Demonstrating a Process for Systemic Advocacy

Ohio Centers for Independent Living (CIL)
Disability Rights Ohio (DRO)

Disability Advocacy Seminar Series
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The chat feature is disabled. Please type questions in the Q&A.

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Live captions are also enabled. Go to the subtitle settings to enlarge captions on your individual screen.

Please pin the ASL interpreter as needed.

A transcript will be available by request approximately one week after the presentation.
The mission of this workshop is to educate individuals with disabilities about how to become their own advocate and to demonstrate effective ways to engage in systemic advocacy.

- Objective 1: Understanding of Disability History, the Disability Rights Movement, Grassroots Advocacy and Community Organizing
- Objective 2: Understanding of civil rights violation, lobbying, how a bill becomes a law, state vs. federal legislation, and local policy
- Objective 3: How to become involved with government, addressing issues with legislators, effective letter writing, and giving testimony
- Objective 4: An understanding of creating coalitions, recruiting, and marketing
A Little History Worth Knowing

In this century, democratically elected state legislatures have referred to people with disabilities as:

- “anti-social beings” (Pennsylvania)
- “unfit for companionship with other children” (Washington)
- “a blight on mankind” (Vermont)
- “a danger to the race” (Wisconsin)
- “a misfortune both to themselves and to the public” (Kansas)
- "required to be segregated from the world" (Indiana)
- “a defect...wounds our citizenry a thousand times more than any plague” (Utah)
- "do not have the right to liberties of normal people" (South Dakota)
The United States Supreme Court upheld an opinion by Justice Oliver Wendell Holmes upholding the constitutionality of a Virginia law authorizing the involuntary sterilization of disabled persons and ratified the view of a person with a disability as a "menace." Holmes went on to say that people with disabilities "sap the strength of the state" and to avoid "being swamped with incompetence," he ruled, "It is better for our world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind."
Justice Antonin Scalia said he saw *no constitutional reason* why state agencies cannot discriminate against persons he referred to as 'handicaps.'

Some states 'may not have made it easy for handicaps to vote,' he said, but that is not reason enough for Congress to subject states to lawsuits, he said.

Chief Justice William H. Rehnquist agreed
Independent Living

- A movement
- A Civil Rights Movement
- A Social Movement
Social Movements

Deinstitutionalization

- an attempt to move people, primarily those with developmental disabilities, out of institutions and back into their home communities.
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.
The "Self-Help" Movement

- really began in the 1950s with the founding of Alcoholics Anonymous, came into its own in the 1970s. Many self-help books were published and support groups flourished.

*Self-help and peer support are recognized as key points in independent living philosophy.*
De-medicalization

- a movement that began to look at more holistic approaches to health care.
Consumerism

- one in which consumers began to question product reliability and price.
Independent Living Leaders

- Ed Roberts
  - “father of independent living”
- Judy Heumann
  - New York Activist
  - With Ed started first IL center
- Joan Leon
  - Co founded the World Institute on Disability with Ed and Judy
- Wade Blank
  - Founded Atlantis and ADAPT
More leaders in the movement...

- Max Starkloff, Charlie Carr, and Marca Bristo founded National Council on Independent Living

- Justin Dart:
  - played a prominent role in the fight for passage of the Americans with Disabilities Act
  - seen by many as the spiritual leader of the movement today

- Lex Frieden:
  - co-founder of Independent Living Research Utilization (ILRU)
  - directed preparation of the original ADA legislation and its introduction in Congress.

