

History of Independent Living

By Gina McDonald and Mike Oxford

This account of the history of independent living stems from a philosophy which states that people with disabilities should have the same civil rights, options, and control over choices in their own lives as do people without disabilities.

The history of independent living is closely tied to the civil rights struggles of the 1950s and 1960s among African Americans. Basic issues--disgraceful treatment based on bigotry and erroneous stereotypes in housing, education, transportation, and employment--and the strategies and tactics are very similar. This history and its driving philosophy also have much in common with other political and social movements of the country in the late 1960s and early 1970s. There were at least five movements that influenced the disability rights movement.

Social Movements

The first social movement was deinstitutionalization, an attempt to move people, primarily those with developmental disabilities, out of institutions and back into their home communities. This movement was led by providers and parents of people with developmental disabilities and was based on the principle of "normalization" developed by Wolf Wolfensberger, a sociologist from Canada. His theory was that people with developmental disabilities should live in the most "normal" setting possible if they were expected to behave "normally." Other changes occurred in nursing homes where young people with many types of disabilities were warehoused for lack of "better" alternatives (Wolfensberger, 1972).

The next movement to influence disability rights was the civil rights movement. Although people with disabilities were not included as a protected class under the Civil Rights Act, it was a reality that people could achieve rights, at least in law, as a class. Watching the courage of Rosa Parks as she defiantly rode in the front of a public bus, people with disabilities realized the more immediate challenge of even getting on the bus.

The "self-help" movement, which really began in the 1950s with the founding of Alcoholics Anonymous, came into its own in the 1970s. Many self-help books were published and support groups flourished. Self-help and peer support are recognized as key points in independent living philosophy. According to this tenet, people with similar disabilities are believed to be more likely to assist and to understand each other than individuals who do not share experience with similar disability.

Demedicalization was a movement that began to look at more holistic approaches to health care. There was a move toward "demystification" of the medical community. Thus, another cornerstone of independent living philosophy became the shift away from the authoritarian medical model to a paradigm of individual empowerment and responsibility for defining and meeting one's own needs.

Consumerism, the last movement to be described here, was one in which consumers began to question product reliability and price. Ralph Nader was the most outspoken advocate for this movement, and his staff and followers came to be known as "Nader's Raiders." Perhaps most fundamental to independent living philosophy today is the idea of control by consumers of goods and services over the choices and options available to them.

The independent living paradigm, developed by Gerben DeJong in the late 1970s (DeJong, 1979), proposed a shift from the medical model to the independent living model. As with the movements

described above, this theory located problems or "deficiencies" in the society, not the individual. People with disabilities no longer saw themselves as broken or sick, certainly not in need of repair. Issues such as social and attitudinal barriers were the real problems facing people with disabilities. The answers were to be found in changing and "fixing" society, not people with disabilities. Most important, decisions must be made by the individual, not by the medical or rehabilitation professional.

Using these principles, people began to view themselves as powerful and self-directed as opposed to passive victims, objects of charity, cripples, or not-whole. Disability began to be seen as a natural, not uncommon, experience in life; not a tragedy.

Independent Living

Ed Roberts is considered to be the "father of independent living." Ed became disabled at the age of fourteen as a result of polio. After a period of denial in which he almost starved himself to death, Ed returned to school and received his high school diploma. He then wanted to go to college. The California Department of Rehabilitation initially rejected Ed's application for financial assistance because it was decided that he was "too disabled to work." He went public with his fight and within one week of doing so, was approved for financial aid by the state. Fifteen years after Ed's initial rejection by the State of California as an individual who was "too" disabled, he became head of the California Department of Rehabilitation--the agency that had once written him off.

After Ed earned his associate's degree at the College of San Mateo, he applied for admission to the University of California at Berkeley. After initial resistance on the part of the university, Ed was accepted. The university let him use the campus hospital as his dormitory because there was no accessible student housing (none of the residential buildings could support the weight of Ed's 800-lb. iron lung). He received attendant services through a state program called "Aid to the Totally Disabled." This is a very important note because this was consumer-controlled personal assistance service. The attendants were hired, trained, and fired by Ed.

In 1970, Ed and other students with disabilities founded a disabled students' program on the Berkeley campus. His group was called the "Rolling Quads." Upon graduation, the "Quads" set their sights on the need for access beyond the University's walls.

Ed contacted Judy Heumann, another disability activist, in New York. He encouraged her to come to California and along with other advocates, they started the first center for independent living in Berkeley. Although it started out as a "modest" apartment, it became the model for every such center in the country today. This new program rejected the medical model and focused on consumerism, peer support, advocacy for change, and independent living skills training.

