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The Development of the Disability Rights
Movement as a Social Problem Solver

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Abstract

A sociological overview of the development of the rights movement is provided. The movement arose to combat the oppressive marginalization of persons with disabilities. It sought both to empower them to take control of their own lives and to influence social policies and practices to further the inclusion of individuals with disabilities into the societal mainstream. It developed in three phases. In the first phase, a definition of both what the problem is and of what its sources are, was offered. In the second, a consensus was established and acted upon as to a collective solution to the problem. In the third phase, it responded to the aftermath of new policies and practices.

Keywords: disability rights movement, marginalization, oppression

This paper provides a sociological overview, based on the work of Fuller & Myers (1941), Blumer (1971), Mauss (1975), and Spector & Kitsuse (1977), of the development of a particular social movement, the disability rights movement in the United States. Of course, the United States is but one of the many countries in which such a movement has arisen (See: Charlton 1998; Newell 1999; Cooper 1999; Jayasooria 1999; Hayashi and Masako, 2001; and Gottlieb, 2001). As with many social movements, the disability rights movement arose to offer solutions to a social problem, viz., the oppressive marginalization of persons with disabilities. Its solution is basically, albeit not entirely, twofold. First, to empower persons with disabilities to take control of their own lives; and, second, to influence social policies and practices so as to further "the integration and full inclusion of individuals with disabilities into the mainstream of American society," as is now put in federal law (amended Rehabilitation Act of 1973, Title VII, Chapter 1, Section 701).

The disability rights movement, while by no means a monolith, is one whose slogan may well be that cited by Charlton, "Nothing about us without us," an expression he traces (1998: 3) to an international disability rights conference. In sum, then, disability rights movements seeks to replace oppression with

empowerment, and, marginalization with full inclusion.

As with the development of any social movement, that of the disability rights movement can be said to develop in phases (Fuller & Myers 1942, Blumer 1971, Mauss 1975: 57-70, and Spector & Kitsuse 1977). In particular, the disability rights movement can be said to entail three phases: 1) definition of the problem; 2) solutions; and 3) aftermath. In the first phase, the movement offers a definition of the problem which involves a statement of both what the problem is, and what its sources are. In the second phase, a consensus is established and acted upon that not only is something wrong, but that something ought to be done about it on a collective, not individual, basis. Generally, the second phase can be said to end with the enactment of appropriate law, i.e., law which seeks to redress the grievances identified by the movement and legitimates solutions it supports. Indeed, the "volume and depth" of such appropriate laws may well be, as Mauss (1975:70) suggests, "the most important indicator of the 'success' of a social problems-movement." Nevertheless, the second phase may also spawn solutions involving non-governmental organizations as well.

In the case at hand, the disability rights movement, the first two phases entail the establishment of a consensus that without the protection of the law, persons with disabilities will be subject to an oppressive marginalization; and that the adoption of new public policy and practices are needed to eliminate, or at least reduce, the problem. It also spawned the Independent Living Movement.

Unfortunately, even years after the successful conclusion of its second phase, social movements often find problems have been more often ameliorated than solved. Moreover, solutions to old problems can bring new problems in their wake. There is, then, a third phase of a social movement, that of dealing with the aftermath of new policies and practices. The aftermath generally involves dealing with both remnants of the old problem, e. g., some oppressive marginalization remains, and new problems, that arise out of conditions created by the solution, perhaps, including a backlash seeking a return to the status quo ante. For example, affirmative action attacked discriminatory college admissions practices, but, in its wake, came questions about the abilities of the students admitted as a result of affirmative action. Consequently, in some places, notably California, affirmative action itself came to be seen as a problem to be eliminated.

Of course, the development of a social movement may be uneven. Calls for governmental action may come before there is a clear understanding of the problem the action is to solve. Some, for example, would argue that those who call for school vouchers paid for by the state or federal government have not shown how vouchers will help and/or that the state of American schools warrants such "drastic" action. In sum, a sociological analysis of the development of a social movement need not be a social history of its development. What follows, then, is a sociological, but, not necessarily a chronological, analysis of the disability rights movement.

Phase I: Definition of the Problem

As indicated above, a social movement seeking the solution of a social problem will develop an understanding of the problem and sources. That is, the movement will define the problem by explaining both what it thinks is wrong, and what it regards as the sources of the problem (see: Fuller & Myers 1941, Blumer 1971, and Spector & Kitsuse 1977: 130-158). In the case of the disability rights movement, the problem is that persons with disabilities are marginalized and, consequently, oppressed. The sources of these problems, as with related problems such as racism and sexism, are said to be both constituted on a personal or interpersonal level and constructed by institutional practices (Oliver 1990: 82-83). That is, from the standpoint of the disability rights movement, the oppressive marginalization of persons with disabilities is, in part, rooted in the prejudices or misconceptions, but, also, in the good intentions, in the minds of persons without a disability as they are manifest in their interactions with persons with disabilities.

However, it is also rooted and constructed by the dominant or hegemonic ideas and practices, which Berger & Luckmann (1966: 45) term a "plausibility structure". Such a structure provides for unobtrusive control of the premises upon which decisions are rendered plausible and, thus, acceptable (see: Perrow 1986 128-130). That is, the dominant ideas and practices, the plausibility structure, by virtue of its control over the definition of the situation of persons with disabilities, enables otherwise decent people to adopt policies and programs which they regard as reasonable, plausible, but, which the movement views as a major source of the oppressive marginalization of persons with disabilities. Consequently, "the oppression of people with disabilities does not [always] derive from a backward set of attitudes." To the contrary, "it is the product of [the] dominant culture" which even though often well-meaning, nevertheless, "marginalizes people" with disabilities (Charlton 1998: 82).

Marginalization and Oppression

In its first phase, the disability rights movement, as noted above, defined the claim that persons with disabilities are: 1) subject to marginalization; and 2) are, consequently, oppressed. In this phase, then, marginalization was first identified and its oppressive nature exposed. And in order to understand the problems encountered by persons with disabilities, the disabilities rights movements makes important distinctions between: 1) impairment and disability, and, 2) stigmatization and marginalization.

The disability rights movement generally accepts the definitions of "impairment" and "disability" offered by UPIAS (Union of the Physically Impaired Against Segregation 1976: 14 as quoted in Barton 1998: 56). Specifically, "impairment" is the condition of a person "lacking part or all of limb, organ or mechanism of the body." "Mechanisms of the body" may be sight, hearing or some higher cognitive function such as reading. "Disability" is "the disadvantage or restriction of activity caused by a contemporary social organization which . . . excludes [people with physical impairments] from participation in the mainstream of social activities."

Social organization is here understood as a combination of the prevailing mode of doing things, the social structure, and

the prevailing ideas of what is right, normal or otherwise appropriate behavior, the normative structure. The social structure refers to how things are done; the normative order, to how they ought to be done. The social structure and/or the normative order may reflect not only prevailing wisdom, but prevailing prejudices and stereotypes.

