

Social Work Practice with People with Disabilities in the Era of Disability Rights

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ABSTRACT. Social workers, especially those in health care and rehabilitation systems, must consider practice changes necessitated by recent legislation and the growing activism of disability rights groups. The authors review essential elements of the emerging sense of both oppression and empowerment that is occurring for many people with disabilities and groups; consider key aspects of ADA and other pertinent legislation that place new emphases on the self-determination of people with disabilities; and discuss what implications changing practice roles might have for social workers' relationships and patterns of interaction with other professionals in medical, health care and rehabilitation settings. The authors outline a beginning effort at designing a conceptual framework that promotes practice that: (1) maximizes clients' involvement in exploring an expanded range of options and choices; (2) prepares clients to be more effective in dealings with professionals, bureaucrats and agencies that often do not understand nor appreciate their need for self-determination; and (3) at the organizing level, mobilizes and helps to empower groups of people with disabilities to consider policy and program alternatives that can improve their situation. This framework may also be useful in work with people who have other long term care needs, chronic conditions, etc. *[Article copies available for a fee from The Haworth Document Delivery Service:*

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Over the years, social work practice in health care has managed to innovate and adapt many of its essential functions. Traditionally these functions have included information and referral, counseling, resource acquisition (brokerage) and case advocacy. Such elements of practice are congruent with the norms, procedures and interdisciplinary arrangements encountered in health and rehabilitation organizations. Increasingly, however, some people with disabilities are questioning the efficacy and assumptions inherent in social work's traditional helping role. Many individuals with disabilities are becoming increasingly interested in empowerment. In the process, some have come to distrust social workers and other professionals whom they believe often do things *to* rather than *with* people with disabilities (Kailes, 1988, p. 4; Mackelprang & Salsgiver, 1996, p. 11; Zola, 1983b, pp. 355-356).

As these attitudes emerged and gathered strength during the 1970s and 1980s, alternatives to various social work activities took shape, influenced in large measure by the disability rights movement (Frieden, 1983; Lachat, 1988; Roberts, 1989). This movement sought to gain some of the services necessary for people with disabilities to be able to live in communities outside institutions and they pressed for more formal acknowledgements of their right to do so. New associations and organizations were formed to meet the needs of people with disabilities and raise their levels of awareness about their basic civil rights as well as the possibility of achieving new levels of integration into community life. Included among these were groups that focused solely on policy, legislative change and community organizing such as American Disabled for Assistance Programs Today (ADAPT¹) the World Institute on Disability (WID), the American Coalition of Citizens with Disabilities (ACCD), Disabled in Action (DIA), and others. In part because of grass roots support from these and other groups of people with disabilities, new laws, such as the *Americans with Disabilities Act* (ADA) were drafted to protect the rights of individuals

with disabilities and to remove structural barriers hindering their integration into society.²

THE DISABILITY RIGHTS MOVEMENT

While intellectual and academic support for advancing the civil rights of people with disabilities began as early as the 1940s (Berkowitz, 1980, chap. 6; Meyerson, 1990), it was during the 1970s and 1980s that people with disabilities began to organize for political action. A principal purpose was to be able to gain increased opportunities for independent and self-determined lifestyles in the wider community. They founded organizations that advocated the integration of people with disabilities into mainstream communities to the maximum extent possible. Such advocacy groups were formed by consumers to benefit consumers (DeJong, 1981, chap. 2; Frieden, 1983; Lachat, 1988). With help from others, these groups were successful enough to have their conceptualizations 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), the *Individuals with Disabilities Education Act* (1997) and the *Americans with Disabilities Act* of 1990. The Acts contain mandates for the inclusion of people with disabilities into mainstream American life to the maximum extent possible.

These laws are symbolic of a dramatic shift in legislative thinking about the concept of disability. Hahn (1984) has called this change in perspective a transition from a “medical” to a “minority group” perspective. Legislation has increasingly recognized people with disabilities as a minority group subject to and, or, at risk of exclusion and discrimination. Since 1973, disability laws, especially at the federal level have increasingly emphasized the need for the protection of their rights to inclusion in mainstream American life.

