Introduction

Modern health systems recognise the importance of human functioning in addition to diagnosis and disease prevention. Thinking about how people manage their lives on a day-to-day basis is important – in fact inevitable – in the context of chronic disease, mental health, ageing and disability. The increasing number of people living with chronic conditions and disabilities requires the development of coherent whole-of-government policies and information systems, aligned with and supporting integrated, comprehensive and inclusive services. In other words, we need to see the same person and understand their difficulties in functioning through the same prism, whether they are encountering a health service, the education or transport system or in their daily work. As reported in the World report on disability (WHO and World Bank, 2011) understanding functioning across all domains of life and providing integrated services is essential to realise participation and productivity.

In this paper we focus on the infrastructure needed to achieve this goal: common values reflected in over-arching policy instruments; shared concepts about functioning; related, coherent and enabling policy parameters (e.g., about eligibility); and coherent and consistent data to support efficient and effective costing and development, monitoring and evaluation, and responsive systems.

There are now international resources that provide key elements of the infrastructure to achieve the goal of integrated, comprehensive and inclusive services. This paper discusses related infrastructure requirements, drawing chiefly on examples from Australia and also reflecting a wider discussion, especially that promoted worldwide following the release of the World report on disability.

Common values and shared concepts about functioning are available

The UN Convention on the Rights of Persons with Disabilities (CPRD) provides a philosophical and moral framework that recognises disability rights as human rights and mandates integrated and strategic policy for States Parties. The World report on disability urges the preparation of coherent national plans to ensure the vision of the UN Convention is achieved – namely that people’s participation in society is enabled, as their right, and that they have access to all ‘mainstream’ services and, when needed, to specialist supports (WHO and World Bank, 2011).

The International Classification of Functioning, Disability and Health (ICF) provides a technical framework consistent with the CPRD. It recognises the multi-dimensionality of human functioning and disability in terms of body functions and structures (and impairment thereof), activities (and activity limitations) and participation (and participation restrictions). Crucially, the ICF also recognises that functioning varies with environment. That is, when difficulties in functioning are identified, these need to be understood in relation to their environment and the physical, social and attitudinal barriers that may exist in that environment. The ICF provides classifications for each component – body functions and structures, activities and participation, environmental factors – to enable consistent national and international data to be assembled.

How are these frameworks translated to coherent policy parameters?

The evolution in using these frameworks in major services in Australia illustrates the complexity for countries with large pre-existing programmes. Other countries, with fewer or less rigid programmes, may be able to move more quickly to incorporate these frameworks into policy and data.

The Australian Disability Support Pension (DSP)

In Australia the main income support payment for people with disabilities, the Disability Support Pension (DSP), is in the process of emerging from the ‘medical model’ of disability towards one that takes an approach closer to considering functioning in its current standard meaning (ICF). Historically the assessment of eligibility for the DSP has been a two-stage process:

- the assessment of ‘impairment’ (identified as a medically defined condition), and
- the assessment of ‘continuing inability to work’ or (its administrative name) ‘job capacity’.

While the Social Security Act 1991 and its schedules state that ‘impairment’ is being assessed, the assessment in fact often involves, in ICF terms, consideration of a range of activity limitations and participation restrictions. Phrases such as ‘difficulties with everyday activities’ are used frequently in the instructions on how to assess the ‘severity’ of impairment.

The use of the term ‘impairment’ in the Social Security Act is thus quite different from the term as now understood in the international standard, the ICF, the assessment of ‘impairment’ involves consideration of the health condition, impairment of body functions and structures and often also activity limitations or participation restrictions. The environmental context is also implicitly evaluated, as many of these limitations or restrictions are couched in terms of ‘norms’ or cultural appropriateness.

Does this mixing of concepts – medical and functional – matter? There seem to be several reasons why the mixed concepts do indeed matter and why clarification of concepts would be an advantage:
Lack of clarity can be accompanied by a lack of ability to extract meaningful data from the records, leading to a lack of understanding of anything more than eligibility – there is no health or disability profile of recipients and hence a related loss in capacity to understand trends.

• The more the ‘impairment’ tables of the Act consider broad aspects of functioning, the more they are potentially duplicating the second stage of assessment: job capacity.

• A very common condition associated with DSP receipt is psychiatric disorder, and using the ICF framework for assessment may have advantages. For instance, the extra effort that those with a psychiatric condition report having to make in order to achieve their functional capacity (e.g., to overcome poor motivation or anxious cognitions) can be assessed. This approach may help disentangle the underlying impairment from commonly cited difficulties at work such as perceived pressure or relationship issues.

In recent years there has been greater emphasis on promoting return to work via the job capacity assessment process; ideally this includes attention to barriers in the environment. Most recently there has been an attempt to reframe the ‘impairment tables’ by making more use of ICF concepts and simultaneously to limit access to the DSP. It remains to be seen how much this attempt clarifies the separate components of functioning and enables transparent and equitable access to this income support.

