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Ending Disability Discrimination: Strategies for Social Workers

Gary May
Martha Raske

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CHAPTER 5: Changing the Future of Disability: The Disability Discrimination Model

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CHANGING THE FUTURE OF DISABILITY: THE DISABILITY DISCRIMINATION MODEL

GARY E. MAY

INTRODUCTION

The Disability Discrimination Model is designed to give professional social workers a way to conceptualize disability so that their work can play a role in the transformation of how people with disabilities are treated in our society. The guiding principle of this text is that disability-related impairment is a social construction rather than an immutable, objective reality. Impairment operates as a set of beliefs supported by theories and practices within society so that deviations from normative expectations in physical and biological makeup and function are defined as limiting and excluding. The Disability Discrimination Model proposes a theoretical model along with a set of practice principles upon which social workers can restructure their practices.

The model is based on Pfeiffer's conceptualization of the disability paradigm (Chapter 2), that includes the following components:

The disability paradigm states that the study of the experience of people with disabilities focuses on the following variables which impinge on the phenomenon of disability and interact with each other and other human characteristics: (1) the process in which the performance of social roles and tasks produces discrimination; (2) the discriminatory treatment of people with disabilities produced by the organization of society; (3) the recognition that an impairment does not imply tragedy and a low quality of life; (4) the stark reality that people with disabilities are an oppressed minority which experiences discrimination; (5) the need of all people including people with disabilities for various services in order to live independently; (6) the realization that all people have agendas so that the unstated assumptions of disability policy must be revealed; (7) the knowledge that people over time move on a continuum from non-disabled to disabled so that eventually

everyone experiences disability; (8) the rejection that there is “normal” human behavior on which social policy can be based; and (9) the all pervasiveness of discrimination against persons with disabilities (May & Raske, 2004, p. 80).

This chapter will introduce social work students, educators, and practitioners to the Disability Discrimination Model and show how this alternative view of disabilities can transform how our society interacts with persons with disabilities. The authors believe that it is through the daily acts of social work practice that social change takes place. However, individual workers need a fully constructed model of practice to compete with the power of the accepted paradigm—the medical model. If social workers are to transform their work with persons with disabilities they need a theory, supported by clear practice examples, that guides their use of the strengths and empowerment perspectives.

This work follows a long tradition of social work reform. For generations, social workers and other scholars have used theories to transform practice (Brzuzy, 1997; Cummerton, 1986; Daly, 1973; Fraser & Gordon, 1994; James & Thomas, 1996; Merrick, 1994; and Ringma & Brown, 1991). In recent years, for example, empowerment theory has helped social workers develop partnerships with marginalized groups such as persons of color and persons living in poverty (Fisk, Rowe, Brooks, & Gildersleeve, 2000; and Kosciulek, 1999). Unfortunately, empowerment theory has limited impact on practice with populations more affected by the mainstream medical model (Bucaro & Kapfstein, 1999; Goodley & Moore, 2000; Linton, 1998; Morris, 1991; Moxley, 1992). This is most evident in work with persons with physical and mental disabilities (Allison, 1999; Brooks, 1991; Brown & Ringma, 1989; Felske, 1994; Thapar & Bhardwau, 1999; Ward & Meyer, 1999; and Zola, 1989).

The implications of this new lens for assessment will be discussed along with the implications of traditional views for social work and social workers. Normality will be looked at as a limiting concept in our thinking about disabilities; and finally, a case study will be used to exemplify the consequences of the traditional view of disability and the dramatically different consequences when a more comprehensive, accommodating perspective is adopted. The reader will be able to appreciate the contribution of the Disability Discrimination Model in furthering understanding, acceptance, and shared responsibility for corrective interventions.

DISABILITY DISCRIMINATION MODEL

The Disability Discrimination Model necessitates acceptance of an understanding of disability where “disability” and “impairment” are not inherently linked. This theory asserts that the concepts of disability and impairment are socially constructed, and that the “facts” concerning the consequences of disability are not immutable, objective realities, but merely affirmations of a pejorative and stereotypic perspective.

Pfeiffer, in Chapter 2, (May & Raske, 2004) in critiquing the Human Variation Model of Disability, attributed this axiom to that model: "In a flexible social system which fully accommodates a person with a disability, the disability disappears." This view precludes the simultaneous existence of a disability—which may be defined as the presence of an appearance or functional characteristic that is a departure from normative expectations—and positive connotations that might be associated with the label "disabled." Seemingly, one cannot have a disability and feel good. Thus, this perspective implicitly validates the traditional medical model where a disability is a negative aberration that becomes the focus of preventive or remedial intervention.

