WHO-FIC NETWORK MEETING

Tokyo, Japan
16-22 October 2005

Use of ICF in health information systems and surveys

Richard Madden, Ros Madden, Ching Choi, Ken Tallis, Wen Xingyan

Abstract

There are various approaches to the use of ICF for measurement of health. Clarity of purpose for different uses is essential.

The ICF offers an array of components, domains, classifications and measurement ideas relevant to the description of human functioning and disability, and health outcomes. 'Together, information on diagnosis plus functioning provides a broader and more meaningful picture of the health of people or populations. The information on mortality (provided by ICD-10) and on health outcomes (provided by ICF) may be combined in summary measures of population health for monitoring the health of populations and its distribution.' (ICF, p4).

Measurement provides some challenges to ICF implementation. Further collaborative work internationally will ensure that the classification achieves its aim of improving the quality and comparability of information on functioning, disability and health.

There are a growing number of ICF applications around the world, including in health information systems and surveys. Some of the criteria for useful applications, where 'usefulness' is gauged in relation to desired improvement in quality and comparability of information, could be:

- *The purposes of information collection*
- *The selection of components and domains 'fit for purpose'*
- *Operationalisation of qualifiers including the 'constructs' of capacity and performance*
- *Relationship to existing applications and data sources.*

The WHO-FIC Network should take a lead in establishing more broadly based mechanisms for discussion of health status measurement.

Content

Use of ICF in health information systems and surveys.....1

Abstract Use of ICF in health information systems and surveys.....1

1. Health information systems and surveys—what do we need to know?.....3

2. The ICF and its place in health information systems and surveys.....4

3. ICF and survey applications: gauging their ability to improve quality and comparability of data on functioning and disability.....6

ICF and the Australian disability population survey.....6

Joint Canada / United States Survey of Health (JCUSH) and the US National Health and Nutrition Examination Survey.....9

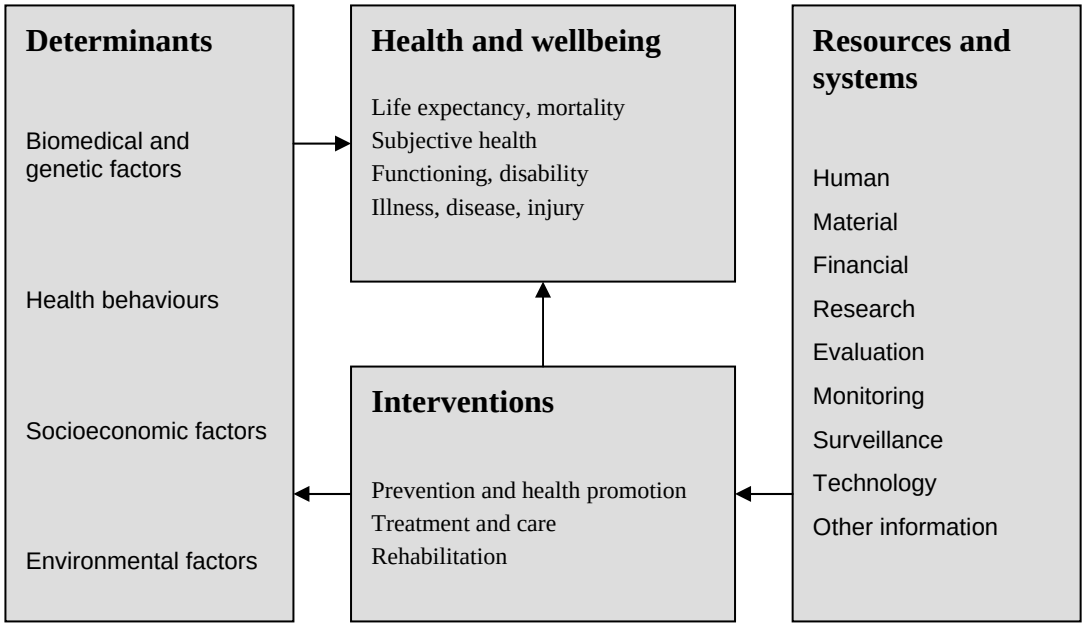
ICF and Washington Group on Disability Statistics 10
Measurement of 'health state' 11
4. Discussion and conclusion 13
No standard subset of ICF domains—and select purpose-built subsets with care 14
Measure the environment rather than capacity 15
More discussion so that the ICF model informs future survey development 15
References 15
Attachment 1: Survey screening question items, Australia 2003 Survey of Disability, Ageing and Carers 17
Attachment 2: Modules in the Joint Canada/United States Survey of Health (JCUSH) – Restriction of Daily Activities and Health Utility Index 18