The emphasis on civil rights exhibited by many disabilities interest groups is partly due to a growing recognition that historically people with disabilities have been systematically persecuted, neglected and forced into isolation. In the early part of this century in the United States many people with disabilities were incarcerated and even sterilized against their wills. At one point virtually every state had laws that supported the segregation or sterilization of various categories of people with physical, mental and developmental disabilities often ra-

tionalizing this on social Darwinist or similarly eugenic grounds (Berkowitz, 1980; Johnson, 1903; Reilly, 1991; Varela, 1983; Wolfensberger, 1969). By the late 20th Century laws in support of eugenic policies had been virtually eliminated. Even so, authors such as Goffman (1963) and Wright (1960, chap. 2) recognized the prevalent stigma and biased treatment accorded to people with disabilities. There is little doubt that all too often people with disabilities remain isolated and effectively segregated from mainstream society today, in part because of a lack of physical access, but also because of stereotypical attitudes about their capabilities. While laws no longer actively prevent people with disabilities from participating in society, a range of physical barriers and disability related discrimination has continued to result in a lack of opportunities for disabled people to become integrated into American society.

This is not so much the product of a will to discriminate on the part of the general public, but rather a failure to take the needs of people with disabilities into account. We design buildings with steps, doors that are too narrow and floors that are too slick for many of our citizens. Educational systems continue to use timed tests in ways that bias against intelligent students who process or write what they know comparatively slowly. We forget that people of all abilities need to use public washrooms. This prompted an early pioneer of the movement to observe that decades after Rosa Parks moved to the front of the bus, many people with disabilities still could not even get on one (Roberts, 1989).

The crux of the new thinking about disability is that it is not so much a person's impairment that is disabling, but rather the *lack of accommodation* for them that creates problems. Discrimination is less likely to result from open hostility than from omitting them from consideration altogether. We do not put stairs in buildings because we hate disabled people. We simply fail to take the needs of people who use wheelchairs into account. This failure to be responsive to the needs of people with disabilities has resulted in social and physical conditions that effectively bar many people with disabilities from full participation in society.

Social attitudes that have made people with disabilities the quintessentially "worthy poor" have ironically also had the reverse effect of making them the objects of pity and charity (Adler, Wright, & Ulicny, 1991). This orientation to disability emphasizes the *inabilities* (literal-

ly characterizing them as pitiful) of people with disabilities rather than their capabilities, particularly with regard to their ability to lead full and productive lives that include working, studying, maintaining social relationships and consuming in the marketplace in much the same way as everyone else.

The main purpose of the *Americans with Disabilities Act (ADA)*, passed in 1990, was to help eliminate impediments, whether they be physical barriers or related to stereotypical attitudes. This law does not so much overturn past legislation which served to prevent inclusion (as did prior civil rights law) but rather promotes accommodation. Physical and social accommodations of people with disabilities that had heretofore been merely hypothetically possible are now mandated by law. Failure to accommodate the needs for social and physical inclusion of people with disabilities is now considered a violation of their civil rights.

Traditional Approaches to Disability in Health and Rehabilitation Settings

Efforts to provide medical rehabilitation, particularly as it gained effectiveness and prominence following World War II, brought social workers into more frequent contact with people with disabilities. Medical rehabilitation efforts generally utilized a team approach that relied heavily on the contributions of social workers (Berkowitz, 1980, chap. 4). The professional role of preparing the family and the individual with a new disability for life outside the hospital milieu was highly compatible with social casework approaches already in use (Bartlett, 1957, p. 87; Burling, Lentz, & Wilson, 1956, p. 128; Cannon, 1930 pp. 90-96).

Historically medical rehabilitation efforts have sought to “re-store” patients to their fullest levels of physical functioning (Cannon, 1952, 205; Wright, 1960, pp. 18-19) Originally this was undertaken for the express purpose of encouraging patients to enter or return to remunerative occupations by *altering* patients in ways that made them more physically capable of dealing with an unaltered world (Berkowitz, 1980, pp. 109-112). This has remained an important part of the rehabilitative process, particularly in the acute stages, when it is still unknown what level of physical functioning people with new disabilities will be able to regain. However, the goal of maximizing physical functioning can also have unintended psychological consequences for the patient, particularly when carried to extreme levels. Decades ago

Wright (1960, chap. 2) observed that more narrowly focused efforts to help people maximize their physical functioning can lead to feelings of shame about their disability by emphasizing the notion that their limitations were unacceptable and needed to be removed. She noted that this stood in contrast with attitudes toward persons of various racial and ethnic groups. When people of color embraced characteristics particular to the cultural norms of their group, they were thought to have appropriate pride in their heritage. People who accepted their impairments and were ready to build lives that included them (particularly if this meant not accepting heroic or invasive corrective procedures) have often been labeled as persons with neurotic adjustment problems.

Partisans in the independent living and disability rights movements take a different approach. They accept the impairment in the person and emphasize organizing and working for environmental accommodations to physical limitations. Rather than altering the patient, they favor altering the norms and structures that limit full participation in society. Barriers, whether they be physical or attitudinal, are being challenged as discriminatory and unnecessary (Hahn, 1984; Kailes, 1988).