The Disability Discrimination Model contends that being labeled "disabled" is no different from being labeled "female," "African American," "Hispanic," or any other nominal distinction, but for the consequences of the label. Historically, people with disabilities, unlike these other groups, have not been socialized to experience pride and associate a positive connotation with the label "disabled." We believe that proud, positive connotations can and do accompany the label "disabled," even under conditions when the consequences of the label are constructed as negative, limiting, and pejorative. For example, the fact that I have bilateral above-the-knee amputations (a deviation from appearance and functional norms) does not mean that I cannot be proud of my total being, including that portion of my body and functionality that is appropriately labeled "disabled."

As Pfeiffer (Chapter 2) suggests, a hospitable environment that accommodates my appearance and functional deviations (read "disability") is desirable, but the absence of such an accommodating environment does not mean that I move from a nondisabled state to a disabled state. The absence of such necessary and desirable accommodations merely suggests that the socially constructed environment *causes* impairment. I may still proudly maintain the label "disabled" in either instance.

In the previously cited examples of women, African Americans, Hispanics, and others, we do not insist that they relinquish identity or proud adherence to the labels that connote their group's deviation from the majority. Nor do we suggest that they no longer occupy a role and status within their labeled group if they experience an accommodating social system. Indeed, great effort is expended to ensure that everyone understands the value of diversity (read "deviation") in contemporary U.S. culture. Not so when disability is the issue. Here, the focus is on "restoring" the person who is labeled "disabled" so he or she no longer deviates from normative expectations. There is no systematic effort to identify sources of pride or to instill positive connotations on being "disabled."

The implications for social workers and other intentional helpers are profound and require a "working with" orientation with the disabled client versus a "working on" orientation. From this "working with" perspective, the client system is not merely the collection of difficulties or clinical symptomatology, but is one component of an interactive system that may produce impairment. Solutions, then, are not to be found solely in the person with the disability, but in the larger social environment.

Decisions about what needs to be done and who should do it are reached through collaboration and consultation, not merely clinical practice or psychotherapy. The Disability Discrimination Model asserts that the “client” system is victimized by poor quality social interaction, not by the client’s personality or behavioral characteristics.

As noted earlier, the Disability Discrimination Model makes an essential distinction between disability and impairment and views impairment as a socially constructed phenomenon. From this perspective, disability becomes disabling, or impairment, where an observed or perceived atypical appearance or functional characteristic intersects with a negative, stereotypic, limiting set of expectations. Typically, the possessors of the atypical appearance or functional characteristics are labeled “disabled,” and the holders of the negative, stereotypic, limiting expectations are labeled “non-disabled.” Such a depiction allows the person with a disability to continue to “own” and even celebrate the disability, and implicitly, membership in the disability culture, and explains deferential treatment and limiting elements associated with disability as consequences of the social and physical environment.

From the Disability Discrimination Model, interventions are enacted in a broader field and necessarily include all important elements of the client’s experience. Important human elements, such as family and friends, will need to be educated about the important contributions they can make to the quality of life of the person with a disability. Resistance to this novel perspective that shifts responsibility from the identified client to the milieu as the insidious influence of traditional victim-blaming perspective is substantial. The shift from “working on” to “working with” may not be easy.

Normality As a Limiting Concept

The modern concept of normality—ostensibly denoting the average, usual, and ordinary—has its origins in the mid-nineteenth century in the pervasive belief in progress. It enjoyed cultural popularity in the advent of evolutionary theory. Normality was “. . . a dynamic concept for a changing and progressing world, the premise of which was that one could discern from the observation of human behavior the direction of human progress, or evolution . . .” (Baynton, 1997, p. 83). Normality, in actual usage, generally excluded only those defined as below average, even though the term denotes the average, usual, and ordinary. In this era, physical and mental abnormalities were depicted as instances of atavistic reversions to earlier stages of evolutionary development. For example, Down syndrome was originally called mongolism by the doctor who first identified it in 1866 because he believed it to be a biological reversion of Caucasians to the Mongol racial type (Baynton, 1997). More recently, the contiguous displays of “defectives” and “primitives” at the 1904 World’s Fair confirmed the intersection of classification schemes for both individuals and races seen as inferior (Baynton, 1997, p. 85).

This comparison led to the emergence of the eugenics movement to combat the threat to human progress by identifying and eliminating undesirable

characteristics. Disability has represented a danger to progress and evolution and thus one of the greatest threats to the progress-defined “modern era” (Baynton, 1997, p. 84). In the late nineteenth century, progress was depicted as a phenomenon of increasing purity, where the world is rid of imperfection and “contaminants.” Consequences of this view have included withholding life-saving surgical interventions from disabled infants (a practice referred to as “the Greater Surgery”—the surgery that cuts away the bad and leaves only the good, pure, sweet, and clean), “pure oralism” for the deaf, sterilization and eugenic euthanasia in the United States and mass killings of “defective” individuals in Germany (the first to die in Nazi Germany were people with disabilities) (Baynton, 1997, p. 85).