1. Health information systems and surveys—what do we need to know?

Health information systems and surveys may cover a broad range of content. Increasingly, information infrastructure has been developed so as to promote order, quality, relevance and comparability of information in this diverse field. Such infrastructure includes:

- Frameworks for organising information topics; an example is provided in Figure 1, used for some years in Australia's Health, the biennial report to Australia's Parliament on the national health and health system (AIHW 2004a); this model bears a close relationship to the Canadian Roadmap (CIHI 1999) and to the older OECD Pressure-State-Response framework (OECD 1993).
- Indicator frameworks (usually related to the above organising frameworks) defining key measures providing an overview of a national health and health system (ref to Australian docs)
- International classifications; those in the WHO Family of International Classifications provide the world standards in the areas of mortality and disease (ICD), functioning and disability (ICF)—these two being the current reference classifications— as well as other relevant classifications such as the International Classification of External Causes of Injury (ICECI).
- Metadata specifications, such as those contained in the Australian health data dictionary (AIHW 2003a) and on-line metadata registry (the AIHW's METeOR); these in turn relate to all the above, specifying data items that support the frameworks and make use of standards such as the international classifications.

Figure 1: Conceptual Framework for Australia's Health



Source: AIHW 2004

Figure 1 also points us to the components used in measuring health status. 'Health status' is a broad concept and includes disease, functioning and disability, as well as some risk factors. These components of health should be separately measured, and not be confused. (Mortality is not included if we are talking about individual health status, although it is relevant if we are talking about population health.)

The terms 'health outcomes' and 'quality of life' overlap each other, as well as these three components of health status; they tend to be imprecise terms and appear not to relate to clear concepts. Health outcome and quality of life instruments often include disability measures (especially activity limitation), as well as indicators such as pain and sometimes more subjective measures of wellbeing. SF 36, for example, is an example of a 'quality of life' measure containing a mixture of concepts — a mixture that can be very useful for some purposes, but one that should not be equated to a simple concept or framework. Health outcome measures often relate to outcomes of treatment or intervention, but the measures themselves are essentially quality of life measures. Because 'health-related quality of life' instruments characteristically group together a range of diagnostic, functioning and subjective well-being items, they have been described as 'in need of reconstructive surgery' (Cummins 2004).

2. The ICF and its place in health information systems and surveys

The ICF has provided a greatly needed international standard in the area of functioning and disability, and more broadly in health (WHO 2001).

The ICF is increasingly being used in major national information systems in Australia. The national disability surveys have, since 1981, used first the ICIDH and then the ICF; the surveys also use the ICD in recording related health conditions (e.g. ABS 2003). There are related disability modules that can be used in other population surveys in areas such as housing, time use, Indigenous health. A 'stripped down' version of the disability module will be used in the 2006 Australian population census.

Administrative data collections in Australia are also using the ICF. The national data collection on disability support services uses a data item reflecting the ICF Activities and Participation domains, as well as 'assistance' measures based on the national population survey (AIHW 2004b, 2004c). A national medical indemnity collection uses the body structures dimension (AIHW 2004d); a proposed children's disability data item uses the A&P domains.

In Australia, ICF data items have been published as national data standards (AIHW 2003b) and are planned for inclusion in the Australian Institute of Health and Welfare (AIHW) meta-data repository, METeOR, for use in the health, housing and community services sectors (AIHW 2005. The proposed Functioning and Related Health Outcome Module (FRHOM) are derivatives of these data items (my colleague Catherine Sykes is speaking about FRHOM at this meeting). The FRHOM is designed to be a user-friendly data capture tool, clearly relating the ICF domains to the proposed measures. The FRHOM will be a key application of these data items, promoting their use in a wide range of intended fields, such as health, community

care and rehabilitation, especially where data sharing and comparison are the goals of information analysis.

