Chapter 1

The ICF and the biopsychosocial model of health: From 'disease' to 'health condition'

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The foundations of modern biomedicine are based on the recognition that biological processes underlie clinical findings and symptoms presented by the patient. One of the founders of this scientific biomedical approach is Rudolf Karl Virchow (1821–1902) with his seminal work on cellular pathology published in 1847 (Benaroyo 1998).

Interestingly, Virchow is also considered to be the founder of 'social medicine', having coined the phrase 'medicine is a social science'. He recognised, with the same scientific acumen that guided his pathology studies, that the fight against epidemics that were rampant at his time in Europe (e.g. typhus) could only be successful with social change improving living conditions, especially of the poorer population (Virchow 1848). At almost the same time (1854) Dr John Snow (1813–1858) was tracing the source of the cholera epidemic in London to the water supply by drawing a systematic map of Soho where the victims of cholera died. His work led to separate water systems for clean and waste. The story is compellingly told by Steven Johnson (2006).

The 19th century was the period when people first began to collect information on diseases in a systematic way, notably with the work of the medical statisticians William Farr (1807–1883) in the UK and Jacques Bertillon (1851–1922) in France. In August 1900, the French government organised the first conference to review the 'International Classification of Causes of Death'. This was followed by a succession of conferences during the 20th century, particularly with the aim of fighting the epidemics of cholera, typhoid and smallpox. In 1923, an International Health Organization was established in Geneva but only in 1948 did it become the international body that today is known as the World Health Organization (WHO; World Health Organization 2012). Although it had its origins in meetings and conferences with a focus on death rates and their statistics, the WHO eventually developed into a worldwide organisation with the broad aim of improving the general health of populations.

This change of perspective is also reflected in the expansion of the classification systems developed by the WHO, and it characterises a shift in the conceptual understanding of the relationship between disease and health. Initially, taxonomies such as the International Classification of Diseases (ICD) were based on a biomedical model of disease; this later expanded to include information about psychological and social determinants of health, and reflected the adoption of the biopsychosocial model of health, which was recognised to be better fitted to the need to represent and describe the many aspects of people's lives as part of a broader definition of health (Engel 1977).

In the **biomedical model**, ill health is seen as a problem that arises directly from diseases, trauma or other health problems, and is situated within the person. The care required to treat an ill person is provided by health professionals, whose goal is to achieve healing with treatments or surgeries, adaptation to the condition if it is not curable, and behavioural changes of the individual.

The WHO's **biopsychosocial framework for health** – the International Classification of Functioning, Disability and Health (ICF) (2001) – grew out of the WHO's (1980) development of the International Classification of Impairments, Disabilities and Handicaps (ICIDH). With the input of colleagues around the world, and the perspectives of people with disabilities, the ICIDH was revised and updated by the WHO to better describe the effects and the interactions of the context with a person's life on their health. This classification was endorsed in 2001 by the 191 Member States of the WHO (Fifty-Fourth World Health Assembly 2001). Since 2007, the Children and Youth Version (ICF-CY) has been available in English (WHO 2007). In this book, the abbreviation 'ICF' relates to general statements about the framework and classification, and the abbreviation 'CY' refers specifically to the version for children and young people. Figure 1.1 shows the ICF framework, illustrating the several elements of the ICF and the interconnectedness of the parts to one another.

In the **biopsychosocial model**, representing 21st century thinking, health is conceptualised as a person's functioning within a context. A problem of functional health (see Chapter 3) can be caused by both intrinsic biomedical disorders, and external contextual factors impacting on the person. Consequently, helping to improve functional health is not a domain restricted to healthcare professionals. The goals for functional health can include the options described above, but also involve identification and