As the concept of never-ending progress has waned, so has the concept of normality lost some of its cultural potency. The rebellions of the 1960s against an oppressive conformity, sameness, and anonymity moved American culture away from the sense of normality as defined in the modern era. Indeed, the concept of normality has been the target of serious, sustained challenge in most areas of popular culture. In spite of changes, the ideology of normality, as applied to people with disabilities, is still represented as binary oppositions, with one side held as a universal norm and the other side as a deviation from that norm.

Challenges to the conceptualization of normality became a prominent feature early in the women’s rights movement. Women were depicted as strong, capable, and upright, in contrast to weak, “degenerate” men who were identified as “idiots” or “lunatics” (Baynton, 1997, p. 86). The argument was then made that it was unconscionable to place women in the same category with those who were *justifiably* denied social and political rights. Obviously, these comparisons did nothing to challenge the assumptions about normality as applied to people with disabilities.

The successes of the women’s movement, efforts to extend civil rights protections to people of color, and an emerging cadre of well-educated, assertive people with disabilities in the social environment of the 1960s, which encouraged tolerance and acceptance, provided a rich impetus for the emergence of a disability rights movement. This movement refutes the assumptions of the medically-oriented model, which classified, people with disabilities on the basis of functional limitations.

Disability Content in Social Work Education

The revised Educational Policy and Accreditation Standards (EPAS) of the Council on Social Work Education (CSWE) took effect on July 1, 2002. According to the standards, social work educators are to prepare students for work with persons with disabilities “without discrimination, with respect, and with knowledge and skills” (correspondence from CSWE to deans and directors of CSWE member programs on June 30, 2001, p. 6). Thus, along with age, class, color, culture, ethnicity, family structure, gender, marital status, national origin, race, religion, sex, and sexual orientation, disability must be a core issue in BSW and MSW degree pro-

grams throughout the United States. Social work educators need tools, such as the proposed text, to comply with these new standards.

Gilson and DePoy (2002) argue that viewing disability from a social constructionist perspective has more utility for social workers than the more traditional, deficit-oriented, diagnostic perspective. The implications for viewing disability from a social constructionist perspective are reflected in disability-related content in key elements of professional social work texts (p. 158, Table 1). The essential differences are the aperture through which disability is defined and the environment in which change is sought. In the diagnostic (medical) model, disability—and the related impairment—are an objective condition in the person with a disability. The constructionist perspective asserts that a disability-related impairment comes from the relationship of the person with a disability to the social environment. This perspective shifts intervention targets to the person with a disability and his or her environment and establishes shared “ownership” of the disability-related impairment. Consequently, interventions to remediate disability-related impairment must be shared and require accommodations in the individual with the disability *and* his or her environment. This stands in sharp contrast to the nominal position taken by the academy relative to the education of social workers regarding disability (Gilson & DePoy 2002), where the emphasis is on rehabilitation and mitigation.

The Council on Social Work Education’s 1992 Curriculum Policy Statement and the 1994 *Handbook of Accreditation Standards and Procedures* are ambiguous regarding disability definition and content requirements (Gilson & DePoy 2002). Most commonly, disability is defined diagnostically so that persons with disabilities are aggregated in the “populations at risk” category. Thus, pedagogy, limited though it is, is confined to diversity content courses, already chock full of mandates and advocacy for including numerous discrete populations thought to be “at risk” as a consequence of their membership in identified “out” groups. A consequence of this reality is that disability content is irregular and education sometimes superficial. Some instructors report that there isn’t enough time to “cover” the plethora of specifically identified populations in such diversity courses. The consequences include some sad confessions by diversity instructors, as reflected in the following account.

During a conversation between the first author and a diversity instructor, the instructor was lamenting the lack of interest by his graduate students in his diversity course. The course is among the last required prior to the completion of graduate studies. “They’ve had about all the diversity content they can stand,” he opined. He then listed the topics and populations that had been the focus of his instruction during the term. Somewhat sheepishly, he apologized for “not getting around to disabilities” because there “just wasn’t enough time.” Interestingly, a student with blindness was enrolled in this section of the course. The instructor hastened to add, “I apologized to him, too.”

