Rehabilitation and the International Classification of Functioning, Disability and Health: Past, Present, and Future Directions

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Abstract: This article provides a brief overview of the history of disability in the United States and discusses the three paradigms: rehabilitation, independent living, and support and empowerment that have guided rehabilitative services for persons with disabilities. Within the context of this historical background, the article also presents various models used to define and classify disability. The effect and influence of society's perceptions of people with disabilities on the evolution and refinement of disease and disability models is also discussed. The International Classification of Functioning, Disability and Health, which is a currently utilized disability model is discussed in detail and information is provided as to its applicability to rehabilitation.

Key Words: disability history, disability models, International Classification of Functioning, Disability and Health, rehabilitation paradigms

The term disability has many different definitions and connotations. If 20 people were asked "what is a disability?, there would likely be several different responses many of which might be negative in nature focusing on what a person cannot do. Literally, the word "disability" means "not being able to." The American Heritage College Dictionary defines disability as "a disadvantage or deficiency, especially a physical or mental impairment that impedes normal achievement; something that hinders or incapacitates"[1]. Yet, in actuality, many people with disabilities are competent, capable, and productive individuals. In fact, many are truly exceptional. For example, in the 18th century, Hokiichi Hanawa, lost his vision in early childhood, but acquired an education and became a notable professor of literature and spent many years compiling the *Gunsho Ruiju*, a collection of Japanese Classics[2]. Likewise, Ludwig Van Beethoven was deaf when he composed his 9th Symphony and Thomas Edison, the inventor of the light bulb, had a learning disability and was unable to read until he was twelve years old[3]. Although these individuals had a disability, they are perceived as being capable, not disabled. The language used pertaining to persons with disabilities is often based on society's view of them.

This article will provide information about the International Classification of Functioning, Disability and Health, also referred to as the ICF, which is the current model used to describe and discuss disability. However, in order to establish a

conceptual basis for the development and refinement of disability models and classification systems, a brief overview of the history of disability in the United States will be presented. Previous models of disability and rehabilitation and how society's perceptions of people with disabilities influenced the evolution and refinement of these models will also be discussed.

Brief Overview of the History of Disability in the United States

Historically, having a disability has been viewed as being tragic. In pre-industrial times, when people with disabilities were often unable to support themselves or their families, they were seen as recipients of charity, objects of pity, or social dependents. Through society's fear or ignorance, people with disabilities were typically labeled as beggars or indigents. The word "handicap" itself is said to derive from "cap in hand," a posture often associated with panhandling. During this time and perhaps continuing today, American society assumed a paternalistic approach toward people with disabilities. By the 19th century, it was common for people with disabilities to be separated from society in asylums and other types of hospitals. People with disabilities were defined as patients or clients who needed curing; however, disabilities were not often curable. This system effectively excluded persons with disabilities from mainstream society[4].

America's involvement in World Wars I and II had a profound impact on the way American society viewed people with disabilities. The first vocational rehabilitation programs were established in the 1920s to provide services to veterans with disabilities. But perhaps the biggest changes came with the civil rights movements of the 1960s. As African Americans, women, and other social minorities gained political consciousness, so did people with disabilities[5].

Many people with disabilities look at the admission of Ed Roberts to the University of California at Berkeley in 1962 as a pivotal moment in the history of the disability movement. Roberts was paralyzed from the neck down due to childhood polio and overcame considerable resistance and opposition to achieve admission to the University of California at Berkeley. A newspaper headline at the time announced: "Helpless Cripple Attends UC Classes." Roberts lived in the campus hospital, a living environment he found unacceptable. Within a short period of time, several other men and women with disabilities joined Roberts on campus. Calling themselves the "rolling quads" they joined forces to fight for better services and for the right to live independently, away from the hospital. With a grant from the U.S. Office of Education, they started the Physically Disabled Students Program, the first of its kind on any college campus. In effect, this was the start of the independent living movement[5].

The independent living movement has a philosophical basis grounded in a core set of values including consumer control, self-advocacy, and economic self-sufficiency. Independent living is about people with disabilities making their own choices and controlling their own destinies. Thus, the independent living philosophy rejects the supremacy of medical professionals in decision-making and asserts the rights of people with disabilities to self-determination[6].

