

Ann Arbor Center for Independent Living

University of Michigan  
Model SCI Care System

Michigan Resource Guide  
for Persons with Spinal Cord Injury



# Social Policies & Advocacy

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Introduction

“If we don’t protect our rights,  
who will?”

*--Justin Dart*

Legislation and social policy can have a significant impact on the ability of persons with spinal cord injuries to live independently and be integral players in community life. Access to financial resources and to places of business, houses of worship, educational institutions, and other public accommodations have become much more of a reality due in part to the legislation and policies discussed here. Services crucial to health and independence, such as personal assistance services, are more available as a result of significant advocacy efforts by persons with disabilities and our allies.

This information is just a sampling of policy and legislation affecting independence and community participation. The more you know, the more access you have.

## People In Action

Reprinted from Winter  
2003 *SCI access*

### **Don Anderson: Part of the Solution** by Kathy Klykylo

Don Anderson was in junior high school in 1968 when he dived into a gravel pit and broke his neck. He survived, but he was paralyzed with a spinal cord injury. In the pre-halo splint days, he spent four months in a circle bed.

A self-described “jock” with “all the nasty prejudices against people with disabilities,” Don had played football and other sports. Very self-conscious about his disability and emaciated appearance, he only went out at night. After several summers in a rehabilitation hospital, he was told he would probably never have a full-time job or a quality life. Even though Don’s dream of graduating with his high school class was realized, he was socially isolated and very depressed. At Lansing Community College, Don asserted himself and asked strangers to

sign his petition to be on the ballot for student government. There were 10 open seats and he came in 11<sup>th</sup>. But one of the elected students transferred to another school, so Don got the last seat. While in school, he worked with issues of accessibility at the college and community level, and attended the

White House Conference on Needs of People with Disabilities in 1974. Though he didn’t know it, this was the beginning of his career in disability advocacy.

After graduation, Don lived at home with his parents, where he painted and wrote. Although life was comfortable, he wondered, “What about 10 years from now? Will I have to live in a nursing home?” Even with a graduate degree in counseling, he felt he was doing what he *could* do, not what he really *wanted* to do.



Donald Anderson, MA,  
Eastern Michigan  
University Access  
Services Office,  
Chair, UM Model SCI Care  
System Advisory Council

In 1983, 15 years after Don’s accident, two things changed the direction of his life. His mother died and he received a settlement from his diving accident, which provided a financial cushion for him. After a successful but unsatisfying job as a stockbroker, Don realized the work he had most enjoyed was in disability politics. “By this time I had learned about stigma and about internalized oppression. To refuse to do work for the disability community out of some false sense

of pride would be untrue to myself.” In 1992 he went to the Ann Arbor Center for Independent Living and witnessed the Americans with Disabilities Act (ADA) coming into its own. After five years at the AACIL, Don worked at Wayne State University in Services for Students with Disabilities, then recently came to Eastern Michigan University’s Access Services Office. Don likes the university environment because “It allows an aging radical like myself to be rewarded for stirring up trouble!” He thinks about the totally different society we will have in the future as an aging baby-boom population struggles with disability issues. He believes involvement with college students today will impact the world 20 years from now. Don has two sons—“great kids”—ages 18 and 14, several good friends, and a sister in Lansing with whom he remains very close. He still writes; is involved in local, state, and national politics; and chairs the UM Model SCI Advisory Council. He is also working on a business plan for a

resort/ spa/ conference center in the Caribbean for people with disabilities and their families. As a young man, Don’s biggest challenge was to get past internalized stigma about his disability. Today his challenges are living with the uncertainty of funding for persons with disabilities and dealing with day-to-day life with a disability. But Don says, “I have had fun and have been able to do an amazing number of things. I have been driven by the John F. Kennedy ethos, ‘If you are not part of the solution, you are part of the problem.’ I have been able to meet and work with so many cool people—like Justin Dart, Ed Roberts, and Judy Heumann. And I have been able to play a small role in making this a more accessible society.” This exemplifies Don’s modesty about his accomplishments as a true public servant. He has been, and continues to be, part of the solution.

