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The Role of Choice in Empowering People with Disabilities: Reconceptualizing the Role of Social Work Practice in Health and Rehabilitation Settings¹

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Abstract. Disabled people have throughout history been one of the most disadvantaged minorities. Despite this, it has only been recently that social workers and others, including the people who have disabilities, have focused on their oppression and empowerment. Social workers who will be working with people with disabilities, especially in health and rehabilitation settings, must have as part of their professional repertoire a conceptual framework for their practice which: (1) maximizes clients' involvement in ascertaining the full range of available options and choices; (2) prepares clients to deal effectively with professionals, bureaucrats and agencies that may neither understand nor appreciate their need to be self-determining; and, (3) empowers groups of disabled people to consider policy and program alternatives that can improve their situation.

In this age of post-modernism and political correctness, it has become fashionable to question even the very notion of progress. In looking at the history and background of the treatment of people with disabilities in America, important questions are, what sort of progress has there been? What is its nature?

The best evidence from historical and anthropological sources suggests that pre-industrial era societies' actions toward people with disabilities were harsh. This was particularly true when the disability was discovered at birth, and when the nature of the disability seemed to be physically limiting. In virtually all cases of severe physical disability, infanticide was the common practice among pre-industrial peoples. The prevalence of infanticide may partly explain the extremely limited amount of information or historical data on disability (Neubert & Cloerkes, 1987, pp. 80-89; Oberman, 1965, chap. 3). Interestingly there is also a lack of information about adults who experienced disabling traumas or illnesses. This may be ascribable to the fact that in most of those situations the rate of survival was low. Still the absence of facts, as opposed to speculation, is striking.

¹Many of the points and issues identified and discussed in this essay were developed in collaboration with Samuel H. Taylor, D.S.W. at the University of Southern California School of Social Work.

Biblical, Classical and other ancient sources support modern anthropological evidence gathered from non-industrialized peoples. Virtually all such cultures castigated disabled people to some extent, often attributing disability to supernatural causes such as demonic possession or the wrath of God(s) (Neubert & Cloerkes, 1987, p. 80-81). The Romans, for instance, allowed fathers to expose to death any child that was born either "deformed or female" (Hewett & Forness, 1984, p. 4). 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, emphasis original)

To some extent the Judeo-Christian tradition encouraged tolerance and charity toward isabled people. This orientation is still, to some degree, codified in law (Merkens, 1988, p. 59). This same tradition, however, has also inspired some of the most inhumane treatment of people with disabilities, especially during the Inquisition and during periodic witch hunts (Oberman, 1965, chap 3). In the few cases where people with disabilities are mentioned in the Bible, 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. Marxian political philosophy identified how workers in industrialized society became non-human objects, how they lost their humanity and became merely the means of production. In this climate people with disabilities were not only seen as a sub-standard "means of production" but as an actual threat. They were forcibly made to work, and when they could not, laws were enacted to insure that they would not be able to beg (Blaxter, 1976, Oberman, 1965). One of the English Poor Laws...

"...classified people into three categories. In the lowest category 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, early institutions were constructed in order to force people with disabilities to work and to prevent public vagrancy and begging.

Over time America 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, males were separated from females, and society was protected not just from the harm that vagrancy and begging were presumed to cause, but from the "flawed" genes of people with disabilities (Wolfensberger, 1969). At its zenith, the pseudo-science of eugenics even sterilized all manner of "defectives" in order to protect the well being of society (Reilly, 1991; Ludmerer, 1972, chap. 2). During their early history institutions that housed indigent people with disabilities were little better than

prisons. This never really changed over the years and may have served to influence or spur on the deinstitutionalization movements of the 1960s and 1970s (Wolfensberger, 1969; Hull, 1979).

Prominent members of both the segregation and sterilization camps were active members of the National Conference on Charities and Corrections. Alexander Johnson, for instance, who was president of the National Conference in 1897, was a prominent segregationist (See for example, 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 advocated for the passage of sterilization laws at the New Jersey Conference on Social Work (Reilly, 1991, pp. 131-132). While the manifest purpose of most social work practice with disabled people was to be helpful, indeed many may have had social control of "defectives" as their principal goal.

