

Demonstrating a Process for Systemic Advocacy



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

Disability Advocacy Seminar
Series

Zoom Housekeeping

- This is a webinar presentation, so attendees are muted and will not have video capabilities.
- The webinar is being recorded for future distribution and will be stored for public re-use and access.
- The chat feature is disabled. Please type questions in the Q&A.
- If you do not wish to have your name recorded when posting questions in the Q&A, set your name to anonymous. You may also send your questions privately to panelists.
- CART Captioning or C-Print can be accessed in a separate browser by using the link found in the Q&A.
- 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.

Goals and Objectives

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.

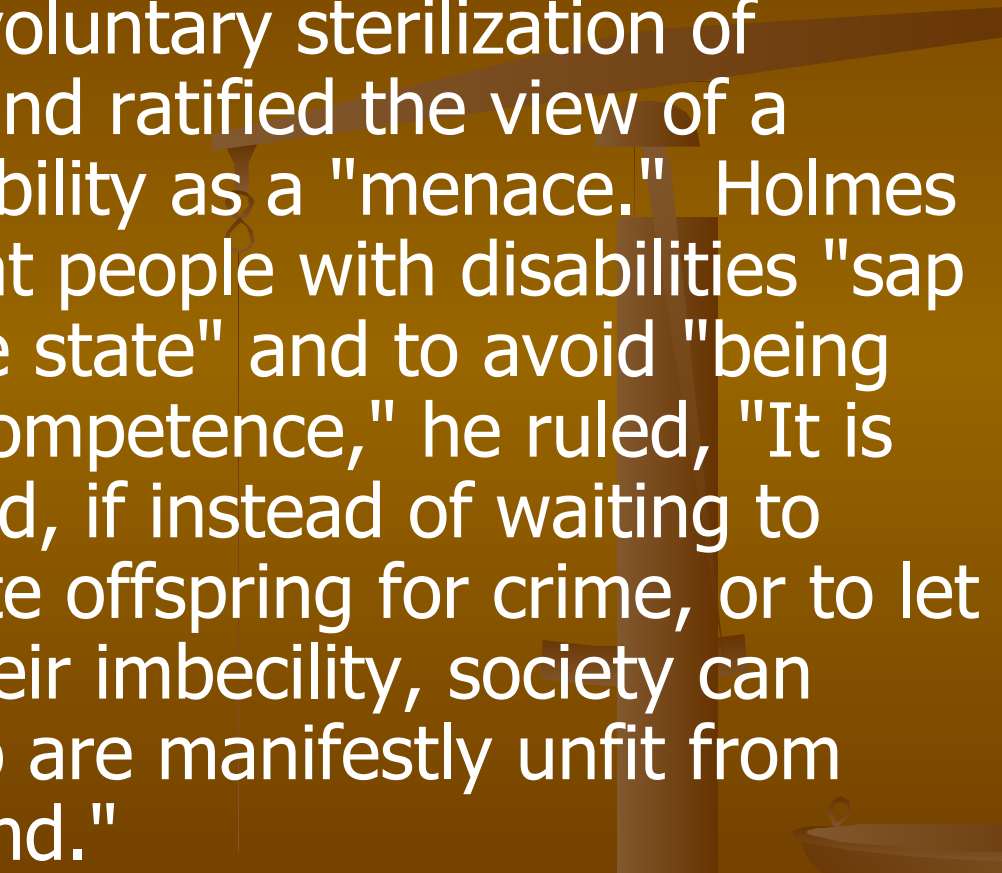
- ▶ Objective 1: Understanding of Disability History, the Disability Rights Movement, Grassroots Advocacy and Community Organizing
- ▶ Objective 2: Understanding of civil rights violation, lobbying, how a bill becomes a law, state vs. federal legislation, and local policy
- ▶ Objective 3: How to become 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."



January 14, 2004

- 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

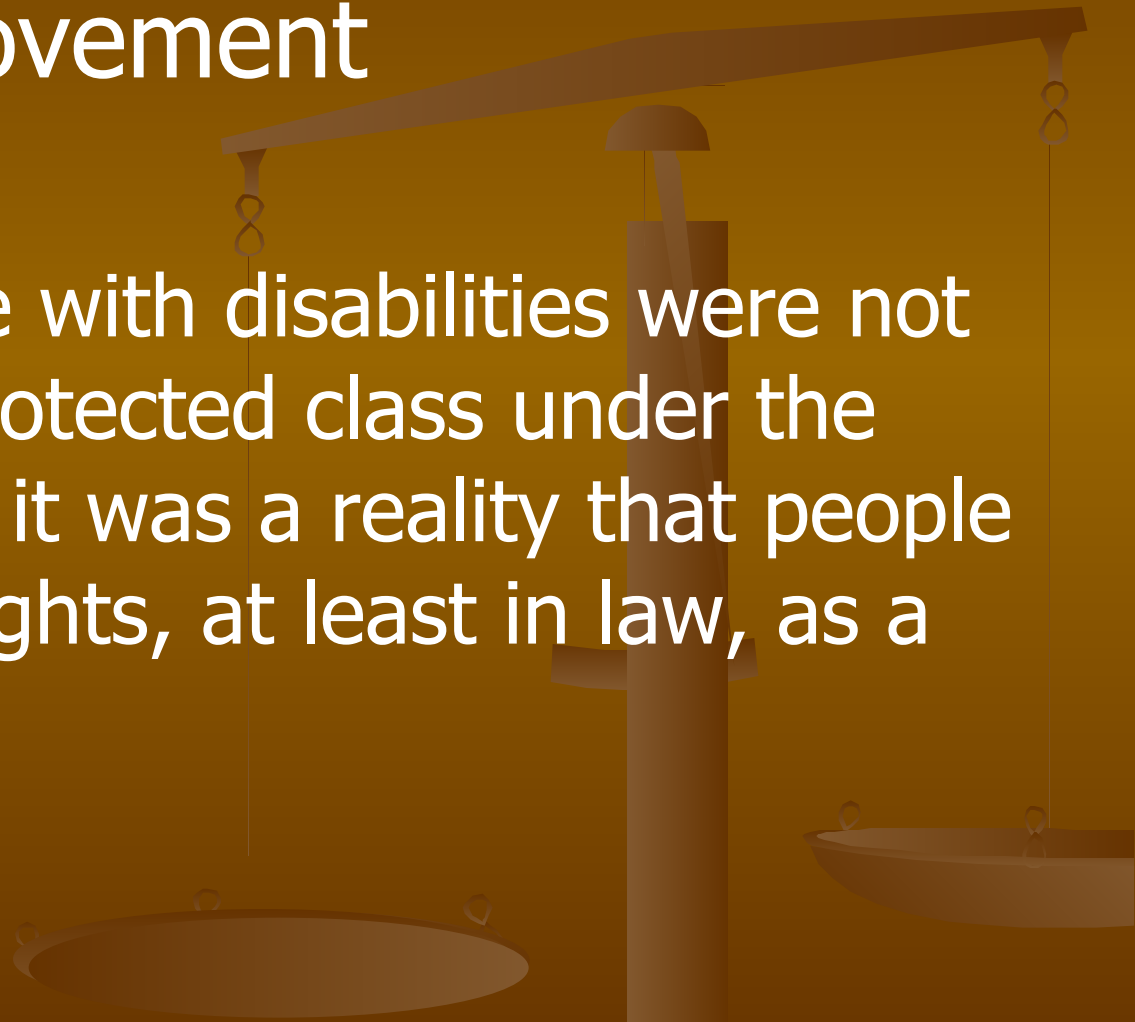
Deinstitutionalization

- 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

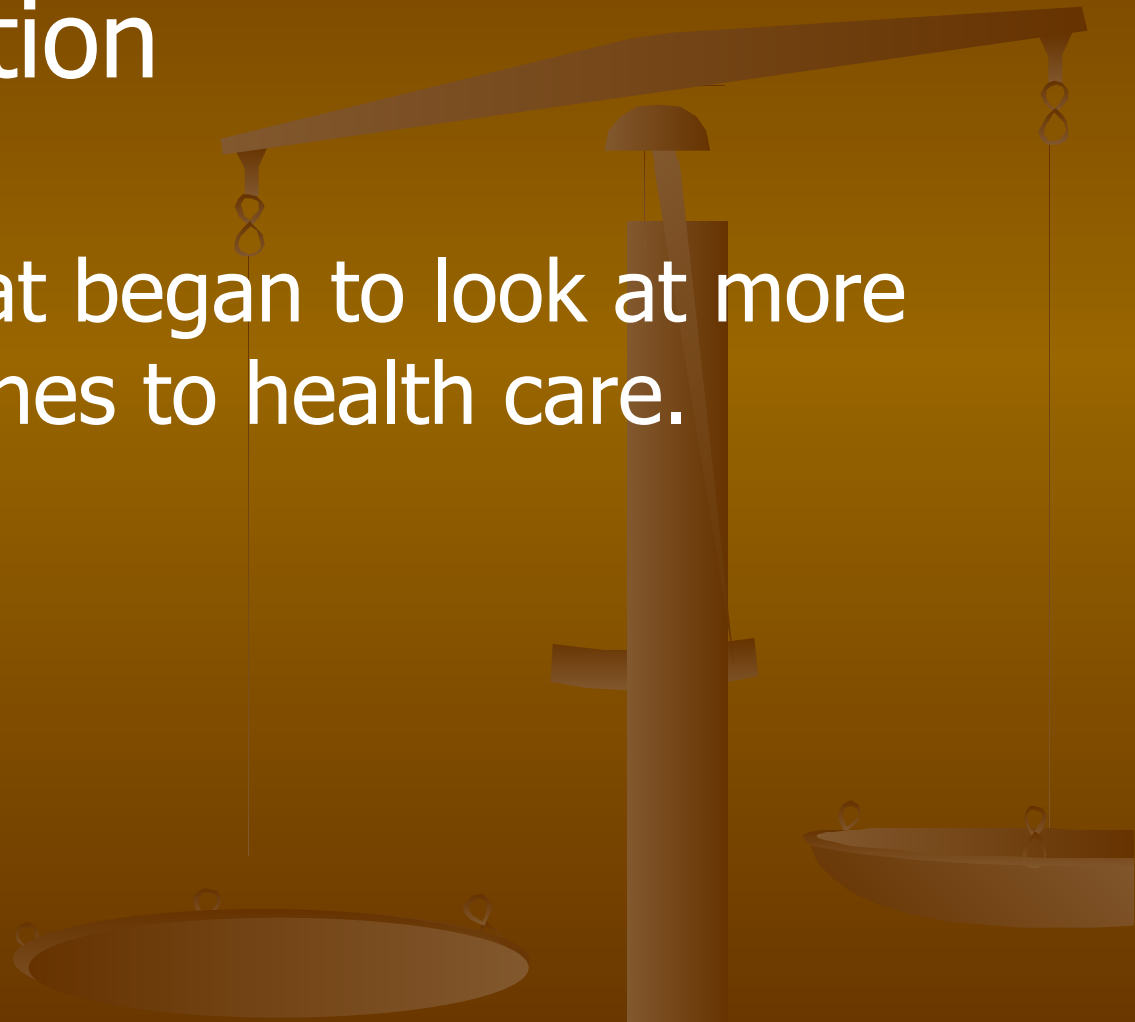


- really began in the 1950s with the founding of Alcoholics Anonymous, came into its own in the 1970s. Many self-help books were published and support groups flourished.

