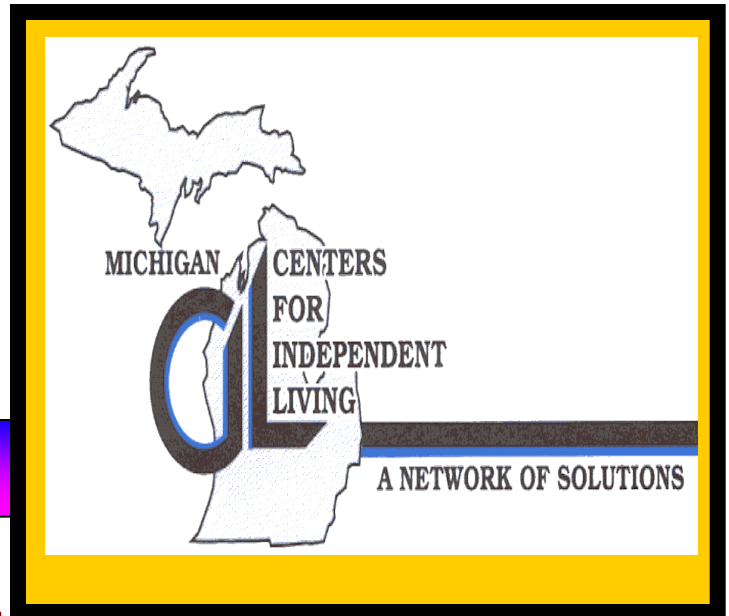


Ann Arbor Center for Independent Living

University of Michigan  
Model SCI Care System

Michigan Resource Guide  
for Persons with Spinal Cord Injury



# Centers for Independent Living

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In 1976, thirty years ago, we created the Ann Arbor Center for Independent Living because our community was filled with overwhelming physical and attitudinal barriers that kept people with disabilities from living full and productive lives. Many of us could not cross the street, ride a bus, go to church or school, enter a workplace, fly on an airplane, use public restrooms or live in the community outside of our family homes or state-run institutions. We established the Ann Arbor CIL, the fourth CIL in the nation in a current network of over 600 such organizations, because we wanted a place where people with disabilities could find support. Through peer advocacy we worked to change mind-sets and reduce structural barriers that prevented full participation in our community. We have worked with many individuals and organizations to create a disability community filled with pride, power, and personal style. Please join us as we celebrate our rich history and forge ahead into a dynamic future.

*~Jim Magyar, Director, Ann Arbor CIL*

## People In Action

### Full Circle

By Tom Hoatlin

I was 28 years old with a promising career in the hotel industry, but nothing could prepare me for an event that would change my life forever. Ten days before Christmas in 1991, I was working in the evening in a suburban hotel. Two men jumped the counter and held me at gunpoint as they emptied the safe and cash drawers. In the end, regardless of my cooperation, I was shot at the base of my neck and left to die. A hotel guest saw me lying on the ground and called 911. I was airlifted to U of M Hospital, where I would spend the next six months, first fighting to survive, while on a ventilator, and then four months of rigorous physical therapy learning to live with a spinal cord injury (SCI). In the end, I was left paralyzed from my upper chest down and, barring a cure, would never walk again.

Enter the Ann Arbor Center for Independent Living. One day on the rehab floor, a man from the AACIL rolled into my room in a wheelchair. He introduced himself and

began to speak of his experience with a SCI. I remember thinking to myself that regardless of what he was saying I did not need to know it; my situation was temporary. I would not be a member of his disability population. I did somehow hear him when he offered the AACIL as a resource, and indeed it would have a lasting effect on my new life with a disability.

Just months after leaving the hospital I decided to take the AACIL peer training course, where I would sit amongst others with disabilities and share stories of triumph and failure. We would first come to terms with our own disability experience and then focus on being effective at offering resources and personal support to others with, in my case, SCI. I would someday roll into someone's room and share my disability experience.

