

Data standards, data dictionaries, and the ICF

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Outline of presentation

- Importance of information standards
- How health and community services information standards are achieved and maintained in Australia
- Data standards in the disability field in Australia
- Standard set of disability data items based on the ICF

Potential uses of the ICF

- Wide range of applications in the health and community services fields, such as:
 - In health information systems, e.g. national data on rehabilitation services
 - Summary measures of functional status (e.g. as a way of including data on functioning in electronic health records)
 - Measuring client outcomes in relation to a service provided (e.g. better participation)

Why have national information standards?

- Agreed standards allow data from diverse sources to inform:
 - Policy: What should be done?
 - Planning: How and where?
 - Provision: What happened?
 - Performance: Did it work?

Achieving agreed national information standards

- Co-operative effort is required to reach agreement on information standards
- Australia's National Community Services Information Development Plan provides:
 - A national approach to information development
 - Agreed strategies and priorities for developing information standards

Infrastructure for achieving national data standards

- An agreed process for endorsing data items: National Community Services Data Committee
- An authoritative repository of data items: National Community Services Data Dictionary
- A standard way of defining data items: data item template (based on ISO standard)

National Data Dictionaries

- Two main Australian data dictionaries:
 - National Community Services Data Dictionary
 - The National Health Data Dictionary
- Authoritative repository for endorsed data definitions and coding classifications
- Common understanding of the meaning of data
- Designed to improve data comparability and reduce duplication of effort in data development

The ISO-based template for data items in the dictionary

- Definition: *What is it you want to know about?*
- Context: *Who wants to know it and why?*
- Data domain: *What is the range of possible answers?*
- Guide for use: *Which answer should I choose?*
- Collection methods: *How and when should this information be obtained?*
- Related data: *What other information is connected and in what way?*

The AIHW Knowledgebase

- Electronic repository of data standards
- Covers community services, health and housing assistance
- Being redeveloped now
- Access to the Dictionary and the Model

www.aihw.gov.au

Data standards in the disability services field

- Advisory Committee on Australian and International Disability Data (ACAIDD)
 - Aim: to improve quality and consistency of data
 - Work plan has included advising on ICF development and testing, and now implementation
 - Membership: governments, non-government service providers, service users, Indigenous and overseas-born representatives, independent experts
- National Disability Administrators

Nationally agreed disability data items (1)

A set of 15 nationally agreed disability data items:

- operationalise ICF concepts and classifications
- are for use in a broad range of data collection applications
- are an important basis for achieving data consistency
- a key component of ICF implementation in Australia

Nationally agreed disability data items (2)

- The disability data items
 - were developed with input from ACAIDD
 - are in the National Community Services Data Dictionary
 - are being recommended for inclusion in the National Health Data Dictionary

<p>Data element concepts:</p> <ul style="list-style-type: none"> • Disability • Functioning • Activity • Participation • Assistance with activities and participation 	<p>Data elements:</p> <ul style="list-style-type: none"> • Body functions • Body structures • Impairment extent • Activities and participation domains • Activity – level of difficulty • Participation extent • Participation – satisfaction level • Environmental factors • Environmental factors – extent of influence • Disability grouping
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<p>Disability (data element concept)</p>	
<p>Definition:</p>	<p>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. Disability is a multi-dimensional and complex concept and is conceived as a dynamic interaction between health conditions and environmental and personal factors.</p>
<p>Collection methods:</p>	<p>The concept 'Disability' can be described using a combination of related data elements as building blocks.</p> <p>The data elements selected may vary depending on the definition of disability used. For example in hospital rehabilitation the focus may be on the impairment and activity dimensions and in community-based care the focus may be participation primarily.</p>

<p>Activity—level of difficulty (data element)</p>	
<p>Definition:</p>	<p>The level of difficulty that an individual has in executing an activity.</p>
<p>Context:</p>	<p>Activity limitation varies with the environment and is assessed in relation to a particular environment; the absence or presence of assistance, including aids and equipment, is an aspect of the environment.</p>
<p>Data domain:</p>	<p>0 No difficulty 1 Mild difficulty 2 Moderate difficulty 3 Severe difficulty 4 Complete difficulty 9 Not stated/inadequately described</p>
<p>Guide for use:</p>	<p>The area in which an individual experiences an activity limitation is indicated in the data element 'Activities and Participation domains'. The presence of an activity limitation with a given activity is indicated by a non-zero response in this data domain</p>

Support needs data item in disability services collection

- 'How often does the consumer need personal help or supervision with activities or participation in the following life areas?'
- Life areas consistent with 'Activity and Participation domains' data item

Medical indemnity national data collection

- The primary body structure or function of the person alleged to have been affected as a result of the incident
 - Uses ICF body function and structure domains, combined into single code list; maps to body functions and body structures data items in NCSDD
- Extent of 'harm'
 - 'temporary', 'minor' and 'major'; maps to 'impairment extent' data item in NCSDD

In summary ...

- The nationally agreed disability data items represent an important step towards improving data consistency and encouraging the use of the ICF in Australia
- Next step: promote the use of the data items in a broad range of data collection activities – within the disability field, and more broadly