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# *Ros Madden: Participation and environment: out of the melting pot and into …?*

# Participation and environment: out of the melting pot and into …?

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**Session 4: Implications of the new 'elements' of the ICF for measurement of disability focusing on Participation and Environment.**

## 1. Introduction

Today I want to share and discuss some ideas with you. These ideas do not represent an 'Australian position'. Rather they represent some thought and discussion occurring within the Australian Collaborating Centre.

In thinking about implementation of the ICF, and in particular Participation and Environment, it is necessary to think about what the new classification says about:

- the single list of domains of Activities and Participation and options for using them;
- qualifiers, which are recognised as being essential to meaningful application;
- the 'information matrix' as conceptualised by WHO; and
- the Environment component, its qualifiers, and how to use them.

I want to touch on all these topics today.

The ICF is intended to be a multi-purpose classification and, in any discussion, it is probably useful to clarify the particular purposes, which underlie any approach to implementation. So first I will describe the Australian Collaborating Centre and the context in which we work.

### The AIHW

The Australian Institute of Health and Welfare is Australia's national agency for health and welfare statistics and information, and the Australian Collaborating Centre for ICF and ICD.

We work on national data development, collection, analysis and dissemination. In the area of national data development we work with and support nationally constituted data committees, under national information agreements which oblige all Australian jurisdictions, the Institute and the Australian Bureau of Statistics to work to develop and exchange national data on health, housing and community services.

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[1] A number of people in the Australian Collaborating Centre have provided stimulating comments on this paper, including Richard Madden, Ching Choi, Catherine Sykes, Louise Golley, Paul Magnus, Trish Ryan and Diane Gibson. The paper contains the views of the author and does not necessarily represent those of the ACC.

Two of the main products resulting from these efforts are the national data dictionaries for health and for community services (eg AIHW 2000). These are major pieces of national information infrastructure. They contain national information models, and associated data elements, specified in accord with ISO standards. The dictionaries provide a menu of data items from which national minimum data sets can be specified, relating to the major national collections in these fields.

### Trial disability data items in the Australian data dictionary

The Institute's involvement in the ICIDH revision has stemmed from all aspects of our national role, but most obviously our responsibilities for national data development. The ICIDH offered us the chance to increase the consistency of disability data within Australia, which was seen as a high priority. We have been advised on our work on the ICIDH revision and on moving towards national consistency by a broad advisory group of government officers, representatives of people with disability and non-government services providers and independent experts.

Trial disability data items were approved for inclusion, on a trial basis, in the National Community Services Data Dictionary (NCSDD—AIHW 2000). These were based on the Beta 2 version of ICIDH-2, and an information annexe was included in Appendix 4 to explain all the items and their inter-relationships. 'Disability' as an overarching concept, as presented in the NCSDD (see Attachment 1).

While we wish to promote a wide range of uses of ICF it is probably true that our own focus now is on national consistency of disability and health information, and challenges relating to health status measurement, disability surveys and national datasets generally. It is this perspective that shape my paper today.

## 2. The final ICF: Key features as they affect Participation and Environment

ICF is a classification of human functioning and disability. It is a core member of the WHO family of health-related classifications, complementary to the other core member, the ICD. The ICF is organised in two parts. The first part recognises two main components of functioning and disability:

- A body component comprising classifications of body function and body structure
- An Activities and Participation component providing a complete set of domains for aspects of functioning from both an individual and societal perspective.

A person's functioning and disability is conceived as a dynamic interaction between health conditions and environmental and personal factors (WHO 2001:6). Environmental factors are presented in the second part of the classification.

Disability is the umbrella term for any or all of: an impairment of body structure or function, a limitation in activities, or a restriction in participation.

The interactions between the components of functioning, disability and health can be represented visually as in Figure 1 of the Final draft.

## Activity and Participation

Key definitions are:

> ***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.

The classification provides a single list of Activity and Participation domains, or life areas, with options for use. WHO reflects several years of difficulty in reaching consensus on a definitive separation of two lists of domains for Activities and Participation, in both Beta 1 and Beta 2 testing, when it states that (page 14 (7) of the Final draft):

> It is difficult to distinguish between Activities and Participation on the basis of domains… Therefore ICIDH-2 provides a single list that can be used if users wish to do so to differentiate Activities (A) and Participation (P) in their own operational ways … Basically there are four possible ways of doing so:
>
> (a) to designate some domains as A and others as P, not allowing overlap;
>
> (b) same as (a) above, but with partial overlap;
>
> (c) to designate all detailed domains as A and use the broad category headings as P;
>
> (d) to use all domains as both A and P.

## Qualifiers of A and P

Two constructs — 'capacity' and 'performance' — can be used to qualify the A and P domains that is, to record some kind of measure of the extent of the activity limitation (the extent of 'difficulty') or participation restriction (the 'problem' with participation). Performance relates to 'the current environment' and capacity to a 'standardised' environment (either actual or assumed—see page 13(3) of the Final draft). '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'. These two qualifiers were included in the classification after the Beta testing phase and have not been subjected to development and testing.

