

CHAPTER 3

MODELS AND APPROACHES TO DISABILITY

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An Overview of Disability Models and Approaches

Disability Across Time

DISABILITY IS A CONCEPT as ancient as injuries to hunters from recalcitrant beasts, as old as interruptions in the hand functioning of gatherers due to osteoarthritis, and as antiquated as the earliest genetic anomalies seen within human offspring. In primitive times, people with disabilities died through natural causes, neglect, or at the hands of members of tribal societies. During the medieval ages, disability was often considered a punishment from God or the work of the devil. People with disabilities were alternately shunned, condemned, or used for entertainment purposes, e.g., as court jesters. By the late 1800s disability was seen as a public health issue, and a movement emerged based on the belief that disability could be ameliorated through institutionalization and training. By the end of the 1900s, a number of models and approaches to disability had evolved that—to a more or less degree—challenged these historical perspectives.

Disability is a phenomenon that is usefully thought of as a reflection of the zeitgeist of a particular time or era. That is, what is considered a disability at a certain point in time derives from a formal and informal societal process, through actions and interactions, whereby subjective definitions of disability become objective and socially accepted. For example, much of the general public think of disability within the medical model—as the form of physical impairment or functional limitation a person has: a “blind man” or a “paralyzed woman.” This represents a shift in thinking about and describing disability when terms such as “invalid” or “cripple” were socially acceptable. Slowly, contemporary views of disability are expanding beyond descriptions of medical conditions or functional limitations to the use of “people first language”: placing the individual first rather than the disability (e.g., a person with mental retardation rather than a mentally retarded person).

Purpose of the Chapter

The purpose of this chapter is to increase the reader’s knowledge and understanding of the role, validity, and usefulness of diverse conceptualizations of disability. The chapter outlines each of three primary models of disability: medical, functional, and social

approaches to disability. In theory and practice, components of these models may be mixed. Thus, the chapter provides examples of several integrated models of disability. Within the discussion of each model, the reader is provided an overview of the model, examples of how or where the model is implemented, analysis of the approach, and a discussion of the implications of the model for public health. The reader is cautioned that the summarization process may have inadvertently over- or under-emphasized components of the models or the debate surrounding them.

Medical Models of Disability

General Approach

When public health considers disability, many of its activities derive from the conceptualization of disability from a medical model perspective. Under the medical model, disability derives from a disease, trauma, or health condition that impairs or disrupts physiological or cognitive functioning. The basic tenets of the model include conceptualizing disability as a condition (such as heart disease) or deficit (such as mental retardation) that resides within an individual and can be cured or ameliorated through a treatment or a particular intervention (Bernell 2003; Bickenbach 1999; Iezzoni and Freedman 2008; Johnston 1996; Llewellyn and Hogan 2000; Rioux 1999).

The medical model relies strongly on what Talcott Parsons (1951) has described as the “sick role.” This is the notion that individuals with specific conditions or attributes are lacking in some way and are exempt from certain social obligations because they are “sick” and can be “cured” by adhering to the medical regime prescribed by the health professional. Interestingly, this approach results in a shift in responsibility when “sick” patients do not adhere to the medical regime or are not “cured.” Physicians seem to act as if patients don’t “die” per se; they “fail to respond to treatment.”

Because of the medical model’s origin within the health profession and the disease model, it is naturally oriented to the notion of treatment, cure, and prevention. Disability is generally viewed in categorical terms (e.g., cerebral palsy, multiple sclerosis) with much less regard for severity (i.e., degree of impairment or symptoms). The model also promotes the belief that it is the human element that can be changed through treatment, rather than external elements such as the environment (Bernell 2003; Iezzoni and Freedman 2008; Llewellyn and Hogan 2000; Marks 1997). Underlying Parson’s “sick role”—and implicit in the medical model—are assumptions that disability is a negative deficit, that disability lies only within individuals, and that disability derives solely from a physiological basis due to damage or disease.

Analysis of the Medical Model

Historically, the primary purpose of medical model research has been to identify a cure for specific diseases or conditions. In medical model research, the condition itself is typically the focus of research attention, e.g., the study of autism focusing on its physiological causation through autoimmune disorder or the study of cognitive problem-

solving or linguistic patterns of speech of people diagnosed with autism. The aim of the research is to understand the condition and its etiology in order to control or eliminate the prevalence of the condition or its symptoms in the general population (Rioux 1999). This emphasis creates an a priori assumption that disability is a non-normative or abnormal state. Another aspect of medical model research is oriented to “fixing” the individual and decreasing their care needs. For example, research on post-stroke rehabilitation has introduced new ways stroke survivors can learn how to bathe and dress after a stroke.