It was as if confessing excused not teaching. In the absence of clear standards and consistent direction from the Council on Social Work Education, it is likely this sad scenario will play itself out in other CSWE-sanctioned programs. What’s

needed is leadership on this issue and support for instructors and students who strive for an understanding of disability and disability-related impairment that is consistent with social work's values and that facilitates effective intervention by social work practitioners at all levels.

Payne (1997) identified three views of social work: reflexive–therapeutic, socialist–collectivist, and individualist–reformist. The *reflexive–therapeutic* view sees social work as a reactive therapeutic response aimed at achieving “the best possible well-being for individuals, groups, and communities in society by promoting and facilitating growth and self-fulfillment” (p. 4). The *socialist–collectivist* view sees social work as seeking “cooperation and mutual support in society so that the most oppressed and disadvantaged people can gain power over their own lives” (p. 4). Finally, the *individualist–reformist* perspective sees social work as individually therapeutic as well as improving service delivery systems—“It meets the individuals’ needs and improves services of which it is a part, so that social work and the services can operate more effectively” (p. 4).

Gilson and DePoy (2002) advocate for a combination of the diagnostic and constructionist viewpoints in disability content in social work education. “The knowledge, theory, and skills that would emerge from this complex, multifaceted, and contemporary treatment of disability would reflect social work’s professional commitment to social justice and locate discussions of disability within the larger discourse on diversity” (p. 163). This would seem to place it within the socialist–collectivist view of social work in Payne’s typology (1997).

Payne (1997) advanced the premise that social work itself is socially constructed. This construction includes creating the need for a social worker. Thus, social workers are defined by occupational expectations in encounters with clients. Social and political forces and perceptions about need shape the response to needs. The organization of services and agencies within the broader culture reflect legislative and popular sanction for social workers and their services. These definitions, based on occupational expectations, perceptions about needs and responses and the existence of services and agencies in the context of the broader culture, expose areas of actual or potential conflict (p. 16). In the area of disability, such conflicts, actual or potential, may center on the role of social workers in the lives of individual persons with disabilities.

Should the social worker strive for rather passive “acceptance” of the disability by the owner? To what extent do the worker’s definition and understanding of disability influence what roles they enact? What is the social worker’s obligation regarding client education and in broadening horizons regarding self-advocacy, empowerment, or self-actualization? What is the role for social work when social and political forces devalue or narrowly reframe needs and responses to needs? How does social work rise to the challenge when the consumers of our services are defined as “undeserving” and “unworthy” by the public? Finally, what should social work’s position be when the definition of the “problem” of disability is narrowly crafted and leads to a one-dimensional response?

These questions suggest that social work is but a component in a network of related professions and occupations. Thus, our understanding of theories that

explain and predict human behavior and our subsequent adoption of practice models and intervention strategies need to be seen as reflective of the assumptions and beliefs that we accept. Gilson and DePoy (2002) seem to suggest that, as it pertains to disability, many of the assumptions and beliefs we accept do not serve the broad, long-term interests of persons with disabilities. Acceptance of the medical model, especially when not critically examined, and assuming a diagnostic framework for understanding and intervening in disability, is limited and limiting.

Hiranandani (2002) has suggested that social work would be well served by a more critical perspective regarding disability. Relevant questions from this critical perspective include, “How are deficits of the body and mind interpreted and dealt with in different societies? How is an individual’s identity as a person affected by the cultural connotations of disability? How do processes of cultural transitions shape local understanding of disability?” (p. 10). Definitions of disability constructed around measurements of functional limitations fail to address these cultural and contextual issues.

So, constructing and defining clients with disabilities as composites of impairments *caused* by their disabilities predicts a narrow, reflexive–therapeutic (Payne 1997) approach by the social worker. This linear depiction minimizes and suppresses the full range of possible social work responses. Conversely, defining *impairments* of clients as *caused* by the broader sociocultural construction of disability unleashes the inclusive, dynamic social system orientation that characterizes social work.

Discrimination Model

Pfeiffer (Chapter 2) has suggested that a new disability paradigm is necessary. He identified limitations in the traditional medical model for understanding disability and for policy formation. Similarly, Pfeiffer cited deficiencies in the social constructionist and oppressed minority models of disability. In the former, the “problem” is defined as judgments made about people with disabilities by those with no disabilities on the basis of a departure from normative expectations. In the case of the oppressed minority, the model is lacking because it does not explain the variation in experiences by persons with disabilities.

For example, one would be hard pressed to defend the assertion that Christopher Reeve (the contemporary U.S. actor, whose most prominent role was “Superman” in movies, and who is now a quadriplegic as a result of an accident) is oppressed. He has sufficient resources to ensure his life in the community, to continue his work—albeit in a different primary role—and to provide for his family. Neither the medical model, with its individualistic, deficit-oriented definition of disability and related impairment, nor the social constructionist model, with its “eye of the beholder” orientation, nor the oppressed minority model fully explains Reeve’s experience. At various times, however, Reeve surely faces impairment in functioning and access that is related to his disability.

