

Operationalisation of the ICF in population surveys

Ken Black

Operationalisation of the ICF concept and definitions of disability in population surveys

As stated by the WHO, the ICF provides a unified and standard language and framework for the description of health and health-related states that permits comparison of data within and across countries, health care disciplines, services and time.

But how do you use the concepts and definitions of disability in the ICF in statistical collections to produce statistics on disability?

Issues to consider:

- f* purpose/data needs
- f* domain selection and item reduction
- f* questionnaire development and testing
- f* collection design

Overview of this session

- Determining user needs for disability data
- Question types relating to the ICF and how to choose approach
- ABS population measures of disability
 - f* Survey
 - f* Module
 - f* Census
- Mapping of ABS survey, module and census items to the ICF components and domains

Consultation on information needs

- It is important to develop surveys in conjunction with key users of the statistics and people with disabilities
- ABS does this by convening Advisory Groups, to advise the ABS on information need
 - f* Identify and document broad issues, as well as fine level details
 - f* Identify and document the key policy issues that will be informed by the survey data
 - f* Where there are competing needs for information, sometimes need to compromise to ensure achievement of the highest priority information needs
- Invite broad representation of key clients including:
 - f* Govt (all levels)
 - f* Peak bodies and advocacy groups
 - f* People with disabilities
 - f* Academics and researchers

Purposes for disability statistics

- Washington Group has researched the range of purposes for disability data. Some of the most important of these include:

- f* understanding nature and extent of disability

- f* planning of services

- f* advocacy

- f* equalisation of opportunity

- The key purpose(s) of the data help determine the overall approach and the domains to include in any disability data collection

Operationalising the concept and definition of disability in statistical collections

Need to:

- Understand the international classification - ICF
- Understand the parameters set by the collection methodology
- Be guided by international guidelines and recommendations on collecting disability data
- Identify broad survey approach designed to meet key user needs:

- f* Which components to cover?

- f* Which domains/life areas are of interest?

- f* Impairment and/or Activity limitation/Participation restriction approach?

Overview of ICF components

- In the context of health:

- f* **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 or structure such as a 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

Question type examples

1. Impairment (in body functions or structures)

Does the person have any long-term impairments, disabilities or handicaps?

- Incomplete use of legs, feet
- Incomplete use of arms, fingers
- Partial or total loss of sight
-

 **Question type examples (continued)**

2. Activity limitation


Is this person limited in his/her daily activities (at home, at work, at school) because of a long-term physical or mental condition (lasting six months or more)?

- Seeing (even with glasses, if worn)
- Hearing (even with hearing aid if used)
- Communicating (talking, conveying information, listening)
-

3. Participation restriction

Because of the condition you have told me about, do you have any difficulties with employment such as these?

- Restricted in type of work can do
- Restricted in the number of hours can work
-

 **Question type examples (continued)**

4. Environmental factors

Use of aids/equipment


Do you use any of these aids to help you move around?

- Canes
- Crutches
- Walking frames
- Wheelchair (manual)
-


Receipt of assistance

Do you receive assistance from any of these sources?

- Nurse
- Home care worker
-

 **How to choose?**

- Depends upon:
 - f* Purpose
 - f* Method of collection of information
- Be guided by international guidelines
- Examples from ABS experience
 - f* General disability population is very broad and covers all the domains of Body functions and Body structures and all life areas in Activities and Participation components
 - f* "Severe/profound" disability population is based on need for assistance with core activities of mobility, self-care and communication

 **ABS measures of disability**

1. Disability survey

The main source of population measures of disability in the Australian population is the Survey of Disability, Ageing and Carers (SDAC):

- First run in 1981, and then 1988, 1993 and 1998
- Last conducted in 2003, and then 6 yearly
- 45 minute interview on average
- Computer assisted interviews
- Interviewer enumerated, personal interview survey
- Sample covers both households and cared accommodation
- Originally based on the ICIDH, now the ICF



ABS measures of disability (continued)

2. Disability module

- The ABS also uses a disability module to identify the disability population in a range of other social surveys, such as education and household expenditure surveys. Included in the ABS General Social Survey 2002.