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

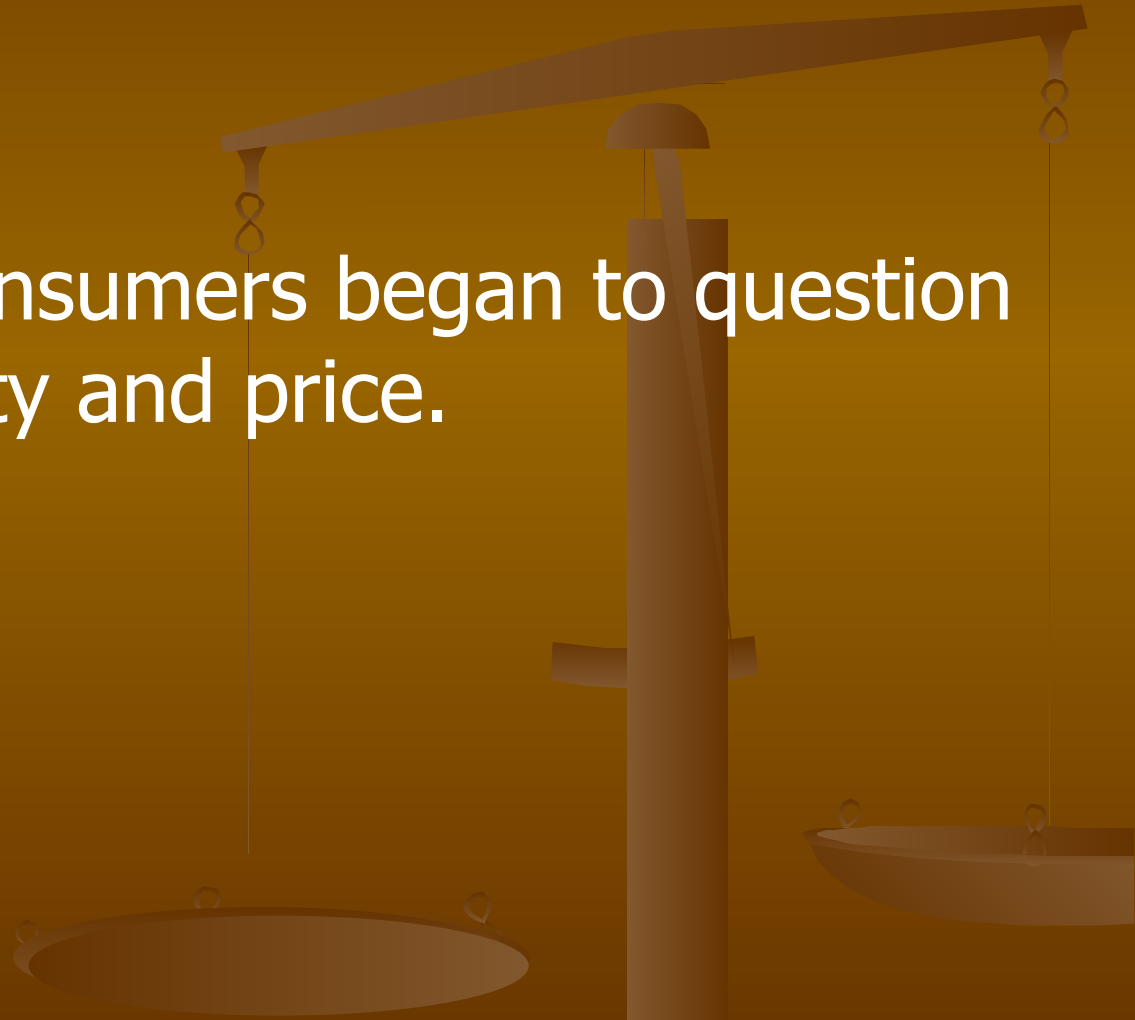
De-medicalization

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



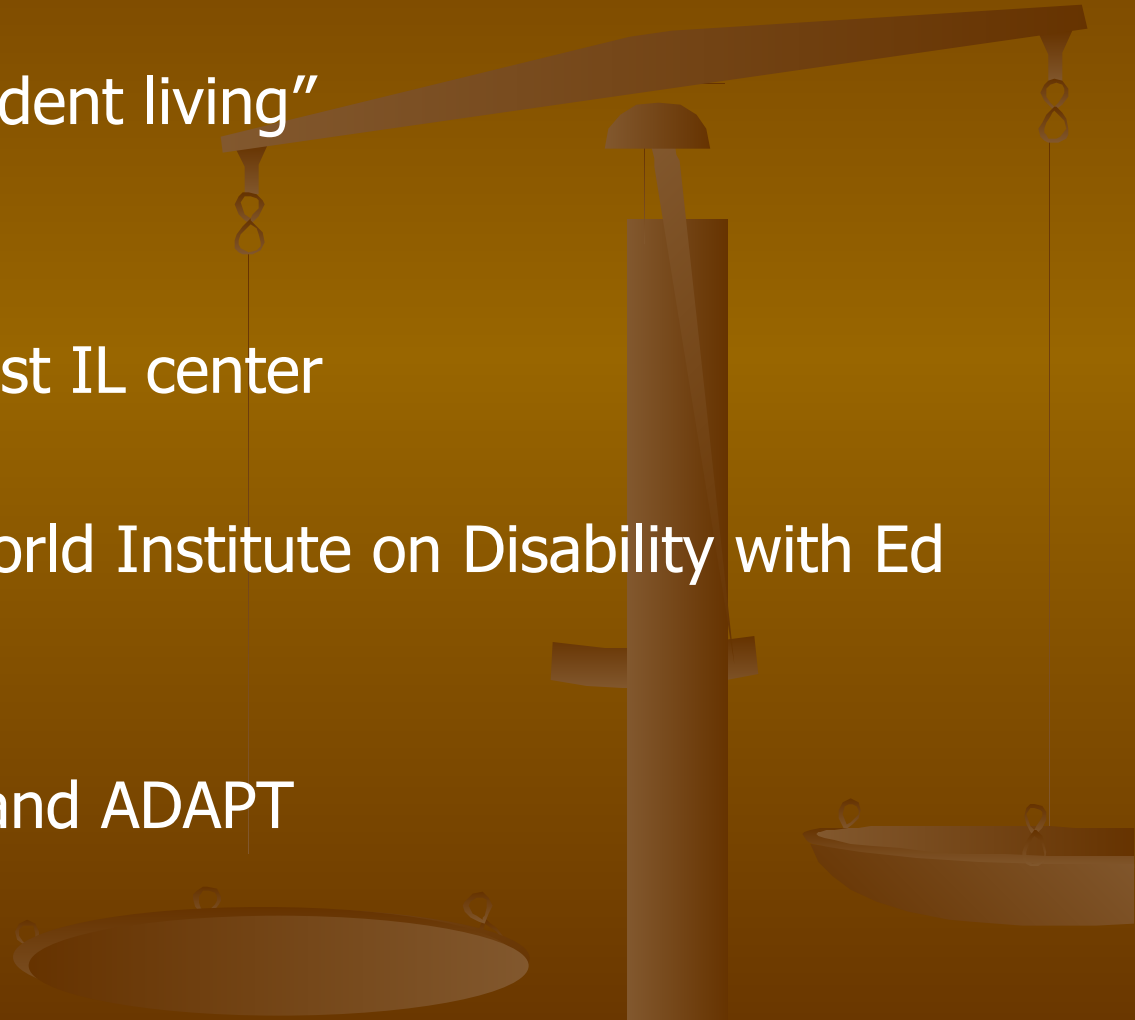
Consumerism

- 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.

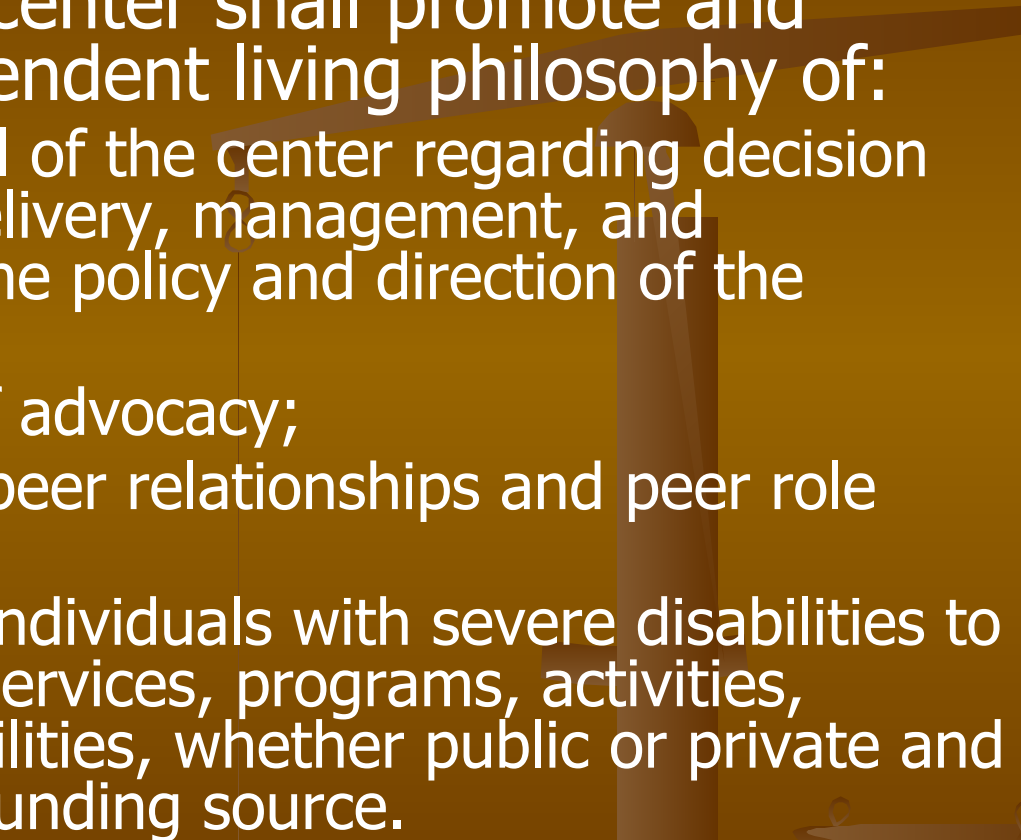
Rehab Act Regulations

- 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.