In any case, where floors above the ground floor of a building can be reached by use of a stairway, the use of stairs is part of the social structure as well as that of the building's physical structure. Where use of any other means of entry is seen as improper or inappropriate sloth, use of the stairs may also be part of the normative order. Where elevators are widely available in addition to stairs and an acceptable mode of entry to upper floors, then using stairs may not be part of either the social structure or the normative order. Furthermore, paraplegia, which is an impairment in any case, is rendered a disability only where elevators are not available or their use frowned upon.

The distinction between impairment and disability is made very clear in the classic study of the place of deaf people in the mainstream of the towns of West Tisbury and Chilmark, Massachusetts (Groce 1985). In these towns, there were many people who were congenitally deaf. However, since everyone in these towns spoke sign language, they were not disabled, they were not excluded from the mainstream of social activities in their respective towns. Conversely, left-handedness may be a disability where, as was noted in recent testimony before New York City's city council (Bumiller 2000: B4), door handles, bannisters, guard rails, or a computer mouse, are designed for right-handed people. However, it is not an impairment as no "limb, organ or mechanism of the body" is lacking.

Social attitudes may also exclude individuals from the mainstream of society and, thus, disable them. Left-handed people were once suspect. The term "sinister" derives from the Latin for "on the left hand" (Urdang 1968: 1228). And teachers used to do their utmost to encourage, even require, left-handed students to write with their right hand. Clearly, then, the status of a particular condition may change over time.

Poor eyesight and the consequent use of corrective lenses is a case in point. That is, "spectacles are [now] a necessary aid for many with a visual impairment, but they have been so 'normalized' that wearing glasses [or contact lenses] is no longer regarded as a mark of a disabled person . . ." (Barnes, Mercer & Shakespeare 1999: 25).

"Impairment," then, is a physical or biological condition, including, of course, cognitive impairment. "Disability," is a social condition, part and parcel of the prevailing social organization. While certainly desirous of the elimination of both impairments and of disabilities, the disability rights movement focuses on the latter.

In addition to the distinction between impairment and disability, the understanding of the disability rights movement is also informed by the distinction between stigmatization and marginalization. Stigmatization is the process whereby an individual comes to be viewed as having "an attribute [a stigma] that is deeply discrediting" (Goffman 1965: 4). "The central feature of the stigmatized individual's life . . . is a question of . . . 'acceptance.' Those who have dealings with him[/her]

fail to accord him[/her] the respect and regard which" would otherwise be their due (Goffman 1965: 8).

Marginalization is the process whereby one is kept outside, on the margins of, activities in the mainstream of one's society. It is a process which denies one effective "citizenship . . . resources . . . [and] access to education, employment, housing and other areas of . . . life" (Williams 1998: 17). In short, a marginalized person is excluded from the mainstream of the polity and economy of his/her society. Moreover, marginalization deprives one of autonomy over one's life.

Stigmatization and marginalization are each a process which works to exclude persons with impairments from participation in the mainstream of social activities. Each, then, is a process which disables people. The essential difference between the two is that stigmatization generally occurs in the realm of primary groups, those involving face-to-face interpersonal encounters such as with family, friends, between neighbors or informal groups in an otherwise formal work setting where interaction "is typically spontaneous, informal and personal" (Michener & DeLamater 1999: 318).

Marginalization generally occurs in the realm of secondary groups, those in which interactions "tend to be formal, impersonal and non-spontaneous" (Michener & DeLamater 1999: 318) such as in a bureaucracy. Moreover, marginalization generally refers to one's relationship to the economy and the polity of one's own society. Thus, in a marginalized world, "employers turn away qualified and competent workers simply because they are disabled" (Hunt 1998: 14). It is also a world in which public policy concerning people with disabilities is established, e.g., at school board meetings, without their participation in the policy making process; a world, in which with respect to people with disabilities, much about them is indeed done without them.

While the disability rights movement would prefer that people with disabilities are neither stigmatized nor marginalized, given its primary concerns with the exercise of economic and political rights, the rights to a job and to having a voice, the rights to autonomy, self-sufficiency (independence) and self-determination, it has "not found stigma a helpful or useful concept." The analysis of stigmatization focuses on primary or interpersonal relations, and not on political or economic rights (Oliver 1990: 68). The movement, then, focuses on marginalization.

The goal of the disability rights movement is, then, the elimination, or at least amelioration, of the disabling marginalization of persons with impairments, and, thereby, to empower them to influence social policies and practices so as to further the integration and full inclusion of individuals with disabilities into the mainstream of American society. Concomitantly, it is to facilitate their taking control of their own lives. That is, the goal is to enable persons with disabilities to be productive, contributing citizens who "choose a way of life that confronts all the options and risks throughout . . . life that are inherent to living in, rather than outside [on the margins of] society" (Brisenden 1998: 26). Thus, the movement's goal is to create a society in which persons with disabilities can truly say, "we are able to take responsibility for our own lives, . . . do not need or want [others] to manage

our affairs; we best understand what is best for us; we . . . control our own organizations and programs and influence . . . government funding, public policy, and economic enterprises that directly affect us" (Charlton 1998: 128). In order to attain its goal, then, the movement has sought, first to explain why marginalization is oppressive, and, then, to identify its root source.

From the standpoint of the disability rights movement, the right and ability to exercise autonomy over one's own life is the basic, defining, characteristic of what it means to be human. Marginalization (and, for that matter, stigmatization) is, therefore, oppressive. It is dehumanizing in that it deprives persons with disabilities of their autonomy, their ability both to make their own meaningful choices, free of unwarranted constraint, and to carry them out. Furthermore, since, as indicated above, marginalization precludes one from confronting the risks that are inherent in living a life and the failures that selecting a poor risk can bring, it is oppressive. "Without the possibility of failure, the disabled person lacks . . . the ultimate mark of humanity, the right to choose for good or evil" (DeJong 1983: 20). The disability movement, then, can be seen as an "incarnation of an old theme in American life the idea of self-help" or autonomy (Zola 1983: 49). "There has," as Varela (1983: 48) observes, "always been someone, somewhere fighting against laws, attitudes and practices that restrict personal autonomy," and are, thereby, oppressive.

To succeed in the fight against such oppression, the movement needed to demonstrate that the oppression of persons with disabilities is "related to an ideology or group of ideologies which justify and perpetuate" it (Abberley 1967: 7). That is, to succeed as a social movement, the disability rights movement had to identify the ideas which exert unobtrusive control over the premises defining the issues which concern them. It needs to do so because these controlling ideas constitute a structure of policy and practice, i.e., a plausibility structure which renders it plausible for ordinary, well-intentioned people to accept and put into practice ideas which the movement regards as oppressive.