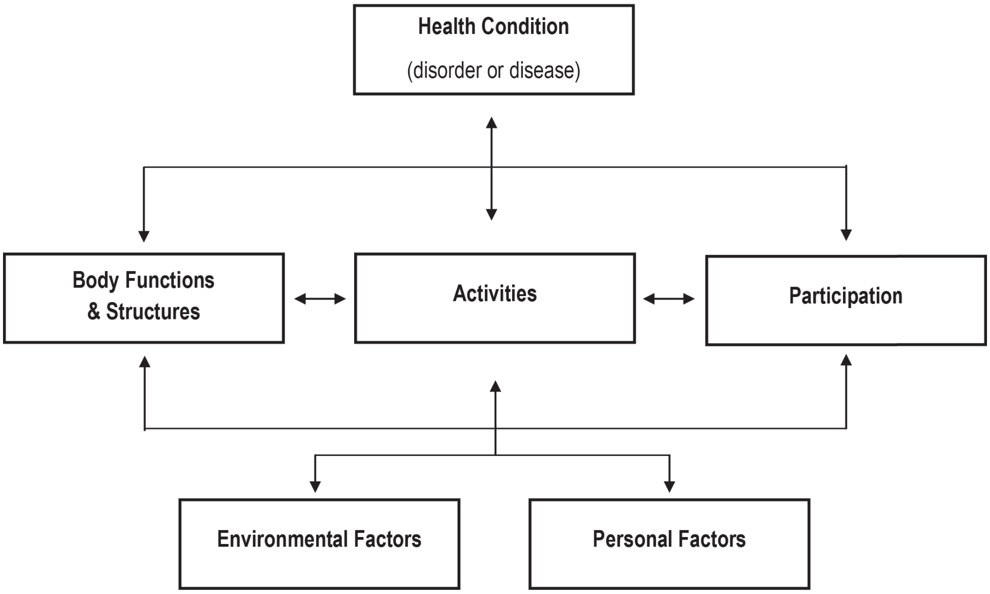

Figure 1.1 The ICF framework

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removal of legal, physical and societal/social barriers to achieving full integration of the affected person into society. Examples of barriers include the obvious physical challenges of access for people with functional challenges of, for example, vision or mobility, as well as less apparent attitudinal factors that limit employment and social opportunities for people with impairments. By contrast, facilitators can include a host of workplace and school accommodations beyond the 'usual' physical access to enable people who need these to work and study during flexible hours, or from home, and facilitate their access to transportation. Further facilitators are technical aids, such as voice recognition software, that help people communicate effectively based on intellectual ability rather than on physical limitations, In this way of understanding, 'restricted functional health' is not a characteristic of a person, but is seen as a complex set of interconnected conditions, many of which are created by the social environment and frequently require social action. It is the collective responsibility of society to shape the environment in a way that allows the full participation of people with health problems in all areas of social life.

With reference to human wellbeing, anthropology plays a fundamental role in theories regarding therapeutic interventions. In addition to the cognitive, the conative, the affective and bodily dimension of our being human, spirituality should be viewed as a coherence factor that deals with purposefulness and meaning. It contributes to wholeness as an expression of hope and an intimate sense of belongingness (Louw 2016).

Huber et al. (2016) demonstrated that patients value the aspect of spirituality as an important component of health. The person-centred use of the ICF leads to an expanded view of the biopsychosocial model, called a bio-psycho-social-spiritual approach (De Villiers et al. 2014, World Health Organization 2013).

To do justice to these psychological and environmental factors, the ICF – as well as the ICF-CY – is divided into two major parts: (1): Functioning and Disability, and (2): Contextual Factors. Functioning and Disability is further divided into: a) Body Functions and Structures, and b) Activities and Participation. Contextual Factors are also further divided into: a) Environmental Factors and b) Personal Factors. Each of these four components in turn is subdivided into individual chapters, in which the user finds sub-categories (items) that aim to describe, as fully as possible, all variations and aspects of functional health (see the Functional health section). For example, the chapter on Communication is a component of Activities and Participation and has, among others, the items d330 Speaking and d345 Writing Messages.

The practical application of the ICF is based on the identification of those items that most comprehensively and accurately describe the individual situation of a person at the current time, in order to be able to provide the best possible support and treatment relevant to current strengths, issues, realities and challenges. This manual is designed to help with this task.

Functional health

This central concept of the ICF is defined as follows:

A person is considered *functionally healthy* if, taking in account their entire life background (concept of Contextual Factors):

- their bodily functions (including cognitive functions) and body structures correspond to generally accepted standards (concepts of Body Functions and Structures),
- they do or can do activities of the type and to the full extent as is expected from a person without any health problem (concept of Activities), and
- they can develop their existence in all areas of life that are important to them, in the way that a person without impairments of body functions/structures and activity limitations would do (concept of Participation).

In consequence, and as a corollary, *disability* is defined as a negative interaction between a person (whose health condition may correspond to the definition of an ICD-coded diagnosis) and the contextual factors that affect the person's functioning (Leonardi et al. 2006).

Specifically, a disability is present when this negative interaction impacts the person's participation in specific life areas (e.g. in the nursery, school, play, work or leisure activities) that are important to them. Disabilities are thus not absolute, nor do they reside within the person, but are relative to life areas and the 'fit' between person and environment (Leonardi et al. 2006).