The theme of 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 were at the heart of the development of vocational rehabilitation. The mission of both was to train people with disabilities who would otherwise be indigent or dependent on others, so that they could enter the work force and earn their keep, either in a sheltered or a competitive setting. This was accomplished through training, rehabilitating or otherwise *altering* the person with the disability to fit conditions in the work place. In order to accomplish this mission such training was only offered to people who were clearly judged to be improvable (Wolfensberger, 1969, pp. 89-94; Varela, 1983). This tendency to select only those persons with the best prognosis for re-entry into the work force characterized vocational rehabilitation from its inception until the 1960s (Berkowitz, 1980).

Medical rehabilitation, which began around the turn of the century, did not directly challenge vocational rehabilitation or segregation but did introduce the goals of medicine to the treatment of some people with disabilities. Medicine sought to "restore" patients to the fullest levels of physical functioning. Originally this was undertaken for the express purpose of allowing patients to enter or return to remunerative occupations. However, physical and rehabilitation medicine was not concerned about the actual return to work, but rather with the preparation for such, by way of *altering* the physical functioning of the patient (Berkowitz, 1980, pp. 109-112). 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, p. 205).

Medical rehabilitation brought social workers into the treatment arena for people with disabilities. Medical rehabilitation, while lead by physicians, favored a team approach to treatment which often required the contributions of social workers (Berkowitz, 1980, chap 4). It is likely that the first professional

social workers called upon to assist people with disabilities were among the first 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 focus of the casework was to prepare and adjust the disabled person for life with a disability outside the hospital milieu (Cannon, 1930, 90-96; Burling, Lentz & Wilson, 1956, 128; Bartlett, 1957, 87).

After World War II, those who were involved in advancing medical rehabilitation downplayed vocational goals. This served to spearhead the provision of treatment for severely disabled individuals—people who would not have been considered viable candidates for vocational rehabilitation (Berkowitz, 1980, chap 5). 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 which were to follow, many of the leaders came from among the most severely disabled (DeJong, 1981, chap 2) who were among the first people to be rehabilitated under the medical model. Earlier they would not have been rehabilitation patients or clients at all and therefore, hospitalized for life.

During the 1960s and 1970s, people with disabilities, especially those with severe disabilities, began to organize for political action in order to be able to maintain a more independent and self-determined lifestyle in the community. They formed organizations which engaged in and advocated for the integration of people with disabilities into mainstream communities to the maximum extent possible. Such advocacy groups were formed by consumers for consumers (DeJong, 1981, chap 2; Lachat, 1988; Frieden, 1983). These organizations, with help from others, were successful enough to have their principles of self-determination, consumer control and non-discrimination 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 inclusion of people with disabilities into the mainstream of American life to the maximum extent possible. This includes their active and informed involvement with the decision making processes regarding their medical and vocational rehabilitation and treatment. While some members of the disability movement are hostile toward almost all professionals, for the most part the emphasis of the movement is on allowing consumers the maximum self-determination in the selection, direction and termination of the treatment they are to receive.

The emphasis both in the disability movement and in the previously cited legislation is on creating change in society and in local communities to "reasonably accommodate" people with disabilities. This is 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 which sought to *alter* them so that they could fit in with society. Partisans in the disability movement seek to alter society to accept and include them. Barriers,

whether they be physical or attitudinal, are being challenged as discriminatory and unnecessary.

Disability advocates maintain that all of 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, medical and vocational rehabilitation programs still receive the lion's share of available funding. There is little doubt that many people with disabilities are still isolated and effectively segregated from mainstream society. Indeed, one of the goals of the Americans with Disabilities Act when it was passed in 1990 was to help eliminate such isolation. June 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 which promote real independent living options for people with disabilities" (Kailes, personal communication, 1990). This has caused some activists within the disability movement to question whether there is a role 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) has contended 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.