In 1983, Ed, Judy, and Joan Leon, co-founded the World Institute on Disability (WID), an advocacy and research center promoting the rights of people with disabilities around the world. Ed Roberts died unexpectedly on March 14, 1995.

The early 1970s was a time of awakening for the disability rights movement in a related, but different way. As Ed Roberts and others were fighting for the rights of people with disabilities presumed to be forever "homebound" and were working to assure that participation in society, in school, in work, and at play was a realistic, proper, and achievable goal, others were coming to see how destructive and wrong the systematic institutionalization of people with disabilities could be. Inhuman and degrading treatment of people in state hospitals, schools and other residential institutions such as nursing facilities were coming to light and the financial and social costs were beginning to be considered unacceptable.

This awakening within the independent living movement was exemplified by another leading disability rights activist, Wade Blank.

ADAPT

Wade Blank began his lifelong struggle in civil rights activism with Dr. Martin Luther King, Jr. to Selma, Alabama. It was during this period that he learned about the stark oppression which occurred against people considered to be outside the "mainstream" of our "civilized" society. By 1971, Wade was working in a nursing facility, Heritage House, trying to improve the quality of life of some of the younger residents. These efforts, including taking some of the residents to a Grateful Dead concert, ultimately failed. Institutional services and living arrangements were at odds with the pursuit of personal liberties and life with dignity.

In 1974, Wade founded the Atlantis Community, a model for community-based, consumer-controlled, independent living. The Atlantis Community provided personal assistance services primarily under the control of the consumer within a community setting. The first consumers of the Atlantis Community were some of the young residents "freed" from Heritage House by Wade (after he had been fired). Initially, Wade provided personal assistance services to nine people by himself for no pay so that these individuals could integrate into society and live lives of liberty and dignity.

In 1978, Wade and Atlantis realized that access to public transportation was a necessity if people with disabilities were to live independently in the community. This was the year that American Disabled for Accessible Public Transit (ADAPT) was founded.

On July 5-6, 1978, Wade and nineteen disabled activists held a public transit bus "hostage" on the corner of Broadway and Colfax in Denver, Colorado. ADAPT eventually mushroomed into the nation's first grassroots, disability rights, activist organization.

In the spring of 1990, the Secretary of Transportation, Sam Skinner, finally issued regulations mandating lifts on buses. These regulations implemented a law passed in 1970—the Urban Mass Transit Act—which required lifts on new buses. The transit industry had successfully blocked implementation of this part of the law for twenty years, until ADAPT changed their minds and the minds of the nation.

In 1990, after passage of the Americans With Disabilities Act (ADA), ADAPT shifted its vision toward a national system of community-based personal assistance services and the end of the apartheid-type system of segregating people with disabilities by imprisoning them in institutions against their will. The acronym ADAPT became "American Disabled for Attendant Programs Today." The fight for a national policy of attendant services and the end of institutionalization continues to this day.

Wade Blank died on February 15, 1993, while unsuccessfully attempting to rescue his son from drowning in the ocean. Wade and Ed Roberts live on in many hearts and in the continuing struggle for the rights of people with disabilities.

These lives of these two leaders in the disability rights movement, Ed Roberts and Wade Blank, provide poignant examples of the modern history, philosophy, and evolution of independent living in the United States. To complete this rough sketch of the history of independent living, a look must be taken at the various pieces of legislation concerning the rights of people with disabilities, with a particular emphasis on the original "bible" of civil rights for people with disabilities, the Rehabilitation Act of 1973.

Civil Rights Laws

Before turning to the Rehabilitation Act, a chronological listing and brief description of important federal civil rights laws affecting people with disabilities is in order.

1964--Civil Rights Act: prohibits discrimination on the basis of race, religion, ethnicity, national origin, and creed; later, gender was added as a protected class.

1968--Architectural Barriers Act: prohibits architectural barriers in all federally owned or leased buildings.

1970--Urban Mass Transit Act: requires that all new mass transit vehicles be equipped with wheelchair lifts. As mentioned earlier, it was twenty years, primarily because of machinations of the American Public Transit Association (APTA), before the part of the law requiring wheelchair lifts was implemented.

1973--Rehabilitation Act: particularly Title V, Sections 501, 503, and 504, prohibits discrimination in federal programs and services and all other programs or services receiving federal funding.

