

INDEPENDENT LIVING PHILOSOPHY AND HISTORY

PARTICIPANT MANUAL

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I. Workshop Objectives

The objectives for today's workshop are:

- To identify the origins and understand the development of Independent Living Philosophy.
- To explore the history of Disability Rights and Independent Living.
- To examine how Independent Living Philosophy impacts the structure and operation of Independent Living Centers.

II. IL Philosophy

Definition of a Philosophy:

- A philosophy is a collection of beliefs, values and principles that guide people and organizations.

Beliefs of People with Disabilities

- People with disabilities are individuals. Each is unique, even when their disability is similar (not all wheelchair users can transfer).
- People with disabilities know best what they need and what works for them.
- People with disabilities are not static. Issues and needs may change over time due to changes in the person's disability.
- People with disabilities are not broken and do not need to be fixed. (Some can be treated but not fixed.)
- People with disabilities have goals and desires just like non-disabled and have the same rights as non-disabled.
- Programs for people with disabilities should include all disability types and be managed by people with disabilities.

Beliefs and I L Philosophy

- NO Stereotyping or Assumptions
 - Each person should be treated as a unique individual without assumptions based on their disability.
 - People should not assume they know what is best for a person with a disability based on their education, good intentions, their own disability or background.

- There is no “one size fits all” or “what worked last year should work this year” answer to issues and needs.
- Disabling conditions can change and so can personal and assistive equipment needs.
- Being disabled is not a death sentence.
 - Many disabilities are permanent and can not be treated or cured with medicine (blindness, deafness, spinal cord injury, cerebral palsy, learning disabilities.)
 - People with these disabilities are not sick or broken. Their “condition” may limit their ability to engage in some activities or require that they modify the way they engage in activities.
 - Their condition does not prevent them from participating in life.
 - Other permanent disabilities may be treatable (mental illness, diabetes, lupus) but not completely cured.
 - These “disabling conditions” are a “normal” part of those individuals, just like nearsightedness or farsightedness is a “normal” limitation of sight. Prescribed care for people with disabilities should not limit their inclusion in life activities.
- Freedom of Choice/Self Determination.
- People with disabilities work, go to school, get married, have children, buy houses and do all the things non-disabled people do.
- People with disabilities have the same rights and freedoms that non-disabled have.
- People with disabilities have the right to make choices and change their mind.
- No person, family member, government official or agency, educator, employer or medical professional has the right to make decisions or choices for a person with a disability without their consent.
- Children with disabilities have the same rights as non-disabled children.

Influencing factors in the development of IL Philosophy?

- Public/community view of disability.

- People with disabilities made the public uncomfortable and should be shut away from society. Special schools, nursing homes or hospitals were the best places for the disabled. They could be cared for and allowed to live in a protected environment for their own safety. Pity for “those unfortunates” often resulted in people turning away from or being overly helpful to people with disabilities.
- Medical view of disability (The Medical Model)
 - The physician is the expert; the patient is expected to cooperate and assume the “sick role.” A “sick” person is exempt from normal responsibilities and activities. The main purpose of medical treatment is to provide restorative care. People with disabilities were not well and needed medical care to help them fit into society. Like fixing a broken bone, medicine believed that a disability should be fixed.
- Regulatory view of disability
 - Severely disabled people needed to be cared for because they cannot work and are unable to care for and support themselves. People with disabilities did not have the same rights as “normal” people in society. Laws were passed to protect people with disabilities and protect society from people with disabilities. People with some disabilities could be a danger to themselves and others.

Shifts in society that changed points of view about people with disabilities.

- US Civil Rights Movement - Equal Rights.
 - The Civil Rights Act of 1964 banned discrimination based on age, gender, race or ethnic origin. Although the law did not include people with disabilities, it did raise their awareness that they could achieve equal rights under the law.
 - By making it illegal to discriminate in employment, it opened the door to making employment discrimination based on disability illegal. It also required municipalities to provide people with disabilities the opportunity to vote and run for elected office.
- Consumerism Movement- Consumer Control.
 - The consumerism movement gained recognition and popularity through the efforts of “Nader’s Raiders” and consumer research groups. Work in consumer product safety and the development of a Consumer Product Safety Commission gave consumers the power to demand quality and choice in the products and services they purchased.