The disability rights movement has generally identified the medical or rehabilitative model of disability as the main basis for regarding impairment, and, the ensuing disability, as a personal tragedy rather than as a the result of social oppression. Thus, the medical or rehabilitative model makes it plausible, through control of premises as to the nature of being disabled, for otherwise well-intentioned people to see as acceptable what the movement regards as oppressive, viz., the marginalization of people with disabilities as people in need of individual care and not as people in need of collective efforts to ensure their rights as citizens.

The Medical Model as an Oppressive Plausibility Structure

The focus of the medical model is, of course, on impairment, the physical or biological condition of people with disabilities. Moreover, the medical model views impairment as a condition which can be, and, more importantly, ought to be repaired, after which the individual may be rehabilitated and returned to "normal life," or as close to it as possible. In other words, the medical

model treats a person with an impairment as one would a person with a illness such as measles. Consequently, the medical model calls for a person with an impairment/disability to act as a sick person or patient is expected to act, that is, to assume the "sick role."

The "sick role," as described in Parsons' classic description (1951: 436-437) consists of four components. The first two provide a sick person with "privileges and exemptions" (Parsons 1951: 437; see also Crewe et al. 1983: 17). These exemptions are: 1) "the exemption from normal . . . responsibilities . . . relative to the nature and severity of the illness [or impairment];" and 2) the exemption from moral accountability for the illness [impairment] (Crewe et al p. 17). That is, there is no expectation that one can take care of oneself and nor is there the expectation that one can do what needs to be done. The second exemption provides "a bridge to the acceptance of 'help'" (Parsons 1951: 437). Indeed, given the second two components of the sick role, the "acceptance of 'help'" becomes obligatory.

The last two of the four components of the sick role identified by Parsons define the obligations which a "sick" or impaired person is expected to assume in order to preclude abusing his/her privileges and exemptions. Specifically, the impaired (sick) person is: 1) obligated "to want to 'get well'" and to define "being ill as itself undesirable" (Parsons 1951: 437); and 2) obligated "to seek technically competent help, . . . [usually] that of a physician and to cooperate with him[/her] in . . . trying to get well" (Parsons 1951: 437). As a consequence of these obligations, the impaired, or so-called sick person, is expected to view being impaired (sick) as "an unfortunate state . . . to get out of as expeditiously as possible" (Parsons p. 437). In other words, the "sick role is intended to be a temporary one" (Crewe et al. 1983: 17) of dependency on the medical profession to ameliorate or cure.

The medical model, then, constitutes a plausibility structure, a set of policies and procedures, whose implicit premises, namely, those defining the privileges and obligations of the sick role, unobtrusively control, indeed, oppress, persons with impairments and render them disabled and dehumanized. Unfortunately, "the sick role cancels the [impaired] person's obligation to take charge of his or her own affairs." Indeed, it encourages them "to accept the dependency under the sick role as normative for the duration" of the impairment (Crewe et al 1983: 17).

However, as Kassenbaum & Baumann suggest (1965: 18), where the "illness" or impairment is "not temporary, . . . [sick] role-expectations are clearly inapplicable." An impairment, of course, may be anything but temporary, it may exist for a lifetime. Moreover, defining the problems facing persons with disabilities as a "medical problem presumes a corresponding solution . . . the domination of [their] lives by a vast army of allied [medical or health] professionals" (Barnes et al., 1999: 25). The impaired (sick) person is, then, passive, acted upon, by technically competent health professionals, rather than active on his/her own behalf. Consequently, there is a form of paternalism which, as Charlton (1998; 53) notes, works to view "people with disabilities . . . [as] unable to take responsibility for their

own lives." In short, the sick role works to deprive an impaired person of the autonomy, the control of one's own affairs, which is the defining mark of human personhood.

In its initial phase, then, the disability rights movement came to view the medical model as oppressive, a major source of the exclusion from the mainstream of society, the domain of healthy, unimpaired people; and, therefore as a major source of the oppressive marginalization of people with impairments. In its second phase, the movement sought to undercut the hegemony of the medical model and to replace it with a new model. It also called for legislation which would enable those with disabilities to claim their rights as citizens and to attain a productive role in the nation's economy and for the creation of independent living centers in which the new model would be employed and which would empower those with disabilities as citizens with a productive role in the nation's economy.

Phase II: Proposed Solutions

In all, the disability rights movement proposed solution to the problem of the oppressive marginalization of people with disabilities entails a three pronged approach: 1) the ideological, challenging the medical model and proposing to replace it with a new one, the social model, as the proper model for understanding disability; 2) the legislative, proposing new laws, e.g., the Americans with Disabilities Act (ADA), to guarantee the rights of those with impairments; and 3) the organizational, proposing the creation of Independent Living Centers in which those with impairments are be responsible for their own success (or failure).

The Social Model

The old, medical model, as noted above, is a plausibility structure, i.e., a set of policies and procedures, whose premises unobtrusively control the lives of people with impairments. Indeed, it is a structure which oppresses such persons by rendering them disabled and dehumanized. Specifically, according to the medical model, the problems facing persons with a disabilities are, simply, medical problems. Medical problems, of course, call for treatment by an array of medical professionals. Submission to professional treatment, as viewed by the medical model, renders the impaired (sick) person passive, unable to exhibit the defining mark of personhood, the control of one's own affairs. Consequently, the disability rights movement views the medical model as oppressive, a major source of the exclusion of people with impairments disabilities from the mainstream, the putative domain of "healthy," unimpaired people.

In the view of the disability rights movement, then, the medical model is part of the problem, not the solution. A solution would require that the model be replaced. Efforts to replace it were twofold. First, efforts were made to demonstrate that not only was the medical model oppressive, as noted above, but, when applied to a person with a disability, it was based on a false premise and, therefore, inappropriate. Second, a new, social, model was proposed to replace the old, medical, model. The new model was designed to be liberating, not oppressive, a basis for inclusion, not marginalization.

The medical model was shown to be inappropriate in that it posits that the condition, the impairment or "illness," in question is temporary. Thus, according to the medical model, a person with an impairment could plausibly or reasonably be asked to forgo control of one's own life, handing that control over to the medical professional who would treat the condition, the impairment. After all, the condition was only "temporary" and would be cured soon enough. Consequently, the pain of being deprived of autonomy, of control over one's life, the usual price for the "privilege" of receiving medical treatment for a sickness, would be temporary. Under the medical model, the pain of losing one's autonomy is analogous to pain following a serious operation, or to the side effect of an otherwise beneficial, short-lived, medical treatment: unwanted, unpleasant, but unavoidable, and, thus, an acceptable, consequence of a successful treatment. However, many, if not most, impairments are forever.

Blindness, multiple sclerosis, developmental disorders, for example, are rarely cured. Thus, if the medical model prevails, a person with an impairment might, justifiably, be asked to forgo his/her autonomy forever. Those in the disability rights movement did not wish to pay such a price, especially, when the treatment of an impairment as a temporary misfortune or ailment, rather than as what it so often, a long-term, even lifetime, condition is considered a "mis-treatment."