The uptake of the ICF in research and clinical applications is also growing. In recognition of this widespread interest the AIHW (as the Australian Collaborating Centre for WHO-FIC) is planning an ICF User Forum in February 2006. Following the forum, a new edition of the Australian ICF User Guide is planned (AIHW 2003c)

There are three challenges that we are recognising in Australia, in relation to the role of the ICF in health information systems and surveys. The first lies in the rapid spread of the ICF. There is a need to find the balance between encouraging new uses and applications, and striving to maintain some level of consistency, so that we reap the hoped-for benefits of a new standard approach, rather than spawn new areas and types of inconsistency..

Second, the health field has a perhaps longer and more varied history of information development and analysis than the disability and community services fields. Efforts to promote comparability across health surveys also have a long history and are quite closely related to the development and adoption of 'health-related quality of life' instruments. Perhaps it is no coincidence that, while a number of Australian population surveys have used the ICF-related disability module, the health survey has not.

The third challenge was well recognised during the years of ICF development and since – the issue of measurement. The use of the qualifiers generally requires thought, to determine how to apply the generic five-point scale. Equally, the constructs of 'capacity' and 'performance' have been the subject of debate. No successful application can be pointed to, that operationalises the concept of 'capacity', largely because it requires first the definition of a 'standard environment'. Further, the notion of capacity frequently brings with it the need to attempt to use and measure older health ideas such as that of an intrinsic health status or functional ability. This approach is increasingly at odds with the more ecological framework of the ICF that seeks understanding of a person in an environment . The complexities in attempting to compare experiences across environments were empirically illustrated, when the experience of paraplegia and epilepsy in Cameroon and Australia was compared and the related 'burden' found to be ranked very differently in the two countries (Reidpath et al 2001).

The existence of these two constructs — performance and capacity — emphasises, perhaps imperfectly, the environmental component of the ICF model: it is impossible to record a person's disability without describing and measuring the environment. If environment is adequately recorded, it may then not be important to name a performance in one environment as 'capacity' and another, in another environment, as the actual 'performance'.

Rather, it can be seen that there is a large spectrum of possible functional performance for any individual, highly dependent on the environment at the time. The real challenge is not to measure 'capacity' but to measure environment, so that

performance at different times and in different environments, can be better understood.

Measurement is indeed a worthy theme for this meeting.

3. ICF and survey applications: gauging their ability to improve quality and comparability of data on functioning and disability

A question that this paper will therefore now pose is: What use will health applications make of the ICF model? Will they use the entire ICF model, or will they conscript pieces of it into pre-existing models? If the latter, does it matter?

In order to consider these questions we discuss four case studies in the health and disability fields, three of them attempting to achieve international consistency in surveys, and one relating to the Australian disability survey. The case studies are discussed in relation to four criteria by which we evaluate them.

- The purposes of information collection
- The selection of components and domains 'fit for purpose'
- Operationalisation of qualifiers including the 'constructs' of capacity and performance
- Relationship to existing applications and data sources.

ICF and the Australian disability population survey

The ICF and the International Classification of Diseases 10th revision (ICD–10) are two major international classifications used in the Australian population disability survey. Unlike in some developed countries, such as the USA, where the collections of disability information are largely components of health surveys, in Australia, separate from the National Health Survey, the Survey of Disability, Ageing and Carers (SDAC) is specifically designed to obtain comprehensive information about disability in the Australian population.

The ICD has been used as a framework and coding system to classify long-tem health conditions in the SDAC. However, ICD provides only a diagnosis classification for diseases, disorders and other health-related conditions. The ICF provides a 'multi-perspective framework and systematic classification of functioning and disability associated with health conditions' (WHO 2001). The two systems are therefore complementary when they are used in describing and classifying disability and related health conditions in the population survey.

The main objectives of the SDAC are to measure the prevalence of disability in the Australian population and consequent need for assistance; provide a demographic and socioeconomic profile of people with a disability compared with the general population; and obtain information about unpaid carers who provide care for people with a disability (ABS 1999).

Australia was one of the first countries to apply the conceptual framework and

concepts of the ICF and its predecessor, the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) to population surveys. The first was in the 1981 Survey of Handicapped Persons, just about a year after the first version of the ICIDH was published in 1980 (ABS 1984). The subsequent ABS disability surveys were conducted in 1988, 1993, 1998 and 2003, and used basically the same conceptual definitions as those used in the 1981 survey.

