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Chapter 9

**SELF-DETERMINATION AND CONSUMER  
CONTROL: GUIDING PRINCIPLES IN THE  
EMPOWERMENT MODEL AS UTILIZED BY THE  
DISABILITY RIGHTS MOVEMENT**

Richard L. Beaulaurier

*School of Social Work, Florida International University*

Samuel H. Taylor

*School of Social Work, University of Southern California*

During the 1970s and 1980s, groups of disabled consumers began to suggest new and fundamentally different alternatives to traditional models of practice. These alternatives were designed and advanced by people who belonged to and were influenced by the disability rights movement (Frieden, 1983; Lachat, 1988; Roberts, 1989). The central belief of the founders of this movement was that if a critical mass of disabled people could be empowered and their civil rights were formally recognized, then severely disabled people could live and work in local communities rather than in institutions (Roberts, 1989). New associations and organizations were formed to raise the levels of self and public awareness regarding the basic civil rights of disabled persons and to suggest the possibility of their integration into community life. Some of these groups focused on policy, legislative change and community organizing such as American Disabled for Access Power Today (ADAPT), the World Institute on Disability (WID), the American Coalition of Citizens with Disabilities (ACCD), Disabled in Action (DIA), etc., while others (the Center for Independent Living [CIL] in Berkeley, the Boston Center for Independent Living [BCIL], etc.) focused on advocacy as well as on efforts to obtain unavailable services in an effort to promote and facilitate community living by disabled people. In part the success of both of these types of organizations related to their ability to empower disabled people, many of whom had never before lived outside institutional or special residential care settings. In recent years, many of the policies developed and promulgated by these groups have become the guiding principles in laws such as the Americans with Disabilities Act (ADA), which

was drafted to protect the rights of disabled people and to remove structural barriers hindering their integration into society.

## THE DISABILITY RIGHTS MOVEMENT

The emphasis on civil rights exhibited by many of the disabilities oriented interest groups is partly due to a growing recognition that historically people with disabilities have been systematically persecuted, neglected and even coerced into isolation. Within the last century the United States and other nations<sup>1</sup> have incarcerated and in some noteworthy instances even sterilized many people with disabilities (Reilly and Philip, 1991; Wolfensberger, 1969). In some instances the proponents of such policies have been prominent members of the social work community of their time (Renz-Beaulaurier, 1994, p. 197). Despite recent legislative successes there is little doubt that many people with disabilities are still isolated and effectively segregated from mainstream society. Indeed, one purpose of the Americans with Disabilities Act, passed in 1990, was to help remedy this situation.

Intellectual and academic support for advancing the civil rights of people with disabilities began as early as the 1940s (Berkowitz, 1980a; Berkowitz, 1980b; Meyerson, 1990), but it was during the 1960s and 1970s that people with disabilities began to organize for political action (Roberts, 1989). A principal purpose was to be able to gain new opportunities for independent and self-determined lifestyles in the wider community. Toward this end, many disabled people joined new organizations and associations that aimed to empower and help them integrate into mainstream communities. Such organizations had a strong self-help ethos and were formed by consumers to benefit consumers (DeJong, 1981; Frieden, 1983; Lachat, 1988). In combination with other factors, the efforts of these groups were successful enough so that their conceptualizations of self-determination, consumer control and non-discrimination were included in a variety of laws, the most important of which are the Rehabilitation Act of 1973, its amendments (1978 and 1992) and the Americans with Disabilities Act of 1990. These acts contain mandates that promote the notion of inclusion of people with disabilities into mainstream American life to the maximum extent possible.

## INDEPENDENT LIVING

The Rehabilitation Act of 1973 stipulated that disabled people were entitled to the same rights which protected women and racial minorities through a

significant advance in terms of their general or overall civil rights status. This legislation did not fully address the particular barriers that went beyond attitudes and discrimination such as physical and structural barriers. Although strong arguments have been made that disabled people should be considered a somewhat unique oppressed minority (Hahn, 1984; Hahn, 1996) in that people with disabilities needed changes to the physical environment as well as to attitudes and social structures. As one of the founders of the disability rights movement put it: "Before the civil rights movement, black people had to go to the back of the bus to find seating. Many people with disabilities could not even get on the bus" (Roberts, 1989, p. 231).

