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Session 1 – Invited paper

ICF[1] IN THE AUSTRALIAN CONTEXT

Submitted by Australian Bureau of Statistics[*]

[1] International classification of functioning, disability and health.

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1. Health and disability statistics in Australia

1. In Australia, the landscape for development, collection and analysis of information on health and disability reaches across a number of government agencies, including the Australian Bureau of Statistics (ABS), the Australian Institute of Health and Welfare (AIHW), Australian government policy departments at national and state and territory levels, and the research community.

2. The development of information to inform policy in health and disability is governed by an established structure of information committees in the separate Health and Community Services sectors, ultimately reporting to relevant Ministers.

3. As the national statistical agency, the ABS plays a significant role in the collection of national statistics in these fields, through an established program of social surveys. As well, the ABS collates, codes and publishes the national vital statistics data, including the births and deaths collections.

4. The AIHW coordinates the compilation of national minimum datasets largely drawing on administrative data collected in the States and Territories. These are agreed through the health and community services governance arrangements. As well as this, the AIHW is involved in the collection of some statistical information through surveys, and manages the metadata repositories for the health and community services fields. The AIHW is the Australian collaborating centre for the WHO Family of Classifications, and promotes the use of these classifications in the Australian setting.

5. The ABS and the AIHW, as well as other parties, work collaboratively to develop and implement various measures of health and disability. This includes measures of health status from surveys covering disease, functioning, disability and risk factors. The ABS program of household surveys includes three yearly National Health Surveys; six yearly Surveys of Disability, Ageing and Carers; and regular surveys covering a number of other areas of social concern, such as Education and Training; Income and Housing; and Household Expenditure.

2. ICF concepts

6. Published by the World Health Organisation in 2001, and representing the outcome from significant international collaborative effort, the ICF is a framework which can be used to conceptualise health status and disability.

7. The aims of the ICF are stated as being to:

- provide a scientific basis for understanding and studying health and health-related states, outcomes and determinants;
- establish a common language for describing health and health-related states in order to improve communication between different users, such as health care workers, researchers, policy-makers and the public, including people with disabilities;
- permit comparison of data across countries, health care disciplines, services and time;
- provide a systematic coding scheme for health information systems.

8. The model presented in the ICF is multi-purpose and multi-dimensional and was developed to serve a number of different broad purposes. The components of the highest levels of the ICF are described below.

Table 1: Overview of ICF components

1. FUNCTIONING & DISABILITY	
Body Functions and Structures	Includes two classifications: 1. Body functions (physiological) e.g. seeing functions 2. Body structures (anatomical parts of the body) Intended to be used along with the Activities and Participation components.
Activities and Participation	Aspects of functioning from both an individual and a societal perspective, covering a full range of life areas. Includes key qualifiers of *performance* and *capacity*.
2. CONTEXTUAL FACTORS	
Environmental Factors	Impacts on all components of functioning and disability.
Personal Factors	Includes gender, race, age, fitness, lifestyle, habits, coping styles. (Not classified in current version of ICF due to the large social and cultural variance associated with them.)

9. Within each of these broad areas the ICF provides a more detailed classification. Theoretically, each of the components of health described within the ICF, at the broad and detailed levels, would be needed for a complete description of a person's health state and its context. In practice it this isn't achievable, as the level of detail covered by the ICF is far more than can be covered in household surveys (or administrative processes), due to issues of respondent burden.

10. Two constructs can be used to qualify the Activities and Participation domains to qualify the classification – 'performance' and 'capacity'. These constructs indicate the effects of the environment in which measurement is taking place.

11. According to the ICF (WHO 2001):

performance…describes what an individual does in his or her current environment, and
capacity…describes an individual's ability to execute a task or an action…(and) aims to indicate the highest probable level of functioning that a person may reach in a given domain at a given moment. To assess the full ability of the individual, one needs a 'standardised' environment to neutralise the varying impact of different environments in the ability of the individual. This 'standardised' environment may be (a) an actual environment commonly used for capacity assessment in test settings; or (b) in cases where this is not possible, an assumed environment which can be thought to have a uniform impact.