The qualifiers are measures coded after the relevant domain of any components (body structure or function, activity, participation, environmental factor). These qualifiers are recognised as being essential to meaningful use of the classification because of the neutral domains of its components. But the instructions for use leave a great deal of discretion in the hands of the user. A and P both are to be used with a 'generic qualifier' (none, mild, moderate, severe, complete) which, it is recognised, needs calibration:

- Without qualifiers codes have no meaning (page 167).
- The ICIDH-2 codes are only complete with the presence of a qualifier, which denotes the magnitude of the level of health (e.g. the severity of the problem) (page 19).
- Assessment procedures have to be developed through research (page 20). Broad ranges of percentages are provided [to scale the qualifier] for those cases in which calibrated assessment instruments are available to qualify the impairment, capacity limitation, performance problem or barrier…

It is stated that both capacity and performance:

- are measured in relation to 'population norms' i.e. to record the 'discordance' between the observed level and what is expected of a similar individual without the health condition (page 13(5); and
- can be measured with or without assistive devices (page 13(4)).

## The 'information matrix'

WHO states that the information 'gathered from the list' of A and P, suitably qualified, provides an information matrix recording performance and capacity in each of the life domains (see page 12 of the Final draft).

The importance of the matrix to WHO, first indicated at the Madrid meeting, is underlined in Appendix 3, where the options for the use of the single A and P list are discussed and their implications for the matrix spelled out, as follows.

- Option (a) — to designate some domains as A and others as P, not allowing overlap — 'provides the full information matrix without any redundancy or overlap'.
- Option (b) — as (a) above, but with partial overlap — is for users who believe that 'codes in overlapping categories may mean different things when they are coded in A and not in P … However one single code has to be entered into the information matrix for the specified qualifier column'.
- Option (c) — to designate all detailed domains as A and use the broad category headings as P — results in decisions as for options 1 and 2, depending on whether overlap is required.
- Option (d) — to use all domains as both A and P — creates the possibility of two different values for the same cell in the information matrix (or redundancy when the qualifiers for A and P have the same value)[2]. In the case of differing values, a decision rule is required for choosing which value to include in the matrix, since 'the official WHO coding style is this:

d *category* $q_P q_C$'

This statement about the official coding style could be interpreted as suggesting that WHO will interpret the single list as A (or A/P, or P) as they please, and will focus on the 'constructs' of capacity and performance as they apply to these domains, whatever their possibly blurred meaning.

The possibility of coding further qualifiers is recognised in Appendix 2 (page 176).

Appendix 3 concludes with a statement recognising that practice must be built up, recorded and analysed regarding the operationalisation of A and P.

[2] It is suggested in Appendix 3 that 'one possible way to overcome this redundancy may be to consider the capacity qualifier as Activity and the performance qualifier as Participation'. This suggestion does not appear compatible with the structure of the classification, nor its definitions, and is not pursued in this paper. See related confusion on page 14 (4.3).

### The E dimension and its qualifiers

***Environmental factors*** make up the physical, social and attitudinal environment in which people live and conduct their lives. There are five chapters comprising: products and technology; natural environment and human made changes to environment; support and relationships; attitudes; services, systems and policies.

These environmental factors can have a positive or negative effect on any or every component of the person's functioning and disability. They should be coded from the perspective of the person. There are three possible coding conventions to code the environmental factors (see Appendix 2). They can be coded:

a) alone, without relating the codes to the components of body function and structure, activity and participation;

b) for each of BF, BS, A and P; or

c) for capacity and performance qualifiers in the A and P component for every item used.

The qualifier records the extent to which the factor is a facilitator (5-point positive scale) or a barrier (also a 5-point scale) (see e.g. page 20 (8)).

## 3. Thoughts on implementation

This section outlines some current thinking on each of these four areas of the new ICF.

### A and P and the WHO options for use

Recent years of Beta testing resulted in much comment on perceived overlap between A and P domains. The ACC consistently stated its preference for non-overlapping domains. However no international consensus was reached on how to split the domains to ensure there would be no such overlap and that there were clear criteria for the split. The result is the combined A-P list in the Prefinal version.

The ACC also consistently pointed out that the qualifiers were a critical part of the classification, and were essential for implementation of the classification.

Following the release of the December Prefinal version, the ACC began to work on a non-overlapping split of A and P domains, expecting almost without discussion that Option (a) would be our preferred option. In parallel with this work we also tried to refine criteria we had previously drafted to assist in this delineation. The latest version of our criteria for delineation is as follows:

i. Activities focus on the person's individual functioning, while Participation emphasises the person's involvement in society.

ii. A is completely externally observable. P refers to the lived experience of the person[3].

iii. Activity *can* relate to a 'test' environment (although it can also relate to a 'real' environment), with or without equipment. Participation is essentially 'confounded'

[3] This criterion has implications for measurement i.e. qualifiers. It also resonates with the requirement that quality of life measures should have an 'objective' and a 'subjective' element, and to the Doyal and Gough framework that places 'health' (A relates) and 'autonomy' (P relates) at the pinnacle of indicators of human well-being.

with the environment, i.e. the concept has little meaning without consideration of the physical and social environment, and it cannot be 'assessed' in a 'test' environment.

iv. 'Involvement in society' relates in particular to societal roles. This highlights the confounding of Participation with that part of the environment that shapes expected roles and societal norms.

v. A is fine grained whereas P is broad brushed.

vi. A is about action or process, P relates to the overall goal of actions or sets of actions.