Some new developments from the revision of the ICIDH were incorporated into the 1998 disability survey. For example, in the 1998 survey the term 'handicap' was replaced by 'specific restrictions'; in the 2003 survey the term 'activity restriction' is replaced by 'activity limitation' in order to be in line with the ICF terminology . Despite the changes in the terminology, the basic survey operational definitions and measurements remain the same, as the survey already used concepts such as 'difficulty' used in the ICF and 'assistance', also recognised as a useful general concept in the measurement of disability. The ABS is continuing to work towards ensuring conformity with the ICF.

The SDAC survey screening questions 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 (Appendix 1). 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.

The SDAC survey questions cover most domains of the ICF components of 'activity and participation', while the coverage is less complete in the domains relating 'environmental factors' and 'personal factors '(Table 1).

The SDAC survey questions relating to the domains of the Activity and Participation component of ICF focus on the 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. The detailed information about performance in activities and participation provides opportunities to use the ICF qualifier codes in data classifications and analysis.

The Australian 2006 Census will include disability-related questions on need for assistance with activities corresponding to three domains of the ICF activity component (self-care, mobility and communication).

Table 1: 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	

Joint Canada / United States Survey of Health (JCUSH) and the US National Health and Nutrition Examination Survey

Two surveys that are conducted in the United States (and, in the case of JCUSH, in both the US and Canada) illustrate approaches to the ascertainment of health, functioning and disability status that might provide a springboard for the implementation of an ICF-based approach to measurement.

The Joint Canada / United States Survey of Health (JCUSH: www.cdc.gov/nchs/about/major/nhis/jcush_mainpage.htm), which was conducted for the first time between November 2002 and March 2003, illustrates the way in which concepts of functioning and disability have been embedded in a health survey. JCUSH was a telephone survey involving around 5,200 US and 3,500 Canadian respondents. Its principal aim was to gather comparable health data for the two participating countries, using a common survey instrument and a common collection methodology.

JCUSH covered a wide range of health topics, such as:

- Overall self-assessed health status
- Chronic health conditions – including asthma, arthritis, heart disease, diabetes and depression
- Risk and protective factors – including smoking, weight and height and physical activity
- Contact with health professionals and other health services
- Use of medicines.

Of most interest in the current context are the segments of JCUSH that deal with human function and the Health Utility Index (HUI, see Attachment 2). These segments:

- Cover some but not all ICF body functions.
- Cover some but not all ICF body structures.
- Obtain a good deal of information about the relationship between health conditions and activity and participation. In particular, the HUI asks survey respondents many questions about activities that involve seeing, hearing and speech, mobility, memory and thinking, and so on. Although all of these questions involve self-assessment, there is some attempt in JCUSH to inject some standardisation of setting. So, for example, vision is described in terms of ability to read newsprint or to recognise a friend across the street; and hearing is described in terms of ability to hear a conversation in noisy and quiet social settings.
- Obtains a good deal of information about respondents' activities and participation with and without aids and assistance.

• Obtains a small amount of information about environment.

Refer to Attachment 2 for more detail.

The US National Health and Nutrition Examination Survey (NHANES) takes a different approach (www.cdc.gov/nchs/nhanes.htm). It uses both personal interviews (somewhat similar to the JCUSH self-assessement of health status and functioning) and, for a subsample of respondents, physical examination in a mobile centre that moves from community to community. Of interest in the current context are the tests, within a standardised environment, of functioning (such ability to walk and time taken to walk a standard distance; cardiovascular fitness; balance; hearing; vision and so on). The NHANES measurement strategy provides, within its ambit of domains, an approach to the ascertainment of 'capacity', as it is conceptualised in the ICF .

JCUSH and NHANES provide other interesting models for surveys (based on less and more expensive measurement strategies) that countries might develop to obtain ICF-consistent measures of health, functioning and disability.

ICF and Washington Group on Disability Statistics

The primary purpose of the Washington Group (established in 2002) is to facilitate monitoring equalisation of opportunities and there are three main agreed objectives:

• To guide the development of a small set(s) of general disability measures, suitable for use in censuses, sample based national surveys, or other statistical formats, which will provide basic necessary information on disability throughout the world.

