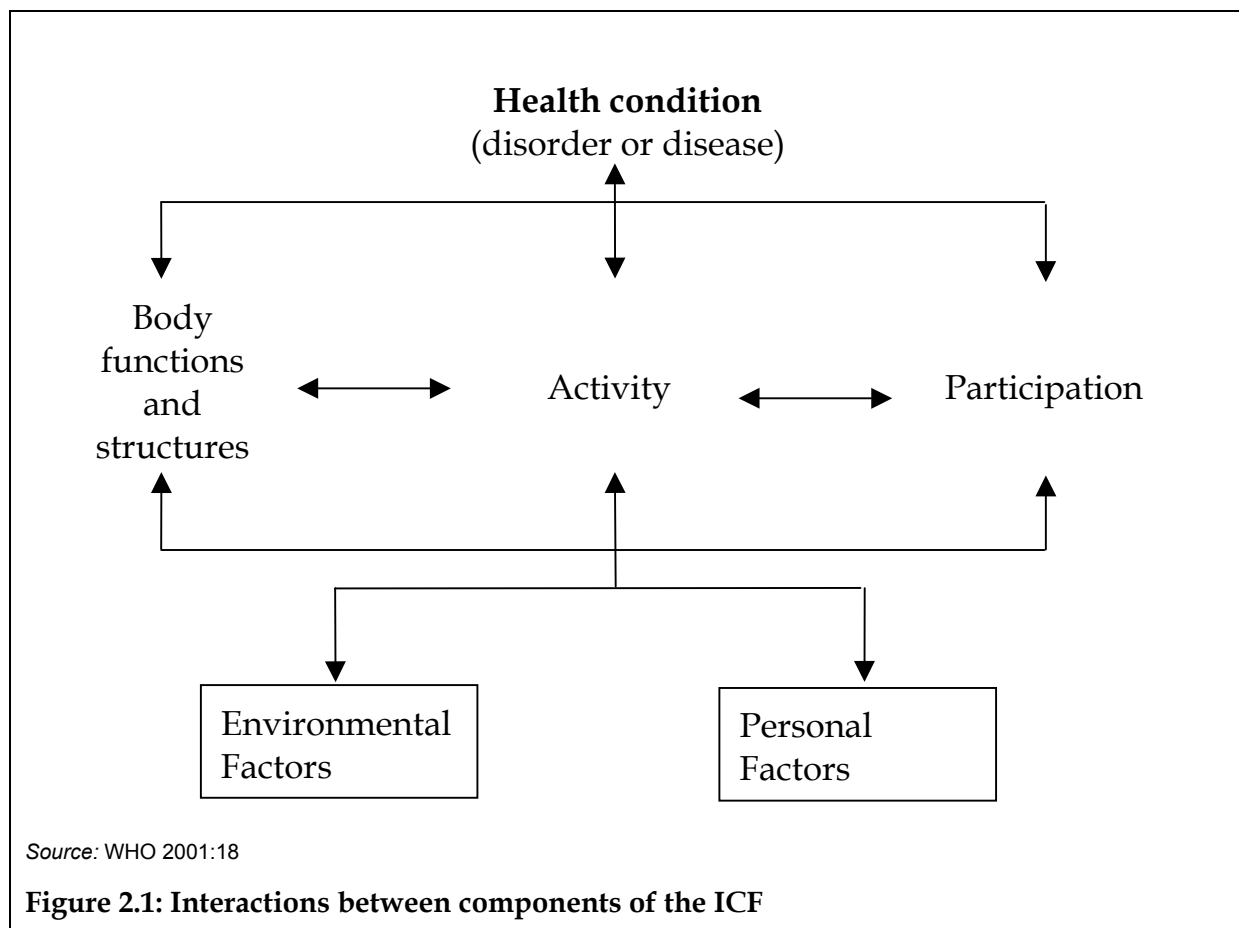
2.1 Components of the ICF

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.

Table 2.1: ICF components and domains, with examples of contents

Component	Domains/Chapter headings
<p>Body Functions: eight chapters</p> <p>Body Structures: eight chapters</p>	<p>Mental functions e.g. memory function, intellectual functions</p> <p>Sensory functions and pain e.g. hearing function, smell function</p> <p>Voice and speech functions e.g. articulation functions</p> <p>Functions of the cardiovascular, haematological, immunological and respiratory systems e.g. blood pressure functions, respiratory muscle functions</p> <p>Functions of the digestive, metabolic and endocrine systems e.g. ingestion functions, endocrine gland functions</p> <p>Genitourinary and reproductive functions e.g. menstruation functions</p> <p>Neuromusculoskeletal and movement-related functions e.g. mobility of joint functions</p> <p>Functions of the skin and related structures e.g. repair functions of the skin</p> <p>Structures of the nervous system e.g. spinal cord and related structures</p> <p>The eye, ear and related structures e.g. structure of eyeball, structure of inner ear</p> <p>Structures involved in voice and speech e.g. structure of mouth</p> <p>Structures of the cardiovascular, immunological and respiratory systems</p> <p>Structures related to the digestive, metabolic and endocrine systems e.g. structure of intestine, structure of gall bladder and ducts</p> <p>Structures related to the genitourinary and reproductive systems e.g. structure of the urinary system, structure of pelvic floor</p> <p>Structures related to movement e.g. structure of head and neck region</p> <p>Skin and related structures e.g. structure of skin glands</p>
<p>Activities & Participation: nine chapters</p>	<p>Learning and applying knowledge e.g. learning to read, solving problems</p> <p>General tasks and demands e.g. carrying out daily routine</p> <p>Communication e.g. speaking, conversation</p> <p>Mobility e.g. getting around inside or outside home</p> <p>Self-care e.g. washing oneself, dressing</p> <p>Domestic life e.g. preparing meals, acquiring a place to live</p> <p>Interpersonal interactions and relationships e.g. relating with strangers, formal relationships, family relationships</p> <p>Major life areas e.g. work and employment, remunerative employment</p> <p>Community, social and civic life e.g. recreation and leisure, religion and spirituality</p>
<p>Environmental Factors: five chapters</p>	<p>Products and technology e.g. products and technology for communication; design, construction and building products and technology of buildings for public use</p> <p>Natural environment and human-made changes to environment e.g. physical geography, light, sound, air quality</p> <p>Support and relationships e.g. immediate family, health professionals</p> <p>Attitudes e.g. individual attitude of friends, individual attitude of health professionals</p> <p>Services, systems and policies e.g. social security services, systems and policies</p>

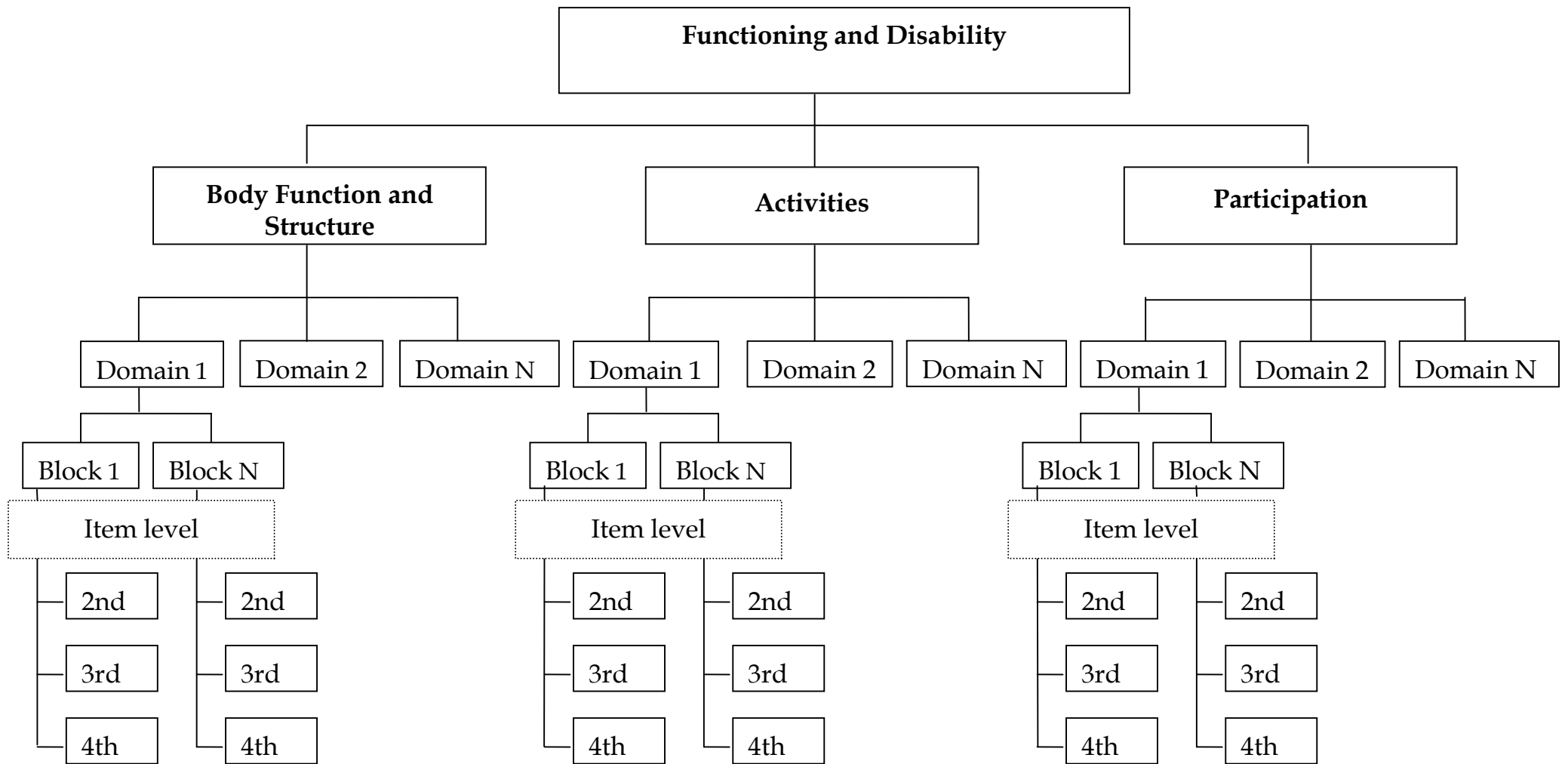


Figure 2.2: Hierarchy of classification in the ICF

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:

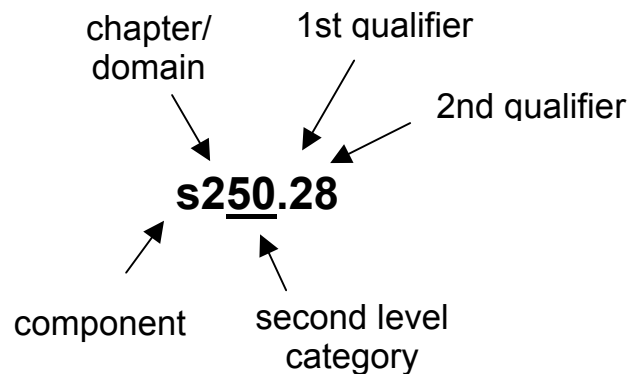
The gap between capacity and performance reflects the difference between the impacts of current and uniform environments, and thus provides a useful guide as to what can be done to the environment of the individual to improve performance (WHO 2001: 15).

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.

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 support¹. 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

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’² 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’.

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

Discipline	Use of ICF
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.

4. Getting started: general advice on use

The following is a suggested checklist for new users.

1. Start by reading Section 2 to ensure a broad understanding of the ICF.

It is almost certain that, if you go beyond this step, you will need a copy of the ICF itself (see Section 11 for details on how to obtain it).

2. Think about how your ideas and information needs fit the ICF framework.

For example:

- What do you need to know about functioning and disability?
- What conclusions do you want to be able to make, or what hypotheses do you want to test? List up to 10 of these, in fairly plain language.
- Can you relate the underlying ideas you are working with to the ICF framework (Figure 2.1)? Are you interested in some or all of the following: impairment? participation? activity? environment? What will be missing if you do not use all components?
- Who will be interested in the results? What questions will they ask? How detailed is the information they will seek?

3. At what level do you want to use the ICF?

For instance:

- Do you want to use the ICF as a framework to organise thoughts and ensure that major factors of interest are not omitted from a plan, explanation, argument or set of information?
Section 2 of this document is a useful starting point, but you will probably still need to examine the chapter headings in the ICF itself.
- Do you want to use the ICF classification, perhaps as a menu to select the *domains* most relevant to the information you need. Then, at which level do you want to use the classification: chapter level (for instance, 'mobility'), at block level (for instance, 'walking and moving'), second-level category (for instance, 'walking') or third-level category (for instance, 'walking short distances')?
See Section 2. See also Section 10 for applications using the ICF in data collections.

- Do you want to use the ICF *qualifiers*, for instance, to develop a measurement, or to assist a researcher select a scale that is either directly related to the ICF or that ensures the data collected will map to an ICF qualifier?

In this case, you need to read the ICF itself and Sections 2, 5 and 7 of this guide. You should also refer to Section 10 where current users illustrate their approach to these issues.

4. What information is already available?

It is always worth investigating whether the information you need already exists. Visit the web sites of bodies such as the AIHW and the ABS. See also the *AIHW Data Starter* (AIHW, ACROD & NCDCO 2000).

5. What can be learnt from other similar applications?

See Section 10.

6. How can you share your ideas with other interested users?

Refer to specific sections with templates (Sections 5 and 6).

5. Activities and Participation: application in Australia

The purpose of this section is to:

- introduce users to the concepts, definitions and options for use, relating to the Activities and Participation component of the ICF;
- recommend some approaches to the WHO options for use, to increase consistency of ICF application in Australia; and
- suggest methods of recording uses and applications to ensure that the Australian experience is shared and discussed.

5.1 Activities and Participation in the ICF

Key definitions are:

- *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.

The ICF provides a single list of Activities and Participation domains, or life areas, with options for use. This approach reflects the inability of ICF developers to reach consensus on devising two separate lists of domains for Activities and Participation (WHO 2001:16):

It is difficult to distinguish between Activities and Participation on the basis of domains...Therefore ICF provides a single list that can be used if users wish to do so to differentiate Activities (A) and Participation (P) in their own operational ways...Basically there are four possible ways of doing so:

- (a) to designate some domains as Activities and others as Participation, not allowing any overlap;
- (b) same as (a) above, but with partial overlap;
- (c) to designate all detailed domains as A and use the broad category headings as P;
- (d) to use all domains as both A and P.

Based on experience in Australia during the testing of the draft ICF, options (b) and (d) appear the most useful approaches. Option (a) may also be useful

for specific applications where agreement can be achieved among stakeholders.

This section outlines the basis for these suggestions, and recommends how to proceed during application.

Option (c) appears to be untried, and at this stage this User Guide contains no advice on its use.

Qualifiers of Activities and Participation, and the concepts of performance and capacity

Qualifiers are measures coded after the relevant category code of any component (Body Structures or Functions, Activities and Participation, Environmental Factors). Qualifiers are recognised as essential to the meaningful use of the ICF classification because the domains themselves are neutral:

The ICF codes are only complete with the presence of a *qualifier*, which denotes a magnitude of the level of health (e.g. severity of the problem) (WHO 2001:21). Without qualifiers codes have no inherent meaning (WHO 2001:222).

The instructions in the ICF allow considerable discretion in the hands of the user. Both Activities and Participation, for instance, are to be used with a 'generic qualifier', which indicates the extent of difficulty, using the scale:

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

WHO recognises that the scale requires calibration.

All three components in the ICF (Body Functions and Structures, Activities and Participation, and Environmental Factors) are quantified using the same generic scale...For this quantification to be used in a universal manner, assessment procedures need to be developed through research...The percentages are to be calibrated in different domains with reference to relevant population standards as percentiles (WHO 2001:22).

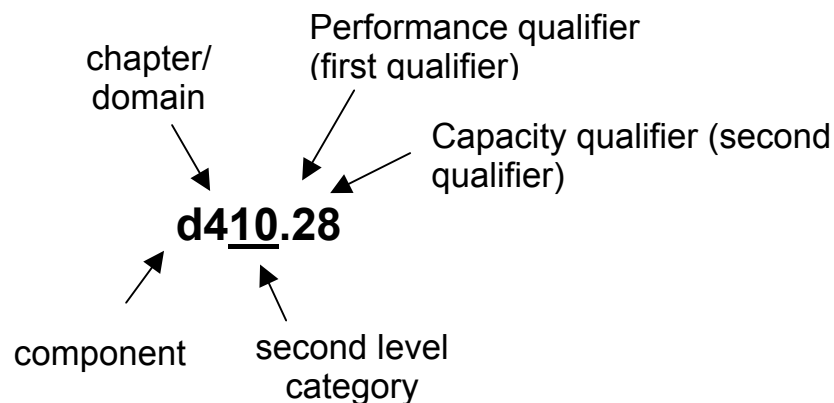
Performance and capacity

Two constructs – 'performance' and 'capacity' – can also be used, together with the generic qualifiers, for the Activities and Participation domains. These

constructs indicate the environment in which measurement is taking place (see Section 2.2). Performance relates to the ‘current’ environment. Capacity relates to a ‘standardised’ environment (either an actual test environment or an assumed one) – and also an ‘optimum’ environment, in that the ICF also states that:

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).

It is suggested that the performance-related qualifier be coded first, after the category code and a decimal point that separates the domain or category from the qualifying measurement; and any capacity-related qualifier is coded second (WHO 2001:229). Thus, the officially recommended coding style is illustrated in the following example:



In this example, the performance qualifier indicates moderate difficulty (2) with performance, in this case changing basic body position, and the capacity qualifier indicates that capacity is not specified (8).

The prefix d may be used to denote the component ‘Activities and Participation’ or ‘a’ or ‘p’ may be used to denote an activity or participation respectively (WHO 2001:14). This coding convention is also relevant to the discussion in the ICF of an ‘information matrix’ (see Section 5.6).

The ICF (WHO 2001:15) states that both capacity and performance:

- are ‘assessed against a generally accepted population standard’ i.e. to record the ‘discordance’ between the observed level and what is expected of a similar individual without a similar ‘health condition’; and
- can be measured with or without assistance (personal or assistive devices).

Operationalising performance and capacity—and the concept of ‘need’

In developing approaches to these qualifiers, it is helpful to consider three typical coding situations (using Activities domains).

1. The person has moderate difficulty in their current environment with the aid of some equipment, and severe difficulty in their current environment without it.
2. The person has moderate difficulty in their current environment with the aid of equipment (e.g. a walking stick). An assessment of ‘capacity’ in a clinic results in a recommendation that the person gets a new aid (e.g. a walking frame).
3. The person has moderate difficulty in their current environment with the equipment, severe difficulty in this environment without it, and expresses the need for both new equipment and a better environment in order to experience only mild difficulty (e.g. a walking frame, home modifications, additional personal assistance – i.e. three environmental enhancements).

To code all the information in each example, using what is given in the ICF, the following must be recorded:

- difficulty with the activity;
- environmental factors that are in use (or predicted or recommended to be in use); and
- the type of environment (whether current or standardised/optimum).

This amounts to coding convention 3 for Environmental factors (see Section 6 and WHO 2001:225-6):

Convention 3

Environmental factors are coded for capacity and performance qualifiers in the Activities and Participation component for every item.

Performance qualifier _____ E code _____

Capacity qualifier _____ E code _____

In addition, however, examples 2 and 3 illustrate the ‘predictive’ concept of ‘need’, i.e. it is predicted that different environmental circumstances could enhance performance. This prediction may be made by various people, for instance, the person expressing their own needs, or a clinician, possibly in a ‘standard environment’.

To recapitulate, the following points are relevant in operationalising the concepts of performance and capacity in the Australian context:

- *Performance* relates to the *usual* or *current* environment.
- *Capacity* relates to the *standardised* or *uniform* environment (see second ICF qualifier). Capacity also appears to relate to an ‘optimum’ environment as

the ICF describes capacity in terms of indicating ‘the highest probable level of functioning that a person may reach in a given domain at a given moment’ (WHO 2001:15).³

- *Need* relates to the environmental factors (such as personal assistance, equipment, environmental modifications) that are present in the standardised or ‘optimum’ environment (where maximum capacity is achieved) but are not in the current environment (where current performance is achieved); that is, ‘need’ relates to closing the ‘performance gap’ between the current and the optimum environments for the person.

Additional qualifiers

The possibility of coding further qualifiers is recognised in Annex 2 of the ICF (WHO 2001:230–32). The advice given is as follows:

- *Qualifiers indicating the use of assistance:* Performance (or capacity) may be measured with and without assistance (assistive devices or personal assistance). WHO specifies an order for recording them using four successive qualifiers: (1) performance with assistance; (2) capacity with no assistance; (3) capacity with assistance; (4) performance without assistance (WHO 2001:230).
- *Qualifiers indicating involvement:* ‘The fifth digit position is reserved for qualifiers that may be developed in the future, such as a qualifier for involvement or subjective satisfaction’ (Annex 2, WHO 2001:231).

