The Disability Rights Movement

Willie V. Bryan

Lack of Concern

Since World War II, there has been an increasing emphasis on human and civil rights in the United States. Minorities and women have spoken out on their own behalf attempting to gain the privileges, freedoms, and rights guaranteed for all Americans by the Constitution. While legal and social ground has been won and lost throughout the years, many minorities and women now enjoy a somewhat more equal existence in the United States than some forty years ago. Still, the battle for equality is far from victorious. While other groups continue their struggle, individuals with disabilities have joined forces to end discrimination in their lives and claim a life of equality in the United States.

The Civil Rights movement of the 1960s resulted in legislation designed to bar discrimination based on sex, race, and national origin; however, prohibition of discrimination based on physical and/or mental disabilities was not included (Burns 1990). As Thomas D. Schenck (1992) reminds us, a bill introduced in Congress in 1971 to amend Title VI of the Civil Rights Act of 1964 to prohibit discrimination based on physical or mental disability died in committee. Similarly, in 1972, another bill introduced in Congress, this time to amend Title VII of the Civil Rights Act to bar discrimination in employment based upon physical or mental disabilities, also died in committee. This may be seen as somewhat of a barometer of the level of concern lawmakers and many other nondisabled Americans had with regard to the civil rights of persons with disabilities.

Perhaps the lack of concern demonstrated by these actions of Congress is more of a reflection of ignorance of the needs and capabilities of persons with disabilities rather than a blatant desire to deny the civil rights of a group of people. At the time, the thought was that employers should not be forced to hire persons who could not adequately perform the required tasks. Persons with disabilities and their friends certainly were not advocating employment of nonqualified persons, they were simply asking that employers be required to look beyond a person’s limitation to see his abilities and attempt to match them with the required job. Employers also had a number of misconceptions with regard to employing persons with disabilities, such as they would not be able to secure insurance for the person and the company’s insurance premiums would increase. Another major misconception was the belief that persons with disabilities were unsafe employees. This erroneous belief was held despite safety records indicating that persons with disabilities had fewer accidents than nondisabled employees (Henderson and Bryan 1984). Many employers were aware that by making modifications to the work site and/or its environment, a significant number of jobs could be made accessible to persons with disabilities; however, these same employers harbored the belief that making those accommodations would be too expensive. Again, this belief was held even though the DuPont Company had demonstrated that many changes to a work site could be done inexpensively.

These and other misconceptions were firmly held by employers because persons with disabilities and their advocates did not vigorously dispute them. The lack of opposition to discrimination against persons with disabilities with respect to employment allowed long-held stereotypes and prejudices to continue unchallenged. Activism would be necessary to dramatize the extent of the lack of concern for the rights of persons with disabilities and cause action to be taken to correct the neglect that had become an accepted method of treatment of persons with disabilities.

Minority Status

The political wheels of American progress appear to turn best when pressure is applied. For example, protests by minorities, particularly African Americans, led to the Civil Rights Act of 1964. Similarly, women’s organizations engaged in various activities that placed pressure on state and federal government leaders to enact legislation that required equality of rights for women. One may assume that in a free and open democracy which most of us enjoy in America, there would be available on an equal basis to all citizens, the right to vote, to live wherever one can afford, the right to eat wherever one desires, and the right to be educated at the maximum level of one’s abilities. However, it was precisely the denial of these basic rights, rights upon which this country was founded, rights for which thousands of Americans have paid the supreme price, that led multitudes of Americans into the streets to practice civil disobedience, until these and other basic rights were granted.

In the process of securing these rights, the minority groups learned that their minority status was not shameful. In fact, they learned that they were a very important cog in the wheel of American life and by withholding their labor and being selective as to how and where they spent their hard earned money, they could considerably slow down the democratic wheel of progress. These groups also learned that by networking they added strength to their demands.

Until recently, persons with disabilities were not widely considered a minority group. In fact, it was not until the Rehabilitation Act of 1973 that they were considered a “class” of people. Persons with disabilities are members of other groups of people, they are male or female, and they have an ethnic identity; their rights and privileges are associated with whatever cultural and/or gender group they belong. It is ironic that with regard to human rights their disabilities were secondary to their cultural and/or gender identity, but with regard to their rights as citizens, their disabilities were primary, overshadowing gender and/or cultural identity. Since disability groups were not considered a culture at the time, the person with a disability was viewed as a “disabled member of another class.” To be more specific, they were considered to be a disabled female or a disabled American Indian female, and/or an economically disadvantaged disabled American Indian female. Hopefully, the point has been made. It is in part because of this dual and sometimes triple classification that the disability label was not considered a class unto itself.

Another reason for the lack of class status is that there are large numbers of disabilities and each one is considered a separate condition within its own group identity. For example, there are persons who have disabilities resulting from polio, arthritis, visual
impairments, hearing impairments, lupus, mental illness, mental retardation, amputations, and paralysis, to mention only a few. In most cases, there was and continues to be associations or foundations which are considered the official representative for all who have a particular condition. This has the effect of segregating disabilities into distinct disease groups, thus causing each disabling condition to stand alone and not be part of a larger whole. This internal segregation, combined with society's segregation of persons with disabilities, has been devastating to efforts of persons with disabilities to unite and demand their constitutional rights.