Informal networks of people with disabilities formed in the 1960s. This was followed by the sometimes linked yet often parallel development of independent living centres that formed in the 1970s, run by people with disabilities (Lachat, 1988, p. 1). The Center for Independent Living (CIL) in Berkeley was the first such organization. Founded in 1972 by University of California students, and growing out of the student organization they had founded earlier, CIL provided services such as peer counselling, advocacy, van transportation, training in independent living skills, attendant care referral, health maintenance, housing referral, and wheelchair repair (DeJong, 1981, p. 12). CIL was founded as a self-help group that was largely controlled and managed by people who were themselves severely disabled. Other centres with similar organizational structures and purposes quickly followed in Boston and Houston. Using these first centres as a model, others sprang up throughout the United States. By 1981 there were 18 free-standing centres in California that were quite similar to on the original model in Berkeley (DeJong, 1981, p. 12). Richards and Smith (1990) have spotlighted the most noteworthy difference between traditional service providers and independent living centres:

What makes independent living centers very different from these other organizations is that [independent living] centers have substantial involvement of people with disabilities making policy decisions and delivering services. Why this emphasis on control by people with disabilities? The basic idea behind independent living is that the ones who know best what services people with disabilities need in order to live independently are disabled people themselves.

While the array of services may vary from one program to another, most centres offer a core group which includes peer counselling, information and referral,

independent living skills training and advocacy. Other common services are community education, equipment repair and home modifications (Richards and Smith, 1990). Since their inception, ILCs have stimulated the politicization of disabled persons and fostered a sense of community (Kailes, personal communication, 1990). In the process they have forged a model of empowerment practice for people with disabilities that is rooted in the principles of self-determination and consumer control.

## EMPOWERING PEOPLE WITH DISABILITIES

Ed Roberts, one of the early founders of the disability rights movement and the first director of the CIL in Berkeley, observed that the disability rights movement was launched more in spite of rather than in conjunction with rehabilitation, medical and social services professionals; he is not alone in that perception and perspective (Berrol, 1979; DeJong, 1981; Kailes, 1988; Roberts, 1989; Zola, 1979). In many ways, the disability rights movement remains a self-help movement to this day (Richards and Smith, 1990; Zola, 1979). However, some authors envision and support the notion of participation and active roles for social workers and other professionals as educators, advocates, allies and even leaders, providing they are able to engage consumers in ways that are empowering rather than domineering (Berrol, 1979; Hahn, 1991; Varela, 1983). This approach to empowerment is fairly compatible with some of the current conceptions of empowerment (Bricker-Jenkins and Hooyman, 1986a; Gutiérrez, 1990; Mondros and Wilson, 1994; Solomon, 1976). However, the principle of consumer control in the disability rights and independent living movements suggests that the degree of collaborative decision-making found in some empowerment models may not be appropriate for this model (Gutiérrez, 1990, p. 151). As viewed from the disability rights perspective, professional practitioners do not so much "collaborate" as offer options and discuss outcomes; in actual decision-making, practitioners follow the consumers' lead. In this sense such philosophical positions closely resemble the pluralism and participation approach set forth by Grosser and Mondros (1985).<sup>2</sup>

The following sections of this paper serve as an initial effort to articulate a framework for empowerment practice largely based on the conceptions of self-determination and independent living which are central to the disability rights movement. This practice model includes five major areas of knowledge and skill: (1) facilitation of goal setting and solution attainment by the consumer—without the practitioner setting the goals; (2) developing consciousness-raising skills which seek to impart or enhance consumer

awareness of the potent limitations that reside outside themselves—in the form of attitudinal and structural barriers in the environment; (3) community liaison skills and knowledge in order to facilitate the creation and maintenance of interorganizational and intercommunity channels of communication and linkage; (4) educational skills to enable consumers to prepare for and control their own transition from dependence to independence and from segregated living facilities to community based facilities; and (5) specific knowledge of the tasks and activities necessary to facilitate transitions from medical, rehabilitation and other structured living facilities to community based, mainstream living arrangements.

### Goal Setting

Social workers, especially those in health settings who may encounter some of the more disabled people in the course of their professional duties, have sought to offer forms of help that aid in coping with an unaltered environment (Renz-Beaulaurier and Taylor, in press-b). Increasingly, however, disabled people and their advocates are insisting that programs and services focus even more effort on making changes in the environment to accommodate their impairments (Hahn, 1996; Kailes, 1988). Social workers hoping to empower their disabled clients need to be aware of their own attitudes regarding selection of targets, potential for change and needed outcomes in order to collaborate more effectively in formulating the broadest possible range of choices for their clients.