- Liz Savage and Pat Wright: "mothers of the ADA"
Several laws support the notion of civil rights for people with disabilities.
Civil Rights Laws

1964--Civil Rights Act
1968--Architectural Barriers Act
1970--Urban Mass Transit Act
1973--Rehabilitation Act
1975--Developmental Disabilities Bill of Rights Act
1975--Education of All Handicapped Children Act
1978--Amendments to the Rehabilitation Act
1983--Amendments to the Rehabilitation Act
1985--Mental Illness Bill of Rights Act
1988--Civil Rights Restoration Act
1988--Fair Housing Amendments Act
1990--Americans with Disabilities Act
Rehabilitation Act of 1973

- Passed by Congress in 1972
- Veto by Nixon prevented from law
- Disability activists launched fierce protests across the country
- Judy Heumann, staged a sit in on Madison Avenue with eighty other activists
- September 1973: Congress overrode Nixon's veto - finally became law
Key language in the Rehabilitation Act, found in Section 504 of Title V, states that:

- No otherwise qualified handicapped individual in the United States shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance.
Rehab Act Regulations

- 1977: Nixon & Ford gone – Carter President
- Joseph Califano is Secretary of Health, Education and Welfare
- Refused to issue regulations
- Was given an ultimatum and deadline of April 4, 1977
April 5, 1977

- demonstrations in 10 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.
- more than 150 people with disabilities, had taken over the federal office building and refused to leave.
- stayed until May 1. Califano had issued regulations by April 28, but the protesters stayed until they had reviewed the regulations and approved of them.
STANDARDS FOR INDEPENDENT LIVING CENTERS

(1) Philosophy. The center shall promote and practice the independent living philosophy of:

(A) consumer control of the center regarding decision making, service delivery, management, and establishment of the policy and direction of the center;

(B) self help and self advocacy;

(C) development of peer relationships and peer role models; and

(D) equal access of individuals with severe disabilities to society and to all services, programs, activities, resources, and facilities, whether public or private and regardless of the funding source.
(2) Provision of services. The center shall provide services to individuals with a range of severe disabilities. The center shall provide services on a cross disability basis (for individuals with all different types of severe disabilities, including individuals with disabilities who are members of populations that are unserved or underserved by programs under this Act).

- Eligibility for services at any center for independent living shall not be based on the presence of any one or more specific severe disabilities.
Develop Goals for Independent Living

(3) Independent living goals. The center shall facilitate development and achievement of independent living goals selected by individuals with severe disabilities who seek such assistance by the center.
Increase Community Options

(4) Community options. The center shall work to increase the availability and to improve the quality of community options for independent living in order to facilitate the development and achievement of independent living goals by individuals with severe disabilities.
Provide Core Services

(5) Independent living core services. The center shall provide independent living core services and, as appropriate, a combination of any other independent living services specified in section 7(30)(B).
(6) Activities to increase community capacity. The center shall conduct activities to increase the capacity of communities within the service area of the center to meet the needs of individuals with severe disabilities.
Conduct Resource Development

(7) Resource development activities. The center shall conduct resource development activities to obtain funding from sources other than this chapter.
Core Services

1. Advocacy
2. Information & Referral
3. Peer Support
4. Independent Living Skills Training
5. Transition Services:
   a. from an institutional setting to community living
   b. youth transitioning
   c. divergence from an institution
ADVOCACY

- Self-Advocacy (personal advocacy)
  - Addressing specific issues to achieve change in one's own life

- Individual Advocacy
  - Action on behalf of, for, and most importantly with, an individual

- Systems Advocacy
  - Working to create change within a system, agency, jurisdiction, etc.
The term self-advocacy, which means speaking up for oneself and one's interests, is used as a name for civil rights movements and mutual aid networks for disabled people.

The term arose in the broader civil rights movements of the 1960s and 1970s, and is part of the disability rights movement.
What is a Self-Advocacy?

• Speaking up for yourself
• Making your own choices about your life
• Learning how to get information and resources
• Understand your rights and responsibilities
• Creating a support system
• Reaching out to others when you need help
• Problem solving, listening & learning, developing self-determination
Systems advocacy activities...

- speaking out on policies, laws, benefits, and/or practices that affect many people with disabilities
- community organizing
- making legislative contacts
- lobbying
- testimony
- petitions
Before you can lead, you must first learn to follow

Team Building – Being Part of a Team

- Effective Communication
- Watch, Listen, Learn
- Ask Questions
- Embrace diversity, differences and equality
- Be Reliable
- Be Responsible
- Be Committed
- Respect
Great leadership is about your level of influence, not your level of authority

- Know the facts about your issue(s)
- Educate others about your issue(s)
- Build Relationships – Community Involvement
- Build a Team
- Build Confidence
- Be Patient, but Persistent
- Learn to Listen
- Be Aware of Your Body Language
- Be Reliable
Great leaders are as good at listening as they are at communicating

Pay attention and acknowledge when someone is talking to you. Listen with your body: this can be difficult for some depending on disability.