Either emphasis of medical model research (reduction of future care needs or elimination of the condition) reduces biomedical disease and health status to negative anatomical, biochemical, or physiological variables. Disability advocates have long rejected the notion that people with disabilities are “ill” or abnormal (Krahn 2003; Llewellyn and Hogan 2000). As such, there is a widespread belief within the disability community that health care professionals and medical researchers engage in activities that marginalize and oppress people with disabilities (Bernell 2003; Bricher 2000).

The reductionism of the medical model can also overlook the important role physical, cultural, environmental, and political factors play in determining disability status (Imrie 1997; Minaire 1992; Rioux 1999). Thus, a strictly medical approach may ignore the role society plays in impacting health status and creating disability through prejudice or other negative attitudes. At another level, the medical model has been criticized by psychologists for failing to take into account that activity limitations or reductions in health status (disability) may result from psychological distress emerging from experiencing societal prejudice or neglect (Marks 1997).

Functional Model of Disability

General Approach

Similar to the medical model, the functional model of disability focuses on disability as deriving from an individual's impairments or deficits. Where this model differs from the medical approach is that, while the source of the disability is individualistic and linked to medical, physiological, or cognitive impairments or deficits, the *expression* of disability is the inability to perform a number of functional activities. For example, someone has a disability under the functional model if, due to an underlying impairment (such as mental retardation) or condition (such as cerebral palsy), they are unable to perform vital physical or mental activities such as moving, breathing, working, or living independently (Bickenbach 1999; Rioux 1999).

The logic of the functional approach is to focus program delivery on individuals (albeit individuals with impairments or deficits) who need services to function. The underlying presumption of the functional model is that, while acknowledging the conditional or pathological source of the disability, the most important part of the disability is the disruption in functioning (Imrie 1997; Rioux 1999). The functional model considers the expression of disability (the disrupted functioning) as something that can be treated much like a doctor treats a disease (Imrie 1997). Thus, the functional approach stresses the adoption of a treatment regimen, strategy, or service that improves functional capacity rather than addressing the underlying condition or impairment.

Functional approaches to disability are currently used in a number of important programs in the United States. For example, Section 223(d)(1) of the Social Security Act defines *disability* as the

inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months.

The Act makes clear in Section 223(d)(2) that it is not the presence of medically determinable physical or mental impairments that creates a disability; disability is considered present only if the impairments result in an inability to engage in "substantial gainful work which exists in the national economy." Under the Social Security Act,

then, disability benefits are determined by the presence of physical and mental impairments that interfere with a person's capacity to work.

Another example of a functional approach to disability is contained in the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (42 USC 15001 *et seq.*), known as the DD Act. Under Section 102 of the DD Act, *developmental disability* means a severe, chronic disability of an individual that:

- i) is attributable to a mental or physical impairment or combination of mental and physical impairments;
- ii) is manifested before the individual attains age 22;
- iii) is likely to continue indefinitely;
- iv) results in substantial functional limitations in three or more of the following areas of major life activity:
 - a. Self-care
 - b. Receptive and expressive language
 - c. Learning
 - d. Mobility
 - e. Self-direction
 - f. Capacity for independent living
 - g. Economic self-sufficiency; and
- v) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

Section 101 of the DD Act describes the Act's purposes as:

to assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life, through culturally competent programs authorized under this title.

Under the DD Act, then, access to programs is limited to persons with mental and/or physical impairments that have three or more functional limitations in the previously described major life activities.

Analysis of the Functional Model

Historically, the purpose of the functional model has been to identify and ensure treatment for disruptions in functioning that emerge from underlying impairments or conditions. This emphasis creates an a priori assumption that a disruption in functioning or a disability is a non-normative or abnormal state. Despite being less categorical than the medical model, the functional approach still treats disability as dichotomous and

supports the belief that there are two types of people: those with functional limitations (the “disabled”) and those without functional limitations (the “able-bodied”). It also produces an implied corollary: you have to be able-bodied to be successful (Imrie 1997).

All disruptions in functioning may not be the same, however. Imrie (1997) and Rioux (1999) suggest that there is a hierarchy of disability that ranks disruptions in physical and occupational functioning as the most important and deserving of remediation. Whether a hierarchy exists or not, professionals and researchers using the functional model are sometimes criticized for substituting their own perspectives on which functions to pursue remediation for, at the cost of choice by the individual with the functional impairment (Rioux 1999).