Although it would not be until the passage of the Rehabilitation Act of 1973 that persons with disabilities would obtain the classification of minority status and be officially viewed as a class of people, several years before the passage of the act they began to think of themselves as a minority. And more importantly, they began to view their life conditions as having been deprived of their basic human rights similar to other minority groups. They also began to think of themselves as being oppressed and disenfranchised. With this realization, they began to unite and to speak openly about the manner in which they were being excluded from full participation in society's activities. Thinking of themselves as oppressed minorities, they also thought of the manner in which other minority groups had placed their agenda before the American people; thus a "grassroots disability rights movement" began, which resulted in the passage of the Americans with Disabilities Act, or ADA, in 1990.

**The Grassroots Movement**

Despite the concern exhibited by charitable organizations and Congress, the one aspect often missing was the involvement of persons with disabilities. For example, much of the legislation prior to the Rehabilitation Act of 1973 had been developed with little, if any, input from persons with disabilities. Charitable organizations established telethons to raise funds for research and provide services without giving much thought to the negative images being projected. This was "business as usual" or stated another way, it was the continuation of the paternalistic attitude that has existed in America for many decades. Perhaps without meaning harm to persons with disabilities, nondisabled persons have treated them as though they are incapable of determining and expressing how they would like to live their lives. Regardless of how well-intended the motivation of a nonoppressed person, there are some things he/she will either overlook or not understand with regard to the effects of being oppressed. Therefore it is imperative that those affected must be involved in determining the best methods for eliminating the problems created by oppression.

There are undoubtedly many reasons why it took persons with disabilities approximately two centuries before they organized and began to speak out on their own behalf. With "sit-ins," marches, and attempts to integrate previously segregated southern schools, the 1950s served as the "staging" years of the civil rights movement; then in the 1960s the final "assault" years were launched which culminated in victory with the passage of the Civil Rights Act of 1964. Similarly for the disability rights movement, the 1960s served as the "staging" years with emphasis on consumerism, self-help, and deinstitutionalization. Perhaps the 1970s can be considered the "watershed" years for that movement.

The 1960s was the decade when persons with disabilities began to view themselves as oppressed minorities and demanded their constitutional rights. Similar to the civil rights movement which culminated in the Civil Rights Act of 1964, the disability rights movement led to what has been called the Civil Rights Act for persons with disabilities: the Americans with Disabilities Act of 1990.

**Activism**

Most early rehabilitation legislation's primary focus was "vocational" rehabilitation of persons with disabilities. In the early 1970s, rehabilitation leaders backed by disability rights groups began to push for changes in the legislation to advocate a broader nonvocational role for rehabilitation programs. In 1972, such legislation was passed by Congress, and Vervloet (1979) informs us that President Nixon vetoed the legislation because it "strayed too far from the essential vocational objective of the program."

This Act had provisions for Independent Living Centers. It would take six more years before this important concept would become a reality. The veto of the 1972 Rehabilitation Act is a classic example of not involving those most affected. Perhaps the veto served a useful purpose in that it became an issue around which the grassroots movement could unite. While attempting to get the Independent Living Centers provisions included in future legislation, the disability rights organizations gained considerable experience in politics, coalition building, and lobbying, as well as the act of compromising, thus gaining the respect of lawmakers and the admiration of millions of persons both with and without disabilities.

In the interim, additional legislation was passed with provisions to issue directives that persons with disabilities were not to be discriminated against nor treated as second-class citizens. One such piece of legislation was the Rehabilitation Act of 1973. Included in this legislation was Section 504 which forbade any United States institution that received federal financial assistance from discriminating against persons with disabilities in employment, etc.

**Independent Living Movement**

The quest for independence by most Americans does not occur by accident, but is a quality that is taught and reinforced to every American youth, both by formal teaching and by example. American history is replete with both fictional and factual persons accomplishing or attempting to accomplish extraordinary deeds to establish or maintain their independence.

Independence is therefore highly valued in American society; it is considered an essential building block in constructing and maintaining a democracy. Freedom, to an extent, is reliant upon its citizens having the independence to build better lives for themselves and in the process of accomplishing their dreams, they lift freedom and democracy to new levels. Conversely, being dependent is devalued in American society and those that are considered so are often assigned lower positions on the social totem pole. To many, the word "dependent" denotes lack of initiative, laziness, and a burden upon society. Although public and private social welfare agencies and organizations including hospitals, clinics, and rehabilitation centers, to mention a few, have been developed to assist persons who by virtue of illness, accident, or birth defects must rely upon assistance services, the recipients are often viewed in a negative light and at best given sympathy instead of empathy and understanding.

Illness or disability often places the individual, and sometimes the family, in a state of dependency: For some it is a permanent situation, but for the majority it is temporary. The degree to which a person becomes dependent is obviously affected by several things, the least of which are attitudes. Attitudes of family, friends, medical and rehabilitation personnel as well as employers have an impact on the level of dependence of the person with a disability.