12. The ICF also states that '..The gap between capacity and performance reflects the difference between the impacts of current and uniform environments, and thus provides a useful guide as to what can be done to the environment of the individual to improve performance'.

13. The extent to which 'capacity' can be adequately measured using survey methodology is an important issue to address. Capacity is defined as the 'highest

probable level of functioning that a person may reach in a given domain at a given moment' in a 'standardized' environment. The concept of capacity is a hypothetical construct which is difficult to measure using survey methodology. It could only be measured in terms of a theoretical environment by trained medical assessors, although for international purposes, even standardised environments will vary across countries. Many surveys do not include capacity because of these measurement issues. However many surveys do ask about current environment which then provides the context for the level of function (AIHW 2005).

3. Measurement of functioning in Australia

14. Australia has made significant efforts to align its disability surveys as far as possible with the ICF. Its program of surveys on this topic include a five yearly survey, the Survey of Disability, Ageing and Carers (SDAC) that collects detailed information that maps to many of the key broad and detailed areas of the ICF. So that aspects of disability can be measured in surveys spanning other areas of social concern, the ABS has also developed a shorter module which measures a subset of the SDAC. As well, from the 2006 census questions will be included in the population census on the concept of 'need for assistance' which will enable more detailed geographic analysis of the social and demographic characteristics of the disability population most like to need direct services. This approach has enabled the ABS to collect a substantial amount of information about people with disabilities while managing respondent burden. Each of the three approaches is described in detail below.

3.1 Surveys focusing on disability

15. Since the 1980s the ABS has run a series of national surveys on disability, in addition to its regular program of national health surveys.

1981 **Handicapped** Persons Survey
1988 Survey of **Disabled** and **Aged Persons**
1993 Survey of **Disability, Ageing** and Carers
1998 Survey of Disability, Ageing and Carers
2003 Survey of Disability, Ageing and Carers

16. The survey is now included in the ABS household survey program every six years. It is a detailed and complex survey aimed at exploring the topic of disability closely, and across most of the ICF domains. The survey also collects information on older persons and carers.

17. As well as taking account of national policy directions for provision of services to people with disabilities, the ABS has been guided by international classifications and frameworks current at the time of development of these surveys. So, the International Classification of Impairment and Disability and Handicap (ICIDH) was used as the conceptual framework for the 1981 survey, and new developments from the revision of the ICIDH (later to become the ICF) were incorporated into the 1998 disability survey. The 2003 survey was developed to enable comparison with the 1998 survey as far as possible. Its alignment with the ICF was improved with some changes in terminology used. For example, in the 1998

survey the term 'handicap' was replaced by 'specific restrictions' and in the 2003 survey the term 'activity restriction' was replaced by 'activity limitation' in order to be in line with the ICF terminology. Largely though, the basic survey operational definitions and measurements remain the same, as the survey already used concepts such as 'difficulty' and 'assistance' used in the ICF.

18. The SDAC survey uses screening questions to determine the population of interest. These cover specific impairments corresponding mainly to the various domains of 'body function' and 'body structure' components of the ICF, but also emphasising related effects on daily life. The last item of the screening questions about 'any other long-term condition that restricts everyday activities' allows the survey to collect information that may relate to most ICF body function and structure domains, which are not covered by other items of the screening questions.

19. For those who are selected into the survey through the screening, the SDAC survey questions then cover most domains of the ICF components of 'activity and participation', and ,with less completeness, the domains relating 'environmental factors' and 'personal factors' (Table 2).

20. The Activity areas used in the SDAC were based on advice from the User Advisory Groups set up for the development of the earlier disability surveys (primarily for the 1981 and 1988 surveys, and confirmed to continue by later advisory groups). Domains such as meal preparation, home maintenance, health care etc are included in the SDAC because they were seen as areas that were often triggers to people needing extra assistance to be able to stay in their own home as opposed to having to move to cared accommodation.

21. The SDAC survey questions relating to the domains of the Activity and Participation component of ICF focus on performance (what a person actually does in their everyday situation) and not capacity (what a person could do in a standard environment). For each activity or participation domain, specific survey questions are used to identify difficulties, assistance needed/received as well as use of aids and equipment.