The demonstration that the medical model which, while suitable for a truly temporary, short-lived misfortune, is unsuitable when applied to those with a long-term impairment was a key facet of the disability rights movement's efforts to provide an ideological basis for its efforts to provide a solution to the problems facing those with disabilities. A second, key facet was to offer its own model of what disability is and of how to respond to it. Indeed, following Turner's (1969: 391) observation, the disability rights movement could only be a "a significant social movement" if it could offer "a revision in the manner in which . . . people look at some misfortune," here long-term impairment, "seeing it . . . an injustice which is intolerable in society."

The revision offered by the movement, the social model, holds that disability is not a tolerable, necessary result of an individual's impairment, but something created, in large part, by a society's response to the impairment. Indeed, it is a society's response to an impairment which disables a person, not the impairment itself. Moreover, such a societal response brings with it the injustice of unwarranted denial of the autonomy of people with an impairment. Moreover, if, as the disability rights movement contends, disability is a social oppression, "then disabled people will be seen as the collective victims of . . . society rather as individual victims of circumstance (Oliver 1990: 2). Moreover, if disability is a result of societally induced oppression, societal action, such as passing appropriate laws, would be called for to facilitate the elimination, or, at least, reduction, of that oppression. It was important, then, for the movement to offer a new definition, a new model of disability.

The new model, as indicated above, is based on two premises:
1) social conditions convert an impairment into a disability, not

the impaired person; and, 2) the focus of efforts on behalf of those with a so-called disability should be rooted in respect for their personhood, i.e., on their ability and right to make their own, autonomous, decisions as to how they are to live with their so-called disability, and not on the impairment per se. That is, it is not the "welfare of the handicapped" that is at issue, but "the human rights of people with disabilities" (Charlton 1998: 115).

In other words, the first premise of the social model is that disability is both a social construction and a social creation (see; Oliver 1990: 82-83). Disability is constructed, individually and collectively, as a consequence of views held by people without a disability and expressed both in hostile social attitudes and in the stigmatization of those with a so-called disability in interpersonal encounters or primary relationships. However, disability is also a social creation in that it is a consequence of the laws, policies and institutionalized practices of society evident in the restrictions faced by those with disabilities in the secondary relationships which characterize the polity and the economy. In short, the first premise is that disability is not the direct result of impairment, but of social restrictions. Such restrictions may, for example,

occur as a consequence of inaccessible built environments [no ramps or lifts to provide access for the handicapped], questionable notions of intelligence and social competence [the impaired are also stupid and incompetent, unable to care for themselves], the inability of the general population to use sign language, the lack of reading material in Braille or hostile public attitudes to people with non-visible disabilities [such as mental illness] (Oliver 1990: xiv).

In short, people with impairments "are disabled by a society that is geared to the needs of those who can walk, have perfect sight and hearing, can speak distinctly, and are intellectually dexterous" (Brisenden 1998: 23).

Whatever the specific restriction, the social model views disability as a form of oppression. Moreover, it views "disabled persons . . . as the collective victims of an uncaring or unknowing society rather than as individual victims of circumstances [such as impairment] (Oliver 1990: 2). Thus, while not denying "the significance of impairment in people's lives . . . [it] concentrates on those social barriers which are constructed 'on top of' impairment" (Barnes et al. 1999: 2). In short, the social model holds that "people with . . . impairments are disabled by society's blatant failure to accommodate to their needs" (Barnes et al. 1999: 2). Such failure, of course, marginalizes people, preventing their access to the activities of the mainstream of society. Where the social model's first premise is accepted, however, inclusion would replace marginalization.

The second premise of the social model is that people with impairments can and should take control of their own lives as much as possible. That is, above all, their personhood, their ability to be autonomous, to make their own choices, free of unwarranted constraint, and to carry them out, must be respected. This premise is augmented by the view that everybody, with or

without impairments have a range of things they can and cannot do, "a range of abilities both mental and physical that are unique to the individual" (Brisenden 1998: 23). Moreover, the social model renders it plausible to reject policy and practice based on the view that the impairment itself should primarily inform one's conception of a person with an impairment. That is, it renders it implausible for the personhood, the "humanity [to be] stripped away and the person . . . obliterated, only to be left with the condition" (Charlton 1989:54). People are not, as Charlton (p. 54) notes, to be "described by a noun 'the blind,' 'the deaf,' 'the disabled,'" their person equated totally with their "condition." To the contrary, the social model calls for the autonomy of all to be respected, regardless of the degree or form of impairment.

Among the reasons for such a call is that impairments may be such as to require medical treatment for extended periods, even for life. Were the medical model to be applied, as noted above, that impaired person would become a patient for life, expected to passively accept the treatment offered, no questions asked, their autonomy held in abeyance. However, the social model with its focus on autonomy calls for a "shift from cure to care" (Zola 1983: 54) and a recognition that treatment should "no longer . . . involve the doctor doing and the patient receiving."

Of course, the premise does not call for one "to oppose good physical functioning . . . [but, simply to] stress choice, risk and self-determination" (Varela 1983: 44). However, it does hold that "for treatment to succeed at all, . . . the patient ha[s] to be an active participant" (Zola 1983: 54). Moreover, the second premise, the premise of autonomy, calls for the recognition that persons with an impairment should be allowed, indeed, encouraged to make "decisions for themselves based on many other factors as well as medical ones" (Brisenden 1998: 25) and calls also for all to value the autonomy or independence of a person with an impairment and "ask how this can be assisted and promoted without taking the right of control away from the individual" (Brisenden's 1998: 25).

Where the social model proffered by the disability rights movement is adopted, people with disabilities would be empowered, not oppressed, and included, not marginalized. Of course, the movement recognized that an improved ideology would not suffice to advance its cause. Legislation to guarantee the rights of those with impairments would also be needed, as would the creation of so-called Independent Living Centers in which those with impairments would be responsible for their own success (or failure).

Legislation to Empower and Include

The history of the efforts of the disability rights movement on behalf of legislation which would facilitate the attainment of its twin goals of the inclusion and empowerment of persons with disabilities can be said to begin in the 1950s. Specifically, it can be traced (Varela 1983: 35) to the "paralyzed veterans . . . fighting for more parking spaces, and for more accessible commodes . . ." and to the fight by people with disabilities "for local and state accessibility laws throughout the 1950s."

The first significant federal legislation advancing the goals of the movement came in 1965 with the creation of the

National Commission on Architectural Barriers to the Rehabilitation of the Handicapped. The Commission was to "study the problems involved in making all federal buildings accessible to disabled citizens" (Varela 1983: 36).

