CHAPTER 1

Conceptualizing Functioning, Health, and Disability

INTRODUCTION

From the time an individual is born, life unfolds in an environment that is both physical and social. Throughout history, attitudes toward health and disability have reflected broad social and cultural values of the time. As social patterns change and evolve, so do concepts of health and disability. As a way to conceptualize disability and its relationship to health, a number of models have emerged throughout history. Each model carries with it fundamental assumptions about health and disability, and about these concepts' relationship to the social norm. These assumptions affect attitudes, expectations, and actions of individuals with disability as well as individuals within society as a whole, and have the potential to influence social and political policies related to disability issues.

PAST MODELS TO CONCEPTUALIZE HEALTH AND DISABILITY

The Medical Model

In the United States, for many years understanding of chronic illness and disability was delineated by the *medical model*, which focused on specific medical conditions that were viewed as "problems" and intrinsic to the individuals experiencing them (Smart, 2001). The medical profession was considered the authority, central to curing, altering, or managing the specific medical condition, while the individual with the condition was viewed as the passive recipient of medical care. The medical model was diagnosis driven, emphasizing pathology, defining and characterizing the condition by standardized measures, and focusing on medical treatments and solutions to "eliminate" or control the condition, thereby returning the individual to "normal" (Fowler & Wadsworth, 1991; Longmore, 1995; McCarthy, 1993). The underlying philosophy of the medical model emphasized "normalcy" based on valued societal roles and norms. When, in some way, an individual deviated from the "norm," the goal was to return that person to "normal." Given this premise, it followed that anyone who was in need of "cure," yet proved incurable, deviated from the "norm" and was, consequently, considered "abnormal," "dysfunctional," or "disabled." This conceptualization of disability carried with it a notion of social incapacitation that often engulfed an individual's social identity, which was subsumed by medical labels.

The medical model emphasized the diagnosis and any corresponding limitation or functional incapacity relative to the societal norm (Stucki, Cieza, & Melvin, 2007). In reality, however, diagnostic labels alone can neither predict nor describe actual functional capacity of the individual within the context of his or her daily life. Emphasis on the medical condition alone not only ignored the individual's function within his or her environment or within the broader context of society, but also overlooked the roles that society and the environment play in the individual's ability to function.

The Social Model

The social model of disability represented a reaction to the medical model (Paley, 2002). Rather than viewing disability as a condition of the individual to be cured so that the person can conform to social norms, the social model emphasized societal and environmental barriers as primary contributors to disability. A key component of the social model was equality (Hurst, 2003); thus a major focus was not to "cure" the individual, but rather to make changes in society and the environment, which would provide equality and opportunity. The social model paralleled the civil rights/human rights movements, which were the catalyst for the development of a number of social policies and legislative actions. In the United States, the Americans with Disabilities Act, enacted in 1990, established the right of individuals with disability to receive reasonable accommodations that would enable them to function in the environment and prohibited discrimination based on their disability.

In accordance with the social model, disability was viewed not as a specific medical condition, but rather as the result of the restrictions imposed through society's lack of attention and accommodation to the needs of individuals with disability. The social and physical environments within which individuals live and interact can either enhance their ability to function or exaggerate a disability. Consequently, social and physical environments can determine the extent and type of function that individuals experience. Although recognizing that individuals with disability may experience functional limitations as a direct result of their condition, the social model emphasized society's failure to take these limitations into account as the major contributor to disabling effects of the condition.

The Biopsychosocial Model

The *biopsychosocial model* was proposed as an alternative to prevailing medical and social models, which were perceived as being excessively narrow (Engel, 1977). The biopsychosocial model uses concepts from both the medical model and the social model of disability.

Philosophically, rather than focusing solely on the medical condition or solely on the societal or environmental barriers as contributors to disability, the biopsychosocial model posits that it is the complex interaction of biological, psychological, and social factors in combination that play a significant role in an individual's ability to function. Consequently, the effects of any one health condition would be dependent on the individual involved, and the social context and circumstances surrounding that person. The biopsychosocial model implies that many variables, other than the chronic illness or disability itself, determine the extent and type of function that individuals with a health condition experience. Conceptualizing chronic illness and disability as health conditions in terms of functional capacity rather than as a medical diagnosis permits a greater understanding of the individual's subjective experience of his or her health condition.