An additional criterion was used in attempting the split (e.g. in Table 1), namely that the split was done using broad groups of codes, so that 'slabs' went into either one column or the other. This keeps comparison with the single list (and any other split) as simple as possible.

### An approach to delineating between A and P

In delineating between A and P in practice, one could then apply:

- the WHO definitions (see above) and
- the ACC draft criteria (see above);

The purpose is to:

- split the A-P domains; or
- using the totality of the A-P domains AND the suggested qualifiers, achieve delineated approaches to A and P.

These two possibilities will now be discussed.

### Using the domains alone

Despite the international failure to agree on an A-P split based on the domains, Table 1 attempts an A-P split of the domains in the single A-P list, reflecting the WHO definitions and ACC criteria as far as possible. Comment has been sought within the Institute, and the italicised comments show how much agreement there is on the split (so far) and the differing views in some areas.

**Table 1: Draft A-P split: for discussion, development and testing**

| **Activity** | **Participation** |
|---|---|
| Ch 1: Learning and applying knowledge<br>• Purposeful sensory experience d110-129<br>• Basic learning d130-159<br>• Applying knowledge d 160-179<br>*All agree this is A* | |
| Ch 2: General tasks and demands<br>• Undertaking a single task d210<br>• Undertaking multiple tasks d215<br>• Carrying out daily routine d220 | Ch 2: General tasks and demands<br>[ d230 handling stress etc – one person wonders if this is P] |

| | |
|---|---|
| • Handling stress and other psychological demands d230<br>*Most agree this is A* | |
| Ch 3: Communication<br>• communication—receiving d310-d329<br>• communication—producing d330-d349<br>• using communication devices and techniques d360-369<br>*Most agree these are all A* | Ch 3: Communication<br>• conversation d350-359<br>*Disagreement on this. Some would like it in A to keep the whole 'slab' together.*<br>*If separated, could call one group 'communication activities' and the other 'participation in conversation/communication.* |
| Ch 4: Mobility<br>• changing and maintaining body position d410-d429<br>• carrying, moving and handling objects d430-449<br>• walking, moving and related activities d450-459 (excluding 460469)<br>*All agree these are A* | Ch 4: Mobility<br>• moving around in different locations (home, other buildings, outside) d460-469<br>• moving around using transportation d470-499<br>*Disagreement on this. Some would like these in A to keep the whole 'slab' together. A difficulty is that 'the home' could perhaps be better separated from the other parts of d460-469, but this makes an awkward split.*<br>*Others are concerned that this is a fundamental human rights issue, not just a means to other ends---how can you participate in your society if you can't move around in it.*<br>*If separated, could call one group 'movement activities' and the other 'participation in movement around the home and community'.* |
| Ch 5: Self care<br>• Washing oneself d510<br>• Caring for body parts d520<br>• Toileting d530<br>• Dressing d540<br>• Eating d550<br>• Drinking d560<br>• Looking after one's health d570<br>*All agree these are A* | |
| Ch 6: Domestic life<br>*See discussion opposite. Some would put this entire chapter in A.* | Ch 6: Domestic life<br>• Acquisition of necessities d610-629<br>• Household tasks d630-649<br>• Caring for household objects and assisting others d650-669<br>*There is a lot of disagreement here. Some would put all this in A, and suggest that some areas e.g. 'household tasks' are very much like activities without very much social focus. Others see this group as so socially and environmentally determined as to make it difficult to ascribe meaning without the context of the physical* |

| | |
|---|---|
| | *household environment and the social expectations on the roles involved. Some see both sides!* |
| | Ch 7: Interpersonal interactions and relationships<br>• General personal interactions d710-729<br>• Particular personal relationship d730-779<br>*All agree these are P.* |
| | Ch 8: Major life areas<br>• Education d810-839<br>• Work and employment d840-859<br>• Economic life d860-879<br>*All agree these are P.* |
| | Ch 9: Community, social and civic life<br>• Community life d910<br>• Recreation and leisure d920<br>• Religion and spirituality d930<br>• Human rights d940<br>• Political life and citizenship d950<br>*All agree these are P.* |

Some of the disagreement (italicised in Table 1) originates in the different service perspectives that different analysts have brought to the discussion. Those with a disability service perspective are accustomed to thinking about Participation across a broad range of life areas and are uncomfortable with Participation being too narrowly constricted. Those more involved with aged care services seem more accustomed to a focus on delivering assistance with Activities, and do not wish unnecessarily to constrain the domains considered to be A. The national government is at present enunciating 'social and economic participation' as important goals for income security recipients, and in this context it is perhaps only Chapters 8 (major life areas) and 9 (community social and civic life) that are of particular interest. How much more debate can we expect as we extend the discussion to a range of different service types and research perspectives?

