

Conceptualizing Chronic Illness and Disability

The relationship between cultural belief systems and societal attitudes toward individuals with disability is well known and has been studied extensively (Mallory, 1993). The culture and society that one inhabits significantly influence the context in which disability is viewed. Individuals with disability are found in every country and every culture of the world. The way disability is viewed and the extent to which individuals with disability are included or excluded in their environment is in the context of their particular culture and society. As countries and cultures undergo change, beliefs about disability also change, and those changes have direct consequences for individuals with disability.

In the United States for many years, understanding of chronic illness and disability has been delineated by the *medical model* (Smart, 2001). This model emphasizes pathology, or cause of chronic illness and disability; has objective, standardized measures to define and characterize the condition; and focuses on treatment and prognosis. (Fowler & Wadsworth, 1991). From this perspective, efforts are made to diagnose, treat, and theoretically “cure” the pathology, so the individual can return to the idealized “norm” (Longmore, 1995; McCarthy, 1993). The ideal consequence from this point of view would be a world in which chronic illness or disability is eliminated. Hence, given the premise of this “ideal,”

it follows that any deviation from the “norm” would be viewed as “abnormal” and, essentially, “undesirable.”

The underlying philosophy of the medical model can have significant implications for individuals with chronic illness or disability. From this perspective, pathology and associated problems related to the chronic illness or disability lie within the individual. If individuals are unable to be “cured,” the implication is that they are “abnormal” or “dysfunctional” and, consequently, are passive recipients of treatment having little or no control or choice related to the treatment they receive. Conceptualization of chronic illness and disability from the standpoint of the medical model largely ignored the individual’s role and function within the broader context of society and the environment. From this viewpoint, alteration of the individual’s role and function from the societal expected norm results in social reactions and social comparisons that devalue or stigmatize individuals with chronic illness and disability, often making them objects of prejudice.

The way individuals with chronic illness and disability are viewed in society is, however, changing. Disability is not a consequence of biological forces or societal conceptualization alone, but rather the result of a complex interaction of factors. Rather than being solely a physical or mental condition, disability is an

experience in which body, behavior, and society are intertwined (Imrie, 2004). The medical model emphasizes the diagnosis and any corresponding limitation or functional capacity relative to the societal norm (Stucki, Cieza, & Melvin, 2007), but individuals do not exist in isolation. Diagnostic labels alone neither predict nor describe actual functional capacity of the individual within the context of his or her daily life. The social and physical environments within which individuals live and interact can either enhance their ability to function or can exaggerate a disability. Consequently, social and physical environments can determine the extent and type of disability experience. Defining disability in terms of functional capacity rather than medical diagnosis permits a greater understanding of the individual's subjective experience of the disability.

The term "experience" implies that how individuals perceive disability is not only the result of the condition itself, but also the result of limitations, barriers, or circumstances they encounter within their social and physical environments. 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 transportation.

The experience of disability is dynamic and varies in different life stages and in different environments. Developmental factors affect individuals' experience of disability. Specifically, the experience of disability is different for each age group. As individuals pass through various life stages, they face new challenges associated with a particular stage of life, which would occur whether or not they had a disability. These life stage challenges, in turn, influence individuals' experience with disability. For

instance, the experience of chronic illness and disability during childhood is different from the experience of the same condition during adulthood. The experience of chronic illness and disability in adolescence is different from what would be experienced by an individual with the same disability in the later years of life.

How individuals experience chronic illness or disability also varies within different environments. For instance, the experience of disability at home may be different from the experience of disability in the workplace. The experience of disability in the grocery store may be quite different from the experience of disability at the beach. In short, there is a dynamic interaction between individuals' functioning and disability within a given context.