THE EXPERIENCE OF DISABILITY

The experience of disability is individual, is dynamic, and varies in different circumstances and in different environments. The term "experience" implies that not all individuals—even those with the same medical condition—are affected by disability in the same way. How individuals perceive disability and the impact such disability has on function are not only the result of the condition itself, but also the result of personal factors and the circumstances that the individual encounters within his or her own particular social and physical environment (Imrie, 2004).

Personal factors can relate to temperament, beliefs, past experiences, innate abilities, individual goals, age, or any number of other factors that contribute to an individual's experience of disability. Social environments exist at many levels, extending from the insular level of family and friends, to the larger social environment of community and work, and finally to the broader level that encompasses cultural, economic, and political environments. Physical environments include not only physical barriers within the immediate environment, but also other factors such as climate, weather, housing, and transpiration. Developmental factors also affect individuals' experience of disability. Each age group and each life stage present new challenges associated with that particular stage of life, which would occur whether or not individuals had a disability. These life-stage challenges, in turn, influence individuals' experience with disability. For instance, the experience of disability during childhood is different from the experience of the same condition in adulthood. The experience of disability in adolescence is different from that which would be experienced by an individual with the same disability in later years of life.

Social environments also affect individuals' experience with disability. The degree to which an individual has strong social support in terms of family or friends, the beliefs and attitudes of individuals in the community, and cultural expectations and norms of the individual's social group all influence how the affected person will experience disability.

The experience of disability also varies with the environment. The experience of disability at home may differ significantly from the experience in the workplace. The experience of disability while conducting household tasks may be much different than the experience of disability during recreational activities.

In short, there is a dynamic interaction between individuals' experience with disability and their consequent functional capacity within a given context. The experience of disability is multidimensional and unique to each individual. Individuals with the same disability do not experience disability in the same way.

CLASSIFYING DISABILITY

The concept of disability is complex and has been interpreted in a variety of ways. As the concept evolved from an emphasis on "cure" to an emphasis on the individual experience and functional capacity within the context of the environment, it became evident that a medical diagnosis alone revealed little about how an individual would experience a health condition in terms of functional outcomes. Likewise, a medical diagnosis alone was insufficient to determine the types of accommodations needed to enhance an individual's ability to function in his or her environment. It became evident that there was a need to develop a common language by which consequences of health conditions and individual outcomes could be measured.

In response to these changes in perception, the World Health Organization (WHO) worked to develop a unified, standard classification of consequences of health conditions. The result was a manual entitled the International Classification of Impairments, Disabilities, and Handicaps (ICIDH; WHO, 1980). The ICIDH was still based on the medical model but defined consequences of medical conditions with classifications related to function. The terms "impairment," "disability," and "handicap" were used to indicate the level and type of impact that the medical condition had on the individual's function. Impairment was defined as an abnormality in body structure or appearance; disability was defined as the consequence of the impairment in terms of performance; and handicap was defined as a disadvantage the individual experienced as result of the impairment or disability.

As concepts continued to evolve and the medical model fell increasingly out of favor, the ICIDH was revised (De Kleijin-De Vrankrijker, 2003). In 2001, WHO adopted a new model to conceptualize function, disability, and health. The new classification system, called the *International Classification of Functioning, Disability, and Health* (ICF), replaced the ICIIDH.

PHILOSOPHICAL UNDERPINNINGS OF THE INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY, AND HEALTH

The new ICF presents a different way of conceptualizing chronic illness and disability; that is, it is a classification of *health* rather than *disease*. In the past, from the perspective of the medical model, the focus was on diagnostic labels and causes of disability, with emphasis on deficits and limitations and medical interventions to treat them. This perspective overshadowed the individual's potential and abilities, and it failed to recognize the degree to which his or her potential and abilities were hampered or enhanced by the social and physical environment. The ICF changed this perspective by placing a positive focus on function and health, emphasizing the integration of health conditions (disease, injury, or other biological factors) and personal, societal, and environmental factors. The ICF places health on a continuum, acknowledging that everyone has the potential to experience a decline in health with some degree of disability. Rather than viewing disability as a personal attribute that is directly caused by disease or injury and that requires medical care to "correct" the problem, the ICF addresses disability as a social construct that is a synthesis of biological, individual, and social factors and reflects the interaction between the individual and his or her social and physical environment (WHO, 2001). Thus the ICF promotes the concept of disability not as a "problem" within the person, but rather as the result of assets or barriers found within the social or physical environment (Peterson & Kosciulek, 2005). This new conceptualization recognizes that the potential for disability is a universal human experience and not limited to a minority of the population.