• To recommend one or more extended sets of survey items to measure disability or principles for their design, to be used as components of population surveys or as supplements to specialty surveys. These extended sets of survey items will be related to the general measures.

Measures identified in objectives 1 and 2 will be culturally comparable to the extent possible. The ICF model, a useful framework to assist in the development of these measures, will be utilised in developing the measures.

• To address the methodological issues associated with the measurement of disability considered most pressing by the Group participants.

For the general disability measure, the four core domains selected are seeing, hearing, mobility (walking or climbing steps) and cognition (remembering or concentrating). Self-care and communication domains have also been added — considered as 'additional or optional' by some but by others as essential.

The proposed 'general disability measure', then, covers some, but not all, of the domains of the ICF. As illustrated by the ICF framework, disability experience is often complex and multi-dimensional. While a very small number of selected domains may be relatively easy to use for collecting some comparable disability

data, the small number of domains will influence the scope of the effective definition of disability across the world. In turn, this will affect the Group's success in reaching their stated aims i.e. being able to monitor equalisation of opportunity.

The extended set(s) of disability measures may cover more of the components of Body function/structure, Activity/participation and Environmental factors of the ICF. Currently, two 'extended sets' of questions have been proposed for the next Group meeting, which are based on existing survey questions. The first extended set includes a total of 30 questions extracted from WHS 17, WHO-DAS-12 and the Eurostat core health module. The second extended set is proposed to cover more detailed information on activities and participation as well as environmental factors. These include five of the nine ICF domains of Activities and Participation: Self-care, Domestic life, Interpersonal interactions and relationships, Major life areas, and Community, social and civic life; and questions about need for assistance with activities of self-care, mobility and communication.

The Washington Group has, then, engaged seriously with the attempt to operationalise the ICF in censuses and disability surveys that are to be conducted in a wide range of countries. The selection of a relatively small number of activity domains for censuses has been, and continues to be, robustly debated with the aim of ensuring that the questions are suitable for all countries, not only those with fairly extensive disability surveys (such as Australia). Information on performance, not capacity, is sought. 'Extended sets', covering more ICF Activity and Participation domains, are provided for those countries able to collect more extensive information in surveys.

Measurement of 'health state'

In May 2004, UNECE, WHO and Eurostat convened a meeting in Geneva to consider the measurement of health status. The meeting report (UNECE 2004) states that 'Indicators of health status include diseases and injuries, impairments, health states and mortality risks.' 'Health status', then, includes something called 'health state'. The report does not include a clear definition of 'health state' (in fact it was recognised that languages other than English may not distinguish health status and health state). But it makes the following points:

- 'Health state' consists of aspects that do not change with local social and environmental factors
- 'Health state' includes both impairments and activity limitations
- Measurement of 'health state' should be linked to the conceptual framework of the ICF, using the capacity construct and ICF domains.

'Health state' is described in such a way in the first two points, that it can focus only on the capacity construct of the ICF and a limited representation of its components (some impairments and activity limitations, no participation

restrictions). The health status of the population, then, is described only in terms of indicators of functioning and disability that specifically exclude performance and participation.

Thus the meeting's view of health status was more restrictive than that of the ICF itself. Given that one of the meeting's co-sponsors was the WHO, this is puzzling and the issue is not addressed in the meeting report. The ICF states at P4:

'Together, information on diagnosis plus functioning provides a broader and more meaningful picture of the health of people or populations … The information on mortality (provided by ICD-10) and on health outcomes (provided by ICF) may be combined in summary measures of population health for monitoring the health of populations and its distribution.'

While the term is not used, this is a clear statement about the WHO view on how to approach the measurement of health status now that the ICD and the ICF are both in place as reference classifications .

This description of health status is multi-dimensioned, and in line with that used in national surveys. Health conditions (described using ICD) form part of health status. And all four dimensions of the ICF need to be considered) — Body Functions and Body Structures; Activities (execution of tasks or actions) and Participation (involvement in life situations). The Environmental Factors dimension describes the physical, social and attitudinal factors that can have a positive or negative effect on any of the other components (ICF page 16).

This construction of health status includes the performance of individuals in their current environment.

