



Chapter 5

EMPOWERING PEOPLE WITH DISABILITIES: THE ROLE OF CHOICE

Richard Renz-Beaulaurier, Ph.D.
*Florida International University, North Miami*¹

THE HISTORY OF REHABILITATION

In this postmodern era, questioning progress has become fashionable. When one looks at the history of treating people with disabilities in the United States, important questions arise. What sort of progress has there been? What is its nature?

Historical and anthropological sources indicate that preindustrial societies acted harshly toward people with disabilities. This was particularly true with disabilities discovered at birth or with those that seemed physically limiting. In virtually all cases of severe physical disability, preindustrial peoples commonly practiced infanticide. The prevalence of infanticide may partly explain the extremely limited amount of information or historical data on disability (Neubert & Cloerkes, 1987; Oberman, 1965). Interestingly, there is also a lack of information about adults with disabling traumas or illnesses. One can ascribe this to the fact that most of these people had a low survival rate. Still, the absence of facts is striking. Biblical, classical, and other ancient sources support modern anthropological evidence gathered from nonindustrialized peoples. Virtually all such cultures castigated disabled people to some extent, often attributing disability to supernatural

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causes such as demonic possession or the wrath of god(s) (Neubert & Cloerkes, 1987). The Romans, for instance, allowed fathers to expose to death any child born either "deformed or female" (Hewett & Forness). In his essay on Politics, Aristotle wrote, "As to the exposure and rearing of children, let there be a law that no *deformed* child shall live" (1943, p. 315).

To some extent, the Judeo-Christian tradition encouraged tolerance and charity toward disabled people. This orientation is still partly codified in law (Merkens, 1988). This same tradition, however, has also inspired some of the most inhumane treatment of people with disabilities, especially during the Inquisition and periodic witch hunts (Oberman, 1965). In the few places the Bible mentions people with disabilities, they are referred to as unclean (Leviticus 21), disabled as a result of sin (Luke 5), or victims of demonic possession (Matthew 12).

The industrial revolution brought about the first major change in the treatment of people with disabilities. Marxist theory has identified how workers in industrialized societies become nonhuman objects, losing their humanity in becoming merely the means of production. In these societies, people with disabilities are seen not only as a substandard "means of production" but also as an actual threat. Historically, when society could not force them to work, laws prevented them from begging (Blaxter, 1976; Oberman, 1965). One of the English Poor Laws divided people into three categories. The lowest included "those who's defects make them an abomination." It was decreed that "they shall be obliged to work, and if they refuse, a few stripes and the withdrawal of food and drink" (Oberman, 1965, p. 59).

In line with this perspective, institutions were built to force people with disabilities to work and to prevent public vagrancy and begging. Over time, the United States also embraced the two themes of shielding society and contributing to economic production. Warehousing became segregation. Work camps were located farther away from the cities, men were separated from women, and society was protected not just from the harm that vagrancy and begging were presumed to cause, but also from the "flawed" genes of people with disabilities (Wolfensberger, 1969). At its zenith, the pseudoscience of eugenics even sterilized all manner of "defectives" to protect the well-being of society (Ludmerer, 1972; Reilly, 1991). Institutions that housed indigent people with disabilities remained little better than prisons for years until the deinstitutionalization movements of the 1960s and 1970s (Hull, 1979; Wolfensberger, 1969).

Prominent supporters of both segregation and sterilization were active members of the National Conference on Charities and Corrections. Alexander Johnson, for instance, president of the National Conference in 1897, was a prominent segregationist (see Johnson, 1903; Perry 1903). Other social workers, such as Marion S. Norton, worked for organizations such as the New Jersey Sterilization League in the 1930s and 1940s, which

publicly advocated the passage of sterilization laws (Reilly, 1991). While the manifest purpose of most social work practice with disabled people was to be helpful, many may have aimed primarily at social control of "defectives."

