ABS approach to collecting disability data and relationship to the ICF

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1.   Introduction

This paper outlines the ABS approach to collecting disability data and presents results from mapping the dimensions and domains included in the surveys to the ICF.

There are three collection vehicles the ABS uses to collect disability data in Australia: The disability survey, disability module and the census. The main source is the Survey of Disability, Ageing and Carers (SDAC). The disability survey provides the official estimates of the prevalence of disability in the Australian population and estimates of severity of disability (for example, people with severe/profound core activity restrictions). The disability module was developed for use in some of the non-disability surveys to identify the disability population. The module can be used to examine other characteristics of the disability population, for example, when used in the Household Expenditure Survey, the expenditure of households including people with disabilities can be compared with households without people with disabilities to examine differences in expenditure patterns between the two populations. Lastly, the ABS has attempted to include disability questions in past censuses to obtain small area estimates of the disability population.   These three methods of collecting data about the disability population are described in more detail in the next sections.

2.   The disability survey

The SDAC, first enumerated by the ABS in Australia in 1981, was developed around the concepts and principles contained in the first draft of the 1980 WHO ICIDH. It has been run in 1981, 1988, 1993, 1998, and will be next run in 2003 with a 6 yearly rotation cycle. The survey includes people in both private and non-private dwellings, and in particular, includes people in cared accommodation.

Key initial decisions in the development of the survey were that detailed information would be obtained relating to the effects of disability on everyday living, covering both ADL's and IADL's. Wherever possible, this would be done using a personal face-to-face interview to ensure that responses reflected the person's own perspective - particularly important when assessing need for assistance and unmet need for assistance. It was also decided that only disability of six months or more duration, or likely to be of six months or more, would be considered.

To avoid undue respondent load, and to enable the survey to be conducted within reasonable time and cost restraints, initial contact at selected households was with the first responsible adult member contacted. General demographic details for all household members were

obtained from this first contact person. A set of screening questions were developed, tested and refined to identify the sup-population most appropriate to be sequenced to the very detailed questions relating to disability, with these screening questions also being asked of the first contact person. All household members recorded with a positive response to one or more of the screens were then personally interviewed. Note that average household interview time in 1998 was 47 minutes, with some households taking up to 5 hours.

The screening questions were largely impairment based (impairment of body function in ICF terms), with the exception of 'difficulty gripping or holding things' and 'whether is restricted in physical activities or in doing physical work' which bring in the ICF activity component and 'whether receiving treatment for any long-term condition' which brings in the ICF environment component.

The seventeen screening questions in the SDAC (thirteen in the 1981 survey) were designed to ensure that as far as practical all people with a disability would be identified and correctly sequenced to the more detailed, personal interview based, question set in the survey. Of particular importance in this regard was the inclusion of the broad activity and environment questions, the coverage of a broad range of impairments, and the use of a final screen question asking whether any household member has any other condition, lasting or likely to last for six months or more, not already mentioned - with a prompt card listing eight conditions which testing showed could be otherwise underreported. These were Alzheimer's disease, angina, arthritis, back problems, dementia, diabetes, hypertension, and nervous tension/stress. (Note in particular that for the final condition based screen, and for many of the impairment based screens, a second question was asked which determined whether the person was 'restricted in everyday activities' as a result, thus moving the end focus from 'impairment' to 'activity'. Only those people who were identified as restricted in the second component of these screens were defined as having a disability, effectively making these screens more ICF activity based.)

For each SDAC screening question, a positive response also elicited a question to identify the 'main causal condition', with the identified condition being coded to a collapsed version of the WHO ICD10.

Since release of data from the 1981 survey, the respondents with a positive response to one or more of the screening questions (keeping in mind the secondary 'restricted in everyday activities' component of many of the screens) have been identified as the population of 'people with a disability', with information from the detailed follow-on personal interview being used to establish severity. Responses to question sets on 'frequency of need for assistance', 'difficulty', and 'use of technical aids', in relation to the activity areas of 'self-care', 'mobility' and 'communication' were used to record, in ABS terms, 'core activity restriction'. Similar data were also obtained in relation to a range of other activity areas, as well as information relating to school education and/or employment restrictions.

3.   The disability module

There was an identified need from users for data on the 'disability population' in relation to information collected in other ABS surveys, but too complex/time consuming to be included in the SDAC. The SDAC uses up to 75 questions to establish both disability and severity of core activity restriction, and a less time consuming approach was needed to be able to include

'disability' as a component in non disability specific surveys. A disability module has been developed and tested by ABS, based on the SDAC, but shortened by using the same screening criteria in a prompt card approach, rather than asking each screen as a separate question (and not obtaining details about the underlying medical condition which is obtained in SDAC). It uses a prompt card approach to determine severity of disability in relation to self-care, mobility, communication, and restricted participation in school education and employment. A copy of the disability module questions, derivations and output items is provided as Attachment 1. Testing has shown this approach yields a population which is not identical to that which would be obtained from the full survey approach, but similar enough in its characteristics to be able to use the data for analysis alongside the SDAC data (but not for updating prevalence estimates).