### Self-determination and the Range of Choices

Disability rights authors place a high degree of emphasis on self-determination (Hahn, 1984; Kailes, 1988). At times such authors have expressed suspicion about social workers and other "helping professionals" whom they perceive as often predetermining and circumscribing their range of choices (Kailes, 1988; Mackelprang and Salsgiver, 1996; Zola, 1983).

What is needed, according to Berrol (1979), is for professionals to seek a greater range of services from which disabled consumers are able to make informed selections. In addition to the traditional rehabilitative services, professionals need to help identify and locate services that "...allow for upward mobility and access to the community at large" (Berrol, 1979, p. 457). Increasingly this perspective is being reflected in legislation such as the amendments to the Rehabilitation Act of 1992, which is the premier piece of legislation funding



disability programs in the United States. The purpose of this act is "...to empower individuals with disabilities to maximize employment, economic self-sufficiency, independence, and inclusion and integration into society" (US Department of Education, 1992, Title I, Sec. 101).

Social workers need to be alert and sensitive so that they do not direct clients or steer them toward "preferred" treatment options, especially when those options do not offer any future possibility of living and working in mainstream community settings (Renz-Beaulaurier, 1997). Rather their role is to work to expand the range of viable and available options. As the following examples demonstrate, however, it is not uncommon for the range of choices to be unnecessarily circumscribed. Nor is it unusual for options which seem similar at first glance to be quite different in practice.

### **The Example of Attendant Care**

Many impaired persons with limited strength, mobility or coordination find that they must spend hours on simple household and personal hygiene activities that then leave them physically exhausted. By contrast, many other disabled people have learned that having an attendant help them with such activities leaves them with the time and energy to pursue more rewarding activities. An acquaintance of the authors spent two years in rehabilitation learning to dress himself without assistance. During this time he was not informed by any rehabilitation professionals or social workers about other options for completing the task. After considerable time and effort he managed to gain marginal competence, but the process left him physically exhausted. Later he learned that he could hire an attendant from outside the normal rehabilitation channels. He and his attendant currently spend just minutes on activities such as dressing and preparing breakfast, thus enabling him to pursue other, more financially, personally and professionally rewarding activities (Paul K. Longmore, personal communication, spring 1992). Although the rehabilitation literature has at times considered receiving assistance from another individual to be suggestive of dependence on that individual, some disability rights authors have suggested that this is only the case when the attendant is not under the direct control of the consumer (DeJong, Batavia, and McKnew, 1992; DeJong and Wenker, 1983; Zola, 1983). Independent living centres keep lists of personal attendants. In accord with the principles of the independent living service model, disabled people are encouraged to hire, train and, if necessary, fire their own personal attendants.

An important consideration as both social workers and disabled people look at the range of service choices available is the degree of consumer control

that can be exercised within each particular option. The essential question concerns whether the disabled person will continue to be able to make choices and exercise options once an initial selection has been made. In the prior example, the disabled person was able to exercise considerable ongoing control over the activities of his attendant by virtue of the fact that he hired her, trained her and paid her for her services (DeJong and Wenker, 1983).

Not all attendant care promotes self-determination. Increasingly, people with disabilities, as well as seniors and others with chronic health conditions, are being offered home-care options, which at face value seem quite similar to the "attendant care" model described above. However there are often sharp and distinct differences with regard to who controls the training, hiring, firing and activities of the attendants. The model of care which predominates in the home-care industry is one in which a nurse or other professional, or paraprofessional trained and supervised by the agency, is responsible for care (DeJong et al., 1992). In this model the disabled person may have very little control or influence on the services offered or provided and even less to say about who will provide them. Some authors argue that these approaches are neither as effective nor as empowering as the independent living centre model of attendant care when it comes to furthering the client's goals (DeJong et al., 1992; Haggstrom, 1995).

