The new international classification of disability: its relevance to people’s lives

Ros Madden, Australian Institute of Health and Welfare

Abstract and introduction
The new International Classification of Functioning, Disability and Health (ICF) conceptualises disability as multi-dimensional — relating to the body functions and structures of people, the activities they do, the life areas in which they participate, and factors in their environment which affect these experiences. The ICF conceptualisation reflects and has the potential to shape discussion, policy and information about disability. This presentation will explore this potential of the classification and its relevance to a number of the conference themes: health, disability and inclusion; citizenship and inclusion; social inequality; retirement and ageing; organisation and delivery of community services. Some challenges in improving the quality and consistency of disability data will also be discussed.

Before starting, it may be useful to explain that the AIHW is a statistical organisation and it is from this perspective – the need to develop, analyse and publish statistical information on disability and related services – that we approach our work. We try to understand what is important to people and policy makers, and relate this, however imperfectly, to statistics and information.

What is the ICF?
Today, I’ll first briefly outline the International Classification of Functioning, Disability and Health (ICF), and then relate this new classification, and its use, to aspects of people’s lives, and to relevant service developments and data developments.

The ICF describes functioning and disability as multi-dimensional concepts, relating to the body functions and structures of people, the activities they do, the life areas in which they participate, and the factors in their environment which affect these experiences. 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 and Figure 1).

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. All these dimensions of disability are crucially influenced by the environment.

To illustrate, disability may be described in terms of:
- an impairment, e.g. severe impairment of the spinal cord;
- an activity limitation, e.g. difficulty in mobility; and/or
- a participation restriction, perhaps in the area of employment.

The environment is crucial; for instance, employment restrictions can be removed by the provision of appropriate computing equipment and constructive attitudes of work colleagues.

The ICF thus specifically recognises and reflects the social model of disability.
Key definitions of the ICF components are as follows:

- **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.

The chapter headings of the classification of each component, set out in Table 1, provide an idea of the content.
Table 1: ICF components and domains, with examples of contents

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

The ICF contains a hierarchy of classifications and codes for each of its main components: Body Functions and Structures, Activities and Participation, and Environmental Factors. You’ll have seen that the terms, definitions and codes of the classification are expressed in neutral language. 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
coded, according to the extent to which they facilitate participation and activities, or the
extent to which they are a barrier. Work remains to be done on operationalising these
qualifiers and relating them to instruments in the field, or new measuring tools being
developed.

The ICF was endorsed for international use by the World Health Assembly in May 2001. It is
regarded by the World Health Organization as one of the two core international
classifications for health and health-related information, the other being the International
Classification of Diseases and Related Health Problems (ICD). While the ICD focusses on
illness and death, the ICF focusses on the manner of life, in relation to health – that is, on
functioning and disability.

The potential 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.

This is why the AIHW became interested in the ICF—because of the need to depict,
nationally, the experience of people with disabilities in a whole range of services. To obtain a
broad view, it is a great advantage to be able to relate information from different sources
and different data sets, and the ICF offers a common framework to enable this to happen.

We have developed an Australian User Guide which is on our website, and which
highlights some existing uses (AIHW 2002a). There are many potential applications of the
ICF across many fields, some of which I will touch on today and others of which are
described in the User Guide

So, let’s look briefly at some of the services relevant to people with disabilities.

**Disability and health**

There has been a growing body of recent research on health outcomes for people with
disabilities and their less than optimal experience in the health system (for a brief overview,
see AIHW 2003 forthcoming).

If we want to be able to report systematically on their health status and on their experience
in the health system, the question arises: how are these people identified or described in the
health system or in health surveys? Can the use of standardised definitions based on ICF
concepts help here?

Consider also a more specific sector of the health system – those professionals who deal with
rehabilitation. It seems that among them, the underlying models of disability are still
actively being debated. In relation to rehabilitation assessment (and in turn, presumably,
treatment), the discussion seems to turn around the degree to which rehabilitation
assessment tools should look at social goals and outcomes and environmental factors, as
well as impairment and selected activity limitations outcomes. This debate sometimes
reflects a community-based treatment focus as compared to a more purely clinical focus.

A very new arena for discussion is that of electronic health records. By their nature they are
designed for multi-disciplinary information sharing. But would they focus chiefly on
disease or on functioning in everyday life? Could people with intellectual disabilities, for
instance, benefit significantly from having health records shared (with their agreement)
more widely, to ensure that health conditions, once recognised, were not neglected perhaps
because of medical professionals’ communication difficulties with some people? And what are the risks to the general well-being of the population if health records focus only on the merely medical, and fail to encapsulate broad ‘functional’ outcomes. In order to support such records, if introduced, there is a need for useful and acceptable indicators of disability and functioning, constructed with reference to the ICF.