In 1971, the first Center for Independent Living opened in Berkeley providing peer support, information, referral services, and advocacy training to enable people with disabilities to live on their own or in communities of their choice. The establishment

of other independent living centers soon followed. In 1978, the Rehabilitation Act was amended to provide federal funding for the establishment of independent living centers. As a result, there are now centers in every state and virtually every U.S. territory[6].

The 1960's and 1970's were a time of civil rights legislation for persons with disabilities. In 1964, the Civil Rights Act was passed. This act prohibits discrimination on the basis of race, religion, ethnicity, or national origin, and creed. Later, gender was added as a protected class, but persons with disabilities were not included[7].

In 1973, the Rehabilitation Act, particularly prohibited discrimination in federal programs and services and all other programs or services receiving federal funding. From a legal perspective, this legislation initiated a profound and historic shift in disability public policy. For the first time, the exclusion and segregation of people with disabilities was viewed as discrimination. Previously, it had been assumed that the problems faced by people with disabilities, such as unemployment or a lack of education, were inevitable consequences of the physical or mental limitations imposed by the disability itself. The Rehabilitation Act of 1973, particularly Section 504, was also historic because for the first time people with disabilities were viewed as a class - a minority group. Previously, public policy had been characterized by addressing the needs of particular disabilities by category based on diagnosis. Each disability group was seen as separate, with differing needs. Section 504 recognized that while there are major physical and mental variations in different disabilities, people with disabilities as a group faced similar discrimination in employment, education and access to society. People with disabilities were seen as a legitimate minority, subject to discrimination and deserving of basic civil rights protections. This "class status" concept has been critical in the development of the disability rights movement and advocacy efforts[7].

Another significant legislative act was the Education of All Handicapped Children Act enacted in 1975. This legislation mandated that a free, appropriate public education in the least restrictive environment possible be provided for children with disabilities. This law is now called the Individuals with Disabilities Education Act (IDEA).

In 1978, Amendments to the Rehabilitation Act provided for consumer-controlled centers for independent living. Legislation continued into the 1980's with the 1985 Mental Illness Bill of Rights Act that required protection and advocacy services for people with mental illness and the Fair Housing Amendments of 1988 which prohibited discrimination in housing against people with disabilities and families with children[7].

Despite the important changes that resulted from initial disability rights law, people with disabilities did not achieve broad civil rights protections until 1990 with the enactment of the Americans with Disabilities Act (ADA). The ADA is considered the most important civil rights statute in the quarter century since the enactment of the Civil Rights Act of 1964. The ADA ensures people with disabilities have equal access to employment opportunities, state and local government, private commercial facilities that offer activities, goods, and services to the public, transportation, and telecommunications. The ADA guarantees that no individual with a disability can be excluded, segregated, or otherwise treated differently than individuals without disabilities. In passing the ADA with overwhelming bi-partisan support, Congress identified the full participation, inclusion, and integration of people with disabilities into society as a national goal[8].

Rehabilitation Paradigms

The historical context of disability has had an influence on the paradigms that guide rehabilitation practice. A paradigm can simply be defined as a conceptual framework that provides a rationale for practice. A paradigm shift occurs when the consensus regarding the conceptual framework for any field or profession breaks down and another emerges. Over the past fifty years or so, there have been three paradigms that have influenced the services provided for persons with disabilities in the United States. These paradigms include the rehabilitation, independent living, and support or empowerment paradigms. These changing paradigms also reflect a more general change in viewing disability from a social, rather than medical, model.

The rehabilitation paradigm was prevalent in the 1950's and early 1960's. Under this paradigm, the individual with a disability was the "source" of the problem that included physical impairment, lack of vocational skill, psychological maladjustment, and a lack of motivation or cooperation. The role of the person with a disability was a passive one, that of a patient or client. Intervention by physicians, physical and occupational therapists, vocational counselors and other professionals was considered to be a solution to the problem. Professionals had a very active role and were in control of the rehabilitation process. Under the rehabilitation paradigm, the goal was to "cure" or "fix" the problem and desired treatment outcomes included independence in activities of daily living, gainful employment, psychological adjustment and improved motivation for persons with disabilities[9,10].