**Advocacy:  
How to be  
Your Own  
Best Friend**

If you are having trouble gaining access to services, or if you feel like your rights are not being observed, there is nothing like a little self advocacy. Be your own best friend. No one can advocate for you and your needs like you! Make a persistent, polite pest out of yourself. Persistence succeeds like nothing else. Learn about the law. Learn what your rights are. It’s sad but true, but too often no one is standing over the shoulder of business or government agencies to make sure that they observe the Rehab Act or the ADA. No one, that is, but YOU!

Some practical tips on self-advocacy

Ask questions. Find out who is in charge and who can help with the matter at hand. Keep a notebook where you write down facts: name, date, telephone number,

and the title of the person to whom you are speaking. If they can not help, who can? Make them accountable. Follow up. If you get an answer you do not understand, or if someone gives you facts which you know to be wrong, say so. Always ask for the statement to be sent to you in writing. Make this request when speaking to insurance companies, health care providers, Medicaid, community agencies, hospitals, landlords, restaurant owners, business, government or non-profit agencies. Keep a file folder with written replies. Organize your subject matter either chronologically or by subject. Join an advocacy group that focuses on your area of concern. There is strength in numbers. A call to your local CIL can provide tips on where to find others concerned about the same things. You can make a change. You can make a difference.

## Advocacy Groups

### **MICHIGAN DISABILITY RIGHTS COALITION (MDRC)**

[www.copower.org/mdrc/MDRC.htm](http://www.copower.org/mdrc/MDRC.htm)  
780 West Lake Lansing  
Road, Suite 200  
Lansing, MI 48823  
800-760-4600

MDRC works to build opportunities for people with disabilities so they may live fully integrated lives within their chosen communities, now and in the future. Full citizenship is the expected role that people with disabilities will play, and their hopes and dreams parallel those of citizens without disabilities.

MDRC is a state-wide network of individuals and organizations that advances the issues of Michigan's disability community through grassroots activism, public education and advocacy.

### **NOT DEAD YET**

<http://www.mcil.org/mcil/mcil/ndy.htm>

The Memphis CIL  
1633 Madison Avenue,  
Memphis, TN 38104  
(901) 726-6404  
Since 1983, many people with disabilities have opposed the assisted suicide and euthanasia movement. Though often described as compassionate, legalized medical killing is really about a deadly double standard for people with severe disabilities, including both conditions that are labeled terminal and those that are not.

### **NATIONAL ASSOCIATION OF THE PHYSICALLY HANDICAPPED**

[www.naph.net](http://www.naph.net)  
7545 Staeger Street  
Akron, OH 44306  
Gerri Meadows  
734-623-8651  
(MI contact)  
800-743-5008  
(access 01)  
This is a national organization of physically handicapped adults and non-handicapped associates banded together to advance the social, economic and physical welfare of people with disabilities.

**NATIONAL  
COUNCIL ON  
DISABILITY**

[www.ncd.gov](http://www.ncd.gov)

The National Council on Disability (NCD) is an independent federal agency making recommendations to the President and Congress on issues affecting 54 million Americans with disabilities. NCD is composed of 15 members appointed by the President and confirmed by the U.S. Senate. In its 1986 report *Toward Independence*, NCD first proposed that Congress should enact a civil rights law for people with disabilities. In 1990, the Americans with Disabilities Act was signed into law.

NCD's overall purpose is to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities, regardless of the nature or severity of the disability; and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, inclusion and integration into all aspects of society.

NCD is currently coordinating a multi-year study on the implementation and enforcement of the ADA and other civil rights laws.



**Rehabilitation  
Act of 1973**

The Rehabilitation Act of 1973 made possible all the governmental agencies and departments that support today's programs for people with disabilities. It was the original disability legislation in the United States.

The Rehabilitation Act of 1973 is the federal legislation that authorizes the formula grant programs of vocational rehabilitation, supported employment, independent living, and

client assistance. It also authorizes a variety of training and service discretionary grants administered by the Rehabilitation Services Administration.

The Act authorizes research activities that are administered by the National Institute on Disability and Rehabilitation Research and the work of the National Council on Disability. The Act also includes a variety of provisions focused on rights, advocacy and protections for individuals with disabilities. For more information:

[www.ed.gov/about/offices/list/osers/rsa/index.html](http://www.ed.gov/about/offices/list/osers/rsa/index.html)

"You must be the change you wish to see in the world."

