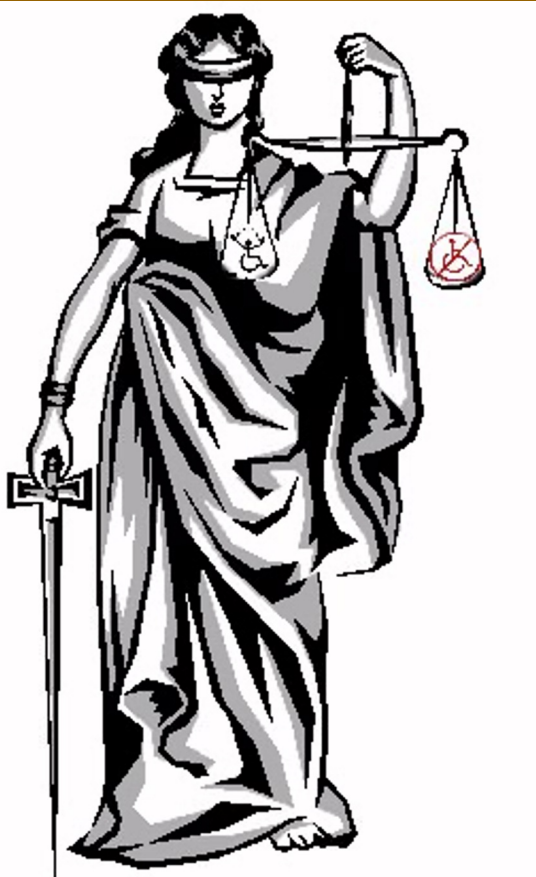


Disability Advocacy Seminar Series



Session 1: Understanding Disability Rights

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

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 access and re-use.
- 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 & Objectives

- Objective 1: Understanding Disability History and the Disability Rights Movement
- Objective 2: A Better Understanding of Terminology
- Objective 3: Understanding Independent Living History and Philosophy
- Objective 4: How to Become Involved with Advocacy, Grassroots Advocacy and Community Organizing and Understanding Disability Pride

Objective 1

Understanding Disability History and the
Disability Rights Movement



Disability History Timeline

Art, poetry and philosophy

Written and visual documentation of prostheses for warriors wounded in battle; Aristotle said "those born deaf become senseless and incapable of reason"

0-1700

BC-0 AD

Recognition, exploitation

Asylums created worldwide; patients chained and on display; deemed witches; discriminatory Poor Laws established in Europe.

Schools

Schools for deaf established throughout Europe

1700-1800

1800-1900

Widespread schooling, Civil War, notable individuals

Schools for deaf, blind and "crippled children"; more than 30,000 amputations for soldiers; Louis Braille, Thomas Gallaudet

Institutionalization to Systems Change

Mental illness contained in institutions and workhouses; eugenics and Hitler; WWI, WWII, Korean and Vietnam veterans with disabilities, non-profit orgs, civil rights laws, ADA