One of the implications of the functional model is that some individuals eligible for services under a medical approach might not be eligible under a functional approach if the underlying impairment does not result in a corresponding loss of functioning or has been ameliorated. For example, a farm worker with dyslexia may not have a loss of functioning in an agrarian environment that does not include written communication. Alternatively, under a functional model a person with a leg limb loss may not be viewed as “disabled” after a prosthetic device results in a return to mobility, even though under the medical model—as well as to many laypersons—the presence of the amputation defines the disability.

The functional model’s emphasis on individual performance can overlook the important role external factors (physical, cultural, environmental, or political) play in creating disability status (Bickenbach 1999; Rioux 1999). For example, someone who is blind may have received services that allow them to read and write Braille, use a screen-reader, and function productively in the workplace, but society may only “see” a blind person and not a productive employee.

Social Models of Disability

General Approach

A number of social models of disability have been developed that offer an alternative to medical and functional approaches to disability. In general, social approaches to disability shift the concept of disability from counting or categorizing deficits or impairments within an individual to a focus on barriers people face interacting with the environment (Bernell 2003; Drum 1998; Drum et al. 2005; Humphrey 2000; Iezzoni and Freedman 2008; Tregaskis 2002).

Under the medical model, the inability to carry out activities results from an impairment or condition, e.g., a person is not mobile because of a spinal cord injury. The cause of the disability (lack of mobility) is attributed only to the medical condition (spinal injury). Under the functional model, a spinal cord injury would be considered a “disability” if it results in a lack of mobility such that one cannot work or take care of oneself.

The social model of disability takes a broader view that the ability to undertake activities is dependent upon accessible environments (see Figure 1). It argues that the limitation of activity is not caused by the impairment but is a consequence of social organization—hence the phrase “social model.” A woman with quadriplegia (paralysis of all four limbs, usually as the result of injury to the spine) who wants to work only has a disability under the social model if her intended work site does not have a wheelchair accessible bathroom, or if the bus driver on her local route refuses to stop for chair users because the lift takes too long to use.

Figure 1. Social Model of Disability

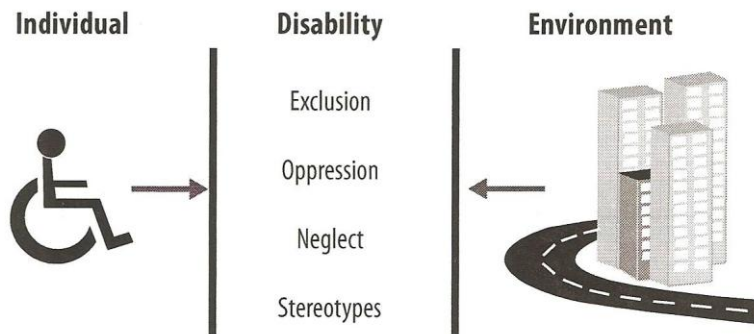


Table 1. Social Environmental Barriers

Type of Barrier	Example
Exclusion	Business policy forbidding hiring people with epilepsy for sales jobs
Exclusion	Nursing home firing a new employee after she reveals in a new employee orientation that she has a mental illness
Neglect	Architect designing a commercial building without considering how someone with a mobility limitation will access the building
Neglect	Elections clerk authorizing polling places in inaccessible locations
Oppression	Sterilizing people with developmental disabilities that live in state institutions
Stereotypical Imaging	Tiny Tim, disability as punishment, disability as deformity
Stereotyping	"Super-crips," people with disabilities as childlike

Under the social model, *environment* is defined broadly and includes social, physical, economic, and political dimensions (Bernell 2003; Dewsbury et al. 2004; Hahn 1985; Humphrey 2000; Marks 1997; Tregaskis 2002). Physical dimensions of the social model include the built environment, such as commercial buildings, housing, and transportation. Economic dimensions include exclusion from educational and occupational opportunities, and political dimensions involve locus of control issues. Authors have described a number of social environmental barriers, including exclusion, oppression, neglect, stereotypical imaging, and stereotyping (Bickenbach 1999; Dewsbury et al. 2004; Humphrey 2000; Marks 1997; Tregaskis 2002). Not every person with an impairment or condition will experience all of these dimensions. For illustrative purposes only, an example in each area is provided in Table 1. Here, oppression is defined as the "unjust exercise of power."