#### The Example of Rehabilitation Technology

Zola (1983) noted that many disabled people may choose to eschew complex and sophisticated technological interventions. He notes that such approaches may actually make people with disabilities more dependent on the array of professionals and technicians who are required to come to repair, service, maintain and adjust them. A friend of the authors found himself in such circumstances when he purchased a "conversion van" that was equipped with a hydraulic lift for his wheelchair. He discovered, to his chagrin, that the lift broke down rather frequently and that ordinary auto mechanics did not know how to service it. Each time the lift broke down he found himself stranded until a professional mechanic from the lift manufacturer could be dispatched. Eventually, our friend was able to find a car into which he could manually lift his wheelchair, obviating the need for a mechanical lift. While this required more effort, there was no fancy machinery to break down. Some manufacturers have begun to address this problem by making some of their vehicles and conversions simpler and less high-tech. To address consumers' needs for such vehicles, at least one German disability journal, *Leben und Weg*, actually reviews unmodified, production automobiles for their practicality and use by disabled persons.



The flip side of this problem, however, is that once people have "graduated" from a rehabilitation system, they may no longer be apprised of ongoing technological advances. Zola (1983) reported that many disabled consumers are prevented from gaining needed benefits from newly designed or advanced assistive devices simply because they are not aware of their existence. By way of example, several blind persons known to the authors use computers for writing and reading that are fitted with software and hardware that allow their computers to "talk." They continually encounter people with virtually identical situations who are still struggling along with less technologically sophisticated devices, such as audio tapes, mechanical brailers and ordinary typewriters. In such cases the benefits of recent computer technology more than compensate for maintenance and service problems.

Another example identified by Zola is in the area of materials technology. It is currently possible to make assistive devices such as canes and prostheses that are lighter and stronger than their predecessors. Such advances, however, are of little use unless consumers are aware of them (Zola, 1983). This suggests that social workers need to be aware of the benefits of technology, but they also need to become informed about potential costs, the degree to which disabled persons will be able to maintain and service the technology themselves and the extent to which new technologies also require an ongoing reliance on specialized professionals for repairs and maintenance.

#### **Choices between Changing Disabled Individuals or Changing the Environment**

One set of guidelines that social workers would be well advised to take into account when seeking to maximize the choices of clients are those set forth under the Americans with Disabilities Act (ADA). The principle behind "reasonable accommodation" is that the environment rather than the person should be modified whenever it is possible to do so without creating huge expenses or Herculean efforts. In the past, services to people with disabilities have tended to emphasize changing the individual (DeJong, 1981; Renz-Beaulaurier, 1997). The social work practitioner in working with a disabled client should note whether changes to the environment as well as to the client have been explored, considered or even suggested. If not, the social worker should seek to identify reasonably helpful accommodations that can be made in the home and work environments of clients. At work, as well as in many consumer related facilities such as transportation systems, service providers, shops and restaurants, "reasonable accommodation" is a matter of law under the ADA. While this is not always the case in residential facilities, such

Figure 1: Trade-Offs in Goal Setting: Equating Needs and Benefits

	<b>High Consumer Control</b>	<b>High Professional Control</b>
<b>Level of Technology</b>	Low-technology solutions are often easier and cheaper to maintain. The disability rights community is increasingly suspicious of high-tech solutions to problems which may in turn contribute to greater dependence.	Consumers who have not been in the "rehabilitation system" for some time may not be regularly informed or updated regarding technological advances in adaptive technology and apprised of the potential costs, limits and benefits of such advances.
<b>Professional Helpers</b>	Many people with disabilities prefer to maintain consumer controlled over helpers and attendants, where the disabled person is able to control the hiring, training and firing of the attendant, as well as determine the tasks that will be performed.	Disabled people may fear that professionals, attendants and home health aids will circumscribe rather than expand their range of choices, particularly where they are certified and controlled by an agency or health-care system.
<b>Change Target</b>	Recent directions in legislation support consider making changes in the environment to accommodate physical impairments at least equally important in comparison with the traditional approach of changing the individual.	Traditionally, service agencies, especially health and rehabilitation agencies, have sought to change individuals in ways that make them more able to adapt and navigate an unmodified environment.
<b>Costs and Benefits</b>	Many care options favoured by people in the disability rights movement, such as modifications in the physical environment, the hiring of an uncertified attendant or low-tech, are relatively inexpensive. However, advocacy efforts may be required before third party insurers or service agencies will pay for them.	Traditional approaches to service delivery which include long-term care, rehabilitation or high-tech assistive devices are at times more expensive than other approaches and place access to services and resource allocation under the control of certified or approved contract providers.

guidelines may still be helpful in determining what changes should, or can, be made to facilitate living in mainstream communities. Moreover, many independent living centres offer assistance either in modifying existing housing or finding other housing which has already been made accessible to people with disabilities (Richards and Smith, 1990; see also <http://copwww.ci.phoenix.az.us/NONPRFIT/abil.html>).