3. Census module

- Disability questions were included in the 1976 census, but deemed not of sufficient quality to repeat. Development and testing for the 1996 and 2001 surveys failed to produce quality census disability questions
- A new approach is being tested for possible inclusion in the 2006 Census



ABS approach to measurement of disability

- The survey and module question sets identify the disability population using a set of screening questions based on a broad range of impairments to body function and structure and some activity limitations or participation restrictions. Also covers need for assistance with selected activities.
- The census questions focus on need for assistance with selected activities
- The range of items able to be included in the screen questions differs between the three question sets because of the operational constraints on the three types of collection involved



Comparison of the methods

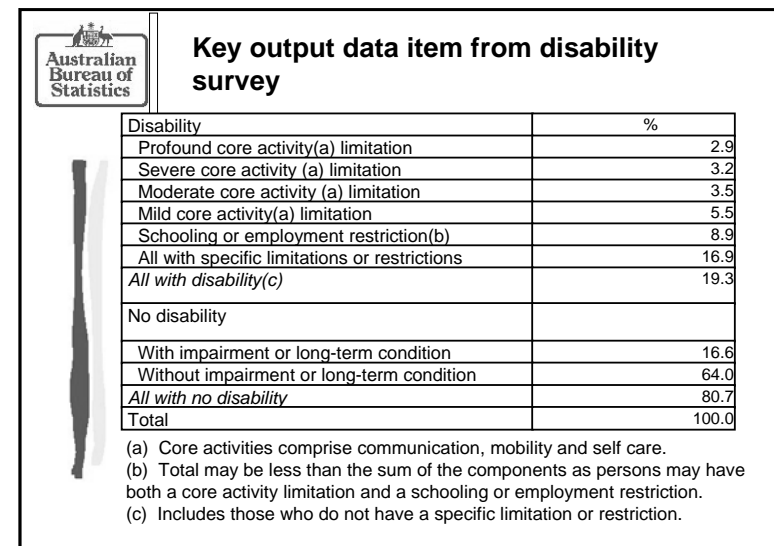
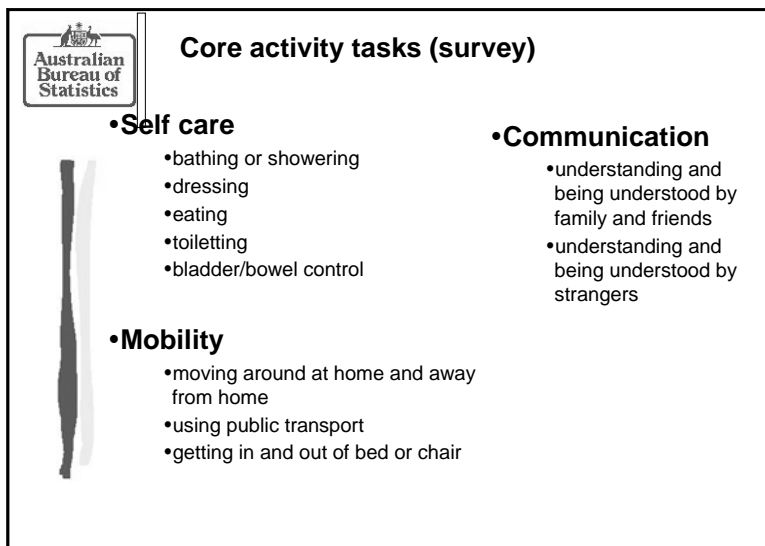
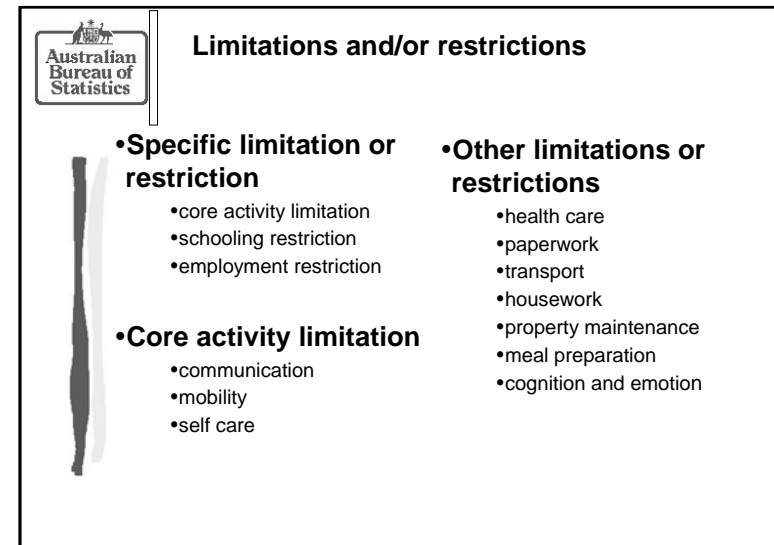
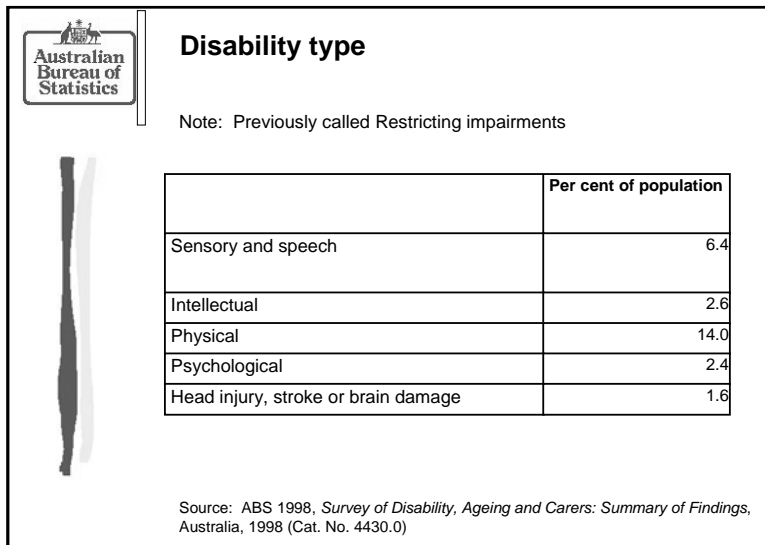
Disability Survey