Social workers, especially those in health and rehabilitation settings, must operate in what has become a politically and socially charged environment. In order to empower people with disabilities who are in their case loads, social workers will now be called on to 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 will be called upon to help insure that their clients become more capable of self-determination and that there are commensurate increases in the choices they have regarding the treatments they will receive.

The major service manifestation of the disability movement has been the growth of independent living centers and programs. These centers, starting with the first in Berkeley California, have been operated by people with disabilities for people with disabilities (DeJong, 1981, p. 12). The express purpose of such organizations is the empowerment of their constituents. Essentially, this movement was the outgrowth of 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)

In order to accomplish this, social workers must distinguish between the differing philosophies and orientations of rehabilitation and independent living.

The recent debate over cochlear implants for children which has arisen in the deaf community is a case in point. Some members of the medical community, as well as in some conservative deaf organizations, have advocated for the use of such devices even when the level of improvement in auditory functioning is only marginal. Some more militant members of the deaf community view this as maiming of 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 is a basic philosophical difference with regard to 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 which often produce no more than marginal hearing ability. They argue that potential recipients of these procedures should be informed and made aware of all of their options and the potential consequences.

The philosophical contrast can be made sharp. Medical and rehabilitation institutions are likely to view the problem of disability as the inability of a person to perform certain activities of daily living (ADLs). In this perspective the problem is located within the individual, since the *person's* *inabilities* are the problem. It is, therefore, the individual that needs changing. Changing the individual to improve his or her performance on ADLs requires that the individual follow a treatment plan laid out by technical experts (i.e. the rehabilitation team). Such treatment plans are characterized by medical and technological solutions which often employ invasive—even experimental—procedures.

From the perspective of medical and rehabilitation professionals the role of the disabled person is as a passive beneficiary of their treatment regime. Control of the process is in the hands of the technical experts whose goal is to maximize physical functioning. However, since functioning cannot always come up to "normal" standards, success is often thought of in terms of completion of the treatment regime, rather than actual functional "normalization." In the example of cochlear implants, many medical professionals prefer to perform surgery in order to gain a quite marginal improvement in hearing, even if

this results in only marginal functional benefits, and even when it creates social difficulties for the patient. Dependency on technical experts is fostered, not just for the technology of treatment, but also for its goals and definitions of success. What this requires of people with disabilities is that they 1) view the rehabilitation professional as an expert, 2) view themselves as in an undesirable state, and 3) work toward a prognosis and recovery that has been defined for them.²

Organizations that operate within the independent living disability movement emphasize empowerment through increasing levels of self-determination on the part of disabled people, rather than reliance on technical experts. Such organizations rely 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. At minimum this includes enhanced information and referral services, so that individuals will be able to use them to pick and choose the services necessary for their particular disability. Peer counseling by other people with disabilities links the individual with the greater disability community and provides positive role models of non-dependent people with disabilities. Independent skills training focusing on the necessary activities to integrate in communities. Rather than focuses on the ADLs which the person is or is not able to accomplish, independent living skills training focuses on *how* to live independently in the community and society in spite of physical limitations. Finally, client as well as class advocacy services are provided in order to overcome environmental, societal and bureaucratic barriers. These services are necessary since, in the view of the disability movement, the problem of disabled people is not their particular physical limitations, but rather the failure of society to accommodate to their differences. This serves to marginalize them. Interventions to change the functioning of the individual are not necessarily the first step; rather, the first step may be to acquire the services and exercise the rights to live and work in the mainstream 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.³

Social workers, especially those in medical and rehabilitation settings, must begin to re-focus their activities to begin the transition toward empowerment objectives: to maximize and expand the range of life choices of clients

²These points embellish and expand on points made by G. DeJong (1981, p. 31)

³This characterization of independent living centers is taken in large part from Richards and Smith (1990).

with disabilities, assist and facilitate client decision making with regard to life choices, and to bolster and promote achievement of life choices. These objectives will often be at odds with the practices and perspectives of other professionals in medical and health settings. For this reason social workers must function as change agents to empower disabled people so that they can achieve their aspirations and exercise their newly legitimated civil rights. Social workers must be prepared to use their unique skills and their legitimate expertise to foster the ability of persons with disabilities to choose the goals and the criteria for success for the medical and rehabilitative interventions they receive. In short, social workers must begin to move in the directions pioneered by people with disabilities, and their movements and the organizations they have formed to achieve those ends.