In some cases modifying the environment may even represent a cost savings over treatment options that seek to enhance certain areas of physical functioning of a disabled person. Renz-Beaulaurier (1997) reported the case of a disabled person who found his wheelchair so much easier and energy saving as a means to get around that he abandoned the use of crutches altogether. For the client who would prefer the wheelchair, this might well be a viable alternative to lengthy and expensive medical rehabilitation efforts. Renz-Beaulaurier and Taylor (in press-a) have argued that many third party payers, in an era of managed care, may not be particularly open to suggestions about an expanded range of treatment options, especially when they seem to be non-medical in nature. However, pressing and advocating for such options may be more welcome if they are couched in terms of potential long-term cost savings.

### Consciousness-Raising

One of the roles of social workers is to help people with disabilities begin to recognize themselves as the definitive experts on their particular conditions. To be empowered they must come to see themselves not merely as recipients of continuing treatment but also as the persons best qualified to decide on its course. Zola (1979, p. 454) asserted that many problems encountered by disabled people simply cannot be understood by able-bodied persons simply because they have not lived with the impairment and stigma associated with having a disability. Disability rights authors explain that this level of disability consciousness may not be obvious even to people with disabilities, especially when they have been socialized to passively accept the wisdom of experts (DeJong, 1981). Roberts (1989, p. 238-239) argues that special efforts may be necessary to convince disabled people (and others) that even severely disabled people can "...live independent, productive lives with dignity and respect." The social worker's role can be very instrumental in helping people with disabilities become aware of their rights and assisting them in developing what Roberts calls a "can do" attitude (p. 239). Moreover, as people with disabilities become aware of their rights they are more likely to come to see themselves as deserving, rather than dependent on the largess of a sometimes indifferent

society. As consciousness rises, disabled clients eventually begin to realize that they are not the "half-persons" they are stereotyped to be. They may discover that their state is in fact unique, and in many cases has unrecognized or even unappreciated values and aspects. In fact, a study by Weinberg (1988) reports that many of the people who have lived with their disabilities for a longer time find qualities of uniqueness in their identity as disabled people and would not wish to become able-bodied even if they were given the opportunity.

Another important element of consciousness-raising involves the discovery of others who have a similar problems. It is tempting to categorize disabled people by the type of disability or with others who have the same or similar functional impairments (e.g., cerebral palsy, spinal cord injury, post-polio, etc.). Indeed this is understandable because hospital wards, support groups and umbrella organizations such as the Multiple Sclerosis Foundation, Inc., the March of Dimes, etc., often limit their attention and focus toward relatively specialized areas of physical impairment. However, many disability rights activists are now taking the perspective that the most important problems facing disabled people have to do with stigma and discrimination. This minority group perspective is rapidly replacing the older functional limitations labelling process in legislation and policy-making (Hahn, 1996). Social workers must recognize that for many disabled people the physical and attitudinal barriers to employment, mobility and other life activities may be more persistently problematic than their impairments in and of themselves. Moreover, the discrimination, paternalistic attitudes and lack of physical accommodations faced by people with cerebral palsy, spinal cord injury, blindness and other disabilities may be very similar even though the physical nature of their impairments are often different. As a result, social workers need to help make people with disabilities aware of the ways in which the lack of physical and attitudinal accommodations can impact and effect all disabled people. This is an essential precursor for efforts to help them develop strategies for countervailing these barriers.

Finally, it is not merely the consciousness of disabled people that needs raising. Disability consciousness is not merely for disabled people any more than feminist consciousness is just for women (Bricker-Jenkins and Hooyman, 1986b). A critical examination of environmental interventions that are beneficial to disabled people suggests that such changes are also beneficial to non-disabled people. Examples are as replete as they are mundane. Anyone who has recently strolled with a baby carriage, biked or skated on the sidewalk or wheeled groceries in a cart for several blocks knows the value of curb cuts. Ramps and other alternatives to steps and stairs are beneficial to many non-

disabled people in that they allow all manner of wheeled traffic—from lawyers pulling a box of legal briefs on a luggage cart to parents pushing baby carriages. Similarly, non-slip floors are not only beneficial to mobility impaired persons but to all the people who might otherwise have slipped and fallen on them. A traveller walking through any modern airport is likely to see an astounding variety of wheeled luggage. While this may not be a direct consequence of disability access policies, one cannot help but wonder if all this wheeled traffic would be practical without ubiquitous curb cuts, elevators and other environmental changes in airports which were required to become more user-friendly to disabled people—and also, therefore, to wheeled luggage.