Disability support services in Australia

The Australian National Disability Agreement (2008) sets out agreements among the national and the eight state and territory governments about responsibilities for disability services but is silent on eligibility for specialist disability support services. This is in contrast to the previous national agreement, which stated that, for its purposes, ‘people with disabilities’ meant people with disabilities attributable to any of a wide range of impairments, likely to be permanent, and resulting in the need for significant ongoing and/or long-term episodic support in self-care/management, mobility and/or communication.

While the language of disability support services still focuses on these three areas of activity limitations, the data collected about the recipients illustrate the importance of having a full picture across all the ICF domains of activities and participation. The data show that the support needs of recipients are relatively high:

• Almost 70 per cent of service users needed support in education, work and/or community life.

• Around 70 per cent needed support in interpersonal interactions and relationships; learning, applying knowledge and general tasks and demands; and domestic life.

• Some 50 per cent needed support in self-care, mobility and/or communication (2007–08 data from AIHW, 2009).

This last figure compares with 6.3 per cent of people of all ages in the general population who needed assistance with self-care, mobility and/or communication in 2003.

An enhanced national scheme for disability and long-term care is being developed in Australia at present (Productivity Commission, 2011). It is to be hoped that its eligibility criteria and data will relate to the full scope of functioning encapsulated in the ICF and the CPRD.

Health systems

New directions in health and human services envisage ‘person-centred’ services capable of supporting people over time and across system components (Madden et al., in press). To be person-centred – across systems and time – requires interconnectedness of all system components. This interconnectedness should be supported by a language for communication among individuals using the systems, professionals working in the systems and those framing policy. For interconnected information, a common language is needed about functioning as well as disease. There is much greater scope for using the ICF in health systems planning, costing, resource allocation and outcome measurement.

The ICF and WHO’s International Classification of Diseases (ICD) together form a complete basis for describing health and functioning of individual people and populations. The ICD is the standard classification and code list for disease monitoring and related health information systems. The use of the ICD in the formulation of national hospital statistics is unquestioned in Australia, and it has underpinned strong national data on mortality and morbidity for many years. The ICF should be similarly embedded as the basis for data on functioning and disability. The use of both together will provide a full understanding of health.

Coherent and consistent data to support monitoring, costing and development

There is mixed experience as yet with implementing international data concepts fully in Australian data collections.

National statistics bodies

The two main national statistical organisations – the Australian Bureau of Statistics (ABS) and the Australian Institute of Health and Welfare (AIHW) – use the ICF in national data collections. Disability survey questions, a related census question and disability modules in health and social surveys are based on the ICF as an international standard. This consistency of disability concepts across social surveys and the census means that people with disabilities are ‘visible’ in the population, establishing information about their health, housing and economic status in comparison to the rest of the population. For instance, by using consistent disability concepts across disability and Aboriginal and Torres Strait Islander social surveys, it was possible to estimate disability rates among this numerically small but nationally important population group; adult Indigenous people were found to have more than twice the rate of disability of other Australians (ABS and AIHW, 2005).

National data standards and coordination

Australia’s system for setting national data standards in health and community services was established to promote consistency in these sectors (Madden et al., 2003). The standards are approved by senior administrators in each sector in each jurisdiction as well as by national statisticians. ICF-related national data standards are available online, comprising a suite of metadata items covering all dimensions and domains of the ICF (NCSDC, 2008).
The benefits in using such standards are numerous, including efficiency in design effort and the possibility of building a coherent statistical system that provides information about functioning in whatever setting, with each source adding to integrated national knowledge. The value of ensuring that population data (indicating need and demand) and disability services data (on supply) are based on the same concepts has been illustrated by studies of unmet demand for disability support services that have highlighted the need for new funding (references in Madden et al., 2011).

**National data design for disability support services**

National data about Australia’s disability support services and recipients are collated from thousands of services each year in a National Minimum Data Set comprising 14 questions about service outlets and 17 questions about service users. One question relates to people’s ‘support needs’, based on the ICF activities and participation domains and also on the disability population survey question on frequency of need for support (see, for example, AIHW, 2009).

