New directions in health care and disability: the need for a shared understanding of human functioning

Abstract

Objective: Human ‘functioning’ is about how people live on a day-to-day basis. This paper sets out the case for adopting a common language about functioning that would improve population health information and information sharing across health and community service systems.

Approach: Modern health systems recognise the importance of human functioning in addition to diagnosis and disease prevention. ‘Functioning’ is important in the context of chronic disease, mental health, healthy ageing, and the right of people with disabilities and their carers to participate in society. We outline major directions in the health system and their relationship to the concept of functioning.

Conclusions and implications: The concept of functioning has not been used explicitly and consistently in Australian health and human service systems, which nevertheless deal with the 20% of the population who experience difficulties in functioning. The International Classification of Functioning, Disability and Health (ICF) is the international standard for definition, classification, information and measurement of functioning. While it has been partially implemented in Australia, it should be used more broadly, across health and community services, as the basis for information on functioning. This is an intended parallel to the use of the ICD as the standard classification and code list for disease monitoring and related health information systems. Monitoring health status and planning interventions and resources require information about people’s functioning in their daily lives as well as their diseases. Such information should be based on the international standards developed for this purpose.

Key words: disability evaluation, activities of daily living, disability, assessment, ICF

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Modern health systems increasingly recognise the importance of human functioning, as well as diagnosis and disease prevention. Functioning is a crucial, though often implicit, component in definitions of ‘health’ that extends beyond the prevention of disease to the promotion of well-being. The purpose of this paper is to make the concept of functioning more explicit and to outline the advantages of its consistent use across health and community service systems.

Approach

Major directions in the health system are outlined and their relationship to the concept of functioning discussed.

New directions in health and disability systems: ‘functioning’ an unacknowledged theme

There is widespread recognition that health and disability systems in Australia must change in order to respond effectively to trends in demography, population health, health system costs, health workforce, and consumer rights, needs and expectations.

New directions in health and human services systems envisage ‘person-centred’ services capable of supporting people over time and across system components. The aligned purposes of two major national inter-governmental agreements (the National Healthcare Agreement and the National Disability Agreement) focus on: the needs of patients or people with disabilities, their families and communities; the maintenance of health, quality of life, participation and inclusion; an integrated approach, across the continuum of care, to all forms of health maintenance and care; and equitable access by all Australians to quality health services. These directions are outlined against the background of population growth and ageing, increasing chronic disease, advances in technology, workforce shortages, and the imperative to address health inequalities, especially with regard to ‘closing the gap’ in Indigenous health.

Three major reports commissioned by the Australian government explicate the changes required in primary health care, in preventive health and in health system redesign. These reports also outline rising community expectations of the health system. Desiderata for care models include: patient-centred; connected and integrated; responsive to people’s needs; and capable of providing feedback information to achieve improvements in quality. A final theme in
all three reports is the need for improved systems, methods and infrastructure: specifically, in access and equity; funding methods; workforce capacity; and information systems capable of supporting integrated care. These health reports discuss service connections self-referentially – for instance ‘stepping down’ from hospital services – but do not identify the key connecting thread for people, namely their ability to function in their usual environment at home and in their communities.

An inquiry into a ‘disability care and support scheme’ to provide long-term care and support on an entitlement basis noted ‘inadequacies in information for planning and co-ordination, which frustrates evidence-based approaches to service delivery and outcomes “and makes it difficult to plan for and manage future costs”. A review of aged care similarly identified the need for person-centred services, better assessment processes and better information.10

Major new directions for Australian health and human service systems thus envisage person-centred services, capable of supporting people over time and across different system components. The necessary interconnectedness requires a language for communication among the people, professions and systems concerned, and for interconnected information – a common language about functioning as well as disease.