Advocates point out that there may be some good reasons for embracing a disability. Some are obvious. For example, a person might choose an artificial prosthetic foot made of light composite materials because of the greater range of motion it offers when engaging in sports, making it preferable to a less functional prosthesis that looks more "normal."³

Another example involves arranging for assistance from others. An individual with a disability may well be inclined to seek assistance from another person, such as a personal care attendant, even for things they are physically capable of doing by themselves. An acquaintance of the author uses a personal care attendant to help with getting dressed in the morning although he is physically able to dress himself without such help. The reason is that dressing by himself takes about two hours and leaves him physically exhausted. By contrast, the attendant enables him to get dressed in about ten minutes. He is then able to use the time gained for more rewarding activities related to his career as a university history professor. This is not so much an argument against achieving gains in physical functioning, but rather is an

effort to call attention to alternative factors that can promote social independence.⁴

***ORIENTATION TOWARD THE ROLE OF THE PATIENT:
THE PATIENT-CONSUMER CONUNDRUM***

Many disability rights authors maintain that many, if not most, medical and rehabilitation professionals have tended to view people with disabilities as relatively passive beneficiaries of their treatment regimes (DeJong, 1981; DeJong, 1983, pp. 15-20; Kailes, 1988; Mackelprang & Salsgiver, 1996, p. 9; Nosek, Dart, & Dart, 1981, p. 1; Zola, 1983a). As medical and rehabilitative treatment strives to return the person with a disability to the most “normal” state of physical functioning possible, control of the process tends to be maintained by the technical experts (DeJong, 1981, pp. 28-31; Zola, 1979, 453-454). However, since the actual functioning levels of people with disabilities cannot always fully reach “normal” standards, success is often thought of in terms of completion of the treatment regime. The goal of working to achieve actual social integration and a normalization of social relations is not emphasized and may not even be one of the principal objectives of rehabilitation (DeJong, 1983, pp. 15-20).

Dejong (1981) suggests that this makes for a rather sharp philosophical difference between the goals of *traditional* medical and rehabilitation institutions and disability rights groups. The former tend to define disability as the inability of a person to perform certain *activities of daily living* (ADLs) as the working problem. In this view problems are located within the individual, since they are seen to be *caused* by a *person's* *inabilities* and impairments. It is, therefore, the individual who needs changing. It follows that changing individuals to improve their performance on ADLs requires that they follow a treatment plan laid out by experts in rehabilitation medicine and technology (e.g., the rehabilitation team). The exclusive focus on the impairment is often reflected in the language that professionals use to describe patients, who are often referred to by their condition (e.g., “paraplegics”) rather than as *people with* a disabling condition.⁵

Conversely, disability rights groups tend to define and perceive the “disabler” as outside the person. This emerging perspective considers that some of the most important problems of people with disabilities reside in inflexible and insensitive health organizations that are more

interested in maximizing profits and maintaining the status quo than in assisting them with what they believe to be their actual needs (DeJong, 1981).⁶ In an era of cost cutting and cost consciousness, health administrators usually seek to set up a menu of standardized treatment options designed to maximize achievement of ADLs at the lowest possible cost. The emphasis is on medical aspects of the impairment rather than social advocacy aimed at bringing about important alterations in living and work environments.

The disability rights perspective departs radically from such viewpoints. Advocates tend to view people with disabilities (a) as experts on their particular condition, and (b) the most appropriate persons to make decisions about the kind and the course of treatments they are to receive. Client self determination is operationalized by the disability rights movement as being active and informed involvement with the key decision making processes that are central to the medical and rehabilitative treatment of the person being treated. One of the most important roles of the social worker may be to help both the team and the person with a disability to move toward this type of complementary role arrangement. During the course of medical and, or, rehabilitation treatment, social workers need to be able to help the person take control of the process to the fullest extent possible. One of the ways that social workers can do this is by educating and advocating on behalf of the importance and the rights of patients to control of these decisions. Another is by helping patients to advocate on their own behalf in order to realize their wishes and goals. While some patients, due to an inability to articulate their desires or the acute nature of their condition, may not have much control over treatment processes in the beginning, social workers should be expected to work to help them achieve maximal decision making control as soon as practicable and certainly before they are discharged. This process involves helping patients with the critical change as they move from being passive recipients of care in the medical system to active *consumers*: persons with basic rights and the capacity to understand and even control the course of their treatment.