*Non-verbal signals are wordless communication, body position, facial expression, hand movements, gestures, eye contact, attitude and tone of your voice, muscle tension and the way you breathe*

- Don't Interrupt
- Repeat what they said
- Respond to what they said
Great leaders create stability and drive change

- Lead by example: The Best Way to Influence Is Setting an Example
- Actions Speak Louder Than Words
- Leadership Is Behavior, Not Position
- Leadership is about people
- Understand the value of listening
- Promote diversity
- Focus on change
- Be human and admit mistakes
Great leaders use their power by giving it to others

Information IS power, but only when you give it away. Be the givers of power.
Roland Sykes, Thu, 26 Apr 2001

How to build an army

- Research, Research, Research
- Fact Check – Multiple Sources
- Make accurate information available to team
- Assign Responsibilities
- Allow for individual innovation and growth
ADAPT

- Organized by Wade Blank
  - Heritage House Nursing Facility
  - Started Atlantis
- Americans Disabled for Accessible Public Transportation
- Americans Disabled for Attendant Programs Today
- Money Follows the Person
Disability-related Public Policy Transition:

From segregation to rehabilitation, charity, and medical models to a civil rights and social justice model.
## INDEPENDENT LIVING AND TRADITIONAL PARADIGMS

<table>
<thead>
<tr>
<th></th>
<th>MEDICAL MODEL &amp; REHABILITATION PARADIGM</th>
<th>INDEPENDENT LIVING PARADIGM</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Definition of problem</strong></td>
<td>physical or mental impairment; lack of vocational skill (in the VR system)</td>
<td>dependence upon professionals, family members and others; hostile attitudes and environments</td>
</tr>
<tr>
<td><strong>Locus (or source) of problem</strong></td>
<td>in the individual (individual needs to be &quot;fixed&quot;)</td>
<td>in the environment; in the medical and/or rehabilitation process itself</td>
</tr>
<tr>
<td><strong>Solution to the problem</strong></td>
<td>professional intervention; treatment</td>
<td>1. barrier removal  2. advocacy  3. self-help  4. peer role models and counseling  5. consumer control over options and service</td>
</tr>
<tr>
<td>Social role</td>
<td>MEDICAL MODEL &amp; REHABILITATION PARADIGM</td>
<td>INDEPENDENT LIVING PARADIGM</td>
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<td></td>
<td>individual with a disability is a &quot;patient&quot; or &quot;client&quot;</td>
<td>individual with a disability is a &quot;consumer&quot; or &quot;user&quot; of services and products</td>
</tr>
<tr>
<td>Who controls</td>
<td>professional</td>
<td>&quot;consumer&quot; or &quot;citizen&quot;</td>
</tr>
<tr>
<td>Desired outcomes</td>
<td>maximum self-care (or &quot;ADL&quot;); gainful employment in the VR system</td>
<td>independence through control over ACCEPTABLE options for every day living in an integrated community</td>
</tr>
</tbody>
</table>
This cartoon helps illustrate the medical versus independent living models of disability. The able-bodied woman views the disability as the problem, whereas the wheelchair user views the environment and stereotypes as the problem.
DISABILITY PRIDE
The Disability Pride Flag

- **Black background:** mourning for those who have suffered and died, and also rebellion/protest.

- **Diagonal stripes:** people with disabilities navigate lots of barriers and use creative methods to do so.

- **Parallel stripes:** despite our differences, people with a variety of disabilities have shared experiences and support each other.

- **Multiple colors of the stripes:** the diversity in our community, includes those with mental illness, intellectual and developmental disabilities, invisible and undiagnosed disabilities, physical disabilities, and sensory disabilities.