Is this a problem? If the discussants and potential users preserve the concepts of A and P, does it matter that they wish to use and interpret the domains somewhat differently in different circumstances? Is it in fact a blessing that WHO has left us with some freedom to adapt and experiment in this difficult area?

My tentative conclusion is that we should take another look at Options (b) and (d).

### Using qualifiers as well as domains? Application in a current data development

Further insights are emerging during a more practical exercise. A practical application of the new ICF including A and P is being attempted in a current redevelopment of a

national minimum data set (MDS) for disability support services in Australia[4]. It is now considered that there are two main areas of the new CSDA MDS where the ICF can usefully be applied: A+P 'support needs' and Participation outcomes.

*Activity and Participation support needs*

Because the disability support services provided under the CSDA may address any area of A and P, and because any area of A and P may affect the intensity of support needed, there appears to be no need to split the single list for the 'support needs' question in the new CSDA MDS. What is required, rather, is to:

- Group the A and P chapters so that the groupings are meaningful and not too onerous for service delivery agencies to fill in. Retain the combined 'A and P' name, as it does not seem necessary (in an information sense) to say whether the support provided is directed to A or P but just to that domain.
- Qualify the domains – this will be done using the concepts of difficulty and assistance in a way that maintains consistency with the Australian Bureau of Statistics population survey; these are interpreted as performance related.

The table at Attachment 2 depicts the information to be sought on support needs.

*Participation outcomes*

The over-arching goal of the CSDA is to improve the quality of life for people with disabilities by improving their participation. The Participation domains chosen for this purpose must reflect the broad human rights focus of the CSDA. At this stage it is envisaged that they will be used to:

- Develop a 'Participation module' as a long-term outcome measure. Service funders and providers can use this module for any related administrative purpose e.g. client review at various stages, overall assessments of quality of life, overall service and needs planning, periodic client satisfaction surveys. The module would produce data as comparable as possible to those collected in the broader ABS population survey. 'Qualifiers' would have to be developed but, in the first instance, we are starting with the qualifiers in the NCSDD (AIHW 2000), as they are based on quite extensive research and development (see current draft information framework at Attachment 3).
- Provide a high level framework into which more service-specific outcomes (related to service specific goals) can be mapped. This will ensure that the service specific outcome indicators relate to the overall CSDA outcome indicators and thence to some population measures[5].

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[4] The Institute is working with senior disability administrators in the nine Australian jurisdictions to redevelop the national data set for disability support services provided under the Commonwealth / State Disability Agreement. This is a national ($2.5 billion) program for people with ongoing support needs, over 50% of whom have an intellectual disability as their primary disability.

[5] For instance, one of the CSDA high level goals could be interpreted to be increasing participation in employment. Participation outcomes for CSDA clients could be compared to the rest of the population by ensuring that the high level participation module uses national data items such as labour force status (used in labour force surveys and in the ABS disability survey). Service-specific goals for employment

Thus, for this application (the CSDA MDS redevelopment) we are finding:

- Purpose and measurement needs will drive the A-P split, along with the WHO definitions, our draft criteria, the domains and the qualifiers.
- It is useful to be able to use the full single list as A+P. 'Support needs' do not focus exclusively on A.
- The key data-related decision here was the delineation of P, that is, to select suitable domains for P. Because of the broad, human rights ethos of the CSDA, there may be conceptual pressure to include parts of the communication, mobility and domestic life domains in Participation for the CSDA (see disputed areas of Table 1).
- It may, in general, be hard to restrict the domains of P to the point where a universally agreed set of P domains, not overlapping with any A domains, also 'fills the bill' for the CSDA.

This process of data development seems again to confirm the possible utility of Options (b) or (d).

## Qualifiers of A and P

It is logically obvious that if any domain can be used for either A or P, then the delineation between A and P must involve the use of different qualifiers. The above discussion of one (developing) application in Australia illustrates how this inevitably follows—see Attachments 2 and 3.

In ICF terms, this would seem to mean that, if Options (b) or (d) are adopted, then countries must adapt the 'uniform qualifier' into suitable language for A and P separately.

There is also the closely related issue of calibration of the 'generic' or uniform qualifier. Applications cannot wait for such calibration, or for a plethora of new tools to be developed around the new classification, (especially if the focus is clinical). The reality is that many existing assessment tools are in use, and are firmly embedded in measurement and even payment methods in services around Australia (and around the world probably).

In Australia such calibration and mapping has already been undertaken in the disability data development described above (to confirm the feasibility of collecting data as in Attachment 2). It should also be undertaken in new developments including aged care 'dependency' measures, health status measurement, and in assuring continuing alignment of disability population surveys with the new ICF[6]. Such work will enable final data elements in the NCSDD to be fully useable in the range of applications to which the new classification should be applied.