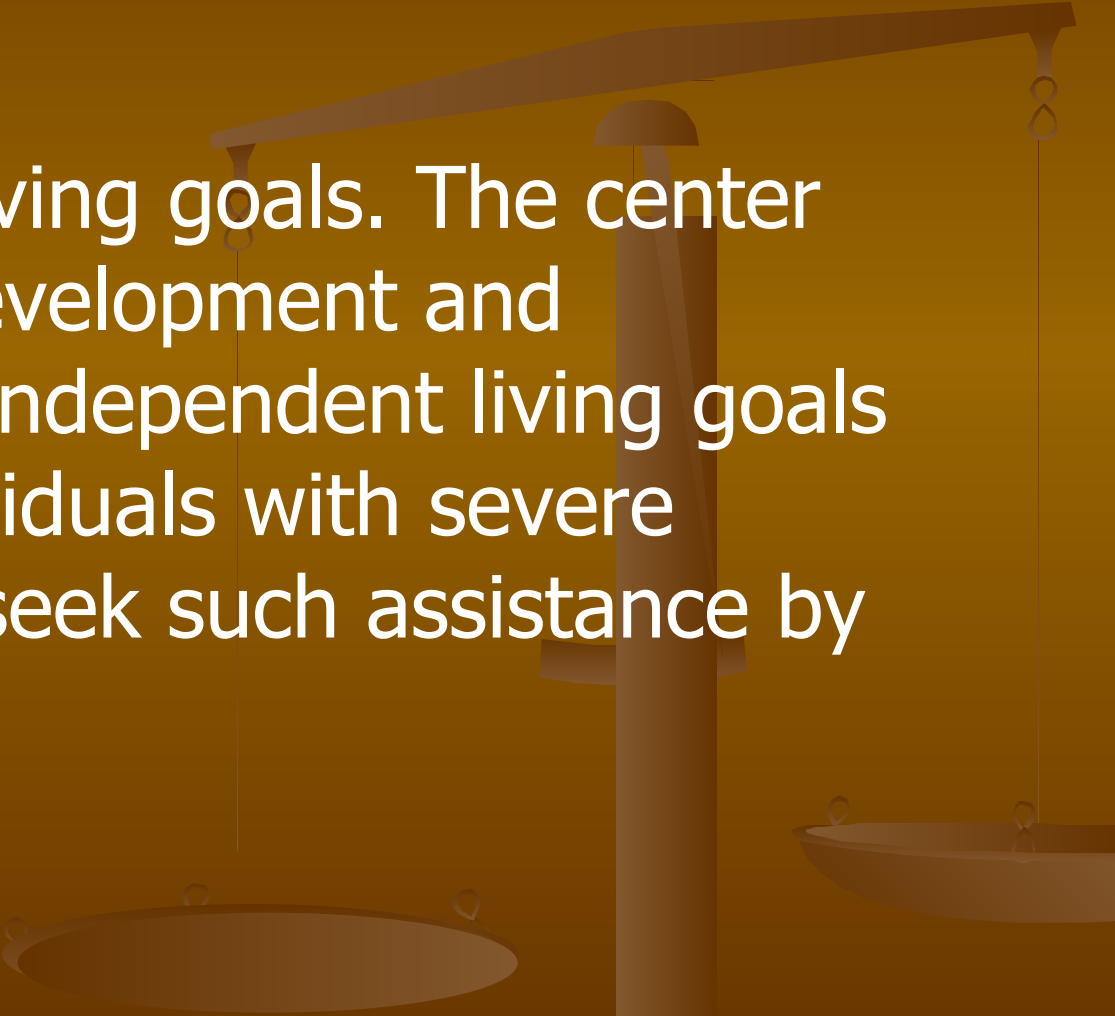
Cross Disability

(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.

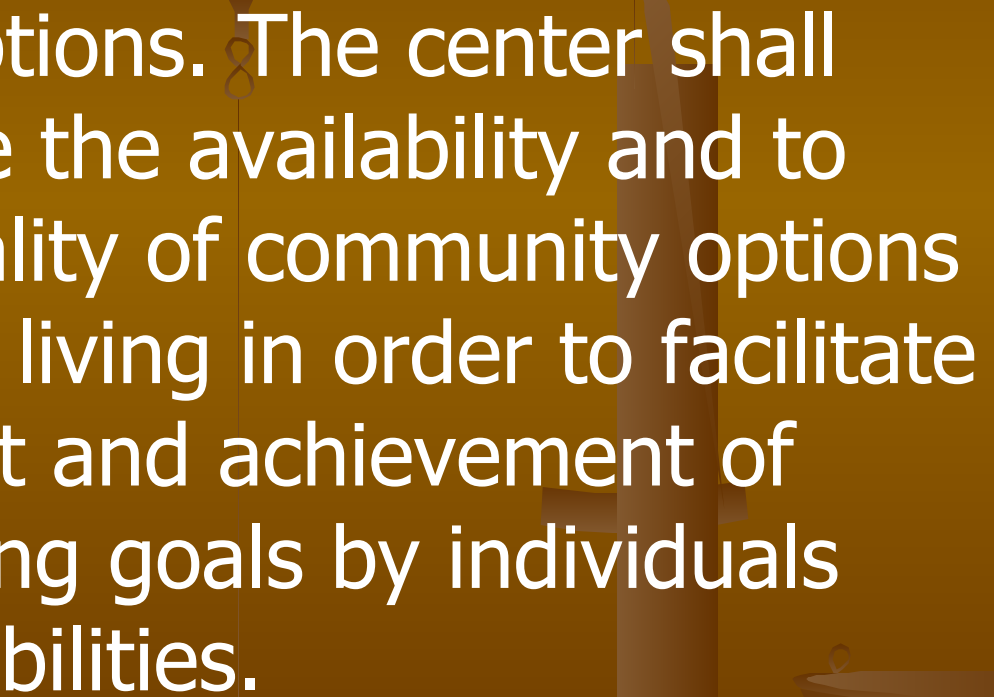
Develop Goals for Independent Living

(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.



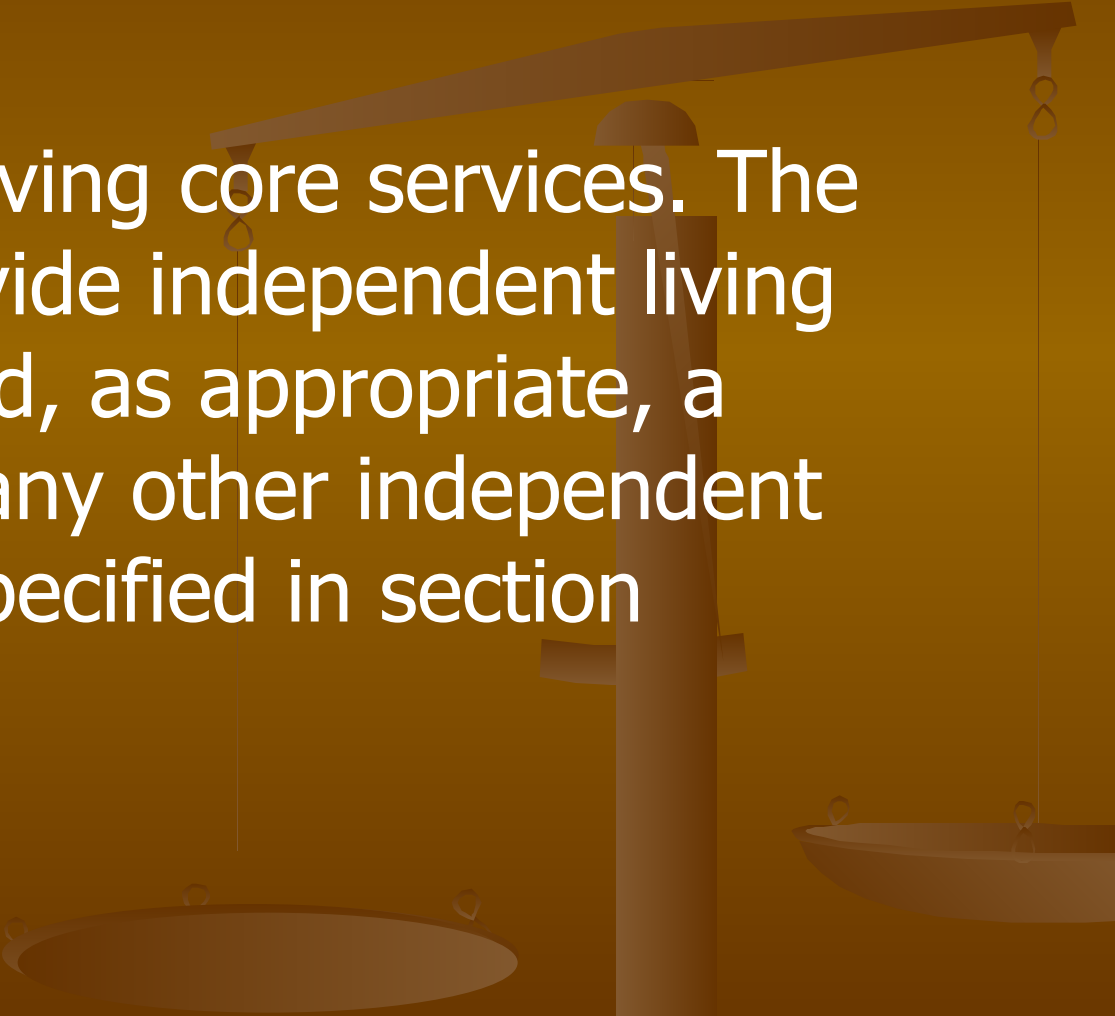
Increase Community Options

(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.



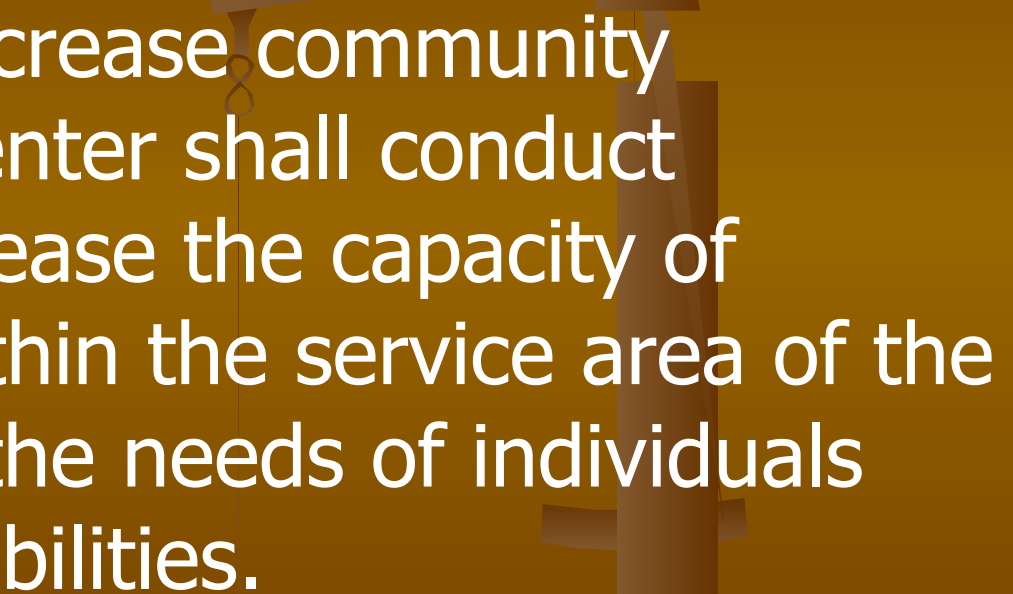
Provide Core Services

(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).



Increase Community Capacity

(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.



