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Struggle for Freedom

Disability Rights Movements

Willie V. Bryan

LACK OF CONCERN

Since World War II, there has been an increasing emphasis on human and civil rights in the United States. Minorities and women have spoken out on their own behalf attempting to gain the privileges, freedoms, and rights guaranteed for all Americans by the Constitution.

While legal and social ground has been won and lost throughout the years, many minorities and women now enjoy a somewhat more equal existence in the United States than some fifty years ago. Still, the battle for equality is far from victorious. While other groups continue their struggle, individuals with disabilities have joined forces to end discrimination in their lives and claim a life of equality in the United States.

The Civil Rights Movement of the sixties resulted in legislation designed to bar discrimination based on sex, race, and national origin; however, prohibition of discrimination based on physical and/or mental disabilities was not included. As Thomas D. Schneid reminds us, a bill introduced in Congress in 1971 to amend Title VI of the Civil Rights Act of 1964 to prohibit discrimination based on physical or mental disability died in committee. Similarly, in 1972, another bill introduced in Congress, this time to amend Title VII of the Civil Rights Act to bar discrimination in employment based upon physical or mental disabilities, also died in committee. This may be seen as somewhat of a barometer of the level of concern lawmakers and many other nondisabled Americans had with regard to the civil rights of persons with disabilities.

Perhaps the lack of concern demonstrated by these actions of Congress is more of a reflection of ignorance of the needs and capabilities of persons with disabilities rather than a blatant desire to deny the civil rights of a group of people. At the time, the thought was that employers should not be forced to hire persons who could not adequately perform the required tasks. Persons with disabilities and their friends certainly were not advocating employment of nonqualified persons; they were simply asking that employers be required to look beyond a person's limitation to see abilities and attempt to match them with the required job. Employers also had a number of misconceptions with regard to employing persons with disabilities, such as they would not be able to secure insurance for the person and the company's insurance premiums would increase. Another major misconception was the belief that persons with disabilities were unsafe employees. This erroneous belief was held despite safety records indicating that persons with disabilities had fewer accidents than nondisabled employees. Many employers were aware that by making modifications to the work site and/or its environment, a significant number of jobs could be made accessible to persons with disabilities; however, these same employers harbored the belief that making these accommodations would be too expensive. Again, this belief was held even though the DuPont Company had demonstrated that many changes to a work site could be done inexpensively.

These and other misconceptions were firmly held by employers because persons with disabilities and their advocates did not vigorously dispute them. The lack of opposition to discrimination against persons with disabilities with respect to employment allowed long-held stereotypes and prejudices to continue unchallenged. Activism would be necessary to dramatize the extent of the lack of concern for the rights of persons with disabilities and cause action to be taken to correct the neglect that had become an accepted method of treatment of persons with disabilities.

MINORITY STATUS

The political wheels of American progress appear to turn best when pressure is applied. For example, protests by minorities, particularly African Americans, led to the Civil Rights Act of 1964. Similarly, women's organizations engaged in various activities that placed pressure on state and federal government leaders to enact legislation that required equality of rights for women. One may assume that in a free and open democracy which most of us enjoy in America, there would be available on an equal basis to all citizens, the right to vote, to live wherever one can afford, the right to eat wherever one desires, and the right to be educated at the maximum level of one's abilities. However, it was precisely the denial of

these basic rights, rights upon which this country was founded, rights for which thousands of Americans have paid the supreme price, that led multitudes of Americans into the streets to practice civil disobedience, until these and other basic rights were granted.

In the process of securing these rights, the minority groups learned that their minority status was not shameful. In fact, they learned that they were a very important cog in the wheel of American life and by withholding their labor and being selective as to how and where they spent their hard earned money, they could considerably slow down the democratic wheel of progress. These groups also learned that by networking they added strength to their demands.

Until recently, persons with disabilities were not widely considered a minority group. In fact, it was not until the Rehabilitation Act of 1973 that they were considered a "class" of people. Persons with disabilities are members of other groups of people, they are male or female, and they have an ethnic identity; their rights and privileges are associated with whatever cultural and/or gender group they belong. It is ironic that with regard to human rights their disabilities were secondary to their cultural and/or gender identity, but with regard to their rights as citizens, their disabilities were primary, overshadowing gender and/or cultural identity. Since disability groups were not considered a culture at the time, the person with a disability was viewed as a "disabled member of another class." To be more specific, they were considered to be a disabled female or a disabled American Indian female. Hopefully, the point has been made. It is in part because of this dual and sometimes triple classification that the disability label was not considered a class unto itself.

Another reason for the lack of class status is that there are large numbers of disabilities and each one is considered a separate condition within its own group identity. For example, there are persons who have disabilities resulting from polio, arthritis, visual impairments, hearing impairments, lupus, mental illness, mental retardation, amputations, and paralysis, to mention only a few. In most cases, there was and continues to be associations or foundations which are considered the official representative for all who have a particular condition. This has the effect of segregating disabilities into distinct disease groups, thus causing each disabling condition to stand alone and not be part of a larger whole. This internal segregation combined with society's segregation of persons with disabilities has been devastating to efforts of persons with disabilities to unite and demand their constitutional rights.