The challenge then is: how to use the classification in a consistent way when so much work remains to be done on qualifiers i.e. **measurement**.

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services are articulated as helping people get jobs, and the existing indicators agreed between service funders and providers record the number of jobs gained over a period, the duration of jobs etc.

[6] The Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers is now undertaken at five-yearly intervals. Since the first survey in 1981 it has been reasonably well aligned with some ICIDH concepts. The ABS has been involved in the ongoing discussion in Australia on ICIDH development and is presenting a paper at this U.N. seminar.

Measurement is a topic on which the new classification offers little enlightenment, particularly in relation to Participation. In 1999 I spoke about a range of measurement issues that needed consideration in the ICF (Madden 1999), including:

- the need to clarify purpose before deciding method;
- the importance of understanding the role played by 'perception' in measurement (i.e. who measures — sometimes oversimplified as a distinction between 'objective' and 'subjective');
- the vital role played by people with disabilities in the ICF revision and the hope that this more inclusive model of development would permeate the other members of the WHO 'family of classifications'.

I cannot go into detail on these thoughts and indeed concerns, but they are all still there almost two years later.

A possible way forward is to use more of the work that was done during the revision years and again develop some protocols for sharing experience as the calibration work proceeds. Language and concepts relating to separate qualifiers for A and P was developed during the years of revision, for instance the language of 'difficulty' and 'assistance' for the Activity dimension[7]. This language, while still to be found within the final version, was well developed in the revision years and could be more fully used to operationalise Options (b) and (d). In Australia we carried out work on Participation qualifiers, and these are now included as trial data elements in the NCSDD.

International communication on such qualifiers would be of value, including a framework:

- for developing language, concepts and measures for A and P qualifiers;
- of protocols for calibration in a broad range of fields of application;
- of methods for sharing and publishing results, to promote discussion, quality and consistency.

We cannot move on measurement of P without such a development framework, because the answers are not in the classification.

### Next steps on A and P and related qualifiers

The process thus far suggests that, increasingly, people will want to experiment with different approaches. This was actually envisaged by WHO.

Next steps in the Australian context are likely to include:

- continuing work on the types of data development outlined in this paper —this will need to look to international consistency, use the best available tools, and try to avoid locking other Australian applications into non-tenable positions;
- encouraging people in a number of major areas of application to have the same discussion and development as is outlined above for the CSDA;
- in particular, engage in discussion of health application;

[7] A paper by the Netherlands CC was influential in this regard, and provided a useful review of a range of related assessment measures (van Buuren et al 1996).

- organise wider consultation within Australia and stay involved in the international communication;
- ultimately, revise the data elements for the NCSDD.

If these are the next steps, then during the implementation of the new ICF in Australia, it may be fruitful actively to promote testing and development within broad spheres of application. This would allow the ICF to be more widely explored and reported on for a period, as various application areas come to grips with it. For instance, we could:

- adopt Options (b) or (d) and not immediately insist on a clear split of domains for all purposes;
- encourage a sensible framework for testing, development and reporting on reasoning and results (see above for qualifiers);
- prepare principles for use, and protocols for recording practice and reasoning; the principles would include careful adherence to the ICF definitions, possibly via something like our draft criteria, suitably enhanced, and 'translated' for the particular application.

### The 'information matrix'

If we do indeed adopt Option (b) or (d), then we are creating an expanded information matrix. If, for instance, Australia opted to use the qualifiers in our NCSDD (AIHW 2000) then our expanded matrix could look like Table 2 (drawn to correspond to Option (b)).

The matrix illustrates the fact that those who use certain domains as either A and P, and thus an expanded interpretation of the qualifiers, must then choose what they include in 'the' information matrix submitted to WHO. WHO has flagged they want to receive only 'the' matrix (see for instance in Section 2 above concerning 'the official coding style'). If they wish to use the 'information matrix' as an international framework for information sharing, they may wish to work with those countries who are using an expanded matrix to ensure they receive results that can be combined on an international basis.

Again, there appears to be work to be done before we can deal with the matrix. And again it would appear useful to work towards an international modification (or, failing that, a multinational modification), within the boundaries set by the new classification. The less satisfactory alternative is to allow national modifications to emerge and deal with international consistency later.

Proactive international effort would seem preferable, as the matrix will surely be a component of any WHO framework for health status measurement. Does it matter if perhaps only Activity is a component of international health status measurement? Perhaps not, as long as it is appreciated that health status measurement does not, then, incorporate the full framework of human functioning.

Table 2. Expanded information matrix for Option (b) — some A-P overlap

| Domains | Qualifiers | | | | |
|---|---|---|---|---|---|
| | Performance | | | | Capacity |
| | Activity | | Participation | | |
| | Difficulty | Assistance | Extent | Satisfaction | |
| Learning & applying Knowledge | | | | | |
| General tasks and demands | | | | | |
| Communication | | | | | |
| Mobility | | | | | |
| Self Care | | | | | |
| Domestic life | | | | | |
| Interpersonal interactions and relationships | | | | | |
| Major life areas | | | | | |
| Community, social & civic | | | | | |

Key:

| | |
|---|---|
| | Domains less likely to relate to Participation |
| | Domains less likely to relate to Activity |
| | Domains that may relate to Activity or Participation |

Shading is illustrative only, not a recommended split of the domains.