- This eventually included medical care and equipment for people with disabilities. Consumer control, a critical element of I L Philosophy, can be attributed to the consumerism movement.
- Self-Help Movement - Peer Support
 - With roots established in support group programs like Alcoholics Anonymous, people with disabilities connected to the Self-Help movement because of the peer-to-peer relationship and support. They believed that individuals with the same or closely similar disability, best understood and appreciated the challenges faced by their peers. Sharing peer perspective and experience is an integral part of I L Philosophy and independent living. Similar to the Consumerism movement, Self-Help allowed people to exercise control over their own life and problems.
- Deinstitutionalization Movement
 - Institutionalization was common for a range of disabilities. The majority of people with mental illness, learning disabilities multiply disabled and severely physically disabled were often in institutions. Deinstitutionalization is based on the idea that to achieve “normal” behavior, the person should be in as “normal” a setting as possible.
 - Providers and parents of people with developmental disabilities supported this idea and worked toward de-institutionalization.
 - “Warehousing” children in nursing homes and special schools was another form of institutionalization. As “main-streaming” programs became more popular, parents and individuals demanded placement in regular schools and learning centers, allowing for a normal home life. Deinstitutionalization allowed people with disabilities to be a part of their community and not be shut away from society. It also supported greater self-determination for the individual.
- Demedicalization Movement - Health Care Decision Making.
 - Moving away from traditional “doctor / patient” roles, the demedicalization movement embraced the person’s involvement in their own health care and in exploring alternative medical options. Combined with the consumerism movement, “patients” were empowered and exercised control in requesting alternative treatment methods in health care decisions.
 - The extent of “consumer control” includes the person’s right to refuse treatment, even when needed to sustain life. This supports the I L Philosophy belief of self-determination and consumer control in life and death.

To better understand the Independent Living Paradigm by Gerben DeJong, refer to the attached table.

For a more detailed review of these movements described above, refer to the attached article entitled, "History of Independent Living," by Gina McDonald and Mike Oxford.

III. History of Disability Rights and Independent Living

Independent Living and Disability Rights Timeline.

The following is a select list of national milestones highlighting people, events and legislation that effect independent living and disability rights.

- 1972 - The Berkeley Center for Independent Living was founded by Ed Roberts and associates with funds from the Rehabilitation Administration. It is recognized as the first center for independent living.
- 1973 - The Rehabilitation Act of 1973 was passed. Sections 501, 503 and 504 prohibited discrimination in federal programs and services and all other programs or services receiving federal funds. Key language in the Rehabilitation Act, found in Section 504, states "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."
- 1975 - The Education of All Handicapped Children Act (PL 94-142) required free, appropriate public education in the least restrictive setting. This Act was later renamed The Individuals With Disabilities Education Act (IDEA).
- 1977 - Joseph Califano, U.S. Secretary of Health, Education and Welfare, refused to sign meaningful regulations for Section 504. After an ultimatum and deadline, demonstrations took place in ten U.S. cities on April 5th. The sit-in at the San Francisco Office of the U.S. Department of Health, Education and Welfare lasted until May 1st. More than 150 demonstrators refused to disband. This action became the longest sit-in at a federal building to date. Section 504 regulations were issued.
- 1978 - Title VII of the Rehabilitation Act Amendments of 1978 established the first federal funding for consumer-controlled independent living centers and created the National Council of the Handicapped under the U.S. Department of Education.
- 1983 - The World Institute on Disability (WID) was established by Ed Roberts, Judy Heumann and Joan Leon.

- 1988 - The Civil Rights Restoration Act counteracted bad case law by clarifying Congress' original intention. Under the Rehabilitation Act, discrimination in any program or service that receives federal funding – not just the part which actually and directly receives the funding – is illegal.

The Fair Housing Act amendments prohibited housing discrimination against people with disabilities and families with children. It also provided for architectural accessibility of certain new housing units, renovation of existing units and accessibility modifications at the renter's expense.

- 1990 - The Americans with Disabilities Act was signed by George W. Bush. The Act provided comprehensive civil rights protection for people with disabilities. Closely modeled after the Civil Rights Act & Section 504, the law was the most sweeping disability rights legislation in history. It mandated that local, state and federal governments and programs be accessible, that businesses make "reasonable accommodations" for disabled workers and that public businesses make "reasonable modifications" to ensure access. The act also mandated access in transportation, communication, and in other areas of public life.

