Margaret R. Kyrkou

Abstract

Consequent to the United Nations designating 1981 as the International Year of Disabled Persons, with themes of full participation in community life and equality of life for people with a disability, there was increasing need for global disability statistics. The International Classification of Impairments, Disabilities and Handicaps and resulting International Classification of Functioning, Disability and Health has facilitated World Health Organization analysis between countries, and cross country/cross center clinical and research collaboration, increasing the understanding of the needs not only of an individual, but also the community and region in which that person lives. As life expectancy for individuals with intellectual and developmental disability (IDD) becomes progressively aligned with that of the general population, socio-economic factors are increasingly being recognized as important determinants of health. Although the International Classification of Functioning, Disability and Health does not specifically include those non-health factors such as socio-economic circumstances, the impact of those can be measured indirectly using its framework.

Introduction

Health researchers until the mid-1970s [1] mainly considered the health of populations and research samples in terms of mortality and morbidity, pre-

M.R. Kyrkou, OAM, MBBS, FRACGP, DCCH, Ph.D. (\boxtimes)

Disability and Community Inclusion, School of Medicine, Flinders University, GPOBox 2100, Adelaide, SA 5001, Australia

e-mail: margaret.kyrkou@flinders.edu.au

suming disability had to be associated with poor health. The move towards people with IDD remaining with their families for longer, families maintaining involvement after the person with IDD has left the family home, and the development of smaller, community-based living situations in place of institutions has facilitated earlier identification and treatment of health issues in the community. Increases in lifespan for many [2], and quality of life and social inclusion are being recognized as meaningful health outcomes. Professor Norman Berven, Professor and Chair

of the Rehabilitation Psychology program at the University of Wisconsin stated in his foreword to the International Classification of Function (ICF) [3], 'the ICF holds great promise in facilitating understanding and the formulation of responses to the disability and health-related needs of both individuals and groups'

The International Classification of Impairments, Disabilities and Handicaps (ICIDH) [4], created as a trial version in 1980 by the World Health Organization (WHO), provided a unifying framework for classifying the health components of functioning and disability. Following the trial, after 9 years of international collaboration coordinated by WHO, and after endorsement by all 193 member states, in 2001 the World Health Assembly approved the International Classification of Functioning, Disability and Health (ICF) [3]. The ICF differs substantially from the 1980 ICIDH in the depiction of the difference between function and disability. This difference can be illustrated by comparing two people with the same disability diagnosis, such as one with mild cerebral palsy, the other with quadriplegia. The ICIDH would give the same classification for both, whereas the ICF would indicate them to be markedly different in terms of functional ability. As described in the Introduction to the ICF, it has moved away from the 'consequence of disease' classification of the ICIDH to being a 'components of health' classification.

The ICF complements WHOs International Classification of Diseases-10th Revision (ICD-10) [5], which contains information on diagnosis and health conditions, but does not address functional status. It provides a framework for understanding the impact of social and physical environments on the health of people with IDD, thus leading to the expansion of strategies to address these issues [2]. The ICD-10 and ICF together constitute the core classifications in the WHO Family of International Classifications (WHO-FIC) [3], with the WHO defining health as a 'state of complete physical, mental and social well-being, not merely the absence of diseases and infirmity'. Although philosophically correct, the WHO-FIC lacked the precision necessary for the clinician or researcher. The ICF provides unified and standard language and framework to describe health and health-related states.

In the twentieth century, the prevailing model used in medicine was the biomedical model [6] in which health was conceptualized as an absence of disease, with healthcare providers having the locus of control, deciding what medical care was required without input from the patient. Although this model was effective when managing acute and infectious diseases and illnesses, it was less effective when managing chronic disease, or psychological, social and behavioral dimensions of health. Consequently the bio-psycho-social model evolved, which emphasized the importance of the patient's decisions, behaviors and environment, with the recognition that patient participation in planning is essential for achieving a successful outcome.