--Gandhi

## Americans With Disabilities Act

The Americans with Disabilities Act is probably one of the single most important pieces of legislation passed for citizens with disabilities. Signed into law in July of 1990, it is composed of three sections which cover these areas: Employment (Title I), Discrimination (Title II), and Public & Commercial Accommodations (Title III). While it has taken whole volumes to describe what protections each of these offers the disabled, it is important to know that they are there, and that governmental bodies, especially, are obligated to abide by them. “Enactment of the ADA reflects deeply held American ideals which treasure the contributions which individuals can make when free from arbitrary, unjust, or outmoded societal attitudes and practices that prevent the

realization of their potential.” (ADA Handbook, Preamble, page 1. Published by the Equal Employment Opportunity Commission and the Department of Justice) The Resources section below, Resources, outlines some of the sources that can help you learn more about how the ADA can help you to know your rights to prevent discrimination, and to obtain equal access to facilities.



## The New Freedom Initiative

President Bush announced the New Freedom Initiative on February 1, 2001, as part of a nationwide effort to remove barriers to community living for people with disabilities. The New Freedom

Initiative is a comprehensive plan that represents an important step in working to ensure that all Americans have the opportunity to learn and develop skills, engage in productive work, make choices about their daily lives and participate fully in community life. The initiative’s goals are to

- Increase access to assistive & universally designed technologies,
- Expand educational opportunities,
- Promote home ownership,
- Integrate Americans with disabilities into the workforce,
- Expand transportation options, and,
- Promote full access to community life.

To learn more, click on: [www.usdoj.gov/crt/ada/adahom1.htm](http://www.usdoj.gov/crt/ada/adahom1.htm)

## Resources

ADA Home Page: [www.usdoj.gov/crt/ada/adahom1.htm](http://www.usdoj.gov/crt/ada/adahom1.htm)

The U.S. Department of Justice provides information about the Americans with Disabilities Act (ADA) through a toll-free Information Line. This

service permits businesses, State and local governments, or others to call and ask questions about general or specific ADA requirements including questions about the ADA Standards for Accessible Design.

ADA specialists are available Monday through Wednesday and Friday from 10:00 AM until 6:00 PM and on Thursday from 1:00 PM until 6:00 PM.



For general ADA information, answers to specific technical questions, free ADA materials, or information about filing a complaint, call:

**800-514-0301\***

\*Spanish language service is also available.

The ADA prohibits discrimination on the basis of disability in:

-- Places of public accommodation, including all hotels, restaurants, retail stores, theaters, health care facilities, convention centers, parks, and places of recreation;

-- Activities of state and local governments, including public transportation and employment; and

-- Employment practices of private employers with 15 or more employees.

**MICHIGAN ADA STEERING COMMITTEE  
Michigan Protection and Advocacy Service, Inc.**

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

Livonia Corporate Towers  
29200 Vassar Blvd.  
Suite 200

Livonia, MI 48152-2116  
800-414-3956

**Services of the Great Lakes ADA & IT Access Center:**

[www.adagreatlakes.org](http://www.adagreatlakes.org)  
1640 Roosevelt Road  
Room 405

Chicago, IL 60608  
800-949-4232

Technical Assistance

The regional Disability and Business Technical Assistance Centers operate a national toll-free information line for answering questions about the ADA. Anyone seeking information is encouraged to use this service.

800-949-4232 (Voice/TTY)

Education and Training

The GLDBTAC provides training on request, tailored to the specific needs of each group, agency or company. The GLDBTAC also partners with agencies throughout the year to offer general education seminars. The Center's professional training staff has over 75 years experience in disability law, issues and trends. Training sessions include lecture, discussion and hands-on participation. Training topics can include:

- Employment rights & responsibilities (job descriptions, interviewing, medical inquiry)
- Reasonable accommodations

- State & local government responsibilities
- Disability awareness
- Modification of policy & practices
- Accessibility standards & guidelines
- Effective communication
- Subject specific (i.e. accessing emergency response systems, child care, or recreation environments).