Designed by disabled activist Ann Magill
Demonstrate a Process for Systems Advocacy
Use existing laws to report discrimination and solve problems
When is something a civil rights violation?

**What civil rights laws protect people with disabilities?**

- _Americans with Disabilities Act_
  - Prohibits certain acts by employers; state and local government; places of public accommodation; and telecommunication providers
  - Requires reasonable accommodations
  - Sets basic architectural standards

- _Individuals with Disabilities Education Improvement Act_
  - Prohibits certain acts by schools that receive federal funding
  - Requires students to receive a free appropriate public education in their least restrictive environment

- _Fair Housing Amendments Act_
  - Prohibits discrimination by landlords and other housing providers
  - Requires reasonable accommodations and modifications
  - Sets architectural standards for new, multi-family housing
• At Centers for Independent Living, we often hear from people who believe their rights have been violated. But what does that mean? When have someone’s rights been violated?

• Sometimes people treat others rudely, or unfairly, but it is not a civil rights violation.
  • If an act is not a civil rights violation, you can engage in self-advocacy, instead of legal or systems advocacy.
When is something a civil rights violation?

• Must violate a law (person who is acting must be obligated by the law; person treated unfairly must be protected by the law; action must be in violation of a rule with no exceptions)
• How do I know if someone violated a law?
  • Online research
    • ADA.gov
    • U.S. Access Board, https://www.access-board.gov/
    • ADA National Network, https://adata.org/
    • National Disability Rights Network, https://www.ndrn.org/
  • Technical Assistance Lines
    • Great Lakes ADA Center
    • Access Board
    • Department of Justice, Civil Rights Division
    • Ohio Civil Rights Commission
    • Fair Housing Centers
    • Fill out an Intake Form with Disability Rights Ohio
    • Ask an attorney
When is something a civil rights violation?

- Complainant: must be a person with a disability as defined under each law
  - Example: broken foot, service dogs in training

- Bad Actor: must be a party that the law applies to
  - Example: Private School that does not accept federal funding

- Action: must have done something that violates one of the rules set forth in the law and has no exceptions
  - Examples: automatic door openers, emotional support animals

When are those civil rights laws violated?
What is the process to escalate a concern/issue?

- Send a letter, putting your concern in writing
- File a Complaint with an Administrative Agency:
  - The Department of Justice, Disability Rights Division, https://www.justice.gov/crt/disability-rights-section
  - U.S. Department of Education, https://www2.ed.gov/about/offices/list/ocr/complaintprocess.html
  - Ohio Civil Rights Commission, https://crc.ohio.gov/
- File a Complaint in Court
  - Hire an Attorney
  - Disability Rights Ohio
  - Legal Aid
Why do individual complaints matter in systems advocacy?

- The ADA created a broad standard of accessibility, but the world is always changing.
  - For example, elevators break down, new businesses open up in historic buildings, accidental barriers are created.
- There is not consistent enforcement of the ADA, instead the law relies on individuals and organizations to file complaints and lawsuits to maintain accessibility.
- The law gives us the power to advocate.
- One “individual’s” complaint will likely help an entire community of people.
Get involved in the legislative process

The best people to advise on legislation are the people who are impacted by it! That means YOU!
Understanding Administrative Agencies

Legislative

Executive

HHS

DOJ

Judicial

Edu

Understanding Administrative Agencies
Understanding Administrative Agencies

https://www.usa.gov/federal-agencies
• Agencies are generally established either by legislation or executive order

• Most of the agencies we deal with are part of the executive branch

• Legislation passed by the U.S. Congress can delegate rule making and rule enforcement to a federal agency

• Administrative Procedures Act
How does a bill become a law?
How does a bill become a law?

