

**ILRU Community
Living Partnership**

National State-to-State
Technical Assistance Center



PARTNERS

INDEPENDENT LIVING
RESEARCH UTILIZATION
(ILRU)

BOSTON COLLEGE GRADUATE
SCHOOL OF SOCIAL WORK

FAMILY VOICES, INC.

HUMAN SERVICES
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INSTITUTE FOR
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INSTITUTE ON DISABILITY
UNIVERSITY OF
NEW HAMPSHIRE

UTAH STATE UNIVERSITY
(CENTER FOR PERSONS
WITH DISABILITIES)

STUDY GUIDE

To accompany DVD

INDEPENDENT LIVING HISTORY AND PHILOSOPHY

**Independent Living Research Utilization
At Memorial Hermann|TIRR and
Utah State University Center for Persons with Disabilities**

STUDY GUIDE

To accompany DVD

INDEPENDENT LIVING HISTORY AND PHILOSOPHY

- Module 1:** **A Brief History of Disability**
- Module 2:** **Emergence of Independent Living**
- Module 3:** **Codification of Independent Living: *It's the Law***
- Module 4:** **Disability Policy Framework and Advocacy**

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This study guide is a companion piece to the DVD IL History and Philosophy: Orientation for IL Staff produced by ILRU in collaboration with Utah State University Center for Persons with Disabilities. If you received the study guide without the DVD, contact ILRU to request a copy of the DVD.

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IL History and Philosophy

STUDY GUIDE TO ACCOMPANY DVD

Note to the Group Facilitator: The Study Guide is designed for small group discussion. The intent is to enable those involved in systems change and home- and community-based services to reflect on the lessons learned from the *IL History and Philosophy* DVD, and to apply these principles to their own work. Included in the Guide, by module, are general discussion questions, questions that require more research to answer, and a section “Do you want to know more?” containing a brief annotated bibliography of relevant resources. As a Facilitator, encourage the group members to share responses and build from each other’s ideas. Responses should not focus on the “correct answers” to these questions, but rather on how the issues examined impact the progress of systems change in your community and state.

MODULE 1: A BRIEF HISTORY OF DISABILITY

This module provides a historical perspective on Independent Living -- its role in shaping societal attitudes, defining what disability is, and creating solutions to the issues surrounding disability.

Discussion Questions for Module 1

- 1) As a child, how did you first learn about “disability?” How did that experience affect your perceptions and expectations of individuals with disabilities? In what ways have your perceptions and expectations changed?
- 2) Why do people without disabilities think they know what is best for people with disabilities? Discuss the concept of “benign paternalism.”
- 3) Read the quote from the U.S. Sanitary Commission following the Civil War: “As far as possible, invalids should be restored to their original homes, and the communities to which they belong should absorb them, by assigning to them, by conventional agreement, the lighter occupations; and no provisions separating them from their families or diminishing their domestic responsibilities should be encouraged.”

Has our society done this today? Are there still traces of paternalism in the language, for example: “absorb them,” and “lighter occupations”? In what ways is your state working to change the paternalistic approach?

- 4) Following the Civil War, World War I, and World War II, disabled veterans returning home were hailed as heroes. Other people with disabilities were not treated the same way and were often placed in long term institutional residences. Why do you think returning veterans were treated differently than other people with disabilities?
- 5) Do you believe that participating in civil disobedience can change how a person perceives their disability or who they are as a person with a disability?
- 6) What are the premises of the Brown v. Board of Education Supreme Court decision that became a foundation for the disability rights movement? What are examples of these?
- 7) What “segregated” programs for people with disabilities are there in your community? Are these perceived as discriminatory or appropriate? For example, are separate classrooms perceived as discriminatory or appropriate? What about separate residences (e.g., small group homes, small Intermediate Care Facilities)?
- 8) Who are the leaders in the disability advocates in your community? How have they been involved in your systems change efforts?

Research Questions for Module 1

- 1) Read the statement:

“Most organizations were formed and administered by people without disabilities (often parents and friends) acting on behalf of people with disabilities in ways they thought were best, with little input from the people with disabilities themselves.” Research the history of the American Association of People with Disabilities or the National Council on Independent Living (NCIL) as organizations formed by people with disabilities.
- 2) What impact is the war in Iraq and Afghanistan having on the perception and treatment of people with disabilities in the U.S. today?
- 3) Research the cochlear implant controversy in the deaf community.
- 4) Research the 1988 uprising at Gallaudet University over the appointment of a president who was not deaf.
- 5) Research the views of people with disabilities regarding “end of life” issues

Do you want to know more about Disability History?