Pfeiffer (2000) suggests that disability exists where discrimination exists. As noted earlier, he opined, “In a flexible social system which fully accommodates a

person with a disability, the disability disappears" (May & Raske, 2004). This model seems wanting also, however. It suggests that the experience of and with disability is mediated by the external environment. For example, would such a model suggest that a person with amputations is *not* disabled if they are in a "flexible social system which fully accommodates" them? If the answer is affirmative, how is this reconciled with the "disability pride" movement? Doesn't this model contain the major limitations of the constructionist model, to wit, relinquishing to others the matter of *defining* disability? Recent advocates have asserted that there is a disability culture (*Vital Signs*) and that membership in this culture is not anathema to feeling pride and a strong identity with this culture.

What is necessary is the construction of a theory that is responsive to the broad range of experiences of persons with disabilities. The challenge is to capture the disparate disability-related experiences, which range from abject deferential treatment and exploitation to empowerment and enlightenment. For example, see Cleland's (2000) description of the positive, transformative implications of his disability as he describes his adjustment to his very serious injuries in Vietnam. The construction of such a theory in social work seems best built on the foundation of methods, values, and philosophies that underpin the field of social work.

CONSTRUCTIONISM

Witkin (1990) describes constructionism as a theory that seeks to "elucidate the sociohistorical context and ongoing social dynamic of descriptions, explanations, and accountings of reality" (p. 38). Particular attention is devoted to the historical and cultural contexts of knowledge. Constructionists view theory and the dominant forms of understanding as shaped and limited by cultural assumptions, history, sociocultural mores and norms and language (Patterson, 1997).

From the constructionist perspective, language is a method for generating meaning and knowledge rather than a representation of an intrinsically objective "truth." The contemporary language and rhetoric of disability, with its individualistic portrayals of personal tragedy, then, suggest that disability and impairment exist independent of cultural, historical, or other contexts. Contrary to the dominant emphasis on cultural influences on human behavior in other arenas, social workers, as well as other professional helpers, seem to accept the intrinsic objective "realities" of disability and impairment, thereby overlooking environmental factors.

"Disability," from the constructionist perspective, is not a singular, concrete concept. There are cultural and individual differences in definition, evaluation, perception, and expression of "disability." Taxonomical expediency, rhetorical limitations, patterned, circular discourse, and an unwillingness to challenge disability "truths" perpetuate the antithesis of this reality.

For social workers operating from this "reality," their assessment of "problems," "solutions," "strengths," and "weaknesses," will be skewed, and ultimately serve to perpetuate the dominant, unchallenged medical depiction of disability. The burden for change will be borne disproportionately by the person with the

disability, as he or she is made to conform to the expectations of others. “Failures” will be attributed to personal attributes (read “limitations”); the explicit expectation that success includes “overcoming” so-called “real” barriers will endure. The sad consequence for people with disabilities is the poor showing on quality-of-life standards (N.O.D./Harris Survey of Americans with Disabilities, 2000).

Understanding disability as a constructed phenomenon, rather than an intrinsic objective reality calls into question the assumptions that are the foundation of social work involvement with this population. Most of the knowledge in this area is from medicine. Medical concepts and perspectives are assimilated and operationalized. The Disability Discrimination Model provides a theoretical framework from which to rethink disability in empowering, positive, self-actualizing terms (as discussed in the case later in this chapter)—a perspective true to social work’s heritage.

ASSESSMENT

Assessment is a key component in social work intervention. It both represents the biases of the examiner and directs the nature, focus, and methods of intervention. Over the past several years, attention has been focused on assessment as it is applied to persons with disabilities. The interest seems focused on identifying an alternative to the traditional medical model of assessment.

This model is a deficit-oriented, pathology-based, individualistic, static approach that is predicated on the assumption that the physical condition is an irrefutable objective reality. From this stance, the purpose of assessment is to define the disability as a departure from objective normative expectations. These variations are typically depicted as deficiencies or inadequacies. The intervention that is suggested by this assessment is remedial and corrective in nature. The deficit, having been identified, becomes the target for intervention and the person possessing the deficit is little more than the vessel containing the deficit. Intervention is narrow, deficit oriented, restorative, and administered by trained professionals, who are identified as possessing all necessary and helpful information. The role for client self-determination is minimized, as treatment professionals administer their “cures” of the identified deficits. Trieschmann (1980, p. 24) pointed out that in this model, behavior (B) is seen as “. . . a function of treatments to the organic variables (O) unless hindered by underlying personality problems” $B = F(O \times p)$ (Mackelprang & Salsgiver, 1999, p. 214).