Given the value placed on independence by American society, no one should be amazed that persons with disabilities began to recognize and resent the limited role
society drafted for them. They correctly perceived that society equated disability with dependency. They also recognized that this perception created a very low ceiling and an almost insurmountable wall around their abilities to function and achieve...

In the early 1970s, persons with disabilities began to realize that to be truly free they must take and maintain control of their lives. This train of thought resulted in the development of Independent Living Centers (ILCs). Dejong (1982) provides a brief history of the genesis of Independent Living Centers as he reveals that a small group of persons with disabilities at the University of Illinois and at the University of California at Berkeley moved out of their residential hospital setting into the community and organized their own system for delivery of survival services. The centers established by these students became the blueprint by which future centers would be established...

When one considers that the independent living movement was initiated by persons with disabilities, many of whom were persons with severe disabilities such as spinal cord injuries, it became quite apparent that these individuals exhibited courage of the highest magnitude. Although prior to the movement they lived in conditions that made them totally dependent upon others, it was however a safe environment; therefore, moving from this safe environment to face the many uncertainties created by a society with many barriers and obstacles certainly qualifies the founding members as pioneers...

Laurie (1982) contributes to our understanding of the goal of independent living centers with these comments:

Independent living is freedom of choice, to live where and how one chooses and can afford. It is living alone or with a roommate of one's choice. It is deciding one's own pattern of life: scheduling food, entertaining, vices, virtues, leisure and friends. It is freedom to take risks and freedom to make mistakes.

Frieden and Cole (1985) define the independent living concept as control over one's life based on the choice of acceptable options that minimize reliance on others in making decisions and in performing everyday activities. This may include managing one's affairs, participating in day-to-day life in the community, fulfilling a range of social roles, and making decisions that lead to self-determination and the minimizing of physical or psychological dependence upon others...

While it is very important to note that the independent living movement was begun and defined by persons with disabilities, it must also be noted that to strengthen and stabilize independent living centers and their concept, federal legislation was needed, especially in the area of funding. Funding was needed to expand and improve upon the delivery of services as well as expand the centers throughout the United States. The 1972 Rehabilitation Act had provisions which would have accomplished this, but unfortunately the Act was vetoed by President Nixon. Despite this temporary setback, the seed had been sewn and Congress had demonstrated by the passage of the Act its support for this type of center. Fortunately, the Rehabilitation Act of 1973 was amended in 1978 to add Title VII, Comprehensive Services for Independent Living. With this amendment, Congress authorized support for community-based independent living centers, which had the effect of establishing a major change in federal disability policy...

References

More Than Work

Work is so much a central part of most Americans' lives that it, in part, defines who we are. It is common for Americans to describe someone by identifying their occupation. For example, we may identify someone as Mary Smith the attorney, or John Smith the teacher. Work has been the defining feature in American lives for many years. The Puritan work ethic is a standard by which Americans often judge each other. While we no longer subscribe to the theory of hard work for all, we most certainly subscribe to the idea of work for all. Work provides us with economic power to purchase goods and services which in part by virtue of the amount and types of goods we accumulate determines our social standing in America. Social condemnation is the reward for those that are able to work but do not. Work not only is a means by which we develop, maintain, or improve our societal standing in American society; it also is patriotic. In a capitalist society, it is through the production of products that our nation develops its standing in the world as compared to other nations.

Obviously, work has many important meanings to Americans and American society. Considering the position work holds in American life, it is easy to understand why virtually all rehabilitation legislation prior to the 1972 Rehabilitation Act emphasized "vocational rehabilitation." In fact, when we speak of rehabilitating a person with a disability we think the ultimate goal of the rehabilitation process is to make the person ready for a job. There is one thing wrong with this approach: what about the person who is unable to work because of the severity or perhaps type of disability? Unless they and/or their families have sufficient financial resources, they have to rely upon sympathy and charity of others as well as some social welfare assistance from the federal government. Because of the social stigma of not working and receiving charity, these persons' independence, self-dignity, and ability to participate as full American citizens are in jeopardy.

Perhaps these reasons, as well as others, caused the disability rights movement leaders to lobby Congress to deemphasize vocational in the Rehabilitation Act of 1972... In part, what they were saying, and perhaps today we are just beginning to hear, is that a person's worth, self-respect, and dignity should not be measured by employment and moreover measured by whether employed in a job, especially if that person is unable to work. The leaders were wise to note that no person with a disability would be totally free until all persons with disabilities had opportunities to more fully participate in American life. Again it was this type of thinking that led them to push for independent living centers and the abolishment of the segregation of persons with disabilities so they could not only become more involved in American society but also make decisions that would effect the quality of their lives. In short, they recognized that life for a person with a disability meant more than being able to work...
Disability beyond Stigma: Social Interaction, Discrimination, and Activism

Michelle Fine
Adrienne Asch

Introduction

Between 1981 and 1984, the Eastern Paralyzed Veterans Association, Disabled in Action of New York City, and other organizations of people with disabilities fought a court battle with the New York City Metropolitan Transit Authority (MTA) to gain architectural access to the city's mass transit system. The MTA opposed modifying the system, claiming that the expense would never be made up by rider fares of those mobility-impaired people then denied transit access. "The New York Times" (Editorial) 1983: "The $2,000 Subway Token" 1984, along with most other sectors of the community, generally favoring progressive social change, supported the Transit Authority in the fight it eventually lost (Katzmann 1986).