During the mid 1960's and 1970's, civil rights legislation and increased activism by persons with disabilities led to a paradigm shift. The rehabilitation paradigm was replaced by the independent living paradigm in which the social role of persons with disabilities was that of a consumer of services. According to this paradigm, problems or "deficiencies" were located in the environment, society, or the rehabilitation process, not in the individual. Problems were defined in terms of dependence on professionals, relatives, and others and inadequate support services as well as architectural and economic barriers. People with disabilities no longer saw themselves as broken or sick, certainly not in need of repair. Issues such as social and attitudinal barriers were the real problems facing people with disabilities. The answers were to be found in changing and "fixing" society, not people with disabilities. Peer counseling, advocacy, self-help, and the removal of barriers and disincentives were viewed as potential solutions to many of the problems experienced by persons with disabilities. Most importantly, the independent living paradigm stressed that the individual with the disability should be making decisions related to intervention. These decisions should not be made by the medical or rehabilitation professional. Within the independent living paradigm, desired outcomes for persons with disabilities included self-direction, social and economic productivity and participation in least restrictive environments[9,10].

The 1980's and 1990's saw the emergence of a new paradigm, that of support and empowerment for persons with disabilities. As within the independent living paradigm, the locus of the problem in the new paradigm is within society, the environment and the rehabilitation process. Attitudinal, political, economic and administrative barriers to participation as well as inadequate supports within society is viewed as being problematic. The social role of the person with a disability has changed from that of a patient or client within the rehabilitation paradigm, to that of a consumer of services

within the independent living paradigm, to a community member and participant within the support and empowerment paradigm. Neither professionals nor persons with disabilities are totally in control of rehabilitation and services; the focus is on people collaborating or in alliance with each other. Environmental modifications to schools, homes, work places and other community facilities and the redesigning or restructuring of health care systems, transportation and social environments are potential solutions to problem situations. The desired outcomes under this paradigm include a pluralistic society that includes all people, self-defined quality lives for persons with disabilities, and self direction embedded in collaborative decision making and problem solving with professionals[11]. It will be interesting to see what paradigms emerge in the 21st century.

Defining and Classifying Disability

The language and models used to define and classify disability are closely related to the paradigms guiding rehabilitation and other services. Language shapes our perceptions by calling certain things to our attention. When we use language that focuses our attention on race, class, gender, disability, or any other single aspect of a person, we limit our perception of that person. In other words, we tend to perceive others through the labels we use to describe them. Language is a powerful tool. The written and spoken words that we use and the images that we create reflect our attitudes, beliefs, and assumptions. The use of appropriate language about people with disabilities can be an important tool in building a community that accepts all people. Additionally, the use of a uniform, professional language can be very useful in health care and rehabilitation as the need for a common language across professions concerned with persons who live with disabilities has become ever more clear. Traditionally, all professions develop a jargon that is familiar to all members of that group, but which may be confusing and alienating to others, including persons with disabilities and their families. The goals of language, enabling meaningful professional communication, can only be achieved if terms are used that have the same meaning and refer to the same concepts for all persons involved in the communication[12,13].

The World Health Organization has a mandate to develop a global common language in the field of health, broadly understood to include physical health, mental health, and social-well being. This organization has developed a number of classification systems for the medical and health care professions that use a uniform language to convey a wide range of health-related information and promote communication between various health related disciplines and sciences[14].

In 1853, at the First International Statistical Congress of the World Health Organization, the first uniform classification of the causes of death was established. This classification system has been revised several times and The International Classification of Disease, currently in its tenth edition, offers an etiological framework for classifying health conditions such as disease, injury, or trauma. The ICD was developed to explain health problems. In the ICD, diseases, disorders, and complaints are classified according to etiology or organ system, basically for epidemiological and statistical purposes concerning morbidity and mortality. It does not address the consequences of living with the effects of a health condition and is entirely based on a medical model[15].