3 The construct of ‘capacity’ appears to relate to a conceptualisation of health that distinguishes between what is sometimes called ‘within the skin’ factors and external factors. This distinction in turn relies on the notion of a separate individual with intrinsic capacity, where better health outcomes can be promoted by health interventions and environmental modifications. This approach is based in an egalitarian, human rights philosophy and has much to commend it in theory. The need to introduce the idea of ‘capacity’ into the classification appears to be driven at least in part by the desire to measure the performance of health systems and how well they are closing the gap between capacity and performance. This purpose brings with it the need to define and confine the scope of the health system, not holding it accountable for measures that, while promoting good human health and functioning, are beyond the scope of many health systems. This aim, of assessing health systems, thus may require a measurement of ‘capacity’, but also requires the measurement of the level of health and human functioning (to indicate the ‘performance gap’).

5.2 Approaches to delineating Activities and Participation

Activities and Participation are two distinct concepts in the ICF with distinct definitions but measured along the same domains. The ICF offers four possible ways of delineating activities and participation (WHO 2001:16):

- (a) to designate some domains as Activities and others as Participation, not allowing any overlap;
- (b) same as (a) above, but with partial overlap;
- (c) to designate all detailed domains as Activities and use the broad category headings as Participation;
- (d) to use all domains as both Activities and Participation.

Annex 3 of the ICF concludes with a statement recognising that practice must be built up, recorded and analysed regarding the 'operationalisation' of Activities and Participation.

This section explores this issue further, leading on to suggestions for practice in Australia and for recording experience.

Draft criteria for delineating Activities and Participation

The delineation of the concepts of Activity and Participation has been a consistent goal of the Australian Collaborating Centre (ACC) and its advisers. Criteria for distinguishing the two concepts, in line with their definitions in the final ICF, were accordingly developed, revised and discussed during the process of revising the ICIDH.

The ACC draft criteria for distinguishing Activities and Participation are included here for use and comment:

- i. Activities focus on the person's individual functioning, while Participation emphasises the person's involvement in society.
- ii. A is completely externally observable. P refers to the 'lived experience of the person' (WHO 2001:15).
- iii. Activity *can* relate to a 'test' environment (although it can also relate to a 'real' environment), with or without equipment. Participation is essentially 'confounded' with the environment, i.e. the concept has little meaning without consideration of the physical and social environment, and it cannot be 'assessed' in a 'test' environment.
- iv. 'Involvement in society' relates in particular to societal roles. This highlights the confounding of Participation with that part of the environment that shapes expected roles and societal norms.

- v. A is fine grained whereas P is broad brushed.
- vi. A is about action or process, P relates to the overall goal of actions or sets of actions.

These draft criteria expand on the WHO definitions (see Section 2.1). Both could be applied together in delineating Activities and Participation in practice.

The purpose is either to:

- split the A-P domains, so that some apply to Activities and the others to Participation, i.e. option (a)
- use the A-P domains with partial or total overlap, together with qualifiers, in order to achieve delineated approaches to Activities and Participation, i.e. options (b) or (d).

These two options are discussed in Sections 5.3 and 5.4.

5.3 Splitting the domains to delineate Activities and Participation—option (a)

Table 5.1 attempts an A-P split of the domains in the single A-P list of domains, reflecting the WHO definitions and Australian Collaborating Centre draft criteria as far as possible. Comment has been sought within the AIHW and from its advisers. The italicised comments in the table show how much agreement there was on the split and the differing views in some areas.

An additional criterion was used in attempting the split; namely the split was done using broad groups of codes, so that ICF 'blocks' went into either one column or the other. This keeps comparison with the single A-P list (and any other split) as simple as possible.

Work along similar lines was undertaken by the Canadian Institute for Health Information on behalf of the North American Collaborating Centre (NACC) (CIHI 2001). Several options for splitting the domains were suggested, but the NACC has not adopted a particular split of the domains.

If option (a) is to be adopted, this table must be finalised to prevent overlap; that is, it must split the domains into activity domains and participation domains, so that no domain remains indeterminate, i.e. able to be used for *either* Activities or Participation.

Option (a) has been impossible to achieve over several years of testing. Although it is possible for individual users, it is not possible across different fields. Table 5.1 stems from different perspectives in the aged care and disability fields.

Table 5.1: Attempted split of Activities and Participation on the basis of domains

Activity	Participation
<p>Ch 1: Learning and applying knowledge</p> <ul style="list-style-type: none"> • Purposeful sensory experience d110–129 • Basic learning d130–159 • Applying knowledge d160–179 <p><i>All advisers agree these are 'A'</i></p>	
<p>Ch 2: General tasks and demands</p> <ul style="list-style-type: none"> • Undertaking a single task d210 • Undertaking multiple tasks d215 • Carrying out daily routine d220 • Handling stress and other psychological demands d230 <p><i>Most agree these are 'A'</i></p>	
<p>Ch 3: Communication</p> <ul style="list-style-type: none"> • Communication—receiving d310–d329 • Communication—producing d330–d349 • Using communication devices and techniques d360–369 <p><i>Most agree these are all 'A'</i></p>	<p>Ch 3: Communication</p> <ul style="list-style-type: none"> • Conversation d350–359 <p><i>Disagreement on this. Some would like it in 'A' to keep the whole 'slab' together.</i></p> <p><i>If separated, could call one group 'communication activities' and the other 'participation in conversation/communication'.</i></p>
<p>Ch 4: Mobility</p> <ul style="list-style-type: none"> • Changing and maintaining body position d410–d429 • Carrying, moving and handling objects d430–449 • Walking, moving and related activities d450–459 (excluding d460–469) <p><i>All advisers agree these are 'A'</i></p>	<p>Ch 4: Mobility</p> <ul style="list-style-type: none"> • Moving around in different locations (home, other buildings, outside) d460–469 • Moving around using transportation d470–499 <p><i>Disagreement on this. Some would like these in 'A' to keep the whole 'slab' together. A difficulty is that 'the home' could perhaps be better separated from the other parts of d460-469, but this makes an awkward split.</i></p> <p><i>Others are concerned that this is a fundamental human rights issue, not just a means to other ends—how can you participate in your society if you can't move around in it?</i></p> <p><i>If separated, one group could be called 'movement activities' and the other 'participation in movement around the home and community'.</i></p>
<p>Ch 5: Self-care</p> <ul style="list-style-type: none"> • Washing oneself d510 • Caring for body parts d520 • Toileting d530 • Dressing d540 • Eating d550 • Drinking d560 • Looking after one's health d570 <p><i>All advisers agree these are 'A'</i></p>	

(continued)

Table 5.1(continued): Attempted split of Activities and Participation on the basis of domains

<p>Ch 6: Domestic life</p> <p><i>See discussion opposite. Some would put this entire chapter in 'A'.</i></p>	<p>Ch 6: Domestic life</p> <ul style="list-style-type: none"> • Acquisition of necessities d610–629 • Household tasks d630–649 • Caring for household objects and assisting others d650–669 <p><i>There is considerable disagreement here. Some would put all these in 'A', and suggest that some areas (e.g. 'household tasks') are very much like activities without very much social focus. Others see this group as so socially and environmentally determined as to make it difficult to ascribe meaning without the context of the physical household environment and the social expectations on the roles involved. Some see both sides!</i></p>
	<p>Ch 7: Interpersonal interactions and relationships</p> <ul style="list-style-type: none"> • General personal interactions d710–729 • Particular personal relationship d730–779 <p><i>All agree these are 'P'.</i></p>
	<p>Ch 8: Major life areas</p> <ul style="list-style-type: none"> • Education d810–839 • Work and employment d840–859 • Economic life d860–879 <p><i>All agree these are 'P'.</i></p>
	<p>Ch 9: Community, social and civic life</p> <ul style="list-style-type: none"> • Community life d910 • Recreation and leisure d920 • Religion and spirituality d930 • Human rights d940 • Political life and citizenship d950 <p><i>All agree these are 'P'.</i></p>

Advice to users

- The Australian Collaborating Centre is **not** able at this stage to recommend a split of the domains for general use; that is, it is not able to recommend option (a) as a general solution to delineating Activities and Participation.
- Option (a) may nevertheless be suitable for specific applications, where users can obtain agreement among stakeholders on a suitable split of the domains, consistent with the ICF definitions. *In this case, please record your experience in the template in Sections 5.6.*

5.4 Using the qualifiers as the basis for delineating Activities and Participation—options (b) and (d)

The previous discussion prompts the question: are the different perspectives reflected in Table 5.1 a problem? If potential users preserve the separate concepts of Activities and Participation, does it matter that they wish to use and interpret the domains somewhat differently in different circumstances? Is it in fact more useful to use the freedom offered in options (b) and (d) to adapt and experiment in this difficult area?

It is logically obvious that if any domain can be used for *either* Activities or Participation, then the delineation between Activities and Participation must involve the use of different qualifiers as the only other tools available in the classification for this purpose.

In ICF terms, this means that, if options (b) or (d) are adopted, then the ‘generic qualifier’ must be translated into suitable language for Activities and Participation separately, and/or additional qualifiers must be provided, such as a qualifier for participation, indicating ‘involvement in life situations’ (see Section 5.1).

5.5 Qualifiers for Activities and Participation—and A–P delineation

This section describes a suggested approach, for use in Australia, to qualifiers for Activities and Participation. The aim is to provide qualifiers that:

- can be used to help delineate Activities from Participation for users using options (b) or (d)
- can also be used with option (a)
- are consistent with the ICF.

Qualifiers for Activities

The ICF gives us:

- Activities domains
- A qualifier about ‘difficulty’ with the activity (the generic qualifier); the statement is made that difficulty can be measured with or without assistive devices or personal assistance, and as capacity or performance; the constructs of performance and capacity relate to the person in a specified environment;

- Environmental factors that may facilitate or be a barrier to the activity.

Further, it was said in Section 5.1 that:

- Performance relates to the usual or current environment (see first ICF qualifier).
- Capacity relates to the standardised or uniform environment (see second proposed ICF qualifier). Capacity also appears to relate to an ‘optimum’ environment as the ICF talks of capacity in terms of indicating ‘the highest probable level of functioning that a person may reach in a given domain at a given moment’ (WHO 2001:15).
- Need relates to the Environmental factors (such as personal assistance, equipment, environmental modifications) that are present in the standardised or ‘optimum’ environment but are not in the current environment (where current performance is achieved).

Work in progress

What has emerged from discussion in the Advisory Committee on Australian and International Disability Data (ACAIDD) is the need to operationalise more explicitly a concept of ‘Assistance with Activity’. This is considered to be an important subset of Environmental factors on which much measurement work has been done, and a major component of disability and aged care services policy in Australia. Work to date conceptualises ‘Assistance with Activity’ as a multidimensional concept, relating to the duration, frequency and intensity of assistance; information on various scales in use is being assembled. This qualifying concept would be used to describe aspects of the current or standardised or optimum environment, in terms commonly used in measurement and assessment tools – i.e. to record more detail than just ‘with or without assistance’ as currently envisaged in the ICF. Thus, this concept would be consistent with the ICF and would supplement the information obtained by using the ICF. It is planned to continue work on this idea, starting with including a relevant data concept in the National Community Services Data Dictionary (NCSDD) V3, as a supplement to data elements based on components of the ICF (AIHW 2003a).

Thus two possible qualifiers for Activities are suggested. The ICF generic qualifier (‘difficulty’) and the qualifying concept suggested above (‘Assistance with Activity’) can be used in different environments; each could, of course, result in different measures depending on which environment is present.

A guide for use (to be developed) could indicate:

- how questions asked would vary to indicate which construct (performance or capacity) and which corresponding environment was being considered

- how to record the results (possibly by positioning of qualifiers – this is the method for distinguishing performance and capacity specified in the ICF).

Qualifiers for Participation

Work has been carried out in Australia on the measurement of participation, both during the revision years and since publication of the ICF in May 2001. Two qualifiers were developed for inclusion in the NCSDD V2 on a trial basis – ‘Participation extent’ and ‘Participation – satisfaction level’ (AIHW 2000). A recent review of measures of participation has confirmed these ideas as appropriate templates for the development of new data elements for the NCSDD V3 (AIHW 2003a; Bricknell & Madden 2002).

The qualifier ‘Participation extent’ corresponds to the ICF generic qualifier and indicates the extent of participation restriction. This will correspond to an externally observable (or ‘objective’) measure of participation.

The qualifier ‘Participation – satisfaction level’ corresponds to the person’s own perspective on their participation, and reflects their attitude to their participation in the various life domains. It is essentially a summary measure in which are embedded the concepts of satisfaction, choice, opportunity and importance. This corresponds to the qualifier for ‘involvement or subjective satisfaction’ allowed for in the ICF (Annex 2). Such a qualifier may indicate a ‘performance gap’ for participation, in that a person may indicate life areas where they are not satisfied, and may indicate environmental factors that could ameliorate the situation (see also Section 5.6).

Data elements for Activities and Participation qualifiers

Data elements have been drafted for these qualifiers to operationalise these ICF concepts and options (b) and (d) for Australian use of Activities and Participation. See Section 7 for further detail on this work, and the related national data dictionaries.

5.6 The ‘information matrix’

WHO states that the information gathered from the list of Activities and Participation, suitably qualified, provides an information matrix, recording performance and capacity in each of the life domains (WHO 2001:14).

If option (b) or (d) is adopted, then an expanded information matrix is created.

If, for instance, users opted to use the qualifiers described above, to delineate Activities and Participation, then codes for both Activities and Participation would be recorded in the following format:

- *axxxx.q_pq_c* – the first qualifier being difficulty with Activity in the current environment and the second being difficulty in a standard or optimum environment; if qualifiers for assistance are developed (see Section 5.5) these would be additional.
- *pxxxx.q_pq_c* – the first qualifier would relate to extent of Participation and the second to Participation in an optimum (or standard) environment; if qualifiers for satisfaction are developed (see Section 5.5) these would be additional.

As outlined in Section 5.1, these qualifiers (recorded measures) can only be interpreted if the environment is also recorded – whether the environment is current, optimum or standard, and whether it is a facilitator or barrier (using the qualifiers offered by the ICF).

The expanded matrix could then look like Table 5.2 (drawn to correspond to Option (b) and Table 5.1). The ‘assistance’ and ‘satisfaction’ qualifiers are not yet included in the expanded matrix but are recommended for use by Australian users.

Table 5.2: Expanded information matrix for Option (b) – some A-P overlap

Domains	Qualifiers							
	Performance				Capacity			
	Activity		Participation		Activity		Participation	
	Difficulty	Assistance*	Extent	Satisfaction	Difficulty	Assistance*	Extent	Satisfaction
Learning and applying knowledge								
General tasks and demands								
Communication								
Mobility								
Self-care								
Domestic life								
Interpersonal interactions and relationships								
Major life areas								
Community, social and civic life								

Key: (shading is illustrative only, not a recommended split of the domains)

	Domains less likely to relate to Participation
	Domains that may relate to Activities or Participation
	Domains less likely to relate to Activities

* ‘Assistance’ may be a set of supplementary measures or qualifiers, reflecting the multidimensional nature of ‘assistance’ (see Section 5.3).

5.7 Moving forward on measurement and the qualifiers

The scales of the suggested qualifiers, including the generic or uniform qualifier, require calibration with existing measures and assessment tools, and more description as to rating. Many existing assessment tools are in use and are firmly embedded in measurement and even payment methods in services around Australia.

In Australia some calibration and mapping has already been undertaken in the disability services field (see the CSTDA NMDS module in Section 10.1). It would be of benefit if it were undertaken in other new developments including aged care 'dependency' measures and health status measurement, as well as in assuring continuing alignment of disability population surveys with the new ICF.⁴ Such work will enable final data elements in the NCSDD V3 to be fully useable in the range of applications to which the new classification should be applied.

The challenge then is how to use the classification in a consistent way when much work remains to be done on qualifiers, i.e. **measurement**. In 1999 a range of measurement issues that needed consideration in the ICF were suggested (Madden 1999), including:

- the need to clarify purpose before deciding method
- the importance of understanding the role played by 'perception' in measurement (i.e. who measures – sometimes oversimplified as a distinction between 'objective' and 'subjective') and, related to this point,
- the vital role played by people with disabilities in the ICF revision.

Testing and development

WHO envisages that, in the early period of ICF implementation, users will wish to experiment with the different approaches suggested in the classification. During the early implementation period of the new ICF in Australia, it will be fruitful to promote testing and development within broad spheres of application and to record and share experience. This would allow the ICF to be more widely explored and reported on for a period, as users in various application areas come to grips with it.

4 The Australian Bureau of Statistics Survey of Disability, Ageing and Carers is now undertaken at 6-yearly intervals. Since the first survey in 1981, it has been reasonably well aligned with some ICF (and previously ICIDH) concepts.

Current work in Australia includes:

- developing and discussing the draft data elements for the NCSDD V3 (see Section 7)
- continuing work on the types of developments outlined in this User Guide – this will involve having regard to national and international consistency, using the best available tools, and avoiding ‘premature closure’, i.e. recommending Australian solutions that do not suit all Australian applications
- encouraging potential users to undertake discussion and development, and to refer to and contribute to this User Guide
- engaging in discussion of health applications
- organising further consultation within Australia and staying involved in the international communication.

5.8 Advice to users—and how to contribute to national development by recording use in a ‘test template’

This section has focused on Activities and Participation, both in terms of the life domains listed in the ICF, and the measures relating to them.

On the A-P list and the possibility of delineating Activities and Participation on domains according to WHO’s option (a) it is suggested that agreement on splitting the domains may not generally be possible. One Australian application now developed (see Section 10.1) illustrates the benefits of using the flexibility offered by the classification with the new combined list and the options for use.

The qualifiers remain a major issue. Measurement is largely unresolved by the classification, and much work remains to be done, to avoid fragmentation in the early years of implementation. Progress is important because of the persisting possibility that some applications, particularly those with large resources, will swamp those that move more slowly or are less adequately resourced. It will be important to build up knowledge about measurement, and its purpose, its method and the impact of the perspective of the measurer. If options (b) or (d) are used for Activities and Participation, then different qualifiers are needed.

This approach, of providing additional qualifiers to delineate Activities and Participation, is the one suggested in this section, in the form of:

- a generic qualifier for Activities – difficulty with Activities, and one also for Participation – extent of Participation
- an additional qualifier for Participation, the option offered by the ICF (see Section 7)
- a supplementary, summary concept about assistance with Activity. This is still under development, and may need to be accompanied by advice on data collection.

This User Guide therefore proposes that Australian users:

- consider adopting options (b) or (d) for delineating between Activities and Participation, i.e. use qualifiers to delineate rather than splitting the A-P domains for that purpose
- if option (a) is preferred for any particular application, then record the split of domains and the reasoning for it
- use and comment on the draft data elements for Activity and Participation qualifiers (see Section 7)
- calibrate measures being used for the ICF generic qualifier
- record their experience in the suggested ‘test template’.

A ‘test template’ for promoting consistent use and recording experience

The ICF should prove invaluable as a conceptual and information-oriented framework for a wide range of applications relating to human functioning. These applications are likely to increase quickly and significantly. The ICF classification has significant implications for national and international data collections, both in terms of the content of the collections and the scope of collections that could be affected.

This section has highlighted a number of areas where the classification allows some flexibility for the user. It is suggested that Australian users take advantage of this flexibility, but also record their experience systematically, so that knowledge can be built and shared rapidly.

Communication is essential to harness and harmonise the rapid progress that is likely to occur. Table 5.3 aims to act as a framework for this communication and promotes :

- a means of developing language, concepts and measures for Activities and Participation qualifiers
- protocols for calibration in a broad range of fields of application

- methods for sharing and publishing results, to promote discussion, quality and consistency.

The goal of such a template is to promote coherent ongoing development, and consistency where it is achievable. The template is structured as a set of suggestions for use and a corresponding 'area for comment'.

It must be emphasised that this template supplements the ICF. It is to be used alongside the ICF, and as a guide in areas where the classification has left some discretion to the user. All material in this section is designed to be consistent with the ICF but to guide the user in areas where flexibility remains.

Table 5.3: A and P options: a recommended template for ICF use and development in Australia

Area of user choice	Suggestion for use in Australia	How to record application
Distinguishing A and P conceptually	Use draft Australian criteria (see Section 5.2) to supplement the ICF.	Comment on the criteria. Record any refinements for use in a particular area of application.
Area of user choice	Suggestion for use in Australia	How to record application
Use of options (a) to (d)	We suggest use of options (d) or (b). If using one of these options, record experience as indicated.	Record and explain the split of domains if option (b) is used. Use draft Australian qualifiers to delineate A and P (see Sections 5.2 and 7). Record comments and suggestions.
	If using option (a), record experience as indicated.	Record: <ul style="list-style-type: none"> • reasons for choice of option (a), • what the split of domains is and why it was chosen.
Use of the generic qualifier	If used with option (a), calibrate as indicated.	Calibrate for field of application and explain calibration.
Use of (draft) A and P qualifiers from the NCSDD—see Section 7	We suggest their use for options (b) or (d).	Calibrate for field of application. Record comments on use and suggested refinements.
	If used for option (a) then record application as shown.	Explain which qualifiers were used and why. Calibrate for field of application. Record comments on use and suggested refinements.
Performance, Capacity and Need		Record ideas and comments
PLEASE ALSO FILL IN THE FOLLOWING:		
Your contact details.....		
Would you like your contact details added to an Australian ICF User Network?.....		
May we include your answers in this template in Section 10 of the User Guide?.....		
Would you be willing to contribute a short description of your application for inclusion in the User Guide, to supplement the template? If possible, please include now.....		