In 1982 and 1983, the national media described two cases where the parents and doctors of infants with disabilities denied the infants medical treatment based on their impairments. In the first case, an infant with Down's syndrome died of starvation six days after birth; in the second case, the parents finally consented to the surgery. The impairments of the infants were used as the basis for denying them treatment that could have alleviated certain of their medical problems but left them with permanent disabilities that no treatment would cure. Virtually the only support the infants' right to treatment over parental objections were those commonly associated with the right-wing and right-to-life sectors of society, and perhaps also people with disabilities themselves (Disability Rag 1984). . . .

In 1983 and 1984, and again in 1986, Elizabeth Bouvia, a young woman whose cerebral palsy made it impossible for her to control any of her limbs save some functions of one hand, sought to get California's hospitals to allow her to die by starvation. The American Civil Liberties Union (ACLU), generally regarded as championing the progress of many social causes, wrote a brief in her behalf describing her disability as causing her "pitiful existence," referring to her "affliction" as "incurable and . . . intolerable", and commenting on the "indignity and humiliation of requiring someone to attend to her every bodily need" (ACLU Foundation of Southern California 1983, 14, 17, 35). The entire tone of the brief implied that it was not at all surprising that someone with her level of disability would wish to end her life. The ACLU was not dissuaded from its line of argument by testimony of the Disability Rights Coordinating Council (DRCC), including a psychologist who was also quadriplegic, suggesting that Ms. Bouvia's situation was complicated by a host of stresses apart from her disability: "death of a sibling, marriage, pregnancy, multiple changes in residence, financial hardship, miscarriage, increased physical pain, terminal illness of a parent, and dissolution of marriage" (DRCC 1983, 3). The DRCC did not dispute that people had the right to take their own lives. It disputed the unquestioned assumption that disability was a reason to end life.

In Bouvia v. Superior Court of California, unmovied by those who sought to disentangle Ms. Bouvia's request from the situation of people with disabilities generally, endorsed her request, saying among other things: "She, as the patient, lying helplessly in bed, unable to care for herself, may consider her existence meaningless. She cannot be faulted for so concluding." Later, in describing it, it stated: "Her mind and spirit may be free to take great flights, but she herself is imprisoned, and must lie physically helpless, subject to the ignominy, embarrassment, humiliation, and dehumanizing aspects created by her helplessness" (Bouvia v. Superior Court of California 1986, 19, 21).

Defining the Population of Interest

In 1980 Rowe estimated the total population of people with disabilities in the United States to be 36 million or perhaps 15 percent of the nation's people. In 1986, the New York Times reported some 17 million people over 15 years of age with disabling conditions ("Census Study" 1986). As Asch (1984) has discussed elsewhere, the mere attempt to define and enumerate the population shows that disability is a social construct. The Rehabilitation Act of 1973, as amended in 1978, defines a handicapped individual as "any person who (i) has a physical or mental impairment which substantially limits one or more of such person's major life activities, (ii) has a record of such an impairment, or (iii) is regarded as having such an impairment."

We can say the following with assurance: The nation's population includes some 10 percent of school-aged children classified as handicapped for the purposes of receipt of special educational services somewhere between 9 percent and 17 percent of those between sixteen and sixty-four years of age report disabilities that influence their employment situation (Haber and McNeil 1983); nearly half of those over sixty-five indicate having one or more disabilities that interfere with their life activities or are regarded by others as doing so (Defior and Lifches 1983).

Laws governing the provision of educational and rehabilitation services, and prohibiting discrimination in education, employment, and access to public programs all stress the similarities in needs and in problems of people with a wide variety of physical, psychological, and intellectual impairments. In this space, however, it is important to acknowledge the differences among disabling conditions and their varied impact on the lives of people in this group.

First, different conditions cause different types of functional impairment. Deafness, mental retardation, paralyis, blindness, congenital limb deficiencies, and epilepsy may pose common social problems of stigma, marginality, and discrimination, but they also produce quite different functional difficulties. Several of these disabilities obviously interfere with functions of daily life, but the last, epilepsy, may not. Some persons with epilepsy have no inherent limitations whatever. Nevertheless, they are likely to be regarded as having an impairment.

Furthermore, people with disabilities have different degrees of impairment: Amounts of hearing and visual loss differ; some people with impairment of mobility can walk in some situations while others cannot. Mental retardation ranges from profound to mild—to mild that many out of school never get the label. In addition, some disabilities are static, while others are progressive. Multiple sclerosis, muscular dystrophy, cystic fibrosis,
some vision and hearing impairments, some types of cancer and heart conditions present progressive disabilities that cause ever-changing health and life situations. Some conditions are congenital, others are acquired. All of these factors that distinguish the origin, experience, and effects of disability must be kept in mind in social science research on disability.