Orientation Toward Independence

The key to comprehending how disability has been reconceptualized is to understand the term *independence* as it is used by disability advocates. Traditionally, both rehabilitation professionals and mem-

bers of the disability rights movement have favored the maximization of independence as an important and desirable goal of rehabilitation. As noted earlier, many rehabilitation specialists believe the term has a very particular meaning: the ability to do things with minimal assistance either from other people or from machines. This creates a hierarchy of desirable treatment outcomes. Best is when the patient becomes able to approximate the activities of an unimpaired, robust individual without human or mechanical assistance. Next best is when the person can perform such tasks with the use of the latest assistive devices. The least desirable outcome is when, at the end of the rehabilitative process, the individual still requires human assistance to perform the activities of a robust, unimpaired individual (Zola, 1983b).

The meaning of the term “independence” is more complex and less obvious when defined and used by members of the disability rights movement. Their usage tends to emphasize *social* independence and has a meaning closer to self-determination and the ability to “call one’s own shots.” This meaning is clearer in some other languages. In German, for example, independent living is referred to as “selbstbestimmtes Leben,” literally, “self-determined living.” For people in the disability rights movement, the most important determinant of independence is not whether one relies on others or devices for assistance, but the degree to which decisions about assistance and other aspects of life are determined by the individual with a disability. Zola (1983b) contended that the emphasis of medical and rehabilitation professionals was almost exclusively in relation to *physical independence* rather than *social independence*. The former is independence from devices or attendants while the latter is the ability to be fully involved in planning the course of one’s own treatment and care. He contends that when these two values are at odds, gains in physical independence are almost never worth the losses in social independence (pp. 345-347).

To be sure, this does not always create a dilemma, particularly in the acute stages of the rehabilitation process when major gains can be expected in physical functioning. It becomes more of a dilemma when the expectation is for small gains in physical functioning or where “solutions” are intrusive, highly time-consuming, very fatiguing, experimental or do not really contribute to psycho-social reintegration into mainstream life. In the earlier example of the former rehabilitation patient who has given up dressing himself and now allows an attendant help him with this activity, it is notable that he initially spent

many months in rehabilitation learning to dress himself, only to give up the activity when he decided on a more efficient alternative approach. Most often social workers are the only members of rehabilitation teams who have the knowledge and responsibility to focus on the *social* life and needs of patients. Therefore it is incumbent on social workers to help the teams recognize this “new” definition of social independence and client self-determination.

It may also be necessary for social workers to more fully emphasize their role as educators in their work with patients and the teams. Social workers need to be attuned to the new realities of life with a disability which make it far less restrictive and offer consumers more life options than were available in the past. Overemphasis on dealing with fears about life with a disability, and “heroic” efforts to restore “normal” functioning are often perceived by the disability rights community as misguided. They contend that such forms of practice are based on stereotypes, on overly gloomy visions about what life with a disability will be like, or visions of life in institutionalized settings. Most of the general public are probably unaware of the many people with disabilities who are now able to live, work and shop in mainstream communities, while also forming meaningful social relationships, in spite of severe disabilities. Social workers need to become familiar with case examples and be able to communicate this perspective (or even connect patients with such individuals) so that newly impaired individuals and their families may become aware of how life can be full and rich even with the acquisition of a severe impairment. Such an awareness may also lead them to reconsider the effort and attention they are asked to expend in order to achieve relatively minor gains in physical ability that may be less than worth the effort.⁷

Another important role for social workers is helping both the rehabilitation team and the patient with the process associated with transitioning decision making power from the professionals to the patient. By the time of discharge, and ideally even before that, people with disabilities should be able to weigh and articulate their desires and preferences with regard to the various treatment options.

On a seemingly more mundane level it is important to remember that a sense of consumer control tends to be maximized to the extent that assistance personnel are hired and fired by the person with the disability (Haggstrom, 1995). For this reason many people in the disability movement tend to eschew professional helpers who are not

under their control, but rather answer directly to a third party health system or payer. Disability rights advocates tend to favor the use of low cost, paraprofessional aides that they themselves are able to hire and fire rather than more skilled aides such as home health nurses (DeJong, Batavia, & McKnew, 1992). In recent years disability activist groups have been working to create payment schemes that make personal care attendants more widely available and bring them under greater consumer control (DeJong et al., 1992). Zola (1983b) noted that such aides often contribute to the sense of “independence” of people with disabilities by helping them to perform basic tasks quickly, easily and reliably. In many cases, these are everyday activities that more professionalized helpers do not perform since the tasks are not medical in nature. However, these are the very services that are often vital to an individual’s ability to remain socially independent. One of the major priorities of the disability rights movement today is to develop political and legislative support for funding such paraprofessional helpers. To this end, the largest and most important disability activist organization, ADAPT, has shifted its activities from an emphasis on public transportation to attendant care services.⁸