1900-2000

2000- Present

Battle for equality continues

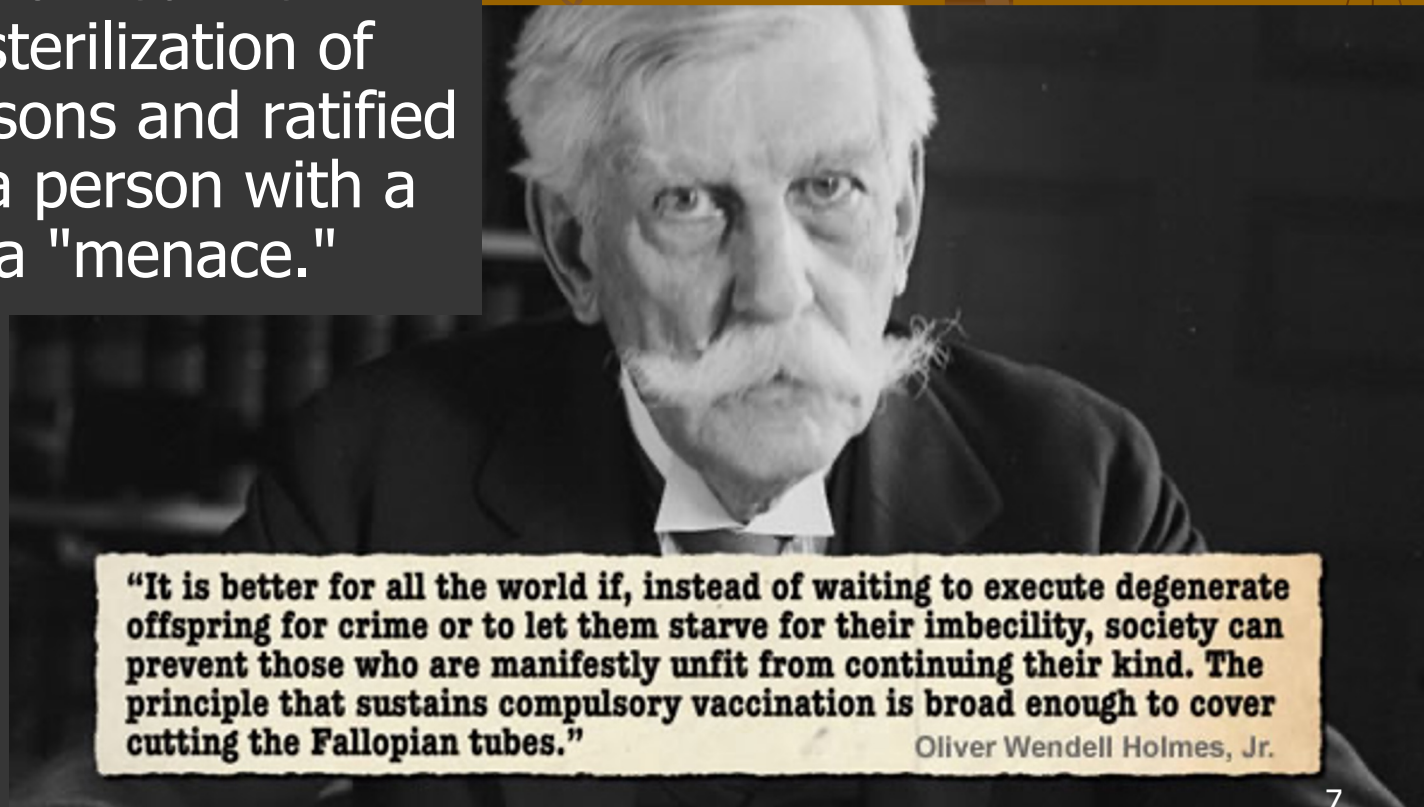
Disability pride, internet accessibility, police brutality, COVID-19 unequal treatment

US Disability History Worth Knowing:

1. In the past 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)

2. In 1927, the United States Supreme Court upheld an opinion by Justice Oliver Wendell Holmes:

- Holmes upheld the constitutionality of a Virginia law that authorized the involuntary sterilization of disabled persons and ratified the view of a person with a disability as a "menace."
- Holmes said that people with disabilities "sap the strength of the state"



"It is better for all the 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. The principle that sustains compulsory vaccination is broad enough to cover cutting the Fallopian tubes."

Oliver Wendell Holmes, Jr.

3. Dr. Paul Longmore, humanities expert and historian of the disability rights movement, and The Bargain:

- The Bargain was an article that appeared in *Disability Rag* magazine in 1989 and was written by Mary Johnson.
- In it, Longmore said President Franklin Roosevelt struck a bargain with non-disabled, normal American society, to tolerate individuals with disabilities as long as these individuals would strive to be as much like normal society as possible and do it cheerfully.