Researchers (Davis 1961; Goffman 1963; Ladieu, Adler, and Dembo 1948) have long been aware that the degree of visibility of impairment or the age at which it was acquired (Barker 1948) may influence the psychological consequences and the social situation of people with disabilities. More recently, scholars have addressed the impact of ethnicity, class, and gender upon the experience of disability (Fine and Asch 1981).

Assumptions about Disability

Considered below are a set of common assumptions about what disability means. For each, there have been important methodological and theoretical consequences:

1. It is often assumed that disability is located solely in biology, and thus disability is accepted unconditionally and as an independent variable. The disability and the person are assumed to be synonymous, and the cause of others' behaviors and attitudes. Several experimental social psychologists (Katz 1981; Kleck, Oto, and Hastorf 1966) have simulated disability in the laboratory to verify Goffman's reports that handicapped people arouse anxiety and discomfort in others and are socially stigmatized. In these experiments, researchers have simulated disability by using a confederate who in one experimental condition appeared disabled and in another appeared nondisabled. The experiments did support the hypothesis that nondisabled people react differently to people with disabilities than they do to people without them. Nevertheless, it should be remembered that the confederate’s only experience of having disability may have been simulating it by sitting in a wheelchair, employed none of the strategies commonly used by disabled people to ease the discomfort of strangers in first meetings (Davis 1961; Goffman 1963). By focusing on initial encounters with strangers and by using a confederate whose only experience with disability might be simulating it, these experiments tell us nothing about how disabled people actually negotiate meaningful social interactions. Reports by Davis (1961) and Goffman (1963) acknowledge that obvious disability is generally prominent in initial social encounters. However, the extent to which an experimental confederate’s naiveté about living with a disability can contribute to the prominence and the awkwardness of disability has not been recognized as an intervening variable. In these experiments, disability is viewed as an independent variable, much as gender had been considered prior to the early 1970s (Unger and Denmark 1975). Disability is portrayed as the variable that predicts the outcome of social interaction when, in fact, social contexts shape the meaning of a disability in a person’s life.

Most social-psychological work using disability to examine the concept of stigma takes the experience as equivalent, regardless of such factors as the disabled person’s race, culture, class and gender. Becker and Arnold (1986) provide valuable corrective by viewing the situation of disabled people through the disciplines of anthropology and history.

2. When a disabled person faces problems, it is assumed that the impairment causes them.

In a very thoughtful expansion of Goffman’s notion of stigma, Jones and colleagues (1984) elaborate on the consequences for the “marked” person of being singled out by others. Throughout their discussion of marking and its social-psychological consequences for disabled and nondisabled alike, however, these authors never question the extent to which disability per se poses difficulties in social participation, as contrasted with difficulties caused by the environment—architectural, social, economic, legal, and cultural. For example, in their discussion of changes in the life situations of people who became disabled, the authors never question that the disability keeps the person from continuing the employment or from going to restaurants or other recreational facilities. The entire discussion of stigma and marked relationships assumes as “natural” what Hahn aptly terms as disabling environment; it views obstacles as being solely the person’s biological limitations rather than the human-made barriers of architecture or discriminatory work practices.

Even Barker’s (1948) early work went only part way to indicting the environment as an obstacle to the disabled person’s participation. Far ahead of his time was called for antidisability laws in education and employment, although he failed to challenge the architecture, the transportation, and the communication methods that confronted people with disabilities and hampered full participation. Barker’s concluding comments took social arrangements as given, urging counseling and psychotherapy for people with disabilities so that they could come to accept “the fact that the world in which [they live] presents serious restrictions and frustrations.” He went on to say that education and antidiscrimination laws cannot “remove all restrictions on the physically deviant in a world constructed for the physically normal. The ultimate adjustment must involve changes in the values of the physically normal. The ultimate adjustment must involve changes in the values of the physically disabled person.” (37).

Barker’s (1948) view is understandable twenty-five years before the passage of federal legislation to modify public-sector physical environments. Jones and his colleagues’ (1984) obliviousness to environmental issues is not. Their otherwise valuable work on the social-psychological consequences of disability and stigma suffers seriously from such omissions. We can contrast these omissions of attention to environmental effects with Sampson’s (1983) work on justice. Sampson urges students of justice and of resource allocation to attend to and be critical of current systems rather than merely to accept them and their consequences. We urge the same for students of disability.