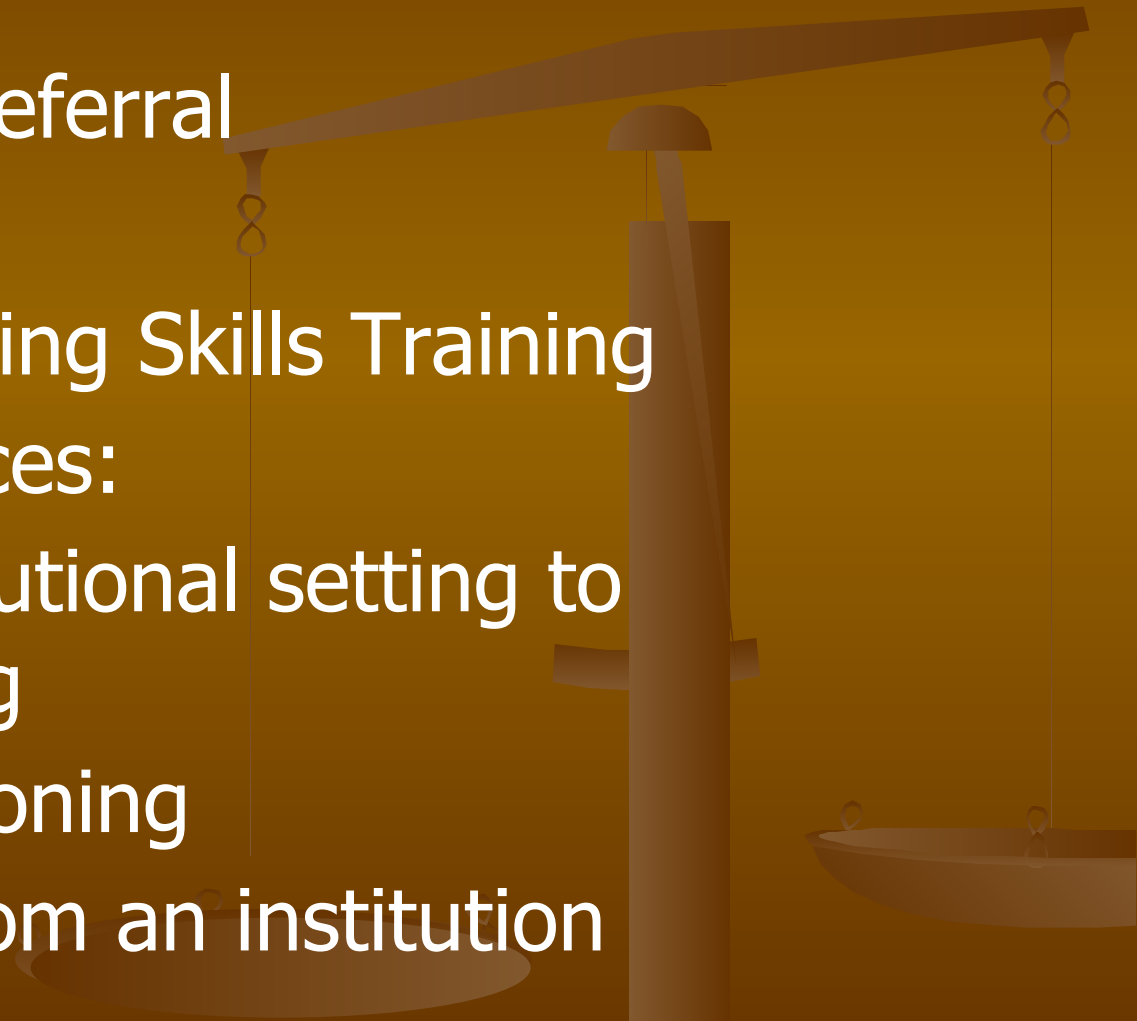
Conduct Resource Development

(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.

SELF-ADVOCACY

From Wikipedia, the free encyclopedia

The term self-advocacy, which means speaking up for oneself and one's interests, is used as a name for civil rights movements. 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.

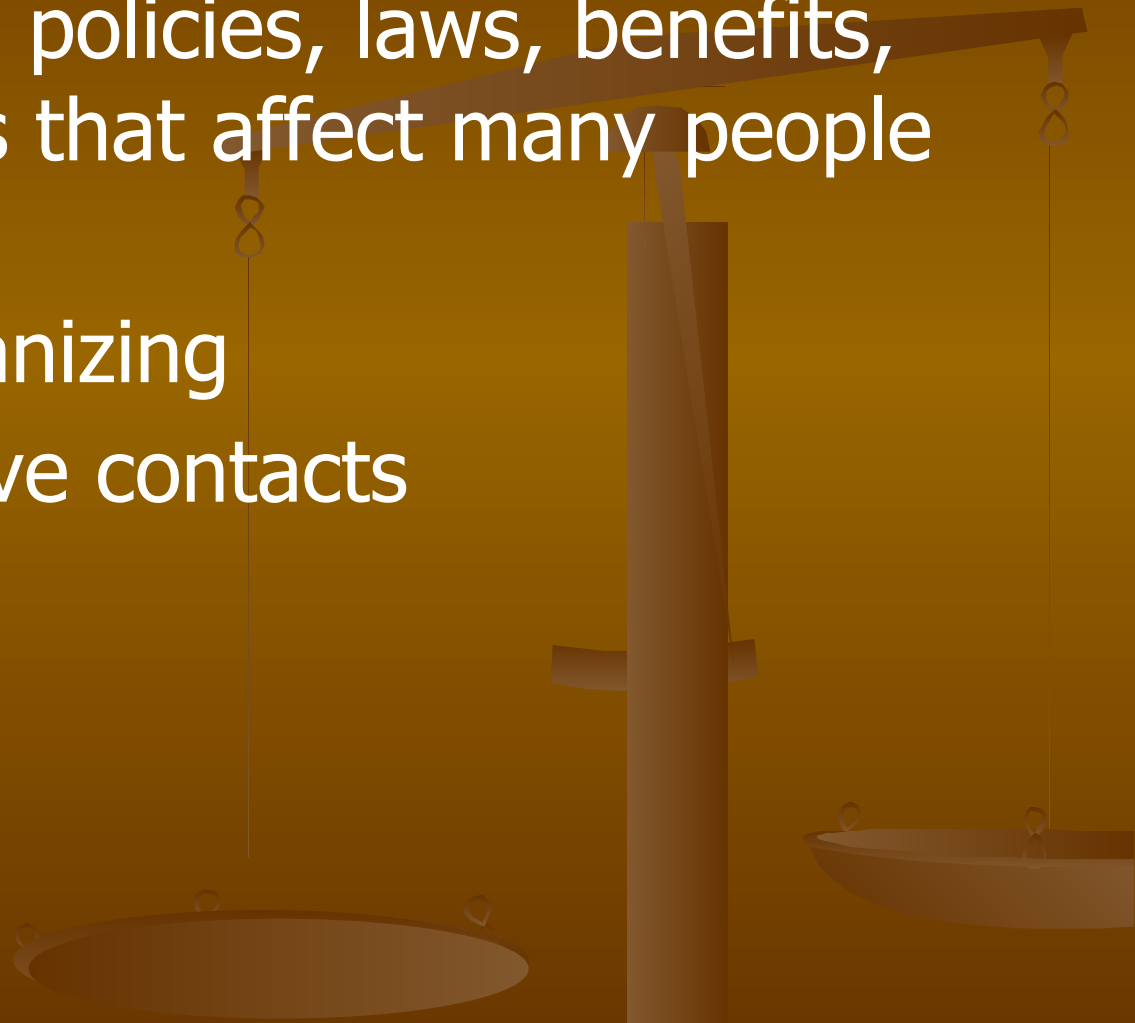


What is a Self-Advocacy?

- 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





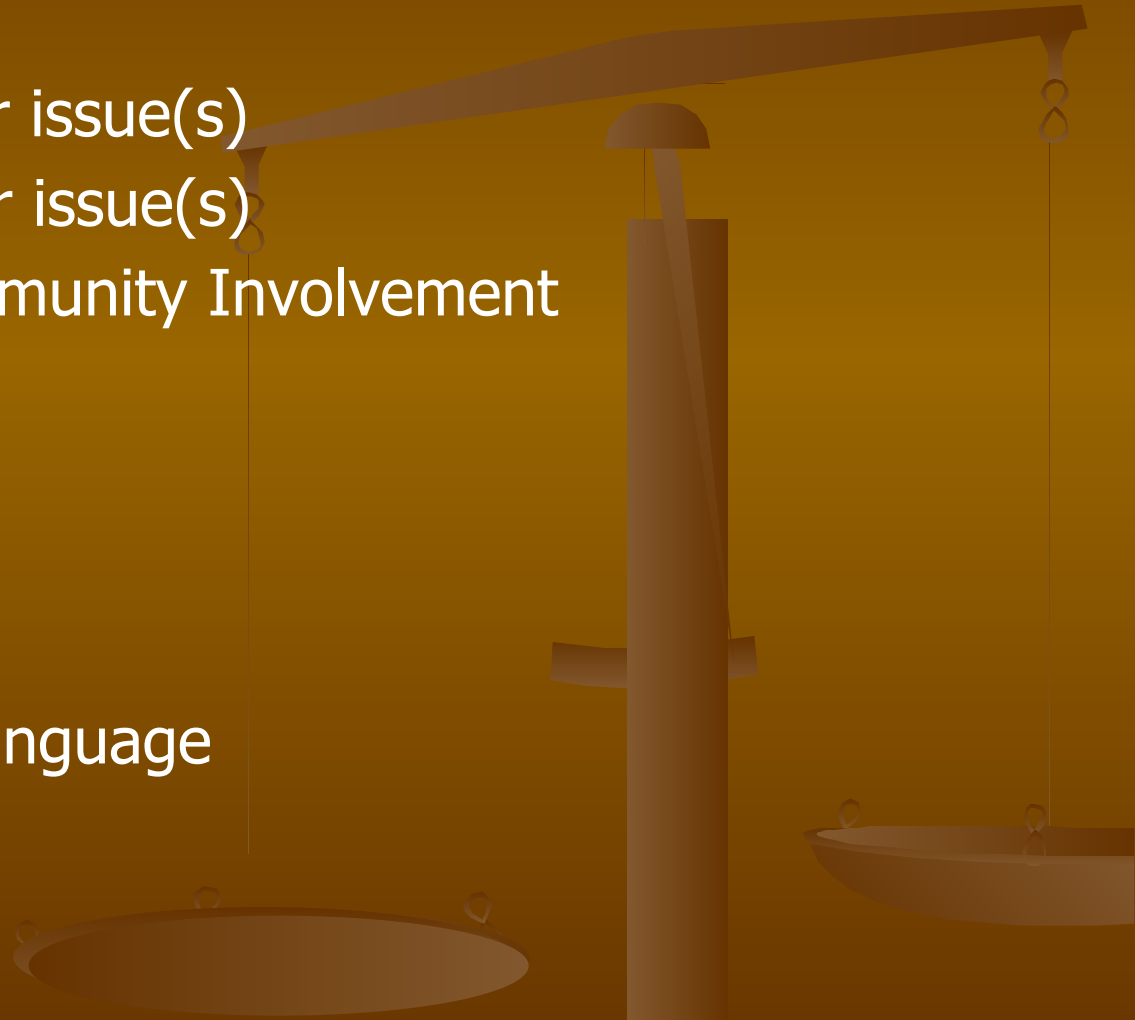
**Before you can lead, you
must first learn to follow**