- The Bargain is only possible in a society viewing disability as "a private, emotional or physical tragedy," Longmore says.
- This "medical model" of disability sees disability as a problem to be dealt privately, between doctor and patient.
- "The Bargain," Longmore points out, "disallows any collective protest against things like prejudice or discrimination."
- Additionally, "disabled people can't complain, can't whimper."
- According to The Bargain, a disabled person achieves validity only to the extent she attempts to become normal. If one flaunts one's disability, if one flaunts normalcy, one has no right to decent treatment.

Disability Rights Key Events

- Relevant Civil Rights Laws
- Architectural Barriers Act 1968
- The beginning of the Independent Living (IL) Movement
- Willowbrook State School investigation and lawsuit
- Rehabilitation Act 1973
- Section 504
- ADA Signed in 1990
- ❖ The 2020 film, *Crip Camp: A Disability Revolution*, provides a personalized perspective on several of these events: [Crip Camp on youtube.com](https://www.youtube.com/watch?v=UW33W333333), also available on Netflix

Civil Rights Laws

1964--Civil Rights Act (disability not included)

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

Civil Rights Laws cont'd

1985--Mental Illness Bill of Rights Act

1988--Civil Rights Restoration Act

1988--Fair Housing Amendments Act

1990--Americans with Disabilities Act

1996--Telecommunications Act

1996--Air Carrier Access Act



Architectural Barriers Act (ABA) of 1968

- The ABA was the first Congressional act to ensure access to the built environment for people with disabilities.
- Prior to the ABA, great discrepancies in accessible design requirements from state to state, and in some cases, from city to city.
- The law required that buildings or facilities that were designed, built, or altered with federal dollars or leased by federal agencies after August 12, 1968 be accessible.
- Developed and set clear and consistent nationwide accessibility guidelines, which provided physical access and equal opportunity to public education, colleges and universities, community living, employment, health care, etc.

The IL Movement



- 1962: Ed Roberts, a ventilator dependent quadriplegic, was admitted to The University of California- Berkeley and was forced to live in the student health center because his iron lung could not be accommodated in the dorm
- 1965-66: A formal program for students with disabilities was begun at The University of California- Berkeley