Underlying the social approach to disability is the belief that disability is a social construct. The social construction of disability is one aspect of the social construction of reality. The social construction of reality is "the processes by which any body of 'knowledge' comes to be socially accepted as 'reality'" (Berger and Luckmann 1966). "Reality construction" is the "process whereby people continuously create, through actions and interactions, a shared reality that is experienced as objectively factual and subjectively meaningful" (Berger and Luckmann 1966). In essence, it's a process whereby the subjective becomes objective. From this perspective, disability is created by the societal view (the "shared reality") that people with certain conditions or impairments are different or abnormal.

From this perspective, disability emerges out of the prejudicial imposition of societal perspectives that disadvantage a person with a condition or impairment (Bickenbach 1999; Llewellyn and Hogan 2000). Bickenbach and colleagues (1999) argue, "the limitations people with disabilities face in education, employment, housing, and transportation are not the products of their medical condition, but of social attitudes of neglect and stereotypical images about their capacities and needs." For example, disability emerges out of the imposition of the societal viewpoint that impairments are abnormal (Hutchinson 1995; Llewellyn and Hogan 2000).

In activist discourses, the social model is often described as in direct opposition and challenging the medical model. Humphrey (2000) argues that the medical model—which reduces disability to an interruption in physiological processes within the body or mind of an individual—results in the medical and health professions having the power to “define, control, and treat” people with disabilities. Impairment classification is, in fact, the purview of doctors and other health professionals. Put another way, some authors suggest that the social model represents a dichotomy between those professions that stigmatize disability by classifying it and those who argue that disability represents the inherent variability within the human race (Stiker 1999).

The social model locates disability not in an impaired or malfunctioning body, but in an excluding and oppressive social environment (Marks 1997). As a result, some social model adherents create a raw dichotomy between what they view as “oppressors and oppressed”: people with and without disabilities. After all, this line of reasoning follows, it has been people without disabilities that have organized and controlled the physical, political, and economic society. *Ipsa facto*, responsibility for creation of an excluding and oppressive social environment lies with people without disabilities (Humphrey 2000; Shakespeare and Watson 2002).

However, a number of North American adherents of the social model consider the social environment to be the creation of institutions, rather than the product of individual “prejudiced” people (Llewellyn and Hogan 2000; Marks 1997), and provides a basis for suggesting greater access to institutional-based resources (Bickenbach 1999). Hahn’s sociopolitical definition of disability focuses on the institutional creation of disability. Hahn’s three major premises (Hahn 1993) are:

- 1) social attitudes rather than physical inabilities are the primary source of the problems confronted by disabled women and men;
- 2) all aspects of the social and built environment are shaped or molded by public policy; and
- 3) public policy is a reflection of pervasive social attitudes and values.

Because of the theoretical and sociological basis of the model, there are few examples of the social model of disability in a legislative or regulatory context in the United States. One of the few exceptions is contained in the Americans with Disabilities Act (ADA), which is an equal protection law governing employment, access to state and local governmental programs and services, and access to the services of private businesses, such as retailers or restaurants. Under the ADA, an individual is considered to have a “disability” if s/he has a physical or mental impairment that substantially limits one or more major life activities, has a record of such an impairment, or is regarded as having such an impairment. The first part of the definition makes clear that the ADA applies to persons who have impairments and that these must substantially limit major life activities such as seeing, hearing, speaking, walking, breathing, performing manual tasks, learning, caring for oneself, and working. An individual with epilepsy, paralysis, HIV infection, AIDS, a substantial hearing or visual impairment, mental retardation, or a specific learning disability is covered, but an individual with a minor, nonchronic condition of short duration, such as a sprain, broken limb, or the flu, gen-

erally would not be covered. The second part of the definition protecting individuals with a record of a disability would cover, for example, a person who has recovered from cancer or mental illness.

The third part of the definition protects individuals who are regarded as having a substantially limiting impairment, even though they may not have such an impairment. For example, this provision would protect a qualified individual with a severe facial disfigurement resulting from a burn injury from being denied employment because an employer feared the “negative reactions” of customers or coworkers. This is, in fact, an example of a social approach to disability because the disability is both being defined externally to the individual with the condition and by socially created perceptions of the condition.

Examples of Other Social Models

There are several examples of other social models of disability that are variants of the primary social model, which suggests that disability is socially created and lies in an individual’s inability to access the environment. Brief descriptions of three additional social models (the Legal Rights, Minority Group, and Affirmation models) are provided below.