The question about ‘support needs’ (the need for personal help or supervision) was designed so as to be comparable with the main population data, enable the results from the main assessment tools in the field to be recorded using it and be consistent with national data standards based on the ICF. The result of development, consultation and testing was a ‘data capture matrix’ comprising rows reflecting the nine ICF activities and participation domains and columns reflecting the national survey question (see Table 1). For each of nine life domains, there are (essentially) three simple categories for the frequency of need for support: needs no help/supervision; sometimes needs help/supervision; always needs help/supervision. This simple two-dimensional data capture framework has useful and desirable statistical qualities, and enables

### Table 1

<table>
<thead>
<tr>
<th>LIFE AREA</th>
<th>Unable to do or always needs help/supervision in this life area</th>
<th>Sometimes needs help/supervision in this life area</th>
<th>Does not need help/supervision in this life area</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Self care</strong> e.g., washing oneself, dressing, eating, toileting</td>
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<tr>
<td><strong>Mobility</strong> e.g., moving around in home and away from home (including getting out of bed or chair, walking, using transport)</td>
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<tr>
<td><strong>Communication</strong> e.g., making oneself understood and understanding others, in own spoken language or with preferred method of communication</td>
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<tr>
<td><strong>Interpersonal interactions and relationships</strong> e.g., making and keeping friends, interacting according to social rules, regulating emotions</td>
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<tr>
<td><strong>Learning, applying knowledge and general tasks and demands</strong> e.g., understanding new ideas, remembering, problem-solving, decision-making, paying attention, planning or carrying out daily routine</td>
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<tr>
<td><strong>Domestic life</strong> e.g., organising meals, cleaning, shopping, cooking, disposing of garbage, home maintenance</td>
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<tr>
<td><strong>Education</strong> e.g., the actions, behaviours and tasks a person performs at school, college or in any educational setting</td>
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<tr>
<td><strong>Working</strong> e.g., actions, behaviours and tasks to obtain and retain paid employment (including self-employment)</td>
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<tr>
<td><strong>Community, civic and economic life</strong> e.g., recreation and leisure, religion and spirituality, human rights, political life and citizenship, economic life such as handling money</td>
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</table>

Source: This table is a slight simplification of questions used in the Australian national data collection for disability services (see, for example, AIHW, 2009; Anderson and Madden, 2011). The Australian collection groups some ICF domains together (e.g., community life and economic life) and subdivides others (e.g., work and education are in ‘major life areas’ in ICF along with economic life). The domains in the Australian collection are ordered differently from the activities and participation chapters in ICF.

Note: Examples within life areas can be modified to suit local context – see ICF itself for the full scope of each domain.
the collection of data from thousands of services using varying assessment methods (Anderson and Madden, 2010).

Conclusions

Discussions are active in all regions of the world, following the World report on disability, on how to improve services and related data about functioning and disability, in line with the CPRD, and using the relevant international classification and technical resource, the ICF.

This paper has briefly illustrated the mixed experience in Australia in three major areas:

- Better data could be produced from the large data set emanating from the administration of the DSP. Data could better inform management and monitoring of this costly system if they were recorded in closer alignment with national and international data standards; the health conditions, impairments, activity limitations and participation restrictions could be more clearly and separately understood; and the factors influencing costs and trends more adequately identified.
- Disability services and population data have aligned more closely with the ICF, and cross-cutting policy analysis has benefited accordingly. With policy changes on the way it is hoped that this adherence to the international standard will continue and the body of data from these sources be added to rather than depleted.
- The health system should base its data on both ICF and ICD. Together these international classifications provide a complete basis for describing the health and functioning of individual people and of populations. This could enhance technical and allocative efficiencies in the system.

The CPRD, the ICF and the coordinating structures that enable data standards to be agreed and implemented have all contributed to clarity of concepts and to national data quality in Australia. Nevertheless, there remain challenges in making changes in older systems based on the medical model and on confused concepts of functioning, disability and health.

These same challenges highlight opportunities for other countries that do not have large and rigid systems and can begin afresh. These countries can go straight to the appropriate rights-based model of disability (CPRD) in their policies and to the related, internationally agreed technical resource (ICF) in their data collections.

References


Endnote

1 This article is based on the following paper, in which further references can be found: Madden, R., Glozier, N., Mpofu, E. and Llewellyn, G. (2011). Eligibility, the ICF and the UN Convention: Australian perspectives. BMC Public Health, 11(Suppl 4): S6. www.biomedcentral.com/1471-2458/11/S4/S6 [This special supplement of BMC Public Health contains similar papers from other countries.]

Ros Madden, Elias Mpofu and Gwynnyth Llewellyn work at the Faculty of Health Sciences, The University of Sydney, Sydney, Australia. Ros Madden, MSc, leads the Australian ICF Disability and Rehabilitation Research Program (AIDARRP) and has played a major role in the development of national disability definition, measurement and statistics in Australia. Elias Mpofu, Ph.D., DEd, CRC, is Professor of Rehabilitation Counselling and Editor of the Australian Journal of Rehabilitation Counselling and the Journal of Psychology in Africa. Professor Gwynnyth Llewellyn, PhD, is Dean of the Faculty of Health Sciences and Director of the Australian Family and Disability Studies Research Collaboration. Associate Professor Nick Glozier is the head of the Psychiatry Program at Royal Prince Alfred Hospital, Sydney Medical School, The University of Sydney.