Table 2: Australian disability survey data items and ICF components

Body functions and structures	**Activities and participation**
Survey screening questions on impairment, limitation or restriction	Specific 'restrictions': core activities (self-care, mobility and communication), schooling and employment.
Main condition causing each of the above impairment, limitation or restriction listed in the screening questions	Other activities: health care, paperwork, transport, housework, property maintenance, meal preparation and cognition and emotion.
All long-term conditions	Severity of core activity limitation
Main disabling condition	Need for assistance with daily activities
Cause of main disabling condition	Schooling
Age when main condition/accident happened	Employment
Whether main condition is expected to change over the next two years	Social/community participation
SF-12 self assessment of health status	Culture/leisure participation

Environmental factors	**Personal Factors**
Index of relative socio-economic disadvantage (SEIFA)	Demographic characteristics (age, sex, marital status)
States and Territories	Country of birth
Capital city or rest of the State	Education
Households or cared accommodation	Labour force status
Availability of public transport	Occupation (industry, sector)
Living arrangement	Weekly cash income
Home modifications	Principle source of cash income
Type of class/school (e.g. special class or special school)	Housing tenure status
Informal carer and assistance	
Main providers of assistance	
Access to formal services	
Access to aids and equipment	
Access to government benefits	
Where the accident happened	

22. Overall one in five people report a disability - a condition which results in a core activity limitation or other restriction, where disability severity is measured through core limitations in the areas of communication, mobility and self-care. A further one in five report a long-term health condition which is not considered a disability. Table three below provides further detail of the size of these populations as measured in the 2003 survey.

Table 3: Disability prevalence from the 2003 Survey of Disability, Ageing and Carers

Disability	
Profound core activity[(a)] limitation	3%
Severe core activity[(a)] limitation	3.3%
Moderate core activity[(a)] limitation	3.5%
Mild core activity[(a)] limitation	5.3%
Total with core activity[(a)] limitation	15.2%
Schooling or employment restriction only	1.9%
All with specific restrictions	17.1%
Without specific restrictions	2.9%
All with disability	20%
No disability	
With long-term health condition	20.9%
Without long-term health condition	59.1%
All with no disability	80%
Total	100%
[(a)] Core activities comprise communication, mobility and self care	

3.2 Short Disability module

23. The SDAC uses up to 75 questions to establish both disability and severity of core activity limitation, and the average household interview time was 44 minutes (the longest was about 5 hours). A less time consuming approach was needed to be able to

include a measure of disability in other household surveys, such as the 1997 Survey of Education and Training, and the 2002 General Social Survey. A 'disability module' was developed for this purpose.

24. The module is based on the SDAC questions, but shortened by using a prompt card approach to the screening question set, rather than asking each screen as a separate question (and not obtaining details about the underlying medical). This module approach also uses a prompt card to determine severity of disability in relation to self-care, mobility, communication, and 'restricted participation in school, non-school education and employment'. The module contains ten questions and five prompt cards. It can be included in a range of personal interview vehicles and takes on average less than two minutes in interview time. Although the number of areas covered in the survey module is limited when compared to the SDAC, coverage within the areas included is similar between the module and the longer survey.

25. The areas of ICF covered by the module are similar to the full SDAC survey for 'body function'. For the activity and participation domains, the module focus is on 'self-care', 'mobility' and 'communication', all considered to be 'activities of daily living. The module also includes questions relating to participation in the major life areas of education and work, and questions about the use of technical aids and equipment which relates to the 'products and technology' domain of the environment component. Questions relating to the domain of 'support and relationships' are included in the context of identifying the existence of a need for assistance from people and/or formal services. Unlike the full survey, the extent to which the need for assistance is met, if met at all, is not assessed.

26. Extensive ABS testing has shown that disability is a difficult and complex concept to measure, particularly in a short question set, and there are quality limitations with any measurement tool. The ABS Disability module is no exception, with the disability population identified via the module being larger than that which would be obtained from the same sample using the full SDAC question set. This is an effect of combining the survey's individual screening questions and the 'restricted in everyday activities' question qualifier into a single prompt card. Not all respondents read and/or retain the restriction qualifier concept. Despite this difference, the survey and module populations reveal similar patterns of corresponding disability prevalence across population subgroups by age, sex, country of birth and other variables. There is a high level of confidence in the module data for examining characteristics of the population of 'people with a disability' within particular surveys. However, the ABS cautions against using the module data for measuring change over time in between the five yearly SDAC prevalence estimates.