In recent years, challenges to the medical model have emerged from a variety of theoretical perspectives (Barnes, Mercer, & Shakespeare, 1999; Pfeiffer, 2000; Handbook of Disability, 2001; Hahn 2000). These challenges have come from a variety of academic fields, including anthropology, political science, history, rhetoric, and disability studies. Unfortunately, social work and social workers have not been in the forefront of this charge.

The rethinking of the medical model and its implications should find a comfortable home in social work, with its commitment to the broad systems perspective,

the focus on social and economic justice and a pervasive empowerment perspective for most other oppressed populations.

Social work's increasing clinical orientation and the fact that social work is rarely the primary profession in organizations and institutions employing social workers seem to conspire to suppress assertiveness and critical thought in the area of disability awareness and assessment. In this and other instances, the activist social work perspective is muted by the influence of more powerful medical-model driven professional perspectives and by the influence of funding sources that favor rehabilitation and mitigation-focused approaches.

An alternative, identified by Trieschmann (1980) (Mackelprang & Salsgiver, 1999, pp. 214–215), is a learning model. This model introduces the additional variables, or targets for evaluation, of the person and the environment, both largely absent in the medical model. In this model, *person variables* include personality style, coping mechanisms, and internal and external loci of control. *Organic variables* include age, health, and severity of disability. *Environmental variables* include family support, finances, and public policies. The assessment range is expanded to include the psychological and environmental variables, but the individual remains the primary focus of the assessment. The outcome of assessment from the learning model is the identification of knowledge deficits that the client needs to function independently. In this model, behavior (B) is seen as a function of the person (P), the organism (O), and the environment (E): $B = F(P \times O \times E)$. (Mackelprang & Salsgiver, 1999, p. 215).

Other models include the economic model (Condeluci, 1995), which emphasizes the inability of the person with the disability to earn a living (either because of the limitations of the disability or because of the limited expectations of the evaluators) and the minority group model (Hahn, 1991), which stresses a broader social versus individual approach, where social stigma is the major problem facing people with disabilities.

Marxist analysts view disability as a social problem that is directly linked to the changing mode of production. The mode of economic production influences other important institutions, such as political organizations, ideology, religion and culture: "the ideas of the ruling class are in every epoch the ruling ideas; that is, the class which is the 'ruling material force' of society, is at the same time its ruling intellectual force" (Marx & Engles, 1994, p. 15). From this perspective, the individualized and pathologized approach to disability is a consequence of the functional necessity for a workforce that is physically, intellectually, and emotionally able to serve the demands of industrialization. In short, standards more suited to machines were applied to people with disabilities. If the machine was determined to not serve the interests of production, it was judged to be of little or no use. In this model, modifying the mode of production is not considered. This is a very durable model that exists today, in spite of employers' insistence that they distinguish between fixed mechanical assets and human capital.

A more recent paradigm for assessment is the social model. In this model the roles in the traditional medical model are reversed. The person with the disability becomes the expert, while professionals occupy the role of responding to

the needs or wishes of the person with the disability. This model does not presume that the knowledge or opinions of professionals are superior or that they trump the knowledge of the person with the disability. It is predicated on the assumption that the person with the disability is the expert in his or her own life.

The social model, more than most others, introduces the important role played by the environment. For example, from this perspective, wheelchair users are not “confined to the wheelchairs,” but use wheelchairs because of environmental obstacles that impede their mobility. This model also emphasizes people’s strengths and other assets, a refreshing departure from the deficit-oriented medical model. It also addresses the role of pervasive institutional oppression and devaluation to which people with disabilities have been subjected (Mackelprang & Salsgiver, 1999, p. 217).

Because of its expanded universe of elements for examination, and because it recognizes the knowledge and control of the person with the disability, the social model is offered as the preferred model for social workers (Mackelprang & Salsgiver, 1999, p. 218). While the social model does represent an improvement, a major deficiency is its emphasis on the responsibility of the person with the disability to correct identified barriers to inclusion and appropriate interdependence.