Aims of the International Classification of Function

The ICF is not a classification of people. Instead, it classifies people's health characteristics, irrespective of disability, within the context of their individual life situations and environmental impacts. It is actually the interaction of the health characteristics and the contextual factors that results in disability, but the ICF avoids stigmatization by using neutral, if not positive, terms with concrete language throughout, at the same time mindful of 'sanitizing terminology'. At the same time, the ICF seeks to mainstream disability, stating that the experience of disability is a universal human experience. A shift of focus from the cause of disability to its impact puts all health conditions on an equal footing, allowing for more accurate comparison when using consistent terminology.

The ICF has successfully merged the medical model (a condition with a direct cause requiring medical care to effect a cure) and the social model (a condition of predominantly social origin, requiring environmental modification to allow full participation in all areas of social life) to espouse the bio-psycho-social approach, which encompasses health from biologic, individual and social perspectives. It puts the notions of health and disability in a new light, acknowledging that every human being has the

potential to experience a decline in health, and potentially experiencing some degree of disability. The ICF [3] is able to serve both as a basis for assessment and the measurement of disability in scientific, clinical, administrative and social policy contexts.

As a multipurpose classification, the ICF is designed with the specific aim of serving various disciplines as well as different sectors [4], and includes

- Provision of a scientific basis to understand and study health and health-related states, outcomes and determinants.
- Establishment of a common language to be able to describe health and health-related states in order to improve communication between different users, such as health care workers, researchers, policy-makers and the public, including people with disabilities, with a common taxonomy and related knowledge base shared between different disciplines thus increasing the potential for quality care.
- Facilitation of data comparison across countries, healthcare disciplines, services and time.
- Provision of a systematic coding scheme for health information systems.

Although stated separately, these aims are interrelated, as the need for and uses of the ICF require the construction of a meaningful and practical system able to be used by various consumers for health policy, quality assurance and outcome evaluation in different cultures.

Applications of the International Classification of Function

When the ICF was endorsed by the 54th World Health Assembly [3], member states were urged to use it where appropriate in their research, surveillance and reporting and, on request from member states, the Director General would provide support to implement use of the ICF. Since the development of the first Collaborating Centers in Australia, Canada, Italy, India, Japan and Mexico, centers have also been developed in other countries, including Brazil, China, France, Germany, Italy,

Kuwait, Mexico, Netherlands, Norway and other Nordic Countries, Republic of Korea, Russian Federation, South Africa, Thailand, United Kingdom, United States and Venezuela.

Being a health and health-related classification, the ICF is useful for a broad spectrum of applications such as social security, evaluation in managed healthcare, and population surveys at local, national and international levels. It also offers a conceptual framework for information relating to personal healthcare, including prevention, health promotion, and the improvement of participation in healthcare both by removing or mitigating societal hindrances, and encouraging social supports and facilitators to achieve this outcome. It has an added advantage of being able to be used in many sectors including insurance, social security, labor, education, economics, social policy and general legislation development, as well as in environmental modification. As such, it has been accepted as one of the United Nations' social classifications and is referred to in and 'The Standard Rules on the incorporates Equalization of Opportunities for Persons with Disabilities' [3], making the ICF an appropriate instrument for the implementation of stated international human rights mandates, as well as national legislation. The ICF is a powerful tool for evidence-based advocacy, by providing reliable and comparable data to make a case for change. The ICF [3] can be used for multiple purposes:

- A statistical tool for collecting and recording data, such as in population studies, surveys, and management information systems.
- A research tool to measure outcomes, quality of life or environmental factors.
- A clinical tool in needs assessments, matching treatments to specific conditions, vocational assessment, rehabilitation and outcome evaluation.
- A social policy tool of use in social security planning, compensation systems, policy design and implementation.
- An educational tool of use in curriculum design, to raise awareness, and undertake social action.