Beyond Affliction: The Disability History Project

This four hour documentary radio series describes the shared experiences of people with disabilities and their families since the beginning of the 19th century. This Web site includes excerpts from the series as well as many of the primary source documents - extended interviews, images, and texts - from which the on-air programs were developed. <http://www.npr.org/programs/disability/>

Disability History Museum

Disability, like race and gender, is a central part of the human experience. The Museum's goal is to create a theme-based, searchable collection of primary source materials that will help expand knowledge and understanding about the historical experience of people with disabilities in the United States. The Disability History Museum's Library is a digital archive that only exists online. It contains digital versions of images, texts, and other artifacts -- related to disability history -- that have been gathered from libraries and private collections across the country. <http://www.disabilitymuseum.org/lib/>

The Disability History Dateline

An ongoing project of San Francisco State University's Institute on Disability, is designed to serve as a teaching and research tool. This ever-expanding chronology encompasses all aspects of the history of disability: major events, issues and themes, prominent individuals and organizations, cultural expressions and images, laws and public policies, activist and advocacy efforts, and more. The entries cover all historical eras and every geographical region, as well as referring to both disability-specific and cross-disability historical occurrences. Although many of the current entries have a U. S. focus, the Dateline is and increasingly will become world historical in scope. <http://bss.sfsu.edu/disability/dateline.html>

About the Brown v. Board of Education Case

Five legal cases, under the heading of Brown V. Board of Education, sought the same solution, to tear down the legal basis for racial segregation in schools and other public places. The Supreme Courts decision in 1954 drastically altered the future policies of human rights and changed the course of history. <http://brownvboard.org/summary>

Challenging Views on Euthanasia and other ethical issues

This book contains writings from Peter Singer, a philosopher of bioethics at Princeton University's Center for Human Values. It discusses his challenging views on animal rights, environmental accountability, abortion, euthanasia, and other ethical issues including the killing of unwanted neonates born with severe disabilities. Singer, Peter. (2000). *Writings on an Ethical Life*. New York: Ecco Press

Unspeakable Conversations: Harriet McBryde Johnson

Reflections by a disability activist and attorney from South Carolina who participated in a debate with Peter Singer, professor at Princeton University on issues of ethics and disabilities. <http://www.racematters.org/harrietmcbrydejohnson.htm>

Getting Life: a Novel

Getting Life offers a rare glimpse behind the closed doors of long term care. This fictional story draws readers into the wheelchair of Emily Mason, a 35-year-old nonverbal woman with cerebral palsy, and allows you to share each of her experiences—painful, thrilling, or confusing as she struggles to leave the nursing home behind and join the community. Cole, Julie Shaw (2000). *Getting Life*. Louisville: Avocado Press

Not Dead Yet

Many people are unaware that Hitler's extermination policies began with the large-scale elimination of people with disabilities. Proponents of physician- assisted suicide are offended when allusions are made to this piece of disability history in the course of debate over the so-called "right to die." The fact is that Hitler stole most of his ideas on eugenics from publications originating in the USA. Not Dead Yet is an organization that opposes legalized assisted suicide. <http://www.notdeadyet.org/>

MODULE 2: EMERGENCE OF INDEPENDENT LIVING

This module discusses the ways in which Independent Living philosophy and concepts differ from the medical model and traditional rehabilitation. The module familiarizes the listener with some of the disability leaders and events that launched, developed and now sustains the Independent Living movement.