Creating economic good out of the labors of people whose economic potential has been limited by disabilities began with the founding of special training schools, which lay at the heart of vocational rehabilitation. Both strove to help people with disabilities enter the workforce and earn their keep, in either a sheltered or a competitive setting. This was accomplished through training, rehabilitating, or otherwise *altering* people to fit conditions in the workplace. Such training however, was only offered to people clearly judged to be improvable (Varela, 1983; Wolfensberger, 1969). This tendency to select only those with the best prognosis for entry into the workforce characterized vocational rehabilitation from its inception until the 1960s (Berkowitz, 1980).

Medical Rehabilitation

Beginning around the turn of the century, medical rehabilitation did not directly challenge vocational rehabilitation or segregation. It did, however, broaden the goals of medicine to include some people with disabilities. Medicine sought to "restore" patients to the fullest levels of physical functioning. Originally, professionals undertook this specifically to allow patients to engage in remunerative occupations. Even so, the concern centered not on the actual return to work, but rather on the preparation for such by way of altering the physical functioning of the patient (Berkowitz, 1980). Medical social workers of the time seemed to agree with this goal. One of the most prominent early medical social workers stated that the object of treatment with a recently disabled patient was to see "that the patient may regain in fullest extent his function as a normal person" (Cannon, 1952).

Medical rehabilitation brought social workers into the treatment arena for people with disabilities. Though led by physicians, this kind of rehabilitation favored a team approach to treatment, which often required the contributions of social workers (Berkowitz, 1980). The first professional social workers called on to assist people with disabilities were most likely medical social workers. The 1913 edition of Ida Cannon's book on social work in hospitals includes some of the first case studies of practice with people with disabilities (Cannon, 1930). The casework focused on preparing and adjusting the disabled person for life outside the hospital milieu (Bartlett, 1957; Burling, Lentz, & Wilson, 1956, p. 128; Cannon, 1930).

After World War II, that medical rehabilitators downplayed vocational goals spearheaded the provision of treatment for severely disabled individuals—people not considered viable candidates for vocational rehabilitation

(Berkowitz, 1980). As a result, people with disabilities too severe to have been accepted for vocational rehabilitation became clients of medical rehabilitation. It is interesting to note that in the disability and independent living movements that followed, many of the leaders were among the first severely disabled people to have been rehabilitated under the medical model (DeJong, 1981). Earlier, they would have been hospitalized for life. Today, Ed Roberts, who helped found the Center for Independent Living in Berkeley, uses a portable respirator and a motorized wheelchair. In the times of vocational focus, he would not have qualified as a candidate for rehabilitation services at all.

Modern Movements

During the 1960s and 1970s, people with disabilities, especially those with severe ones, began to organize for political action toward maintaining a more independent and self-determined lifestyle in the community. They formed organizations that practiced and advocated the integration of people with disabilities into the mainstream to the maximum extent possible. Such advocacy groups, formed by consumers for consumers (DeJong, 1981; Frieden, 1983; Lachat, 1988), succeeded enough to have their principles of self-determination, consumer control, and nondiscrimination codified in a variety of laws, the most important of which are the Rehabilitation Act of 1973, its amendments (1978), and the Americans with Disabilities Act of 1990. These acts mandate the fullest possible inclusion of people with disabilities into U.S. society. For example, all people with disabilities can choose active and informed involvement with the decision-making processes regarding their medical and vocational rehabilitation and treatment. While some members of the disability movement show hostility toward almost all professionals, for the most part the movement emphasizes allowing consumers the maximum self-determination in the selection, direction, and termination of their treatment.

Both the disability movement and the cited legislation center on creating change in society and in local communities to "reasonably accommodate" people with disabilities. This represents a radical departure from the past, when segregation-oriented groups sought to remove people with disabilities from the general population as well as from the rehabilitation that sought to alter them to fit into society. Partisans in the disability movement seek to alter society to accept and include them. Barriers, whether physical or attitudinal, are being challenged as discriminatory and unnecessary or harmful.