The Education for All Handicapped Children Act was amended and renamed the Individuals with Disabilities Education Act (IDEA).

- 1992 - Amendments to the Rehabilitation Act were infused with the philosophy of independent living. Provisions for Statewide Independent Living Councils (SILC's) were added.
- 1999 – The Ticket to Work and Work Incentives Improvement Act (TWWIIA) was enacted to improved Social Security and health care barriers to work for people with disabilities.

The following items are milestones achieved in New York State over the past four years.

- 1999 – Passage of the New York State Special Education Reform Act.
- 2000 – Federal Court decision that mandates New York State counties are solely responsible for the accessibility of polling places.
- 2001 - Advocate Ted Galusha takes New York State and DEC to Federal Court and wins a consent decree that improves access and opens specific state trails to people with disabilities.

Advocates ensure that the revised building code maintains 100% adaptability in new apartments with four or more dwelling units.

Alternative Format Legislation becomes law. Ensures, among other things, that students with disabilities have access to all instructional materials in accessible format.

- 2002 – Enactment of a Medicaid Buy-In program for New Yorkers with disabilities.

IV. Operation of ILC's

Taken from the Standards of Service and Operation, Title 7 Standards (725) of Rehabilitation Act of 1992, as amended.

The Center shall promote and practice independent living philosophy of:

- Consumer control of the center regarding decision making, service delivery, management, the establishment of policy and the direction of the center,
- Self-help and self-advocacy,
- The development of peer relationships and peer role models,
- And equal access of individuals with severe disabilities to society and to all services, programs, activities, and facilities, whether public or private and regardless of funding source.

What Do I L Philosophy Standards Mean?

- Consumer Control of the center regarding decision making, service delivery, management, the establishment of policy and the direction of the center.
 - The center will have a Board that is the principal governing body of the center and a majority of which shall be composed of individuals with severe disabilities. The center will ensure that the majority of the staff, and individuals in decision-making positions of the center are individuals with disabilities.
- Cross disability representation – managers, staff members, board members, committee members, volunteers and consumers are individuals with differing disabilities from the community.
- Community based – The center, the staff and the board members are from the community they serve. Services offered and advocacy issues addressed originate from the needs of the consumers from the community.
- Non-Residential –Although centers can provide housing assistance, they are prohibited from offering residential services. This does not prevent centers from actively promoting accessible housing programs in their community.

I L Philosophy, Services, and Systems Advocacy.

- Besides providing the four core services (i.e., peer counseling, information and referral, independent living skills instruction, and self and systems advocacy), centers can provide services consistent with the Act and the State Plan for Independent Living (SPIL).

- Centers must also participate in systems advocacy activities. Such activities represent:
 - A core service,
 - A purpose of Chapter 1, Title VII of the Rehabilitation Act, as amended.
 - Allows a consumer to maximize personal leadership, empowerment, independence, and productivity.
 - Addresses a systemic barrier or issue so that future generations won't have to experience the same problems (i.e., Medicaid Buy-In).

INDEPENDENT LIVING PARADIGM, DeJong¹

Table 1: Comparison of Rehabilitation and Independent Living Paradigms

Item	Rehabilitation paradigm	Independent living paradigm
Definition of problem	Physical impairment/ lack of vocational skill	Dependence on professionals, relatives, etc.
Locus of problem	In individual	In environment: in the rehab process
Solution to problem	Professional intervention by physician, physical therapist, occupational therapist, voc rehab counselor, etc.	Peer counseling, advocacy self-help, consumer control, removal of barriers
Social role	Patient/client	Consumer
Who controls	Professional	Consumer
Desired outcomes	Maximum ADL Gainful employment	Independent living

¹ DeJong, Gerben.: Independent living: from social movement to analytic paradigm. Arch Phys Med Rehabil 60: 435-446, 1979.

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 to be 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 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.

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 (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. 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.

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, fights, 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 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 (NCEL) in 1980. NCEL 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 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.

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Paradigm," Archives of Physical Medicine and Rehabilitation 60, October 1979.

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