The division of the Contextual Factors into Environmental Factors and Personal Factors serves to remind us that the activities that are important for an individual also depend on personal inclinations and interests, rather than being about the fulfilment of absolute standards. Personal Factors are not classified into items and coded, because they may strongly depend on cultural as well as personal values (see Chapter 3).

To allow a better description of functional health in infants and young children, the Child and Youth version of the ICF-CY contains numerous additional child and youth-specific categories in the areas of Body Functions and Structures, Activities and Participation as well as in the Contextual Factors, many of which have been integrated into ICF 2017. This work of updating the ICF is an ongoing task supported by the Functioning and Disability Reference Group (FDRG) of the World Health Organization Family of International Classifications (WHO-FIC Network http://www.who.int/classifications/network/).

In relation to the components of health, some definitions have been established by the WHO:

- Body functions are the physiological functions of body systems (including psychological functions).
- Body structures are anatomical parts of the body such as organs, limbs and their components.
- Impairments are problems in body function or structure such as a significant deviation or loss.
- 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.
- Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives.
- Personal factors are a particular background of an individual's life and living, and comprise features of the individual that are not part of a health condition or health states (WHO 2007).

The goals of intervention planning should be based on the possibilities for children to engage in activity and participation in their environment. The German Association for Early Intervention explicitly calls for a systematic use of the ICF-CY in order to capture relevant information and obtain a view of the health status of children within their contexts (ViFF (Vereinigung für Interdisziplinare Frühförderung) 2003; 2009). Such a detailed presentation can be useful for family- and patient-centred planning of support, therapies and assistance. Making use of the ICF allows people to capture the needs expressed by patients and families and also those identified by different professionals. This information, using a common framework and language, facilitates the process of shared decision-making when determining the most urgent needs to be addressed.

The consequence of using the ICF for intervention planning (therapy, early intervention, counselling and coaching) is that the goals are not necessarily related to the 'normalisation' of specific body functions. The goals of individual families and children might be very distinct and will need to be addressed within their specific contexts. These individualised intervention goals might be operationalised using tools such as the Canadian Occupational Performance Measure (COPM) (Law et al. 2005, McColl et al. 2005), and the Perceived Efficacy and Goal Setting (PEGS) tool (Missiuna et al. 2006). Tools like these are designed to take into account daily activities of children and their expectations, and allow people setting these goals to define meaningful targets from the perspective of the person with the health need rather than the professional.

The Participation and Environment Measure for Children and Youth (PEM-CY) is a recent measure developed to assess participation and contextual factors when planning for the rehabilitation of children and young people. It is a good example of the modern tools that are being developed based on the principles of the ICF (Coster et al. 2012) (see https://www.canchild.ca/en/resources/248-participation-and-environment-measure-for-children-and-youth-pem-cy).

Core sets and checklists

In contrast to the ICD, which has specific codes for specific diagnoses like epilepsy, cerebral palsy, obesity, traumatic brain injury or emotional disorders, the ICF codes are not specific for distinct diagnoses or conditions. This reflects the non-categorical nature of the ICF (meaning that none of the ICF ideas is diagnosis-specific). It is possible, however, to select a number of codes that might require more attention when dealing with a certain diagnosis. This approach is similar to the process when taking a clinical history: after initial general questions, we start to ask more specific questions according to the condition suspected, in order to confirm it ('rule it in') or move it lower in probability ('rule it out'). If the ICF codes that are common to a certain diagnosis are collected in a systematic way, the result can be aggregated into a 'set' or a group of codes coming from various domains of the ICF, such as Body Functions, Body

Structures, Activities and Participation and Environmental Factors. Such groupings are called ‘Core sets’,as they are believed to represent core elements common to most patients with a defined diagnosis. Many core sets have been developed over the years for adults, following a standardised procedure (Selb et al. 2015). They exist for patients with multiple sclerosis, bipolar disorders and cancer, to name a few (Bickenbach et al. 2012). In the paediatric field, there is still very little experience using core sets. They have been developed for cerebral palsy and for autism spectrum disorders (Schiariti & Masse 2014, Bölte et al. 2014). Over 10 years ago, at the University Hospital in Freiburg, Germany, the Department for Child and Youth Psychiatry used a subset of items for planning purposes and environmental assessment of patients with diagnoses such as autism, attention-deficit–hyperactivity disorder and eating disorders (Kolch et al. 2007). In the field of Early Intervention, using a checklist with age-specific categories (not diagnosis-specific) was proposed in Germany (Kraus de Camargo 2007, Kaffka-Backmann et al. 2007).