The need for a common language about functioning

‘Functioning’ matters. Functioning describes how people are doing in their everyday lives, in the activities they undertake, and in the areas of life in which they participate. An estimated 20% of the Australian population had a disability in 2003 (difficulty in everyday functioning in their usual environment).11 Rates were higher (56%) for people aged 65 years or older. It is estimated that between 2010 and 2050, the proportion of people aged 65 years and older will increase from 14% of the Australian population to 26%.12 Disability involves significant personal, social and economic and older will increase from 14% of the Australian population to 26%.12 Disability involves significant personal, social and economic costs. Services which can assist people to function and participate optimally benefit both the person and society.

Health reform in Australia is about people’s health in the broadest sense, including the maintenance of health and functioning and the promotion of participation, inclusion and quality of life. It is about how to provide and manage systems that support this. Functioning (in terms of difficulties or support needed in daily activities) is often the main indicator of need for services such as mental health, chronic disease management and aged care. For instance, the availability of basic care, appropriate and agreed medication, or informed community attitudes may enable a person with a mental health condition to function and participate easily. Without such environmental supports, the person and their family may experience difficulty and discrimination in day-to-day life.

Without functioning being overtly acknowledged and consistently defined, the stage is set for disconnected services, measurements and funding approaches. People with a complex chronic condition should not be expected to co-ordinate their own care or translate among different professionals – doctors, allied health workers, long-term support workers – who use different terms for, and focus on different aspects of, the person’s overall goals.

The ICF as the foundation for shared understanding

The need for coherent conceptual underpinning in health and disability systems is internationally recognised,13,14 and there is a standard framework and classification for functioning, disability and health to provide it. The World Health Assembly adopted the International Classification of Functioning, Disability and Health (ICF) as the world standard framework and classification system in 2001,15 complementary to the older classification of diseases.16 Functioning and disability can be experienced as effects on any or all of body functions and structures, activities that people do, and participation in society.11 Disability results from the interaction of health conditions with the physical, social and attitudinal environment (Figure 1). The ICF provides definitions, classifications and codes for its major components: body functions and structures, activities and participation, and environmental factors.

Experts from many different disciplines and countries, including experts with disabilities, were involved in the drafting and testing of the ICF. It has been widely welcomed,11,13 and used.19 The ICF is valuable as a unifying and standardising framework of classification at both the individual and population levels, in understanding trends, patterns and policy implications.20 Functioning, as recognised internationally in the ICF, provides the common language to: 1) gain consistent understanding across professional services and with the people concerned; 2) deliver a common basis for measurement; and 3) regularise outcomes definition for interventions.

The benefits of shared basic concepts

ICF has been partially implemented in Australia. National data standards, based on the ICF, have been developed and approved for use across health and community services.21 Australia’s system for setting national data standards provides the infrastructure for connected and comparable information and measurement in these sectors with each source adding to integrated national knowledge.22 There is, however, scope for wider use of these standards.

Population surveys

Shared disability items related to ICF are now used in three major national surveys – on health, mental health, and disability, ageing

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**Figure 1: Interactions among the components of ICF**

[Diagram showing the interactions among the components of ICF: Health Condition (disorder/disease) flows to Body functions & structures (Impairment), which then leads to Activities (Limitation) and Participation (Restriction). Environmental factors and Personal factors are indicated at the bottom.]
and carers. An analysis combining data from all three surveys reveals the poorer health status and higher exposure to health risks of people with a disability.

Rehabilitation

The etiologically neutral ICF framework is ideal to structure consumer/patient problems, particularly in multidisciplinary rehabilitation, where the emphasis of intervention is placed on functioning and improvement of well-being rather than simply the treatment of disease. In this context, the ICF framework has at least three main advantages: 1) to promote improved communication between patients and health professionals, which in turn reduces misunderstanding and improves patients’ understanding of their own functioning; 2) to enable patients to proactively and collaboratively set up their rehabilitation goals, building a stronger alliance with the health-care providers; and 3) to enable rehabilitation professionals to identify individual functioning limitations or environmental barriers and develop a treatment plan that is patient-centred. The ICF framework acts as a ‘road-map’ to delineate the rehabilitation process of restoring functioning by optimising individual strengths.