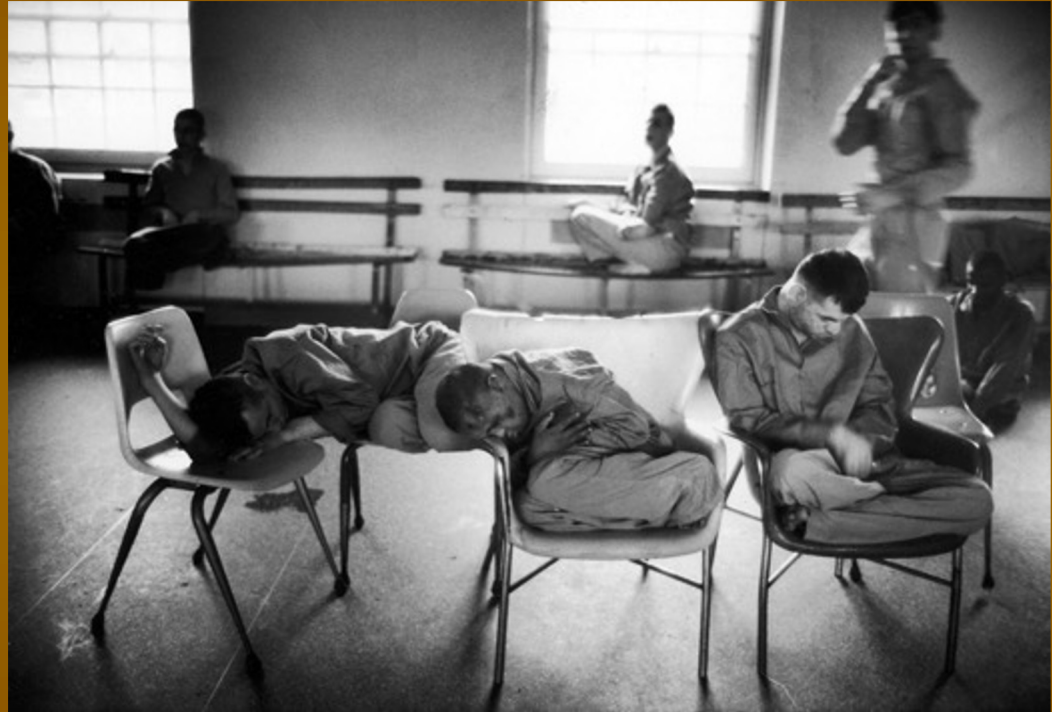
The IL Movement, cont'd

- 1970: Ed Roberts and friends at The University of California- Berkeley formed the "Rolling Quads" and the Disabled Students' Program on campus.
- 1971: The first Center for Independent Living was founded by Ed Roberts and fellow activists, becoming the first independent living organization



Willowbrook State School, Staten Island, NY

- Opened as Army Hospital during WW II
- New York State Dept. of Mental Hygiene took over in 1942
- Beginning in the 1950s, hepatitis studies were performed on children at Willowbrook
- By 1965, over 6000 children with cognitive disabilities were being housed there, beyond the maximum capacity of 4000



Willowbrook State School, Staten Island, NY

- In 1965, Robert Kennedy toured the facility and said the individuals were, "living in filth and dirt, their clothing in rags, in rooms less comfortable and cheerful than the cages in which we put animals in a zoo"
- By 1972, Geraldo Rivera produced an exposé, *Willowbrook: The Last Great Disgrace*, revealing the deplorable conditions and abuses to residents by the staff



Willowbrook State School, Staten Island, NY continued

- As a result of the exposé, a class action lawsuit was filed against the state of New York by 5000 parents of residents.
- In 1975, the Willowbrook Consent Decree was signed, directing New York State to improve community placement for the individuals in the lawsuit
- By 1987 Willowbrook was officially closed
- The media exposure of the inhumanity at Willowbrook contributed to the deinstitutionalization movement and passage of Civil Rights of Institutionalized Persons Act of 1980.

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 80 other activists
- September 1973: Congress overrode Nixon's veto - finally became law

Rehab Act Key Language

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.

found in Section 504 of Title V

Rehab Act Regulations

- 1977: Nixon & Ford gone – Carter President
- Joseph Califano, Secretary of Health, Education and Welfare refused to issue regulations
- Was given an ultimatum and deadline of April 4, 1977
- On April 4, demonstrations in 10 cities nationwide
- By the end of the day, demonstrations ended except in San Francisco where protesters refused to disband
- More than 150 people with disabilities took over the federal office building and refused to leave until Califano issued regulations and protesters approved them, which took 28 days

Section 504 Demonstration



-CBS Evening News

Americans with Disabilities Act

- During 1980s disability community educates legislatures and the courts to uphold Section 504
- Justin Dart travels throughout the US to educate law makers about the lives of people with disabilities
- April 1988: First version of ADA legislation introduced to Congress
- Senator Kennedy, Senator Harkin, and Representative Owens make commitment to getting legislation passed
- May 9, 1989: New version of ADA legislation introduced
- Legislation stalls in the House Committee on Public Works and Transportation prompting activists to protest

Americans with Disabilities Act



Americans with Disabilities Act Continued

- March 12, 1990: Men and women of all ages and disabilities abandon assistive devices and crawl up the steps of the Capitol
- Sit in at the Capitol Rotunda
- July 26, 1990: Signing on the White House lawn