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

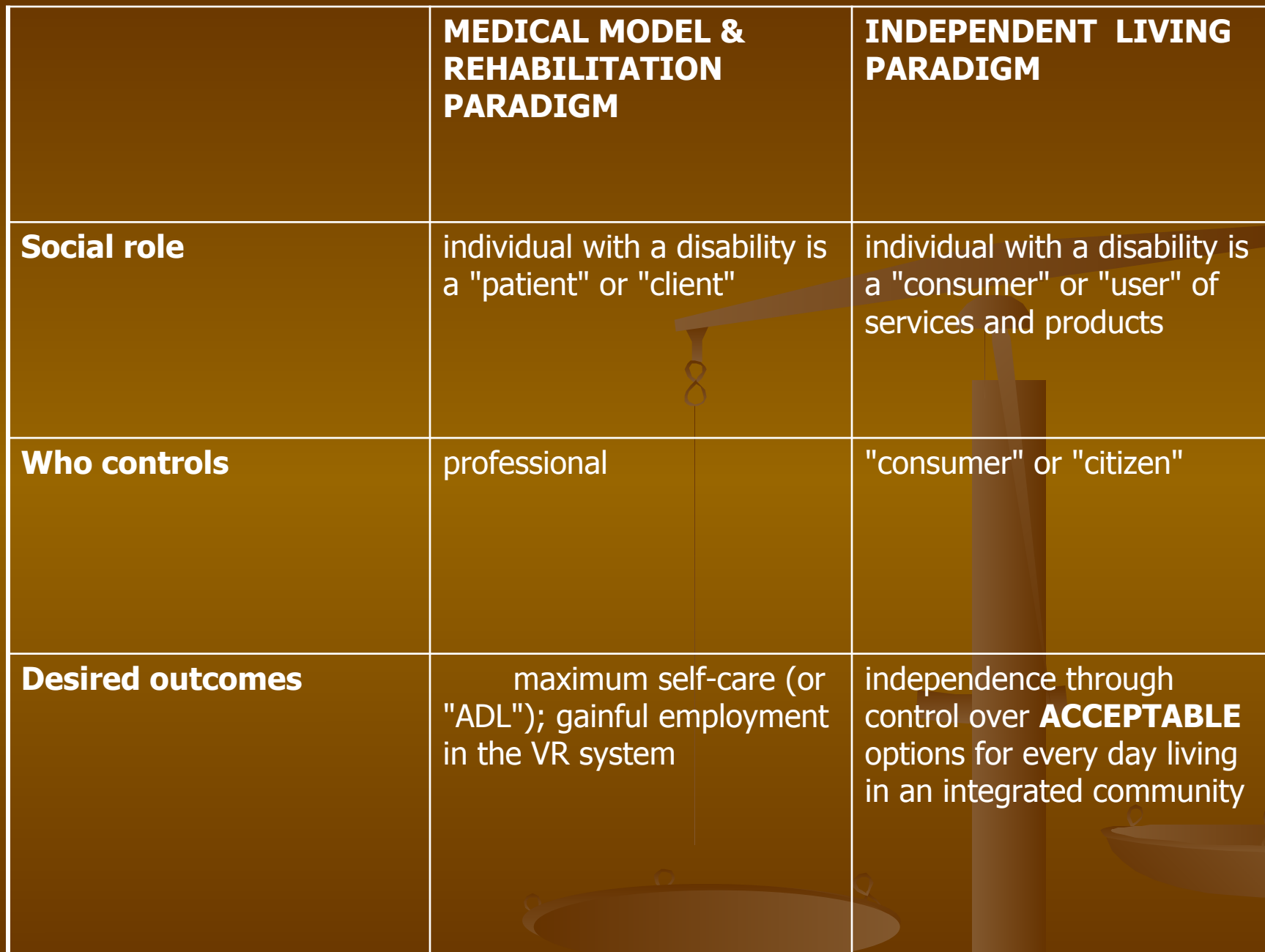
Disability-related Public Policy Transition:

From segregation
to
rehabilitation, charity, and medical models
to
a civil rights and social justice model.



INDEPENDENT LIVING AND TRADITIONAL PARADIGMS

	MEDICAL MODEL & REHABILITATION PARADIGM	INDEPENDENT LIVING PARADIGM
Definition of problem	physical or mental impairment; lack of vocational skill (in the VR system)	dependence upon professionals, family members and others; hostile attitudes and environments
Locus (or source) of problem	in the individual (individual needs to be "fixed")	in the environment; in the medical and/or rehabilitation process itself
Solution to the problem	professional intervention; treatment	<ol style="list-style-type: none">1. barrier removal2. advocacy3. self-help4. peer role models and counseling5. consumer control over options and service



	MEDICAL MODEL & REHABILITATION PARADIGM	INDEPENDENT LIVING PARADIGM
Social role	individual with a disability is a "patient" or "client"	individual with a disability is a "consumer" or "user" of services and products
Who controls	professional	"consumer" or "citizen"
Desired outcomes	maximum self-care (or "ADL"); gainful employment in the VR system	independence through control over ACCEPTABLE options for every day living in an integrated community



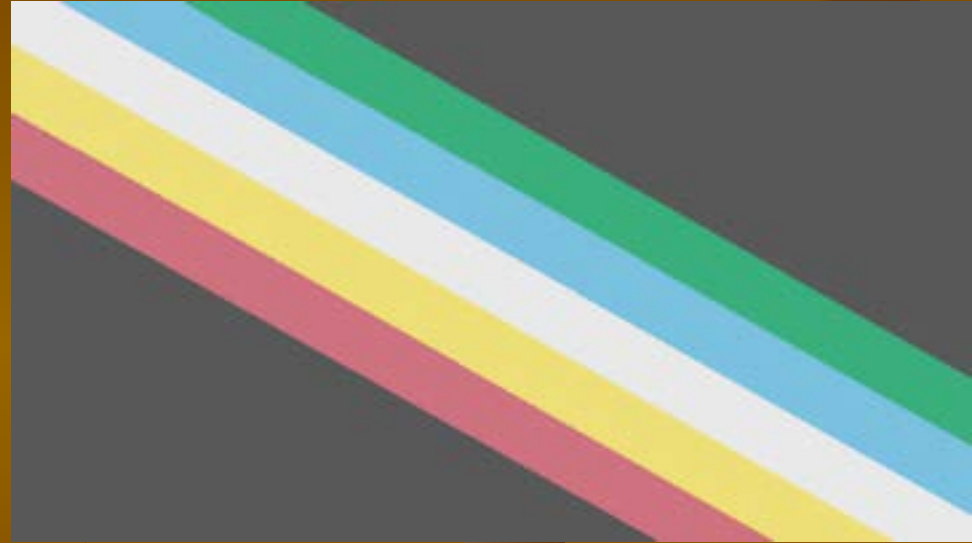
This cartoon helps illustrate the medical versus independent living models of disability. The able-bodied woman views the disability as the problem, whereas the wheelchair user views the environment and stereotypes as the problem.

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



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

What civil rights laws protect people with disabilities?

- 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/>
 - U.S. Department of Education, <https://sites.ed.gov/idea/>
 - 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

**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



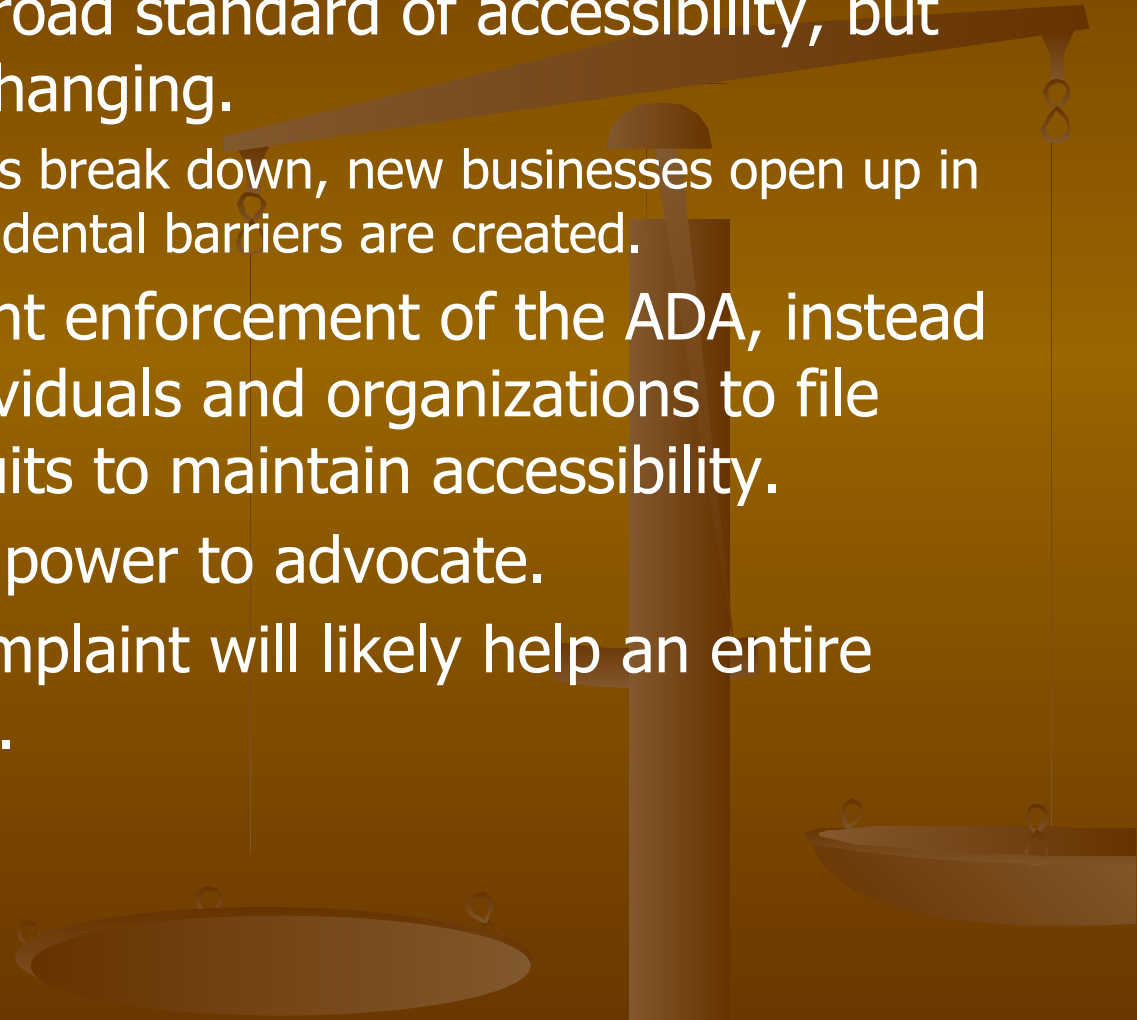
When are those civil rights laws violated?