Although it would not be until the passage of the Rehabilitation Act of 1973 that persons with disabilities would obtain the classification of minority status and be officially viewed as a class of people, several years before the passage of the act they began to think of themselves as a minority. And more importantly, they began to view their life conditions as having been deprived of their basic human rights similar to other minority groups. They also began to think of themselves as being oppressed and disenfranchised. With this realization, they began to unite and to speak openly about the manner in which they were being excluded from full participation in society's activities. Thinking of themselves as oppressed minorities, they also thought of the manner in which other minority groups had placed their agenda before the American people; thus a "grassroots disability rights movement" began which has resulted in the passage of the ADA in 1990.

GRASSROOTS MOVEMENT

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Despite the concern exhibited by charitable organizations and Congress, the one aspect often missing was the involvement of persons with disabilities. For example, much of the legislation prior to the Rehabilitation Act of 1973 had been developed with little, if any,

input from persons with disabilities. Charitable organizations established telethons to raise funds for research and/or provide services without giving much thought to the negative images being projected. This was "business as usual" or stated another way, it was the continuation of the paternalistic attitude that has existed in America for many decades. Perhaps without meaning harm to persons with disabilities, nondisabled persons have treated them as though they are incapable of determining and expressing how they would like to live their lives. Regardless of how well-intended the motivation of a nonoppressed person there are some things he/she will either overlook or not understand with regard to the effects of being oppressed. Therefore it is imperative that those effected must be involved in determining the best methods for eliminating the problems created by oppression.

There are undoubtedly many reasons why it took persons with disabilities approximately two centuries before they organized and began to speak out on their own behalf. With "sit-ins," marches, and attempts to integrate previously segregated southern schools, the fifties served as the "staging" years of the Civil Rights movement; then in the sixties the final "assault" years were launched which culminated in victory with the passage of the Civil Rights Act of 1964. Similarly for the Disability Rights Movement, the sixties served as the "staging" years with emphasis on consumerism, self-help, and demedication demands as well as demands for self-care rights and deinstitutionalism. Perhaps then the seventies can be considered the "watershed" years of the movement. The sixties was the decade when persons with disabilities began to view themselves as oppressed minorities and demanded their constitutional rights. Similar to the Civil Rights Movement which culminated in the Civil Rights Act of 1964, the Disability Rights Movement led to what has been called the Civil Rights Act for persons with disabilities: The American's With Disabilities Act of 1990.

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Activism: . . . In the early seventies, rehabilitation leaders backed by disability rights groups began to push for changes in the legislation to advocate a broader nonvocational role for rehabilitation programs. In 1972, such legislation was passed by Congress and Verville informs us that President Nixon vetoed the legislation because it "strayed too far from the essential vocational objective of the program."

This Act had provisions for Independent Living Centers. It would take six more years before this important concept would become a reality. The veto of the 1972 Rehabilitation Act is a classic example of not involving those most effected. Perhaps the veto served a useful purpose in that it became an issue around which the grassroots movement could unite. While attempting to get the Independent Living Centers provisions included in future legislation, the disability rights organizations gained considerable experience in politics, coalition building, and lobbying, as well as the act of compromising, thus gaining the respect of lawmakers and the admiration of millions of persons both with and without disabilities.

In the interim, additional legislation was passed with provisions to issue directives that persons with disabilities were not to be discriminated against nor treated as second-class citizens. One such piece of legislation was the Rehabilitation Act of 1973. Included in this legislation was Section 504 which forbade any United States institution that received federal financial assistance in the amount of \$2,500 or more and all federal and state agencies from discriminating against persons with disabilities in employment. . . .

INDEPENDENT LIVING MOVEMENT

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 The quest for independence by most Americans does not occur by accident, but is a quality that is taught and reinforced to every American youth, both by formal teaching

and by example. American history is replete with both fictional and factual persons accomplishing or attempting to accomplish extraordinary deeds to establish or maintain their independence.

Independence is therefore highly valued in American society; it is considered an essential building block in constructing and maintaining a democracy. Freedom, to an extent, is reliant upon its citizens having the independence to build better lives for themselves and in the process of accomplishing their dreams, they lift freedom and democracy to new levels. Conversely, being dependent is devalued in American society and those that are considered so are often assigned lower positions on the social totem pole. To many, the word "dependent" denotes lack of initiative, laziness, and a burden upon society. Although public and private social welfare agencies and organizations including hospitals, clinics, and rehabilitation centers, to mention a few, have been developed to assist persons who by virtue of illness, accident, or birth defects must rely upon assistive services, the recipients are often viewed in a negative light and at best given sympathy instead of empathy and understanding.

Illness or disability often places the individual, and sometimes the family, in a state of dependency. For some it is a permanent situation, but for the majority it is temporary. The degree to which a person becomes dependent is obviously affected by several things, not the least of which are attitudes. [A]ttitudes of family, friends, medical and rehabilitation personnel as well as employers have an impact on the level of dependency of the person with a disability.