After completing the training, I volunteered at the Center for several months. I became charged; someone depended on me to show up at a job again! The AACIL Executive Director asked to take a look at my resume and talk about my

interests and abilities. I was hired as a part-time fundraising assistant. The staff, over 50% of whom have disabilities, welcomed me with open arms. I quickly learned that this was not a place to share the tragedy of your experience, but to almost embrace your disability and adopt the belief that disability is a normal part of life; not to disregard the tragedy but to put it to good use, or as "good" as possible.

The most meaningful opportunity the CIL has given me is the coordination of the AACIL with the University of Michigan Model SCI Care System. This partnership focuses on support services for patients with new SCI. I, along with other CIL staff and volunteer peers who have SCI, meet new patients and forge friendships with them. We offer valuable information on communication, health and wellness, sexuality, employment, and recreation, but the most important resource for me is the emotional support. Most days it is my strength. Because I remember the catastrophic grief and anger associated with this life-altering event, I can actually say, "I

know how you feel. I, too was in this room for six months.” It is one thing for a doctor or therapist to offer support to a new patient but another when someone rolls into a room and the patient sees a healthy person in a wheelchair that is happy, is working, and has a family. This shows them promise and offers hope. I will never forget the day a patient’s mother came back after a group session with tears in her eyes. She expressed gratitude for my involvement because it was the first time she had seen her son smile and laugh since his injury.

With the help of the AACIL, I have come full circle. What started as a tragedy in 1991 has turned into a life-altering experience and opportunity to do work I would never have dreamed I could do. I have painful days, both literal and mindful. I allow myself those days and work very hard to minimize them. My injury provided blessings. I have met and made life-long relationships with people whom I otherwise would never have met. My life is not about disability; it is about living. I take the greatest joy from watching my daughter grow into a

beautiful young lady. I realize our very existence is so fragile, and I thank God each and every day for my life. When my injury occurred, my marriage was new, my only child was an infant, and my family ties were close. Now married nearly 20 years, my daughter is in her early teens, and my family couldn’t be closer. It is because of this that I am able to get out of bed every day and negotiate the journey my life has become.

## A 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 refused to give up her seat in 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 we 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 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. in 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.

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, 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, Section 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), and 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

<p>the funding – is illegal.</p>	<p>Rehabilitation Act and its regulations.</p>	<p>ongoing fight for implementation and revision of the law</p>
<p>1988 Air Carrier Access Act: prohibits discrimination on the basis of disability in air travel and provides for equal access to air transportation services.</p>	<p>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.</p>	<p>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.</p>
<p>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.</p>	<p><b>The Rehabilitation Act of 1973</b></p> <p>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 an early leader for disability fights, Judy Heumann, staged a sit-in on Madison Avenue with 80 other activists.</p>	<p>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.</p>
<p>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</p>	<p>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</p>	<p>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 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.</p> <p>On April 5, demonstrations by people with disabilities</p>

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 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 (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 ELRU 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.

*Disability is not a “brave struggle” or “courage in the face of adversity”.... disability is an art. It’s an ingenious way to live. – Neil Marcus, 1993*

### **References**

DeJong, Gerben. “Independent Living: From Social Movement to Analytic Paradigm,” Archives of Physical Medicine and Rehabilitation 60, October 1979.

Wolfensberger, Wolf. The Principle of Normalization in Human Services. Toronto: National Institute on Mental Retardation, 1972.

## Centers Across Michigan

All CILs provide four core services, with each individual CIL adding supports tailored to the needs identified by its own local disability community. As a person with a SCI, you may want to tap these services. The four core services include:

1) Peer Support  
Centers offer the unique resource of people with disabilities who themselves have successfully established independent lives. Peer members and peer support groups help people explore options, develop goals and overcome barriers.

2) Information and Referral

Perhaps the single most empowering service is information. Centers offer sources of information such as accessible housing, transportation, employment opportunities, personal care attendants, interpreters, readers and many others.

3) Individual and Systems Advocacy

Centers provide two kinds of advocacy. Consumer advocacy works with the

individual to access the community's many resources. Community advocacy seeks to remove barriers and initiate changes in systems to make it easier for all citizens including those with disabilities to live more independently.