The four performance qualifiers are as in AIHW 2000 (data dictionary)

## Capacity

Table 2 also neglects (so far) to take up the challenge of the 'construct' of 'capacity' and its relationship to an ideal or standardised environment. This 'construct' appears to relate to a conceptualisation of health that distinguishes between 'within the skin' factors and external factors. This distinction in turn relies on the notion of a separate individual with intrinsic capacity, where better health outcomes can be promoted by health interventions and environmental modifications. This approach is based in an egalitarian, human rights philosophy and has much to commend it in theory[8]. In practice it provides extreme challenges to measurement. Conceptually it also appears at odds with the more organic or ecological inter-relationships pictured in the ICF diagram.

The need to introduce the idea of 'capacity' into the classification is driven at least in part by the desire to measure the performance of health systems and how well they are closing the gap between capacity and performance. This purpose brings with it the need to define and confine the scope of the health system, not holding it accountable for measures that, while promoting good human health and functioning, are beyond the scope of many health systems. This is all well enough if our aim is just to assess health systems. But if we are hoping also to assess the level of health and human functioning, it is inadequate.

Much of this debate is yet to take place, but these possibilities remind us of the importance of operationalising the concept of Participation, and working on its measurement. The risk of not doing so is to lose the concept of Participation altogether.

The ICF is intended to be grounded in a human rights philosophy, and its relationship to the UN Standard Rules on Equalisation of Opportunities for Persons with Disabilities is acknowledged. Operationalising these Rules, however, does not require the introduction of 'capacity' but relies on performance ie the actual participation experience of people with disabilities.

## The E dimension and its qualifiers

How do the ideas, outlined so far, fit with the Environmental Factors? Because of the definitions of Activity and Participation, and of capacity and performance, the A and P (with qualifiers) are not meaningful without E also being coded. This is, of course, in line with the definition of Participation and the whole philosophy that disability is largely environmentally determined. The rising reported prevalence of ADHD (attention deficit hyperactivity disorder) illustrates this point. Can we adequately report on such changes in prevalence without also being able to quantify changes in school organisation, community tolerance of certain behaviours, as well as changes in medical practices, pharmaceutical resources and the rates of prescribing of related drugs?

It was noted above that WHO offers three coding conventions for E, essentially to code factors:

a) as they affect the person overall;

b) as they broadly affect each of body structure and function, activity and participation;

c) against every single BS, BF, A or P code used.

Beta testing in Australia generally revealed reluctance for the third option, at least for the test 'vignettes', not only because it was very labour intensive, but also because of the duplication involved—a number of environmental factors occurred repeatedly as impacting on more than one code in another dimension.

Nevertheless there may be applications where it will be important to relate each environmental factor to each individual impairment, activity limitation or participation restriction. There may be other applications where one of the other two options may provide information adequate to the purpose (or where data design will be required to obtain summary information in the interests of 'provider burden').

Within the one application it could be possible to use more than one option. For instance, in the data development described above for national disability support services the following possibilities are being contemplated:

- the use of Environmental factors (personal assistance and equipment) to help describe support needs in areas of A and P (essentially an example of (c)—see Attachment 2);
- the presence of a family member or friend who regularly assists, as an overall environmental descriptor (example of (a));
- the need for equipment or environmental modifications as indicators of specific unmet needs (again essentially (a)). (This is a way of investigating the 'gap' between the ideal environment and the actual one, and an alternative to introducing a theoretical 'capacity' measure for the same purpose.)[9]

These are relatively minor adjustments of a national data set to incorporate the classification, but they will still represent progress.

The qualifiers of the Environmental factors are well conceptualised. Because of their newness, it will be important systematically to record and share information and experience as they come into more and more common use. As practice builds up, calibration will be important here too.

The more general challenge is to ensure that we use this new aspect of the classification to its fullest extent and, each time we use the classification, to ask whether we have adequately incorporated environmental factors into our applications.

## 4. Conclusion: ICF as an information framework

This is an exciting and challenging time. The new classification has significant implications for national and international data collections, both in terms of the content of the collections and the scope of collections that could be affected.

On the four topics discussed in this paper, the following conclusions have been suggested:

- On the A-P list and the possibility of delineating A and P on domains alone: This paper suggests agreement may not be possible. One Australian application now being attempted (described here) illustrates the benefits of using the flexibility that is offered by the classification, with the new combined list and the options for use. Options (b) or (d) appear attractive.
- The qualifiers remain a major issue. That is, measurement (the topic of this paper and this session) is largely unresolved by the classification, and much work remains to be done if we wish to avoid fragmentation in the early years of implementation. Progress is important because of the persisting possibility that some applications, particularly those with large resources, will swamp those that move more slowly or are less adequately resourced. It will be important to build up knowledge about measurement, and its purpose, method and the impact of the perspective of the measurer. If Options (b) or (d) are used for A and P, then different qualifiers are needed and work done during the revision years can be mined for this purpose, rather than starting afresh.