The WHO definition of health is not revisited in the ICF, and remains 'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity'.

The Geneva meeting's desire to measure 'health state' as a capacity construct using some dimensions and some domains of the ICF is being pursued by a working party established at that meeting. It is important that the process of selecting domains be open, and clearly related to purposes; the criteria for selection need to avoid the perhaps understandable trap of using highly specific criteria that may appear to be selected on the basis that they will enable the choice of domains and concepts used in the heath field for many years, co-opting only those areas of the ICF that fit these older models.

For individual countries, one important purpose of measuring population health via health surveys is to collect data and inform the development of health strategies and health priorities, resource allocation and research. This may facilitate the work to achieve fundamental health goals such as improving population health levels, and reducing health inequalities. However, if we really want countries to implement the standard questions in their national population

health surveys, we need more serious consideration of some key issues:

- Can the selected domains/questions to be used to measure the population health in various countries and meet this purpose for monitoring population health?
- Do these selected domains/questions really have the explaining power for the patterns of health inequalities and differences in population health of individual countries?
- Can these selected domains support comparisons across countries and across time?

Many countries will not agree that their purpose for monitoring population health will be met by collecting data based on narrowly defined 'health states' which consist of highly selected domains and measurements of individual's 'capacity' to function in each domain.

The term 'health state' is a far more general term, and one that should in time be clearly defined in the ICF. In the meantime, the concept coming out of the Geneva meeting should be re-termed with meaning closer to the apparent desires of the meeting.

More generally, any use of the ICF framework needs to be explicit about the purpose of the application, and to state clearly which parts of the framework are being used and which are not being used. Elaboration of ICF terminology should be the responsibility of the WHO-FIC network, which in turn needs to act on priority issues. Perhaps the definition of 'health state' is such an early ICF update or revision task!

A further issue is whether and how a limited set of ICF domains are to be chosen for different applications. The Washington Group has sensibly approached this task through establishment of the general set and extended sets, so that no domain is necessarily excluded. To select a small number of domains for an application such as a census question, an extensive process of consultation and testing is underway. Australia has followed a similar approach (in surveys and the census). This seems far preferable to development of a set of exogenous criteria to prefer some domains over others.

4. Discussion and conclusion

The ICF has certainly made its presence felt in the field of health and disability surveys.

In the Australian disability survey we see an application that has, since 1981, made extensive use of the international standards (ICIDH and now ICF) and has collected rich information on disability over more than two decades (for some recent analyses see AIHW 2003d, 2004e, 2004f).

In the JCUSH we see an initiative by two countries to combine efforts in surveying health and functioning. The NHANES illustrates a possible way operationalising the

'standard environment' and measuring 'capacity'. Taking the same approach in a wide array of countries for international comparisons requires consideration of costs and other aspects of feasibility.

In the work of the Washington Group we see a more ambitious enterprise, involving a wider range of countries and with the goal of establishing both a 'general measure' of disability and 'extended sets'—for use perhaps in censuses and surveys respectively. Of necessity the general measure must be of brief length, involve few domains, and pay attention to the need to operationalise questions — and provide for some continuity of data — across a wide range of countries, cultures and statistical histories. The selection of a relatively small number of activity domains for censuses has been debated by the Group and compromises made, in a protracted and open discussion over a series of meetings, teleconferences and e-mail exchanges. The extended sets provide items for surveys that more adequate cover the full ICF.

The work started by the 2004 Geneva meeting on 'health state' and 'health status' is still developing but needs much wider discussion among people interested in improving the measurement of functioning and disability across the world. Members of the group appear to bring a history of health measurement to the task. Is the focus on selecting ICF elements that fit older models, rather than using the full ICF model to capture information on human functioning? The criteria being used for selection of domains need to be the subject of considerable debate Defining 'health state' is a task that needs wide debate, especially when it relies on inclusion of the ICF notion of 'capacity' in a 'standard environment' which has not been generally operationalised. This task should perhaps be taken up by the WHO-FIC Network.

There are, then, many new ICF applications and adaptations. Even those initiatives trying to harmonise international effort and promote international comparisons are themselves injecting new sources of variation into the field.

Some of our conclusions at this stage are as follows.