Orientation Toward Technology

The development of technologies such as portable respirators, powerful but cheap computing devices, longer lasting batteries and light weight materials have helped make it possible for many people with disabilities to live independently. In light of these innovations and their contributions to people with disabilities it is somewhat ironic that the disability rights community tends to favor the use of “low technology” assistive devices whenever possible. Their reasoning is rather straightforward: The simpler the technology, the easier and cheaper it is likely to be to repair and maintain assistive devices. Space age technologies are often high cost, and are accompanied by hordes of professionals who are needed for training, servicing and repairs. This can lead to an ironic situation in which disabled people feel controlled and limited by the devices that held promise for offering independence.⁹

However, Zola (1983b) concluded that an intervention that is profitable to build, requires periodic attention by health professionals, and is “technologically fascinating” will often be promoted as the next best thing to a “cure” when it is presented in the rehabilitation literature.

“Thus does high-technology medicine pursued in a questionable manner contribute to greater dependence of those who seek its help” (Zola, 1983b, p. 346).

Disability rights advocates, more often than not, favor reliable, low-technology solutions that also allow for greater social integration. Examples of such arrangements include the construction of ramps, hiring and training of attendants and sign-interpreters, negotiated accommodations with employers, accessible housing and other *environmental* changes that promote the person’s ability to participate in mainstream life. A friend of the authors, for example, who has a mobility impairment traded in his van with an electronic lift for a car into which he could comfortably place and store his wheelchair. While this arrangement required a little more effort, it did not break down the way his electric lift often did, leaving him stranded until a technician-specialist could arrive to repair it.

Many in the deaf community would argue that the debate over cochlear implants for children is another case in point. Members of the medical community, as well as some of the more traditionally oriented deaf services organizations have advocated for the use of cochlear implants even when the level of improvement in auditory functioning is only marginal. More radically militant members of the deaf community view this as surgical “maiming” of innocent deaf children, potentially ostracizing them from their *birthright of deafness* and inclusion in the deaf community, as well as segregating them from the hearing community that will never accept them as “normal” (Barringer, 1993; D’Antonio, 1993). A part of this debate is a basic philosophical difference with regard to the nature of deafness. For most professionals in the medical community, deafness is a crippling medical condition to be conquered. For many in the deaf community, deafness is not so much a limiting handicap as a difference, one with its own culture and benefits. Deaf advocates argue that the *option* of deafness is worthy of consideration; one that may well be chosen over the alleged benefits of invasive procedures that all too often produce no more than marginal improvements in hearing ability. They favor informing potential recipients about all of the various consequences these procedures may have, as well as presenting information about other options. In the case of cochlear implants, medical professionals often prefer to perform surgery in order to gain even a marginal improvement in hearing, though this often creates social difficulties for the patient. Dependency

on technical experts is fostered, not just around the technologies of the procedure and treatment, but also for its prescribed goals and criteria of success. This requires that people with disabilities: (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 predefined for them (DeJong, 1981, p. 31). As this example suggests, the goals may be defined too narrowly in terms of function and not in terms of social costs. The former holds that *some* hearing is better than none. Activist elements of the deaf community would argue that it may well be better to be part of *their* community than not to be fully integrated into *any* community. Often a person with a cochlear implant, they reason, does not gain *enough* hearing to be seen as “normal,” but may have just enough so that they no longer fit into the deaf community.¹⁰

Relatively low tech, non-medical services may even be sufficient to help many individuals with severe disabilities remain in their homes. At one time such persons would have required institutionalized care. For patients to remain at home, social workers need to become aware of some different community based resources. Volunteer or moderate cost carpentry, plumbing, house cleaning, paraprofessional attendant care, etc., are available in many communities but they do not tend to advertise and must be sought out. Independent living centers are often well versed in these necessary services, have resource locators and in some cases have developed independent living educational materials for both consumers and providers (Shreve & Access Living, 1993). Independent living centers can be found in most urban areas due in large part to the support they receive from federal funding as well as local resources (U. S. Congress, 1978).¹¹

OPERATING OUT OF A DISABILITY RIGHTS PERSPECTIVE

Social workers may need to initiate ongoing liaisons with independent living centers and other alternative sources of information if they are to expand their knowledge to include options, resources and services that go beyond what is currently available (Zola, 1983b, pp. 346-347). This suggests that there may be a role for social workers to engage in client and systems advocacy within their organizations,

with third party payers and with legislators, to ensure that funding and services are available for people with disabilities.