However, the import of the work of the Commission on such problems is not limited to problems of access. As Varela (1983: 36) observes, "the work of the Commission, and, more importantly, of disabled activists . . . [changed] attitudes toward disability" The change was from "an emphasis on services (that is, on doing something about 'those people')" to "an emphasis on civil rights (that is, the notion that once certain obstacles were removed, disabled people would be able to do a lot more for themselves than society had imagined)" (Varela 1983: 36). In short, efforts to include those with disabilities became efforts to empower them as well. Moreover, the notion that environmental obstacles and not just the impairment of individuals were worthy of attention rendered it plausible to seek the enactment of laws and regulations that would do so. In other words, "environmental variables, unlike individual characteristics can be rectified through legislative and administrative action" (DeJong 1983: 25).

In 1968, the Architectural Barriers Act was passed. It stipulated that any facility built with or merely receiving federal funds had to be accessible to all. However, enforcement was minimal (Varela 1983: 36). Fortunately, the Rehabilitation Act of 1973, in a provision welcomed by the disability right movement, established the Architectural and Transportation Barriers Compliance Board (A&TBCB) to investigate and enforce compliance with established standards. Unfortunately, it "never received the funding it needed to enforce the law or even to investigate all . . . violations . . . reported by disabled consumers" (Varela 1983: 37). Nevertheless, the fight for accessibility did advance the cause of the disability rights movement. It helped make it clear that barriers included "social, political and intellectual obstacles, as well as physical ones" (Varela 1983: 37).

Moreover, the 1973 Rehabilitation Act contained provisions in addition to the establishment of the A&TBCB which were important to the movement (Varela 1983: 40-41). It required the establishment, by state rehabilitation agencies, of selection methods that would ensure that people with severe impairments were not excluded from the agency's programs. In effect, then, the Act made it clear that no impairment, no matter how severe, was to be allowed as a consequences of a state agency's denial of services to become a disability. In addition, the 1973 act included provisions for client rights and for civil rights. Specifically, Section 504 prohibited discrimination against persons with so-called disabilities by any federally supported program. Thus, Section 504 was important to persons with so-called disabilities "who were looking for jobs . . . who wanted to use the same clinic as everyone else, who wanted the same choice of apartments, and who wanted to get into the polling places on election day" (Varela 1983: 42), who wanted simply to be an autonomous, contributing member of society.

The next step in the history of legislation to empower and include people with impairments was the passage of Individuals with Disabilities Education Act (IDEA, originally called the Education for All Handicapped Children Act of 1975, P. L.

94-142). IDEA set "forth a comprehensive scheme" to ensure "two basic substantive rights of eligible children with disabilities" These were: "(1) the right to a free appropriate public education, and (2) the right to that education in the least restrictive environment" (National Council on Disability 2000: 28). The law applied in every state that receives federal funds under IDEA and to all public agencies authorized to provide special education and related services in a state that receives such funds. The Act was amended and reauthorized in 1997 (NCD 2000 30-31).

In 1978, the Rehabilitation, Comprehensive Services and Developmental Disabilities Amendments (P. L. 95-602) of the 1973 Rehabilitation Act were passed. The amendments evinced Congress' endorsement of the autonomy premise of the social model described above. That is, the Amendments acknowledged that persons with disabilities should be involved in forming the policies and practices which affect their lives. Specifically, it mandated that a grant for an independent living center "provide assurances that handicapped individuals be substantially involved in [the] policy direction and management of such center, and will be employed by such center" (P. L. 95-602 as quoted by Varela 1983: 46).

Many, if not most, however, view the enactment of the Americans with Disability Act (ADA) in 1990 as the crowning achievement of the disability rights movement. That act (P. L. 101-336) extended provisions of the Rehabilitation Act of 1973 and the 1978 amendments well beyond the earlier application to federally supported programs and the state rehabilitation agencies and of the IDEA to special education. Indeed, it "codified into law important principles that would henceforth govern the relationship between [American] society and its citizens with disabilities . . . [and] altered public discourse about disability and about the role of people with disabilities in American society" (National Council on Disability 1997b: 4-5).

It did so, first, by, in effect, making the marginalization, the exclusion of people with impairments from the mainstream of society in the United States, illegitimate. Specifically, it declared that "people with disabilities are an integral part of society and, as such, should not be segregated, isolated, or subjected to the effects of discrimination" (National Council on Disability 1997b: 4). Furthermore, it sought to enable "people with disabilities to take charge of their lives . . . by fostering employment opportunities, facilitating access to public transportation and public accommodation, and ensuring the use of our nation's communication system" (National Council on Disability 1997b: 4). Moreover, the principles of the ADA can serve as a basis to test and challenge public policies and practices not consistent with those principles and even to demand they be changed. The ADA, then, "upholds the principle that each individual has the potential, and deserves, the right to participate in, and contribute to, society" (National Council on Disability 1997b: 5).

In the words of President Bush, at the signing ceremony, "The Act . . . will ensure that people with disabilities are given the basic guarantees [of] . . . [i]ndependence, control of their lives, [and] the opportunity to blend fully and equally into the . . . mosaic of the American mainstream" (National

Council on Disability 1997b: 58). In short, ADA enacts the slogan of the disability rights movement, "nothing about us, without us," into law and renders the oppressive marginalization of people with impairments illegal and, perhaps, even un-American or, at least, unacceptable to the mainstream of American society..

Independent Living Centers

With the articulation of the social model and the passage of the Rehabilitation Act of 1973 as amended in 1978, IDEA (1975) and ADA (1990), the ideological and legislative components of the disability rights movement's threefold program to solve problems facing people with disabilities were in place. The third component, the organizational, remained. It calls for the creation of independent living centers in which those with so-called disabilities would both be empowered to make their own efforts to enter society's mainstream and to be responsible for the success (or failure) of their efforts.

The first independent living center was incorporated in Berkeley in 1972. It was run by people with impairments who approached "their problems as social issues" and made "integration into the community its chief goal" (Shapiro 1993 [1981]: 53-54). A similar center began operations in Boston in 1974 (DeJong 1983: 8). The 1978 amendments to the Rehabilitation Act provided statutory authorization for independent living services (DeJong 1983: 10) and, as noted above, also provided support for independent living centers. There are now many such centers of varying types (Frieden 1983: 65ff.) throughout the United States and elsewhere (Tate & Lee 1983).

Despite variations in their particular programs, independent living centers, define "independence as the freedom to choose" (Kasnitz & Shuttleworth 1999: 14) and accept as a goal the provision of services needed, in a given local community, by people with so-called disabilities which "increase their own self-determination and to minimize dependence on others" (Frieden 1983: 62). The services offered to attain that goal may include "housing assistance, attendant care, readers and/or interpreters, peer counseling, financial and legal advocacy, and community awareness and barrier-removal programs" (Frieden 1983: 64). Such services are, of course, consistent with the ideology of the disability rights movement, the social model of disability, in that they focus on the environmental factors important in the determination of whether or not an impairment becomes a disability. Such services are also consistent with the social model by striving to avoid what DeJong (1983: 22) calls "the dependency-inducing features of the relationship between professional and client." Thus, centers seek to minimize dependence on the intervention of health professionals, be they physicians or physical therapists, and to maximize use of advocacy, peer counseling and self-help to remove physical, social and other environmental barriers.