Using the ICF classification system, disability is viewed as more than a medical diagnosis or a medical or biological dysfunction; rather, it is seen as a part of the health continuum as it affects function. Consequently, health and disability are viewed as a universal human experience with emphasis on the integration of biological, individual, social, and environmental aspects of a health condition.

GENERAL USES OF THE ICF

The ICF provides an international standard for describing and measuring health domains and is a universal classification of functional status associated with a number of health conditions (Peterson, 2005; Peterson & Rosenthal, 2005a). Its unified and standard definition of health and disability helps to provide a basis for common understanding.

The uses of the ICF are varied. The ICF can provide a structure to facilitate communication

within and between multidisciplinary groups (Steiner, Ryser, Huber, Uebelhart, Aeschlimann, & Stucki, 2002), clarify team roles and enhance clinical reasoning (Tempest & McIntyre, 2006), organize service provision (Bruyére & Peterson, 2005; Rauch, Cleza, & Stucki, 2008; Stucki,, Bedirhan Ustun, & Melvin, 2005), serve as a catalyst for research (Threats, 2002; Wade & deJong, 2000), and provide a framework for legislative, regulatory, social, and health policy related to disability (WHO, 2001). In addition, it provides a means of comparison for individual experience with disability (Khan, Amatya, & Ng, 2010) and highlights the impact of environmental factors in enhancing or hindering function (Khan & Pallant, 2007).

The ICF classification system serves as a tool not only for standardizing concepts related to functional impact of disability, but also for measuring the efficiency and effectiveness of rehabilitation services (Üstün, Okawa, Bickenbach, Kastanjsek, & Schneider, 2003).

CONCEPTUAL FRAMEWORK OF THE ICF

The ICF addresses more than disability; that is, it also classifies health and health-related states with or without disability because the emphasis is on function and health conditions, both of which may be on a continuum. The *experience* of disability focuses on the individual and his or her personal resources, health condition, and individual environment. Health, as portrayed by the ICF, is a dynamic interaction between function and disability within the context of the individual's environment and personal factors (Stucki & Melvin, 2007).

The focus of the 2001 ICF is on health and function as they relate to disability, rather than on impairment and handicap. The latter terms appeared and were defined in the 1980 ICF (WHO, 1980). The current ICF defines these terms as follows:

• **Health** refers to *components of health* (physical or psychological function) and *components of well-being* (capacity to function within the environment).

- **Function** refers to all body functions, activities, and participation in society.
- **Disability** refers to any impairment, activity limitations, or participation restrictions that result from the health condition or from personal, societal, or environmental factors in the individual's life.
- **Impairment** refers to a deviation from certain generally accepted population standards of function (WHO, 2001).

Although impairments associated with a number of health conditions cause some degree of disability in most people (e.g., spinal cord injury), the degree to which an impairment results in disability is also determined by individuals' unique circumstances. What may appear to be a relatively minor disruption of function may actually have major consequences for the life of the individual affected. For example, loss of an index finger would be more disabling for a baseball pitcher than it would be for a heavy-equipment operator. Spinal cord injury resulting in paraplegia would have a different impact on someone who is an accountant than it would have on someone who is a construction worker. Rather than imposing preconceived ideas about the extent of disability associated with a particular health condition, determining the extent of disability requires that consideration be given to the condition in the context of the individual's life, particular circumstances, and goals.

A health condition that results in a disability for one individual may not result in a disability for another individual with the same health condition. Therefore, the degree of disability an individual experiences as a result of a health condition depends on both the individual's goals and those facilitators or barriers that are present in the physical and social environment.

The ICF emphasizes functional capacity in the individual's natural environment. Evaluation and assessment of an individual's functional capacity in a laboratory or testing environment may not be an accurate reflection of his or her level of function. What individuals are able to do in a standardized environment may be quite different from what they are able to do in their natural environment. For example, an individual, after stroke resulting in hemiplegia, may be able to ambulate to the bathroom in a laboratory setting; in contrast, at home, with no indoor plumbing and only outdoor facilities, the same person may be unable to perform this task. Without assessing function in the context of the individual's everyday life, a realistic view of function may not be obtained. Likewise, there may be a discrepancy between the individual's capacity to function and his or her actual performance. Individuals may have the capacity to perform a task yet lack the motivation or social support to carry it out. For instance, an individual with emphysema may have the ability to carry out household chores, but because of overprotective family members may be discouraged from doing so. Function, therefore, is more complex than merely having the ability to carry out a task or action.