Disability advocates maintain that all the principal historical themes prevalent in the treatment of people with disabilities still exist today. Even with the passage of a premier piece of civil rights legislation, the Americans with Disabilities Act, programs that emphasize altering people still receive

the lion's share of available funding. No doubt, many people with disabilities remain isolated and effectively segregated from mainstream society. Although one of the goals of the Americans with Disabilities Act is to help eliminate such isolation, Kailes, a prominent independent living consultant, has said that the Rehabilitation Services Administration would still rather fund a program to "teach paraplegics to walk on their hands" than to fund programs promoting true independent living options for people with disabilities (Kailes, personal communication, 1990).

This bias has caused some activists within the disability movement to question whether any role exists for professionals in the processes of empowerment for people with disabilities. In their view, rehabilitation professionals have tended to promote dependence rather than independence (Berrol, 1979; Zola, 1979). Zola (1983) contends that worship of the technical expert has actually slowed the progress of the movement and contributed to a lowering of consciousness concerning the social nature of disability.

EMPOWERMENT: GOALS AND IMPEDIMENTS

Social workers, especially those in health and rehabilitation settings, must operate in what has become a politically and socially charged environment. To empower clients with disabilities, social workers now must help people make the transition from medical and rehabilitation settings, where they have little ability to determine the course of their treatment, to community settings, where their self-determination can and should be maximized. Social workers must therefore insure that their clients become more capable of self-determination and try to increase the choices clients have regarding the treatments they will receive.

The role of service in the disability movement shows mostly in the growth of independent living centers and programs. Starting with the first in Berkeley, California, these centers have been operated by people with disabilities (DeJong, 1981). Such organizations expressly aim at empowering their constituents. Essentially, this movement grew from a lay self-help movement (Zola, 1979, 1983). Berrol suggests that professionals seeking to promote independent living and foster the empowerment of people with disabilities must "provide leadership in their areas of expertise without dominance, they must provide services, they must be active advocates, they must share their unique skills, and they must provide training. They must assure that there are the same opportunities to develop positive role models as are available to the able-bodied population" (1979, p. 457). To accomplish this, social workers must distinguish between the orientations of rehabilitation and independent living.

Rehabilitation versus Independent Living

The recent debate in the deaf community over cochlear implants for children offers a case in point. Some members of the medical community, as well as those of certain deaf organizations, have advocated the use of such devices even when the level of improvement in auditory functioning is only marginal. Other members of the deaf community view this as maiming innocent deaf children and potentially ostracizing them from their birthright of deafness and inclusion in the deaf community, as well as segregating them from the hearing community, which will never accept such children as "normal" (Barringer, 1993; D'Antonio, 1993). At the heart of this debate lies a basic philosophical difference about the nature of deafness. For the medical community, *deafness* is a disabling medical condition to be conquered, even if that means incurring some casualties. For some in the deaf community, deafness is not so much a disability as a difference, one with its own culture and benefits. Deaf advocates argue that the option of deafness is worthy of consideration and may well be chosen over the benefits of invasive procedures that often produce only marginal hearing ability. They argue that potential recipients of these procedures have the right to know all their options and the potential consequences of each.

Medical and rehabilitation institutions tend to view the problem of disability as the inability of a person to perform certain activities of daily living (ADLs). This perspective locates the problem within the person, as his or her *inabilities*; therefore, the individual must change. For example, recovered polio patients have usually been encouraged to walk even when they found this exhausting. Some disabled people have begun to discover that a wheelchair suits their needs far better than walking with crutches because it allows them to arrive at their destination faster and fresher. As they make the transition from crutches to wheelchair, however, they see clearly that their problem does not reside in their difficulty with walking, but rather the lack of accommodations for wheelchairs. Essentially, they discover that though they are less "mobility impaired" in their chairs, the environment has failed to accommodate their aid to mobility.