In a less mundane sense, a world that is ready to accommodate disabled people will also be ready to receive those of us who are only “temporarily able-bodied” as we gradually become more functionally impaired over the course of our life spans. In disability rights circles, the term “temporarily able-bodied” or TAB is a slightly pejorative term used to describe non-disabled people. The term particularly connotes persons who do not acknowledge the possibility that they too could be (and perhaps even probably will be) disabled at some point in their lifetimes. Stereotypically, TABs see environmental accommodations for people with disabilities as benefiting others, often at their expense. An alternative view supported by the disability rights movement is to see environmental changes (both attitudinal and physical) as beneficial to most everyone, since virtually everyone will be disabled at some point in their lives or will have a close friend or loved one who is. Seen from this perspective, policies and physical structures which exclude disabled people are shortsighted since over the long term they tend to exclude more than just the minority of “currently” disabled people. Social workers need to begin to see encounters with such attitudes as opportunities to raise the consciousness of non-disabled people.

### Community Liaison

As consciousness levels rise in many disabled clients, they may require contact with disability organizations and support groups which are indigenous to their community. Moreover, contact with disabled persons who are well integrated into their communities tends to raise consciousness and can begin to empower clients by offering them role models and the benefits of the wisdom gained by people who have “been there” (Saxton, 1983). This is similar to the process of finding natural supports which has been described by Pinderhuges. Writing from a traditional ethnic minority perspective, she encourages creating

linkages with natural supports such as family, church groups and fraternal or social organizations (Pinderhuges, 1994, p. 23). The particular groups described by Pinderhuges do not exist in the same way in the "disability rights community." However, an increasing number of independent living centres, disability rights organizations and similar associations focus on such pan-disability issues as discrimination, civil rights and community integration. A partial indication of the extent to which this perspective has permeated the popular culture can be obtained by noting the number of such organizations that are listed on the world wide web (see for example: [http://www.yahoo.com/Society\\_and\\_Culture/Disabilities/Organizations/](http://www.yahoo.com/Society_and_Culture/Disabilities/Organizations/) ).

Social workers need to augment their disabled clients' knowledge of community networks to facilitate such linkages, particularly within the disability community, in order to help clients avoid the historical isolation and disempowerment that has characterized this population. A range of vital and active community supports which can be readily accessed by social workers have been created by people with disabilities. These supports most often take the form of independent living centres which have been founded and administered for and by disabled people, advocacy organizations, newsletters and newspapers, world wide web pages and internet newsgroups. Social workers need to have awareness and an understanding of these functional communities of disabled people in order to be able to link their disabled clients to such important resources. Beyond awareness however, social workers need to have community liaison skills (Taylor, 1985) if they hope to create linkages between these organizations and their services, and the organizations in which they work.

### **Educational Skills**

#### *Attitudes and barriers*

In order to educate, social workers must first be knowledgeable. From the discussion above it is clear that social workers engaging people with disabilities must be knowledgeable about the service communities and task environments in which they work. It is also clear that they will need to be well versed in the range of traditional and non-traditional approaches to treating the problems of disabled people. What is probably not as obvious is the need for social workers to be knowledgeable about the unique and cloaked nature of discrimination toward people with disabilities. Hahn (1996, p. 42) sums up this perspective by noting that, "Unlike the experience of many minorities, opposition to disability rights seldom has been marked by overt displays of bigotry or hostility." This



can be problematic, Hahn continues, if it means ignoring "... patronizing attitudes [that] can be a more formidable barrier to the attainment of equal rights than blatant animosity."

Many disabled people may face subtle forms of conscious or unconscious bigotry which can result in hidden feelings of aversion, paternalism or even antipathy (Hahn, 1996; Yuker, 1988). Unfortunately, it is not uncommon for these attitudes to be manifest in the treatment services offered to people with disabilities. Paternalism can manifest through overprotectiveness, or as a circumscribing or curtailing of clients' decision-making powers "for their own good."

It is important to recognize that an important part of the ability to determine one's own fate is the ability to choose risky options. Zola (1983, pp. 351-353) notes that the laudable goal of protecting vulnerable people from harm may be achieved at the cost of growth and freedom. He goes so far to say that a life without the possibility of risk is not "real" in a world where "real" people are sometimes hurt or make unwise decisions.

