

COMMENTARY

▲ Disability Studies and Health Care Curriculum:

The Great Divide

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Models or paradigms of disability are used to guide health care professionals' perceptions so that they can serve people with disabilities, enhance their futures, and facilitate the resources they need. Health care curricula, which in essence train students to make such decisions, are influenced by these models. The medical model, which locates disability within the individual, assumes the individual with a disability is a victim who must be cured or made more normal. The functional-limitation paradigm expands on the medical model, focusing on the interaction of physical or mental limitations with social and environmental factors. The economic model, based on the concept of employability, emphasizes a health-related inability (or limited ability) to work rather than physical functioning of the individual. The sociopolitical model views disability as a policy and civil rights issue. Health care professionals face a dilemma as the disability rights movement demands a shift in social power from the paternalistic view of the medical model to the autonomist view of the sociopolitical model. The question is asked if curricula are preparing our future health care professionals to distinguish how to view each situation and each individual through the lens of the appropriate model. *J Allied Health*. 2004; 33:184-188.

SEVERAL MODELS THAT ATTEMPT to define disability and understand the disabling process have been proposed,¹ each influenced by the prevailing sociopolitical views. For many years, what is now referred to as the *medical model* prevailed, with a corresponding emphasis on pathology. Challenges by the disability rights movement have resulted in new models that place the emphasis on capabilities and social stigma. Health care curricula and rehabilitation professionals have yet to realize fully the sociopolitical model, however, and the demands of the disability rights movement. To understand better the dilemma facing health care profes-

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sionals as they contemplate the sociopolitical model, several models of disability are presented, and the health care and disabilities studies curricula are compared. The discussion focuses on the social dimensions of disability and models of disability accepted by the disability community rather than on how the medical community manages disability via models of rehabilitation such as the community-based rehabilitation or client-centered rehabilitation, models. The purpose is to contrast the disability (which by definition implies social function) with rehabilitation perspectives and present why both must be included in health care curricula.

Models of Disability

MEDICAL MODEL

The medical model of disability, emphasizing limitation of physical functioning, locates disability within the individual.² It denotes a medical etiology that stresses a causal relationship between the origins and outcomes of disability. Disabilities are treated as diagnostic categories. Medical determination becomes an essential prerequisite for participation in a rehabilitation program. The medical model assigns individuals with disabilities a *sick role*,³ and their disability is defined according to the lack of a valued personal characteristic (e.g., "feeble-minded").⁴ In this role, individuals are exempt from social obligations and held blameless for their condition; however this role requires them to surrender their autonomy to professional direction. Treatment is preoccupied with the incapacities of the individual and focuses on methods to cure or return to normalcy. The medical model attempts to treat the body in isolation from the person inhabiting it by reducing the illness to disordered bodily functions. This type of reductionism precludes consideration of how aspects of the individual's social or emotional life affect their physical health. In addition, little consideration is given to modifying the environment, changing roles and tasks, or altering societal expectations. This model inhibits recognition of the social sources of disability, such as stigma, prejudice, and public policy.⁵⁻⁷

ECONOMIC MODEL

The economic model emphasizes a health-related inability (or limited ability) to work rather than physical function-

ing of the individual.^{2,8} This model is based on the concept of employability and the premise that efficient production of goods and services represents a major societal priority. The premise assumes that people with disabilities are less efficient human resources than people without disabilities.⁶ People with disabilities incur a social cost to society by the extra resources they require as well as their limited productivity at work.⁸ Medical determinations of disability are used to categorize the likelihood of employment. The economic model "blames the victim," the individual with a disability, for being unemployable. This model, similar to the medical model, inhibits recognition of the social sources of disability by assuming the ability to work is determined principally by a person's functional capacities, despite research that indicates employment of persons with disabilities is influenced largely by social and economic trends.²

The earliest disability policies named veterans of war and industrially injured workers as beneficiaries. Early programs, such as the Smith-Sears Vocational Rehabilitation Act of 1918, were designed to help individuals who became disabled by serving the interests of the state in military defense and economic growth. The intention was to return the beneficiaries to work. This definition of disability, founded on the economic viewpoint that stipulates physical capabilities as occupational requirements, has been widely adopted in public policy.² This unidimensional approach to disability was more appropriate when the economy was based on manual labor, as in the Industrial Age, than it is in today's Technology and Information Processing Age. Not only has technology provided an alternate means to engage in work-related activities, but also the sociocultural context has shifted from an emphasis on manual labor to an emphasis on quality of life and human rights.