3. It is assumed that the disabled person is a “victim.” In a great deal of social-psychological research on attribution, the disabled person is seen as a victim who copes with suffering by self-blame (Bulman and Wortman 1977), by interpreting the suffering to find positive meaning, or by denying that he or she is really suffering (Taylor, Wood, and Lichtman 1983). Bulman and Wortman studied 29 people paralyzed in accidents. Lerner (1980) describes these people as “young people who had been recently condemned to spend the rest of their lives crippled” (161). In order for Lerner to make sense of why Bulman and Wortman’s respondents were not displaying a sense of victimization, he posits their belief in a just world and suggests that their interpretations of the disabling events are constructed so as to retain a strong belief that the world is a just place and that bad things only happen to people for reasons. The psychological experiences of the persons with disabilities are thus examined not on their own terms, but instead as a form of denial. Disability is used as a synonym for victimization in this theoretical analysis.

Taylor and colleagues’ (1983) “It Could Be Worse” also illustrated the unchecked assumption of disabled-person-as-victim. The researchers examined the responses of people with cancer shortly after the onset of their condition and discovered that the interviewees consistently maintained that their situations “could be worse.” To explain this finding, five “strategies” used by these “victims” to make sense of their situations were described. It is disturbing to us that these authors, who were interested in the rich qualitative ways that people describe their coping experiences, minimized informants’ consistently expressed view that the trauma was not as severe as it could have been.

As Taylor and colleagues argued, people diagnosed as having cancer are surely traumatized, and they actively generate coping strategies. However, our concerns arise with respect to the authors’ a priori assumptions. First, it should be noted that Bulman
and Wortman, and Taylor and colleagues, studied people quite shortly after the onset of disability, before they had a chance to discover what would or would not be problematic about their lives. Their findings that self-blame (Bulman and Wortman, 1977) and making downward comparisons (Taylor, Wood, and Lichtman 1983) occurred within the first months or years after disability differ dramatically from those of Schultz and Decker (1985) in their study of people with spinal cord injuries live to twenty years after disability. The former authors can be read as suggesting, if inadvertently, that the experience of disability is static in a person’s life and that “coping” is the same at any point in time or in one’s life situation. The work of Schultz and Decker (1985) corrects this prevalent assumption and enriches our understanding of disability by demonstrating that responses at a specific time may not be the ones people retain after living with a disability for several years.

There are two more problems with the interpretations of disabled-person-as-victim put forward by Bulman and Wortman (1977), Janoff-Bulman and Frieze (1983), Lerner (1980), and Taylor, Wood, and Lichtman (1983). First, in contrast to Ladieu and colleagues’ (1948) report on the reactions of disabled veterans after World War II, these later researchers seem to discount the experiences described by the people they interviewed. Taylor and colleagues, for example, view their respondents as having strategies for managing or camouflage what must be truly tragic. To the “outsider,” the researcher, the “objective situation” is that a diagnosis of cancer is primarily a tragedy. That “insiders”, those with cancer, overwhelmingly state that they fared better than they would have expected is not used self-reflexively by the researchers to frame their notion about how people think about traumatic life events. Rather, the statement is interpreted to illustrate psychological defenses that disabled people mobilize in order to manage what researchers feel is not really manageable. What needs to be stated is that disability—while never wished for—may simply not be as wholly disastrous as imagined.

Second, these authors presume that the disability itself constitutes the victimizing experience. None of them emphasize the subsequent reactions or deprivations that people experience because of social responses to their disability or environmentally imposed constraints. While Janoff-Bulman and Frieze (1983) recognize discrimination based on sex or gender to be a societal injustice, disability is assumed a biological injustice and the injustices that lie in its social treatment are ignored.

4. It is assumed that disability is central to the disabled person’s self-concept, self-definition, social comparison, and reference groups. Taylor and her colleagues (1983) describe their respondents as having to make downward social comparisons, lose friendships, and cope with how bad their situations really are. Jones and colleagues (1984), in their discussion of stigma, assume that the recently disabled paraplegic compares herself to others who are also paralyzed. She may, but perhaps only when it comes to assessing her capacity to perform certain activities from a wheelchair. Gibbons (1986) claims that while such severely stigmatized people as those labeled retarded must make only downward social comparison to preserve self-esteem, more “mildly stigmatized” people such as those using wheelchairs seek out similarly disabled people with whom to compare themselves, and avoid social interactions and social comparisons with non-disabled people. Because disability is clearly salient for the non-disabled, it is assumed that the marked person incorporates the mark as central to self-definition.

The above authors forget that the woman who is paralyzed may be as likely to compare herself with other women her age, others of her occupation, others of her family class, race, or a host of other people and groups who function as reference groups and social comparison groups for her. Disability may be more salient to the researchers studying it than to the people being studied, who may define themselves as “similar to” or worthy of comparison with people without disabilities. Gurin (1984) reminds researchers in social comparison and relative deprivation to pay more attention to the conditions under which people choose particular groups with whom to compare themselves, and she stresses that social comparison may have nothing to do with gender, race, or disability.