Aversion to people with disabilities can have even more unpleasant consequences. During this century such antipathy often resulted in segregation or the loss of reproductive rights (Reilly, 1991; Renz-Beaulaurier, 1997; Wolfensberger, 1969). However, it is likely that these days social workers will encounter more subtle feelings and behaviours. For example, the assumption that people with disabilities are likely to feel more comfortable living or working with other disabled people may mask a deeper attitude; namely, that the person making such an assumption may feel uncomfortable living or working with people with disabilities.

#### *Change tactics and techniques*

Clearly, social workers' roles encompass educating disabled people, their families and their personal support systems about the difficulties they are likely to face as they deal with systems and communities that are not sensitive to their needs. Moreover this role may include enabling and thus empowering disabled people to develop competency in client advocacy, class advocacy and the tactics and techniques of community and social change. While an extensive description of these techniques is beyond the scope of this paper, advocacy practice with disabled people by social workers has recently been explored by (Renz-Beaulaurier and Taylor, in press-a) and discussed from a disability rights perspective by Kailes (1988).

Social workers will also need to develop skills and competencies that will allow them to work in, and in some cases create, program and organizational

designs for service delivery that empower people with disabilities. The approach to human services program design and delivery which is probably most compatible with the consumer control and empowerment philosophy of the disability rights movement is that of Rapp and Portner (1992). This approach inverts the traditional organizational chart putting clients at the top. They write that "...the pinnacle of the chart is the client, and all organizational personnel are subservient" (pp. 277-278). Although this approach toward the design and implementation of responsive programs and services resembles the models of administration and organizational design favoured by the independent living community, there are some specific suggestions and features that are unique and worthy of attention. Beyond the professional literature written from a traditional human services perspective, social workers may want to explore the burgeoning literature concerning the management of independent living centres and services. A good starting place is Frieden (1983) and Crewe and Zola (1983, part 3).

Basic models for creating change in communities can be found in Taylor and Roberts (1985), Rothman (1995) and Weil (1995). Berrol (1979) has suggested that one of the most legitimate roles for non-disabled professionals is to educate groups and individuals in order to transfer the skills and knowledge necessary to create social changes. In as much as the practitioner must be careful not to dominate client's decision-making, even while assuming the role of expert, consultant or educator, Berrol's approach is consistent with the "pluralism and participation" approach to community social work developed by Grosser and Mondros (1985). In both Berrol's and Grosser's and Mondros's approaches the social worker facilitates accomplishing goals set by a client or client systems.

### **Conclusion: Empowerment Means Refocusing**

Social workers 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 with disabilities, to assist and facilitate client decision-making with regard to life choices and to bolster and promote achievement of life choices. Social workers must be prepared to use their unique skills and their legitimate expertise to foster the ability of persons with disabilities to choose their own goals, especially in light of their newly legitimated civil rights. In short, social workers must begin to move more collaboratively in the directions pioneered by people with disabilities, their movements and the associations and organizations they have formed to achieve those ends.

The framework outlined above should help social workers to assist people with disabilities to take a strengths perspective with their disabled clients

which focuses not so much on the impairments or inabilities of disabled consumers, but rather on the social and physical barriers which must be removed in order to achieve greater integration into local communities. In this way the social worker helps disabled individuals to see their problems in relation to a non-adaptive and even dysfunctional environment, rather than exclusively as a problem residing in themselves.

Since independent living solutions result from thinking about how to change the environment rather than just focusing on the individual, social workers seeking to empower disabled consumer will need to have community organizing, client and community advocacy, and an understanding of bureaucracies as part of their practice repertoire in addition to their customary clinical skills. The discussion above also highlights, however, that how social workers engage disabled consumers may be as important as what skills or activities they employ. Empowerment of disabled individuals requires that consumers remain in control of the change process. The social worker's role is to facilitate collaboration and partnerships 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 offer more help to individuals in exploring their range of choices. Not only are such goals consistent with the disability movement, they are in line with historic social work professional values that aim to foster the independence and self-determination of clients.

#### ENDNOTES

- <sup>1</sup> For example, there has recently been a scandal in Scandinavia over the sterilization of young women viewed as mentally disabled.
- <sup>2</sup> For an example of the differences between these empowerment approaches see Kailes (1988, p. 5).

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