History of Independent Living

- 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 ties to the civil rights struggles of the 1950s and 1960s among African Americans. Basic issues-disgraceful treatment based on bigotry and erroneous stereotypes 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 A normal setting possible if they were to 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 definitely 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 1970's. 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 a 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. 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 power 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 perceived 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.



As we get older, we realize that disability is just a part of life.

Anyone can join our group at any point in life. In this way the disabilities rights movement doesn't discriminate...

Ed Roberts

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 consumercontrolled 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 Reports 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 a 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 Colflax 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 at the end of the apartheid-type system of segregating people with disabilities by imprisoning them in institutions against their will. The acronym ADAPT because "American Disabled for Attendant Programs Today." The fight for national policy of attendant services and the end of institutionalization continues to this day.

Civil Rights Laws

Before turning to the Rehabilitation Act, a chronological listing & 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 & 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 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.

National ADAPT Visits Washington, DC

April 20, 2013 4 Days of Strong Grassroots Advocacy

- Each spring Action begins with the ADAPT Fun Run, a fundraiser in Senate Park. This year the Fun Run's star was Becky Olge, a national disability rights activist and political policy specialist.
- The night following the Fun Run, ADAPT met with members of the DOJ, including the Chief of the Civil Rights Division for Disability Rights. We were able to report many <u>Olmstead</u> issues to them instances where states have neglected services in the community, in favor of nursing home and institutional placement.
- Centers like LRI risk retaliation, through funding cuts, when we file complaints. But many states, including Pennsylvania, are still out of compliance and still operate county and state institutions with little to no ADA enforcement to end this costly and discriminatory institutional bias.

Happy Monday!

- On a cold Monday morning ADAPT rolled its way to the White House. Since Pennsylvania Avenue was roped off in front of the White House, ADAPT parked in front of the barricades and presented the President with a report card of his failure to deliver on promises to the Disabled Community.
- ADAPT urged Obama to issue a statement of support for legislation that would end the institutional bias in our nation's Long Term Care system and assure that all people with disabilities can choose to live in the community instead of institutions like nursing homes.

- ADAPT also asked President Obama to require the DOL to fully involve the disability community in the development of rules that affect Consumers & Attendants.
- The DOL recently issued proposed changes to the "Companionship Exemption" without any input from the disability community. These changes would require, among other things, overtime pay for Attendants, which would limit Attendants to 40 hours or less per week.
- Changes could also result in loss of Consumer control over firing and hiring Attendants and reduction of people's care plans, forcing some disabled people back into costly, segregated institutions and nursing homes.

"We will not rest."