The use of core sets, questionnaires and tests is common practice in medicine. Nonetheless, a narrative approach can add details and richness not captured with standardised tools. Relying exclusively on a core set to determine a person’s functional level can lead people to miss important individual needs (Grötzbach & Iven 2009, p. 25). It also seems to the contributors to this book that the idea of ‘core sets’ can easily appear to run counter to the basic notion of the openness to an individualised approach with an ICF ‘profile’ as an intrinsically important function of thinking in this ICF-based way.

To understand functional health, especially of younger children, it is important to be aware that relying only on the description of problems and identifying which of the components of the ICF they correspond to might not help in planning for the best support. The context, the family and personal factors, and an understanding of their interactions with other components form such an integrated and interwoven unit in early childhood that the isolation of single factors often does not make much sense (Hollenweger 2009, p. 205).

All attempts to use ‘Core sets’ or ‘Checklists’ to facilitate the use of the ICF-CY need to be undertaken with the recognition that the purpose of using the ICF is to describe the functioning of a person with all their unique and individual aspects (in other words, ‘rule in’ relevant features), rather than to make a diagnosis. It is therefore important to have categories available that, though they might not be typical or frequent in the population of a certain health condition, are relevant for the individual that is being assessed and described. This is particularly the case with environmental factors, both, barriers and facilitators, might vary hugely from one region, and one person, to another. In the future, we expect that functional profiles using the ICF will be created with information technology that allows a greater direct and empowering involvement of people themselves in that process (Snyman et al. 2015).

To avoid the diagnostic specificity of 'core sets' and the associated labelling of such an approach, the German Working Group for the Implementation of the ICF-CY developed age-related Checklists for the ICF-CY that are shorter than the full ICF-CY and can make it easier to use the ICF in those populations. Those age-related lists are available in German on the websites of the participating member associations of the working group, and an English version is found in Appendix 6 of this book, available to download from the Mac Keith Press website or in e-versions (Deutsche Interdisziplinäre Arbeitsgruppe zur ICF Adaptation für den Kinder – und Jugendbereich 2012).

Evaluation of interventions

When children with chronic health conditions or developmental disabilities receive interventions that were planned according to the concept of the ICF-CY, it becomes necessary and important to document the effects and results of such interventions using the ICF. One approach is to use Goal Attainment Scaling (GAS).

GAS is not a specific standardised tool but an approach that is easy to implement in rehabilitation as well as in other settings (McDougall & Wright 2009, Steenbeek et al. 2007). GAS starts with defining a goal with the child/parents, as well as the time frame after which this goal should be reached. At the relevant time after intervention, one determines the degree to which the goal has been attained. A critical aspect of such an approach is often that the process of defining goals might be challenging for children. It might also be challenging to negotiate the potential discrepancies of goals between child and parents or between partners. On the other hand, it is worthwhile and important to be aware of such discrepant expectations and to address them at the beginning of the intervention process. In fact, it is desirable to identify such discrepancies at the beginning of an intervention rather than to try to understand, a posteriori, what the reason might be for apparent 'failure' or 'non-compliance' after the intervention did not attain the established goals.

The PEGS (see Core sets and Checklists section) can be used not only for intervention planning, but also for evaluating such interventions. Another tool is the CAPE (Children's Assessment of Participation and Enjoyment) (King et al. 2007), which is validated for children and young people from the ages 6–21 years. It consists of 55 questions related to their activities of daily living and their preferences. This tool is not designed to measure the quality of performance in executing a certain activity. Rather, the goal is to determine if children are enabled to participate in activities that they prefer, or increase the number of activities in which they are able to participate.

The different ways of describing participation are gaining more importance in the evaluation of early intervention and rehabilitation. The ICF can help to operationalise such an approach by identifying the relevant areas to be assessed, but also to select the appropriate instruments for the assessment. To be able to do this, instruments need to be mapped to the ICF, so they can reveal which components of the ICF are being assessed. For example, the 'Kidscreen/Disabkids' is a collection of questionnaires to assess biopsychosocial health and quality of life, developed by partners in the European Union and available in many languages (Dutch, English, French, German, Greek, Norwegian, Swedish) (https://www.kidscreen.org/english/project/; https://www.disabkids.org). A content analysis of the measure revealed that many questions relate to the Activities and Participation components of the ICF (Fayed et al. 2012).

By no means will 'classic' evaluation tools that measure changes at the level of body structures and functions become obsolete, but in order to be appreciated those detailed accounts of specific functions need to be seen within the larger concept and context of functional health. A detailed overview of clinical measures for the assessment and evaluation of the care of children with developmental disabilities, and their relation to the ICF, can be found in the book *Measures for Children with Developmental Disability: an ICF-CY approach* (Majnemer 2012).

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