6. Environmental factors

The recognition of environmental factors as fundamental to functioning and disability is an important development in the conceptualisation of disability, and the promotion of rights for people with disabilities. Disadvantage associated with disability arises from environments that do not cater to the needs of people with disabilities, preventing them from fulfilling roles appropriate to their age, sex and social and cultural identity. Restricted access to or use of assistive equipment, or failure to enhance environments, may be associated, for example, with higher costs of support services or delayed return to the workforce.

6.1 Environmental factors and the ICF

Environmental factors 'make up the physical, social and attitudinal environment in which people live and conduct their lives' (WHO 2001:10). The ICF identifies environmental factors as a key component in defining the concept of disability. The decision to include these factors as an important new component of the ICF recognises their influence on functioning and disability.

Environmental factors interact with the other ICF components of Body Functions and Structures, Activities and Participation. They can have the effect of improving or hindering an individual's body function, ability to execute an activity, and/or their participation in society, and hence the level of impairment, activity limitation and participation restriction experienced. An environment with facilitators can improve the experience of people with disabilities in society; one with barriers, or without facilitators, will restrict their integration. Different environments, therefore, may have a different impact on the same individual with a given health condition.

To operationalise these concepts, the Australian Collaborating Centre has drafted national data elements for Environmental factors (see Section 7 and AIHW 2003a). Comments on their use are welcome; please use the template in Table 6.1 for this purpose.

6.2 Coding conventions and qualifiers

The Environmental factor qualifier indicates the extent to which an environmental factor acts as a facilitator or a barrier. There is a negative 5-point scale to indicate the degree to which a particular environmental factor is a barrier to a person's successful functioning, and a positive 5-point scale to

indicate the degree to which a particular environmental factor is a facilitator (WHO 2001:172).

WHO (2001:225–26) offers three coding conventions for environmental factors, essentially to code factors:

1. as they affect the person overall, without relating the rating to any particular component;
2. as they broadly affect each of body structure, body function, activity and participation; or,
3. against every single body structure, body function, activity or participation code used.

Testing using ‘vignettes’ during ICF development in Australia generally revealed reluctance for option 3, not only because it was very labour intensive, but also because of the duplication involved. A number of environmental factors occurred repeatedly as affecting more than one code. For instance, a highly accessible physical built environment may facilitate a range of activities in the area of mobility, as well as participation in the areas of employment and community life.

Nevertheless, there may be applications where it will be important to relate each environmental factor to each individual impairment, activity limitation or participation restriction. There may be other applications where one of the other two options may provide information adequate to the purpose (or where data design will be required to obtain summary information to minimise ‘provider burden’).

Within the one application, it could be possible to use more than one option. For instance, in the case of disability support services the following possibilities could be used:

- the use of environmental factors (personal assistance and equipment) to help describe support needs in areas of activity and participation, an example of (3)
- the presence of a family member or friend who regularly assists, as an overall environmental descriptor, an example of (1)
- the need for equipment or environmental modifications as indicators of specific unmet needs, again essentially (1). (This is a way of investigating the ‘gap’ between the ideal environment and the actual one.)

These would be relatively minor adjustments of a national data set to incorporate the classification, but they would still represent progress compared to a collection containing no recognition of some key ICF concepts (see also Section 10.1).

The qualifiers of the Environmental factors are well conceptualised. Because of their newness, it will be important to systematically record and share information and experience about the qualifiers as they come into more common use. As practice builds up, calibration will also become important.

The more general challenge is to ensure that we use this new aspect of the classification to its full extent. Each time we use the classification, we need to check that we have adequately incorporated environmental factors into our applications.

Table 6.1 provides a template for recording use of these factors.

6.3 Current applications

The application of environmental factors is still in its infancy; however, progress has begun with environmental factors being recognised in assessment tools, health and disability surveys, and outcomes research. Three of these applications are discussed below.

Environmental factors and ‘performance gaps’ in participation

One area requiring attention in health and disability data collections is the inclusion of survey questions useful for measuring ‘performance gaps’ in participation. Bickenbach (2002) refers to these gaps as ‘participation gaps’, which he defines as ‘measurable differences in levels or quality of participation between those with, and those without, disability’.

Environmental factors are recognised influences in the creation of such ‘gaps’ and are responsible for different, or lower, levels of participation by people with a disability. Being able to identify performance gaps in participation is crucial to those evaluating the outcomes of disability services and policy.

Using the ICF as a model, Canadian disability data collectors and users have focused on the component data requirements necessary to identify ‘participation gaps’ in the population. This work includes the development of questions about the person’s physical or built environment as well as their social and attitudinal environment. These questions would be used to identify ‘participation gaps’ in conjunction with a common set of screener questions and a set of questions on participation in life areas. It is proposed that such questions be introduced into the Canadian Community Health Survey, as well as the Participation and Activity Limitation Survey, to ensure responses are obtained from both the non-disabled and disabled population. This allows comparison between levels of participation of the two population groups and how the environment of the disabled population acts as a barrier to full participation (Bickenbach 2002).

Modelling the impact of environmental factors associated with activity limitation and labour force participation

Two projects at the Arthritis Community Research and Evaluation Unit in Toronto have modelled the experience of activity limitation and participation restriction with reference to the ICF and the effect of environmental factors. Both projects have focused on the built environment and the use of aids and equipment, and whether these have an impact on completing daily activities and participating in the labour force.

The first of these modelling projects examined activity limitation (limitation in self-care, mobility, meal preparation, shopping, light and heavy housework and looking after personal finances) and the effects of environmental factors, as represented by aids and equipment and home modifications, as well as personal factors and the presence of a physical or sensory disability (Badley et al. 1998). Although activity limitation was mainly affected by the presence of a physical disability, this relationship was at least partially influenced by the environment; that is, a person's access to aids and equipment, or having suitable home modifications, offset some of the limitation associated with the impairment.

In the second project, environmental factors were found to influence labour force participation by people with arthritis experiencing mobility limitations (Wang & Badley 2002). The availability or absence of workplace features such as accessible parking, lifts, and appropriate workstation conditions proved to be important facilitators or barriers respectively to people with arthritis. Although mobility limitation greatly affected labour force participation, the strength of that effect was mediated through workplace features.

Environmental factors and people with a disability in Australia

The AIHW has recently published a report that draws on the ICF to describe the type of environmental factors that potentially influence the lives of people with a disability in Australia (AIHW: Bricknell 2003). The environmental factors defined in the ICF and available in the ABS Survey of Disability, Ageing and Carers were examined in relation to other ICF components (e.g. activities and participation), and personal factors.

The report mainly focuses on the use of aids and equipment, examining the association between the use and non-use of aids and:

- disability status and main disabling condition
- help from a personal carer
- need for assistance with the core activities of self-care, mobility and communication, and other activities (e.g. health care, meal preparation)

- participation in education and employment
- personal factors such as age, sex, and living arrangements.

Additionally, the report investigates services and support for people with disabilities, concentrating on the kinds of services and assistance people with disabilities need and/or receive, specifically in relation to education, employment, public transport and specific daily activities. Such research may suggest how the absence or presence of a particular environmental factor affects an individual's participation extent or ability to perform daily activities.

Table 6.1: Template for recording experience with use of Environmental factors

Area of user choice	Basic description of application	Evaluation
Using the 'current' environment	Please describe briefly: <ul style="list-style-type: none"> • the type of environment, • why it was 'current'. 	How well did this approach to the environment relate to the concept of 'performance' (see Section 5)? Did you obtain useful information about the person's environment and its effect on their functioning? Comments or suggestions?
Using the 'optimum' environment	Please describe briefly: <ul style="list-style-type: none"> • the type of environment, • why it was 'optimum'. 	How well did this approach to the environment relate to the concept of 'capacity' or 'need' (see Section 5)? Did you obtain useful information on the aspects of the person's environment (including equipment) that could be improved in order to enhance his or her functioning? Comments or suggestions?
Using the 'standard' environment	Please describe briefly: <ul style="list-style-type: none"> • the type of environment, • why it was 'standard'. 	How well did this approach to the environment relate to the concept of 'capacity' or 'need' (see Section 5)? Did you obtain useful information on the aspects of the person's environment (including equipment) that could be improved in order to enhance his or her functioning? Comments or suggestions?
Coding options and qualifiers	Did you use option 1: recording the Environmental factors as they affect the person overall?	Please record: <ul style="list-style-type: none"> • reasons for choice of option (1) • comments on use and suggested refinements • comments on how well the qualifiers worked for this option • any opportunities for calibration with other measuring tools.
	Did you use Option 2: recording Environmental factors as they broadly affect each of body structure, body function, activities and participation?	Please record: <ul style="list-style-type: none"> • reasons for choice of option (2) • comments on use and suggested refinements • comments on how well the qualifiers worked for this option.
	Did you use option 3: recording environmental factors against every single body structure, body function, activity or participation code used.	Please record: <ul style="list-style-type: none"> • reasons for choice of option (3) • comments on use and suggested refinements • comments on how well the qualifiers worked for this option.

(continued)

Table 6.1(continued): Template for recording experience with use of Environmental factors

Draft data elements	Refer to National Community Services Data Dictionary (AIHW 2003a) and see also Table 5.3.	Please record comments.
Performance, capacity and need		Ideas and comments on Section 5 of the User Guide?
<p>PLEASE ALSO FILL IN THE FOLLOWING:</p> <p>Your contact details.....</p> <p>Would you like your contact details added to an Australian ICF User Network?.....</p> <p>May we include your answers in this template in Section 10 of the User Guide?.....</p> <p>Would you be willing to contribute a short description of your application for inclusion in the User Guide, to supplement the template? If possible, please include now.....</p>		

7. The ICF and Australian data dictionaries

Countries like Australia with a broad policy on disability require a wide range of data to describe the status of people with disabilities in the population and their access to services. These data should span all areas of disability and relate to each other and to population data as well. A broad common understanding of disability, including common disability definitions, is crucial to understanding and improving outcomes for people with disabilities and the services available to them.

7.1 The ICF as a framework for national disability data

Good data are needed for a wide range of purposes in the disability field. The basics of good data are well-defined data elements, which are part of a meaningful, holistic framework. Without a common conceptual framework we are left with only bits and pieces of unrelated data. (See Section 3.)

The acceptance in Australia of the ICF as a useful conceptual framework for national data arose from years of discussion, consultation and testing (Madden et al. 2003). One of the main processes facilitating the testing of the ICF was the creation of a broad advisory group in 1996 to guide the improvement and unification of national data on disability. This group, consisting of people with disabilities, government departments responsible for policy, statisticians and other experts in the field, worked with the AIHW in both its roles, as a statutory authority with responsibility for improving national data on disability and as a WHO Collaborating Centre during the ICF development. The group made a significant contribution to both of the AIHW's tasks – improving national data consistency, and providing Australian input to the development of the ICF.

Additionally, definitions of disability currently used in Australia were examined to establish consistency and their relationship to the ICF (Madden & Hogan 1997). Many different definitions of disability are used in Australia, both in administrative data collections and in Acts of Parliament. Four main categories of definitions were identified:

- broad inclusive definitions for population research and anti-discrimination measures (such as the Survey of Disability, Ageing and Carers and the 1992 Commonwealth Disability Discrimination Act)

- definitions for generic or ‘mainstream’ services (such as education programs)
- definitions for income support, insurance and social security (such as disability pensions and carer payments)
- definitions for disability support services (such as Commonwealth, state and territory disability services legislation).

It was concluded that there could be no single definition of disability. The goal of disability data development was not to arrive at a single definition of disability but rather to define terms that could be used to relate definitions and data from different systems to each other. The draft ICIDH-2 was seen as a suitable framework in which to map functioning and disability.

The same is true of the final ICF. The terms ‘functioning’ and ‘disability’ are the overarching concepts of the classification – the more a person considers their activities to be limited or their participation to be restricted, the more they may describe themselves as having a disability. Likewise, a service may describe its eligibility criteria in terms of the activities with which people need assistance, the equipment they require to perform an activity without difficulty, or the participation they wish to increase. A different service may ‘set the bar’ to entry at a different point in the framework provided by the ICF.

The utility of the emerging ICF was broadly supported by other tests that explored its acceptability in the field of intellectual disability, and in two Aboriginal communities in the Northern Territory (AIHW 2002a).

All these processes combined to confirm that most of the main disability definitions used in Australia could be mapped to the draft ICIDH-2. The draft ICIDH-2, and then the ICF, appeared to be a useful base on which to draft data elements for national data dictionaries.

7.2 Moving towards national consistency

The collation of national data on service provision and outcomes for people with disabilities is both important and challenging. In particular, there is a need for better quality data from administrative systems – data that can be compared across time, across state and territories and across various health and welfare programs. There is a further requirement – namely that it is possible to compare the statistics produced from administrative sources with those from surveys and censuses, so that we can estimate the need for services and access to services by particular population groups.

National information agreements

To facilitate the development of data for reporting purposes, the relevant policy agencies of the Commonwealth, states and territories and the two statistical agencies (the ABS and the AIHW) have signed four national information agreements for the fields of health, community services, housing and Indigenous housing.

These agreements are high level agreements, signed by agency heads. They provide a structure and consultative mechanism through which governments can work cooperatively, with a national perspective, to improve, maintain and share national health, community services and housing information.

The Australian data dictionaries

Three of the main products resulting from the national information agreements are the National Community Services Data Dictionary (Version 3, 2003a; Version 2, AIHW 2000), the National Health Data Dictionary (Version 12, AIHW 2003b), and the National Housing Assistance Data Dictionary (Version 2, AIHW 2003c). These data dictionaries are compiled by the respective information management groups established under the information agreements and are published by the AIHW. The dictionaries are major pieces of Australian national information infrastructure. They contain national information models, and associated data elements, specified in accordance with International Organization for Standardisation (ISO) standards. The dictionaries provide a menu of standard data elements, from which national minimum data sets can be specified, for the major national collections in the fields of health, community services, housing and Indigenous housing. Minimum data sets established under the community services, health and housing agreements are obligatory for all to report on, and all signatories are obliged to use the relevant national data dictionaries. The dictionaries are also intended to assist a much broader audience, e.g. service providers developing their own information systems, and researchers.

The data dictionaries provide information necessary to understand the meaning of the data elements and ensure consistency in application of the definitions and classifications. The information provided in the dictionary template includes:

- definition (what it is that you wish to know)
- context (who wants to know and why)
- data domain (the range of possible answers)
- guide for use (which answers to choose)
- collection method (when and how to obtain the information)

- related data (other data elements of relevance)
- comments (other relevant information to understand the data item).

7.3 The ICF and national disability data elements

The national data dictionaries offer a mechanism for promoting national disability data consistency, achieved by devising national data elements based on the ICF (Madden et al. 2003).

Disability data elements based on a draft of the ICF (Beta-2 version of the ICIDH-2) were approved for inclusion, on a trial basis, in Version 2 of the National Community Services Data Dictionary (NCSDD) (AIHW 2000). An information annex was included to explain the items and their interrelationships. As the ICIDH-2 Beta-2 version was still a draft classification, subject to further testing, use of excessive detail was avoided. This was to ensure that a balance was struck between remaining consistent with international developments and moving forward in the best possible way to respond to the very significant and urgent need for a more consistent approach to disability data in Australia.

Version 2 of the NCSDD contains:

- a definition of disability as a concept together with
- a suite of thirteen related data elements, with definitions related to each other via a common framework. These data elements currently reflect the draft ICIDH-2 framework.

The third version of NCSDD is due for release in 2003. Following the endorsement of the ICF by the World Health Assembly in 2001, some of the data elements trialled in NCSDD 2000 have been revised or developed in line with the ICF and its components of body functions and structures, activities and participation, and environmental factors.

Five data concepts and ten data elements are to be included, each accompanied by definitions and guides for use. These data items are:

Concepts:

- Disability
- Functioning
- Activity – functioning, disability and health
- Participation – functioning, disability and health

- Assistance with activities and participation.

Data elements:

- Body functions
- Body structures
- Impairment extent
- Activities and participation domains
- Activities – level of difficulty
- Participation extent
- Participation – satisfaction with
- Environmental factors
- Environmental factors – extent of influence
- Disability grouping.

The data concept of ‘Disability’ in the NCSDD guides the user to, and relies on, this set of defining data elements which are intended to be the building blocks for Australian data collections and systems constructed for various specific services and purposes. The resulting systems, and the data produced, will then be able to be related to each other.

7.4 Using the national disability data elements

The disability data elements can be used to:

- build specific-purpose data collections including data elements consistent with national standards
- relate two or more data sets by mapping existing data elements to the NCSDD standard data elements
- guide data collection methods.

The following examples of each of these purposes illustrate the potential benefits of these types of use.

Building specific-purpose data collections

The first steps in building a data collection are to determine its main purpose, the main information needed from it and the main users.

Suppose, for example, that we want to record the number of employees with disabilities in a particular industry sector. To achieve this, we would create a personnel data system that includes data elements based on the data elements in the current Data Dictionary.

We could then relate data resulting from the collection to data from the Australian Survey of Disability, Ageing and Carers, thereby monitoring the achievements of equal employment opportunity goals in relation to numbers of people in the population with similar activity limitations. We could also identify the environmental modifications needed to make the workplace more suitable for people with disabilities.

For another example, see Section 10.1 on how the ICF and NCSDD V2.0 disability data elements were used in the redevelopment of a major national data set for the Australian disability services sector.

Relating two or more data sets

Section 3.2 gives an example of how the presence of ICF concepts in disability service definitions and in population survey data enabled population data to be related to service definitions and data on supply. These common elements allowed the AIHW to estimate unmet needs for these services.

Guiding data collection methods

The main purpose of the national data dictionaries is to place standard data definitions and data elements, with guides for use, in the public domain, so as to promote consistent and high quality data collection in Australia. The inclusion of standard data elements in the national data dictionaries will be an important step in operationalising the ICF in data collections.

8. Disability identifiers

The ICF provides a basis for developing 'disability identifiers' or short sets of questions that can be used in generic service information systems or general population surveys. The goal is to relate the experience of people with a disability to that of the general population, as suggested internationally by the UN Standard Rules on Equalization of Opportunities for Persons with Disabilities, and nationally by Commonwealth, state and territory policies in Australia.

This is an area of considerable importance, but still under development, as the following three examples illustrate.

The Washington City Group (UN Statistical Commission)

This international group was established following a UN seminar on measurement of disability in 2001⁵, soon after finalisation of the ICF. At its meeting in February 2002, members agreed on the following as the groups stated objectives:

1. guiding the development of a small set (or small sets) of general disability measures, suitable for use in censuses, sample-based national surveys or other statistical formats, to provide basic necessary information on disability throughout the world
2. recommending one or more extended sets of survey items to measure disability, or principles for their design, to be used as components of population surveys or as supplements to specialty surveys; these extended sets of survey items will be related to the general measures
3. addressing the methodological issues associated with the measurement of disability considered most pressing by the City Group participants

Measures identified in objectives 1 and 2 will be culturally comparable to the extent possible. The ICF model, a useful framework to assist in the development of these measures, will be used in developing the measures.

The final report of this initial meeting, as well as the papers presented, can be found at <http://www.cdc.gov/nchs/citygroup.htm>.

The work of the group is still progressing.

5 A selected group of papers from the meeting are available from <http://www.cdc.gov/nchs/about/otheract/citygroup/products1.htm>

ABS population surveys and related disability 'modules'

The ABS has carried out five major population Surveys of Disability, Ageing and Carers, in 1981, 1988, 1993, 1998 and 2003 (see, for instance, ABS 1999). The first and subsequent surveys used the concepts of the ICIDH and, in recent years, the ABS is moving to adjust the survey outputs to the new ICF. These surveys have provided the Australian community and policy makers with valuable information during these years.

In recognition of the need to describe the experience of people with disabilities in a wide range of life areas, the ABS has introduced 'disability modules' into a number of its social surveys, including those relating to time use and household expenditure. The resulting data have contributed, for instance, to the 'outcome' analysis described in Section 3.2.

The ABS modules, while useful for this purpose, are quite lengthy and are constructed chiefly with the aim of replicating the main survey concepts and techniques in the other social surveys. They achieve the purpose for which they were designed but may not lend themselves to be readily incorporated into other collections.

Census questions conforming to the ICF

Countries such as Canada and Australia have worked to develop questions on disability for use in the main population census. Although the ABS has not yet developed a question it has been satisfied to use, it is again attempting to develop a question, for use in the 2006 national census. The question should relate conceptually to the ICF and will be judged by its ability to produce data that relate to the data from the major ABS disability population surveys. Successful development of such a question will greatly enhance disability data in Australia, particularly data for relatively small geographic areas and among smaller population subgroups.

Should such a question become a feature of Australian censuses, it would also be a likely candidate for inclusion in administrative and other collections. This would allow comparisons and cross-checking between census data and data from other collections.

It is hoped that future editions of the User Guide will contain suggestions about useful disability identifiers and model questions.

9. Personal factors

The ICF recognises the importance of personal factors in the framework of Figure 2.1 but does not attempt to enumerate or classify them.