- 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

**What is
the
process to
escalate a
concern/
issue?**

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

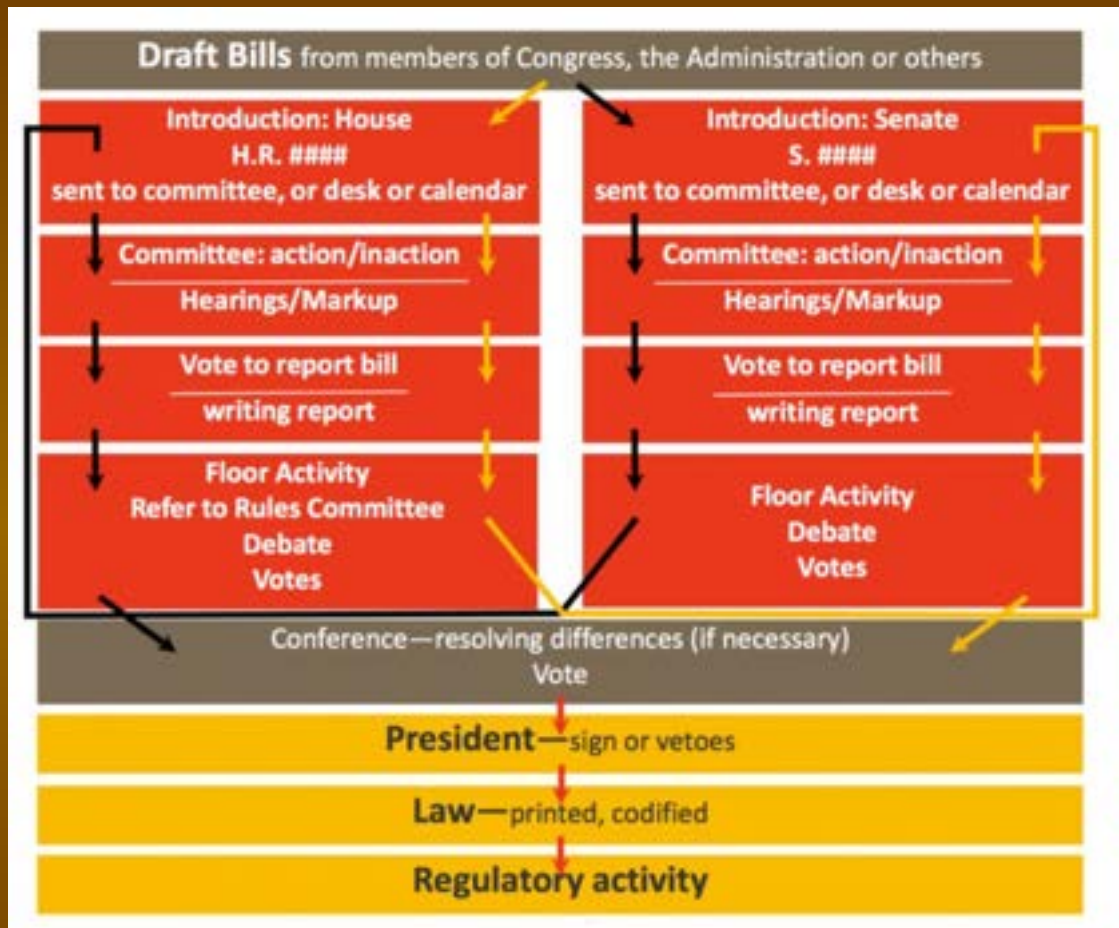
<https://www.usa.gov/federal-agencies>

Understanding Administrative 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

Understanding Administrative Agencies

How does a bill become a law?



How does a bill become a law?

How does a bill become a law?



How does a bill 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?**

How does a bill become a law?

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

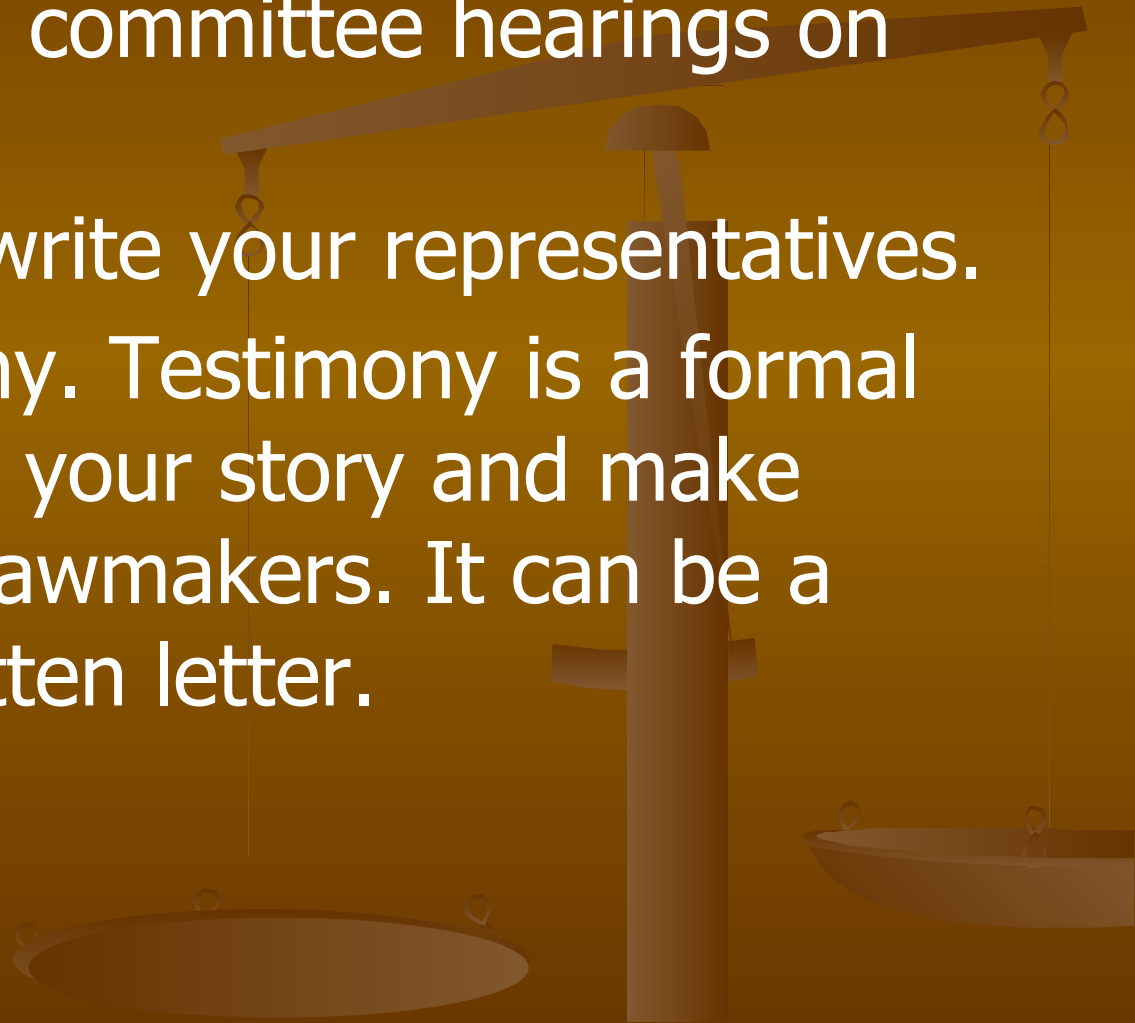
Council votes on the ordinance and must pass by a majority

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

$\frac{3}{4}$ 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



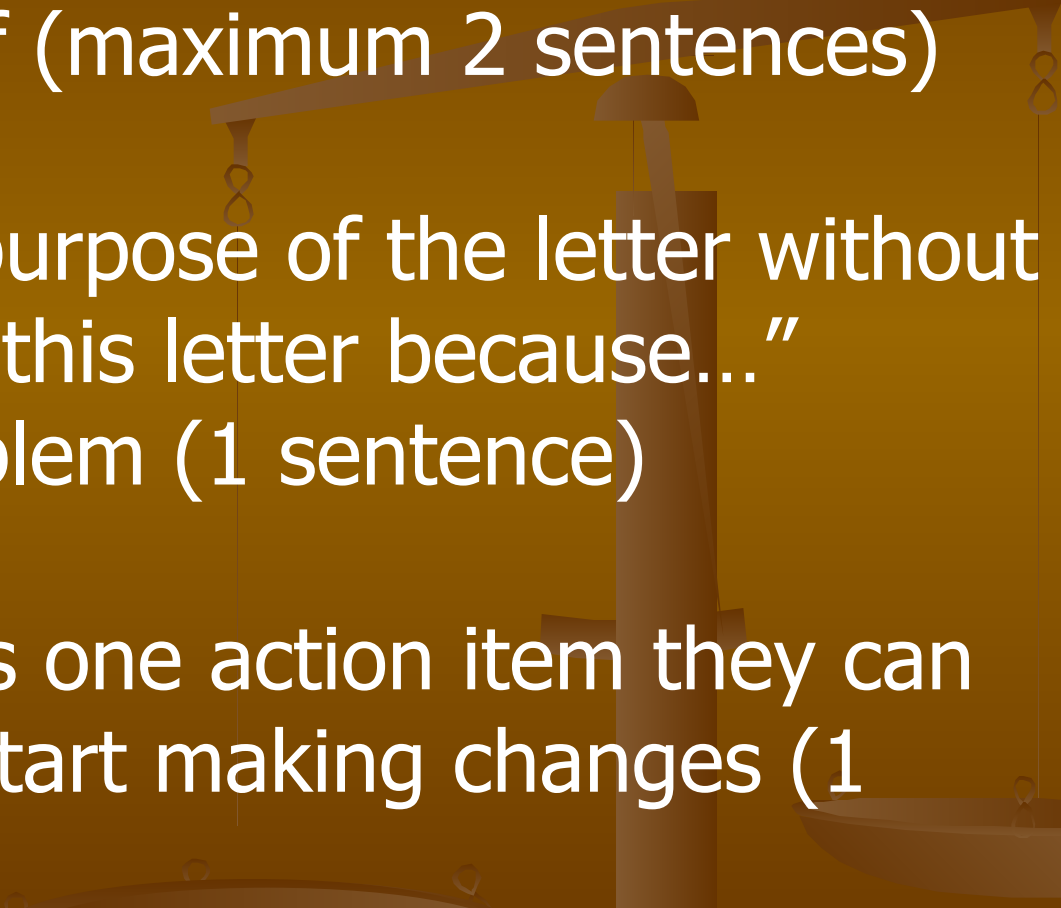
This format can be used for a letter to a representative or for written testimony