4) Independent Living Skills Training

Centers coordinate the provisions of skills training enabling people with disabilities to live more independently. Assistance is provided in such areas as: using public transportation systems, managing a personal budget, dealing with insensitive and discriminatory behavior, securing the assistive technology needed to maintain a job, managing attendant care, etc.

Call a Center near you!



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More  
Important  
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.00.html](http://www.michigan.gov/dleg/0,1607,7-154-28077_28313-14762--,00.html)

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**NATIONAL**

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LIVING (NCIL)**

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The National Council on Independent Living is a membership organization that advances the independent living philosophy and advocates for the human rights of, and services for, people with disabilities to further their full integration and participation in society.

**REHABILITATION  
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INDEPENDENT  
LIVING**

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Through research, training, and dissemination, this project makes available person-environment strategies that enable full participation in society by persons with disabilities from diverse cultures, varying socioeconomic strata, and emerging disability populations. This mission is implemented through multiple research and training activities that are influenced by independent living (IL) philosophy and values; for example, participatory action research is emphasized, in which consumers take an active role throughout the research process. The RRTC develops, tests, and uses measurement tools to investigate the

interactional relationship between personal and environmental factors and their effects on full participation in IL by the designated populations. Based on the project's Analytical Research Framework, the four core areas of intervention development and testing include: (1) increasing the knowledge base about the emerging universe of disability, (2) community participation and wellness, (3) cultural IL accommodations, and (4) personal and systems advocacy. This project participates in the NIDRR Scholars program, providing motivated undergraduates with internship experience in disability research.

**CIL MANAGEMENT  
CENTER (RRTC-ILM)**

[www.wnyilp.org/RRTCILM/index.html](http://www.wnyilp.org/RRTCILM/index.html)

The Western New York Independent Living Project, Inc.

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Buffalo, NY 14214-1384

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RRTC-ILM helps Centers for Independent Living (CIL) become integrated more fully with their communities, this project identifies and applies best practices, finding examples

from both inside and outside the CIL network. The work is conducted embracing, supporting, and emulating the principles of the independent living philosophy, which encompass consumer control, self-help, advocacy, peer relationships, peer role models, and empowerment. The seven projects of the RRTC-ILM are: (1) developing a database of CIL profiles, aggregating the information required to develop and implement a set of related research, training, and dissemination projects whose best practices help to build a secure economic foundation for CILs; (2) designing and testing options for generating funding from alternative sources, through collaborations with others that include building business development strategies and analyzing the policy-related and programmatic consequences of various funding options (such as those independent of public financing); (3) identifying best practices and developing test programs that allow CILs to expand their services to youth with disabilities and their families, including

those from diverse cultural backgrounds, and to interface with existing educational and transitional programs to prepare children and youth for independent living; (4) modifying and testing management models of successful community-based organizations so those strategies benefit CILs; (5) investigating CIL and VR agency policies related to collaborations, and designing strategies for innovative partnerships that promote employment outcomes for individuals with disabilities; (6) coordinating activities with Rehabilitation Services Administration (RSA) and providing them instruments, curricula, methodologies, resource guides, and research findings; and (7) providing training and information for CIL policy-makers, administrators, and advocates on the RRTCs research findings and identified strategies.

**INDEPENDENT  
LIVING RESEARCH  
UTILIZATION  
PROGRAM AT THE  
INSTITUTE FOR  
REHABILITATION  
AND RESEARCH**  
[www.ilru.org](http://www.ilru.org)  
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Houston, TX 77019  
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The ILRU (Independent Living Research Utilization) program is a national center for information, training, research, and technical assistance in independent living. Its goal is to expand the body of knowledge of independent living and to improve utilization of results of research programs and demonstration projects in this field. It is a program of The Institute for Rehabilitation and Research. Follow this link for search for CILs in the United States and U.S. Territories:  
[www.ilru.org/html/publications/directory/index.html](http://www.ilru.org/html/publications/directory/index.html)