1. A senator puts an idea into writing in the form of a bill. The bill is introduced.
2. The bill is assigned to a committee for public debate and input. To advance the bill, the committee votes to report it.
3. The bill is brought to the floor for a vote by all the members of the Senate.
4. The bill moves to the Ohio House to undergo the same process. Both chambers must reconcile any changes into one bill.
5. The bill is sent to the governor. If the governor approves of the bill, it will be allowed to become a law.
Ohio Constitution gives local municipalities the power to adopt police, sanitary, and other regulations that are not in conflict with state law – Art. XVIII.03
How does a bill become a law?

City Council Member has an idea, asks legislative counsel to draft an ordinance

Introduces ordinance to committee

Committee debates ordinance and moves it forward for a full council vote

Council votes on the ordinance and must pass by a majority

Ordinance/ resolution filed with the clerk and must be sent to the Mayor within 10 days; Mayor can sign or veto

¾ of council can override a Mayoral veto
How to be a part of the legislative process

- Attend or watch committee hearings on the bill.
- Call, e-mail, or write your representatives.
- Submit testimony. Testimony is a formal chance to share your story and make suggestions to lawmakers. It can be a speech or a written letter.
How to write an effective letter

This format can be used for a letter to a representative or for written testimony
Elements of Your Letter

1. Introduction
2. Story
3. What needs to be changed
4. Conclusion
Introduction

• Introduce yourself (maximum 2 sentences)

• Clearly state the purpose of the letter without writing “I’m writing this letter because…” e.i. what is the problem (1 sentence)

• Give the recipients one action item they can do immediately to start making changes (1 sentence)
Story

• Keep it relevant to what the letter is about
• Illustrate the issue in the story
• Make it expressive
• Make it personal
• If appropriate, link your story to a larger societal situation
What Needs to Change

• Outline how the system works now (maximum 3 sentences)

• How the current system affects you (maximum 2 sentences)

• How would you change the system (maximum 3 sentences)

• How would system changes affect your life (maximum 2 sentences)
Conclusion

• Restate the problem (1 sentence)
• Describe how it impacts your life (1 sentence)
• Tell the recipient how they can help (1 sentence)
• Thank the recipient
Form coalitions and raise awareness about your cause

Publicity is an important tool in successful systems advocacy!
What is a coalition?
- A group of individuals who share a common interest/goal.

Why form a coalition?
- Empower people in your community. Get more perspectives on an issue. Combine resources and ideas. Many voices are stronger than one voice.

Who should be involved?
- Anyone impacted by and interested in the issue!
Forming a Coalition

1. Gather a “core group” of individuals
2. Recruit new members by...
   a) Posting on social media
      a) Use relevant hashtags. Like: #CareCantWait or #CripTheVote
   b) Connecting with CILS and other community resources
   c) Advertising your group with flyers
   d) Reach out to more stakeholders via email, phone, or letter writing
Working in a Coalition

1. Hold regular meetings to discuss new information and brainstorm ideas.
2. Develop a mission statement to represent the group’s goals and values.
3. Create an action plan.
   a) Make sure your plan is realistic. Try breaking big goals down into small steps.
4. Divide and conquer!
   a) Use your resources by splitting up the work among group members.
5. Always be inclusive and give everyone a chance to speak.
6. Take time to review and celebrate your work!
Marketing

Sharing your ideas can...
• Educate the public
• Empower people and attract more supporters of your cause!
• Create a sense of community and pride

Ways to market...
• Brainstorm a key phrase that captures your cause. Like, Better At Home. Use it as a hashtag!
• Create a logo that represents your group.
• Tell your story on podcasts, blogs, social media. You can even write letters to your local newspaper for the opinion or letter to the editor section.
• Publicize your meetings and update the public on your work.

Top left: Alice Wong is the host of the Disability Visibility podcast. Bottom left: The Black Disabled Lives Matter design is by Jen White Johnson, @jtknoxrox. Top right: The Ohio HCBS Coalition logo.
Advocating and Lobbying
Advocating and lobbying – what’s the difference?

- Advocating is when you educate a legislator or person on an issue — for example, sharing stories and statistics — but you do not ask them to take a specific action.

- Lobbying is when you ask someone directly to support or oppose an action.
Question: Are Centers for Independent Living allowed to lobby?
Answer: Yes, within limits.