Discussion Questions for Module 2

- 1) Medicaid was built on the “medical model.” It was deemed appropriate at the time. Now there are indications that Medicaid is moving toward a more consumer-directed approach. How is that movement playing out in your state? Provide examples.
- 2) Discuss Judy Heumann’s words: “I’m bitter about being handicapped, but not about having a disability.” What do you think she means?
- 3) What physical access barriers have you encountered in implementing your home- and community-based service program? How are you addressing them?
- 4) Are you aware of any civil actions led by ADAPT or other disability advocacy groups in your state? If so, what was their impact?
- 5) Section 504 of the Rehabilitation Act provides that no individuals with disabilities “. . . shall be excluded from participation in programs or activities receiving federal financial assistance.” Discuss why this provision was seen as radical and far-reaching in the early 1970s.
- 6) Discuss changes in society for people with disabilities in the past 10 years from a personal point of view, and, if appropriate, a systems point of view.
- 7) Describe the relationships your organization or program has currently with advocacy organizations? Which other groups do you need to reach out to accomplish the goals of systems change?
- 8) What are the reasons July 26 is celebrated as a birthday for the disability community? Do you recognize and celebrate this date?
- 9) In the early 1960’s, the Vocational Rehabilitation agency in California deemed Ed Roberts as “not feasible for employment.” Fourteen years later he was appointed as director of the same agency. Why did their perceptions change?
- 10) How are people with disabilities represented *within* your program? Within your organization?

- 11) By what authority did the American Coalition of Citizens with Disabilities (ACCD) give President Carter an ultimatum to sign the 504 regulations?
- 12) How does your program interface with diverse disability groups? Which groups do you have little or no contact with? Why?

Research Questions for Module 2

- 1) How did the polio epidemic in the 1940s and 50s influence the broader disability movement?
- 2) What types of disabilities are being acquired today? How is this trend impacting scientific research? How is it impacting treatment for other disabling conditions?
- 3) Research the concepts of “normalization” and “social role valorization”? Why are these concepts relevant to the disability movement?

Do you want to know more about the Emergence of Independent Living?

Disability Rights Movement

More than a history, *The Disability Rights Movement* documents the wrenching evolution of attitudes: From isolation and charity to confrontation and rights; from sheltered workshops to independent living; from telethons of pity to technology's power; from 'cripples' and 'invalids' to People with disabilities! Fleischer and Zames capture the substance and spirit of the disability rights movement and bring it to life. Fleischer, D., & Zames, F. (2001). *The Disability Rights movement: From Charity to Confrontation*. Philadelphia: Temple University

The history of the ADA: A Movement Perspective

This brief history of the ADA and the Disability Rights movement explains the barriers faced politically and socially. Disability advocates fighting for the rights of those with disabilities faced many challenges in passage of the ADA. Written by Arlene Mayerson. http://www.dredf.org/publications/ada_history.shtml

History of the Disability Rights Movement through Stories

With 35 million disabled Americans, the American with Disabilities Act and its implications are here to stay. Shapiro, a U.S. News & World Report journalist, explores in depth the thoughts, fears, and facts behind the disability rights movement. The premise throughout this compelling historical account is that there is no pity or tragedy in disability--it is society's myths, fears, and stereotypes that make being disabled difficult. Shapiro's coverage is thorough, ranging from the movement's beginnings in Berkeley in the 1960s to the issues that will emerge in the future. Shapiro, Joseph (1993). *No Pity*. Temple University Press.

Origins of IL model

DeJong proposed a shift from the medical model to the independent living model. This theory located problems or “deficiencies” in the society, not the individual. The answers were to be found in changing society, not people with disabilities. Most important, decisions must be made by the individual, not by the medical or rehabilitation professional. DeJong, Gerben (1979). Independent living: From social movement to analytic paradigm. *Archives of Physical Medicine and Rehabilitation*, v. 60, October 1979

Emergence of the Independent Living Movement

As with most major social changes or phenomena, the Independent Living (IL) movement did not happen over night in the U.S. There were many significant events in the 1960s and the 1970s that led to its rise and continue to shape its ongoing transition and growth. http://www.disabilityworld.org/09-10_03/il/ilhistory.shtml

Impact of Polio

Smithsonian National Museum of American History main site

In the United States, polio was the most notorious disease of the 20th century until AIDS appeared. On April 12, 1955, it was announced that Jonas Salk, using March of Dimes donations from millions of people, had developed a vaccine to prevent polio.