It is recommended that Australian users refer to national standard data elements in the national data dictionaries (AIHW 2000, 2003a) for items such as the following:

Demographic characteristics

- Date of birth
- Sex

Socio cultural characteristics

- Indigenous status
- Country of birth

Education characteristics

- Education level

Labour characteristics

- Employment status
- Labour force status

Income characteristics

- Principal source of income

Accommodation, living characteristics

- Dwelling
- Homelessness
- Living arrangements
- Residential setting

Address

- Geographic location

10. ICF applications—examples

This section outlines some current applications in Australia, providing examples relating to:

- Applying the ICF to a national disability services data collection (Section 10.1)
- The use of the ICF framework in an allied health outcome measure: Australian Therapy Outcome Measures (AusTOMs) (Section 10.2)
- The ICF and classification for disability athletics (Section 10.3)
- The ICF and accident compensation in Australia (Section 10.4)
- The ICF and speech pathology (Section 10.5)
- The ICF and Rett Syndrome (Section 10.6)
- Classification of support and need (Section 10.7)
- Handicap Assessment and Resource Tool (HART) and the ICF (Section 10.8)
- The ICF and oral health (Section 10.9).

These examples have been contributed by different users who are acknowledged in the relevant section. The examples are included in chronological order – the order in which they were ‘discovered’ by and provided to the AIHW. They are included as interesting illustrations, often of work in progress, to encourage discussion and innovation. They are neither a complete nor an endorsed collection of current applications.

Section 6 on Environmental factors contains examples of applications that focus on this component of the ICF.

10.1 Applying the ICF to a national disability services data collection

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Introduction

This section describes the ways in which the ICF was used when redeveloping the main administrative national data collection used in the Australian disability services sector.

The CSTDA NMDS and its redevelopment

Specialist disability support services in Australia are provided under the Commonwealth–State/Territory Disability Agreement (CSTDA).⁶ This Agreement provides for a national program (\$2.5 billion in 2001–02) for people with disabilities who have ongoing support needs. The Commonwealth State/Territory Disability Agreement National Minimum Data Set (CSTDA NMDS) is both a set of nationally significant data items that are collected in all Australian jurisdictions (i.e. states, territories and the Commonwealth) and an agreed method of collection and transmission.

Since 1994, the CSTDA NMDS⁷ collection has provided funding bodies, service providers, consumers and other stakeholders with valuable information about services delivered under the CSTDA and the people receiving those services. Between 1994 and 2002, this information was collected on one snapshot day in each year of this period. From late 2000, the CSTDA NMDS was redeveloped in a joint project of the AIHW and the National Disability Administrators (NDA). The redeveloped CSTDA NMDS was implemented in the second half of 2002 and from 2002–03 will provide a range of data about all people with disabilities who receive a CSTDA-funded service in a year.

6 The 1991 and 1998 Agreements were known as the Commonwealth/State Disability Agreement (CSDA). The 2002 Agreement is known as the Commonwealth State/Territory Disability Agreement.

7 Between 1994 and 2002, the CSTDA NMDS was called the Commonwealth/State Disability Agreement Minimum Data Set (CSDA MDS).

Applying the ICF to the redeveloped CSTDA NMDS

The ICF was an essential tool in the process of redeveloping the CSTDA NMDS.⁸ The redevelopment exercise demonstrated three general ways the ICF can be used:

- *as a framework* to organise thoughts and ensure that major factors of interest are not omitted from the final data item or minimum data set
- as a set of classifications that can be used as a ‘smorgasbord’ for selecting the *domains* of most interest to stakeholders in the data to be collected via the final data item or minimum data set
- to provide *qualifiers* that assist the researcher to select a scale that is either directly related to an ICF qualifier or that ensures the data collected will map to an ICF qualifier.

In the case of the CSTDA NMDS redevelopment, the ICF Activities and Participation component and qualifiers were applied in two main areas:

- (a) support needs
- (b) participation outcomes.

The next two sections describe how the ICF was applied to the development of these data items.

Support needs

Background

A national indicator of disability support needs has been included in the CSTDA NMDS since its inception in 1994.

In 1999, as part of an initial review of the CSTDA NMDS, the AIHW undertook a project aiming to produce:

- a review of measures of ‘support needs’, the findings being related to policies, practices and developments in Australia in the disability field and in other closely related fields including the Home and Community Care program
- a presentation of options for data items which would encapsulate the main data needs and developments in Australia

8 Much of the data development for this project was done using the draft ICIDH-2. The final data items are, however, based on the ICF. To avoid confusion, this section is written as if the entire data development process was undertaken using the final ICF.

- a discussion of each option in relation to its relevance, quality, relatability to other developments, and comparability to national and international developments in population measures of disability.

The work undertaken for this project was subsequently advanced during the redevelopment of the CSTDA NMDS. The methodology of both the 1999 ‘support needs’ project and the 2000–02 redevelopment project are discussed below to illustrate the usefulness of the ICF in data development of this nature.

The project was not concerned with standardising the assessment of individuals at a local level. Rather it was about clarifying the concepts used to describe people’s support needs so that information gathered during assessment could be mapped to a national indicator (or indicators) and used for national comparison.

The ultimate objective was to develop options for a summary rating or indicator of support needs that was:

- comparable with population data, specifically data collected on individual support needs via the ABS Survey of Disability, Ageing and Carers;
- able to be used for mapping current state, territory and Commonwealth practices in as wide a range of services as possible⁹;
- consistent with current national data dictionaries and collections, thereby potentially increasing the potential for national comparability and reducing duplication in collection.

Methodology

There were a number of constraints or factors to consider in the search for a ‘support needs’ framework.

Firstly, it was essential that any support needs framework relate to the definition of ‘people with disabilities’ in the 1998 CSTDA as:

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 be permanent and results in substantially reduced capacity in at least one of the following:

- self-care/management
- mobility
- communication

requiring ongoing or episodic support.

9 The goal was to reflect enough of the language used in each jurisdiction to ensure that jurisdictions could translate the scales they use into an overarching scale (i.e. that the various types of language could be meaningfully calibrated into an overall scale to which their input could be mapped).

Secondly, as noted above, it was critical that the support needs framework be comparable with population data. This constraint implied that the framework would probably need to be a general support needs indicator, rather than a service-specific support needs indicator; that is, the framework would aim to indicate an individual's overall support needs, rather than their support in terms of services required.

Finally, it was also critical that the support needs framework relate as closely as possible to existing data standards and practice in the area of disability and related support services.

The AIHW therefore aimed for consistency with (and an ability to map to):

- the CSTDA definition of people with disabilities
- the 1998 ABS Survey of Disability, Ageing and Carers
- the National Community Services Data Dictionary Version 2.0 (then in draft)
- assessment tools currently in use in jurisdictions
- the existing CSDA MDS
- other major data collections, assessment tools, data development activities and concepts of relevance, wherever possible.

The issues surrounding 'support needs' were explored by:

- reviewing relevant literature including national and international data dictionaries and classifications
- examining a range of relevant Australian data collections
- investigating a number of well-known tools for assessing support need
- analysing information provided by jurisdictions, detailing policy directions and the assessment tools and frameworks currently in operation or under development
- synthesising this information to elucidate the major issues for discussion at an AIHW-NDA workshop in November 1999.

The AIHW then:

- undertook further research and analysis in accordance with the direction provided by the workshop
- developed a number of support needs data options for NDA consideration.

Using the ICF to develop a 'support needs' framework

Using the ICF as a framework

The ICF domains and scales were used as the framework to which all of the other classifications and tools described above were mapped; that is, the ICF

acted as a central, comprehensive framework and set of classifications in which to organise our comparative analysis and seek areas of commonality. The final support needs framework includes concepts that may be considered Activities and/or Participation (see Section 5 for further discussion).

Using the ICF as a 'smorgasbord' for selecting domains

Domains from the Activities and Participation component were selected, generally at the chapter heading level (e.g. Chapter 3, 'Communication'). All chapters within the Activities and Participation component were included in the support needs framework. However, in the following cases:

- ICF chapters were grouped (i.e. Chapter 1, 'Learning and applying knowledge' was combined with Chapter 2, 'General tasks and demands')
- ICF chapters were separated (i.e. Chapter 8, 'Major life areas' was separated into two separate items 'Working' and 'Education');
- a block from one ICF chapter was grouped with another ICF chapter (i.e. the block of 'Economic life' from within Chapter 8, 'Major life areas' was grouped with Chapter 9, 'Community, social and civic life').

Such grouping or separation was done only when it was either considered to be more meaningful/less onerous for service delivery agencies or to improve the degree to which the framework related to the ABS Survey of Disability, Ageing and Carers, the CSTDA NMDS, and other related classifications and tools. Examples were also included for each support needs domain or 'life area' in the support needs framework. These are selected categories from within each relevant ICF chapter (e.g. for the support needs life area 'self-care' the examples used are d510 washing oneself, d540 dressing, d550 eating and d530 toileting).

The selected domains and examples were tested with consumers, service providers and jurisdictions during the redevelopment of the CSTDA NMDS and refined where necessary.

Using the ICF to select qualifiers or scales

This was probably the most difficult aspect of the data development exercise. There was considerable consistency in the type of domains included in various classifications and tools examined during the 1999 'support needs' project. However, the scales used varied and sometimes related to the whole person and sometimes the person in relation to the specific service required.

The final selected scale relates directly to the ABS Survey of Disability, Ageing and Carers, enabling comparison with population data. The scale relates most closely to the qualifier concepts of 'difficulty and assistance with Activity' (in the *National Community Services Data Dictionary V2.0*; AIHW 2000) and

incorporates concepts of assistance both via personal assistance and/or via the use of aids or equipment (i.e. environmental factors).

The support needs scale also relates to the ICF performance qualifier for Activities and Participation:

The *performance qualifier* describes what an individual does in his or her current environment. Because the current environment includes a societal context, performance can also be understood as ‘involvement in life situation’ or ‘the lived experience’ of people in the actual context in which they live. This context includes the environmental factors – all aspects of the physical, social and attitudinal world which can be coded using the Environmental Factors component (WHO 2001:15).

The way in which the selected support needs scale relates to the ICF performance qualifier is outlined in Table 10.1. This scale also includes a further point ‘Does not need help/ supervision in this life area but uses aids or equipment’. This point does not map directly to the ICF performance qualifier. Instead it gathers additional information about one aspect of the individual's environment. This is consistent with the quoted statement from the ICF above.

Table 10.1: Mapping the CSTDA NMDS support needs categories to the ICF performance qualifier

ICF uniform qualifier	Support needs scale
NO problem	Does not need help/ supervision in this life area and does not use aids or equipment
MILD problem	Sometimes needs help/ supervision in this life area
MODERATE problem	Sometimes needs help/ supervision in this life area
SEVERE problem	Sometimes needs help/ supervision in this life area
COMPLETE problem	Unable to do or always needs help/ supervision in this life area
—	Does not need help/supervision in this life area but uses aids or equipment

The resulting support needs framework

Use of the ICF in redeveloping the ‘support needs’ area of the CSTDA NMDS resulted in the framework shown in Table 10.2.

Table 10.2: Support needs framework

How often does the service user need personal help or supervision with activities or participation in the following life areas?

The person can undertake activities or participate in this life area with this level of personal help or supervision (or would require this level of help or supervision if the person currently helping were not available)	1) Unable to do or always needs help/ supervision in this life area	2) Sometimes needs help/ supervision in this life area	3) Does not need help/ supervision in this life area but uses aids or equipment	4) Does not need help/ supervision in this life area and does not use aids or equipment	5) Not applicable
a) Self-care , e.g. washing oneself, dressing, eating, toileting					
b) Mobility , e.g. moving around the home and/or moving around away from home (including using public transport or driving a motor vehicle), getting in or out of bed or a chair					
c) Communication , e.g. making self understood, in own native language or preferred method of communication if applicable, and understanding others					
d) Interpersonal interactions and relationships , e.g. actions and behaviours that an individual does to make and keep friends and relationships, behaving within accepted limits, coping with feelings and emotions					
In the following questions 'not applicable' is a valid response only if the person is 0–4 years old.					
e) Learning, applying knowledge and general tasks and demands , e.g. understanding new ideas, remembering, problem solving, decision making, paying attention, undertaking single or multiple tasks, carrying out daily routine					
f) Education , e.g. the actions, behaviours and tasks an individual performs at school, college, or any educational setting					
g) Community (civic) and economic life , e.g. recreation and leisure, religion and spirituality, human rights, political life and citizenship, economic life such as handling money					
In the following questions 'not applicable' is a valid response only if the person is 0–14 years old.					
h) Domestic life , e.g. organising meals, cleaning, disposing of garbage, housekeeping, shopping, cooking, home maintenance					
i) Working , e.g. actions, behaviours and tasks to obtain and retain paid employment					

Source: CSTDA NMDS Service User Form 2002

Participation outcomes

Background

A 'participation outcomes framework' was also developed as part of the CSTDA NMDS redevelopment project. The resulting draft framework is included here and is an additional resource for jurisdictions to include in the CSTDA NMDS and related materials, if desired. It is not included as a mandatory item in the national CSTDA NMDS.

Using the ICF to develop a 'participation outcomes framework'

Using the ICF as a framework

The overall goal of the CSTDA is to enhance the quality of life for people with disabilities by assisting them to live as valued and participating members of the community. Thus, quality of life and participation are critical concepts in terms of measuring outcomes for individual consumers. Participation is defined in the ICF as 'involvement in a life situation'. Participation is taken to mean not just 'doing' an activity, but also having an autonomous role and experiencing real involvement and satisfaction.

The ICF concept of participation is thus consistent with the philosophy of the CSTDA, the Australian Disability Service Standards and the UN Standard Rules on Equalization of Opportunity for People with Disabilities. Thus, the Activities and Participation component of the ICF appeared to be a useful starting point for developing a framework that related to all of these philosophies.

Using the ICF as a 'smorgasbord' for selecting domains

A range of life domains was selected from the Activities and Participation component. These domains were selected in discussion with consumers and funding departments and attempt to relate to the areas of most interest to consumers as well as the overall focus on human rights in the CSTDA.

Domains from the Activities and Participation component were selected, generally at the chapter heading level (e.g. Chapter 6, 'Domestic life'). However, in the following cases:

- particular aspects of ICF chapters were drawn out into the participation life area (i.e. Chapter 3, 'Communication' was used in total but the block called 'Conversation and use of communication devices and techniques' was drawn up into the heading to increase its prominence; Chapter 4, 'Mobility' was used in total but the blocks on 'Walking and moving' and 'Moving around using transportation' were drawn up into the heading to increase their prominence)

- ICF chapters were separated (e.g. Chapter 8, 'Major life areas' was separated into two separate participation life areas, 'Participation in education, work and employment' and 'Participation in economic life'),
- some ICF chapters were not referred to in the participation module (i.e. Chapter 1, 'Learning and applying knowledge', Chapter 2, 'General tasks and demands' and Chapter 5, 'Self-care').

Examples were also included for each participation life area. These are selected categories from within each relevant ICF chapter or block (e.g. for the participation life area 'Domestic life', the examples used are d610 acquiring a place to live, d620 acquisition of goods and services, d630 preparing meals, d650 caring for household objects and d660 assisting others).

Using the ICF to select qualifiers or scales

Two scales are included in the 'participation outcomes framework':

- 'Extent of participation' (judged by service provider or assessment process)
- 'Satisfaction with participation' (judged by consumer, with advocate if necessary) in relation to duration, frequency, manner or outcome.

These are the qualifiers in the *National Community Services Data Dictionary Version 3* (AIHW 2003a) and are based on quite extensive research and development. The first qualifier is, essentially, the generic ICF qualifier. The scales also enable data collated using the participation outcomes framework to be related to some population data collected via the ABS Survey of Disability, Ageing and Carers. The use of the different scales, together with the context in which the component information is gathered (e.g. through client satisfaction surveys), makes it clear that the participation outcomes framework is a framework for collating information about participation rather than activities.

How to use the participation outcomes framework

It is important to note that the draft participation outcomes framework is not a proposed question that would appear on a form:

- The framework indicates output and concepts rather than the precise wording that would be used in questions. Separate mechanisms would be used to gather information from consumers and service providers.
- The separate recording for the service provider and person is in line with the established principle that quality of life measures should be based on both 'objective' and 'subjective' measures.
- If adopted, there would need to be user guides. Such guides would explain the ICF framework, including the importance of environmental factors. This could bring in social attitudes, i.e. the 'valued members' aspect of the CSTDA goal.

Thus the participation framework acts as multi-purpose 'participation module' and is proposed for use as a broad outcome indicator meaningful in the CSTDA field. It could be used in the course of service administration when conducting satisfaction surveys, discussing people's overall goals and developing individual service plans (e.g. in case management reviews); and in assessing overall quality of life.

As with support needs there are many measures and instruments relating to quality of life and satisfaction. However, based on work done during the development of the ICF, it is considered likely that these will map to the 'participation framework' (see also Section 5 for a discussion of measurement of Participation). The way the 'participation framework' might relate to other existing (or future) information and planning processes is illustrated in Figure 10.1.

It is important to note that this sort of this participation framework would aim to look at outcomes relating to a whole person, across life domains. The outcomes at this broad level (e.g. satisfactory participation in domestic life) would be difficult to attribute to specific service interventions. However, information about them could be very useful at a general or program level: e.g. to answer questions about the quality of life for people with disabilities (accessing CSTDA-funded services) and to consider priorities for action. Information could also be useful for planning services to meet people's participation goals.

The resulting participation outcomes framework

Use of the ICF in developing the area of participation outcomes in the CSTDA NMDS resulted in the framework shown in Table 10.3.

Table 10.3: Draft 'participation outcomes framework'

Life area	Extent of participation (judged by service provider or assessment process)	Satisfaction with participation (judged by consumer, with advocate if necessary) in relation to duration, frequency, manner or outcome
	<ol style="list-style-type: none"> 1. Full participation 2. Mild participation restriction 3. Moderate participation restriction 4. Severe participation restriction 5. Complete participation restriction 	<ol style="list-style-type: none"> 1. High satisfaction with participation 2. Moderate satisfaction with participation 3. Moderate dissatisfaction with participation 4. Extreme dissatisfaction with participation 5. No participation 6. No participation and none desired
<p>Participation in communication and conversation (e.g. producing and receiving spoken, nonverbal, formal sign or written messages, involvement in conversation, discussion with or without use of communication devices and techniques)</p>		
<p>Participation in mobility within the home and community environment (e.g. changing and maintaining body position; carrying, moving and handling objects; walking and moving; moving around using transportation)</p>		
<p>Participation in domestic life (e.g. acquiring necessities such as a place to live and goods and services; household tasks such as preparing meals; caring for household objects and assisting others)</p>		
<p>Participation in interpersonal interactions and relationships (e.g. relating with strangers, formal and informal social relationships, family and intimate relationships)</p>		
<p>Participation in education, work and employment (e.g. informal education, preschool, school, vocational and higher education; work preparation such as apprenticeships; acquiring, keeping and terminating a job, remunerative or non-remunerative employment)</p>		
<p>Participation in economic life (e.g. basic and complex economic transactions, economic self-sufficiency)</p>		
<p>Participation in community, social and civic life (e.g. community life, religion and spirituality, recreation and leisure, political life and citizenship, human rights)</p>		

Source: CSTDA NMDS Network Guide, 2002

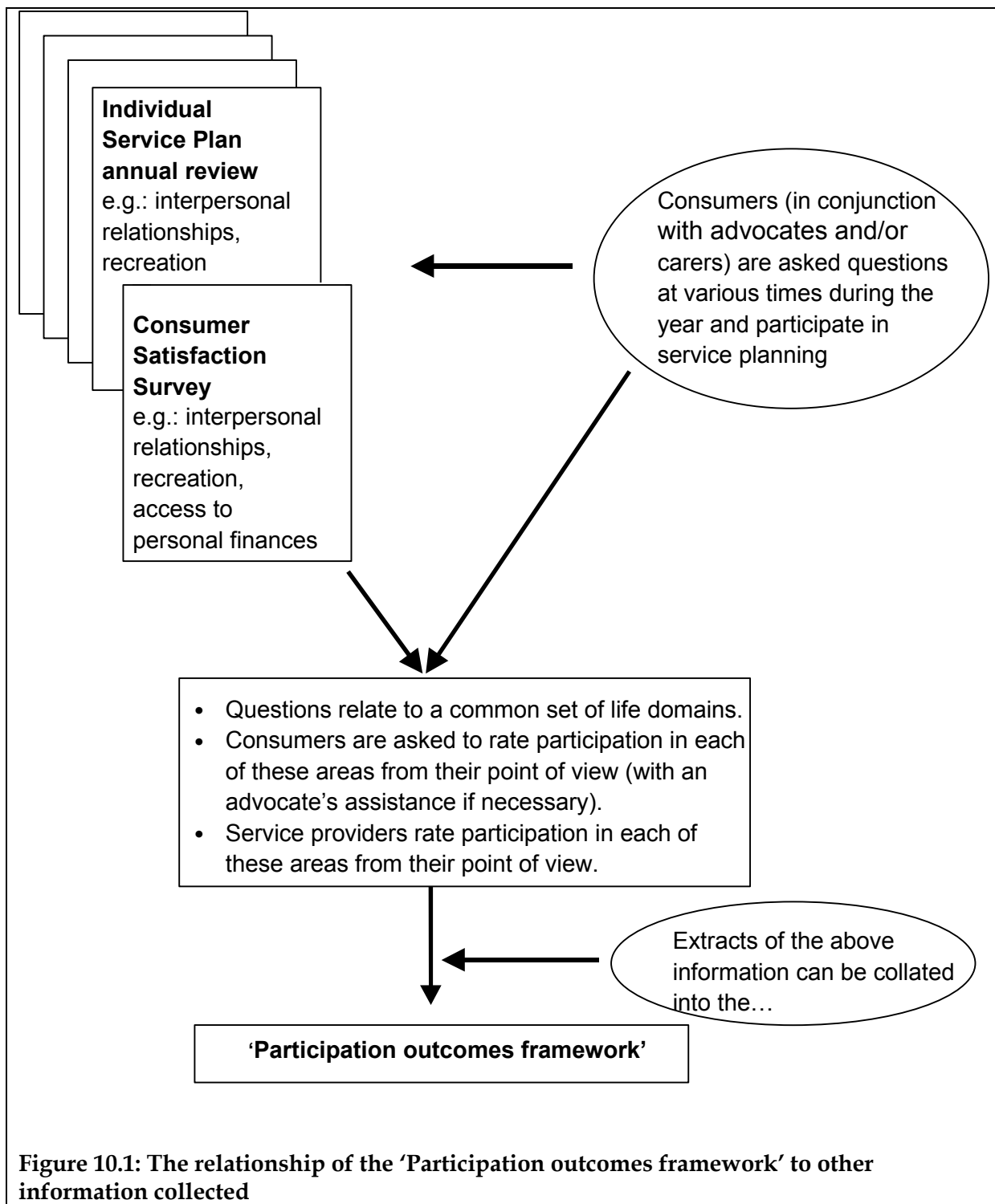


Figure 10.1: The relationship of the 'Participation outcomes framework' to other information collected

10.2 The use of the ICF framework in an allied health outcome measure: Australian Therapy Outcome Measures (AusTOMs)

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Introduction

This section provides a brief overview of the way in which the framework and key concepts of the ICF were used in developing an Australian tool to measure therapy outcomes – the Australian Therapy Outcomes Measures (AusTOMs). This tool is based on the Therapy Outcomes Measures (TOM) developed in the United Kingdom by Professor Pam Enderby and colleagues. As well as drawing on the concepts of the ICF, AusTOMs incorporates descriptors developed by Australian clinicians using focus groups and a modified Delphi survey.