27. The ABS is currently reviewing its program of National Health Surveys which have been run every six years since 1989/90, and are now run every three years. This survey has focussed on measuring health conditions (coded to ICD), risk factors, and health related actions (such as service use, and days out of role). As part of the current review, inclusion of the disability module is being considered, as a way to measure the impact of reported conditions on functioning.

3.3 Census 'need for assistance' question

28. The Census of Population and Housing will, for the first time in 2006, include disability-related questions on need for assistance with activities corresponding to three domains of the ICF activity component (self-care, mobility and communication). This module was developed to address demand for disability data at fine geographic below states and territories, which are not available from surveys because of high relative standard errors associated with small estimates.

29. In ICF terms the identification of the 'core activity – need for assistance' population covers only the Environmental Factors Chapter 3 'support and relationships' in terms of 'need for provision of assistance from others'. This is qualified by the need for assistance being in the ICF activity areas of self-care, mobility and/or communication only, and further by this need being due to 'disability' in the broad sense rather than for other reasons (e.g. 'use of language other than English' as a reason for need for communication assistance).

30. The data collected in the census will complement small area data produced through statistical modelling which has been undertaken using SDAC, census data, and other data from administrative sources. These estimates have been limited in that they cannot take into account significant real local area differences such as the presence or absence of suitable services, climatic factors, or other variables which might influence the relative distribution of people with a disability. This is particularly the case for those people aged under 65 years, among whom disability prevalence rates are relatively low.

4. How the Survey of Disability, Ageing and Carers maps to ICF

31. The ABS and the AIHW have done some work to assess how the SDAC and the 'disability module' map to the ICF. Apendix 1 provides a summary.

32. The SDAC questions cover most of the ICF framework at the domain level in the areas of 'body function' and 'activity and participation'. However, it is less complete in the areas of 'body structure' and 'environmental factors'.

33. Some indirect coverage of the concept of 'body structure' can be obtained through the ICD10 codes from the initial screening questions, and identification of underlying conditions.

34. There are three areas below the domain level within the 'activity and participation component that are not covered by the SDAC. These are:

- within the 'domestic life domain': 'caring for household objects and assisting others' (d650-d669)
- 'particular interpersonal relationships' (d730-d779), although data items on: living arrangements, relationships to other household members and marital status do contribute to this area
- Within the 'community, social and civic life' domain (d910-d999): 'religion and spirituality', 'human rights' and 'political life and citizenship'.

35. For the 'environmental factors' component there is extensive coverage of the domains 'products and technology' and 'support and relationships'. However, two areas are not covered at all, namely 'natural environment and human-made changes to environment' and 'attitudes'.

36. Further work is needed to determine if the above gaps need to be address. This will involve assessing their relative importance for informing policy and/or other research needs. If seen by users as important in the future, then the most appropriate collection vehicle will need to be identified, and development and testing conducted. For the items under 'community, social and civic life',for example, it may be more appropriate to include a disability module within a future social capital survey to collect this type of information.

5. Issues with using ICF

37. The Australian experience of using the ICF as a framework for its disability surveys has highlighted a number of issues. These include:

- a need to measure relevant and appropriately scoped concepts, while managing respondent burden,
- determining approaches to interpreting measures from different surveys, when conceptually they don't map to the same components of the ICF, and
- understanding the differences in concepts being measured when they do map to the same domain or detailed level of the ICF.

38. When assessing the extent of coverage of the ICF by a particular collection vehicle such as the SDAC, care must be taken in interpreting (and in explaining) the results. For example, good coverage of a particular domain cannot be taken as implying coverage of all the second level classifications under the domain heading. This is an important factor when undertaking cross survey, or cross country, comparisons as even though a domain could be said to be covered, very different questions might have been asked. For example, the domain of mobility could be covered by questions asked to determine 'limitations in walking' (d450) in one survey and 'limitations in driving' (d475) in another. In this case both surveys could be said to include the ICF 'mobility' concept, yet direct comparison and interpretation would be problematic without an understanding of exactly what was asked. When using an ICF based approach for comparison within and/or across countries, agreement is needed on the relevant core set of items for which comparability is required.