Moreover active partnerships with social workers to achieve services that promote independent living should go a long way toward ameliorating some of the resentment felt by many people with disabilities. In light of the failure of the medical and rehabilitation establishment to even recognize these relatively new perspectives that are now embraced by the disability rights movement, some activists openly question whether professionals can be counted on for help in working toward the empowerment of people with disabilities. In their view, over the years all too many rehabilitation professionals have tended to promote dependence rather than independence (Berrol, 1979; Zola, 1979). A recent study suggests, however, that social workers may be moving somewhat closer to the aspirations and goals of disabled people (Beaulaurier & Taylor, 2000). The authors conclude based on their findings, that there may be an important role for social workers to perform as intermediaries between health services professionals and organizations and the people they seek to serve.

Before social workers can do that, however, they must become educated themselves, and have their consciousness raised. Health and rehabilitation professionals may have the best of intentions and might be “dismayed” to be told that they are helping to foster “technological dependence” and that this is not supportive of disability rights movements’ goals for empowerment, self-determination and social integration at the community level.

It is important to recognize that up to now the disability rights movement has largely been a self-help movement, and sometimes it has taken on an adversarial role toward professionals whom they have not seen to be particularly supportive. It may be incumbent, therefore, for social workers to demonstrate to such groups that they have valuable skills and knowledge that can be beneficial to their purposes. 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. (Berrol, 1979, p. 457)

As social workers begin to reach out to the disability rights community the roles that may be most valuable to and appreciated are those of educator and advocate (Zola, 1983b, p. 57). These are not new roles for social workers. However, this does suggest that community organizing, organizational practice, case management and advocacy skills may take on heightened importance in working effectively with this population.

Empowering People with Disabilities

Managed care settings may well create even greater needs for social work mezzo and macro skills. Tower (1994, p. 191) has suggested that given increasing caseloads and service demands, and decreasing social service budgets in the health services sector, client self determination may be “the first thing to go” as social workers struggle to balance their workloads. In light of the increasing activism and assertiveness of many people with disabilities this could put social workers at odds with clients and client groups. Effective social work practice with people with disabilities requires a re-focused conceptual framework that will support and promote self-determination. This framework must be designed to enable people with disabilities to:

1. Expand their range of options and choices.
2. Prepare them to be more effective in dealings with professionals, bureaucrats and agencies that often do not understand nor appreciate their heightened need for self-determination.
3. Mobilize and help groups of people with disabilities to consider policy and program alternatives that can improve their situation.

Direct practice with clients with disabilities will certainly remain a primary activity of health and rehabilitation social workers (with perhaps greater secondary emphasis on mezzo and macro skills). However, this practice must increasingly emphasize empowerment objectives rather than mere compliance with medically prescribed treatment plans and, or, our traditional psycho-social clinical interventions. Fostering the independence and empowerment of people with disabilities requires enabling them to become motivated and skilled at helping

themselves. Independent living services, inspired by the disability rights movement, emphasize concepts that rely on preparing consumers to help themselves:

The staff's role is to provide only what relevant training and problem solving is needed in acquiring and using services until the consumer becomes self-reliant. The move from dependence on staff to self-direction marks the shift from "client/patient mentality" to "consumer mentality" (Kailes, 1988, p. 5).

Social workers can approach practice in a similar way in order to help negotiate the transitions that will enable people to move from the passive role of patient to the active role of informed and empowered consumers. Several authors have discussed and outlined approaches to advocacy practice that seem particularly useful for health social workers in their work with people with disabilities. These authors include: Hardcastle, Wenocur and Powers (Hardcastle, Wenocur, & Powers, 1997, chap. 12), Herbert and Levin (1996), Herbert and Mould (1992), McGowan (1987), Mickelson (1995), Sosin and Caulum (1983) and Tesolowski, Rosenberg, and Stein (1983).

Gutiérrez (1990) has identified four psychological changes that are particularly important in empowering clients: (1) self efficacy—the belief that one's actions can produce desired changes, (2) group consciousness—identification as a member of a class and recognition of how political, social and physical structures effect the class, (3) reduction of self-blame for negative consequences of being a member of the class, (4) assuming personal responsibility for change—preparing to take action to improve one's own situation. As social workers assess their practice with people with disabilities they need to focus more on helping them accomplish these person-in-context changes.¹²

The lack of control that many people with disabilities experience while they are in the treatment process is, however, not simply a psychological phenomenon. Social workers in health and rehabilitation settings must develop and demonstrate skills that will facilitate helping their clients to press for inclusion in the planning and decisions that will be made about their treatment. Social workers will also need to consider more emphasis on their practice role as educators in order to help clients become effective advocates and negotiators for their own interests. This will require that practitioners modify customary approaches to include more emphasis on dealing with organizations and systems enabling . . .