The ICF [3] also offers a conceptual framework for information applicable to personal health

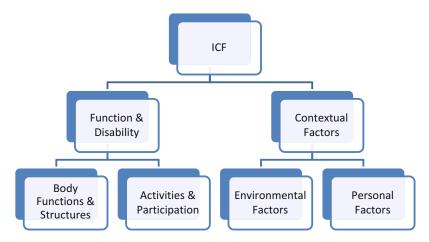


Fig. 12.1 Organization of the international classification of function

care, health promotion, evaluation and policy formulation for health care systems. In addition it improves participation by removing or mitigating societal hindrances, and encouraging the provision of social supports and facilitators.

Components and Domains

The international classification of function has the following components (see Fig. 12.1):

Part I. Components

Body functions and structures, organized according to the body systems [3].

- Change in body function, interpreted through changes in physiological and psychological systems.
- Change in body structure (replaces term organs used in ICIDH) [4], interpreted through changes in anatomical structures.

A significant problem in body function or structure is considered an impairment.

Activities (execution of a task or action by an individual) and participation (involvement in a life situation) covers the complete range of domains denoting aspects of functioning from both individual and societal perspectives.

- Capacity
- Performance

Difficulty in executing an activity is described as an activity limitation, and problems experienced when trying to participate in life situations are described as participation restrictions.

Part II. Components

- Environmental factors, factors in the physical, social or attitudinal world, which impact on all components of functioning and disability, organized in sequence from the individual's most immediate environment to the general environment.
- Personal factors [3] are not yet classified in the ICF due to the complex nature of social and cultural variation.

Coding Guidelines

As the ICF [3] classifies health and health-related states, it requires a series of codes to be assigned best describing the profile of the person's functioning. The functioning of a person can be affected at the body, individual and societal level, requiring the user to take into consideration all components of the classification, including body functions and structures, activities and participation, and environmental factors. The following prefixes denote the first alphanumeric digit of the specific code:

- b for Body Functions
- · s for Body Structures
- d for Activities and Participation could be a or p to specifically denote activities or participation
- · e for Environmental Factors

The first prefix is followed by the first qualifier (descriptor), which indicates the extent of the impairment. The scale ranges from 0 to 4, where 0 indicates no impairment, and the 4 indicates complete impairment.

The first qualifier is followed by the second qualifier, indicating the nature of the impairment. The scale ranges from 0 to 7, where the 0 indicates no impairment, and the 7 indicates qualitative changes in structure, including accumulation of fluid.

The second qualifier is followed by the third qualifier, which describes the location of the impairment, with the scale ranging from 0 to 7, with the 0 indicating more than one region, and numbers indicating the side and part of the body affected.

All three qualifiers have both a qualifier number 8 'Not specified', and a qualifier number 9 'Not applicable'.

Human function and disability is systematically grouped by health and health-related domains, with chapter numbers within each domain, and examples of what is contained in each chapter.

Body Functions

- Chapter 1. Mental Functions (memory function, intellectual functions).
- Chapter 2. Sensory Functions and pain (hearing function, smell function).
- Chapter 3. Voice and speech functions (articulation functions).
- Chapter 4. Functions of the cardiovascular, hematological, immunological and respiratory functions (blood pressure functions, respiratory muscle functions).
- Chapter 5. Functions of the digestive, metabolic and endocrine systems (ingestion functions, endocrine gland functions).
- Chapter 6. Genito-urinary and reproductive functions (menstruation functions).

- Chapter 7. Neuromusculoskeletal and movement-related functions (mobility of joint functions).
- Chapter 8. Functions of the skin and related structures (repair functions of the skin).

Body Structures

- Chapter 1. Structures of the nervous system (spinal cord and related structures).
- Chapter 2. The eye, ear and related structures (structure of eyeball, structure of inner ear).
- Chapter 3. Structures involved in voice and speech (structure of mouth).
- Chapter 4. Structures of the cardiovascular, immunological and respiratory systems.
- Chapter 5. Structures related to the digestive, metabolic and endocrine systems (structure of intestines, structure of gall bladder and ducts).
- Chapter 6. Structures related to the genitourinary and reproductive systems (structure of the urinary system, structure of pelvic floor).
- Chapter 7. Structures related to movement (structure of head and neck region).
- Chapter 8. Skin and related structures (structure of skin glands).