Elements of Your Letter

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

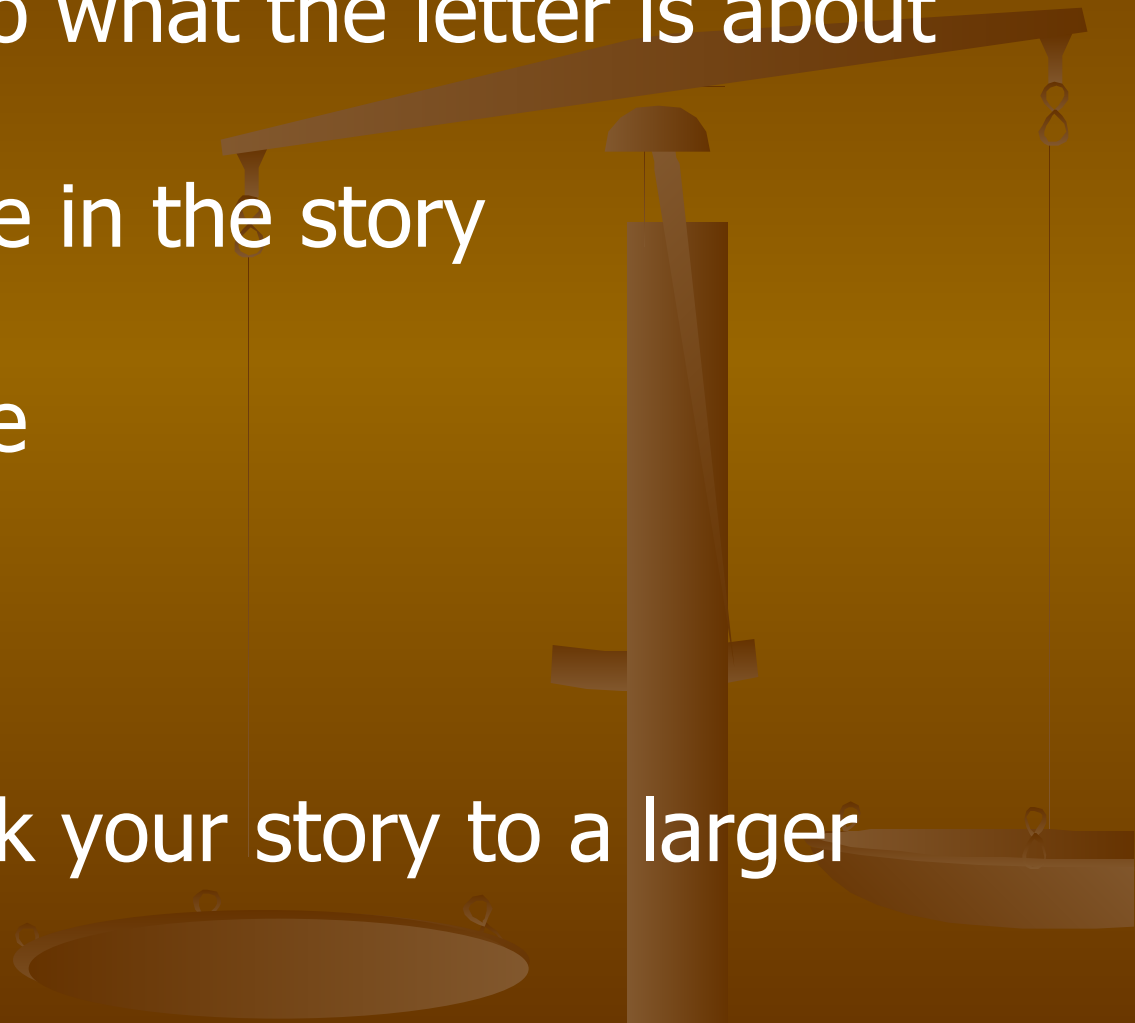


Introduction

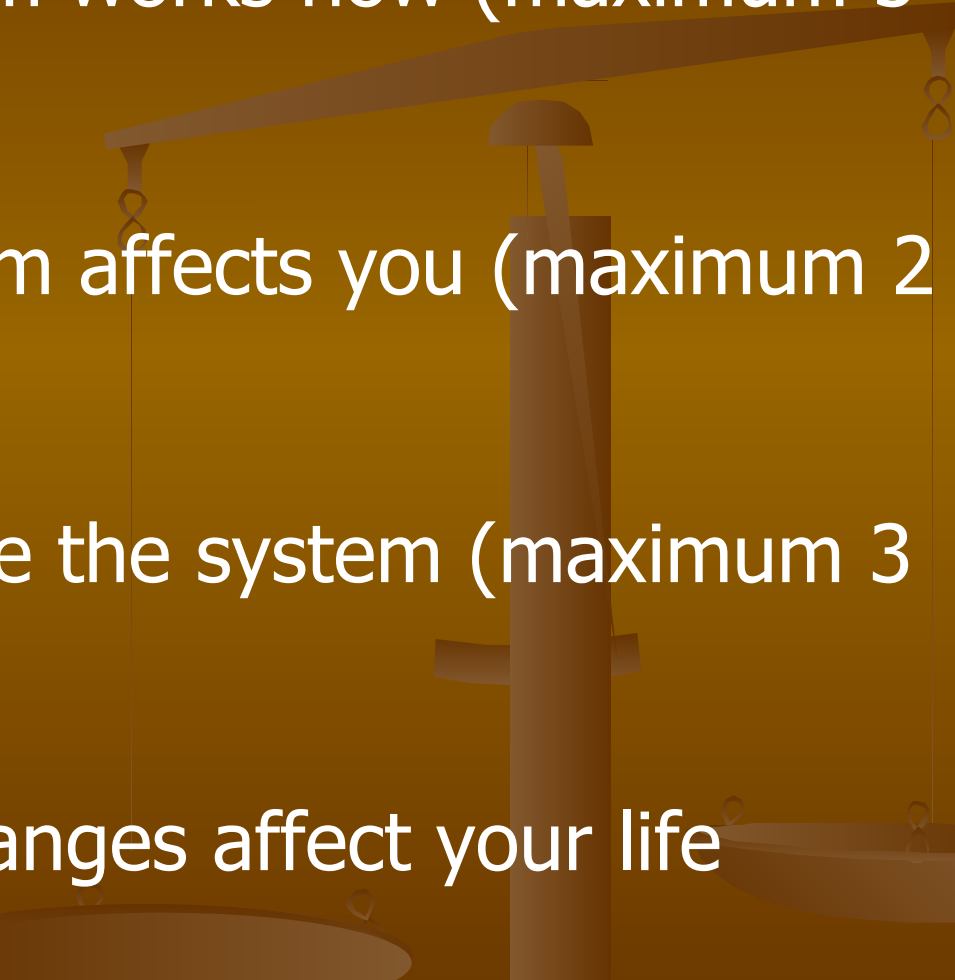
- Introduce yourself (maximum 2 sentences)
 - Clearly state the purpose of the letter without writing “I’m writing this letter because...”
e.i. what is the problem (1 sentence)
 - Give the recipients one action item they can do immediately to start making changes (1 sentence)
- 

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

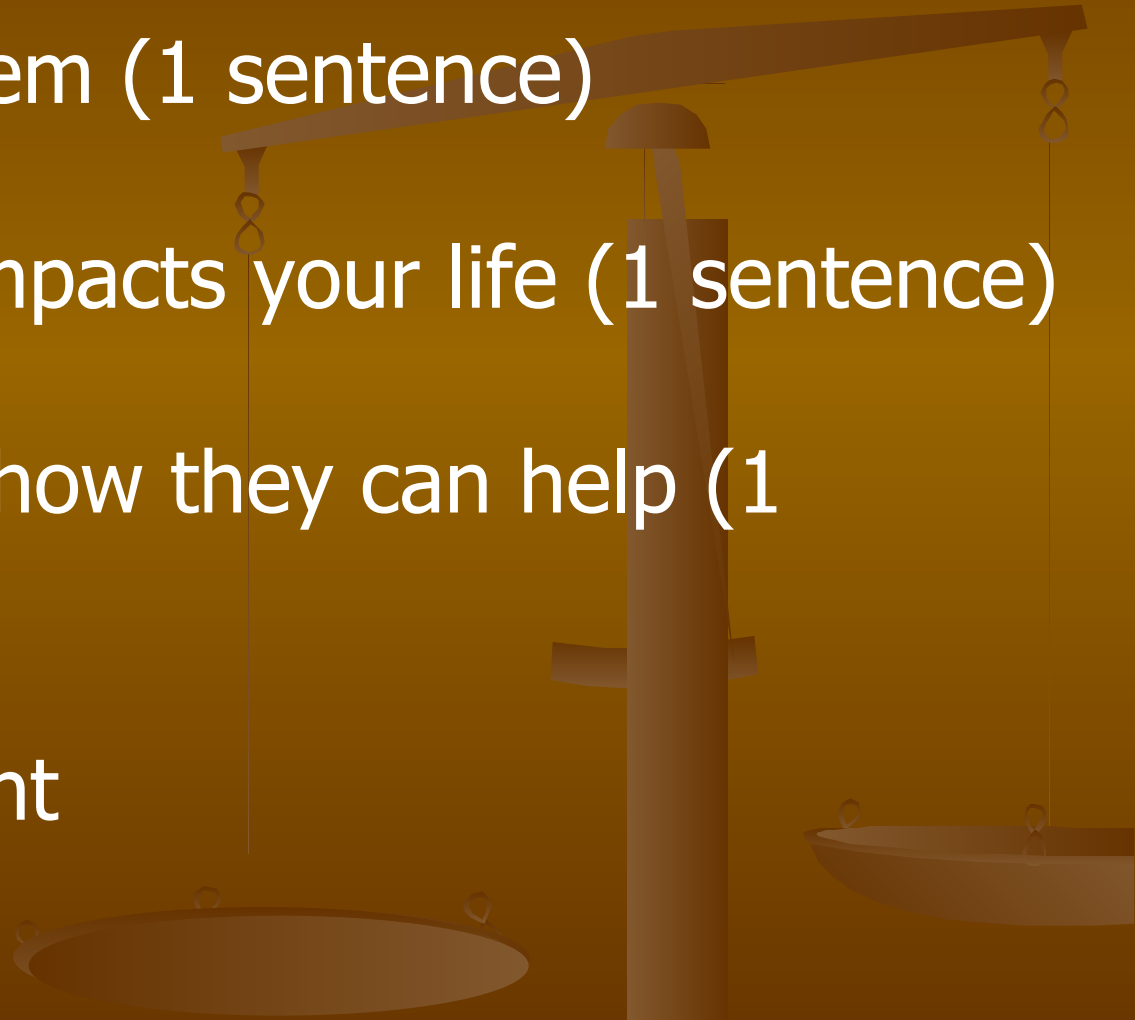


What Needs to Change

- 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

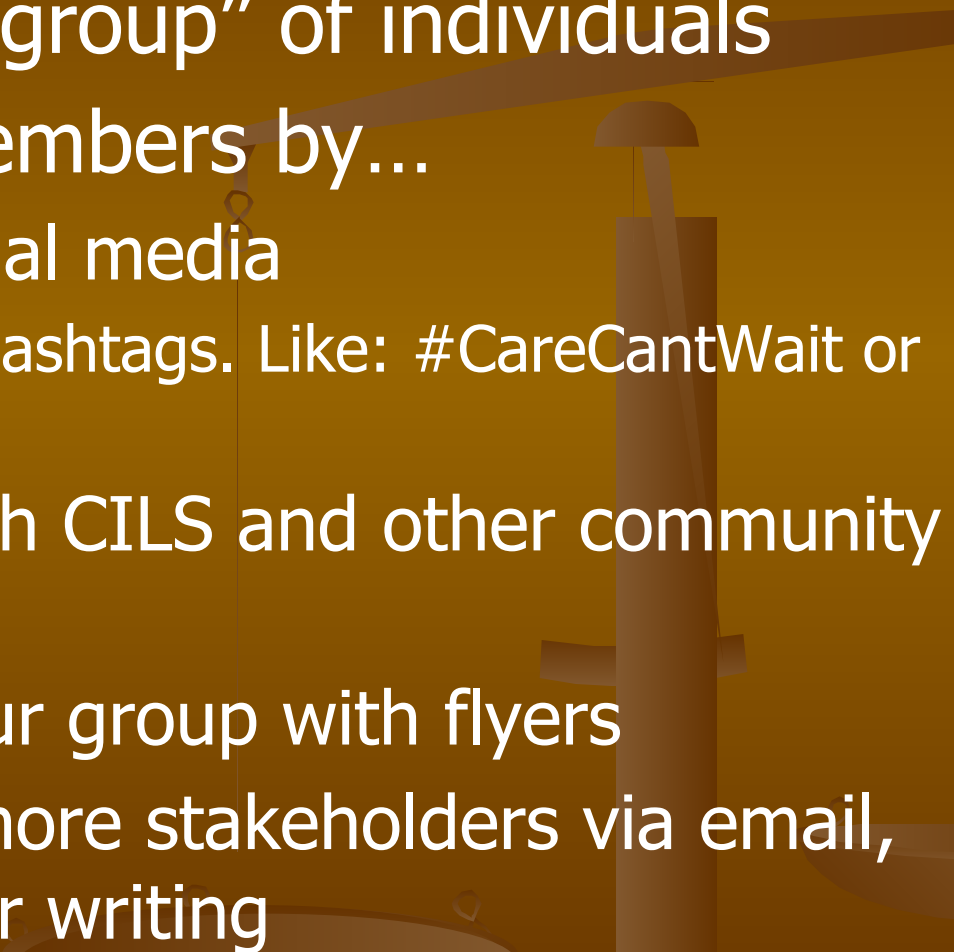
Publicity is an important tool in
successful systems advocacy!