<http://americanhistory.si.edu/polio/howpolio/disability.htm>

A Memoriam to Justin Dart from Justice for All

The disability rights community lost its greatest leader in Justin Dart Jr. on June 22, 2002. Among his many accomplishments, contributions, and honors, Dart was also the visionary leader who gave life to Justice For All and personally funded its development from 1995 to July 2001. <http://www.aapd.com/JFA/JFAMemoriam.html>

Another remembrance of Justin Dart

This obituary of Justin Dart was written by Fred Faye and Fred Palka. Justin’s role in the conceptualization and writing of the ADA is discussed as well as tributes from others in the disability community. <http://www.namisc.org/Experiences/2002/JustinDart.htm>

Disability Studies Perspective on Independent Living

Paul Longmore urges us to establish disability as a category of social, political, and historical analysis in much the same way that race, gender, and class already have been. The essays here search for the often hidden pattern of systemic prejudice and probe into the institutionalized discrimination that affects the one in five Americans with disabilities. Longmore, Paul K. (2003) Chapter 5: The Disability Rights Movement Activism in the 1970s and Beyond. *Why I Burned My Book and Other Essays on Disabilities*, Temple University Press.

Concept of ‘Normalization’

Wolfensberger’s critique of human services and his teachings about the way in which people with disabilities are systematically devalued by the culture gives us different insights into our role in the way people with disabilities are treated and viewed in society. Wolfensberger, Wolf (1972). *The Principle of Normalization in Human Services*. Toronto: National Institute on Mental Retardation.

MODULE 3: CODIFICATION OF INDEPENDENT LIVING: *IT'S THE LAW!*

This module discusses the story of Nick Dupree and how he changed the system in his state by advocating for in-home Medicaid personal assistance services. This module provides an understanding of the statutory, legal and regulatory aspects of IL in order to understand how we may change society through existing laws.

Discussion Questions for Module 3

- 1) How does Nick's Dupree's situation reflect the institutional bias in Medicaid?
- 2) How does the IL philosophy differ from rehabilitation? Are they mutually exclusive?
- 3) What is the power and importance of peer support?
- 4) Describe how consumer control is operationalized in your program?
- 5) What is the difference between case advocacy and class advocacy? Does your program focus on consumer direction or change at the system level?
- 6) List the ILCs in your community and/or state and the other major organizations advocating for people with disabilities. What is their role in your project?
- 7) How does the goal of Independent Living differ from other advocacy organizations? How does your organization support the goal of IL?
- 8) How has each reauthorization of the Rehabilitation Act changed the expectations of Independent Living Centers?

Research Questions for Module 3

- 1) Research one of the following federal laws and describe its strengths and its limitations as it is currently being implemented.
 - Architectural Barriers Act
 - Individuals with Disabilities Education Act
 - Technology Act
 - Ticket to Work and Work Incentives Improvement Act
- 2) Since housing and transportation are the most identified barriers to full participation in the communities, look at both housing and transportation laws.

- Research the Fair Housing Act. What agency or agencies administer housing programs? What agency enforces the Fair Housing civil rights protections? What changes are occurring in this area?
 - What agency is in charge of transportation in your state? What are the federal rules they have to follow? How effective is the transportation system in your community? What is the process for effecting changes to the system? How well does it work?
- 3) How has the Individuals with Disabilities Education Act (IDEA) changed the types of supports that adults with disabilities need?

Do you want to know more about Codification of Independent Living?

A Medicaid Victory

The story of Nick Dupree was broadcast on National Public Radio by Joseph Shapiro. Listen and read about Nick's battle against Alabama Medicaid to get in-home and community supports after he turned 22.

<http://www.npr.org/templates/story/story.php?storyId=974391>

Useful guide on Medicare and Medicaid for consumers with disabilities

This guide explains the critical role Medicare and Medicaid have in the lives and the futures of children, adults, and seniors with disabilities - and gives people with disabilities useful information to help them get the most from these programs. *Navigating Medicare and Medicaid, 2005: A Resource Guide for People with Disabilities, Their Families, and Their Advocates* is published by the Kaiser Family Foundation.

<http://www.kff.org/medicare/index.cfm>

Terms and Leaders in the Independent Living Movement.