Furthermore, while recognizing "the importance of self-care, mobility and employment, independent living has emphasized a larger constellation of outcomes" (DeJong 1983: 24). Thus, for example, centers regard gainful employment as but "one of several ways a person can become independent" and recognize that a person may also be productive through "contributions to family and

community life" (Tate & Lee 1983: 111). Furthermore, while health professionals "tend to define independence in terms of self-care activities such as washing, dressing, toileting, cooking and eating without assistance" (Oliver 1990: 91), independent living centers do not. They "define independence differently, seeing it as the ability to be in control of and make decisions about one's life, rather than doing things alone or without help" (Oliver 1990: 91). Thus, in some instances, the significance of self-care is questioned in an individual living center. For example, it may be noted that a "person who can get dressed in fifteen minutes with human assistance and then be off for a day of work is more independent than the person who takes two hours to dress and then remains homebound" (DeJong 1983: 24).

More generally, the concept of independence is redefined "such that services that make our environment accessible (e.g., personal care assistance, sign language interpretation) are regarded as promoting independence rather than reflecting dependence" (Robertson 1998: 34). Similarly, "adaptive equipment [which] enable a broader sphere of activity" are viewed as liberating (Robertson 1998: 34). Thus, "one is not 'confined to a wheelchair,' but 'uses a wheelchair'" (Robertson 1998: 34). The disability rights movement, then, tends not to define "independence," as is commonly done, in terms of a totally self-reliant, self-sufficient individual who needs nobody and could live alone in the wilderness. (See: Bellah, Madsen, Sullivan, Swidler & Tipton 1985; Slater 1971). To the contrary, the movement recognizes the inevitability of interdependence in a modern society (see also: Reindal 1999, Ells 2001, and Smith 2001). Indeed, as Crewe & Harkins (1983: 328) observe, "None of us living today in Western society is entirely independent." Few bake their own bread, make their own clothes or build our own homes. In short, "everyone has a place somewhere on the continuum between complete dependence and complete independence" (Crewe & Harkins 1983: 328). Consequently, the movement does not regard increasing independence as an increase in how many tasks one can do by one's self, but rather as an increase in one's autonomy, i.e., an increase in one's ability to make one's own decisions and carry them out.

In sum, then, individual living centers hold, with Zola (1982: 396), that "(I)ndependent living must include not only the quality of physical tasks we can do, but the quality of life we can lead." Thus, the goal of an independent living center is to improve the quality of the life of persons with impairments by assisting them in overcoming barriers which undermine one's autonomy by frustrating one's ability to carry out one's decisions. When that goal is attained, the disability rights movement can claim success.

It can claim that the three aspects, the ideological, the legislative and the organizational, of its program to eliminate, or at least alleviate, the problems which people with disabilities face has succeeded. That is, with both the establishment of organizations, namely, independent living centers, whose operations are consistent with the ideology, the social model, preferred by the disability rights movement and the passage of supportive legislation which the movement fought to have enacted, the disability rights movement can be said to be have been successful.

The aftermath of its success ideologically, legislatively and organizationally, has not, however, meant the movement is now trouble-free. To the contrary, despite, or more accurately because of, its success the disability rights movement now finds new problems, often the unintended consequence of their own efforts, must be addressed.

Phase III: Aftermath

Even in the aftermath of its success, the disability rights movement still encounters problems. Some are the unanticipated or unintended consequences of one or another of its successes. For example, the new ideology, the social model, renders it difficult for those in the movement to join others to seek what many regard as needed reforms. Furthermore, new legislation makes many positive results possible, but the quality of enforcement may, nevertheless, be wanting. Finally, a consciousness raised by the suggestion of new organizational forms, such as independent living centers, may lead to a level of self-confidence which, in turn, leads to forgoing some previous forms of aid and some previous alliances or potentially valuable new ones. In short, despite its success, and, in some instances, because of it, the aftermath of success in the realms of ideology, legislation and organization, still finds problems in need of attention if future success is to be attained.

Aftermath of Adopting the Social Model

One of the central tenets of the social model of disability may be stated rather forthrightly: "Disability is not measles. It is not a medical condition that needs to be eliminated from the population" (Rioux 1994: 7). In other words, the social model rejects the notion that disability is a disease, or even that it is primarily a medical condition.

One consequence, perhaps unexpected or unintended, of such rejection is that the disability rights movement finds itself uninvolved in many discussions of reform in the health care system which could benefit people with disabilities. Managed care is one such reform. Rejection of the medical model has also led the movement to oppose legislation, e.g., unlimited abortion rights and the legalization of assisted suicides or euthanasia., supported by many who were allies when the movement looked to for support of its own causes and concerns (Watson 1993).

Since the movement still has unfinished business which may require Congressional action, not supporting those who once supported it may not be wise. It can so weaken the coalition supporting legislation the disability rights movement wants that such legislation will not pass. Legislation is, after all, generally the result of the action of strong coalitions. For example, the Ticket to Work and Work Incentives Improvement Act of 1999 (P.L. 106-170) which hopes to provide opportunities for persons with disabilities to be productive citizens, was enacted following "the inexhaustible effort of the disability community's grassroots organizations . . . to bring this bipartisan measure to fruition" (National Council on Disabilities 1999b: 1). Bipartisan measures require coalition building. Anything which weakens a needed coalition, weakens the movement's ability to bring about the enactment of needed laws.

Specifically, as Watson (1993: 4) suggests, the lack of involvement in discussions of such health care reforms as managed care is, in part, because the disability rights movement, which "worked so hard for so long to separate the issues of health and disability," has had "to be extremely careful about how it brought them back together." Consequently, the disability rights movement has "not offered any substantial measures for containing costs . . ." or any alternative to managed care (Watson 1993: 7). Indeed, it has not been deeply involved in the discussion of what the best health care or managed care system might be. There is concern that such involvement might lead to the appearance of supporting a medical, rather than social, model of disability. Thus, "(w)hen health policy is the topic of discussion, the disability [rights] movement is generally not at the table" (Watson 1993: 3).