- Screen using impairment of body function, some activity limitations and participation restrictions, and environmental factors
- Separate responses obtained for each impairment/activity limitation/participation restriction/environmental factor
- Identifies underlying cause in terms of ICD for each impairment/activity/environment area questioned
- Includes a range of activity limitation/participation restriction and environmental factors
- Need for assistance, difficulty with activities and use of aids is used to derive levels of severity of restriction
- Specific limitations/restrictions covered are mobility, self-care, communication, and employment and school restrictions



Survey disability screening items

- loss of sight
- loss of hearing
- speech difficulties
- breathing difficulties
- chronic pain
- blackouts, fits
- difficulty learning or understanding
- incomplete use of arms or fingers
- difficulty gripping
- incomplete use of feet or legs
- nervous or emotional condition
- restricted in physical activities/work
- disfigurement/deformity
- mental illness, need for assistance
- head injury, stroke, other brain damage
- other long-term conditions



Comparison of the methods (continued)

Disability module

- f* similar screen to the disability survey, but compressed onto prompt cards
- f* no underlying conditions collected
- f* obtains activity limitation and need for assistance in the areas of self-care, mobility, communication and restricted participation in education and employment only

Output data item

- f* similar to full survey output data item
- f* item called "disability and/or long-term health condition" as it includes a broader disability population to that identified in the survey

Disability module analysis

Results from a disability module used in three other surveys have been compared with each other and with the disability survey. Conclusions are:

- Module results cannot be used to update prevalence
 - f* Disability population broader than in disability surveys,
 - filters less effective, more people with long-term health conditions captured
 - f* Smaller population with more severe disability
 - triggers less effective
- Useful for looking at the impact of levels of disability on other life experiences
 - f* Shows clear distinction between no disability, broad disability and severe/profound limitation population groups
 - f* Reasonably good comparability between the disability survey and different surveys using the module

Inclusion of a topic in the Australian census

• All topics must:

- f* be of major national importance and relevant to users
- f* have a demonstrated need for data for small geographic areas or small population groups
- f* be suitable for collection via census methodology

- The disability topic meets the first two criterion, but there is some question about the ability of the census to deliver quality disability estimates

Census module (2001 approach)

- f* two questions
- f* first asking whether have "difficulty" with seven listed activities
- f* second asking cause of difficulty, with long-term health condition, disability and old age comprising the disability population

Census module (2006 approach)

- f* two questions
- f* first asking whether "needs assistance" with any of three listed activities: self-care, mobility, and communication
- f* second asking cause of difficulty, with responses of 'long-term health condition', 'disability' and 'old age' comprising the 'core activity limitation' population
- f* Possibly also include restriction/limitation at work or school, home, or social and community life

Australian Bureau of Statistics

Census question under development (a)

5 Does the person ever need someone to help with, or be with them for, any of the following activities:

	Yes, always	Yes, sometimes	No	Yes, always	Yes, sometimes	No
a self care: e.g. doing everyday activities such as eating, showering, dressing or toileting?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b body movement: e.g. getting out of bed, moving around at home, or at places away from home?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c communication: e.g. understanding, or being understood by, others?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6 What are the reasons for the need for assistance or supervision shown in question 5?