5. It is assumed that having a disability is synonymous with needing help and social support. People with disabilities are perceived to be examples of those ever in need of help and social support (Brickman et al. 1982; Deutsch 1985; Dunkel-Schetter 1984; Jones et al. 1984; Katz 1981; Krebs 1970; Sarason 1986). Such an assumption is sustained both by what researchers study and write about those with disabilities and by their omission of disabled people in their discussions as providers of support. The assumption that disability is synonymous with helplessness is not surprising when we remember that “the handicapped role” in the United States has been seen as one of helplessness, dependence, and passivity (Gleidman and Roth 1980; Goffman 1963). Brickman and colleagues (1982), in their excellent discussion of different models of helping and coping, review the essence of the medical model: the person is responsible for neither the problem encountered nor the solution required. The handicapped role, like the sick role of which it is an extension, compels the occupant to suspend other activities until recovered, to concentrate on getting expert therapy, to follow instructions, to get well, and only then to resume normal life. The non-handicapped person equates having a disability with a bad and eternal flu, toothache, or broken leg. When such conditions are temporary, it may be acceptable to entrust oneself to helpers and to forgo decision making briefly; but when forced to confront a moment of weakness, unsteadiness, or limitation in life’s capacity to see, hear, or move, people experience grave difficulty in adjusting. However, it is erroneous to conclude that their difficulties mirror those of the person who has a long-term disability and who has learned to use alternative methods to accomplish tasks of daily living and working.

The disability is assumed tantamount to incompetence and helplessness has been investigated, and supported in laboratory research. Unfortunately, the writing that has been generated accepts rather than challenges this stereotype. Katz (1981), who found that whites gave more help to “competent” blacks than to ones they perceived to be less competent and enterprising, expected that the same help-giving pattern would be true for nondisabled subjects when confronting a person with a disability. Contrary to his hypothesis, however, he found that non-disabled people gave less help to disabled persons perceived as competent and friendly than to those perceived as incompetent and unfriendly. They also gave less help to the “disabled person” (simulated) than to the non-disabled person. To explain the results, Goffman (1963) and Gledman and Roth (1980) in asserting that non-disabled persons are relatively offended or uncomfortable when confronting a person with an impairment who manages life competently. As Jones and his colleagues (1984) remind us, the able-bodied deny the reality of successful adaptation by the disabled person. They perceive it as the disabled person “making the best of a bad job,” and this view supports their conviction that their own health and capacities are as important, and infallible, as they think (87).

Even while we wonder whether Katz would have gotten the same finding had he asked people who actually had a disability rather than one who had simulated an impairment, it is valuable to have this experimental support for what Goffman, Gledman and Roth, and told us of people with disabilities have described. Unfortunately, Jones and colleagues (1984) fail to try their own unchallenged assumptions in thinking about mapping relationships between people with and without disabilities: Throughout their book, and especially in the chapter by French (1984), it is assumed that the person with the disability is in constant need of help and support, rather than being a victim of nondisabled persons’ projections or fantasies. Thereby, three problems arise: first, that the person with a disability may need assistance with certain acts is generalized to all
aspects of the relationship between a person with a disability and one without. Second, if the person does need assistance, it is assumed that a previous reciprocal relationship will change, rather than new methods or relationships will develop to provide it. Concurrently, it is assumed that the biological condition rather than the environment and social context makes one-way assistance inevitable. Third, it perpetuates the idea that the impaired person is forever the recipient, rather than ever the provider, of help and support. If disabled people are mentioned, they are mentioned as only on the receiving end of a helping transaction.

In French’s (1984) chapter on marriages between disabled and nondisabled people, the assumptions are never challenged that the disability causes marital roles to change fundamentally, that blindness or quadriplegia per se will make a marriage difficult or impossible, that recreation will have to be curtailed. The spouse who performs certain amounts of physical care-taking is seen only as a physical caretaker but as a generous intellectual and emotional caretaker as well. Physical incapacities are perceived as leading inevitably to incapacities in other spheres of life. Wright’s (1983) notion that disability “spreads” throughout a relationship is embedded unchallenged in this entire discussion.

Moreover, it is the disability, not the institutional, physical, or attitudinal environment, that is blamed for role changes that may occur. The person with a disability may initially, or always, need physical care-taking, such as help in dressing, household chores, or reading. It must be asked, however, whether such assistance would be necessary if environments were adapted to the needs of people with disabilities—if, for example, more homes were built to accommodate those who used wheelchairs, if technological aids could be developed to assist in performing manual tasks, if existing technology to convert the printed word into speech or Braille were affordable to all who need it. Thus again, the physical environment as an obstruction remains an unchallenged given. In addition, the author is assuming that the role of human assistant for all these tasks will automatically fall to the “significant other” rather than considering whether such activities could be performed by others, including public sector employees, thus permitting the primary relationship to function in its primary spheres of intimacy, sharing, and emotional nurturance for both participants. If the partners reorganize their roles after the impairment of one member, such reorganizations may result from a variety of factors: the way they think about disability, their relational obligations, the way that health care professionals inform them about the implications of disability, or the difficulties faced in affording appropriate assistance in the United States. These are consequences of how people think about disability and of current national disability policy, not of disability per se. As with all too much of this literature, as Wright (1983) points out, researchers who are outsiders make attributions to persons and thus neglect the powerful role of the environment.