The disability rights movement has, however, been involved in attempts to limit the right to have an abortion and to limit legalized assisted suicides or euthanasia. Advocates of disability rights may base their opposition to unlimited abortion rights, on the fear that the absence of limits renders abortion on the grounds of anticipated impairment permissible (Barnes et al. 1999: 222). In an era of amniocentesis and ultrasound scanners accurate predictions can indeed be made as to whether a neonate will have an impairment such as spina bifida. The justification of the abortion of a fetus with an impairment is generally that a child with a disability "places an excessive burden on the woman/family/society . . ." (Barnes et al. 1999: 222). Such a justification, however, may well frighten people who have grown up with the impairment in question (Watson 1993: 6), especially since many of them live rewarding and reasonably independent lives (Alderson 2001.). At least some may fear that "it is a small step from denying life to a fetus who might be born with an impairment to denying rights to one who already has a similar impairment" (Barnes et al. 1999: 222). Such fear has been furthered by the suggestion by the noted philosopher Peter Singer (2001) that it may not always be wrong to intentionally take the life of an innocent human being such as a severely disabled newborn (see also: Vehmas 1999, Callahan 2001, Conrad 2001, Marzano-Parisoli 2001).

Similar grounds are given for opposing assisted suicide or euthanasia. That is, people with disability may, for example, fear that it is also a small step from shutting off the respirator for a comatose person to assisting, or encouraging, the suicide of one with a severe impairment (Watson 1993: 6). The National Council on Disability (NCD), an independent federal agency, while acknowledging (NCD 1997a: 3), "the benefits of permitting physician-assisted suicide are substantial and should not be discounted," stated that, "the dangers of permitting physician-assisted suicide are immense."

The Council (1997a: 3) also noted that "as society has frequently made it clear that it believes [people with disabilities] would be better off dead, or better that they had not been born," people with disabilities have grounds to fear they would be "among the most likely candidates for ending their lives" via an assisted suicide or euthanasia. Furthermore, NCD doubted that the programs and resources needed to ensure that anyone contemplating an assisted suicide was aware of other

options could be made available. The promise to provide such needed programs, resources and options "strikes many people with disabilities as . . . very shallow" (NCD 1997a: 4). They know, the Council added, "that all too often the programs are few, the resources are too limited, and the options nonexistent" (NCD 1997a: 4).

Aftermath of Legislative Successes

The laws which the disability rights movement worked to pass mark a great step forward in the struggle to end the oppression and marginalization of those with disabilities. However, as Keiser (1999) found in an examination of the disability program within Social Security, laws require interpretation. Moreover, laws are not self-enforcing. Compliance is not apt to be universal. For example, a report conducted on behalf of the National Council on Disability found (NCD 2000: 11) "every state was out of compliance with IDEA [Individuals with Disabilities Education Act] to some degree." Moreover, the report finds that states have failed to meet their obligation to ensure compliance with core provisions of the act at the local level and that "far too often" children with disabilities and/or their families find they have to file complaints on their own to ensure that the law is followed (NCD 2000: 11).

Similar problems, no doubt, exist with respect to Section 504 of the 1973 Rehabilitation Act and the Americans with Disabilities Act (ADA). However, the federal government made greater progress in the years 1990-1994 immediately following the passage of ADA than after that of Section 504 (West 1996: 4). Nevertheless, the federal government lacks an overall strategy to coordinate the efforts of the "[o]ver nine federal agencies . . . significantly involved in implementation" of ADA, e.g., for providing technical support, investigating complaints and litigating when necessary (West 1996: 4). In a similar vein, the NCD (2002a) notes, "the federal agencies charged with enforcement . . . under ADA, to varying degrees, have been overly cautious, reactive," and, as did West, "lacking any coherent and unifying national strategy." Moreover, such enforcement efforts as there have been "are largely shaped by a case-by-case approach based on individual complaints rather than an approach based on compliance monitoring and a cohesive, proactive enforcement strategy" (National Council on Disabilities 2002a). So, even in the aftermath of the enactment of welcome legislation such ADA, problems remain.

Problems encountered by those seeking the enforcement of ADA may, however, go deeper than a lack of coordination among federal agencies. Indeed, "frontier or emergent issues" are encountered and found "to be controversial, complex, unexpected, and challenging" (NCD 2002a). Such problems may stem from possible conflicts among the fundamental values implicit in the act (Koppelman 1996; see also Pfeiffer 1994, Clegg 1999). Such values include equality of opportunity, beneficence and efficiency (Koppelman 1996: 196). Disputes in which these values may come into conflict include: the allocation of health care, the meaning of "qualified but disabled" when applied to persons with mental disabilities, modifications in testing and licensure procedures for persons with impairments, and the possibility of a backlash with respect to accommodations made similar to that

which plagues affirmative action on behalf of people of color (Koppelman 1996: 196-205). Until there is a "better idea of how to understand or rank these values when they conflict," Koppelman (1996: 196) notes, "the meaning and implications of the ADA's promise of protection and opportunity for" persons with disabilities cannot be known.

In addition, key concepts in the ADA and similar acts are difficult to define. These include "nondiscrimination," "reasonable accommodation," and "readily achievable" adjustments to the needs of an individual with a disability. Indeed, even the term "disability" can be hard to define in a particular case. The National Council on Disabilities, not surprisingly (NCD 1997b: Appendix F), has its own working definitions of these and other important terms. Nevertheless, final, binding definitions will require innumerable discussions on the local level between an employer and employee or between a parent and a school board and, of course, Supreme Court rulings.

The last, of course, need not please the disability rights movement. For example, in a series of early cases (*Sutton v. United States Air Lines, Inc.* (No. 97-1943), *Albertsons Inc. v. Kirkingburg* (No. 98-591) and *Murphy v. United Parcel Service Inc.* (No. 97-1992)), the Court "ruled that ADA does not protect people who have conditions or disabilities that are being corrected with medication or assistive devices such as eyeglasses" (National Council on Disabilities 1999a: 2). It is possible, therefore, that contrary to what those in the disability rights movement might wish, "people with treatable conditions such as epilepsy, diabetes, and bipolar disorder [are] outside the law's protection, as well." (NCD 1999a: 2)

Later Supreme Court rulings have also not all been pleasing to the movement. In one such case, (*Board of Trustees of the University of Alabama v. Garrett*, 531 U.S. 356 (2001)), the Court, in the view of a report to the National Council, (NCD 2002b), "devastatingly stripped the right of state workers to sue their employers for money damages for violations of Title I of ADA, which prohibits employment discrimination against people with disabilities." In another ruling, (*Toyota Motor Manufacturing, Kentucky, Inc. v. Williams*, 122 S.Ct. 681 (2002)), the Court, in what the NCD (2000b) views as "inordinately restrictive view of what is required to demonstrate disability under ADA," held "that Congress intended to create a demanding standard for meeting the definition 'disabled' and suggests that people must be visibly and functionally unable to perform in certain specific, socially expected ways before they are entitled to the protection of the ADA." (NCD 2002c).

Another, more recent decision, *Chevron U.S.A. v. Mario Echazabel* (No. 00-1406) the Court held that an employer may decide whether the risk of a given job is too great for a person with a disability even if the person is willing to take the risk, can perform all job functions and poses no threat to anybody else. The decision was declared "appalling" by the NCD. The basis for doing so, is mindful of key elements of the social model. Specifically, a NCD spokesperson, declared that the unanimous decision "not only curtails the civil rights of people with disabilities to equal employment opportunity, but egregiously infringes upon on their human right to assume the risk and responsibility for their own decisions" (NCD 2002e).