Activities and Participation

- Chapter 1. Learning and applying knowledge (learning to read, solving problems).
- Chapter 2. General tasks and demands (carrying out daily routine).
- Chapter 3. Communication (speaking, conversation).
- Chapter 4. Mobility (getting around inside or outside home).
- Chapter 5. Self-care (washing oneself, dressing).
- Chapter 6. Domestic life (preparing meals, acquiring a place to live in).
- Chapter 7. Interpersonal interactions and relationships (relating with strangers, formal relationships, family relationships).
- Chapter 8. Major life areas (work and employment, remunerative employment).
- Chapter 9. Community, social and civic life (recreation and leisure, religion and spirituality).

Environmental Factors

- Chapter 1. Products and technology (products and technology for communication; design, construction and building products and technology of buildings for public use).
- Chapter 2. Natural environment and humanmade changes to environment (physical geography, light, sound, air quality).
- Chapter 3. Support and relationships (immediate family, health professionals).
- Chapter 4. Attitudes (individual attitudes of friends, individual attitudes of health professionals).
- Chapter 5. Services, systems, and policies (social security services, systems and policies).

The ICF is organized in two versions, the short (concise) version with two levels of classification, more suited to clinical practice; and, the full (detailed) version which has the more detailed four levels of classification more suited to research. Each level progressively increases the degree of detail able to be determined. Examples of codes, illustrating the range of codes available:

- b 144 Memory functions
- b 250 Taste function
- b 280 Sensation of pain
- b 320 Articulation functions
- b 455 Exercise tolerance functions
- s 120 Spinal cord and related structures
- s 340 Structure of larynx
- · d 110 Watching
- d 410 Changing basic body position
- d 540 Dressing
- d 710 Basic interpersonal interactions
- d 910 Community life
- e 325 Acquaintances, peers, colleagues, neighbours and community members
- e 450 Individual attitudes of health professionals

Discipline-Specific Endorsement of the Classification

A number of organizations have endorsed the ICF, developing discipline-specific checklists,

questionnaires and assessments based on it, including physical therapy organizations such as the American Physical Therapy Association (APTA), the World Conference for Physical Therapy, and the American Therapeutic association [6]. O'Sullivan [6] welcomed the development of the ICF, and discipline-specific checklists, questionnaires and assessments based on the ICF, stating that physical therapists today practice in complex environments in which they are pressured to reach increasingly complex decisions with significant time constraints. She noted novice physical therapists tended to gather excessive and erroneous data in the mistaken belief that more information must be better, whereas in actual fact this obscured the main issues, risking additional therapy time, tests or measures. Once gathered, all that extra information then had to be organized and analyzed to determine impairments, activity limitations, and participation restrictions, in order to determine causative factors.

The APTA had previously published the Clinical Research Agenda, providing evidence-based treatments for all physical therapists, but in the 2011 revision [7] reflected the rapid changes in health care, and in rehabilitation, identifying broad categories of research consistent with the ICF.

There have been numerous clinical studies and research trials either using the ICF directly, or developing questionnaires and checklists based on it, predominantly physical or rehabilitation conditions, as they are often more easily observable and quantifiable then other conditions. Some, but not all, have included all domains of the ICF.

Rose and colleagues [8] examined the frequency of ICF domains being included in 788 Journal of Hand Therapy articles, and 78 hand therapy articles from other sources, using a scoring system based on the WHO ICF definitions. They found that although body functions and body structures were well represented, this was not the case for the activities, participation and environmental factors domains. They also found that over time, in spite of the emergence of patient-centered disability measures, the trend

remained stable. Their recommendation to scientists was to increasingly incorporate all of the WHO ICF domains in their scientific investigations to demonstrate their societal and personal impact in a language able to be understood and appreciated by a wide array of health care users, policy makers, and third-party payers.