■ THE INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY, AND HEALTH

The need to view chronic illness and disability from a broader perspective has gradually been recognized. As a result there has been increased awareness of the need for a new model to conceptualize functioning, disability, and health. In 2001, the *World Health Organization (WHO)* adopted a new classification system of function in relationship to diagnostic information utilized in health services. This classification system, called the *International Classification of Functioning, Disability, and Health (ICF)*, is an international standard for describing and measuring health and disability and is a universal classification of functional status associated with a number of health conditions (Peterson & Rosenthal, 2005a; Peterson, 2005). The classification system serves not only as a tool for standardizing concepts related to functional impact of disability, but also as a tool for measuring efficiency and effectiveness of rehabilitation services (Üstün, Okawa, Bickenbach, Kastenjssek, & Schneider, 2003).

The ICF grew out of another classification system, the *International Classification of Impairments, Disabilities and Handicaps (ICIDH)* (WHO, 1980), which was based on the medical model. The ICIDH was revised and updated to become the current ICF. The new ICF de-emphasizes consequences of disease and instead focuses on health. It places health on a continuum so that people both with and without disability are included. This view of health acknowledges that everyone has the potential to experience a decline in health with some degree of disability. Thus the ICF, which is much broader than the medical model, 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).

The ICF provides a standard language and framework for conceptualizing health and a variety of health conditions by providing a specific and complete evaluation of health and function in terms of individuals’ daily lives (Bryuère & Peterson, 2005). Using this classification system, disability is viewed as more than a medical diagnosis or a medical or biological dysfunction, but rather as a part of the health continuum as it affects function. Consequently, health and disability are viewed on the continuum and as a universal human experience with an emphasis on both the psychosocial and environmental aspects of chronic illness and disability.

■ PHILOSOPHICAL APPLICATIONS

Although the ICF provides a systematic coding scheme that can be valuable in research, education, and practice, perhaps more important is its philosophical underpinnings, which present a different way of viewing chronic illness and disability. In the past, diagnostic labels often overshadowed individual potential and abilities, focusing only on deficits and limitations. Rather than viewing chronic illness and

disability from the perspective of the medical model, which emphasizes diagnosis, and the biomedical aspects of function, the ICF broadens the perspective, placing emphasis on the integration of biomedical, personal, societal, and environmental factors with a positive focus on function and health. Rather than viewing disability as a personal attribute, the ICF provides a wider framework for addressing human experience in the context of function and disability by considering disability as a social construct, which reflects the interaction between the individual and the environment (WHO, 2001).

■ FUNCTION AND STRUCTURE; ACTIVITY AND PARTICIPATION

The ICF addresses more than disability. 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 core structure of the ICF is divided into two parts, each with two components (see Figure 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; and *body 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 of society. It includes the individual’s ability to fully participate in activities in the broader social system, such as going to school, having 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 does 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. 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 hard-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.

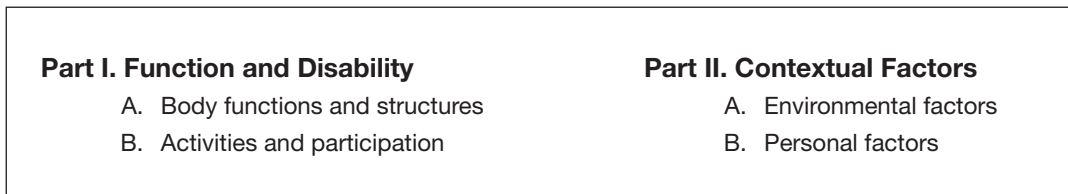


Figure 1–1 Core structure of the International Classification of Functioning, Disability, and Health

■ ACHIEVING OPTIMAL VERSUS MAXIMUM FUNCTIONAL CAPACITY

For individuals to achieve full functional capacity, there must be an awareness not only of the functional implications of various chronic illness and disability, 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, while *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.

■ HEALTH, FUNCTIONING, AND DISABILITY

The focus of the new 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 has a different impact for someone who is an accountant than it would have for 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 the individual’s goals as well as 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; however, 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 but may 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 is more complex than merely having the ability to carry out a task or action.

■ CONCLUSIONS

Reconceptualizing chronic illness and disability 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 chronic illness and disability 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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