• MARK ALL APPLICABLE REASONS.

<input type="checkbox"/> Short-term health condition (lasting less than six months)	<input type="checkbox"/> Short-term health condition (lasting less than six months)
<input type="checkbox"/> Long-term health condition (lasting six months or more)	<input type="checkbox"/> Long-term health condition (lasting six months or more)
<input type="checkbox"/> Disability (lasting six months or more)	<input type="checkbox"/> Disability (lasting six months or more)
<input type="checkbox"/> Old or young age	<input type="checkbox"/> Old or young age
<input type="checkbox"/> Difficulty with English language	<input type="checkbox"/> Difficulty with English language
<input type="checkbox"/> Other cause	<input type="checkbox"/> Other cause
<input type="checkbox"/> No need for help or supervision	<input type="checkbox"/> No need for help or supervision

Australian Bureau of Statistics

Census question under development (b)

7 Does a physical or mental condition or health problem (lasting six months or more) reduce the amount or the kind of activity this person can do:

	Yes, always	Yes, sometimes	No	Yes, always	Yes, sometimes	No
a at work or at school?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b at home?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c in social and community life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Australian Bureau of Statistics

Mapping the ABS disability survey and module to the ICF

- The ABS and the AIHW have jointly mapped a number of disability surveys/questions to the ICF
- The mapping is useful to identify dimensions and domains covered in screening questions in the survey
- However, it is a summary measure only, and does not give the full picture of the approach to the measurement of disability
- Some domains and dimensions are covered in much greater details than others.

Mapping Survey Module and Census to ICF Body Function and Structures

Y - included in some way
Y, indirect - obtained from condition coding
N - not included

Body Function	Survey	Module	Census	Body Structures	Survey	Module	Census
1 Mental Functions	y	y	n	1 Structures of the nervous system	y	y	n
2 Sensory functions and pain	y	y	n	2 The eye, ear and related structures	y, indirect	n	n
3 Voice and speech functions	y	y	n	3 Structures involved in voice and speech	y, indirect	n	n
4 Functions of the cardiovascular, haematological, immunological and respiratory systems	y	y	n	4 Structures of the cardiovascular, immunological and respiratory systems	y, indirect	n	n
5 Functions of the digestive, metabolic and endocrine systems	y	n	n	5 Structures related to the digestive, metabolic and endocrine systems	y, indirect	n	n
6 Genitourinary and reproductive functions	with above	n	n	6 Structures related to the genitourinary and reproductive systems	y, indirect	n	n
7 Neuromusculoskeletal and movement-related functions	y	y	n	7 Structures related to movement	y, indirect	n	n
8 Functions of the skin and related structures	indirect	n	n	8 Skin and related structures	y, indirect	n	n

Mapping Survey Module and Census to ICF
Activities and Participation and Environmental Factors

Activities and Participation	Survey	Module	Census	Environmental Factors	Survey	Module	Census
1 Learning and applying knowledge	y	y	n	1 Products and technology	y	y	n
2 General tasks and demands	y	y	n	2 Natural environment and human-made changes to environment	n	n	n
3 Communication	y	y	y	3 Support and relationships	y	y	y
4 Mobility	y	y	y	4 Attitudes	n	n	n
5 Self-care	y	y	y	5 Services, systems and policies	y	n	n
6 Domestic life	y	n	n				
7 Interpersonal interactions	y	n	n				
8 Major life areas	y	n	y				
9 Community, social and civic life	y	n	y				

		Part 1: Functioning and Disability		Part 2: Contextual Factors	
		Body Functions and Structures	Activities and Participation	Environmental Factors	Personal Factors
Components					
Domains	Body functions Body structures	Life areas (tasks, actions)	External influences on functioning and disability	Internal influences on functioning and disability	
Constructs	Change in body functions (physiological) Change in body structures (anatomical)	Capacity Executing tasks in a standard environment Performance Executing tasks in the current environment	Facilitating or hindering impact of features of the physical, social and attitudinal world	Impact of attributes of the person	
Positive aspect	Functional and structural integrity	Functioning Participation	Facilitators	not applicable	
Negative aspect	Impairment Disability	Activity limitation Participation restriction	Barriers/ hindrances	not applicable	