

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.