What the medical and economic models have in common is that neither provides a clear link between the disability and capabilities for performance.² The more recent functional-limitation paradigm includes not only this link, but also social and environmental and physical experiences of disability.

FUNCTIONAL-LIMITATION PARADIGM

Parsons³ was one of the first to reflect on the social and the biologic definitions of illness. Since the 1960s, other models have expanded on the medical model to include environmental and social factors, including the Nagi model, the Institute of Medicine model, the World Health Organization International Classification of Function model, and the Verbrugge and Jette model.⁹⁻¹³ According to these current models, disability is considered the expression of a physical or mental limitation in a social context. Specifically, *disability* refers to social function, in contrast to pathology and impairment, which refer to organismic function. Pathology occurs at the cellular or tissue level and is caused by disease, trauma, congenital conditions, or other factors. Impairment occurs at the body or organ systems level and results in loss

or abnormality of mental or physical function.^{9,12} As these models developed, the definition of function became controversial, with meanings ranging from an international definition of *physiologic function* to a definition accepted in the U.S. of *performance within the social and physical environment*. As a compromise, the International Classification of Function (ICF) chose, via an international compromise or agreement, to use the term *function* to denote *physiologic function* and the term *activity limitation* to denote what Nagi and Verbrugge and Jette referred to as *functional limitation*: restriction in performing actions or activities (Rune Simmeonson, oral communication, June 2001). Collectively, these models are known as the functional-limitation paradigm.² People with body impairments and functional limitations are not necessarily disabled, or they may be disabled in one environment but not another. The interaction of their physical or mental limitations with social and environmental factors determines their disability.

SOCIOPOLITICAL MODEL

The nature of disability-related legislation began to shift in the late 1960s. The Architectural Barriers Act of 1968 focused on modification of the environment rather than modification of the individual. The Rehabilitation Act of 1973 focused on individuals with severe disabilities rather than on individuals who could return to work. The Rehabilitation Act of 1973 was the first law driven by the sociopolitical model of disability. The Independent Living Movement of the 1970s led to the entitlement of Independent Living Services and Centers. Increasingly the medical and economic models were being challenged by the sociopolitical model of disability.²

The sociopolitical model views disability as a policy and civil rights issue, not as a health impairment or a diagnosis-related funding issue. Individuals with disabilities are considered an oppressed minority faced with architectural, sensory, attitudinal, cognitive, and economic barriers, who are treated as second-class citizens, facing daily prejudice and discrimination.¹⁴ The sociopolitical model is based on the concept of equal treatment, equal access, equal outcome,¹⁵ and a right to full participation in society. Disability is viewed as a product of interaction between humans and their surroundings, shifting the emphasis from the individual to the broader, social, cultural, economic, and political environments. It implies that disability stems from the failure of a structured social environment to adjust to the needs and aspirations of the individuals with disabilities, rather than from the inability of individuals with disabilities to adapt to the demands of society.²

DISCUSSION OF MODELS

The medical and economic models assume that the individual with a disability is a victim who must be fixed, or at least be made more "normal." In contrast, the sociopolitical

model assumes the prejudiced and stigmatizing society and political system and the inaccessible environments are what need to be fixed. The sociopolitical perspective recognizes that policies shaping the environment are a reflection of prevalent social attitudes and values based on the medical model.² The emergence of the sociopolitical model of disability spawned the disability rights movement. The realization that disability could be attributed to the effects of a disabling environment rather than to personal characteristics has had a significant effect on the self-concept of many individuals with disabilities. The disability rights movement stresses that disability is an acceptable form of human variation,¹⁶ supporting self-determinism and a positive sense of identity for persons with disability. In addition, the disability rights movement promotes the positive experience that can be gained from life with a disability when the penalties of social discrimination have been abolished.^{2,16-19} It is important for health care and rehabilitation students to understand and appreciate the influence of all of these models/paradigms: how the medical model has shaped the general attitude society has about people with disabilities,¹⁴ how the economic model has shaped disability policy,² how the functional-limitation paradigm shapes the current health care curricula, and how the sociopolitical model will shape the future of rehabilitation science and policy.