In 1980, the International Classification of Impairments, Disabilities and

Handicaps, also known as the ICIDH, was published to serve as a classification of the consequences of disease. The ICIDH included three conceptual domains namely, impairment, disability, and handicap[16]. Many people have used these terms synonymously or defined them in a variety of ways. The ICIDH provided a definition of each concept. Impairments were defined as a loss or abnormality of a psychological or physiological structure or function at the organ level. A disability was defined as a restriction or lack of ability to perform an activity in a "normal" manner. It is a condition within the person. In contrast, the term handicap is defined as a disadvantage due to impairment or disability that limits or prevents fulfillment of a "normal" role for the person. In other words, the term handicap connotes the accrued result of multiple barriers, either emotional, social, physical, or environmental, that are imposed by society. For example, a person may have spasticity in his or her legs as a result of cerebral palsy. This would be an impairment. If the spasticity was minimal, and the person was able to walk around his or her environment without any difficulty, he or she would not have a disability even though an impairment was present. However, if the spasticity was severe and the person needed to use a wheelchair for mobility, he or she would have a disability. To exemplify the concept of a handicap, consider two situations in which a person uses a wheelchair. In the first situation, the person's home, work, and community environments are accessible. Even though he or she has a disability, a handicap is not present. This same person visits a relative in different city who does not have an accessible home. Additionally, the public transportation, stores and other community facilities are not accessible. In this situation, the person would be considered handicapped.

The ICIDH has been a very useful model for looking at the consequences of a disease in a uniform, consistent manner. However, after two decades of use, the ICIDH required revision in light of a new social understanding of disability as well as changes in health care provision including a change in health care emphasis from acute to chronic conditions and a change in focus from disease to function. This led to the development of the most recent disability model, the International Classification of Functioning, Disability and Health, or the ICF.

One of the primary goals in the development of the ICF was to provide a classification system with a neutral conception of "components of health" rather than a description of the "consequences of disease" that were often characterized in negative terminology in the ICIDH. It is important to know what an individual's capabilities are, instead of his or her inabilities. The ICF framework is a logical approach to viewing diverse aspects of health from biological, individual, and social perspectives and it integrates the two competing and contrasting models, the biomedical and social models of disability[17,18].

As shown in Figure 1, The ICF, reflects the model of human functioning in which functioning and disablement are viewed as outcomes of an interaction between a person's physical, sensory, or mental condition and the social and physical environment[14]. Overall, the ICF organizes information into two parts: Functioning and Disability and Contextual Factors. "functioning" and "disability" serve as two umbrella terms encompassing the components of human functioning[17,18].

The components of human functioning include Body Functions and Structures and Activities and Participation. Each component can have a positive aspect and negative

<table>
<tr><td></td><td colspan="2">Part I: Functioning and Disability</td><td colspan="2">Part II: Contextual Factors</td></tr>
<tr><td>Components</td><td>Body Functions and Structures</td><td>Activities and Participation</td><td>Environmental Factors</td><td>Personal Factors</td></tr>
<tr><td>Domains</td><td>Body Functions
Body Structures</td><td>Life Areas
(tasks,actions)</td><td>External influences on Functioning and Disability</td><td>Internal influences on Functioning and Disability</td></tr>
<tr><td>Constructs</td><td>Change in Body Functions
(Physiological)

Change in Body Structures
(Anatomical)</td><td>Capacity
Executing tasks in a standard environment

Performance
Executing tasks in the current environment</td><td>Facilitating or hindering impact of features of the physical, social, and the attitudinal world</td><td>Impact of attributes of the person</td></tr>
<tr><td rowspan="2">Positive aspect</td><td>Functional and Structural Integrity</td><td>Activities and Participation</td><td rowspan="2">Facilitators</td><td rowspan="2">Not applicable</td></tr>
<tr><td colspan="2">Functioning</td></tr>
<tr><td rowspan="2">Negative aspect</td><td>Impairment</td><td>Activity limitation
Participation restriction</td><td rowspan="2">Barriers/hindrances</td><td rowspan="2">Not applicable</td></tr>
<tr><td colspan="2">Disability</td></tr>
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[World Health Organization (2001). *International Classification of Functioning, Disability and Health ICF*]

Figure 1: Conceptual Model of the ICF

aspect. Functioning, the positive aspect, is defined as the successful completion of major day-to-day activities across a broad range of life areas or expected roles and includes functional and structural integrity, activities and participation. Disability, the negative aspect refers to the inability of a person to complete these critical life tasks and includes impairments, activity limitations or participation restrictions[17,18].

Body Functions and Structures are classified according to the body systems such as the nervous, cardiovascular, respiratory systems. Body functions are the physiological, psychological, or cognitive functions of the body systems, while body structures are the anatomic parts of the body such as organs, limbs, and their components. Impairment is defined under the ICF as an anomaly, defect, loss, or other significant deviation in body function or structure[17,18].