#### Referral Network

The GLDBTAC maintains a database of resources available in our region as well as throughout the United States regarding the ADA. Such resources include written material, consultants, architects, educators, model programs, and other services specializing in accommodating the needs of people with disabilities.

The GLDBTAC supports a Steering Committee in each of the six states served. The State Steering Committees have become the GLDBTAC's main source for developing and implementing local

initiatives. They are composed of individuals representing disability, business, and government entities. The Committees are responsible for enhancing the capacity of individuals and groups to address ADA issues at the local level. This is accomplished through the provision of technical assistance, training and dissemination of materials.

- [ADA for Illinois](#)
- [Indiana State ADA Steering Committee](#)
- [ADA-Ohio](#)
- [Michigan State ADA Steering Committee](#)
- [ADA Minnesota](#)
- [ADA Wisconsin Partnership](#)

#### Materials Dissemination

A library of materials on the ADA, other legislation affecting people with disabilities, and related issues is maintained by the Center. Copies of materials are available in alternative formats - Braille, large print, computer disk, cassette tape, etc.

#### **ADA WATCH**

[www.adawatch.org](http://www.adawatch.org)  
2000 M Street NW  
Suite 400  
Washington, DC 20035  
202-467-2328  
Email:  
[ADAwatch@aol.com](mailto:ADAwatch@aol.com)

ADA WATCH is an informational online network designed to activate grassroots responses to threats to the ADA. We educate and inform people with disabilities, disability advocates, members of the general public, the business community, policy makers, and the media regarding threats to the civil rights of people with disabilities. We also provide support to the ADA WATCH coalition, a national network of organizations united to protect and strengthen the ADA. The ADA WATCH campaign is supported by our partnership with Wired On Wheels, a non-profit Internet accessibility rating service.

#### **STEVE GOLD'S TREASURED BITS OF INFORMATION NEWSGROUP**

[www.stevegoldada.com](http://www.stevegoldada.com)  
Archived articles from attorney Steve Gold.  
These are tools on how

to enforce the Americans with Disabilities Act. An excellent place to start when you need practical “how-to” tips.

Email:  
[GoldADA@cs.com](mailto:GoldADA@cs.com)

More  
Important  
Web Links

**Advocacy Groups and Resources:**  
[www.michigan.gov/mdcd/0,1607,7-122-1558-40725--,00.html](http://www.michigan.gov/mdcd/0,1607,7-122-1558-40725--,00.html)

**A Capital Idea! Successful Strategies for Getting What You Want**  
[www.afb.org/info\\_document\\_view.asp?documentid=1065](http://www.afb.org/info_document_view.asp?documentid=1065)

**Disabled Peoples International**  
[www.dpi.org](http://www.dpi.org)

**The DRM WebWatcher Advocacy Document**  
[www.disabilityresources.org/ADVOCACY.html](http://www.disabilityresources.org/ADVOCACY.html)

**The DRM Regional Resource Directory: Michigan**  
[www.disabilityresources.org/MICHIGAN.html](http://www.disabilityresources.org/MICHIGAN.html)

**FindLaw for the Public**  
[www.public.findlaw.com](http://www.public.findlaw.com)

**FCIC - The Consumer Action Handbook Online Edition**  
[www.consumeraction.gov](http://www.consumeraction.gov)

**FirstGov -- Your First Click to the US Government**  
[www.firstgov.gov](http://www.firstgov.gov)

**Government Guide: Free Money**  
[www.governmentguide.com/benefits\\_and\\_assistance/freemoney.adp](http://www.governmentguide.com/benefits_and_assistance/freemoney.adp)

**2005 Red Book on Employment Support**  
[www.socialsecurity.gov/redbook/eng/main.htm](http://www.socialsecurity.gov/redbook/eng/main.htm)

A summary guide to employment support for individuals with Disabilities under the Social Security Disability Insurance and Supplemental Security Income Programs. An excellent resource, written in an easy-to-understand manner.

**National Consumer Law Center (NCLC)**  
Consumer pamphlets  
<http://www.consumerlaw.org>

**Search Systems**  
Largest free public records database collection  
[www.searchsystems.net](http://www.searchsystems.net)