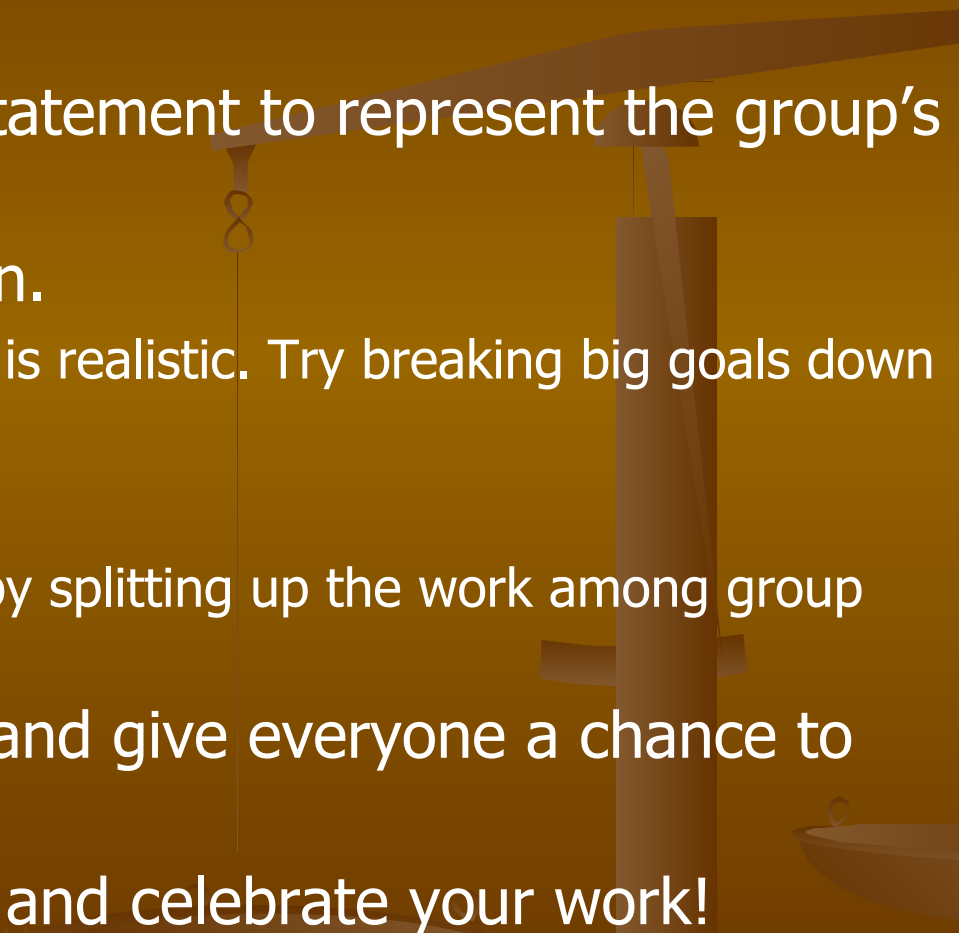


- What is a coalition?
 - A group of individuals who share a common interest/goal.
- Why form a coalition?
 - Empower people in your community. Get more perspectives on an issue. Combine resources and ideas. Many voices are stronger than one voice.
- Who should be involved?
 - Anyone impacted by and 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!
- 

Disability Visibility



Politics • Culture • Media

Hosted by Alice Wong

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.

CILS and Lobbying

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.”

CILS and Lobbying

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.

CILS and Lobbying

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.

CILS and Lobbying



What is NOT lobbying?

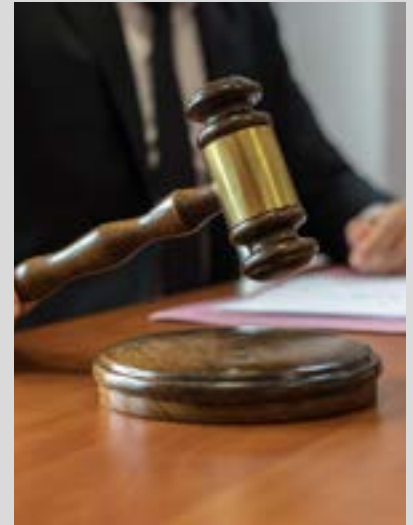
- **Discussing social, economic, and similar policy issues—even if specific legislation on the issues is pending—so long as the discussion does not address the merits of specific legislation**
- **Contacting government representatives in support of or opposition to proposed regulations**
- **Lobbying 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**

CILS and Lobbying

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**

What is not lobbying?



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

■ CILS and 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

August 11, 2021

ATTN: Maureen Corcoran, Director, Ohio Department of Medicaid
Jeff Davis, Director, Ohio Department of Developmental Disabilities
Ursel McElroy, Director, Ohio Department of Aging
CC: Governor Mike DeWine

FROM: The Ohio Olmstead Task Force
RE: The Direct Care Workforce Crisis in Ohio

Dear Director Corcoran, Director Davis, and Director McElroy:

The state of Ohio is currently in a crisis. Due to a lack of in-home care providers, many people with disabilities are forced to choose between living at home with inadequate supports or moving into an institutional setting. We, representing the Ohio Olmstead Taskforce and with the support of the dozens of individuals and organizations across Ohio undersigned to this letter, are writing to ask that ODM, DODD, and ODA develop a joint action plan to solve this ongoing problem.

"I am engaged to a man with a progressive muscle degenerating disability. He is on MyCare Ohio and receives 62 hours per week of home health care. He cannot get in or out of bed independently anymore. In the past four years, he has had four different agencies and about fifteen different aides. He has been stuck in his wheelchair all night because an aide called off and the agency did not send anyone else. Likewise, he has been stuck in bed in the morning for the same reason and had to call 911 to get him out of bed countless times. The agency always tells him he has to have a "backup plan". His son travels for work and is not available whenever an aide is a no-show. The aides who come do the bare minimum and want to leave early. Again, what incentive do they have to come to work? He, too, has depression and has talked about not wanting to live anymore due to the uncertainty of his care."

- 47-year-old woman with cerebral palsy from Willoughby, Ohio

Learn more: Visit
ohioolmstead.com/issues-advocacy/

More examples of 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.



The Ohio Home and Community-Based Services Coalition Interested Party Testimony on House Bill 110 Senate Finance Committee May 13, 2021

Chairman Dolan, Vice Chair Gavalone, Ranking Member Sykes and members of the Senate Finance Committee, thank you for the opportunity to provide written-only, interested party testimony in consideration of House Bill 110 (HB 110)—the state's biennial budget. The Ohio Home and Community-Based Services Coalition (Ohio HCBS Coalition) is a group of over 120 advocacy organizations, individual providers, and advocates with the mission to protect and expand home and community-based services (HCBS) in Ohio.

The Senate Finance Committee should increase provider rates 5% in each year of the biennium.

In addition to the rate increase, language should be included that ensures these investments make it to our direct care workforce. This workforce is significantly underpaid and it is difficult for individuals to find providers. The need for home care workers is projected to increase 34% over the next 10 years, and yet these skilled workers make less than a living wage for a single adult in Ohio. Over the course of a year, 1 in every 2 workers will leave their jobs, often unable to support themselves on the average wage of \$11.08 per hour or just over \$23,000 per year.

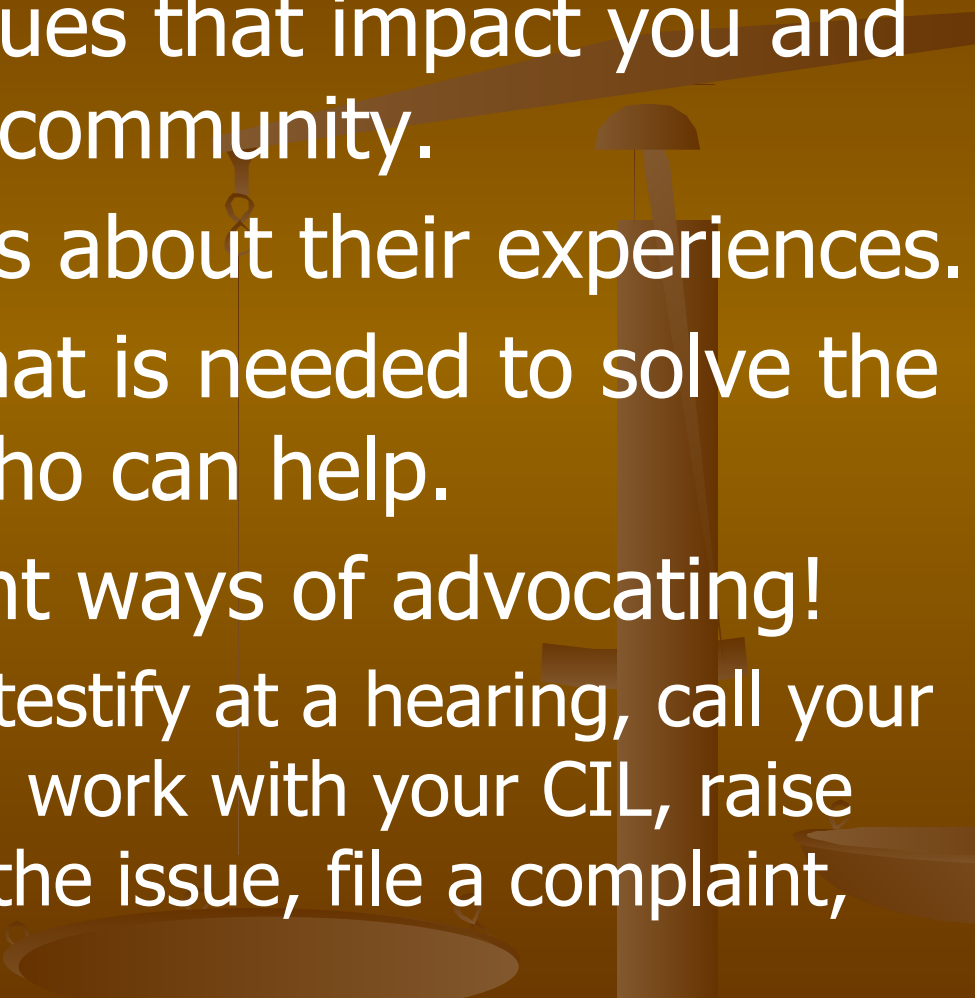
It is important to note, this workforce is disproportionately made up of black, indigenous, women of color. By not supporting this workforce, Ohio is exacerbating inequities in the state and placing additional burden on the working class. Additionally, a large share of this workforce relies on other state assistance programs. Specifically, 53% of home care workers receive public assistance with 39% on Medicaid. In 2018, 57% of the home care workforce was earning less than 138% of the poverty level. Continuing to underpay

This piece is a representation of the voices of Ohioans across the state. Ohio caregiver crisis is extreme! We need an immediate action Plan to deal with this crisis in our homes and communities. We look to our leaders to be change makers for the sake of equal access to care and employment for all.



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.