The component of Activity and Participation refers to an individual's performance of tasks, either physical or mental, that are associated with all aspects of human life. This component involves the integrated use of body functions in a purposeful manner within various contexts including physical, social, and attitudinal environments. Because exclusively separating "Activities" and "Participation" based on their domains was difficult, the current version of the ICF joins these two constructs into a single component. Activities may include learning, communication, mobility, self care, and domestic and interpersonal tasks. Participation involves personal maintenance, mobility, exchange of information, education, work, employment and so on[17,18].

An activity limitation occurs when an individual either has difficulty performing the activity in an expected manner, or is unable to perform it at all. It is assessed on

the basis of an individual's actual ability to perform tasks or activities without taking into account the external influences, such as environmental factors. Participation restrictions are problems an individual may experience in involvement in life situations due to external factors such as the existence of barriers in the environment[17,18].

To illustrate these concepts, let us consider a special education student with a diagnosis of attention deficit disorder. The student has impairments that include poor attention, trouble concentrating, and poor impulse control. As a result of these impairments, he or she has activity limitations, specifically difficulty doing homework and waiting for his or her turn. These activity limitations restrict the student's participation in school. Poor grades, exclusion from class activities and a label as a "problem student" are examples of his or her participation restrictions.

Activity and participation is also comprised of two contrasting constructs, capacity and performance. Capacity refers to the "ability of the individual in executing tasks in the standard environment". In other words, capacity is the highest level of functioning an individual may reach in an environment devoid of any external assistance. Performance, on the other hand, refers to the "ability of the individual in executing tasks in the current environment" which takes into account the physical, social, and attitudinal support provided by the environment[17,18].

Both functioning and disability are regarded as the results of a dynamic interaction between an individual's health conditions and contextual factors. Contextual factors include both personal and environmental factors. Personal factors, as defined in the ICF, refer to the features of an individual, such as age, race, educational background, occupation, experiences, personality, and aptitudes. These factors may have an impact on the individual's health conditions as well as the outcome of interventions. The ICF model acknowledges that personal factors are not direct indicators of a health condition or functional state and that there might be large individual, social and cultural variances associated with these factors[17,18].

Environmental factors, include the natural environment, assistive devices and technology, support and relationships, attitudes, values, beliefs, services, and systems and policies constitute the physical, social, and attitudinal contexts in which an individual lives and conducts his or her life. These factors can have significantly positive or negative influences on an individual's full participation in society. For example, a person who has an HIV infection may not exhibit any impairments or activity limitations but may still be denied access to employment due to the employer's negative perception or attitudes towards the AIDS disease[17].

The ICF is a multi-purpose classification designed to serve different sectors and to provide a common framework for understanding the dimensions of disablement and functioning at three different levels: body, person, and society[17]. The ICF has a very detailed and intricate coding system, a discussion of which is beyond the scope of this presentation. However, this coding system makes several applications of the ICF possible.

The ICF model has many potential applications in the area of rehabilitation and public health. As a research tool, the ICF serves to measure outcomes, focusing not only on functional outcomes, but also on the overall quality of life. Statistical application of the ICF involves collection and recording of data in areas such as population based studies, surveys or development of information management systems.

The ICF has the potential to be applied as a social policy tool in designing and implementing social security benefits, compensation systems, and health policies. In the area of education, the ICF facilitates development or modification of curriculum design. The ICF is a multipurpose health and functioning classification described in a multidisciplinary format, and, as a result, is applicable from a clinical perspective. The model presents a systematic framework for rehabilitation and outcomes evaluation by taking into account client needs and matching interventions with specific conditions. The ICF has the potential to provide a precise understanding of an individual's health status and disability level. Its effectiveness in evaluating the consequences of disability can be well tested in conditions that manifest in a wide spectrum of activity and participation limitations[17,18].

The use of a single worldwide language to discuss issues affecting the disability community promises to enhance the exchange of new ideas and technology, to promote wider reaching social policy and to ensure that the research challenges across disability are examined in a more comprehensive manner. The forthcoming research would be responsive to needs established by and with the disability community, not in terms that were focused on the specific interests or traditions of any particular profession.

Based on changing perceptions and paradigms related to disability, the ICF has been formulated as a conceptual model and offers a scientific framework for understanding the course and consequences of various health related states. The model serves as a holistic classification of health status by focusing on the impact of a particular health state on an individual's body, activity levels, and societal participation, while taking into account the influence of environment[17,18].

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