However, a more favorable decision was reached in Equal Employment Opportunity Commission (EEOC) v. Waffle House, Inc. (122 S. Ct. 54 2002). That decision holds that an arbitration "agreement between an employer and an employee to arbitrate employment-related disputes . . . does not bar EEOC from pursuing victim-specific judicial relief [under ADA] on behalf of an employee" (NCD 2002d).

In sum, while it is clear that the enactment of the 1973 Rehabilitation Act, the IDEA and the ADA, are momentous accomplishments, to which the disabilities right movement may point with pride, the aftermath of their enactment has not always been followed by meaningful compliance. In addition, unresolved questions as to just what the values undergirding these laws and key terms mean in a particular case remain. Many of these matters will be raised and resolved over and over again in negotiations with countless school officials, government officials and business people at all levels. Some resolutions may require Supreme Court rulings. Many, or even most, such resolutions and rulings, in all likelihood, will enable those with disabilities to retain the "raised consciousness" and pride instilled by the success achieved at independent living centers.

Aftermath of Successful Independent Living Centers

A successful independent living center is one in which people with disabilities take control of their own lives, make their own decisions and, perhaps with assistance, carry them out. In short, a successful center is a center replete with autonomous individuals who, while impaired, resist being disabled, that is, resist being oppressed and marginalized. As such success becomes more and more common and more and more visible, it serves to raise the consciousness of people with disabilities both within and outside the centers. As Charlton (1998: 118) notes, a "raised consciousness involves a change in consciousness whereby the (false) notion of disability as a pitiful, medical condition has been replaced by the (true) awareness of disability as a social condition (parentheses original)." Two likely consequences of such a raised consciousness are: 1) an empowered consciousness, and 2) the replacement of feelings among people with an impairment of shame with feelings of pride in who and what they are.

First, as success breeds success, as awareness of the social sources of disability, and as more and more people with impairments act autonomously, their raised consciousness may be transformed into empowered consciousness. Empowered consciousness "means acting together to empower others" and an insistence on "active, collective contestation for control over the necessities of life: housing, school, personal and family relationships, respect, independence, and so on" (Charlton 1998: 119). That is, more and more people become activists in their own lives and on the behalf of others.

Of course, not every one will do so. Indeed, the very success of the disability rights movement means not quite as many may be needed to maintain momentum as was needed to get started. Moreover, insofar as understanding of the disability rights movement is, as Robertson (1998: 32) suggests, "informed not only by the experience of disabled people (sic), but by the civil rights movement, movements of African-Americans and other

minority groups, the women's rights movement and by the current movement for gay and lesbian rights," it is to be expected that a period of success will be followed by one of quiescence on disability rights issues may follow.

In addition to engendering an empowered consciousness, a raised consciousness can also engender pride, rather than shame, on the part of those with impairments, as to who and what they are. That is, they may take pride in those aspects of their respective selves which mark them as "different from the rest of society" but, yet, contribute to making them who they are. One result may be the development of a positive self-identity embracing all aspects of one's self, impaired and unimpaired alike. In other words, rather than viewing an impairment as a deficit, "people with impairments would view their respective impairments as part of [a] whole, complete self " (Robertson 1998: 32) in which they take great pride.

Such pride may, as with any pride, merely precede a fall, or, at least, what people would take to be a fall. For example, some people who are deaf refuse cochlear implants. Such implants involve placing a computerized device into the ear. The device carries signals to the brain which interprets them as sounds, thereby, enabling one who is deaf to hear. Many reject the operation because it suggests that "deafness is a pathology, something to be corrected or eliminated" (Shapiro 1993 [1981]: 224; see also Lane 1992: 203-238).

For those who accept deafness as "part of a whole, complete self," such an operation is not necessary. Many in the hearing community may regard accepting deafness, when it is not necessary to do so, is rather odd, even incomprehensible. However, as the acceptance of the autonomy of those with so-called disabilities is accepted, the acceptance of their right to choose their own identity may well grow as well. Perhaps, at some point the recommendation of the National Association of the Deaf, an advocacy group, that there be a ban on cochlear implants in children "so they could grow up and then decide to choose a deaf identity or a hearing one" (Shapiro 1993 [1981]: 224) will seem neither odd nor incomprehensible (see also: Hollins 2000).

Of course, viewing one's disability as part of a complete self and the high self-esteem that such a view brings may have results in addition to resisting attempts to eliminate the disability. It can lead to people with so-called disabilities increasingly viewing themselves "as members of a distinct minority, possessing a unique and valuable culture" replete with its own symbols, rituals and values (Robertson 1998: 32). Indeed, within such a culture, consciousness may be raised to the point where all, as Hahn (1988:27) suggests, remember that "history discloses abundant proof that images of beauty have changed continually, and that physical differences or disabilities sometimes have been considered attractive and appealing." In short, "disability can be beautiful." Moreover, such a culture could support the social (inclusion) and political (empowerment) agenda of the disability rights movement. It could also support the argument "that, as with women and blacks," those with disabilities "have reached that point in history where having been there is essential to determining where to go" (Zola 1983: 57). If so, the goal expressed in the slogan of the disability rights movement, "nothing about us, without us," has been

realized to a significant extent.

Summary

The disability rights movement has, then, moved through the three phases typical of social movements. First, it has defined a problem, the oppressive marginalization of people with disabilities, and identified its sources in the dominant ideas and practices, the hegemonic plausibility structure, which constitute the medical model of disability.

In its second phase, the movement moved successfully on three fronts, the ideological, the legislative and the organizational, to solve the problems of those with disabilities. Specifically, it proffered a social model of disability which has, to an important degree, replaced the medical model. It supported legislation, such as the Americans with Disabilities Act (ADA), which has been enacted into law to advance the inclusion of those with disabilities into the mainstream of American society and empowered them to act effectively and productively within it. The movement helped create a new form of organization, the independent living center, to assist those with disabilities when they need assistance.

In its third phase, the aftermath of its success, the disability rights movement has found their support of a social model of disability can lead them to stand on the sidelines on some important issues, such as health care reform, and to oppose positions taken by groups whose support they need to build an effective, pro-disability rights coalition. Moreover, in the aftermath of success on the legislative front, the movement has found that, as with all laws, the laws it helped enact are not always well or forcefully applied and that the meaning of its key terms may not be settled. Indeed, it is likely their application will need to be negotiated, by countless individuals with disabilities and their advocates, over and over again with countless school officials, local, state and federal government officials and business people at all levels.

Nevertheless, the success of independent living centers should provide the needed advocates and help instill a pride and confidence in those with disabilities, both individually and collectively, sufficient to insure that they are so included and so empowered within mainstream of American society that nothing about them will ever again be done without them.

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