This guide defines commonly used acronyms and terms used in discussing disability, such as IDEA, ADAPT, OSERS, and ADAAG, independent living philosophy and advocacy. It also has brief bios of disability leaders, such as Ed Roberts, Judy Heumann, Justin Dart, and Kyle Glozier. IL 101 - Terms and Leaders in the Independent Living Movement (2002). http://www.ilru.org/html/projects/ilnet/ilnet_manuals.htm

Comparison Chart - Rehabilitation and Independent Living

A simple chart compares the rehabilitation paradigm and the independent living paradigm. This chart clearly summarizes the major differences between these perspectives on disability. The chart was developed by Maggie Shreve and June Isaacson Kailes. http://www.pacecil.org/downloads/paradigm_comparison_chart.pdf

Brief History of IL

If you want to read more about the difference in philosophy between rehabilitation and independent living, this website has an article titled: *The Movement for Independent Living: A Brief History* by Maggie Shreve.

http://www.ilusa.com/articles/mshreve_article_ilc.htm

Disability Studies as a Field of Study

Claiming Disability is the first comprehensive examination of Disability Studies as a field of inquiry. Disability Studies is not simply about the variations that exist in human behavior, appearance, functioning, sensory acuity, and cognitive processing but the meaning we make of those variations. With imagery and examples, Simi Linton explores the divisions society creates—the normal versus the pathological, the competent citizen versus the ward of the state. Simi Linton, *Claiming Disability: Knowledge and Identity*, New York University Press, 1995.

Disability Studies Perspective on Independent Living

Longmore, Paul K. (2003) Chapter 5: The Disability Rights Movement Activism in the 1970s and Beyond. *Why I Burned My Book and Other Essays on Disability*, Temple University Press.

Consumer Control

This journal article examines the empirical evidence for consumer-directed services at home for persons with disabilities. It addresses: responsibility for key service decisions, management of home care services, and the impact of consumer direction. A.E. Benjamin, December 2001, Consumer-directed services at home: A new model for persons with disabilities, *Health Affairs*, 20:6.

Involving Consumers in quality improvement

This document was an outgrowth of the Cash and Counseling demonstration projects. It presents specific approaches for assuring and improving quality of consumer directed services, and provides resources and information for how to involve consumers as active participants in quality improvement. Produced by the Scripps Gerontology Center at Miami University. A Guide to Quality in Consumer Directed Services (2004). Screen reader version <http://www.hcbs.org/files/43/2100/Guidefronts.html> PDF version <http://www.hcbs.org/files/42/2099/Guidefront.pdf>

DisabilityInfo.gov

The federal government's one-stop Web site for information of interest to people with disabilities, their families, employers, service providers and many others. Topics include: employment, education, housing, transportation, health, technology, community life, and civil rights. www.disabilityinfo.gov

Nothing About Us without Us: Disability Oppression and Empowerment

In the book with this title, James Charlton weaves stunning oral histories of disability activists from ten different countries across five continents. The author argues that barriers to independent living are embedded in the larger social and economic environment. This political manifesto obtains its energy from the author's commitment, anger, and outrage. James Charlton (1998), University of California Press.

Guide to Disability Rights Laws. Concise summaries of all federal disability rights laws, including Americans with Disabilities Act, Fair Housing Act, Air Carrier Access Act, Telecommunications Act, Architectural Barriers Act, Individuals with Disabilities Education Act. The U.S. Department of Justice has produced A Guide to Disability Rights Laws (September, 2005) <http://www.usdoj.gov/crt/ada/cguide.htm>

MODULE 4: DISABILITY POLICY FRAMEWORK AND ADVOCACY

This module explains a framework or set of concepts to help you determine if the work you are engaged in is consistent with IL philosophy. This set of concepts is called the disability policy framework. The module also discusses current and future challenges for the IL movement.

Discussion Questions for Module 4

- 1) What does the phrase “disability is a natural part of the human experience” mean? How would decisions made from this perspective be different than decisions made from a medical model perspective? How do you react personally to the statement?
- 2) What does “fix the environment and not the person” mean in reality? What is your state doing to “fix the environment”?
- 3) From your perspective, what policies and procedures prevent people with disabilities from being productive?
- 4) CILs are required to have 51% of people with disabilities on their boards and staff. If this was the rule in your organization, what would it mean?
- 5) Does your program provide services across disability groups? Across racial and ethnic groups? Psychiatric disabilities, developmental disabilities, physical disabilities? If it does, describe how that happened? If not, what needs to be done to make it happen? What group or groups are left out and why?
- 6) How does your program ensure that the recipients of your program get good information about work incentives? What is one step your program can take to advance this work further?