STRUCTURE OF THE ICF

The core structure of the ICF is divided into two parts, each with two components (see **Table 1-1**).

The first part, *function and disability*, is divided into two components: *body function and structure* and *activity and participation*. In the first component, *body function* refers to physiological functioning of body systems, such as mental function, sensory function, function of the heart, or function of the immune system; *body*

Part 1 Function and Disability	Part II. Contextual Factors
A. Body functions and structures	A. Environmental factors
B. Activities and participation	B. Personal factors

structure refers to anatomical components of the body, such as the structure of the nervous system or the structure of the cardiovascular system.

The second component, activity and participation, is conceptualized by qualifiers of capacity and performance. Activity refers to tasks or actions that individuals carry out in daily life, such as reading, writing, managing daily routines, dressing, and bathing. Participation refers to the individual's involvement in activities of daily life or in society. It includes the individual's ability to fully participate in activities in the broader social system, such as going to school, holding a job, engaging in recreational activities, or being integrated into the community. The qualifier capacity refers to the individual's actual ability, or level of function to perform a task or action, whereas performance refers to what the individual actually does in his or her current environment. For instance, an individual may have the capacity to walk from the front porch to the mailbox, but might not do so because a neighbor brings the mail to the individual's door each day.

The second part of the core structure of the ICF, *contextual factors*, consists of two components: *environmental factors* and *personal factors*. Both components include factors that can be either *facilitators* or *barriers* in helping individuals acquire full participation.

The first component, *environmental factors*, refers to more than the physical environment, such as accessibility of buildings or the availability of accessible transportation. That is, it also includes products and technology (such as telephones or computers), climate (such as dry, humid, hot, or cold), and factors in the social environment (such as social attitudes, norms, services, and political systems). In this context, environmental factors are divided into three levels:

- Individual level: individual systems of support; support network
- Services level: services and resources available
- Cultural/legal systems level: societal and cultural attitudes; political and legal factors (Peterson & Rosenthal, 2005b)

The second component, *personal factors*, is recognized as an important interactive component in defining function, but is not coded in the ICF because of the complexity and highly individualized nature of these factors. Personal factors include gender, race, education, occupation, and difficult-to-quantify human factors, such as past personal experiences, individual temperament, and other intrinsic characteristics, such as state of mind. Although these factors are not coded, they are considered and recognized as contributing to the overall function of the individual.

The core structure of the ICF provides a perspective on health conditions from the standpoint of function. It offers a perspective on how body structure and function affect individuals' ability to function in the context of their particular social and physical environment as well as the direct impact of the social and physical environment on function. The ICF focuses on the dynamic and interactive nature of biological, social, personal, and environmental factors in determining individuals' functional capacity.

OPTIMUM VERSUS MAXIMUM FUNCTION

For individuals to achieve full functional capacity, there must be an awareness of not only the functional implications of various health conditions, but also the implications of the strengths and barriers that are found in the social and physical environment. Emphasis is on building and strengthening personal resources, with the goal of helping individuals achieve *optimal functioning* and full *inclusion* and *participation* in all aspects of life. In this context, both strengths and limitations must be identified.

It is commonly assumed that achieving *maximum function* is the ideal goal; however, *optimal function* rather than *maximum function* is emphasized. Although "maximum" refers to the greatest degree of function possible, maximum function for an individual may not be optimal. *Maximum function* is based on an objective viewpoint, whereas *optimal function* is based on the subjective viewpoint of the individual and derived from his or her own goals and experience. Optimizing function requires a comprehensive understanding of individuals within the context of their environment and within their own frame of reference.

CONCLUSIONS

Conceptualizing chronic illness and disability as health conditions in the context of the continuum of health and function helps to decrease the stigmatization and isolation that have been associated with chronic illness and disability in the past. By emphasizing functional capacity rather than deficits, and by focusing on personal goals and the ability to perform in the context of the environment, optimal function can be achieved. Greater understanding of *health conditions* as an experience rather than as a medical condition can help to decrease the discrimination and prejudice that too often accompany chronic illness and disability and that too often are the major barriers to achievement of optimal activity and participation in the broader community, social, and vocational environments.

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