AusTOMs—using the ICF in an Outcome Measure

The AusTOMs project is a Commonwealth-funded initiative that aims to develop a valid and reliable measure of therapy outcomes for use in the allied health disciplines of speech pathology, occupational therapy and physiotherapy. The project team is based at La Trobe University, Bundoora, Victoria and is working with allied health clinicians both within Victoria and across Australia on the development of the measure.

While there has been a clear focus in outcomes literature on evaluating medical interventions, there is also a growing body of literature on the

outcomes of allied health professions (Benjamin 1995). There is a focus on measuring outcomes not just by assessing an impairment, but by assessing areas that may be more important to clients i.e. functional and societal limitations (Barr 1995). It is recognised, however, that there is not a clear linear relationship between a person's impairment, their limitations in everyday activities, and their level of disability or social limitation (Enderby 1997).

The AusTOMs tool uses the ICF as a basis for the headings and concepts of three out of four domains; thus, clinicians measure changes in clients' Impairments, Activity Limitations and Participation Restrictions, as well as a fourth domain, Wellbeing/Distress.

Each domain is rated on an ordinal scale with six defined points, where 0 = most severe, and 5 = no difficulty. To improve the sensitivity of the scales, clinicians are able to make half-point ratings (e.g. 1.5) to show that a client is performing somewhere between the defined points (e.g. between 1 and 2). Thus the domains effectively represent eleven-point ordinal scales. Each domain is independent of the others, so that a client may show no progress in one domain, while demonstrating great progress in another.

Why use ICF

The AusTOMs project is based on more than ten years of research into outcome measures in allied health, carried out by Professor Pam Enderby, now Dean of Medicine at Sheffield University, UK. Enderby and others developed and rigorously tested TOM, a system of measuring therapy outcomes in the National Health Service (Enderby 1997; Enderby et al. 1998). This system was based on the ICIDH, the predecessor of the ICF.

When in Bristol, Enderby studied the notes of 350 speech pathology cases and discovered that speech pathology goals could be related to the three areas described in the ICIDH – impairment, disability and handicap (Enderby 1992); that is, the domains of the ICIDH were particularly applicable to speech pathology clinicians because these were the areas where they set goals. For example, a speech pathology clinician might aim to increase the client's range and rate of oral movement (impairment goal), increase the client's ability to communicate using speech (disability goal) and increase the client's use of communication to participate in classroom activities (handicap goal).

Enderby felt that there was a fourth category of goals in therapy, not explicitly covered by the WHO ICIDH classification. These goals related to the client's wellbeing. These are feelings of distress or anxiety, which clinicians may hope to alleviate during therapy (Enderby 1992).

The AusTOMs team, in consultation with clinicians, felt that the ICIDH framework was also relevant to speech pathologists, occupational therapists

and physiotherapists in the Australian clinical context. The framework offers a way of describing 'health', and is relevant to all three allied health disciplines. It is because the framework is applicable across all disciplines that the team was able to create a tool that may be used to compare outcomes across disciplines. AusTOMs also provides clinicians with a common language when comparing outcomes. Rehabilitation services often involve many professions working with the same client. Without a common language for describing outcomes, clinicians are hampered when sharing information about client progress; many, even within the same profession, commonly use dissimilar language to relate goals and outcomes (Enderby 1997).

Developing the AusTOMs scales

Stage 1: Examining the measure in the Australian context

The project team at La Trobe University examined the UK Therapy Outcome Measure (TOM) scales. The terminology on these scales was updated to reflect the ICF vocabulary, using 'impairment', 'activity limitation' and 'participation restriction'. A core scale was developed for AusTOMs, from which to develop profession-specific scales.

New scale headings, more appropriate to Australian clinical practice were proposed. In speech pathology and physiotherapy, these scale headings represent an impairment, e.g. impairment of 'voice' or 'fluency' for speech pathology, or impairment of 'musculoskeletal movement related functions' for physiotherapy. In addition, physiotherapists decided to use the ICF terminology for body functions and structures as their card headings. Occupational therapists, on the other hand, developed their scale headings to reflect the 'activity limitation' domain; it was felt that this domain best reflected the focus of occupational therapy intervention. Occupational therapy scale headings were based on the ICF headings for activities and participation, e.g. 'learning and applying knowledge'.

Stage 2: Developing scale descriptors

Once the scale headings were decided, descriptors were developed for each point in the ordinal scales. The research team held focus groups of clinicians across Victoria in each profession for this part of the project. Clinicians were asked to provide detailed terminology to describe impairments and activity limitations under each disorder heading. For example, speech pathologists were asked to provide a written description of what zero (0) (the most severe difficulty) might include for a client with a 'voice impairment'.

Speech pathology and physiotherapy groups focused on developing specific descriptors for 'impairment' and 'activity limitation' domains. Occupational therapy groups, on the other hand, concentrated mainly on the 'activity limitation' domain.

The project team then sought input from clinicians across Australia in determining the face validity of the scales. The scales were sent out in a modified-Delphi (two round) survey to speech pathology, occupational therapy and physiotherapy clinicians across Australia. This was done using the National Allied Health Casemix Committee membership. More than 600 returns across the three professions were received. The scales were modified on the written advice of responding clinicians, and a second round of surveys was sent out for confirmation of the changes.

The research team also sought the views of consumers (clients) during development of the scales. Consumer groups were contacted, and representatives attended a focus group at La Trobe University. Consumer feedback and advice on terminology were particularly useful for the development of the Participation and Wellbeing domains of the scales.

Stage 3: Training clinicians

Fourteen health-care sites in Victoria were recruited for the project data collection. Speech pathologists, occupational therapists and physiotherapists across these sites, all of whom had agreed to participate in the project, were required to attend standardised training sessions in the use of the AusTOM scales. The inter- and intra-rater reliability of the scales were assessed.

Stage 4: Data collection

Data collection on 500 clients per profession, across 14 sites in Victoria, was undertaken during the 6 month period from October 2002 to March 2003. During that time, clinicians were asked to rate clients at the beginning and at the end of a period of therapy, using AusTOMs. Clients were asked to rate their own health using the EuroQol (EQ-5D) measure of health status. This measure has been used widely across Europe and has an accepted Australian version. The score was then correlated with each domain of AusTOMs and the correlation with the EQ-5D was used to assess the concurrent validity of the AusTOM scales.

Data analysis took place at La Trobe University, Victoria. Allied health staff on each site submitted their data entry sheets (standardised forms) to the research team who entered the data onto a centralised database. In total, data from over 1000 interventions across all three professions were received. The data were

used to examine the usefulness of AusTOMs as a valid and reliable tool for assessing outcomes in allied health intervention.

Data analysis shows preliminary evidence for the validity and reliability of the AusTOMs scales. Clinicians have been enthusiastic in their contribution to its development, and have generally reported that the tool is quick, easy to use, and clinically useful.

10.3 The ICF and classification for disability athletics

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Introduction

It has been widely advocated that four of the classification systems currently used in disability athletics (i.e. track and field) should be replaced by a single, unified classification system. The purpose of this module is to:

- provide a brief overview of classification in disability athletics
- establish a rationale for basing a single, unified system on the language and structure of the ICF
- provide specific examples of how the ICF can be applied to enhance the utility and taxonomic integrity of a single unified system.

This module is based on a published paper entitled *Taxonomic Theory and the ICF: Foundations for a Unified Disability Athletics Classification* (Tweedy 2002).

Overview of classification in disability athletics

Sport plays an important role in the lives of people with a disability, providing a valuable, self-directed means of enhancing rehabilitation and long-term health, as well as offering opportunities for recreation, social interaction, and the pursuit of athletic excellence. In 1948 the first Stoke Mandeville Games for Paralysed Individuals, forerunner of the modern Paralympic Games, were held (Vanlandewijck & Chappel 1996). Recognising that competitors would experience differing degrees of disadvantage in sport, the Games were organised so that athletes experiencing similar degrees of disadvantage competed against each other. The aim was to make competition fair, so that athletes who experienced greater disadvantage in sport were not precluded from success. For example, people with quadriplegia competed against each other and did not have to compete against people with paraplegia. The methods for placing athletes into groups were based on conventional medical assessment procedures.

Disability sport now includes people with a wide range of health conditions and impairments, and systems of classification remain a vital yet controversial feature of disability sport (Sherrill 1999; Vanlandewijck & Chappel 1996)

playing an important role from international sport to local 'come and try' days. In general, the purpose of disability sports classification systems is twofold (Tweedy 2002):

- to define eligibility
- to ensure competition among eligible athletes is fair (i.e. that athletes are not precluded from success solely because of the disadvantage they experience as a result of their impairment).

Athletics (i.e. track and field) is one of the most popular organised sports for people with disabilities. This section focuses on four of the systems currently used in disability athletics at the Paralympic Games and many other national, state and local competitions throughout the world. The systems are those of the Cerebral Palsy-International Sport and Recreation Association (CP-ISRA 2001), the International Stoke Mandeville Wheelchair Sports Federation (ISMWSF 1995, 2000) and the International Sports Organisation for the Disabled (ISOD 1993). The latter has one system for amputees and one system for 'les autres'¹⁰. Table 10.4 presents a brief synopsis of people who are currently eligible to compete under the auspices of these organisations.

For a number of years it has been advocated that the four systems presented in Table 10.4 be replaced by a single, unified system. Such a move would streamline the process of classification, as well as provide an opportunity to improve taxonomic integrity and eliminate inconsistencies and ambiguities that currently exist.

Table 10.4: Health condition / impairment eligibility criteria for four of the disability athletics classification systems used at the Paralympic Games.

Organisation	Eligible participants
Cerebral Palsy-International Sport and Recreation Association (CP-ISRA)	People with '...a diagnosis of non-progressive brain damage with motor dysfunction such as cerebral palsy, traumatic brain injury, stroke or similar conditions' (CP-ISRA 2001, Section 1.3). Ineligible are people with intellectual impairment without motor function and people with motor dysfunction that does not have a cerebral origin (CP-ISRA 2001, Section 1.5).
International Sports Organisation for the Disabled (ISOD—Amputees)	People with '...acquired amputations and dysmelia resembling acquired amputations' (ISOD 1993, Section I, Chapter 4.2.1) but not 'dysmelia not resembling acquired amputations' (ISOD 1993, Section I, Chapter 4, Comment #1).
International Sports Organisation for the Disabled (ISOD—les autres)	People with '...locomotor disabilities regardless of diagnosis' (ISOD 1993, Section I, Chapter 4.3.1). Ineligible persons include those with 'severely reduced mental capacity...heart, chest, abdominal, skin, ear and eye diseases without locomotor disability' (ISOD 1993, Section I, Chapter 4.4.1).
International Stoke Mandeville Wheelchair Sports Federation (ISMWSF)	'...persons suffering from spinal cord injury or with a disability which can functionally be equated to a spinal cord injury...' (ISMWSF 1995:2). Historically has included people with spina bifida and polio.

¹⁰ *les autres* is a French term meaning *the others*.

Why base a disability athletics classification on the ICF?

Taxonomically, the ICF and the current disability athletics systems are very closely related. They are all classifications of the functioning and disability associated with health conditions, although they vary considerably in terms of breadth of scope.

The ICF is a very broad classification. Its universe encompasses all aspects of human health and some health-relevant components of wellbeing. It is not only about persons with disabilities, but all persons. The framework of the ICF organises information into two parts (Functioning and disability; and Contextual factors) and their respective components and domains (WHO 2001). This framework is used to describe the universe of the ICF, providing a structure for the meaningful organisation of information (WHO 2001).

In contrast, the disability athletics classifications are very narrow in focus. Their collective universe is limited to people with certain health conditions and/or impairments (see Table 10.4) and to those aspects of human health that relate directly to the activities within the athletic disciplines (i.e. running, jumping, throwing and wheelchair racing). In other words, the scope of the athletics classification systems can be fully described by a small number of the Body functions and structures and Activity domains of the ICF (expressly discussed later in this section).

Linking the development of the highly specific disability athletics classification system to the broad classificatory framework of the ICF has the potential to improve the utility of both systems and to advance understanding of the functioning and disability associated with health conditions.

It would be beneficial to base a unified disability athletics system on the ICF because the ICF provides a well-constructed, taxonomically sound structure and uses standardised definitions that are actively promoted, widely utilised and have been translated into several different languages. Use of the ICF as framework for a unified athletics classification would minimise ambiguity, enhance conceptual clarity and maximise understanding, particularly among non-English speaking stakeholders in the international disability sport community.

Conversely, the ICF benefits from wide use; justification for the development and maintenance of broad classificatory frameworks such as the ICF depend on their widespread application (Fleishman & Quaintance 1984). Moreover, if the ICF were used in the development of a unified athletics system, there would be potential to expand and develop specific domains within the ICF. For example, a new unified disability athletics classification system could expand and enhance relevant Activities codes, specifically those for running (a4552), jumping (a4553), throwing (a4454) and wheelchair propulsion (a465).

Empirical evidence suggests that such 'fractionalising' enhances the usefulness of primary categories in broader, more general systems such as the ICF (Fleishman & Quaintance 1984).

Using the ICF to develop a unified disability athletics classification

Using the ICF, the purpose, structure and language of the four current disability athletics systems have been identified. The remainder of this section identifies areas of weakness in the four current systems and indicates how the language and structure of the ICF could be applied to overcome these weaknesses in a unified disability athletics classification.

Defining eligibility by health condition/impairment type

The clarity and effectiveness of the eligibility criteria presented in Table 10.4 are compromised by use of terms that are not standardised, such as 'functionally be equated' (ISMWSF system), 'similar conditions' (CP-ISRA system), and 'resembling' (ISOD amputee system). For example, it is surely a matter of debate as to which disabilities can functionally be equated with spinal cord injury. Such potential areas for debate would considerably weaken the integrity of a unified system.

Use of the clearly defined, mutually exclusive ICF codes could be used to help define eligibility and improve the clarity of the system. For example, the codes b710–b799 (Neuromusculoskeletal and Movement-Related Functions), s110–s199 (Structures of the Nervous System), and s710–s799 (Structures Related to Movement) best describe the populations covered by the four current systems and would be the most appropriate starting point.

Defining eligibility by 'minimum disability'

In each of the current disability athletics systems, it is possible for an athlete to have a health condition or impairment type that satisfies eligibility criteria but to be ruled ineligible on the grounds that he or she does not meet other criteria, commonly called 'minimum disability' criteria. In column 2 of Table 10.5 the criteria used by each of the current systems are presented. In the lexicon of the ICF, the term 'minimal disability' does not accurately describe the eligibility criteria stated by the respective organisations. Column 3 of Table 10.5 presents a more accurate description of each of the criteria. In a unified system it would be important to ensure that the descriptor used for this area of classification was stated accurately in terms consistent with the ICF.

Column 4 of Table 10.5 presents the rationale that each organisation presents for establishing minimal disability criteria. There are obvious discrepancies

and gaps in the rationale establishing minimal disability criteria in each of the current systems, highlighted by the fact that no rationale is offered by ISMWSF. A necessary prerequisite for the establishment of a unified system would be documentation of a sound rationale for and description of minimum disability criteria stated in terms consistent with the ICF.

Table 10.5: Characteristics of the current disability athletics classification systems

Organisation^Φ	*Minimum disability criteria	Description of current minimum disability criteria in ICF terms	Purpose or rationale for minimal disability criteria	Method for placing into classes
Cerebral Palsy - International Sport and Recreation Association (CP-ISRA)	'If an abnormality can only be detected by a detailed neurological examination and impairment of function is not clearly evident during classification and does not obviously impact on sports performance, then the athlete is not eligible for competition' (CP-ISRA 2001, Section 1.3).	Minimal body function impairment, as well as minimal activity limitation	'seeks to provide sports opportunities for individuals... whose level of neurological impairment disadvantages them in training for, and competing in, sports' (CP-ISRA, 2001 Section 1.1)	Neurological examination including the Ashworth scale (Ashworth 1964) and evaluation of muscle tone together with generic and sports specific tests of activity limitation. 8 classes available
International Sports Organisation for the Disabled (ISOD—Amputees)	'Minimal handicap...[is] amputation through or above the wrist joint' (ISOD 1993, Section I, Chapter 4.2.3). No lower limb criterion identified.	Minimal body structure impairment	Aims to ensure that only athletes with an impairment that prevents them from 'participating on reasonably equal terms' with able-bodied athletes are included, thereby maintaining the credibility of the disability sport movement (ISOD 1993, Section I, Chapter 4.1.1)	Classified according to the limb(s) affected (upper or lower), how many limbs have been affected, and how much of the limb has been amputated (e.g. above knee, below elbow); 9 classes available.
International Stoke Mandeville Wheelchair Sports Federation (ISMWSF)	ISMWSF grades the strength of 54 muscle groups on a scale of 0 to 5 (0 = total lack of voluntary contraction; 5 = normal contraction). Maximum points for lower limbs is 80; athletes who score 70 points or less are eligible. No upper limb criteria are specified.	Minimal body function impairment	No stated rationale	Muscle grading together with generic and sports-specific tests of activity limitation. 8 classes available for field events, 4 classes for track events.

^Φ The ISOD 'les autres' system is not presented in this table or included in the analyses based on this table. This is because the 'les autres' system has a very weak conceptual basis, a fact highlighted by the current IPC policy of using the 'les autres' system to define eligibility but not to place athletes into classes. Instead, athletes who are permitted to compete in disability athletics under 'les autres' criteria are placed into classes using the Amputee or ISMWSF systems.

Clarifying conceptual basis of classification

To ensure the conceptual basis of the current systems of classification are not significantly altered or lost in the development of a unified system, they need to be clarified. This example illustrates how the ICF can be used for this purpose. A précis of the methods used for placing athletes into classes is presented in column 4 of Table 10.5. In general, the conceptual basis of each of the current systems is quite clear and logical. When eligibility of an athlete for a system of classification is defined in terms of the type of health condition or impairment, then the methods used to assess the impairment will be relatively uniform, allowing comparison of results and providing a sound basis for grouping athletes into classes.

A misconception about the conceptual basis of these systems is that they classify (or control for) the *extent of impairment of an athlete*. However this phrase is taxonomically inconsistent with the ICF, being predicated on the outdated notion that activity limitation is *caused by* impairment. The phrase implies that, by measuring impairment, the activity limitation experienced by a person can be predicted. In the ICF, the impairment and activity dimensions are interdependent (WHO 2001:18, Fig. 1); impairment does not cause activity limitation (WHO 2001). Moreover, the ICF removes the ambiguity previously associated with the term *impairment*, using it only to describe limitations in the domains of body structure or body function. *Activity limitations* (not impairments) refer to difficulties experienced by a whole person; therefore, the term *whole-person impairment* (used in some quarters of disability sport) is not valid in the ICF lexicon. Although a range of methods can be used to quantify the impairment of discrete structures or functions, it is not a simple matter of converting an amount of impairment into an amount of activity limitation. The process of evaluating how much a given quantity of impairment will affect the activity of a whole person must begin by defining the activity.