Research Questions for Module 4

- 1) Does your program comply with Bobby Silverstein’s four goals of disability policy?
- 2) Research the current progress of implementing the Olmstead decision in your state.
- 3) What personal assistance services does your state Medicaid program provide? Who can get personal assistance? What is the eligibility?
- 4) What is the current status of the MiCassa or Money Follows the Person legislation in Congress? If these are enacted how will your program be impacted? Why is this idea critical to the concept of living in the

community? How would it affect the people in the program you serve?
How would it affect their ability to stay / live in the community?

- 5) What is your state doing to implement nursing home diversion, that is, providing supports that prevent individuals from entering nursing facilities? What are you doing to help people leave nursing facilities?

Do you want to know more about the Disability Policy Framework and Advocacy?

Original Disability Policy Framework

Read Bobby Silverstein's original article outlining his famous Disability Policy Framework. The framework can be used as a guidepost to evaluate generic, as well as disability-specific, public policies and programs to ensure meaningful inclusion of people with disabilities in mainstream society. It is re-printed on this website: Emerging Disability Policy Framework: A Guidepost for Analyzing Public Policy. *Iowa Law Review*, August 2000, Volume 85, No 5. Text version:

http://disability.law.uiowa.edu/csadp_docs/ILR0800.txt; MSWordversion:

<http://archives.communityinclusion.org/publications/policydocs/lawreview.doc>.

Major Disability Legislation

In the Appendix of this famous article, Silverstein lists the major disability related legislation from 1956-2000. *Iowa Law Review*, August 2000, Vol. 85/No. 5.

http://disability.law.uiowa.edu/csadp_docs/APPENDIX_2_APR.doc (MS Word file)

http://disability.law.uiowa.edu/csadp_docs/APPENDIX_2_APR.txt (text file)

Controversy Over the Use of Statistics and Data

This article connects standard research methodology concepts with the complexities of evaluating disability policy using national data sets. The purpose of the article is to help policymakers and others recognize unwarranted cause-and-effect policy conclusions based solely on existing national survey data and demand better data and stronger research designs to complement the potential over-reliance on correlational studies using problematic survey data to estimate policy impacts. To this end, the article concludes with a practical framework for assessing the adequacy of research regarding the employment rate of persons with disabilities. Robert Silverstein, George Julnes, and Renee Nolan.

What Policymakers Need and Must Demand From Research Regarding the Employment Rate of Persons with Disabilities. *Behavioral Sciences and the Law*, Volume 23, Issue 3, pages 399-448, June 2005. John Wiley & Sons, Ltd.

<http://www.disabilitypolicycenter.org/disabpol.htm>

The Framework and Intellectual Disabilities

Silverstein, Robert (2003). Chapter 10: Statutory Changes in Disability Policy: Types of Legislation, Policies, Goals in *The Human Rights of Persons with Intellectual Disabilities: Different But Equal*, in Stanley S. Herr, Ed. Oxford University Press. This book analyzes human rights and disability rights -- the global struggle to realize equality, dignity, and comprehensive human and civil rights for persons with intellectual

disabilities. In this chapter Bobby Silverstein applies his framework to an analysis of U.S. legislation.

Sound and Fury: Cochlear Implants

A PBS documentary discusses the cochlear implant controversy. Since it was first approved for testing in 1985, the cochlear implant has been engulfed in a storm of controversy. Does the cochlear implant pose a serious threat to deaf culture? Can people with the implant function effectively as members of the hearing world? Do the results justify the expense of surgery and therapy? Two advocates for the hearing impaired discuss these issues. <http://www.pbs.org/wnet/soundandfury/cochlear/debate.html>

State Work Incentive Initiatives

The site includes descriptions of the numbers and characteristics of persons with significant disabilities; descriptions of federal law (including the Ticket to Work and Work Incentives Improvement Act); model state legislation; descriptions of cross-disability Executive and Legislative initiatives; initial planning information gathering and program and fiscal estimates; state work incentives policy options (Medicaid Buy In, Medicaid Waivers, and Income Assistance Demonstrations); emerging implementation. A Resource Center for Developing and Implementing Medicaid Buy In and Related Employment Programs for Persons with Disabilities.