. . . people to identify issues, to partialize the sources of their problem, and to speculate about possible solutions. The worker converses about power and conflict, encourages people to challenge preconceived notions, and works to unleash [their] potential. (Grosser & Mondros, 1985, p. 162)

Emphasis on such practice includes familiarity and skill with the advocacy and negotiation modalities that focus on dealing effectively with bureaucracies, administrative structures and centers of power that make decisions and allocate resources. In order to accomplish this, social workers may need to interact more deliberately and purposefully with practitioners engaged in both the independent living and disability rights movements. This suggests a need for more inter-organizational dialogues and agency agreements for working together to identify issues and concerns, formulate agendas and develop reciprocal understandings.

Finally, health social workers must gain increased levels of knowledge about the particular issues that are of concern to the disability community. Direct services social workers need to be responsive to issues such as the isolation and lack of group consciousness that many people with disabilities experience. These feelings often derive from limited contacts with other people with disabilities. People with recently acquired disabilities need to interact with *empowered* people with disabilities. Pinderhughes, writing from an ethnic minority perspective, encourages creating linkages with natural support systems such as family, church groups, fraternal and social organizations (1994, p. 23). Such natural gatherings of networks of individuals who share similar characteristics and a desire for empowerment simply did not exist among people with disabilities until relatively recently. In the past quarter century however, much progress has been made by people with disabilities who are working to develop and create more functional community supports. In some communities independent living centers have been organized, developed and administered by and for people with disabilities and they often collaborate with more advocacy oriented organizations such as ADAPT, ACCD, DIA and others previously mentioned. They sponsor and produce newsletters and newspapers, electronic bulletin board services and internet newsgroups.¹³ Social workers need to have first hand familiarity with such functional communities in order to be able to link their clients to them. This

requires more than a general awareness that such sources exist. Social workers also need to have the community liaison skills to create and maintain linkages and networks between such groups, services and their own health services organizations (Taylor, 1985; Weil & Gamble, 1995).

CONCLUSIONS

ADA marked a turning point for people with disabilities. With its passage in 1990, the law began to favor the notion of societal integration of people with disabilities whenever practicable and to offer recourse at those times when they were excluded or the victims of discrimination. It also marked a turning point for disability activism in that some of the most important battles, such as for accessible public transportation, accessible public spaces and protection from discrimination, were waged and won. This has not, however, resulted in complacency or a diminution of the movement's militancy.¹⁴ In part this is a recognition that exercising and campaigning for *rights* is only a part of what is necessary to achieve independence and self-determination. What is also required are a range of essential community based services. In particular this means developing and increasing access to personal attendant care as well as related services and programs that support and complement clients' abilities to engage in remunerative work (DeJong et al., 1992; DeJong & Brannont, 1998). In fact, people with disabilities are increasingly seen as leaders in the push for consumer oriented and consumer directed services (Beaulaurier & Taylor, 2001). This trend is especially observable when reviewing the literature on aging, developmental disability and mental health (Ansello & Eustis, 1992; Tower, 1994; Wehmeyer, 1997; Wilk, 1994). For many, "person with a disability" has gone from meaning "person with severe limitations" to "person with rights to accommodation and inclusion" (Beaulaurier & Taylor, 2001). An interesting consequence is that the notion and concept of disability is increasingly being used as a unifying theme in the literature about developmental disabilities, mental illness and aging. There seems to be a recognition that "disability" has a more universal meaning for many different kinds of problems that vulnerable and at-risk groups experience (Racino & Heumann, 1992; Wehmeyer, 1997; Wilk, 1994).

In spite of this activity there have been only a few exploratory

studies on social work practice with people with disabilities that were guided by the assumptions, issues and concerns of the disability rights movement (Renz-Beaulaurier, 1996) At present the authors are not aware of any systematic research that has described or assessed practice modalities that incorporate such perspectives. Clearly research in this area is needed.¹⁵

Even without the benefit of extensive empirical research it is clear that people with disabilities are becoming increasingly militant about their right to be involved in planning and making decisions regarding their treatment. They are no longer content to accept the “wisdom” of experts. They are challenging predominant medical and rehabilitation treatment philosophies that tend to emphasize restoring them to relative physical “normality” all too often at the expense of their social integration. These considerations, in addition to the newly imposed budgetary constraints associated with managed health care, have and will create turbulence in the health and rehabilitation task environment.

It is incumbent upon all social workers to reconsider how they view their practice with people who have disabilities. In the coming years we need to learn to emphasize . . .

