



# Independent Living Movement History & Philosophy

DAIL Advisory Board  
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# Historic Events



# Historic Events

1815: Thomas Gallaudet went to Europe to seek methods to teach the Deaf

1829: Louis Braille invented the raised point alphabet

1860: Braille introduced in America and taught at St. Louis School for the Blind

1861-1865: American Civil War: 30,000 amputations in the Union Army alone

1894: Nation Deaf-Mute College became Gallaudet College

# Historic Events

1939 Hitler orders killing of sick and disabled

1940-1944 908 patients are transferred from an institution (including those who were chronically ill and had intellectual disabilities) to Eglfing-Haar to be gassed

1953 Ed Roberts contracts polio

1963 President Kennedy addresses Congress

# President Kennedy

## Addressing Congress: Reduction to Institutions

*“Over a number of years, and by hundreds of thousands, [in the number] of persons confined” to residential institutions, and he asks that methods be found “to retain in and return to the community the mentally ill and mentally retarded, and there to restore and revitalize their lives through better health programs and strengthened educational and rehabilitation services.” January 1963*

# Historic Events

1970 Rolling Quads formed in the Disabled Students' Program on the University of California Berkeley campus

1971 First Center for Independent Living established in a roach-infested two-bedroom apartment

1972 Rehabilitation Administration grants \$50,000 to the program

# Ed Roberts

## Father of the Independent Living Movement



# Ed Roberts

- 1953 contracted polio
- Mother – Zona Roberts
- Paralyzed from neck down
- Lived in an iron lung
- One child
- MacArthur award recipient



***“ There are very few people even  
with the most severe disabilities  
who can’t take control of their own  
life.***

***The problem is, the people around  
us don’t expect us to.”***

- Ed Roberts

1989 60 Minutes Interview

<https://www.youtube.com/watch?v=ZxidR5SZXxA>

# History Leads to new Philosophy



# Social Movement Impact

- Civil rights movement
- Consumerism
- Self-help
- De-medicalization
- De-institutionalization

“We make such fundamental errors in taking care of people all the time. If you had people taking care of you, making all your decisions, what is there to life, really?” - Ed Roberts



## Berekely, California

The Center for Independent Living, Inc. (CIL) emerged from the independent living movement of the 1960's as a powerful social catalyst on the University of California at Berkeley campus. There Ed Roberts, Hale Zukas, and Jan McEwan Brown joined forces to lead a movement that made the full academic and social life of the college accessible to all.

### **The organization established three guiding principles:**

- Comprehensive programs most effectively meet the needs of people with disabilities
- People with disabilities are the best experts on their lives
- The strongest and most vibrant communities are those that include and embrace all people

# Definition of Independent Living

Independent living is the right of all persons, regardless of age, type or extent of disability to:

- Live in the community, as opposed to living in an institution;
- Have the same range of choices as everyone else in housing, transportation, education and employment;
- Participate in the social, economic and political life of their communities;
- Have a family;
- Live as responsible, respected members of their communities, with all the duties and privileges that this entails; and
- Unfold their potential

# Independent Living

- In the beginning referred to people with disabilities creating and managing our own lives and programs.
- Only a person with a disability can be an expert in personal issues surrounding disability.
- Those with disabilities are the experts about our bodies, our environments, our capabilities, our limitations.

## VCIL Vision Statement

Together we will build communities:

- In which we can achieve our full human and civil rights and equal access to services and opportunities;
- That have available ongoing resources and options for independent living; and
- In which we can realize our power to control and direct our own lives.