39. As well as the issues described above, when comparing disability status across different population groups, information about the environmental context, although difficult to collect, can assist in understanding performance. Measures of capacity which don't take account of the environmental context may make it difficult to compare data across surveys or internationally. For example, two people in different parts of Australia may have similar health conditions (say paralysis of lower limbs), but their mobility may be different because of the quality of the roads or different circumstances in terms of access to a wheel chair or other support. Because of the potential for situations such as this, both the Australian Survey of Disability, Ageing and Carer's and the survey module that is used in other ABS household surveys,

include some measures of environment to contextualise the data collected about body functions and structures, and activities and participation.

40. The next SDAC is scheduled to be run in 2009, and the exercises to map the SDAC to ICF have highlighted issues relating to the disability population identified through the use of screening questions. In the SDAC, all people aged 60 years or more were sequenced to a set of face-to-face personal interview questions on the activity areas of: 'household chores', 'home maintenance/ gardening', 'meal preparation', 'reading and writing tasks' and 'transport' irrespective of their disability status as derived from the initial screening question responses. Whenever a difficulty or need for assistance was identified, subsequent questions identified the reason for the difficulty or need. Some of the response options to these questions (namely 'disability/ health condition' or 'old age' if chosen) indicated that these respondents had a disability in ICF terms, although not all had been screened into the broader questions on activities and participation.

41. Where existing survey question wording combines ICF categories or components, the ABS may consider separating the concepts in future survey design. For example, there may be a need to separate the concepts of treatment (services, systems and policies) and medication (products and technology), which are currently combined in a single screen question. Any such change will need to be considered in terms of the impact on comparison over time, and the importance of the particular measures to users.

6. Summary

42. Over time Australia has developed a program of surveys and question modules to measure disability and functioning. The surveys are part of a broader program of health related collections, which also measure health conditions, risk factors, and health related actions. The Survey of Disability Ageing and Carers supports analysis of change in prevalence levels, and along with the disability module used in other household surveys provides for an understanding of the differences in social conditions of people with disabilities. Australia has used the ICF as a framework for describing the aspects of disability and functioning being measured, and has used the ICF to guide the development of the surveys, as well as ensuring that the data are relevant to policy makers.

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ABS Disability survey and module - coverage of the ICF framework at Domain level **Appendix 1**

Body Function	Survey	Module	Body structure	Survey	Module	Activities and participation	Survey	Module	Environmental Factors	Survey	Module
Chapter/domain			Chapter/domain			Chapter/domain			Chapter/domain		
1 Mental Functions	y	y	1 Structures of the nervous system	y	y	1 Learning and applying knowledge	y	y	1 Products and technology	y	y
2 Sensory functions and pain	y	y	2 The eye, ear and related structures	n	n	2 General tasks and demands	y	y	2 Natural environment and human-made changes to environment	n	n
3 Voice and speech functions	y	y	3 Structures involved in voice and speech	n	n	3 Communication	y	y (with 4 & 5)	3 Support and relationships	y	n
4 Functions of the cardiovascular, haematological, immunilogical and resporatory systems	y	y	4 Structures of the cardiovascular, immunological and respiratory systems	n	n	4 Mobility	y	y (with 3 & 5)	4 Attitudes	n	n
5 Functions of the digestive, metabolic and endocrine systems	y	n	5 Structures related to the digestive, metabolic and endocrine systems	n	n	5 Self-care	y	y (with 3 & 4)	5 Services, systems and policies	y	n
6 Genitourinary and reproductive functions	with above	n	6 Structures related to the genitourinary and reproductive systems	n	n	6 Domestic life	y	n			
7 Neuromusculoskeletal and movement-related functions	y	y	7 Structures related to movement	n	n	7 Interpersonal interactions	y	n			
8 Functions of the skin and related structures	indirect	n	8 Skin and related structures	n	n	8 Major life areas	y	y			
						9 Community, social and civic life	y	n			

y=yes, n=no