[9] Note: This approach, if generalised, could be assuming that all underlying 'capacities' are equal, and all we need to know about is performance and environment.

- The information matrix will need further elaboration, to incorporate the options chosen for Activity and Participation and their qualifiers.
- The Environmental factors dimension, like the others, will benefit in its application from a systematic sharing of knowledge and experience. The more general challenge will be to ensure that it is fully implemented.

This paper has outlined some current Australian thinking on the general topic of ICF implementation and, in particular, measurement challenges for Activity, Participation and Environment. Many other countries and individuals are no doubt seeing many other possibilities. This likely diversity only reinforces the main theme emerging from the discussion in this paper: the ICF is a valuable framework but it needs more work to put flesh on its bones.

The new ICF is likely to prove invaluable as a conceptual and information-oriented framework for a wide range of applications relating to human functioning. These applications may be about to expand significantly. In order to harness and harmonise the rapid progress that is now likely to occur, a development schema would appear to be useful. The goal of such a schema would be to promote coherent ongoing development, and consistency where that is achievable, and it could include something like:

- criteria, principles and protocols for the use of the Activity and Participation dimensions, depending on which of the WHO options is chosen by the user;
- a template for recording experience, purpose, practice and reasoning so as to facilitate the exchange of information about development in all four areas discussed in this paper;
- guidelines for calibration, refining, mapping and relating of existing measures and assessment tools to the ICF, and for the development of new ones;
- methods of sharing and publishing results, to promote discussion, quality and consistency.

We cannot operationalise Participation, let alone measure it, without further development, because the answers are not in the classification. We may actually risk losing the concept of Participation without consistent international development on at least some of the issues outlined in this paper.

In our recent discussions in Australia the analogy was drawn with the introduction of new legislation, and the ensuing process of building up case law and ultimately regulations. Now the ICF is law, we need a systematic way of developing and sharing knowledge and experience with case law. It may be only then that we can finalise the 'regulations' – the coding rules and infrastructure indicated during Beta-2 testing to be needed to support sound implementation.

Internationally we have just finished an exhaustive and exciting process. Collectively we have developed, tested and argued, shared ideas, and tried to seek common ground in the interests of a more valuable and inspirational classification. We now have a new classification. It seems likely that we must continue our collaborative work and our vigorous discussions.

In this spirit, I look forward to comments on this paper.

## References

Australian Institute of Health and Welfare (AIHW) 2000c. National community services data dictionary. Version 2. Canberra: AIHW. (See also www.aihw.gov.au)

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World Health Organization 2001. International classification of functioning, disability and health (ICF). Final draft, full version. Geneva: WHO.

**Attachment 1: Disability data element from Data Dictionary (AIHW 2000)**

# Disability

| *New* | *Status* | *Effective Date* | *Reg. Auth.* | *ID No.* |
|---|---|---|---|---|
| | TRIAL (WHO field trial) | 1/07/2000 | NCSIMG | 000561 |
| *NCSI Model Location* | | | *Data Class* | *Version* |
| Person characteristic/ disability characteristic | | | Cross-Program | 1 |

## Identifying and definitional attributes

***Data element type:*** DATA CONCEPT

***Definition:*** Disability is a multi-dimensional and complex concept. Disability is defined in terms of three dimensions (WHO, 1999): Body structures and functions / impairments, Activity / activity limitation and Participation / participation restriction. Disability is the presence and nature of one, some or all of these dimensions associated with current or previous related health conditions, disease or injury. The three dimensions focus in turn on aspects of functioning and disability relevant to: the body, the individual person, and the person in society. The experience of disability is variable over time and affected by external environmental factors as well as internal personal factors.

***Context:*** Many different definitions of disability are used in Australia, both in administrative data collections and in Acts of Parliament. The consistent identification of disability in national data collections has been recommended in a number of reports, so as to enable:

- the monitoring of access to generic services by people with a disability;
- the collection of more consistent data on disability support and related services, including data on service use by different groups; and
- population data and service data to be related, thereby improving the nation's analytical capacity in relation to the need for and supply of services.

People with a disability often have a need for a variety of support services including day activity, employment, education, home care and accommodation. Defining disability will make it possible to determine the number of people who are accessing services, both disability specific and generic, and also those with a disability in the general population with unmet need. Better definition of disability will aid better targeting of resources to those in need.

## Relational attributes

***Collection methods:***

The concept 'disability' can be made operational as a derived data element by using a combination of related data elements as building blocks.

The data elements selected may vary depending on the definition of disability used. For example in hospital based rehabilitation the focus may be on the impairment and activity dimensions and in community-based care the focus may be Participation primarily. Some applications may require a broad scope for inclusion (eg. discrimination legislation). Data collections relating to services will select combinations of the data elements, which best reflect the eligibility criteria for the service.