The health system itself, then, could look beyond the ‘medical model’ of disability and consider people’s health more broadly. Such a shift is, in fact, in line with the recognition that human health is undergoing an ‘epidemiological transition’. While the focus on illness and death will always remain, this transition brings a greater concern about quality of life for people living longer, with perhaps chronic conditions, where aspects of functioning and disability require attention.

Disability and participation

One of the key themes of this conference is that of ‘social inclusion’. This is, of course, an area where the disability field is expert, and the writing and philosophy in our field has a great deal to offer broader academic studies of the topic.

Outcomes for people with a disability have been reported in the last two of the AIHW biennial reports to Parliament, using the ICF framework to shape an examination of the extent of people’s participation in a broad range of life areas (AIHW 1999b:255–165; AIHW 2001:308–313). These outcomes are reported relative to others in the community, in line with the UN standard rules on equalization of opportunities for persons with disabilities (UN 1994).

People with disabilities in 1998 were participating in many areas of Australian life, although often not to the same extent as the overall population. They were less likely to have finished school and less likely to be in active in the paid workforce. They tended to have lower incomes than the rest of the population, although the receipt of government payments diminished these differences. The main focus of their social activities was family and friends, who were also the main providers of assistance to them.

There were also, for instance, some positive trends. People with disability were more likely in 1998 to be living in the community than in previous years. There appeared to be increasing rates of school attendance, especially in ‘ordinary’ school classes.

Community living and trends in de-institutionalisation

Let’s look further at this increase in community living. As can be seen from Figure 2, ‘de-institutionalisation’ is, in fact, mostly non institutionalisation. The graph illustrates that the number of people living in households has increased by much more than the number of people living in ‘cared accommodation’ has decreased.

Most of this increase in community living is being achieved via an increase in numbers of people living with relatives. Most assistance reported by people with disabilities is what they receive informally (family and friends), rather than from formal services (AIHW 2000, 2003 forthcoming).
Another area where the ICF has something to offer policy and data analysts is in the area of disability and ageing. The AIHW carried out an extensive analysis of available data in its study of disability and ageing (AIHW 2000). To encapsulate a rather large report into a few points, the major findings and implications included:

- the dominance of demography, and the ageing of both the general population, the population with disabilities, and service users in both the disability and aged care sectors;
- the usefulness of flexible services with and emphasis on individual needs, in light of the study findings (see below);
- the importance of clarity in, or good links between, the disability and aged care sectors; and
- the importance of informal or unpaid care as, essentially the linchpin of the overall system.

So what do needs look like when we do put disability and ageing ‘on the same page’? Fortunately, the ABS Survey of Disability Ageing and Carers does use the ICF framework (or its predecessor) and hence similar concepts for needs of people of all ages (avoiding, for instance, the somewhat ‘loaded’ aged care ‘dependency’ concept). One of our study questions was: can we usefully distinguish between disability and aged care clients, with respect to their need for services and assistance? We found, with the available data at least, that needs could not be predicted from any other variable – age, disability group, or age at onset of the disability.
We also considered the question: at what ages are what types and levels of assistance needed? In Figure 3 we see a broad comparison between the under-65 and over-65 age group. There were twice as many people aged under 65 needing assistance with self care, mobility or communication, as over 65, and a sizeable proportion of both age groups actually need assistance with all three of the basic activities (9% of those aged under 65 and 5% of those aged over 65).

![Figure 3: People with a severe or profound core activity restriction: proportion needing assistance for core activities by age, Australia 1998](source)

These types of analysis — synthesising information about ageing, disability and support needs — are important in the context of the possibility that disability and aged care services will increasingly be looked at ‘on the same page’.

The ICF holds out a common framework in which these analyses can be combined, especially as the rhetoric on ‘healthy ageing’ moves closer to the social model of disability reflected in the ICF.

**Data and what all this has to do with people’s lives**

For all these reasons — the possibility of more holistic analyses and the ‘joining up’ of policy areas rather than ‘stovepiping’ — the AIHW is encouraging the use of the ICF as a framework for data development and collection in a wide range of human services.

The more governments wish to develop ‘whole of government policies’ in the areas of functioning and disability — across all ages groups and spanning services such as disability support, aged care and health — the more it is that holistic frameworks such as the ICF are needed, to underpin information system development.
The ICF provides:

- a conceptual framework: how disability conceptualised, and ways of talking about it across various boundaries;
- a set of classifications: how to record information systematically so as to be able to describe people’s experiences and access to services.

The ICF can make an important contribution to the relevance, quality and consistency of disability data.

If we want ‘joined up’ policy we need ‘joined up’ data—and joining data up with a sound disability perspective is a pre-requisite to informed disability policies.

References


AIHW 2002b. Unmet need for disability services: effectiveness of funding and remaining shortfall. Cat. no. DIS 26. Canberra: AIHW.