Condition-specific ‘core sets’ of ICF domains have been developed, for example, in stroke or multiple sclerosis, for implementation in medical rehabilitation practice. Casemix approaches seek to define and fund clinically meaningful groups with approximately equal resource requirements within groups. The two rehabilitation/subacute casemix systems used in Australia are based on commonly used measures of some aspects of functioning, information about length of stay and diagnostic groups (or concepts mixing diagnosis, impairment and activity limitation). AN-SNAP v1 was found to explain only 38% of variance for overnight classes and 29% of variance for day classes, making it a questionable method for funding decisions. Its reliance on the FIM (Functional Independence Measure) is problematic, especially given evidence of limited inter-rater reliability in Australian rehabilitation settings.

An alternative and preferred approach would involve the ICF as the international standard for human functioning to improve existing subacute casemix systems or to develop a new approach to activity based funding as described in national agreements, which recognise the importance of consistent information across the field. Development of casemix models aligned with the ICF has already occurred in other countries. Functional status indicators ‘provided as robust a prediction of health events as did complex comorbidity indices’ and the ICF coding system provided a mechanism for recording such indicators in electronic health records. The ICF enables diagnosis (e.g. Alzheimer’s disease) to be supplemented by information about common associated effects (e.g. effects on memory functions and associated activity limitations such as communication and self care). In Australia allied health practitioners from many disciplines were able to base an Indicator for Intervention, for use in casemix data, on the ICF. Generally, measures that map to the ICF domains are likely to be preferred over time.

Disability programs and databases

Eligibility for long-term support is commonly determined by functioning, disability and the need for support. Relating such criteria to the ICF would produce inter-related disability data without any change in programs. Likewise, eligibility criteria for new programs should focus on functioning (rather than health conditions) and relate to the ICF-related national data standards. There is a lack of suitable assessment tools for a proposed $12 billion national program for disability care and support, and ‘the overarching ICF framework’ is relevant to filling this gap. At the systems level, assessment tools are required for eligibility, long term support, needs assessment and funding. This requires a medium-term rather than a short-term approach to instrument development, nationally.

For example, support for children with developmental disabilities would be distributed more equitably and more effectively if it were targeted according to functional need, rather than diagnosis – that is, using the framework of the ICF rather than the ICD. The ‘Helping Children with Autism’ package supports children with disabilities and their families according to an ICD criterion, i.e. the diagnosis of autism, instead of an ICF criterion. Clinicians report pressure to diagnose children with developmental disability with autism in order to access the package of care, (SE: personal communication). The contribution of ‘diagnostic substitution’ to estimates of the incidence of autism has been documented in the US. The package has since been extended to include children with sight and hearing impairments, cerebral palsy, Down syndrome and Fragile X Syndrome as well as autism. However, if a child has one of the large numbers of other syndromes causing developmental disability, even with severe functional limitations, they are not included.

The ICF is used in the national statistical collection on disability services to structure a ‘data capture matrix’ about the support needs of people. Into this matrix, more than 10,000 disability service organisations around the nation record information obtained from many different assessment methods. The value of the ‘support needs’ questions has been demonstrated. The utility of having population data on demand (or need) and service data on supply based on the same concepts has been illustrated by studies of demand for disability support services.

Conclusions and implications

The next stage is for Australian systems to use the ICF more widely for both population and service data on functioning and disability; for intervention outcome and cost-effectiveness data; and for indicating need for assistance or intervention.

The ICF and 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 has underpinned strong national data on mortality and morbidity. The ICF should be similarly embedded as the basis for data on functioning and disability. The use of both together will often be needed, to provide a full understanding of health. The World
Report on Disability, with recommendations spanning all areas of life and all kinds of services, emphasises the importance of using the ICF to improve worldwide information on human functioning and disability.43

Australia has a proud record in health statistics. Such long term achievements require vision and ongoing effort. The quality of national statistics will decline without national effort to use the ICF. Achieving an enhanced and integrated national information system on health and functioning requires commitment to develop methods and tools based on the ICF, the international standard for this purpose. The Australian health and community services systems provide fertile ground for the next transformation in understanding health and wellbeing of individuals and populations, beyond currently employed disease formulations and approaches.

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