To illustrate, Person A and Person B may both have spinal cord lesions that paralyse 50% of their musculature, resulting in the same total score using the ISMWSF muscle chart. Quantitatively, these persons could be said to have the same extent of impairment. However, if the distribution of the paralysed muscles is spread over the upper and lower body (including the small muscles of the hand) in Person A and restricted solely to the lower body in Person B, then it is likely Person A will be less impaired in the activity of walking/running, but more impaired in the activity of throwing a ball, than Person B is. In this case, a correct restatement of the comparison of Persons A and B is that Person A experiences less activity limitation in walking and greater activity limitation in throwing a ball than Person B does.

As identified in Table 10.5, the current disability athletics systems take account of both observable activity limitation and assessment of impairment. If a

unified system is to remain consistent with the conceptual bases of current classification processes (as interpreted using the ICF framework), then its definitive role should be estimation of the *extent of activity limitation resulting from impairment*. Assessment of impairment alone is not sufficient because the effects of impairment only make sense when interpreted in light of a specific activity. Assessment of activity limitation alone is not sufficient because there are many factors other than impairment that influence activity limitation. Based on the extent of activity limitation resulting from impairment, eligibility can be decided, and eligible athletes can be placed into classes with athletes who experience similar extent of activity limitation to enable fair competition.

Improving social sensitivity

Each of the four current systems of disability athletics classification refers to the process of classifying athletes, thereby making people the units of classification. A more contemporary and socially sensitive view of classification argues that people should not be characterised solely in terms of a classification (WHO 2001). Accordingly, the ICF does not classify people. Rather, the unit of classification is categories within each domain. Adoption of ICF categories as the units of classification in a unified disability athletics system would be consistent with the purpose of the system while improving social sensitivity.

Conclusion

This section outlines how the broad, generalisable taxonomy and standardised language of the ICF may be used to expose inconsistencies and clarify the conceptual bases of the current systems and thus to provide guidelines for developing a new unified system of classification. Such a system will be effective in achieving its intended purpose.

Acknowledgments

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10.4 The ICF and accident compensation in Australia

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Abstract

This paper briefly describes the Australian accident compensation system, with particular emphasis on its process of impairment classification, assessment, and entitlement to damages. It argues that this process is fundamentally flawed, and suggests that the framework provided by the ICF may provide a starting point for future development.

Accident compensation in Australia

Individuals who sustain an injury in Australia may be eligible for a variety of benefits under Accident Compensation, a set of statutory and common law systems generally under the jurisdiction of states and territories (as distinct from the Commonwealth).

More than \$10 billion per annum (about 1.5% of GDP) is collected in premiums and paid in benefits under the various schemes encompassed by accident compensation:

- Workers Compensation (ten statutory schemes)
- Motor Transport Compensation (eight statutory schemes)
- Public Liability Insurance (generally private insurance)
- Medical Indemnity Cover (medical defence and private insurance)
- a variety of self-insurance and pooled arrangements.

The structure of the schemes has been under constant review during the past 20 years in terms of both benefit entitlement and also underwriting structure. Almost invariably, scheme review has followed either cost escalation, leading to affordability issues for premium payers, or perceived inadequacy of benefits, leading to rights issues for injured parties.

Again, almost invariably, these catalysts for reform have been linked in some way to instability, inappropriateness or lack of confidence in the process or method of assessment of impairment or disability.

Eligibility for compensation

For 'no fault' type schemes, *eligibility* for compensation is broadly linked to the circumstances or place of occurrence, e.g. 'in the workplace', 'out of the use of a motor vehicle'. All of Australia's workers compensation systems have at least some no-fault benefits, as do three of our eight motor transport compensation systems.

For 'common law' type schemes, *eligibility* for compensation is contingent on the ability to establish that the injury for which compensation is claimed was due to the negligence of a third party ('the plaintiff'). All of Australia's public liability insurance (including medical indemnity) is based on common law principles. All of our motor transport compensation systems have at least some common law entitlements (in five out of eight this is the only entitlement). All but three of our ten workers compensation systems have at least some common law entitlements.

In some cases these over-riding eligibility criteria are supplemented by *thresholds* or 'entry points', usually based on an assessment of impairment or disability; i.e. eligibility for damages is contingent on meeting a certain percentage of disability. The determination of whether or not this threshold is reached follows a similar process to the assessment of entitlement to damages, described in the next section.

Assessment of compensation entitlements

The nature of the scheme (common law or no-fault) also generally determines the way in which benefits are determined.

Common law

For common law schemes, compensation is generally available for the following major classes of 'heads of damage':

- *Economic loss (past and future)*, requiring an assessment of the extent to which the injury has resulted in a reduced capacity to engage in employment, and so earn income, and for how long this incapacity will remain
- *Care costs (past and future, medical, hospital, attendant care, therapy, aids and appliances)*, requiring an assessment of the treatment, equipment and personal care which will be required to (as far as possible) overcome the disabling affects of the injury
- *General damages (also termed 'non-economic loss' or 'pain and suffering')*, requiring an overall assessment of the significance of the disability or impairment arising from the injury, normally compared to a 'worst possible case', or some other 100% entitlement.

The method of determination of these measures is left to a judicial process i.e. a judge or magistrate who makes a once-and-for-all award based on evidence from a variety of medical and other experts representing both sides of the argument (plaintiff and defendant). There is generally no specified instrument or benchmark to guide this process, the major argument in favour of this being that the subjective power of the judge allows an appropriate consideration of individual circumstances. Damages are payable by way of a single lump sum. In a large majority of cases the common law matter does not receive a judicial verdict at all. The settlement for each head of damage (and in total) is agreed between plaintiff and defendant lawyers, based on precedent judgements leading to a decision about the amount they would expect the matter to be awarded. Therefore the 'assessment' process is even further removed from any rigorous and structured basis.

In my view there are at least four major problems with the subjectivity of the common law assessment process:

- The process has little scientific basis or structure in terms of the concepts of impairment, disability, and incapacity,
- The process is litigious and slow and effectively encourages claimants to prolong their incapacity to maximise financial reward,
- There is only very rough equity between claimants; it is not unusual for very similar claimants to be awarded very different amounts of compensation,
- The process has been found to be unstable at a macro-level. Over time it seems that the balance of judgement gradually moves in favour of the claimant. Hence the convention of what constitutes any 'percentage' incapacity, disability or impairment becomes less and less severe by any objective measure. The result is cost pressure on the scheme, and usually a major review, which typically leads to some short-term restriction on judicial power or some artificial threshold or reduction in entitlements.

Statutory benefits

For no-fault schemes, compensation is generally payable according to statutory benefit rules.

Again the compensation is of three main types:

- *Income replacement benefits (either total or partial)*, which is normally contingent on an assessment of ability to return to usual employment or modified employment ('suitable duties')
- *Medical and care benefits*, usually paid on a 'reasonable and/or necessary' type basis

- *Non-economic loss (or 'permanent impairment', or 'pain and suffering')*, which has a similar meaning to that of the common law equivalent.

Statutory benefits of the first two types (income and medical) are usually payable periodically for as long as entitlement continues. The judgement of when this entitlement begins and ends, and to what extent, is usually made by a medical practitioner based on his or her own experience.

Statutory benefits for non-economic loss are usually paid in lump sum form, with entitlement based on the application of an *impairment guide* or table, of which there are several in use in Australia. There are two main types of such tables:

- *tables of entitlements for specified impairments or 'maims'* – usually in respect of the loss of (or loss of the use of) a body part. These have been developed by individual schemes; and
- *whole Person assessments of impairment*, most commonly using the guidelines of the American Medical Association (4th or 5th Edition).

Disputes over the assessment of entitlement to statutory benefits are heard by a variety of appeal mechanisms, ranging from a judicial process (not unlike the common law) to a binding expert medical panel.

The assessment process in respect of statutory benefits is far superior to that in common law jurisdictions, but still has four major problems:

- For income support benefits, the assessment of incapacity is arbitrary, subjective, and without a well-developed framework to consider the injured person, his or her functional potential, and the mechanical and attitudinal qualifiers required to return to employment
- For medical and care benefits, the process of referral and the assessment of need for ongoing treatment is also arbitrary in most schemes. There are only broad developments in recommended clinical pathways and evidence-based medicine
- For non-economic loss, the process in some schemes has been found to be unstable at a macro-level, for the same reasons as common law is. This problem appears to be assisted by use of the American Medical Association Guides, which place more discipline on the assessment process
- The continued use of 'impairment' as the basis for non-economic loss, however, causes problems for equity reasons. The great benefit of the common law is its desire to differentiate disability from impairment at an individual level (although I would argue it does this imperfectly).

Potential of the ICF in accident compensation

The underlying objective of accident compensation is to provide 'indemnity', i.e. to restore the injured person, as far as possible, to his or her pre-injury condition. In concept, one would imagine that the compensation process should be attempting to define and measure the outcome of the injury in terms of restrictions relative to the pre-injury state and to take steps to modify those restrictions.

However, the process of assessment and compensation described above is arbitrary, unstructured, litigious and focused on monetary compensation rather than facilitated recovery of function. This process has been shown to be unstable and to require constant review. It is also, arguably, detrimental and inequitable to individuals who have sustained an injury.

The ICF potentially provides a basis for clarifying and strengthening the framework for classification, assessment and modifications in the field of accident compensation, leading to a more robust and appropriate compensation system.

Classification

The dimension of body structures and functions provides a more appropriate starting point than the insurance concept of 'impairment' for describing the physical sequelae of an injury or disability.

Assessment

The dimension of activity provides a rigorous framework in which to develop metrics of the insurance concept of 'capacity' in the context of potential for achieving a more positive outcome. This is particularly the case when one combines it with the participation dimension, which can lead directly to the prognosis for future development, such as return to work or social independence.

Modification

The qualifiers to the participation dimension provide a direct parallel with the notion of 'suitable duties' or 'aids and appliances', which are part of the compensation language.

Limitations of ICF

The main limitation of the ICF in providing a framework for assessment and management in accident compensation is the work that will need to be done in moving beyond this framework. The ICF has been developed in a health and

disability paradigm, which historically has operated independently of accident compensation in Australia, and vice versa.

For progress to be made in this area, concerted efforts are needed on both sides. This requires a significant commitment by accident compensation authorities to acknowledge the potential of the ICF and its family of classifications. It also requires sponsors and advocates of the ICF to recognise the commercial realities of accident compensation and to assist in developing more targeted classification and assessment instruments.

The other challenge for the use of the ICF is the transition from a 'framework' to the development of assessment instruments suitable for use at an individual claimant level (e.g. for body structure and functions , activity, and participation). Such instruments will be necessary to improve resource allocation for accident compensation and other statutory entitlement systems.

10.5 The ICF and speech pathology

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Introduction

The Communication Disability in Ageing Research Unit (CDARU)¹¹ has been using the ICF and its predecessors in the education of speech pathologists and audiologists, in clinical practice with older people with hearing impairment and aphasia, and most predominantly as a research tool. The CDARU is based within the Department of Speech Pathology and Audiology at The University of Queensland and the directors are Dr Louise Hickson, an audiologist, and A/Prof Linda Worrall, a speech pathologist. The CDARU have used both the conceptual framework and the classification scheme, and both of these are now discussed under the headings of teaching, clinical applications and research uses.

Use of the ICF in teaching

The conceptual framework of the ICF is introduced to speech pathology and audiology students early in their first year. It is used to frame discussions about communication disability, particularly in relation to speech pathology and audiology assessments and treatments. The framework is used in more detail in a series of aphasia management lectures and in a module about ageing and aged care. A/Prof Linda Worrall and other staff from the CDARU coordinate these modules. They use the framework to provide a structure for lectures and an overview of clinical practice in this area, and students are also examined on the interpretation of the ICF for people with aphasia and other age-related disorders.

In audiology, the ICF is used extensively in teaching as a framework for rehabilitative audiology. The effects of hearing impairment on the lives of people with hearing impairment are described using the ICF terminology, and students are encouraged to consider rehabilitation options for clients in light of their impact on Body Functions and Structures, Activities and Participation. Details about the ICF are provided initially in didactic lectures, and students are subsequently required to apply the ICF in a series of modules about

11 CDARU's web site is at: <<http://www.shrs.uq.edu.au/cdaru>>

rehabilitation for complex cases, e.g. an older person living in an aged care facility, a person experiencing major negative psychosocial consequences of hearing impairment.

Use of the ICF in clinical practice

Staff in the CDARU run student clinics for groups of people with aphasia (and other acquired neurogenic communication disorders) at The University of Queensland, and the Geriatric Assessment and Rehabilitation Unit of the Royal Brisbane Hospital. In an effort to guide students (and many clients) to think more broadly than the impairment level, the Participating in Choice (PIC) approach was developed (Worrall & Davidson 2000). This approach was an extension to the Activity-based Functional Communication Therapy Planner (Worrall 1999). The PIC approach to clinical management begins with an unstructured interview with the client about his or her communication needs. The main question is 'What do you hope to achieve by coming to speech therapy?' The client's goals are then classified according to the ICF components. This process assists the student to choose an assessment and treatment approach that is not only relevant to the client, but also uses an approach suitable to the goal. For example, if developing further social relationships is a goal, then social model approaches may be the first choice for this type of goal rather than impairment-based approaches; that is, the client may be introduced to support organisations or group sessions before syntax retraining occurs.

In audiology rehabilitation practice, students are required to use an audiology tool that is similar to the PIC in many ways. With the Client Oriented Scale of Improvement (Dillon et al. 1997), the clinician works with the client to develop a set of prioritised goals for the rehabilitation process. Clients are asked what they would like to achieve and these goals become the focus of the intervention that follows. Outcomes of the rehabilitation process are assessed in relation to these goals. Client's goals should be as specific as possible (e.g. to understand the guest speaker at the social club meeting) and may relate to Body Structure and Functions, Activities and Participation.

Use of the ICF in research in communication disability

A number of publications of the CDARU team have used the ICF as a conceptual framework or have investigated the validity of the classification scheme. Two of the books that have been written (Worrall & Frattali 2000; Worrall & Hickson, in press) use the ICF framework to structure information and explain the use of the ICF to speech pathologists and audiologists.

Dr Louise Hickson and A/Prof Linda Worrall have also obtained a number of large research grants to evaluate interventions based on the ICF. Examples include a project funded by Blue Care to examine the effectiveness of the Participation Enablement Program (PEP) for older people in aged care facilities, and a current project funded by the National Health and Medical Research Council to examine the effects of the Active Communication Education (ACE) program for older hearing impaired clients. Outcomes are measured at each level of the ICF in both of these projects.

The ICF has also been widely used as a framework for postgraduate work. Dr Madeline Cruice used the ICIDH-2 in her doctoral studies to examine the relationship between communication disability at the Impairment, Activity Limitation and Participation restriction levels to overall quality of life. Bronwyn Davidson and Brigitte Larkins also used the ICF in their doctoral studies, which involved examining the everyday communicative activities of people with aphasia and people with a traumatic brain injury through participant observation. Patrick Stark's masters research project examined the impact of hearing aid fitting on both the person with hearing impairment and his or her significant other, using the ICF framework. Robyn McCooey used the ICF as a rationale for developing the Inpatient Functional Communication Interview as part of her Masters studies. The results of several students' participant observations of everyday communication activities in people with aphasia, traumatic brain injury and hospital in-patients were then used to examine the validity of the chapter on communication in the Activities and Participation component of the ICF (see Worrall et al. 2002).

Two other PhD students in the CDARU are using the ICF framework. Tami Howe is using the Environmental Factors hierarchy to examine communication accessibility for people with aphasia, and Nerina Donaldson is examining the issue of third-party disability in spouses of older people with hearing impairments. The team has also been collaborating with Dr Travis Threats who was the American Speech-Language Hearing Association's liaison for the revision of the ICIDH-2 but is now involved in developing the American clinical manual for the ICF.

Selected key publications of the CDARU involving the ICF or its predecessors are listed for further reference. A full list of all ICF-related publications is available from the authors.

Selected key publications:

Worrall LE & Hickson LMH (in press). Communication disability in ageing: prevention to intervention. San Diego, CA: Delmar Press.

Worrall L, McCooey R, Davidson B, Larkins B & Hickson L 2002. The validity of functional assessments of communication and the Activity/Participation

components of the ICDH-2: do they reflect what really happens in real-life?
Journal of Communication Disorders 35(2):107-37.

Hickson L & Worrall L 2001. Older people with hearing impairment: application of the new World Health Organization International Classification of Functioning and Disability. *Asia Pacific Journal of Speech Language and Hearing* 6(2):129-33.

Worrall L 2001. The social approach: another new fashion in speech-language pathology? *Advances in Speech-Language Pathology* 3(1):51-54.

Worrall L & Frattali C (eds) 2000. *Neurogenic communication disorders: a functional approach*. NY: Thieme Medical Publishers.

Azzopardi S, Baker R & Hickson L 1997. Hearing impairment, disability and handicap in older people from non-English speaking backgrounds. *Australian Journal of Audiology* 19(1):23-33

Stumer J, Hickson L & Worrall L 1996 Hearing impairment, disability and handicap in elderly people living in residential care and in the community. *Disability and Rehabilitation* 18(2):76-82.

10.6 The ICF and Rett Syndrome

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Introduction

Rett syndrome is a relatively rare but serious brain disorder most often affecting girls. Generally, the early development of an infant with Rett syndrome appears normal. However, some time in the first 6 to 18 months of life, the normal pattern of childhood development does not continue (Kerr & Witt-Engerstrom 2001).

In most cases there is a loss of communication and hand skills with the subsequent development of unusual hand movements. In the long term, most children are no longer able to talk, and many find it difficult or are unable to walk. Other clinical features include poor head growth, epileptic fits, spinal curvature, abnormal breathing patterns, and gastrointestinal and sleeping problems. Rett syndrome is, therefore, usually associated with severe intellectual and physical disability, and girls with this condition commonly suffer from considerable health problems. Despite this, however, many parents remark that over time girls may appear to improve in their social awareness and communication skills.

Rett syndrome is a genetic disorder and has recently been shown to be associated with mutations in the methyl-CpG-binding protein 2 (*MeCP2*) (Amir et al. 1999). The *MECP2* gene is on the X chromosome. However, despite these recent genetic advances, there is still little information available about the natural history of the disorder, and we do not know which factors (in the girl, her family and her broader environment) are related to prognosis.

The principal aim of the Australian Rett syndrome research program, which began in 1993, was to define a population based cohort, that could be used for subsequent clinical and epidemiological studies and followed prospectively (Leonard et al. 1997). Baseline data on communication, mobility, symptoms and classification have been gathered since 1993 on individuals as they are enrolled in the cohort. In 2000, data were collected on functional ability in daily living, behaviour, hand function, medical conditions and use of health, therapy and education services (Colvin et al. 2003). In addition, parents used a calendar system to report the occurrence of medical, other health and therapy appointments for the duration of that year. Molecular testing for the presence

of *MECP2* mutations has also now been undertaken on more than 80% of cases, with mutations identified in approximately 70% of cases.

The research program has several aims:

- to assess the burden of Rett syndrome on the affected individual, their family and the community
- to determine which factors contribute most to this burden and which factors may alleviate this burden by determining:
 - how functional ability, behavioural score and medical/health burden at specific ages is influenced by a range of environmental and genetic factors
 - how the outcome for the family, in terms of quality of life, is influenced by the child's genetic characteristics, family functioning, support and resources.

Thus the components of the ICF –

- Body Functions and Structures
- Activities
- Participation
- and contextual factors (Personal and Environmental Factors)

provide a conceptual framework for investigating the broadest aspects of disability and functioning in Rett syndrome.

Body functions and structures

A number of body functions and structures studied in the Rett syndrome research program are relevant to the ICF:

- mental functions/nervous system
- sensory functions/eye, ear
- voice and speech functions
- functions of digestive, metabolic, and endocrine systems
- genitourinary/reproductive functions
- neuromusculoskeletal and movement-related functions
- functions of the skin and related structures.

The ICF framework provides the capacity to identify variation in body function and structure.

In our long-term follow-up studies, we specifically inquire in our parental questionnaire about medical conditions associated with Rett syndrome (e.g. scoliosis, digestive disorders, and epilepsy). During our 1-year intensive

calendar study, parents reported on their daughters' health on a daily basis, which allowed us to gain a window into the day-to-day life of a girl with Rett syndrome.

The assessment of intellectual function is particularly difficult to assess in Rett syndrome because of the apraxia and communication difficulties associated with this disorder. However, we have used the WeeFIM (as is described subsequently in the activities and participation sections) to obtain an estimate of cognitive functional ability (Leonard et al. 2001). Neurological functioning is of particular interest as two-thirds of girls with Rett syndrome suffer from epilepsy (Glaze et al. 1987). In our study, parents document the occurrence of epileptic seizures, which will allow us to categorise their seizure profile.

Visual and hearing function have not been specifically assessed in our research program as these are thought to be normal in Rett syndrome. However, autonomic functioning (in particular involving respiratory and cardiovascular systems) is of interest as it is thought that there is a neurologically mediated disturbance in these areas (Julu et al. 2001). Parents describe the nature of breathing disorders (e.g. hyperventilating) and patterns of occurrence. This has the potential to impact on their growth as it is thought that the 'work' of hyperventilation (or deep breathing) is associated with high levels of energy expenditure (Motil et al. 1994). In addition, clinical studies carried out by our colleagues at the Children's Hospital at Westmead (Sydney) will involve the use of the 'Autonomic Monitor' to specifically test this function.