When evaluating the outcome of wrist surgery, Birch and colleagues [9], using the ICF as a framework in conjunction with the Mayo Clinic wrist score, discovered that pain was the most important factor in determining outcome, far less important than objective measures. As the Mayo Clinic wrist score was less responsive, the researchers concluded classifying the content according to the ICF would better clarify the effects of wrist surgery on the different aspects of health.

In order to improve hand and arm function in people with a cervical spinal cord injury, the most important phase is selection of candidates [10]. With alternative surgical options available, researchers considered the impact of the various surgeries would be best evaluated using the framework of the ICF. They also concluded that the outcome measures selected should reflect changes within the multiple domains of body functions and structures, activity and participation.

In a study designed to determine whether the newly-developed upper limb myoelectric prosthetic hand, with several joints in the fingers and thumb, had more functionality than a more conventional myoelectric prosthetic hand with only a single joint between the thumb and two fingers [11], a test procedure that covered all functional levels of the ICF was used. Although the newer model was more reliable when holding objects, it had less power and was less robust, and was consequently considered to have limited additional functionality.

Although the ICF has been promoted for use in clinical practice, few articles have been published demonstrating its use as a sensitive outcome measure, and not in relation to individuals who have had a lower limb amputation. Kohler and colleagues [12] reviewed patients who were rated on the ICF checklist items at four stages

(preadmission, 1 week post amputation, on discharge from the acute hospital, and 3 months post-amputation). The ICF checklist was able to demonstrate a significant functional deterioration immediately after amputation but with gradual improvement in function over the next 3 weeks, consistent with clinical observations of those patients.

Literature on metastatic tumors of the spine and the clinical outcomes is limited. Street and colleagues [13] sought to identify any previous Health Related Quality of Life (HRQoL) questionnaires, and to validate the new Spine Oncology Study Group Outcomes Questionnaire (SOSGOQ) which was based on the ICF. A systematic review identified 141 studies, of which 3 could be linked to the ICF, in addition to the SOSGOQ. Descriptive statistics were used to examine the frequency and specificity of the ICF linkage. In conclusion, and including all domains relevant for measurement of function and disability, the SOSGOQ had superior content capacity to measure disease burden of the patients with metastatic disease of the spine than any instruments previously identified in the literature.

Content experts McPoil and colleagues [14] were appointed by the orthopedic section of APTA to develop clinical practice guidelines for musculoskeletal conditions of the ankle and foot commonly treated by physical therapists. Their task was to identify impairments of body function and structure, activity limitations, and participation restrictions using the ICF. Patients needed to not only be able to be categorized into mutually exclusive impairment patterns upon which to base intervention strategies, but also measures of changes in function needed to be able to compared over the course of an episode of care. The experts were also to describe interventions and supporting evidence for specific subsets of patients based on the previously-chosen patient categories. The orthopedic section of APTA also acknowledged that a systematic search and review of the evidence related to diagnostic categories based on the ICIDH terminology would not be useful for the ICF-based clinical practice guidelines, as most of the evidence associated with changes in levels of impairment or function

in homogenous populations is not readily searchable using current terminology. Although less systematic, this approach allowed the content experts to limit their searches to classification, outcome measures and intervention strategies for musculo-skeletal conditions commonly treated by physical therapists.

Hinsch and Zick [15] applied the bio-psychosocial perspective using the ICF in the rehabilitation of skin diseases. They considered the ICF to be of prime importance in clinical practice, teaching and research, because it provides a universal language to be used in health care, permitting the characterization of the specific functional problems of individuals.

Hwang and Nochajski [16] evaluated the use of the ICF in patients with AIDS in South Africa, claiming the framework of the ICF offered a sound basis for demonstrating the different dimensions of disablement across national boundaries and cultures. They went on to explain that the ICF's systematic coding scheme, along with uniform terminology, would help promote communication between health care professionals, other sectors, and people with disabilities. A later study [17] of patients visiting the HIV outpatient clinic in Johannesburg, using the ICF checklist, found a high prevalence of physical impairments, participation restrictions selective activity limitations, and were able to demonstrate that environmental factors influenced their level of ability.