<http://www.uiowa.edu/~lhpdc/work/index.html>

Nursing Home Transition

If you are interested in state systems change resources to help with moving people with disabilities from nursing homes into the community, you can find helpful materials on this subject. You can search by topic, type of resource (manual, tool, etc) or even by state. This site has resources for states working on systems change to better support individuals with disabilities. Michigan's "Going Home" is a particularly good resource on this topic. www.hcbs.org

MiCASSA legislation

A brief description of the congressional bill titled "Medicaid Community Attendant Services and Supports Act" (MiCASSA). The bill proposes community-based alternatives to nursing homes and institutions for people with disabilities on ADAPT's website.

<http://www.adapt.org/casaintr.htm>

A Twenty-five Year History of the IDEA

<http://www.ed.gov/policy/speced/leg/idea/history.html>

History and Current status of the Developmental Disabilities Act

http://www.md-council.org/about/dd_act.html

Read the original Supreme Court Olmstead Decision

In the U.S. Supreme Court Decision, *Olmstead v. L.C. and E.W.*, the Court decided that the State of Georgia was discriminating against Lois Curtis and Elaine Wilson by not allowing them to leave the state institution and have supports to live in the community. The full text of the Supreme Court decision is at <http://supct.law.cornell.edu/supct/html/98-536.ZS.html>

Olmstead Implementation State-by-State

This report from the National Council on Disability (NCD) describes the progress made in implementing the Supreme Court decision. You can click on your state name and read the NCD's assessment of progress to date for your state. *Olmstead: Reclaiming Institutionalized Lives (Abridged Version)*. www.ncd.gov/newsroom/publications/2003/reclaimabridged.htm

Personal Assistance Services (PAS) Policy and Practices

The website for The Center for Personal Assistance Services is a good place to find the latest information on personal assistance services (PAS) in the United States. It addresses issues such as: the relationship between formal and informal PAS; support for caregivers; the role of assistive technology (AT) in complementing PAS; policies and programs, barriers, and new models for PAS in the home and community; PAS Workforce development, recruitment, retention, and benefits; and workplace models of formal and informal PAS and AT at work. www.pascenter.org/home/index.php

ADVOCACY ORGANIZATIONS AND INFORMATION NETWORKS

ADAPT

American Disabled for Attendant Programs Today (ADAPT) website advocating for people with disabilities to live in the community with supports instead of nursing homes. www.adapt.org/

The Disability Rights Education and Defense Fund

DREDF is a national law and policy center dedicated to protecting and advancing the civil rights of people with disabilities through legislation, litigation, advocacy, technical assistance, and education and training of attorneys, advocates, persons with disabilities, and parents of children with disabilities. www.dredf.org/

Bazelon Center for Mental Health Law (BCMHL):

A national legal advocate for people with mental disabilities. Through precedent-setting litigation and in the public policy arena, the Bazelon Center works to advance and preserve the rights of people with mental illnesses and developmental disabilities. <http://www.bazelon.org>

Center for Self-Determination

A center that is a highly interactive working collaborative of individuals and organizations committed to the principles of self-determination. The purpose of the collaborative is to change the nature of the support and service system for individuals with disabilities, using the principles of self-determination to help all persons create the lives they want, connected to and with their communities. <http://www.self-determination.com>

National Disability Rights Network

The National Disability Rights Network represents the needs of Protection and Advocacy Agencies (P&As) and Client Assistance Programs (CAPs) to federal agencies and Congress and provides training and technical assistance to member agencies which helps their effectiveness on the state and local level. This is an excellent site for current legislative activities. <http://www.ndrn.org/>

The Ragged Edge

Ragged Edge magazine is successor to the award-winning periodical, The Disability Rag. Includes: today's writing about society's "ragged edge" issues: medical rationing, genetic discrimination, assisted suicide, long-term care, attendant services. It covers the disability experience in America -- what it means to be a "crip" living at the start of the 21st century. www.ragged-edge-mag.com/

Justice for All Email Network

Justice For All and our JFA E-mail Network were formed to defend and advance disability rights and programs in Congress. One JFA goal is to work with national and state organizations of people with disabilities to get the word from Washington D.C. out to the grassroots. www.jfanow.org/ JFA alerts both by subscribing to the Mailing List and by having access to past alerts.