The investigation of digestive system functioning is relevant to Rett syndrome because girls with this condition are commonly affected by gastro-oesophageal reflux disease and constipation as well as growth problems (Motil et al. 1999). Our questionnaires include detailed questions about feeding patterns including the quantity of meals and the time taken to feed. As well as assessing digestive system functioning, we also attempt to assess the way in which these functional problems can be overcome to optimise the subject's wellbeing as well as minimise the burden on families and carers. One example is the use of PEG (percutaneous endogastric tube) insertion to increase caloric intake, decrease feeding time and improve weight and overall health.

The presence of scoliosis, which may be treated by physiotherapy, bracing and/or surgery, is an example of abnormal body structure that affects up to half of girls with Rett syndrome (Stockland et al. 1993). We are currently undertaking a study to assess the impact of these treatments on the progression of scoliosis and on the functioning of girls and women with Rett syndrome. In addition, structural impairments affecting mobility can be overcome with the use of aids such as wheelchairs and walking frames. We

are attempting to quantify the use of these aids and identify any problems or restrictions to their access.

The structural and functional deficits associated with Rett syndrome often require hospitalisations for the purpose of managing acute medical conditions as well as operative procedures to correct problems. These hospitalisations result in a burden on the health system as well as the families who are caring for their children during the illnesses. We are attempting to quantify the impact that this population has on the health system, in terms of hospitalisations, medical visits and allied health services, by analysing data collected from the 'daily calendar' is completed by parents.

Finally, the genetic make-up of an individual can be considered to be part of body structure. As described above, our epidemiological study also includes the mutation status of each individual and the extent to which they have skewing of the X chromosome.

Activities

Our questionnaires include sections about the individual's activities in a number of domains relevant to the ICF:

- activities of learning and applying knowledge
- communication activities
- movement activities
- self-care activities
- domestic activities
- interpersonal activities
- performing tasks and major life activities.

The subject's ability to perform practical, day-to-day communication activities is assessed using the WeeFIM. This is a functional independence measure that we have used to measure independence in activities of daily living taking into account the help and assistance that may be required. Items include the extent of comprehension and ability to verbalise. We also have information about the subject's ability to communicate at all stages of her life, e.g. before she went through regression. Parents are asked to describe equipment used to aid communication.

Mobility is also formally assessed using the WeeFIM, which covers locomotion, toilet/bath and shower transfers and chair/wheelchair transfers. Ability to manipulate objects with the hands is an item of interest in our research because one of the hallmark features of this disorder is loss of functional hand use. We use the hand apraxia score to attribute a value to the

degree of functional hand use (Burd et al. 1990). Furthermore, the use of hand preference in Rett syndrome has also been studied in depth as a result of information collected from parents (Umansky et al. in press).

Activities of self-care are again assessed using the WeeFIM. Specific questions are devoted to bathing, dressing, grooming and toileting. Parents document their daughter's ability in this domain and, as well as scoring her on a predetermined scale, they include extra written information about how she carries out these activities. We include questions about puberty and menstruation in our long-term study to assess sexual development in this population, as this has implications for self-care and parental management. As already indicated, feeding and meal times are important elements of our research because of the practical implications to the child and family. Parents document the quantity of food provided, preparation procedures and mealtime routines. Information about specific equipment used with meals to facilitate feeding and oral functioning is also requested.

Girls and women with Rett syndrome are obviously unable to take an active role in traditional domestic activities such as shopping, meal preparation and housework. However, parents and carers may make an effort to include the girls and women where possible in these activities, e.g. by including them in shopping trips and having them in the kitchen during meal preparation so that they can feel part of the activity. We recognise the potential therapeutic benefit of these activities and parents are therefore able to document them in a section on day-to-day therapy.

In some cases, communication, movement and interpersonal activities have been assessed using a video protocol, whereby families and therapists record the subject performing, where possible, a number of structured tasks. These procedures are preferably conducted in a familiar setting, e.g. home or school to maximise functional ability.

Participation

Our questionnaires include sections about the child's or young adult's participation in a number of domains relevant to the ICF:

- personal maintenance (i.e. self-care)
- mobility
- exchange of information
- social relationships
- home life and assistance to others
- education
- community, social and civil life.

By the nature of their disability, girls and women with this condition are not usually able to participate in work, employment and economic life in the traditional manner.

The extent to which subjects can take part in their personal maintenance is assessed using the self-care domain in the WeeFIM. In addition, parents are able to give quantitative answers about their daughter's ability to care for herself. In general, a subject is usually limited in her ability to participate in personal maintenance but may be able to ease the burden on caregivers, e.g. by indicating when she is soiled. Participation in nutrition is usually limited because of the severity of the disorder, but parents are able to document choice making at meal times, e.g. through use of photographic cards or actual foods. Taking part in a range of therapy services (e.g. physiotherapy, occupational therapy, music therapy, hydrotherapy) can be considered to be participation in health. Using the calendar system, parents documented participation in health services over a period of 1 year during 2000. The extent to which subjects take part in therapy may be influenced by many factors. In our studies, we have found that therapy participation varies according to severity of disability, age and maternal education (Moore 2002).

Mobility is an important area of functioning in girls and women with Rett syndrome because it is often compromised, resulting in a decreased ability to participate in the community (Kerr & Witt-Engerstrom 2001). We have collected specific information about subjects' abilities to mobilise, whether they can do so independently, or by being supported or fully aided with equipment. Mobility is of central importance, and information has been sought about parent's attempts to modify the home environment and their vehicles for this purpose.

Participation in exchange of information can be difficult to assess. Again, the WeeFIM covers social involvement by quantifying the degree of assistance the girls and women require to express their needs and feelings. In addition, the use of communication devices in Rett syndrome is documented in the follow-up study. As well as objectively quantifying the degree of functionality in this domain, parents are able to describe the way in which their daughter communicates e.g. facial movements, gestures. This is closely related to the development of social relationships and ultimately to participation in community, social and civil life. The challenge is to find ways of communicating that will maximise the involvement of subjects and their families. The relationship between the girl/woman and her siblings is explored.

Participation in home life and assistance to others is obviously related to the degree of disability in Rett syndrome. Respondents indicate the accommodation-living situation in the questionnaire. Increasingly, young

women with Rett syndrome are gaining access to group homes and supported living with the assistance of government organisations. This is allowing these women to take on a role in a home environment with like-minded peers.

Participation in education by girls and women with Rett syndrome has undergone significant change during the past 10 years in keeping with shifts in philosophy and policy in special education. In our follow-up studies, parents have been documenting the educational setting as well as the amount of aide support for their daughters. Parents are asked to provide further information about their degree of satisfaction with their child's school arrangements. Furthermore, the participation in informal educational activities (e.g. in the home setting) is included.

Participation in community, social and civic life is an important element of life for children and women with Rett syndrome. Parents have documented participation in family events, religious events such as First Holy Communion, school events such as sports carnivals, and ethnic celebrations such as St Patrick's Day. Participation in recreation and leisure activities will also be specifically included in the upcoming parental questionnaire. This will include activities such as swimming, horseriding and attending cinemas.

Participation facilitation can be related to the extent to which therapy and education professionals are informed about Rett syndrome. Participation restriction is also likely to be related to a number of factors. These include the physical disability and immobility associated with Rett syndrome, which impede access to events/activities. In addition, participation in life situations can be somewhat impaired because of communicative disabilities associated with the disorder and parents' lack of resources for overcoming this aspect of the disability (i.e. communication devices). The attitudes of service providers are also important.

The Australian Rett syndrome research program is based on a biopsychosocial model which integrates aspects of both medical and social models of disability and functioning. The investigation of environmental factors such as equipment and support available to individuals and families and the social capital of the communities in which they live is likely to be integral to understanding the burden of this disorder. The program will use the ICF framework to identify those factors determined to be most beneficial and cost-effective in optimising health, function and quality of life for the affected child and her family.

10.7 Classification of support and need

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Supports Classification and Assessment of Needs Instrument

Work is currently under way on a project to develop a new system for classifying and assessing the support needs of people with disabilities. This is a collaborative project between The University of Sydney, the Royal Rehabilitation Centre Sydney (RRCS) and the Centre for Developmental Disability Studies (CDDS). It is a 3-year project (2002–04), with funding provided through a competitive Australian Research Council grant, with contributions from industry partners RRCS and CDDS.

Rationale

People with a disability (and their families and advocates) now expect to take part in ordinary everyday activities such as leaving home, moving house, joining and retiring from the workforce, developing relationships and raising a family. Providing support to enable people with a disability to live and work within the community is now an accepted part of Australian life. Varying types and intensities of support may be needed for some or all of these activities. In the face of a marked population increase of people with a disability (on average 14% annually or seven times the population growth over the past 5 years) a scientifically sound valid, and reliable needs assessment and support planning system is urgently needed.

All jurisdictions in Australia are grappling with the need to provide rational allocation of limited resources based on support needs, in an era of growing demand for services. Moreover, there is ample evidence in Australian and international literature that a better system is required for assessing the support needs of people with a wide range of disabilities and to translate

those needs into responsive and individualised service delivery (e.g. Schalock 1999). Providing such services with the available resources is a significant government challenge. Already 42% of people needing support are receiving some form of assistance from formal service agencies (ABS 1999). Existing demand (at least 58% of those needing support on 1998 figures) and growing demand (estimated at around 3% per year with the ageing of the population) indicates that a more effective and empirically sound system is required to ensure the resources available reach those most in need in the Australian population.

The support needs classification and assessment system

The project is developing an innovative, rigorous and robust system of identifying and classifying support needs based on the conceptual framework of the ICF (WHO 2001). In line with this framework, the project conceptualises disability as a dynamic state typically incurring restricted function due to:

- the interaction of the person (their health condition including impairment)
- the activities they desire to do (and any difficulties in carrying these out)
- environmental and personal factors (restrictions on participating in the community, e.g. physical access, discriminatory attitudes, particular background of an individual's life and living).

Hence, an individual's functioning in everyday life is the result of a complex relationship between these three components.

The aim of this new system for support needs assessment and classification is to reliably identify the type and intensities of support needed, taking into account the complex interactions that characterise disability (WHO 2001). A valid system will overcome the limitations of existing instruments that either overestimate (lack of sensitivity) or underestimate (lack of specificity) the support needs of people with a wide range of disabilities in varying situations.

The system comprises:

- procedures to involve the person with a disability and those most familiar with the person in identifying and assessing needs
- reliable methods of observing and assessing support needs in situ
- valid measures to identify support needs in a range of life activities, and which take into account the interactive effects of health condition (and impairment), desired activity and context (including environmental and personal factors).

The system is unique in that the person with a disability and people relevant to that person (i.e. the person themselves, parent/s or carer/s, advocate, and key service providers) complete the assessment together in the person's living

environment. They are able to consider the person's hopes, dreams, likes and dislikes, as well as the difficulties and barriers he or she experiences in attempting to fulfil personal goals. This contrasts with the current situation where assessment is typically done 'to' or 'on behalf of' people with disabilities by (well-meaning) professionals often in unfamiliar settings (consulting room or institutional environment) without the benefit of information from those closest to the person with a disability.

A trained facilitator guides the assessment meeting(s) to identify personal goals and activities (such as where and how the person wishes to live, work and spend their time) and what is required to achieve these in the most effective and practical way. The facilitator's role is to encourage differing views to be openly debated in order to develop an action plan that is responsive to the individual's preferences, and that is constructive, achievable, and acceptable to all. This assessment process may last up to 2 hours or require an additional meeting to achieve an agreed record of the individual's personal goals and the type and amount of support required to achieve these on a daily basis in activities and participation domains such as self-care, domestic life, mobility and transport, communication, interpersonal interactions and relationships, health management, emotional and behavioural management and home and community living.

Application of the concept of support has been further guided by the conceptual model of support in the Mental Retardation Definition, Classification and Systems of Support, 9th and 10th editions (AAMR 1992, 2002). This support outcomes model directly links support resources (including the person with a disability and others, technology and services) with the functions of support (e.g. receiving assistance with finances or work, or with home living activities, friendship, instruction) and, the intensities of the support required. Intensities of support considers time duration, time frequency and intrusiveness measures, and allows assessment of whether support is only required occasionally (intermittent); is time- or occasion-specific (limited); is needed over an extended period (extensive); or is of a frequent, intensive and possibly life-sustaining nature (pervasive). This model is based on a 'best fit' assumption; that is, a match between the supports needed and the type and intensity of the support provided results in desired outcomes such as achieving personal goals in key life activities, increased personal satisfaction and enhanced quality of life. A multi-dimensional scoring system is used for key activity and participation domains, with the level of intensity of support needs identified using the categories intermittent, limited, extensive and pervasive.

The system has been trialled extensively for people with an intellectual disability in residential environments. Currently, work is being undertaken to

trial the system among individuals from a range of disability types and across diverse environments.

Expected outcomes

The proposed project will demonstrate:

- the multidimensional and dynamic nature of the support needs of people with disabilities
- the reliability and validity of the proposed support needs assessment and classification system across a wide range of disabilities
- the training and protocols required to ensure proposed system is reliably implemented in diverse settings
- ways that the proposed system can be directly linked with service planning and resource allocation.

10.8 The Handicap Assessment and Resource Tool (HART) and the ICF

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Background

The Handicap Assessment and Resource Tool (HART) was developed in the early 1990s, at a time when the ICIDH was in use. The HART aims to assess 'personal care handicap'. In the ICF, the concept 'participation restriction' replaces 'handicap'. The HART measures just one small part of overall health status – the personal care element of participation (Figure 10.2). This part is critical to decision making about admission or discharge from hospital. It can also help to judge the effectiveness and, hence, the efficiency of various in-patient and community-based rehabilitation programs.

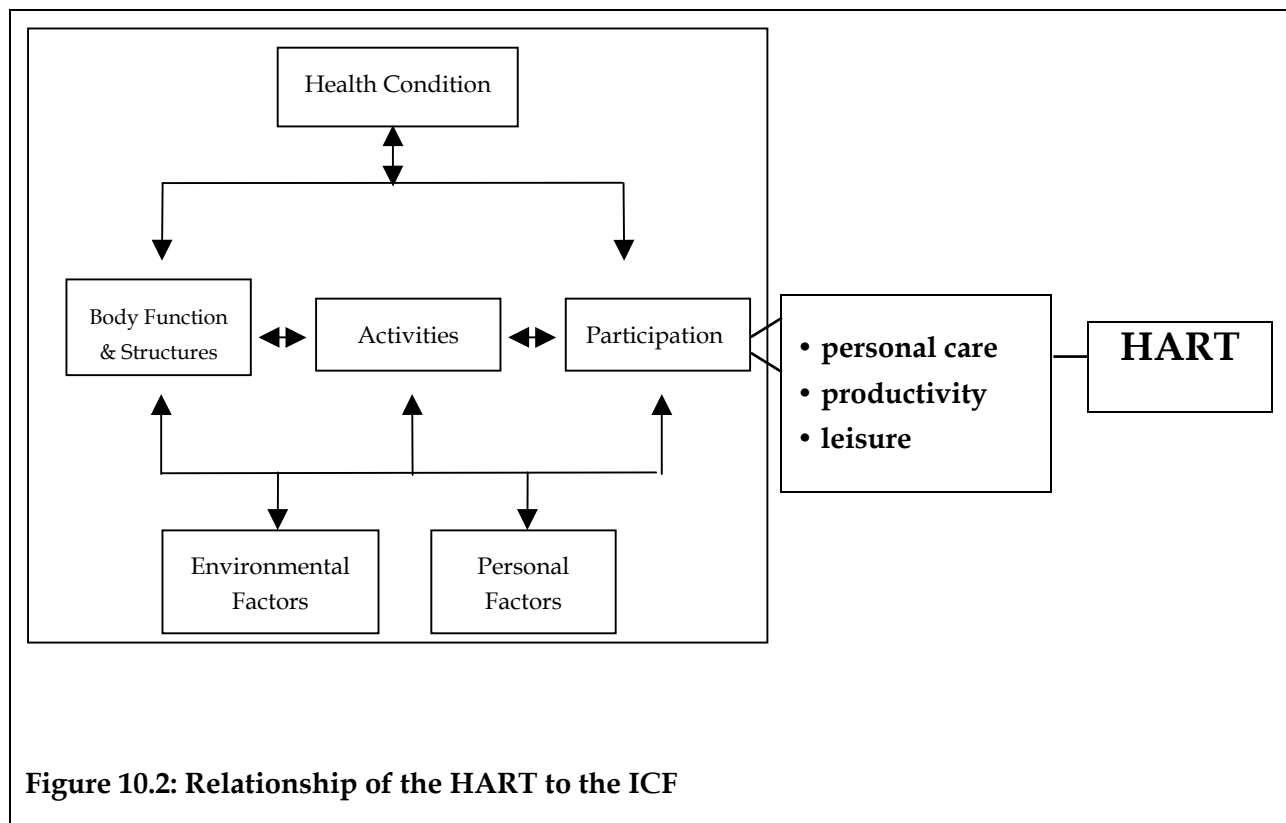


Figure 10.2: Relationship of the HART to the ICF

Rationale

The list of items that could be included from the ICF to reflect participation in life in general is large, as it includes items that relate to personal care, to productivity and to leisure. The HART selects from the very large set of possibilities by measuring just one aspect of participation or participation restriction – personal care. Personal care is defined by the HART as including the following ‘domains’: clothing, hygiene, nutrition, mobility, safety, residence, supports.

Purpose

The purpose of the HART is to establish which areas pose problems for people regarding their personal care, despite their own efforts and those of their usual supports. The HART does not primarily seek to establish what people can do alone. The HART captures what people can do or get done for them in their ‘usual environment’ with the ‘usually available help’ regarding aspects of existence that are vital for survival.

The HART is a practical tool designed to be used by clinicians as part of their usual practice. It provides a time-efficient means of comprehensively assessing participation restriction in personal care in a way that assures the quality of such assessments. It also provides a means of recording and summarising clinical observations. This enables information to be transferred for clinical purposes and for health-service management.

The assessment of functional status to identify areas of need is central in planning the management of people’s difficulties. In community settings, functional assessment could identify people’s unmet needs in the area of personal care (‘participation restrictions’) so that these could be attended to. In hospital settings, the HART could aid the discharge planning process by providing a comprehensive assessment of patients’ functions given the support systems available to them and taking into account their physical domiciliary environment.

Consider, for example, people who have had a stroke and cannot prepare their meals alone. In this case, they could not be discharged from hospital to live alone. However, if someone is always willing and able to provide their meals, then they have no problem with this aspect of personal care. If they have no other participation restrictions in personal care, as defined by the HART, they could be discharged from hospital to the assessed settings. For the purposes of determining whether they can live in the assessed environments, it does not matter that they cannot prepare their meals alone. The HART helps to obtain and collate the information required to make such decisions. The HART also provides a means of conveniently recording the aspects of personal care for

which help is required. Changes in the identified aspects of care that occur as part of the natural recovery process or as a result of rehabilitation can be used to demonstrate improvement; conversely, increased assistance is evidence of deterioration. This can be used to demonstrate the effectiveness of health-care services.

Clinical use of the HART

Clinicians can use the HART to determine and summarise their patients' participation restrictions in personal care (Figure 10.2). Unresolved participation restrictions are made explicit, which helps goal setting for management. In complex cases, the structured assessment ensures that no critical components are forgotten and that quality assurance is maintained in health care processes. The HART also provides a convenient way of communicating patients' personal care restrictions.

There are many questions the HART may help clinicians and managers to explore:

- How many participation restrictions in personal care do patients initially have?
- What types of participation restrictions in personal care are present?
- In the service provided, what are the patterns of change in activity limitations and in participation restrictions in personal care?
- What factors delay change in these activity limitations and in personal-care participation restrictions, and which of these barriers could be readily altered?
- For individual patients, does the participation restriction in personal care justify (continued) in-patient care?

Change in participation restrictions in personal care during episodes of health care can reflect the effectiveness of interventions. Once effectiveness is known, efficiency can be judged. Judgements of effectiveness and efficiency are critical components of quality improvement processes for clinicians and health-service managers. The use of the HART ensures information about participation restrictions in personal care is gathered in a standardised fashion, thus allowing comparisons between different services and practices. This can help in evaluating programs and identifying barriers to optimal practice.

10.9 The ICF and oral health

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Introduction: functioning, disability and oral health

Oral diseases have a substantial impact on the wellbeing of individuals and populations because of several special features of the structure and function of the mouth. From an early age, the mouth and face have powerful influences on psychological wellbeing and social interactions. Craniofacial conditions such as facial clefts, although rare, have profound psychological and sociological significance for children and families. The ability of dental decay to cause excruciating pain has been recognised since antiquity, and toothache continues to be a highly prevalent and disabling condition, even in an era of modern dental care. Although conditions such as dental decay, gum disease, dry mouth and tooth loss have much more subtle impacts on wellbeing, they are highly prevalent and hence contribute to a substantial burden of oral disease within the Australian population. In 1996, dental caries, complete tooth loss and periodontal disease featured among the five most prevalent conditions in the Australian population (AIHW 2002c).