. . . strengths rather than pathology, solution seeking rather than problem detecting, competence promotion rather than deficit reduction, and collaborative partnerships rather than professional expertise. (O’Melia, DuBois, & Miley, 1994, p. 164)

It is equally important for social workers in health settings to augment their practice capabilities with regard to organizational and community work, negotiating skills and advocacy. This practice knowledge and skill must be combined with efforts to acquire clearer understandings of the administrative structures and priorities that operate in health settings and their task environments, so that this knowledge may be used to help people with disabilities develop increased self-determination in their dealings with health systems and professionals.

NOTES

1. The organization has remained one of the most important disability advocacy groups, however the acronym has changed over time to reflect current legislative and lobbying efforts. Originally it stood for “American Disabled for Accessible Public Transportation,” and for a short time “ American Disabled for Access Power Today”

before adopting its current name. Insiders typically refer to the organization simply as “ADAPT.”

2. Other laws include sections of the *Rehabilitation Act* of 1973, the *Education for All Handicapped Children Act* of 1975, The *Individuals with Disabilities Education Act* of 1997, etc.

3. Less obvious is when the advantage is social rather than physical. A person might want to use a wheelchair instead of crutches, since wheelchairs are often more comfortable and less tiring to use even though the wheelchair makes the individual “look” relatively more disabled. The advantages of a wheelchair’s speed and mobility may outweigh the advantages of appearing to be less disabled and more “normal.”

4. Zola has stated (1982, p. 346) “. . . there is literally no physical circumstance in which increased physical independence is worth decreased social and psychological independence.”

5. For an excellent discussion about the subtle bias that language and attitudes of professionals often convey see the discussion by Wright (1980; 1988; 1989). Moreover, activist people with disabilities have expressed a strong preference that the word “people” always appear when describing them, as in “diabetic person,” or “person with a disability.” This article also follows the “person first” rule, as in “person with a disability” which emphasizes the humanity of a person before referring to the person’s condition. This symbolically highlights the fact that the person has a condition rather than suggesting that the condition characterizes the person. Perhaps the best reference on how to talk to and about people with disabilities is available from the Eastern Paralyzed Veterans Association at www.epva.org (Cohen, 1998).

6. As an example, the Southern California Chapter of ADAPT—a militant disability rights organization, chose a prominent health organization as the target of its annual social action in 1994.

7. Akin to overly bleak fantasies about life with a disability are overly rosy imaginings about the benefits of new or experimental treatments. Such prognostications about treatment approaches have made Christopher Reeve and the team working with him something of a lightning rod for criticism by the disability rights movement. Many advocates feel that (a) the chances for a “cure” for spinal cord injury are minimal, and (b) what gains from experimental approaches are actually on the horizon are minimal and expensive. Many people in the disability rights movement feel that the cause of people with disabilities would be far better served by efforts to adapt environments to people with disabilities than to seek rather minimal gains in functioning at enormous expense. Media treatments of the actor generally note how this vital and healthy man in his prime was “struck down,” and is now heroically working to overcome his “terrible affliction.” Rarely do media reports note that he continues to have a full life, maintains a career as an actor, is still relatively healthy, has a warm and supportive family, lives in a non institutionalized setting, heads major charitable enterprises. Some might argue that he has gained far more fame and prominence as a person with a disability than he ever had prior to his injury. In short, he continues to have a life that in some ways may be more full and meaningful by virtue of his impairments. There are many more mundane cases where this is so, and

many individuals now appear to be more conscious of how their lives have continued to be full and rewarding after the onset of disability.

8. The most comprehensive list of such centers is available at <www.ilru.org>.

9. Again, the controversy appears to center around differing notions of “independence.” Rehabilitation professionals tend to view independence as the ability of persons with disabilities to function with minimal assistance from other people.

10. This is particularly the case when there is just enough hearing so that patients (and families) focus on normal speech (which they may well *not* master) and do not learn sign language

11. See the list maintained at <www.ilru.org>.

12. Such client change and development is critical in that it helps people with disabilities begin to constructively deal with their own feelings of powerlessness and their all too frequent exclusion from treatment planning and decision making.

13. These include such electronic media such as “Dimenet” and other resources with links at <www.ilru.org>. The SERIES electronic bulletin board dates back to the late 1980s and allowed disability advocates to communicate about progress on the ADA well before the internet made computerized communication ubiquitous. Many individual ILCs also have publications and newsletters in conventional print form.

14. Hahn and Beaulaurier have recently reported on current militant activities of ADAPT, for example (2001).

15. This may require advocacy targeted toward organizations and institutes that fund research. June Kailes, a prominent independent living consultant, contends that “. . . the Rehabilitation Services Administration would still rather fund a program to teach paraplegics to walk on their hands than to fund programs that promote real independent living options for people with disabilities” (personal communication, Los Angeles, 1990).

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