Assessment Using the Disability Discrimination Model

The Disability Discrimination Model demands an additional element in evaluation and remediation, which shifts the burden from the person with the disability to a shared responsibility between him or her and the socially constructed environment. Corrective actions are not the sole province and in the sole interest of the person with a disability. They are accepted as a beneficial consequence for all, including those *without* disabilities. In assessment from a Disability Discrimination Model perspective, behavior (B) is a function of the interaction of the person (P), the organic (O) (age, health, and severity of disability), and the environment (E), as expressed in ongoing interaction with society (S): $B = F(P \times O \times E)S$. Evaluation must include examination of social forces (versus personal forces) that mediate behavioral outcomes. The essential element is that the origin and maintenance of impairment is not singularly of interest to the person who is marginalized by such impairment, but it is understood to be a shared responsibility. Interventions must include a macro perspective.

ANALYSIS

Andrea was able to transition to the community and realize the U.S. middle-class dream of home ownership because she and her mother experienced an environment that was supportive of her and her atypical needs. This is what Gray (2002) referred to as “environmental receptivity.” According to this perspective, a receptive environment supports participation by a person in the community with

CASE STUDY

BACKGROUND

Andrea is a thirty-seven-year-old female with multiple severe disabilities, including a grand mal seizure disorder since age three, profound mental retardation, and hyperactivity. Her siblings, a thirty-five-year-old brother with learning disabilities, and a thirty-year-old sister with no known disabilities, are settled into adult roles. Andrea's mother is a fifty-eight-year-old executive in a disability service organization. She and Andrea's father divorced nineteen years ago, as the number, severity, and extent of Andrea's physical conditions were becoming more apparent.

Andrea was institutionalized at a state-funded developmental center for the first time at age five. The principal purpose for the admission was because of her uncontrollable seizures, and the impact of family-provided home care. Andrea's brother was three at the time. Mother reports that there was little support for home care from the medical establishment or from the community.

At age ten, Andrea was removed from the developmental center by her family. They were dissatisfied with the level and quality of care there and Andrea was very unhappy there.

From age ten to twelve, Andrea was cared for in the family home. After two years, she was admitted to a private children's home at state expense. Medical professionals advised her parents to "forget about Andrea and take care of the family." There were few supports for Andrea while she was at home and for the family after she went to the children's home. While there, she attended school. She remained at this private children's home until she was eighteen, at which time her discharge was required, as the state would not fund additional services because of her age. She was then readmitted to the state developmental center from which she was previously removed by the family. She was discharged from the state developmental center in 1998 when the facility was closed by the state.

She moved to a rental home with two roommates from the state developmental center. The closure of the developmental center triggered access to a broad range of services and supports for former residents. Andrea's mother became aware of these community-based services, many of which had not existed earlier in Andrea's life, and still others of which were available but not known to the mother. Andrea now has a vagus nerve stimulator to mitigate the seizures. She still experiences daily seizures, but they are less severe than in the past.

Andrea was assisted in finding a residence in the community. She has a roommate who also has developmental disabilities. Andrea and the roommate maintain their own residence with assistance from a personal care attendant. Andrea's mother is her guardian. Andrea was recently approved for a mortgage and is in the process of buying a home near her mother. She and her roommate will live in their new home.

Over the years, what was initially a supportive network for Andrea's mother disintegrated. She lost her husband through divorce. The faith community of her church dismissed her because she would not heed the medical advice to "forget about Andrea" and concentrate on her other children. Similarly, the medical community abandoned the family and did not pursue or consider options other than palliative treatments predicated on low expectations of Andrea.

Mother is now committed to sharing her experiences with other families so that they will not have to repeat the heart-wrenching experiences she has had. The agency for which she works supports people with disabilities in the community by providing services consistent with a person-centered plan. Her guiding motto is, "The community just needs to understand that we're all just people and to be more accepting. We need to make all people part of the community."

disability labels. No demand was made on Andrea to relinquish her “disabled” label, nor was any expectation imposed that negated the pride she might experience in association with the label. She did not become nondisabled when she experienced an accommodating environment. What she experienced may be more appropriately thought of as her extrication from the limiting consequences of her previously socially constructed reality. She still has cognitive, behavioral, and physical characteristics that are departures from norms *and* she has a much better quality of life (read “reduced” or “eliminated impairment”) because of a more hospitable environment as a direct consequence of a different construction of the consequences of her disabilities.

Components of such a receptive environment include the natural environment, which includes the physical surroundings, the climate, the weather, and built elements, including universal design. The receptive environment also includes human changes to the environment, such as modifications to the landscape, access accommodations, environmental controls for temperature, humidity, and so on. Human relationships, supports, and attitudes are another element in the Gray (2002) paradigm. This includes the understanding and support of the social environment. In Andrea’s case, much of her support, including her father, the church, and the medical establishment, turned their backs on her and her mother.