Curriculum

Each of the allied health professions views individuals with disabilities from the perspective of their profession. Each profession facilitates a unique aspect of rehabilitation, such as activities of daily living and occupation, strength and fitness, and speech and dysphagia. These aspects are not only performance skills, but also a necessary function of Current Procedural Terminology (CPT) codes used for reimbursement and professional survival. If professionals did not have unique specialties (i.e., if there was one professional who could perform the gamut of rehabilitation services), the scope of rehabilitation would be severely and incomprehensibly limited. There is, however, an aspect of rehabilitation that crosses all disciplines, that is social and philosophical rather than performance based and addresses how we relate to each other as individuals. This aspect, wed to professional ethics and values, must be driven by professionals, not by CPT codes, and included in health care curricula.

The following examples are intended to operationalize the proposed philosophical language. Some individuals with disabilities want to be cured. Others do not. Rather, they want the views and responses of society and health care professionals to be cured. Some are not sure. They have not experienced empowerment and making decisions for themselves. Some are at a point somewhere in between. Are students prepared to interact with all of these scenarios, all of which could occur in one afternoon in the clinic? Or are we sending the message that it is the health care professional's intervention that will make the difference (the paternalistic patina). The paternal-

istic patina often considers failure of a client to follow non-compliance professional recommendations.

Most payers purchase a wheelchair if it is to be used in the home, but not if it is to be used in the community. Does this mean individuals with disabilities should stay at home, increasing rather than decreasing their disabilities, or should the prescribing professional simply not ask where the chair will be used? Students are our future leaders who will have to challenge these paradoxical situations, at least until the time that full inclusion of people with disabilities in rehabilitation science and disability studies has occurred,²⁰ and the disabilities rights movement has a stronger influence on legislation.

Previously, facilitating normal movement patterns aimed at changing the individual was a predominant intervention strategy. Individuals with physical disabilities were encouraged to attain the highest level of independent movement possible without the use of assistive devices²¹ (i.e., walking no matter what the cost, not providing head support for wheelchair users with poor head control to build muscle). Now, clinicians are challenging the idea that normal patterns are more efficient than abnormal patterns. I have observed individuals with disabilities using motor patterns that require a high degree of motor planning, significantly more elaborate than the motor planning a normal individual would use to accomplish the same task. Motor patterns in some cases should be considered unique rather than abnormal. This philosophical shift from altering the attributes of the individual to altering the task and the environment is changing therapeutic protocol.²¹

I have experienced being singled out by disability rights advocates simply because I am an occupational therapist (OT). Linton in her book *Claiming Disability* singles out OTs.²⁹ Based on these experiences, occupational therapy is used to illustrate how health care curricula remain under the influence of the medical model and functional-limitation paradigm and have yet to respond fully to the demands of the sociopolitical model and the disability rights movement. In reality, these influences apply to many health care curricula. I believe the assumption sometimes made by OTs that the client-centered model is aligned with the disability rights movement is why disability rights activists are targeting OTs. The assumption that the client-centered model is compatible with the sociopolitical model is false.

OCCUPATIONAL THERAPY

As health care has shifted from a system designed to benefit professionals (biomedical driven) toward a competitive medical market (consumer driven),^{22,23} so has the OT's role shifted from a paternalistic to a client-centered role. Occupational therapy theory^{4,16} is based on the dynamic, self-organizing individual and collaboration with the client within the client's own environment. Since its inception, occupational therapy has focused on culturally meaningful function described in terms of performance of activities and

daily occupation.²⁵⁻²⁸ Within the context of client-centered practice, the OT is a facilitator who works within the tapestry woven by the person, their social life, and environment. Although social life and environment are important considerations, the disability remains located within the individual. Although the individual plays more of a consumer role than a sick role, the individual remains at the center of the process. This is where occupational therapy (and other health professions) and disability studies remain at odds: The disability remains with the individuals rather than with society. This is not to say that one perspective is more correct than the other: Both need to be recognized and addressed.

