

## 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).<sup>1</sup> 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 NMDS<sup>2</sup> 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.

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<sup>1</sup> 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.

<sup>2</sup> 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.<sup>3</sup> 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
- a discussion of each option in relation to its relevance, quality, reliability 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

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<sup>3</sup> 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.

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 possible<sup>4</sup>;
- 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.

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.

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<sup>4</sup> 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).

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
<b>a) Self-care</b> , e.g. washing oneself, dressing, eating, toileting					
<b>b) Mobility</b> , 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					
<b>c) Communication</b> , e.g. making self understood, in own native language or preferred method of communication if applicable, and understanding others					
<b>d) Interpersonal interactions and relationships</b> , 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					
<b>In the following questions 'not applicable' is a valid response only if the person is 0–4 years old.</b>					
<b>e) Learning, applying knowledge and general tasks and demands</b> , e.g. understanding new ideas, remembering, problem solving, decision making, paying attention, undertaking single or multiple tasks, carrying out daily routine					
<b>f) Education</b> , e.g. the actions, behaviours and tasks an individual performs at school, college, or any educational setting					
<b>g) Community (civic) and economic life</b> , e.g. recreation and leisure, religion and spirituality, human rights, political life and citizenship, economic life such as handling money					
<b>In the following questions 'not applicable' is a valid response only if the person is 0–14 years old.</b>					
<b>h) Domestic life</b> , e.g. organising meals, cleaning, disposing of garbage, housekeeping, shopping, cooking, home maintenance					
<b>i) Working</b> , 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"> <li>1. Full participation</li> <li>2. Mild participation restriction</li> <li>3. Moderate participation restriction</li> <li>4. Severe participation restriction</li> <li>5. Complete participation restriction</li> </ol>	<ol style="list-style-type: none"> <li>1. High satisfaction with participation</li> <li>2. Moderate satisfaction with participation</li> <li>3. Moderate dissatisfaction with participation</li> <li>4. Extreme dissatisfaction with participation</li> <li>5. No participation</li> <li>6. No participation and none desired</li> </ol>
<p><b>Participation in communication and conversation</b> (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><b>Participation in mobility within the home and community environment</b> (e.g. changing and maintaining body position; carrying, moving and handling objects; walking and moving; moving around using transportation)</p>		
<p><b>Participation in domestic life</b> (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><b>Participation in interpersonal interactions and relationships</b> (e.g. relating with strangers, formal and informal social relationships, family and intimate relationships)</p>		
<p><b>Participation in education, work and employment</b> (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><b>Participation in economic life</b> (e.g. basic and complex economic transactions, economic self-sufficiency)</p>		
<p><b>Participation in community, social and civic life</b> (e.g. community life, religion and spirituality, recreation and leisure, political life and citizenship, human rights)</p>		

Source: CSTDA NMDs Network Guide, 2002