No standard subset of ICF domains—and select purpose-built subsets with care

While many applications may require the choice of ICF domains, making such a selection is a major task. Purposes must be stated, criteria for selection stated and related to the purpose (with, desirably, some scientific justification of the link). This must all be done in the knowledge that the ICF provides a coherent and informative framework. Our Institute's analysis (reported at the June 2005 NACC meeting by Dr Phil Anderson of AIHW) shows that information on people's disability experience is spread across all Activities and Participation domains, especially for large and heterogeneous populations or client groups. The importance of the different domains may vary with different groups, and deleting a domain would have differential impacts on population subgroups. This means that, in no sense would it be possible top develop a 'standard core set' of domains for general use. Neglect of any one domain, then, is neglecting information about human functioning.

Measure the environment rather than capacity

There is a large spectrum of possible functional performance for any individual, highly dependent on the environment at the time. The real challenge is not to measure 'capacity' but to measure environment, so that performance at different times and in different environments, can be better understood.

If people wish to use the construct 'capacity', how is the 'standard environment' operationalised in a way that promotes international comparisons? Does NHANES provide a suitable model? Or could we accept and understand the differences between countries, and interpret the data accordingly—and take the same approach to change over time within countries?

More discussion so that the ICF model informs future survey development

Our brief investigation has illustrated that the large amount of current work on international survey design has significant implications for the international adoption of the ICF model and for the information that will become available.

Groups working in the area have a considerable responsibility to consult with each other, with the WHO-FIC Network and beyond, to people interested in and affected by the results of their work.

The WHO-FIC Network similarly has a responsibility to be involved in these enterprises, and to provide advice to ensure that international standards are applied in an optimal way.

The ICF framework has a coherence that should not lightly be ignored by people responsible for significant national and international work on health information and surveys.

References

ABS (Australian Bureau of Statistics) 1984. Handicapped persons Australia 1981, Second edition. Cat. no. 43430.0. Canberra:ABS.

ABS 1999. Disability, ageing and carers: summary of findings, Australia 1998. Cat. no. 4430.0. Canberra: ABS

ABS 2003. Disability, ageing and carers: summary of findings, Australia 1998. Cat. no. 4430.0. Canberra: ABS (check)

ABS 2002. National Health Survey: summary of results, Australia 2001. Cat. No. 4364.0. Canberra: ABS.

AIHW (Australian Institute of Health and Welfare) 2003a. National health data dictionary. Version 12. Canberra: AIHW.

Australian Institute of Health and Welfare (AIHW) 2003b. National community services data dictionary. Version 3. Canberra: AIHW.

Australian Institute of Health and Welfare 2003c. ICF Australian User Guide. Version 1.0. AIHW cat. no. DIS 33. Canberra: AIHW (Disability Series).

Australian Institute of Health and Welfare 2003d. Disability prevalence and trends. DIS 34. Canberra: AIHW (Disability Series).

Australian Institute of Health and Welfare 2004a. Australia's Health 2004. Canberra:AIHW

Australian Institute of Health and Welfare 2004b. Data Guide: data items and definitions 2004–05 (CSTDA NMDS). Canberra: AIHW.

AIHW 2004c. Disability support services 2002–03: the first six months of data from the CSTDA NMDS. AIHW cat. no. DIS 35. Canberra: AIHW.

AIHW 2004d. First medical indemnity national data collection report: public sector. January to June 2003. AIHW Cat. No. HSE 34. Canberra: AIHW.

AIHW 2004e. Disability and its relationship to health conditions and other factors. Disability Series. AIHW Cat. No. DIS 37. Canberra: AIHW.

Australian Institute of Health and Welfare 2004f. Children with disabilities in Australia. AIHW Cat. No. DIS 38. Canberra: AIHW.

AIHW 2005. Metadata Online Registry — METeOR.

http://meteor.aihw.gov.au/content/index.phtml/itemId/181162

Canadian Institute for Health Information 1999. Roadmap initiative—launching the process [cited February 2001]. Available on Internet: www.cihi.ca/Roadmap/Health_Ind/indciators 2000/toc.shtml

Cummins R 2004. Health related quality of life: a construct in need of reconstructive surgery. Paper presented at Health Outcomes 2004: Perspectives on Population Health. 10th annual national health outcomes conference, Canberra September 2004. Organised by Centre for Health Service Development University of Wollongong, Australia.