Changing the individual to improve his or her performance in ADLs requires the individual to follow a treatment plan laid out by technical experts (the rehabilitation team). Characterized by medical and technological solutions, these treatment plans often employ invasive, experimental, or even dangerous procedures, as in the case of cochlear implants. Indeed, people who have had disabilities for a long time are commonly approached by professionals with new, experimental techniques.

Medical and rehabilitation professionals also tend to define the disabled person as a passive beneficiary of their treatment regime. Control of

the process lies in the hands of the technical experts who aim at maximizing physical functioning. However, because functioning cannot always arrive at "normal" standards, success is often thought of as completion of the treatment regime rather than actual "normalization." Take again the example of cochlear implants. Even when their actions will create social difficulties for the patient, many medical professionals prefer to perform surgery that provides little improvement in hearing and marginal functional benefits. Dependency on technical experts is fostered regarding not just the technology of treatment but also its goals and definitions of success. This requires people with disabilities to (1) view the rehabilitation professional as an expert, (2) view their own states as undesirable, and (3) work toward a prognosis and recovery that has been defined for them (see DeJong, 1981, p. 31).

On the other hand, organizations that operate within the independent-living disability movement emphasize empowerment through ever-increasing self-determination on the part of disabled people, rather than through reliance on technical experts. Such organizations depend on lay people with disabilities for their direction and governance, as well as for the provision of services and advocacy. Such organizations, often called *independent living centers*, emphasize social rather than medical needs. Minimally, this includes enhanced information and referral services that enable individuals to choose appropriate services. Peer counseling links the individual with the greater disability community and provides positive role models. Further, training focuses on the skills needed for disabled people to live within society. That is, rather than focus on *what* ADLs a person can or cannot accomplish, training in independent-living skills focuses on *how* to live independently in the community and society given his or her physical limitations. Finally, client as well as class-advocacy services are provided to help people overcome environmental, societal, and bureaucratic barriers. In the view of the disability movement, these services address society's failure to accommodate disabled people, which marginalizes them.

Intervention to change the functioning of the individual, therefore, is not necessarily a social worker's first step. For instance, a client may first need to find services that allow her or him to exercise the rights to live and work in the main community. Often, this requires action to combat physical, legal, and attitudinal barriers that would place people with disabilities in institutions or under the control of professionals or bureaucracies if left unchallenged. This final notion makes the principle of consumer control extremely important to organizations within the disability movement.²

²I have taken this characterization of independent living centers in large part from Richards and Smith (1990).

EMPOWERMENT STRATEGIES

Social workers, especially those in medical and rehabilitation settings, must refocus their activities to begin the transition toward empowerment objectives: to maximize and expand the range of life choices of clients with disabilities, to facilitate their clients' decision making with regard to life choices, and to bolster the achievement of life choices. Because these objectives will often conflict with those of other professionals, social workers must function as agents of change to empower disabled people to achieve their aspirations and exercise their newly legitimized civil rights. Social workers must use their unique skills and expertise to help clients with disabilities choose the criteria for success of the medical and rehabilitative interventions they receive. To achieve those ends, social workers must begin to move in the directions pioneered by people with disabilities through their movements and organizations.

The Nature of the Problem

Social workers should help people with disabilities redefine their problems in terms of the social and physical barriers that local communities must remove. To give a simple example, the problem of how to get up the steps (problem within the individual) changes to how to get a ramp installed (problem outside the individual). Appropriate social work technologies often include community organizing, client and community advocacy, and an understanding of bureaucracies in addition to traditional clinical skills.

Empowerment of disabled individuals also requires that they remain in control of this change. Social workers serve to facilitate a partnership for the realization of goals and solutions, *not* to set them for their clients. In general, social workers need to consider how to help individuals explore their range of choices, with an eye toward expanding their options rather than setting limits. Such goals are consistent not only with the disability movement, but also with traditional social work values that aim to foster the independence and self-determination of each client.