4.   Disability census questions

For planning and policy purposes, one drawback of survey data has been the inability to obtain reliable data for small geographic areas and/or for small sup-populations e.g. the indigenous population in Australia. Data have been modelled for small geographic areas using data from both SDAC and the most recent census, however this process can not take into account local factors which may be significant e.g. presence or absence of particular services which might prompt the movement of people with a disability to or from a particular area.

The ABS has tested a number of questions for inclusion in the Australian census. A copy of the test version of the census questions, derivations and output items is also provided in Attachment 1. As the identified need was for data related to the SDAC, but at a finer geographic level, the components used to form the questions tested were related to the SDAC disability population, and the success of the questions was largely determined by relatability of the census disability population to that which would have been obtained from SDAC, both in terms of broad numbers and the characteristics of the populations. To date, none of the census questions tested have met this criteria satisfactorily, however there has not yet been a test/retest of the survey itself to determine if the variation identified between the Census and SDAC populations is as large as would at first appear.

Two possible steps for future census testing are to:
-- use the SDAC components used to identify levels of profound or severe restriction (based on need for personal assistance, i.e. ICF environment in relation to the activity areas of self-care, mobility and/or communication) as the initial census screen, rather than the broader impairments/restrictions approach. It is assumed that all, or nearly all, of the population of people with a profound or severe disability would have been identified in the SDAC screening questions, that is, that no significant numbers of 'new' people with a severe or profound disability would be identified from this approach that would not have been identified using the disability screen.
-- consider inclusion of a 'global indicator' arising from the development work of the Washington Group, in order to include a standard measure for international comparison. This would be highly desirable if the global indicator agreed by the group identified a population similar to the severe/profound severity of restriction population. Work would need to be undertaken to test the actual relationship between SDAC and the census population.

5. Mapping ABS disability data to the ICF

As an aid to understanding the relationship between the ABS survey, module and census question approaches to measuring disability, and to understanding how the question sets might relate to international measures, a mapping exercise has been undertaken by the ABS and AIHW to map the three ABS disability collection methods to the ICF . A key driver behind the initial mapping was the need to examine the WHO 'Health and Health System Responsiveness Survey' and 'WHODAS' in terms of their relationship to the Australian disability collection vehicles.

The results of the mapping exercise are presented as Attachment 2. For the module and the census, most of the information listed is used to define the disability population. For the survey however, the mapping identifies all of the elements included in the survey and their relationship to ICF dimensions and domains. Abbreviated summaries of the questions used in the surveys are included in the mapping document. The key summary points are as follows:

SDAC
-- uses ICF 'impairment of body function', and use of activity and environment, to identify overarching 'disability'.
-- obtains detailed information regarding activity/participation and environment (personal and technical assistance) for people identified as having a disability, and people aged over 60.
-- Need for assistance, difficulty with activities and use of aids is used to derive levels of severity of restriction.
-- Core restrictions covered are mobility, self-care, communication, and employment and school restrictions.
-- Other activity areas covered are: healthcare, paperwork, transport, housework, property maintenance, meal preparation, and social and community participation
        Note:
-- separate responses obtained for each impairment/activity/environment area questioned.
-- identifies underlying cause in terms of ICD for each impairment/activity/environment area questioned.
-- considers 'unmet need for assistance', as well as 'need' and 'met need'.

Disability module
-- can be related directly to the full survey approach to deriving 'disability' and 'severity of core activity restriction'.
-- uses mostly ICF 'impairment of body function', with some use of activity and environment, to identify overarching 'disability'.
-- obtains a basic identifier for activity limitation and need for assistance, restricted to the activity areas of self-care, mobility and communication, and for restricted participation in school education and/or employment.
        Note:
-- grouped response only obtained for the impairment/activity/environment areas questioned
-- <u>no</u> underlying condition data obtained

Census disability question - various approaches tested, with the most 'successful':
-- derived from but not directly relatable to the full disability survey or module.
-- using a combination of 'activity' and 'impairment' (focussing on 'difficulty') using a scaled response of 'none', 'a little' and 'a lot'.

-- having a follow-up question to identify the cause of any identified difficulty, with the disability population defined by long-term health condition, disability or old age.

Possible new census approaches (with focus on relatability to SDAC and immediate policy needs):
-- use environment (assistance from others), in relation to selected activity areas. The selected activity areas would be, for relatability to the survey data, those used in the SDAC to identify 'core activity restriction' (self-care, mobility and/or communication), with the possibility of including other activity areas dependent on user needs;
-- - have a follow-on question to identify the reason of any identified need for assistance, with 'Disability' being established by long-term health condition, disability or old age; or
-- consider using an internationally agreed census question set for international comparability, and separately establish its relationship with SDAC measures for internal data users