We join together to celebrate our diversity and our common goal for the full inclusion of *all* persons in the lives of our communities

# Laws that changed the movement



# Section 504 of the Rehabilitation Act

- Took language of the Civil Rights Act of 1964 to the Rehabilitation Act of 1973
- Staffer added language that addressed the issue of discrimination related to disability – most thought was related to the budget
- *No otherwise qualified individual with a disability in the United States. . . shall, solely by reason of her or his disability, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program, service or activity receiving federal financial assistance or under any program or activity conducted by any Executive agency or by the United States Postal Service.*

# 504 Continued

- Until 504 disability was defined by the medical model of rehabilitation or charity and as a personal problem
- The Dept. of Health, education and welfare lead agency and needed to establish regulations that would become the guideline for all federal agencies
- 1973-1977 No regulations were issued (although had been drafted by attorneys in the Office of Civil Rights and sent to the Secretary to sign

# 504 Continued

- HEW sent to Congress and they sent them back
- Secretary Califano would not sign them
- Carter Administration: HEW set a task force with no representatives from the disability community
- Leaks to the disability community, watering down the regulations

# 504 Sit In's



# Demonstrations

- National Coalition of citizens with disabilities was formed
- Eight HEW regional headquarters
  - San Francisco – 28 days!!!
  - 200 people stayed until the end

# ADAPT



# ADAPT

- Lifts on Buses
- Attendant Service Programs
- Judge Rotenberg Center, Massachusetts
- Healthcare- State and National

[The Story of ADAPT Trailer](#)



# Capital Crawl



**Signing of the Americans with Disabilities Act  
July 26th, 1990**



# Justin Dart

*"I call for solidarity among all who love justice, all who love life, to create a revolution that will empower every single human being to govern his or her life, to govern the society and to be fully productive of life quality for self and for all. LEAD ON!"*

# ADA Definition

An individual with a disability is defined by the ADA as

A person who has a physical or mental impairment that substantially limits one or more major life activities;

a person who has a history or record of such an impairment,

or a person who is perceived by others as having such an impairment.

# Disability Rights Related Laws

1934: Telecommunications Act

1973: Rehabilitation Act

1975: All Handicapped Children Act

1980: Civil Rights of Institutionalized Persons Act

1984: Voting Access for the Elderly & Handicap

1986: Air Carrier Access Act

1988: Fair Housing Amendments

1990: Individuals with Disabilities Education Act

1990: Americans with Disabilities Act

1993: Voter Registration Act

2008: ADA Amendments Act



# Money Follows the Person

- 2005 initiative of President Bush's proposal for a MFP program.
- 2005 President's budget request as part of the New Freedom Initiative to integrate people with disabilities into the community
- Advocacy Now: The Empower Care Act includes reauthorization
  - S.2227
  - H.R. 5306



# MFP Act of 2005

- Allowed HHS Secretary to award grants to states for demonstration projects to:
  - Increase the use of home and community-based, rather than institutional, long term care services (rebalancing) under state Medicaid programs;
  - Eliminate barriers or mechanisms that prevent or restrict the flexible use of Medicaid funds to enable Medicaid-eligible individuals to receive support for appropriate and necessary long-term care services in settings of their choice;
  - Increase the ability of state Medicaid programs to assure continued provision of home and community-based long term care services to eligible individuals who choose to transition from an institutional to community setting; and
  - Ensure that procedures are in place to provide quality assurance for eligible individuals receiving Medicaid home and community-based long-term care services and to provide for continuous quality improvement in such services.

# Community Choice Act

A national long-term service policy should not favor any one setting over the other. It should let the users choose where services should be delivered.

Our current system is not neutral, and it doesn't reflect people's choices.



# Respectful Language Bill

2014 Green Mountain Self Advocates led the charge to change offensive language in disability laws and state policy moving forward



# Disability Integration Act

- Civil Rights legislation
- Introduced by Senator Schumer and Rep. Sensenbrenner
  - Co-sponsors include all Vermont delegation
- Address the issue that people who need Long Term Supports and Services (LTSS) are forced into institutions and losing their basic civil rights
- Builds on the work of ADAPT- to end the institutional bias and provide seniors and people with disabilities home and community based services (HCBS) as an alternative to institutionalization

# National Council on Independent Living

*NCIL advances independent living and the rights of people with disabilities. NCIL envisions a world in which people with disabilities are valued equally and participate fully.*



# Vermont Coalition for Disability Rights

[www.vcdr.org](http://www.vcdr.org)

- Member organization
- Legislative Advocacy Platform
- Annual Disability Awareness Day





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