Services, systems, and policies, the absence of which led to Andrea’s institutionalization at various points in her life, are critical components of a receptive environment. Early in her life, the services that might have benefited Andrea were not available; nor were there systems or policies that challenged the “wisdom” of institutionalization for persons like her. Finally, products and technology need to be present in a receptive environment. In Andrea’s case, such technological advances included the development of a more effective method for mitigating her seizures, which made it possible for her to achieve a level of independence that she must not have even imagined before. The synergy and complementarity suggested in this depiction of a receptive environment is apparent. All components must be present to constitute a receptive environment.

Andrea and her family experienced the influence of medical technology and linear thinking when they were offered advice relative to institutionalization. The advice, predicated on the apparently accepted premise that caring for Andrea at home would have a deleterious effect on the overall functioning of the family, in effect, created a self-fulfilling prophecy. Such advice did not include any good faith offer of support or assistance in caring for Andrea at home. The absence of such support, in the form of modifications to the environment, human support through relationships and attitudes, and services, systems, and policies, almost guaranteed that Andrea’s family would not be successful. The absence of success then, became “proof” of the premises upon which the advice was built. The net effect for Andrea was spending the majority of her life in large institutional settings away from her family.

Community participation, on the other hand, is a complex construct with temporal, personal evaluation and receptive environment qualities. The temporal

aspect includes the frequency of a person's engagement in a preferred activity and the amount of preparation time. Personal evaluation involves the importance, choice and satisfaction that the person attaches to the element of participation.

Applying this community participation construct to Andrea's life, one could surmise that, from a temporal perspective, she had little choice relative to frequency or preparation time for participation in the nominal community while she was institutionalized. Choices were made by others. Similarly, because Andrea exercised very little choice, the degree of importance and satisfaction that she derived from the choices made for her by others was negligible. Indeed, her mother reported that one of the agonizing elements of her institutional life was the family's realization that she was fundamentally unhappy and felt trapped in the institutional environments. The conclusion that the institutions did not, in any significant way, represent receptive environments seems inescapable.

CONCLUSION

From the Disability Discrimination Model perspective, then, the extent to which impairment is associated with disability is mediated by the quality of the interaction between the "disabled" person and the "nondisabled" person. Because of the low status and pejorative views of disability and the lack of socialization into the role, persons with disabilities often hold the same negative, stereotypic, and limiting expectations as the nondisabled. The Disability Discrimination Model necessitates challenging the hegemony of the medical model, while recognizing that it has its use in limited, mostly acute, applications.

In the areas of race and gender relations, the presence of an objective characteristic, such as skin color or gender, is not the primary predictor of the quality of life experience. Instead, it is the nature and quality of interaction with others. So, too with disability, the quality of life experience is mediated by interaction.

But in stark contrast to the areas of race and gender relations, where the possessors of the "atypical" characteristics—as defined by deviation from a white, middle-class male standard—are socialized to view their "difference" as nominal or as a source of pride, persons with disabilities, the vast majority of whom have adventitious disabilities, are socialized to view disability negatively, and not as a source of pride. In the former examples, the default view is either neutral or positive. For persons with disabilities, the default view is a deficit-defined negative. This reality blunts efforts to understand and depict disability as a source of pride by either the possessors of disabilities or the nondisabled.

Depictions of causality and explanations of impairment typically state or imply a direct, linear causality from the atypical characteristics to impairment. The presence of an atypical characteristic (disability) is thought to cause impairment. This paradigm influences policy, practice, leadership, quality of life, and opportunities for people with disabilities as well as for the nondisabled. It is the essence of primary prevention campaigns and policy and practice initiatives.

The effort by professionals is to mitigate the atypical characteristics rather than focus on the broader implications of the quality of understanding and interaction between the disabled and nondisabled, where a major obstacle to be overcome initially is the negative, stereotypic and limiting expectations of the nondisabled. Persons with disabilities, who are the focus of interventions because of their low status, become the targets for corrective actions to improve their lives, when attention should be focused on the role of the nondisabled.

Ironically, this approach, that may be termed “benevolent victim blaming,” serves to reinforce and perpetuate the very dynamic which, the Disability Discrimination Model asserts, causes poor comparisons on quality-of-life standards for persons with disabilities. By focusing policy, practice, research, and structural and representational interventions on the qualities possessed by the person with the disability, attention is diverted not only from the quality of the interaction between the disabled and the nondisabled, but also from the responsibility to contribute to corrective efforts by the nondisabled. The result is the reinforcement of the simple, linear paradigm that predicts outcome from the presence of a disability. This reinforcement predicts that subsequent attempts at corrective action will substantially resemble previous ones. That this predictive model is wanting is substantiated by the consistently poor comparisons of people with disabilities with the nondisabled on objective measures of quality of life in the United States (Harris Survey, 2000).

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