

5.2 ADA and IL Movement History

Independent Living History

A Brief History of the Independent Living Movement

At least five parallel and transformative social movements influenced and energized the disability rights and independent living movement during the second half of the 20th century.

Based on an article by Gina McDonald and Mike Oxford

The history of the independent living movement is closely tied to the civil rights movement of the 1950s and 1960s among African Americans. Both movements share basic issues -- disgraceful treatment as a result of bigotry and mistaken stereotypes in housing, education, transportation, and employment -- and their strategies and tactics are very similar.

The history of the independent living movement and its driving philosophy also have much in common with other political and social movements that flourished the late 1960s and early 1970s. At least five parallel and transformative social movements influenced and energized the disability rights and independent living movement during the second half of the 20th century.

SOCIAL MOVEMENTS

The deinstitutionalization movement was and continues to be an effort to move people, primarily those with developmental disabilities, out of institutions and back into their home communities. Providers and parents of people with developmental disabilities took the lead of this movement, based on the principle of "normalization" developed by Wolf Wolfensberger, a sociologist from Canada. He understood that people with developmental disabilities should and could live in the most "normal" setting possible if they were expected to behave "normally." Additional changes happened inside nursing homes where young people with many types of disabilities had been warehoused for lack of "better" alternatives (Wolfensberger, 1972).

The next movement to have an impact on 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 clearly established that people could achieve lawful rights as a class. Seeing and understanding the courage of Rosa Parks as she defiantly rode at the front of a public bus, people with disabilities realized the immediate challenge of even being able to get on the bus.

The "self-help" movement, which 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 became critical factors in the growing 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.

The demedicalization movement began the trend to embrace more holistic approaches to health

care. This movement established the importance of the "demystification" of the medical community. Thus, another cornerstone of independent living philosophy became the shift away from the power-based, authoritarian medical model to a paradigm of individual empowerment and responsibility for owning, defining and meeting one's own needs.

Consumerism is a movement in which consumers actively question product and service reliability and price, as well as the true motives of the corporate establishment. Ralph Nader was the first and most outspoken advocate for this movement, and his staff and followers came to be known as "Nader's Raiders." Perhaps most fundamental to today's independent living philosophy is the idea that consumers have control over the choices and options of goods and services 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. He posited that such issues as social and attitudinal barriers were the real problems facing people with disabilities. Solutions could 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.

Embracing these principles, people began to view themselves as powerful and self-directed, not as passive victims, charity recipients, cripples, or not whole people. Disability began to be seen as a natural, not uncommon – but certainly not tragic -- experience in life.

EARLY LEADERSHIP

Wade Blank began his lifelong struggle in civil rights activism alongside Dr. Martin Luther King, Jr. during the historic march to Selma, Alabama. It was during this period that he learned about the stark oppression 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 essential if people with disabilities were to live independently in the community. This was the year that Americans 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 wheelchair 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 against their will in institutions. The acronym ADAPT became "Americans Disabled for Attendant Programs Today." The fight for a national policy of attendant services and the end of institutionalization continues to this day.

The University of California at Berkeley hesitated to admit Ed Roberts when he initially applied, as he was severely disabled from polio, which he contracted as a teenager. He had virtually no functional movement and used a respirator to breathe. "We've tried cripples before and it didn't work," said the university. They reluctantly admitted Ed in 1962 and arranged for him to live in the campus medical facility, Cowell Hall. His brother, also a student, served as an on-campus PA, often pushing Ed from class to class in an old manual wheelchair. Ed was accustomed to rejection; a year earlier in 1961 the state vocational rehabilitation agency refused to serve him, as he was considered too severely disabled and labeled unemployable. That decision was later overturned. One of the many ironies of Ed's life was that fourteen years later in 1975, Governor Jerry Brown appointed Ed as state Director of California's rehabilitation agency, the same institution that once deemed him too severely disabled to ever work. In his position he was able to influence the establishment of many new CILs throughout the state. He would serve as Director for eight years.

In the late 60's and early 70's Berkeley students with severe disabilities were organized into a group known as The Rolling Quads. Led by Ed, they began exerting pressure on the university to become more accessible and began seeking funding to develop a student organization to work for barrier removal and support services, including Personal Attendant services, for students with disabilities to live independently while attending school. Ed Roberts was launching a self-help movement that would radicalize how people with disabilities perceived themselves. He did it for himself and then began laying the groundwork for the rest of us. Independence and rehabilitation have not been the same since, and will never return to the archaic notions which perceived people with disabilities as passive recipients of charity, unable to self-direct their lives.

After establishing the campus organization, Ed and others realized the need for an off campus, community based organization. In 1972, with minimal funding, the Berkeley Center for Independent Living (CIL) was started. The core values of the Berkeley CIL, dignity, peer support, consumer control, civil rights, integration, equal access, and advocacy, remain at the heart of the independent living and disability rights movements. Today, as many as 400 CILs exist throughout the country, funded with a mix of federal, state, local, fee for service, and private money. In the early 80's Ed and others established the World Institute on Disability in Oakland, a progressive think tank focusing on independence and civil rights for people with

disabilities. Ed traveled the country and the world influencing the lives of people with disabilities. He was featured on a variety of news shows, including 60 Minutes.

Ed died at a far too young an age in March 1995. He was 55 years old. 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.

The 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, one must take a look 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.

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 (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 REHABILITATION ACT OF 1973

The modern history of civil rights for people with disabilities is more than decades old. An essential 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.

In 1972, Congress passed a rehabilitation bill that independent living activists cheered. President Richard Nixon's veto prevented this bill from becoming law. Nixon's veto was not taken lying down. Disability activists launched fierce protests across the country. In New York City, an early leader for disability rights, Judy Heumann, staged a sit-in on Madison Avenue with eighty other activists. They stopped traffic. 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. But in 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 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."

TODAY'S 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 1980. NCIL is one of the only consumer-controlled national organizations that 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 the "mothers of the ADA." They led the consumer fight for the passage of the ADA.

Countless other people have made and continue to make substantial contributions to the independent living movement.

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<https://www.accessliving.org/Independent-Living-History>

Implemented 8/25/2015