Self-Determination

Of course, no one can achieve complete independence. From the perspective of those within the disability movement, however, life is independent to the extent that it is self-determined. This view can free clients and social workers to define the personal criteria of success. Rehabilitation professionals have spent months at times teaching people with mobility impairments such skills as dressing themselves. Many of those who eventually manage to get dressed by themselves find that the process takes hours and leaves them

physically exhausted. By contrast, many disabled people have learned that having an attendant help them dress in the morning takes just minutes, leaving them with the time and energy to pursue more rewarding activities (P. Longmore, personal communication, Spring 1992). One must view dependency and independence in terms of self-determination of life choices rather than the preconceptions of technical experts. Indeed, the German version of the independent living movement is called the movement for *selbstbestimmtes Leben*, literally, *self-determined living*.

Consciousness Raising

Social workers must raise the consciousness of disabled people, that is, help them realize that they are the definitive experts on their particular condition and the best arbiters of their own treatment. This includes making people with disabilities aware of their rights. As persons with rights, people with disabilities can come to see themselves as deserving citizens rather than a marginal people dependent on the largess of an otherwise indifferent society. As consciousness rises, disabled clients may come to realize that they are not the "half-persons" stereotypes depict them to be, but fully human. They may discover that their state is in fact unique and desirable and that a community for them exists, one of people both with and without disabilities.

Social workers need to augment their knowledge of these community networks so they can help clients avoid the isolation and disempowerment that has characterized most of the history of people with disabilities. Functional community supports that social workers can access include independent living centers founded and run by disabled people, advocacy organizations, newsletters and newspapers, electronic bulletin board services, and internet newsgroups. Beyond awareness of these groups and services, social workers need the community liaison skills to link these organizations and those in which they work.

Services

The Americans with Disabilities Act (ADA) has legitimized the idea that the fundamental problems facing people are less medical than social and structural. While ADA may be the most far reaching and important disability law ever passed, it contains little about how to provide specific social, health, or rehabilitation services. Rather, it focuses on removing social and structural barriers to the integration of people with disabilities into mainstream society. To empower people with disabilities, social workers must accept these terms. This acceptance may shift the "legitimate expertise" of social workers in health and rehabilitation from a focus on clinical and psychosocial interventions to community organizing, client and class advocacy,

administration, and the manipulation of relevant bureaucracies. This marks a significant change; up to now, medical social workers have been oriented toward direct service rather than community, administrative, and planning modalities (Pfouts & McDaniel, 1990).

Even so, the adoption of different treatment methods alone will not suffice. Social workers must implement consumer control of services. For example, through periods of medically imposed isolation and lengthy stays under the control of disempowering bureaucracies, an individual client may not be fully capable of assuming control. Social workers must therefore introduce individual clients to the greater disability community, so as to "allow direction [of their efforts] to occur from within the disabled community, reflecting the unique needs of that community and its members" (Berrol, 1979, p. 457).

Specific Practice Principles

Social work practice with disabled people involves helping such clients move from being a passive beneficiary of services to being an active, informed consumer of services. As such, social workers need to help their disabled clients realize that the clients themselves are the definitive experts on their personal disabilities. To enable disabled people to participate fully in the planning and course of their treatment, social workers can and should provide encouragement and technical assistance. They also need to educate people with disabilities about their rights under the law, particularly with regard to their right to self-determination concerning their bodies and treatment. Finally, social workers must forge links between their disabled clients and organizations/resources sponsored by other disabled people and designed to support independence within mainstream communities.

SUMMARY

Throughout history, disabled people have been one of the most disadvantaged minority groups. Despite this, only recently have people begun to focus on the oppression and empowerment of this group. Social workers working with disabled people—especially in health and rehabilitation settings—must employ a conceptual framework for practice that maximizes clients' involvement in ascertaining the full range of their available options; prepares clients to deal effectively with professionals, bureaucrats, and agencies that may neither understand nor appreciate their need to be self-determining; and empowers groups of disabled people to consider policy and program alternatives that can improve their situation.

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