1975--Developmental Disabilities Bill of Rights Act: among other things, establishes Protection and Advocacy services (P & A).

1975--Education of All Handicapped Children Act (PL 94-142): requires free, appropriate public education in the least restrictive environment possible for children with disabilities. This law is now called the Individuals with Disabilities Education Act (IDEA).

1978--Amendments to the Rehabilitation Act: provides for consumer-controlled centers for independent living.

1983--Amendments to the Rehabilitation Act: provides for the Client Assistance Program (CAP), an advocacy program for consumers of rehabilitation and independent living services.

1985--Mental Illness Bill of Rights Act: requires protection and advocacy services (P & A) for people with mental illness.

1988--Civil Rights Restoration Act: counteracts bad case law by clarifying Congress' original intention that under the Rehabilitation Act, discrimination in ANY program or service that is a part of an entity receiving federal funding--not just the part which actually and directly receives the funding--is illegal.

1988--Air Carrier Access Act: prohibits discrimination on the basis of disability in air travel and provides for equal access to air transportation services.

1988--Fair Housing Amendments Act: prohibits discrimination in housing against people with disabilities and families with children. Also provides for architectural accessibility of certain new housing units, renovation of existing units, and accessibility modifications at the renter's expense.

1990--Americans with Disabilities Act: provides comprehensive civil rights protection for people with disabilities; closely modeled after the Civil Rights Act and the Section 504 of Title V of the Rehabilitation Act and its regulations.

The modern history of civil rights for people with disabilities is three decades old. A key piece of this decades-long process is the story of how the Rehabilitation Act of 1973 was finally passed and then implemented. It is the story of the first organized disability rights protest.

The Rehabilitation Act of 1973

In 1972, Congress passed a rehabilitation bill that independent living activists cheered. President Richard Nixon's veto prevented this bill from becoming law. During the era of political activity at the end of the Vietnam War, Nixon's veto was not taken lying down by disability activists who launched fierce protests across the country. In New York City, early leader for disability rights, Judy Heumann, staged a sit-in on Madison Avenue with eighty other activists. Traffic was stopped. After a flood of angry letters and protests, in September 1973, Congress overrode Nixon's veto and the Rehabilitation Act of 1973 finally became law. Passage of this pivotal law was the beginning of the ongoing fight for implementation and revision of the law according to the vision of independent living advocates and disability rights activists.

Key language in the Rehabilitation Act, found in Section 504 of Title V, states that: No otherwise qualified handicapped individual in the United States shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance.

Advocates realized that this new law would need regulations in order to be implemented and enforced. By 1977, Presidents Nixon and Ford had come and gone. Jimmy Carter had become president and had appointed Joseph Califano his Secretary of Health, Education and Welfare (HEW). Califano refused to issue regulations and was given an ultimatum and deadline of April 4, 1977. April 4 went by with no regulations and no word from Califano.

On April 5, demonstrations by people with disabilities took place in ten cities across the country. By the end of the day, demonstrations in nine cities were over. In one city--San Francisco--protesters refused to disband.

Demonstrators, more than 150 people with disabilities, had taken over the federal office building and refused to leave. They stayed until May 1. Califano had issued regulations by April 28, but the protesters stayed until they had reviewed the regulations and approved of them.

The lesson is a fairly simple one. As Martin Luther King said,

It is an historical fact that the privileged groups seldom give up their privileges voluntarily. Individuals may see the moral light and voluntarily give up their unjust posture, but, as we are reminded, groups tend to be more immoral than individuals. We know, through painful experience that freedom is never voluntarily given by the oppressor, it must be demanded by the oppressed.

Leaders in the Independent Living Movement

The history of the independent living movement is not complete without mention of some other leaders who continue to make substantial contributions to the movement and to the rights and empowerment of people with disabilities.

Max Starkloff, Charlie Carr, and Marca Bristo founded the National Council on Independent Living (NCIL) in 1983. NCIL is one of the only national organizations that is consumer-controlled and promotes the rights and empowerment of people with disabilities.

Justin Dart played a prominent role in the fight for passage of the Americans with Disabilities Act, and is seen by many as the spiritual leader of the movement today.

Lex Frieden is co-founder of ILRU Program. As director of the National Council on Disability, he directed preparation of the original

ADA legislation and its introduction in Congress.

Liz Savage and Pat Wright are considered to be the "mothers of the ADA." They led the consumer fight for the passage of the ADA.

There are countless other people who have and continue to make substantial contributions to the independent living movement.

References

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