For many individuals, the impact of oral conditions on wellbeing is a private experience, endured from day to day. Yet this 'silent suffering' creates a substantial impact on the population. For example, in her introduction to the US Surgeon General's Report on Oral Health, Donna E. Shalala, (then) Secretary of Health and Human Services declared, '...oral health problems can lead to needless pain and suffering, causing devastating complications to an individual's wellbeing, with financial and social costs that significantly diminish quality of life and burden American society' (US Department of Health and Human Services 2000). Documentation of the population burden of oral disease has become possible only in the last decade, as dentistry has developed research methods to assess more comprehensively the nature and consequences of oral disease. Much of the research has been stimulated by the WHO's development, first, of the ICIDH (WHO 1980) and, more recently, the ICF (WHO 2001)

The purpose of this section is to review the conceptual and methodological approaches to measuring oral health within the evolving frameworks of the ICIDH and ICF. Recent findings are presented from national surveys

conducted among the Australian and UK populations. The section concludes with recommendations for assessment of oral health using the ICF framework.

Measures of oral health using ICIDH and ICF frameworks

Since the early twentieth century, dental researchers have made detailed epidemiological assessments of oral health using a predominantly clinical focus on disease and tissue destruction. For example, Dean and colleagues in the United States Public Health Service developed the DMF index in their groundbreaking studies of the relationship between dental decay and levels of fluoride in drinking water (Dean et al. 1942). The DMF index, a measure of a person's history of dental decay, is recorded by a trained dental clinician who examines the teeth of study subjects for clinical signs of decay (D), previous treatment of decay by a filling (F) or previous extraction due to decay, leaving a missing (M) tooth. There are comparable clinical indices that measure gingival inflammation, periodontal tissue destruction, dental trauma, occlusal (orthodontic) irregularities, and temporomandibular disorders.

By the 1970s, in response to broader concerns that many clinical indices of general health status were not responsive to population measures of health service provision, Cohen & Jago (1976) advocated the development of 'sociodental' indicators to capture non-clinical aspects of oral disease. They argued that sociodental indicators were necessary to broaden the narrow focus that had emerged within oral epidemiology, which emphasised only the clinical parameters of disease, and therefore failed to document the full impact of oral disorders within populations.

The ICIDH (WHO 1980) provided the impetus for a revolution in the conceptual basis and empirical methods for evaluating oral health. In his application of the ICIDH framework to oral health, Locker (1988) proposed a framework for measuring oral health that extended beyond the confines of clinical indices of disease activity and tissue destruction embodied in the DMF index. Importantly, Locker's model also expanded the scope of ICIDH to include certain feeling states (e.g. pain and psychological discomfort) which are prominent consequences of oral disease. Locker also elucidated subcategories of the ICIDH definition of disability, describing concepts of physical disability, psychological disability and social disability. It is an intriguing footnote to history to observe that some of those same concepts have now been embodied in the ICF definitions of Activities and Participation and that pain (previously excluded from ICIDH) has now been classified as a Body Function within the ICF. Specific references to the oral cavity within the current ICF classification (WHO 2001) occur for seven body functions (b28010, b5100–b5105) and five Body Structures (s3200–s3204). The mouth and face are

involved directly in six forms of Activities and Participation (d330, d5201, d550, d560, d5701, and d7105).

These theoretical developments were matched by a surge in methodological work by researchers around the world who developed instruments to measure oral health and its consequences. Researchers from different countries used various phrases to describe the underlying concepts being measured, including 'social impact of oral disease', 'subjective oral health status', 'oral health related quality of life' or simply 'oral health'. However all of the questionnaires captured, to varying degrees, concepts described in the ICIDH (WHO 1980), Locker's refinement of the ICIDH for oral health (Locker 1988) and, as it turns out, the ICF (WHO 2001). By 1996, when the first international conference for methodological research in this area was held, no fewer than eleven standardised questionnaires had been developed and undergone testing for reliability and validity (Slade 1997a). In a subsequent international conference, new measures of oral health were described that were targeted towards young children and specific clinical conditions such as dry mouth and oral cancer (Inglehart & Bagramian 2002).

While it is beyond the scope of this section to review all of the measures described above, Table 10.6 summarises the features of questionnaires that assess multiple dimensions of oral health described in ICIDH/ICF frameworks and which have been used in clinical research or population studies. Questionnaires range in length, from 3 to 56 items and consequently they vary in the scope of dimensions measured. Although not shown in Table 10.4, most of the questionnaires inquire about the negative consequences of poor oral health, and hence are consistent with the orientation of the ICIDH. However, the Dental Impact Profile (Strauss & Hunt 1993) and UK Oral Health Related Quality of Life questionnaire (McGrath & Bedi 2001) ask about positive and negative consequences of oral status, as embodied in the ICF.

Examples of results from studies that have measured oral health within an ICIDH/ICF framework

In a review of 14 cross-sectional studies of adults, Slade (2002) reported that the following factors consistently have been associated with poorer subjective oral health status: fewer teeth, more diseased teeth, more extensive periodontal disease, other untreated dental conditions, unmet treatment needs, a pattern of episodic/emergency dental visits to treat dental problems, and lower socioeconomic status. In the US, non-whites generally report poorer oral health compared with whites. Slade (2002) also reviewed five clinical studies in which improvements in subjective oral health were found following general dental treatment, replacement of missing teeth, treatment of

temporomandibular (jaw joint) disorders, and surgical treatment for oral cancer.

One of the most comprehensive measures of oral health status, the 49-item Oral Health Impact Profile (OHIP), was developed in Australia (Slade & Spencer 1994a). A shorter, 14-item version OHIP-14 questionnaire has also been developed (Slade 1997b). OHIP questionnaires have been used to assess oral health in 25 studies, ranging from international comparative population surveys through to randomised clinical trials. For example, in a study of community-dwelling South Australians aged 60+ years, 6.6% of those who had one or more teeth reported that they had experienced discomfort while eating because of problems with their teeth, mouth or dentures (Slade & Spencer 1994b). Other impacts reported by at least 10% of people with teeth included difficulty chewing and avoidance of foods; under 5% reported adverse impacts of oral health on social roles and interpersonal relationships. However, people with no remaining natural teeth were approximately twice as likely to report these impacts. In a 2 year follow-up of people who had one or more teeth, Slade (1998) found deterioration in reported oral health status among three hypothesised high risk groups: people who experienced tooth loss during the two-year period; people who usually visited the dentist because they had problems; and people who reported financial hardship in obtaining dental care.

A comparison of OHIP responses among older adults in South Australia, Ontario (Canada) and North Carolina (US), found that tooth loss was consistently associated with high OHIP scores, indicating more frequent adverse impacts on oral health (Slade et al. 1996). Interestingly, there were larger differences in OHIP scores between whites and African-Americans within the US sample than between the three countries, and while those differences diminished in multivariate analyses that controlled for clinical measures and dental visits, African-Americans continued to have the highest levels of impact. This finding lends support to the ICF framework by suggesting that socioenvironmental factors (e.g. social and cultural influences) influence oral health and its social impact. Furthermore, the results indicate the effects of social and cultural diversity may be greater between race groups in North Carolina than between the other countries studied. Consequently, these results lend support to the expanded conceptual model of ICF, in which socioenvironmental factors (i.e. people's living circumstances) interact with the personal dimensions of functioning and disability.

Other researchers have used the OHIP to compare subjective oral health status and generic health status, with the results suggesting that oral health is perceived as a distinct dimension within general health. For example, in a

study of adolescents in New Jersey, Broder et al. (2000) found only weak to moderate correlations between OHIP scores and the SF-36, a widely used measure of subjective health status. Importantly, the SF-36 was not associated with clinical oral status, whereas the OHIP was. Nonetheless, the OHIP was not intended to serve as a screening tool for identification of dental treatment needs, and a study of Canadian adults found that it had poor sensitivity and specificity in predicting the need for dental restorations, periodontal (gum) treatment and dentures (Locker & Jokovic 1996). In two clinical trials comparing treatment for complete tooth loss using the OHIP questionnaire, patients receiving implant-retained dentures had significantly greater improvements in subjective oral health status than patients receiving conventional dentures (Allen et al. 2001; Awad et al. 2000).

Recent findings from national surveys of oral health using the OHIP

The short version OHIP-14 questionnaire has been used in two recent surveys of samples representative of the adult populations in Australia and the UK. This permitted for the first time, a comparison of subjective oral health status between representative populations using a standardised, multiple-item instrument. The prevalence of adverse impacts among dentate adults was markedly similar in the two populations, with 18.2% of the Australian sample and 15.9% of the UK sample experiencing one or more items 'fairly often' or 'very often' during the preceding year. In fact, regional variation in prevalence within the samples was greater than that between the two populations. Conspicuous in the Australian sample was the significantly greater impact reported by people with no natural teeth remaining (23.9%). Although the prevalence of impacts varied only marginally between populations, dentate Australians reported a significantly greater mean number of impacts and perceived greater severity of impacts than their UK counterparts as measured by the sum of affirmative responses to items. The higher impact response of Australians was not distributed equally across all items, but rather was centred on two specific dimensions categorised as pain (aching, pain on eating) and physical disability (diet unsatisfactory, interrupted meals). The former is classified as a domain of the Body Function component within ICF, and the latter is consistent with the Activities/Participation and Body Function components of the framework.

Tooth loss was associated with subjective oral health deficits in both populations and was independent from the effect of age. However, the relationship between tooth loss and impact was neither monotonic nor consistent between populations. In the Australian sample, retention of 25 or more teeth was associated with significantly less impact, whereas in the UK a decreasing gradient in impact was observed with increasing levels of tooth

retention past a threshold of 16 teeth (Figure 10.3). The effect of social and cultural determinants on outcomes was apparent when the Australian sample was categorised according to country of birth (Australia, UK/Ireland, other). Investigation of age and tooth loss associations with OHIP scores for immigrants born in the UK and Ireland revealed almost identical patterns to those observed in the resident UK population. Despite substantial progress in the field of health inequalities, the reasons for such cultural differences and the role of social factors in their development remain to be clarified.

Recently, data from the UK survey were used to evaluate the potential causal pathway among dimensions of oral health defined in Locker's theoretical model (Locker 1988), on which the OHIP was based. Consistent with the ICIDH, Locker's model proposed a series of links connecting dimensions of oral health in a hierarchy, beginning with impairment, and progressing to more debilitating impacts of functional limitation, discomfort and pain, through to disability, and ultimately to handicap. Examination of the combination of survey responses generally supported Locker's model with the majority of response patterns conforming to the theoretical hierarchy. This was not the case however for 10.3% of adults. In almost all of these cases, responses included pain and discomfort *in addition to* functional limitation, indicating a pathway that was not delineated in Locker's model. Accordingly, pathways were revised to omit combinations of dimensions that were not prominent in both the Australian and UK population, and incorporate those reported combinations that were unspecified in Locker's hierarchy. The latter comprised Impairment with Disability, Functional Limitation with Pain or Discomfort, and Pain or Discomfort with Handicap. The modified model highlights the pivotal role of pain in escalating the impact of oral conditions to more debilitating levels. While Functional Limitation alone was not causally linked to Disability or Handicap, in the presence of pain or discomfort, lower grade impacts could advance to these more serious threats to wellbeing.

This finding has implications for tertiary prevention interventions that target symptomatic conditions to avert disability or handicap. For example, if these same patterns of subjective oral health observed in national cross-sectional studies could be confirmed to have causal associations, it would suggest that many aspects of diminished oral function are self-limiting in the absence of pain. Furthermore, as a 'case study' of the WHO theoretical framework of health, these results from oral health imply that pain may play a central role in mediating transitions among subcategories of the ICF domains of Activities and Participation.

Conclusions

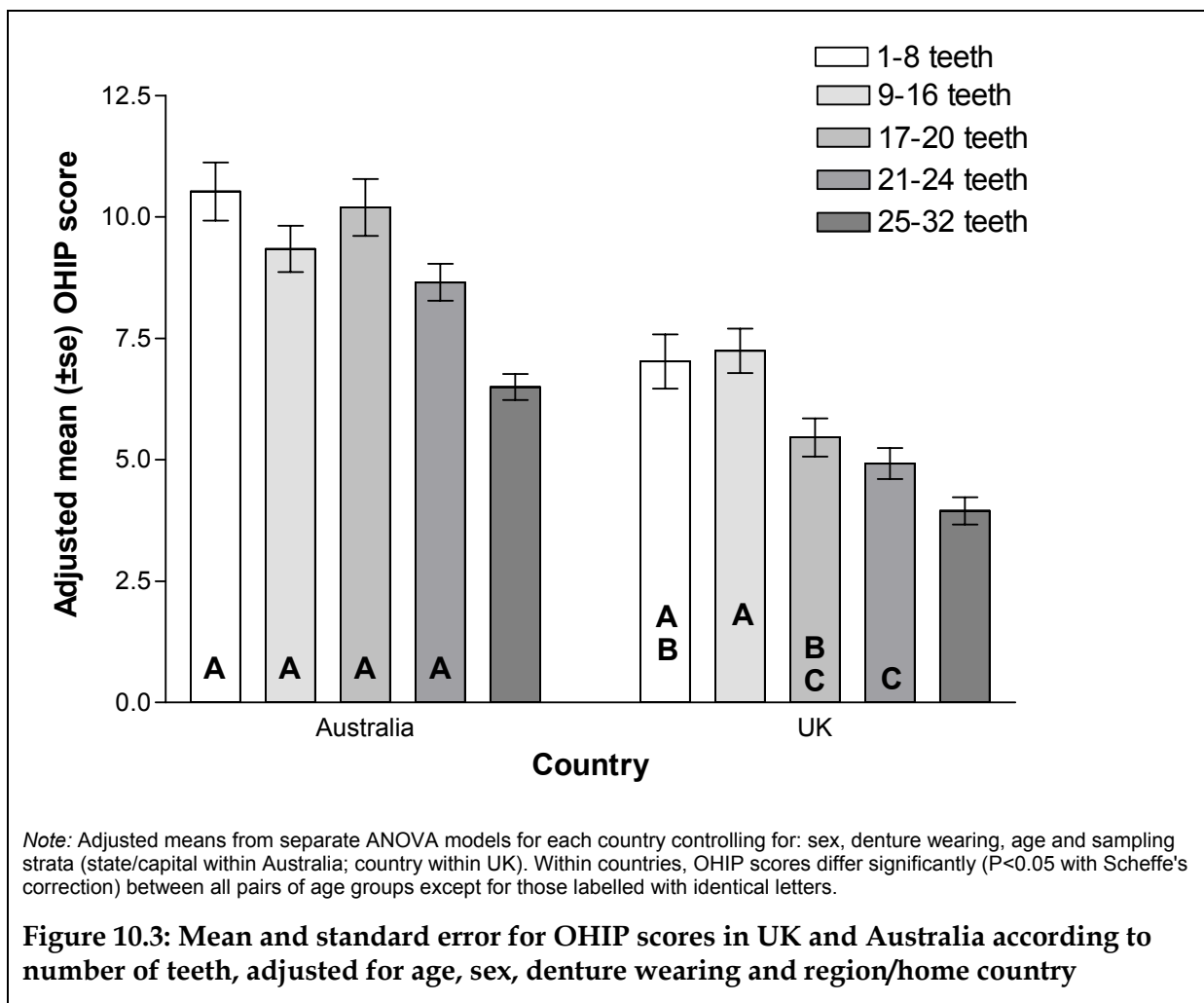
In the last decade, significant progress has been made in measuring oral health within an ICIDH/ICF framework.

- The OHIP is one of the few measures of oral health that incorporates the social dimension of health thoroughly. Historically it has used the ICIDH conceptual structure and remains well aligned to the new concepts of the ICF.
- The OHIP-14 has been used effectively to measure adverse impacts of oral health on wellbeing in national population surveys.
- The population distribution of conceptual dimensions within the OHIP suggests that oral pain plays a central role in mediating transitions among subcategories of the ICF domains of Activities and Participation.
- New work is under way to develop measures suitable for children and other population subgroups
- While some other questionnaires of subjective oral health have captured positive dimensions, they have not been adopted so widely, and methodological problems in measuring both positive and negative consequences using those questionnaires need to be resolved.
- Additional work is needed to move beyond classification and quantification in population health surveys to evaluate interventions that may improve health outcomes captured in an ICF framework.

Table 10.6: Questionnaires measuring subjective oral health status

Questionnaire (authors)	Dimensions measured	No. of questions
Sociodental Scale (Cushing et al. 1986)	Chewing, talking, smiling, laughing, pain, appearance	14
RAND Dental Health Index (Dolan et al. 1991)	Pain, worry, conversation	3
General Oral Health Assessment Index (Atchison & Dolan 1990)	Chewing, eating, social contacts, appearance, pain, worry, self-consciousness	12
Dental Impact Profile (Strauss & Hunt 1993)	Appearance, eating, speech, confidence, happiness, social life, relationships	25
Oral Health Impact Profile (Slade & Spencer 1994a)	Function, pain, physical disability, psychological disability, social disability, handicap*	49
Subjective Oral Health Status Indicators (Locker & Miller 1994)	Chewing, speaking, symptoms, eating, communication, social relations	42
Oral Health Quality of Life Inventory (Cornell et al. 1997)	Oral health, nutrition, self-rated oral health, overall quality of life	56
Dental Impact on Daily Living (Leao & Sheiham 1996)	Comfort, appearance, pain, daily activities, eating	36
Oral Health-Related Quality of Life (Kressin et al. 1996)	Daily activities, social activities, conversation	3
Oral Impacts on Daily Performances (Adulyanon et al. 1996)	Performance in eating, speaking, oral hygiene sleeping, appearance, emotion	9
UK Oral Health Related Quality of Life questionnaire OHQoL-UK(W)© (McGrath & Bedi 2001)	Eating, appearance, speech, breath odour, social life, romantic relationships, confidence, sleep, mood	16

Note: Slade and Spencer defined 'handicap' based on the framework described for ICIDH (WHO 1980). With the publication of the ICF framework (WHO 2001), the terms 'Activities and Participation' replace the formerly used terms 'impairment', 'disability' and 'handicap'.



11. Links and references

11.1 Links

The ICF itself and the WHO web site

- International Classification of Functioning, Disability and Health
<<http://www3.who.int/icf/icftemplate.cfm>>
- World Health Organization
<<http://www.who.int>>

Where to obtain a printed copy of the ICF

- Hunter Publications
<<http://www.hunter-pubs.com.au/>>
- DA Information Services Pty Ltd
<<http://www.dadirect.com.au>>

AIHW web site and materials on it, including the 'family matrix'

- ICF Implementation in Australia (including web version of User Guide)
<<http://www.aihw.gov.au/disability/icf/index.html>>
- Australian Institute of Health and Welfare
<<http://www.aihw.gov.au>>
- International Collaboration on Health and Welfare Information
<<http://www.aihw.gov.au/international/index.html>>
- Family of Health Classifications
<http://www.aihw.gov.au/international/who_fic/index.html>

Australian data dictionaries

- National Community Services Data Dictionary Version 2.0
<<http://www.aihw.gov.au/publications/index.cfm?type=detail&id=6144>>
- National Health Data Dictionary Version 12
<<http://www.aihw.gov.au/publications/index.cfm?type=detail&id=8964>>
- National Housing Assistance Data Dictionary Version 2
<<http://www.aihw.gov.au/publications/index.cfm?type=detail&id=9125>>

Other Collaborating Centres

- **Brazil:** University of Sao Paulo, Departamento di Epidemiologia, Faculdade de Saude Publica
<<http://hygeia.fsp.usp.br/~cbcd/>>
- **China:** Peking Union Medical College Hospital, Chinese Academy of Medical Sciences
<<http://www.imicams.ac.cn/gb/pumc/pumc.htm>>
- **France:** Centre Technique National d`Etudes et de Recherches sur les Handicaps et les Inadaptations (CTNERHI)
<<http://perso.club-internet.fr/ctnerhi/cih.htm>>
- **Germany:** Deutsches Institut für Medizinische Dokumentation und Information (DIMDI)
<<http://www.dimdi.de/en/klassi/index.htm>>
- **Japan:** Office of the ICD, Vital and Health Statistics Division, Ministry of Health, Labour and Welfare
- **Netherlands:** National Institute of Public Health and the Environment
<<http://www.rivm.nl/who-fic>>
- **Nordic countries:** Centre for the Classification of Diseases in the Nordic Countries, Uppsala University
<<http://www.nordclass.uu.se>>
- **North America:** National Center for Health Statistics, in collaboration with Canadian Institute for Health Information
<<http://www.cdc.gov/nchs/icd9.htm>>
- **Russian Federation:** Semasko Scientific Research Institute of Social Hygiene & Academy of Medical Sciences, Department of Public Health Statistics
- **UK:** Office for National Statistics, in collaboration with National Health System Information Authority
- **Venezuela:** Centre Venezolano de Clasificación de Enfermedades (CEVECE)

UN Statistical Commission and Washington City Group

- United Nations Statistics Division
<<http://unstats.un.org/unsd/default.htm>>
- United Nations Statistics Division Statistical Commission
<<http://unstats.un.org/unsd/statcom/commission.htm>>
- Washington City Group
<<http://unstats.un.org/unsd/methods/citygroup/washington.htm>>

North American Collaborating Centre Clearinghouse

- ICF Clearinghouse Newsletters
<<http://www.cdc.gov/nchs/about/otheract/icd9/icfactivities.htm>>

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