Legal Rights Model

This model suggests that the most important issue for people with disabilities is the protection of their basic individual rights, rather than treatment for conditions or impairments or amelioration of functional limitations. As such, legal approaches provide the most effective mechanism for ensuring individual rights such as human rights protection and political representation (Bickenbach 1999; Dewsbury et al. 2004). The ADA, which seeks to eliminate discriminatory attitudes, practices, and environmental barriers, exemplifies the Legal Rights Model. Legal Rights Models are appealing on several grounds. In general, they are effective at identifying specific practices that are viewed as an injustice (e.g., employment discrimination, inaccessible environments). In turn, they may provide specific legal procedures (e.g., filing complaints, lawsuits) to ensure justice. As Kuczewski (2001) has argued, legal rights approaches often precede broader social recognition of an issue. In this way, civil or human rights statutes may have a greater capacity to change specific discriminatory behaviors than to change societal attitudes, even though social attitudes may create as great a problem for people with disabilities as specific behaviors.

Minority Group Model

According to this model, the experiences of people with disabilities are similar to the experiences of racial minorities in that disability derives from both individual and institutional discrimination (Batavia and Schriener 2001; Scotch and Schriener 1997; Tregaskis 2002) that emerges from an oppressive majority population (Imrie

1997). Conceptually, linking the issues of people with disabilities with other recognized minority groups may be a helpful strategy. Some authors have argued, however, that the disability experience is too distinct from the experience of minority groups (Shakespeare and Watson 2002). For example, the experiences of urban Latinos or southern rural African-Americans are significantly different from the disability experience. Perhaps more importantly, at the heart of most social models of disability is the rejection of the underlying impairment or condition. Yet, minority groups typically embrace their minority status as part of an overall empowerment or political strategy. How, then, can people with disabilities be a minority group if they are rejecting the very identity label that creates a minority group?

Affirmation Model of Disability

Another theme that is present in a significant portion of the writings on the social model of disability is an appreciation of the individual and collective disability experience as a normal aspect of the lived experience. Although there may be more than a little esoteria to social models of disability, there is a certain simplicity to suggesting that a wheelchair user is “disabled” by a building entrance that has steps but no ramp (i.e., the barriers in the environment create the disability). The Affirmation Model of Disability provides a potentially more challenging view of disability to the nondisabled majority. The Affirmation Model promotes disability as a positive individual and collective identity rather than a personal tragedy. The model rejects characterizations of disability as negative and emphasizes that disability creates a cultural community which supports people with various abilities (Swain and French 2000). In this way, the model suggests that disability is a normal consequence of life and that the presence of a disability creates unique opportunities for self-expression in everything from advocacy to art.

Analysis of the Social Model

Despite the appeal of shifting disability from an individual’s underlying condition or impairment, arguing that society is the primary creator of disability has certain intellectual instabilities. Emphasizing societal oppression as a primary definer of disability overlooks the history that many nondisabled people—often of minority groups of one kind or another—have also been confronted by lack of access to education, poverty, racism, etc. (Swain and French 2000). Although it is not readily acknowledged, there is a certain hierarchy of disability even among some members of the disability community that ranks physical disabilities before cognitive and mental disabilities, respectively. Taken to an extreme, even people with disabilities can oppress others with prejudices against, for example, persons with psychiatric issues (Swain and French 2000).

Locating the social model strictly within social (dis)organization may separate impairment from disability. In fact, in many ways social models are designed to do this. If one ignores impairment completely, the social model raises the prospect that an individual may have their access issues resolved entirely while overlooking the need, for example, to assess pressure sores that result from wheelchair use. In fact, pain and chronic illness are often examples of medical conditions or impairment that are not ad-

dressed by the social model (Dewsbury et al. 2004; Swain and French 2000). Moreover, certain types of research would not be conducted under a social model of disability if, for example, a researcher could not define the target population with the specificity that the medical model provides.

Some authors argue that disability studies—the study of disability from a primarily social viewpoint—should be the sole intellectual property of people who experience disability. This view is echoed in a social approach that views societies dichotomously: whether or not a person has access to the environment, i.e., whether or not a person has a disability. This is, in fact, a classification scheme arguably as reductionist as the medical model itself. Disability, like the concept of health, may be more helpfully considered as a continuum, rather than something that is fixed and dichotomous (Drum, Horner-Johnson, and Krahn 2008; Zola 1993). Moreover, a social model that overly emphasizes separatism may result in the practice of oppressive acts as egregious as the historical practices criticized by the disability community (Humphrey 2000).