Given the value placed on independence by American society, no one should be amazed that persons with disabilities began to recognize and resent the limited role society drafted for them. They correctly perceived that society equated disability with dependency. They also recognized that this perception created a very low ceiling and an almost insurmountable wall around their abilities to function and achieve.

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In the early seventies, persons with disabilities began to realize that to be truly free they must take and maintain control of their lives. This train of thought resulted in the development of Independent Living Centers (ILCs). Dejong provides a brief history of the genesis of Independent Living Centers as he reveals that a small group of persons with disabilities at the University of Illinois and at the University of California at Berkeley moved out of their residential hospital setting into the community and organized their own system for delivery of survival services. The centers established by these students became the blueprint by which future centers would be established. As might be expected, since the inception of these centers, the scope of services has expanded. Even so, the idea of persons with disabilities taking greater control of their lives remains the same. Perhaps Dejong best summarizes the independent living philosophy when he said the dignity of risk is what the independent movement is all about. Without the possibility of failure, a person with a disability is said to lack true independence and the mark of one's humanity: the right to choose for good or evil.

When one considers that the independent living movement was initiated by persons with disabilities, many of whom were persons with severe disabilities such as spinal cord injuries, it became quite apparent that these individuals exhibited courage of the highest magnitude. Although prior to the movement they lived in conditions that made them almost totally dependent upon others, it was however a safe environment; therefore, moving from this safe environment to face the many uncertainties created by a society with many barriers and obstacles certainly qualifies the founding members as pioneers.

. . . Laurie also contributes to our understanding of the goal of independent living centers with these comments:

Independent living is freedom of choice, to live where and how one chooses and can afford. It is living alone or with a roommate of one's choice. It is deciding one's own pattern of life: scheduling food, entertaining, vices, virtues, leisure and friends. It is freedom to take risks and freedom to make mistakes.

Frieden and Cole define the independent living concept as control over one's life based on the choice of acceptable options that minimize reliance on others in making decisions and in performing everyday activities. This may include managing one's affairs, participating in day-to-day life in the community, fulfilling a range of social roles, and making decisions that lead to self-determination and the minimizing of physical or psychological dependence upon others.

Frieden, Richards, Cole, and Bailey tell us that the independent living movement was based on the premise that with reasonable support services, adults with disabilities could manage their own affairs, and participate as full members of the community in all respects. They continue by speaking to the philosophy of the movement as full participation in community life and point out that the movement also was an advocate for a set of services that would meet the long-term support needs of citizens with disabilities. . . .

MORE THAN WORK

Work is so much a central part of most Americans' lives that it, in part, defines who we are. It is common for Americans to describe someone by identifying their occupation. For example, we may identify someone as Mary Smith the attorney, or John Smith the teacher. Work has been the defining feature in American lives for many years. The Puritan work ethic is a standard by which Americans often judge each other. While we no longer subscribe to the theory of hard work for all, we most certainly subscribe to the idea of work for all. Work provides us with economic power to purchase goods and services which in part by virtue of the amount and types of goods we accumulate determines our social standing in America. Social condemnation is the reward for those that are able to work but do not. Work not only is a means by which we develop, maintain or improve our societal standing in American society, it also is patriotic. In a capitalist society, it is through the production of products that our nation develops its standing in the world as compared to other nations.

Obviously, work has many important meanings to Americans and American society. Considering the position work holds in American life, it is easy to understand why virtually all rehabilitation legislation prior to the 1972 Rehabilitation Act emphasized "vocational rehabilitation." In fact, when we speak of rehabilitating a person with a disability we think the ultimate goal of the rehabilitation process is to make the person ready for a job. There is one thing wrong with this approach: what about the person who is unable to work because of the severity or perhaps type of disability? Unless they and/or their families have sufficient financial resources, they have to rely upon sympathy and charity of others as well as some social welfare assistance from the federal government. Because of the social stigma of not working and receiving charity, these persons' independence, self-dignity, and ability to participate as full American citizens are in jeopardy.

Perhaps these reasons, as well as others, caused the disability rights movement leaders to lobby Congress to deemphasize "vocational" in the Rehabilitation Act of 1972. It is unfortunate that the Nixon Administration did not comprehend what persons with disabilities were saying as they lobbied for removal of "vocational" from the rehabilitation act. In part, what they were saying, and perhaps today we are just beginning to hear, is that a person's

worth, self-respect, and dignity should not be measured by employment and moreover measured by whether employed in a job, especially if that person is unable to work. The leaders were wise to note that no person with a disability would be totally free until all persons with disabilities had opportunities to more fully participate in American life. Again it was this type of thinking that led them to push for Independent Living Centers, and the abolishment of the segregation of persons with disabilities so they could not only become more involved in American society, but also make decisions that would affect the quality of their lives. In short, they recognized that to be free, life for a person with a disability meant more than being able to work.

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