***Related data:***

An explanation of the disability data elements and their interrelationship is contained in the Information annex, 4.4 Disability.

Related to the data elements:

Body structures v.1,
Body functions v.1,
Impairment extent v.1,
Activity areas v.1,
Activity—level of difficulty v.1,
Assistance with activity v.1,
Participation areas v.1,
Participation extent v.1,
Participation—satisfaction level v.1,
Environmental factors v.1,
Environmental factors—extent of influence v.1,
Disability grouping—Australian national v.1,
Disability grouping—International v.1

Related to the National Health Data Dictionary Version 8.0 data elements Principal diagnosis and Additional diagnoses.

## Administrative attributes

***Source document:***

WHO: 1999. ICIDH-2: International Classification of Functioning and Disability. Beta-2 draft, Full Version. Geneva: World Health Organisation.

***Source organisation:***

World Health Organisation

***Comments:***

The data elements relating to disability are based on the draft ICIDH-2, Beta-2, 1999, as the best available conceptualisation suitable to the purpose. The Beta-2 draft is subject to systematic field trials and further consultation until 2001. Use of the ICIDH-2 has not been endorsed by WHO Member States. Endorsement by the World Health Assembly is scheduled to be sought in 2001. Further

information on the ICIDH-2 can be found on the WHO website: http://www.who.ch/icidh

The dimensions of the ICIDH-2 are defined in relation to a health condition. 'A health condition is an alteration or attribute of the health state of an individual that may lead to distress, interference with daily activities, or contact with health services. It may be a disease (acute or chronic), disorder, injury or trauma, or reflect other health-related states such as pregnancy, ageing, stress, congenital anomaly or genetic predisposition' (WHO, 1999). There are a number of ways to record a health condition. An ICD-10 code may have been recorded (See National Health Data Dictionary Version 8, 1999 data elements, 'Principal diagnosis' and 'Additional diagnosis'). A diagnosis may have been reached, after assessment, of the nature and identity of the disease or condition of the person. For further information on disability see the Information Annexe – Disability.

## Attachment 2: Support needs framework (i.e. 'information matrix')

### How often do you need help or supervision in the following life domains?

| I undertake activities (or participate) with this level of assistance (or would require this level of assistance if the person currently helping me were not available) | I am unable to do or always need help or supervision in this area | I sometimes need help/supervision in this area | I do not need help or supervision but use aids or equipment | I do not need help or supervision and I do not use aids or equipment | Not known | Not applic-able[1] |
|---|---|---|---|---|---|---|
| **Self-care** e.g. bathing, dressing, eating, toileting. | | | | | | |
| **Mobility** e.g. getting around in the home or a place away from home, getting in or out of bed or chair. | | | | | | |
| **Communication** e.g. ability to make self understood and to understand others. | | | | | | |
| **Domestic activities** e.g. shopping, organising meals, cleaning, disposing of garbage, housekeeping, cooking, home maintenance. | | | | | | |
| **Learning and applying knowledge** e.g. understanding new ideas, remembering, problem solving, decision making, paying attention, | | | | | | |
| **General tasks and demands** e.g. undertaking single or multiple tasks, carrying out daily routine | | | | | | |
| **Handing money** e.g. actions and tasks needed to budget, use banks and perform financial transactions. | | | | | | |
| **Interpersonal activities** e.g. actions and behaviours that an individual needs to make and keep friends and relationships, behaving within accepted limits, coping with feelings | | | | | | |
| **Education** e.g. the actions behaviours and tasks an individual needs to perform at school, college, or any educational setting | | | | | | |
| **Working** e.g. actions, behaviours and tasks needed to obtain and retain paid employment | | | | | | |
| **Community, social and civic life** e.g. involvement in community life, recreation and leisure, religion and spirituality, human rights, political life and citizenship | | | | | | |

1 Not applicable is used when an activity is not appropriate for the person usually due to age, for example self care for an infant or employment for a child in school.

2 Note: this is not a question but rather an 'information matrix' i.e. a depiction of the information sought.

**Attachment 3**

## Draft Participation 'module' or framework (i.e. 'information matrix')

| **Life domain** | **Extent of participation (judged by service provider)** | | **Satisfaction with participation (judged by consumer, with advocate if necessary)** | |
|---|---|---|---|---|
| | **It is possible and desirable that participation in this domain could be enhanced** | **There is no need for or possibility of enhanced participation in this domain** | **I am not satisfied with my participation in this domain and would like to change the duration, frequency, manner or outcome of my participation in this domain.** | **I am satisfied with my participation in this domain (i.e. not a priority to change)** |
| Participation in communication and conversation | | | | |
| Mobility within the physical and social environment (community?) | | | | |
| Participation in domestic life | | | | |
| Participation in interpersonal interactions and relationships | | | | |
| Participation in education, work and employment (need to split?) | | | | |
| Participation in community, social and civic life (community, religious and economic life, recreation and leisure, politics and human rights) (need to split?) | | | | |