OECD (Organization for Economic Co-operation and Development) 1993. OECD core sets of indictors for environmental performance reviews. Environment Monographs no. 83. Paris:OECD

Reidpath DD, Allotey P, Kouamé A, Cummins RA 2001. Social cultural and environmental contexts and the measurement of burden of disease: An explanatory study in the developed and developing world. Melbourne: Key Centre for Women's Health in society, The University of Melbourne.

UN Economic Commission of Europe 2004. Report of the May 2004 UNECE/WHO/EUROSTAT meeting on the measurement of health status. GE.04-32606. UN Economic and Social Council CES/2004/46.

WHO (World Health Organization) 2001. International classification of functioning, disability and health. Geneva: WHO.

Attachment 1: Survey screening question items, Australia 2003 Survey of Disability, Ageing and Carers

- loss of sight, not corrected by glasses or contact lenses;
- loss of hearing, with difficulty communicating or use of aids;
- loss of speech;
- chronic or recurring pain that restricts everyday activities;
- shortness of breath or breathing difficulties that restrict everyday activities;
- blackouts, fits, or loss of consciousness;
- difficulty learning or understanding;
- incomplete use of arms or fingers;
- difficulty gripping or holding things;
- incomplete use of feet or legs;
- a nervous or emotional condition that restricts everyday activities;
- restriction in physical activities or physical work;
- disfigurement or deformity;
- head injury, stroke or any other brain damage with long-term effects that restrict everyday activities;
- needing help or supervision because of a mental illness or condition;
- treatment or medication for any other long-term condition or ailment and still restricted;
- any other long-term condition that restricts everyday activities.

Attachment 2: Modules in the Joint Canada/United States Survey of Health (JCUSH) – Restriction of Daily Activities and Health Utility Index

(a) Restriction of daily activities:

- Do you have any difficulty hearing, seeing, communicating, walking, climbing stairs, bending, learning or doing any similar activities?
- How often does a long-term physical condition or mental condition or health problem reduce the amount and kind of activity you can do – at home/ at school; at work/ in other activities (for example, transportation or leisure)?

(b) Health status – Health Utility Index (HUI)

- Vision
  - Are you able to see at all?
  - Are you usually able to see well enough to read ordinary newsprint without / with glasses or contact lenses?
  - Are you able to see well enough to recognise a friend on the other side of the street newsprint without / with glasses or contact lenses?
- Hearing
  - Are you able to hear at all?
  - Are you usually able to hear what is said in a group conversation with at least three other people without / with a hearing aid?
  - Are you usually able to hear what is said in a conversation in a quiet room with one other person without / with a hearing aid?
- Speech
  - Are you usually able to he understood completely / partially when speaking with strangers / those you know well in your own language?
- Getting Around
  - Are you able to walk at all?
  - Are you usually able to walk around the neighbourhood with / without mechanical support or the help of another person?
  - Do you require a wheelchair to get around?
- Hands and Fingers
  - Are you usually able to grasp objects or do you require the help of another person or special equipment?

- Feelings
  - Would you describe yourself as usually happy and interested in life/ somewhat happy/… /so unhappy that life is not worthwhile?
- Memory
  - Are you usually able to remember most things / somewhat forgetful / very forgetful?
- Thinking
  - Would you describe yourself as usually able to think clearly and solve problems/ having a little difficulty/…/unable to think and solve problems?
- Pain and Discomfort
  - Are you usually free of pain or discomfort?
  - How would you describe the usual intensity of pain or discomfort – mild/ moderate/ severe?
  - How many activities does you pain or discomfort prevent – none/ a few/…/most?

A supplementary JCUSH module, used for US respondents, included questions with somewhat more specificity or standardisation, and more information about aspects of the environment such as assistance and equipment. For example;

- The segment about moving around asked whether the respondent was able to walk 10 steps / a quarter of a mile without special equipment or assistance.
- The segment about lifting asked whether the respondent could grasp small objects / lift 10 pounds / push or pull a living room chair without special equipment or assistance.
- The segment about daily activities asked the degree of difficulty that the respondent experienced in going out to entertainment / participating in social gatherings / reading or watching TV at home without special equipment or assistance.