Social workers should assist people with disabilities to refocus on the nature of the problem, not as one of inability, but one of social and physical barriers which must be removed by local communities. In this way the social worker helps disabled individuals to see the problem as also one of a disabling environment, rather than exclusively as a problem residing in themselves. 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). Independent living solutions result from thinking about how to also change the environment rather than just focusing on the individual. This suggests that the appropriate social work technologies will often include community organizing, client and community advocacy, and an understanding of bureaucracies in addition to their customary clinically oriented skills. Empowerment of disabled individuals requires that they remain in control of the change process. The social worker's role is to facilitate a partnership for the realization of goals and solutions, but not to set them for people with disabilities. In general, social workers will need to consider how to help individuals explore their range of choices, with an eye toward expanding their options rather than setting limits. Not only are such goals consistent with the disability movement, they are in line with traditional social work professional values that aim to foster the independence and self-determination of the client.

No one, disabled or non-disabled, can achieve complete independence. However, from the perspective of persons within the disability movement, life is independent to the extent that it is self-determined. This can be instructive to the social worker in judging the very nature of outcomes. From the perspective of the rehabilitation professional, a person who relies on an electric wheelchair is more dependent than a person who uses crutches. The former may even be said to be "confined" by the electric wheelchair. On the other hand, to the person with the disability, the wheelchair may be liberating rather than confining, allowing them to get to work without being exhausted by the journey as they might have been had they used the crutches (example comes from: H. Hahn, personal communication, spring 1991) It is important that dependency and in-

dependence be viewed in terms of self-determination of life choices, rather than by the preconceptions of technical experts.⁴

Finally, it is the role of the social worker to help disabled persons realize that they are the definitive expert on their particular condition and the best arbiters of their continuing treatment. This has the effect of raising the consciousness of the individual. The social worker's role is to be instrumental in making people with disabilities aware of their rights. As persons with rights, people with disabilities can come to see themselves as deserving, rather than 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" they are stereotyped to be, but rather fully human. They may discover that their state is in fact unique and desirable and that there is a community for them made up of people with and without disabilities. Social workers need to augment their knowledge of community networks to facilitate such linkages, particularly within the disability community, in order to avoid the isolation and disempowerment that has characterized most of the history of people with disabilities.

The Americans with Disabilities Act (ADA) has given legislative priority to the notion that the fundamental problems facing people are not medical so much as social and structural. While ADA may be the most far reaching and important piece of disability legislation ever passed, it contains little about the provision of specific social, health or rehabilitation services. Rather, the focus is on removing social and structural barriers to the integration of people with disabilities into the mainstream of American life. If social workers are to empower people with disabilities, it must be on these terms. This may shift the "legitimate expertise" of social workers in health and rehabilitation from a focus on clinical and psycho-social interventions to community organizing, client and class advocacy, administration, and the manipulation of relevant bureaucracies. This is a significant change in light of the fact that up to now medical social workers have been more oriented toward direct service rather than the more community, administrative and planning practice modalities (Pfouts & McDaniel, 1990). Adoption of different treatment methods alone will not be enough. Social workers must build in control of services by the consumer. In the case of individual clients, this constitutes client control. Through periods of medically imposed isolation and lengthy stays under the control of disempowering medical and rehabilitation professionals and bureaucracies, an individual client may not be fully capable of assuming control. It is incumbent upon social workers to introduce individual clients to the greater disability community, and 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).

⁴This distinction is clear in the name of the German version of the independent living movement, which is called the movement for "selbstbestimmtes Leben," literally, "self-determined living."

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