The conceptual framework of the ICF [18] was used to study the determinants of participation in patients with severe hemophilia. Self-reported activities showed a stronger association with participation than performance-based activities, the variation not explained by age, psychological health, joint mobility or pain. Self-reported activities significantly contributed to explaining participation (25 %), but performance-based activities did not (3 %). They concluded by stating that as currently used instruments on joint status and activities only partially explained the differences in participation, this aspect of outcome should be included in order to fully assess outcome in people with hemophilia.

Although it is widely believed that exercise improves mobility in people with Parkinson's disease [19], it is difficult to be certain which form of exercise is most beneficial. Outcome measures for two different exercise programs were grouped using the ICF. Outcome measures at the structure/function level were most effective at detecting change after exercise, and revealing differences in improvement between interventions. Rehabilitation is also beneficial for patients with arthritis [20], but lack of a common structure for comparing rehabilitation methods makes it difficult to compare, transfer and implement research evidence into clinical Following a literature review, combining preexisting tools in addition to using the ICF, researchers selected the most important and relevant key elements for describing rehabilitation, key elements across the four domains. They concluded by stating that a common framework may facilitate comparisons of rehabilitation programs across countries and national levels of care.

Rehabilitation practitioners aware of the significant increase in obesity rates and associated health risks were searching for increased understanding of obesity treatment in the context of disability [21]. Aware that interventions for rehabilitation practitioners to use in people with obesity are not clearly articulated in the literature, following a trial of using the bio-psycho-social model of the ICF, they recommended that practitioners use the ICF as a universal framework to classify disability related to the conditions of obesity.

Concern about the number of sporting and recreation injuries [22] and related potential long-term morbidity led to a search for accurate and appropriate outcome measurements. Although the researchers identified six health status and HRQoL measures, as well as five functional outcome measures, none were entirely suitable for this population. They recommended researchers and clinicians use the ICF core set to assist in selecting the combination of outcome measures most appropriate for their needs, with a view to developing a specific sport and active recreation outcome measure.

To summarize and describe the activity limitations and participation restrictions of children with developmental coordination disorder (DCD) [23], clinicians systematically reviewed literature published in peer reviewed journals from January 1995 until July 2008. Articles were coded using the ICF, but data analysis revealed that of 371 articles meeting inclusion criteria, only 14 % presented any data relating to activity or participation issues. In summary, they stated that evidence concerning activity and participation issues in children with DCD is limited in both scope and volume. The clinicians recommended improved understanding of participation and of activity limitations in children with DCD in order to clarify diagnostic criteria, guide assessment, and make evidence-based decisions regarding intervention.

A 2013 scoping review of studies published from 1990 to 2011 [24], based on the environmental domains of the ICF, was undertaken by clinicians to identify and synthesize research evidence regarding the effect of the environment on community participation of children with disabilities. Participation in out-of-school activities of children with disability aged 5-21 years was organized and synthesized. The most common facilitators of children participating in the community were social support from family and friends, and geographic location. The most common barriers included attitudes, physical environment, transportation, policies and lack of support from staff and service-providers. The clinicians urged practitioners and decision-makers to focus attention on specific aspects of the environment which could be changed or at least improved.

Conclusion: Past, Present and Future

Most of the literature relating to clinical and research utilization of the ICF was virtually all published within the past 5 years, yet the ICF was published in 2001, suggesting clinicians and researchers failed to immediately realize the

potential of the ICF. It is pleasing to see the ICF being used with a number of medical conditions, and not just disability. The literature reviewed in this chapter has certainly demonstrated the value of using the ICF to clarify outcomes, and it is hoped more and more clinicians and researchers world-wide will gradually embrace its use. The increasing number of publications involving the ICF will hopefully encourage others to explore its uses.

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