The third problem mentioned above—that disabled people are always seen as recipients—may stem not only from distortions about people with disabilities but also from using disability as a metaphor to illustrate theory rather than to reveal more about the lives of people with impairments. Deutsch (1985) may be correct in speculating that, at least temporarily, resources would or should go to a sick child rather than to a well one: Dunkel-Schetter (1984) may plausibly learn about the mechanisms of social support by studying what people with cancer find valuable and supportive from others after such a diagnosis: Krebs (1970) makes an important point in discussing how assumptions of legitimacy of others’ dependency influence the helping process. Nonetheless, by staying with questions about theories of distributive systems (Deutsch 1985), social support (Dunkel-Schetter 1984), or altruism (Krebs 1970) and by not focusing on ongoing reciprocal transactions, the person with a disability is neverimagined or shown to be a provider of support. It is regrettable that people with disabilities, when studied or considered at all in most social-psychological literature, are examined only in ways that reinforce and perpetuate existing stereotypes rather than in ways that question and challenge them. In this manner, the literature fails to enrich our understanding of the lives of people with handicapping conditions.

Particularly disturbing, as an illustration of disability-as-metaphor, is Sarason’s (1986) discussion of the Baby Jane Doe case. Unfortunately, his laudable effort to call for a renewed commitment to the “public interest” and a lessening of individualism is flawed by uncritically accepting the assumption that the infant with a disability can never be expected to make a valuable contribution to family or society. He consistently refers to the existence of the severely disabled child as a problem to both family and society. Sarason’s examination of the public interest and of the search for community continues in the “disabled-as-helpless” vein. He refers only to “afflicted children”; finds that families who adopt disabled children are “managing their situations in surprisingly adaptive, stable, and inspiring ways” (903); and describes the child only as a “problem,” without any consideration of the possible contributions, benefits, or pleasures the infant born with a disability might bring to its family and society.

It is worth speculating on how these assumptions get made, why they persist, and what functions they serve for researchers and society. It remains a task for future research to discover the plausibility of these speculations.

Jones and his colleagues (1984) contend that the thought or awareness of disability evokes feelings of vulnerability and death. They suggest that the nondisabled person almost wants the one with the disability to suffer so as to confirm that the “normal” state is as good and as important as the “normal” thinks it is. Because disability can be equated with vulnerability to the uncontrollable, observing someone with a disability forces all of us to wonder about the consequences of what one cannot control. In a society seeking to control ever more of life, is there a leap to the assumption that one cannot live with the consequences of what one cannot control? Social researchers are in the business of expanding knowledge of the world and trying to optimize prediction and control. As researchers, we highly prize knowledge and the control it can provide. Does such a commitment to control suggest that social scientists may view disability as fearful, unacceptable, and different because the person with the disability is a reminder that we cannot control all life events?

As discussed earlier, perceptions of disability have been the repository and projection of human needs. How much do the social and psychological problems that many people associate with disability actually pervade all of human life? If one can think of a person with a disability as necessarily in need, how can one consider the person without impairment as strong and as not having needs. By thinking of the disabled person as dependent in a given situation, and the one without disabilities as independent and autonomous, one can avoid considering how extensively people without disabilities too are dependent and sometimes not. Rather than the world being divided into givers and receivers of help, we are all actually interdependent. Attributing neediness and lack of control to people with disabilities permits those who are not disabled to view themselves as having more control and more strength in their lives than may be the case.

Last, perceiving a person with a disability as suffering victim, as a stimulus object, as in need, or as different and strange, all reinforce what Goffman (1963) describes as perception of the stigmatized as “not quite human” (6). In discussing the scope of justice, Deutsch (1985) comments, “Justice is not involved in relations with others.” The
narrower one's concept of community, the narrower will be the scope of situations in which one's actions will be governed by considerations of justice" (36–37). Deutsch goes on to contend that it has been

[a] too-common assumption of victimizers, even those of good will, as well as of many social scientists, that the social pathology has been in the ghetto rather than in those who have built the walls to surround it. The disadvantaged are the ones who need to be changed rather than the people and institutions who have kept the disadvantaged in a submerged position. . . . It is more important to change educational institutions and economic and political systems so that they will permit those groups who are now largely excluded from important positions of decision-making to share power than to try to inculcate new attitudes and skills in those who are excluded. (61)

These words apply as much to the situation of people with disabilities as to that of people with economic disadvantages whom Deutsch considered. By concentrating on cure or on psychological and physical restoration of the impaired person, society and the discipline of psychology have avoided the need to focus on essential changes in the environmental side of the "person-in-environment" situation. If the person with a disability is "not quite human," then that person can remain outside the community of those who must receive just distributions of rewards and resources (Deutsch, 1985). In contrast, if people with disabilities were perceived as having the same rights to mobility and life's opportunities as people without impairments, we would inevitably be compelled to rethink the way that transportation for people with mobility impairments, or access to treatment for infants or adults with disabilities, are gifts or charities that can be withdrawn when time is tight. Once people with disabilities are admitted inside the human and moral community, the task becomes one of creating an environment where all humans—including those with impairments—can truly flourish.

References