Question: What Limits?
Answer: Limits put in place by: 1) the tax code 2) federal guidelines.
IRS Tax Code Limits

Most Centers for Independent Living are 501(c)3 organizations under the IRS tax code, which means they are tax exempt on the basis of their status as “charitable” organizations.

According to the IRS, “no substantial part” of an organization’s activities may involve lobbying.

What does that mean? 501(c)(3) organizations can lobby as long as it doesn’t make up a “substantial part” of their activities.

Non-profit 501(c)(3) organizations cannot “endorse, contribute to, work for, or otherwise support a candidate for public office, nor can it oppose one.”
Federal Funding Limits

Federal funds may not be used to lobby. OMB Circular A-122 describes limits on lobbying with federal funding.

What does this mean? Any lobbying undertaken by a Center for Independent Living receiving federal funding must be funded with other dollars. For example, to remove any potential conflict, some CILs do not use any federal dollars to sponsor their systems advocacy program.
Lobbying vs. Advocacy

There are no limits either under the federal tax code or due to receipt of federal funds for advocacy that is not lobbying.

• Direct Lobbying: Communications that your organization has about legislation 1) with legislators or government officials and (2) with its own members. Direct lobbying would include visiting a congressperson about a bill and being in touch with your organization's members and urging them to contact legislators.

• Grassroots Lobbying: Any attempt to influence legislation through affecting the opinion of the general public. The ceiling for a nonprofit's spending on grassroots lobbying is one-fourth of the total allowable lobbying expenditures.
What is NOT lobbying?

• Discussing social, economic, and similar policy issues—even if specific legislation on the issues is pending—so long as the discussion does not address the merits of specific legislation

• Contacting government representatives in support of or opposition to proposed regulations

• Lobbying by your organization’s volunteers

• Communication that educates an organization’s members about legislation but that does not ask them to support or oppose the legislation
What is NOT lobbying?

• A nonprofit's response to written requests from a legislative body for advice on pending legislation, like responding to public comments;

• Self-defense activity—lobbying legislators on matters that may affect the organization's own existence, powers, tax exempt status, and similar matters

• Making available the results of nonpartisan analysis, study, or research on a legislative issue
Lobbying Summary

Can CILs lobby?

Likely, yes, so long as lobbying does not make up a substantial part of their activities and they do not use federal funding to lobby.

Can CILs engage in advocacy that is not lobbying?

Yes, to avoid lobbying, stay away from:

• Directly endorsing or opposing specific legislation or urging your members or the public to do so;

• However, education and presenting information on issues facing people with disabilities that does not endorse or oppose particular legislation is not lobbying.
What does systems advocacy look like?

For the Ohio Olmstead Task Force, advocacy on the direct care workforce crisis included:

• Hosting public forums around the state (consumers shared their stories, public officials attended)
• Writing a letter to state department directors

Learn more: Visit ohioolmstead.com/issues-advocacy/
Advocacy can also mean providing testimony – written or in-person. On this slide are two examples of testimony that disability advocates provided during the 2022-2023 Ohio State Budget hearings.

Testimony can include statistics, personal stories, and even art! Above is testimony submitted by advocate Alicia Hopkins that included a painting representing the Ohio caregiver crisis.
How will YOU advocate for change?

1. Think about issues that impact you and matter to your community.
2. Talk with others about their experiences.
3. Think about what is needed to solve the problem and who can help.
4. Explore different ways of advocating!
   a) Write a letter, testify at a hearing, call your representative, work with your CIL, raise awareness on the issue, file a complaint, etc.!
Thank You!

Contact Us!

Katie Hunt Thomas, Disability Rights Attorney, The Ability Center: kthomas@abilitycenter.org

Alexia Kemerling, DRO: akemerling@disabilityrightsohio.org

Thank you for joining us over the past five weeks. This has been a two year project by several of Ohio’s Independent Living Centers and Disability Rights Ohio.

Many thanks to our interpreters and captionists.

Recordings, transcripts, and copies of the presentation will be available after the series is complete. You’ll receive more info by email.