DISABILITY STUDIES

Disability studies examine our divided society—a society that has medicalized disability by creating the categories of normal versus abnormal (i.e., regular education/special education, abnormal psychology). Historically the study of disability has been located in the specialized applied fields (psychology, special education, OT). The curriculum has been developed from the perspectives of clinician, teacher, and practitioner and casts people with disabilities into the roles of patient, client, or student. This structure is based on the assumption that there is a logical divide between people with and without disabilities, when in fact there is no logic for the creation of this binary category. The predominant message is to control disability rather than to stop oppression.²⁹ Disability studies seek to dismantle curricula based on intervention and individual change and present people with disabilities in terms of human variation, as a political category, as an oppressed minority, as a cultural group, and an emphasis on values such as autonomy, dignity, competence, wholeness, and community.

Dilemma

People with disabilities are declaring a positive identity. They want a voice, self-determination, and self-definition. They view disability as a source of pride and dignity.^{2,29} They are relinquishing or redefining unattainable values, such as normality, and adopting goals that fit their lives.^{4,30} People with disabilities experience the world differently.² They adjust to their life situations by de-emphasizing the importance of health and mobility and emphasizing the importance of religion and comfort.³¹ From a disability rights perspective, disability has come to be seen as less a matter of personal misfortune than of societal neglect and obstruction.³² This difference is a source of creativity and empowerment.² By adopting the sociopolitical framework, people with disabilities are able to shift their values and how they view themselves from *deviant, broken goods* to *different goods* with a desire to connect with others.³⁰

The conflict between the sociopolitical view and the medical model is profound. The conflict between the

sociopolitical view and the functional-limitation paradigm is less profound because the functional-limitation paradigm considers disability on a continuum of disability to function (International Classification of Function model) and acknowledges the social and physical environments as contributors to disability. Nonetheless, the medical model and the functional-limitation paradigm place the emphasis on the individual rather than on society (the International Classification of Function rates individuals, client-centered is still “client”-centered). The paternalistic patina, although diminished, prevails.

Individuals with disabilities are collectively claiming social power over their destiny (through self-advocacy and self-empowerment)⁷ and are demanding a shift from the paternalistic view of the medical model to the autonomist view of the sociopolitical model. The concept of social power implies the will of one individual or group can prevail over the will of others.³³ Our status in society (or stigma) determines the resources available for the exercise of power. Health care professionals are powerful so that they can get the job done, so that they can heal, care, and comfort people. Even health and education practitioners with disabilities yield a relative power compared with that of the disabled community they serve.²⁹ Statements by persons with disabilities, such as “Hey you health care professionals, you’re using up our resources!” (Susan M. Daniels, PhD, former Deputy Commissioner for Disability and Income Security, personnel communication, November 2001) are a daunting indication of this shift in social power that instills defensiveness in and poses a dilemma for health care professionals.

Health care professional and disability rights views do not have to conflict. Both can be realized if the professional can adopt the perspective of the person with the disability rather than that of an external expert.⁸ There are many situations in which this has occurred. In the field of assistive technology, individuals with disabilities are designing equipment and technology that fits their needs and seeking changes in policy that supports an integrative, rather than segregative, lifestyle. Individuals without disabilities continue to be included in the design, fabrication, and evaluation process.

Conclusion

Health care professionals face a dilemma as the disability rights movement demands a shift in social power from the paternalistic view of the medical model to the autonomist view of the sociopolitical model. As Susan M. Daniels, PhD, stated in her presentation in November 2001: “Professionals don’t own the (disability) issue.” Curricula need to be modified to acquaint students with the social and ethical dimensions of the disability minority group paradigm, preparing them for roles as advocates and monitors of laws protecting the civil rights of people with disabilities.² The first step is to require every student pursuing a health care profession to take a course in disability studies. In addition, health care curricula should support the development of

disability studies programs. Dialogue between health care professionals and disability scholars on physique, impairment, technology, and autonomy should be facilitated. It is not that one model is more correct than the other; rather, that each situation and each individual must be viewed through the lens of the appropriate model. Are we preparing students to make this distinction? Our future clinicians cannot see through a lens they do not know exists. Linton²⁹ summarizes the introduction of disability studies into the curriculum as follows:

It is, of course, on one level, the voice of the pygmy, mad as hell and not willing to play the victim anymore. But it is more significantly the crowd mature enough to take on the complex and difficult job of re-ordering society.

Linton²⁹ also poses the question: Are our curricula preparing students to meet the array of issues they will encounter when they leave school?

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