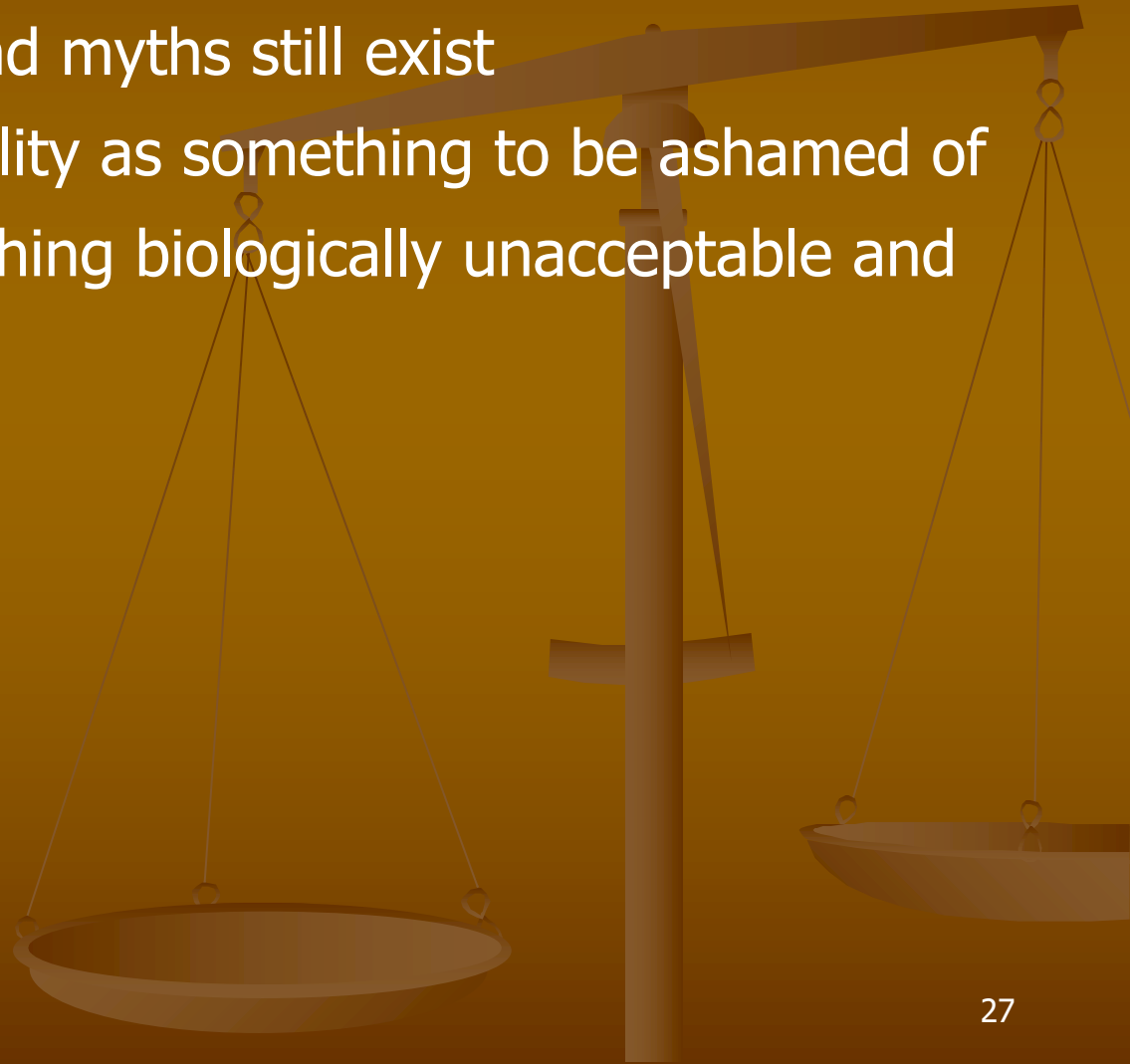
Objective 2

A Better Understanding of Terminology



Stereotypes

- Negative stereotypes and myths still exist
- Society still views disability as something to be ashamed of
- Sees disability as something biologically unacceptable and unnatural



Society Views People With Disabilities As:

- Biologically inferior
- Unfortunate cripples
- Burdens
- Victims
- Outcasts
- Menaces
- Asexual
- Subhuman
- Fragile



Stereotypes

- Sick: to be treated and cured or cared for!
- Need charity and welfare: having little value to society (telethons have perpetuated several of these images.)
- Deficient: without skills and talents
- Deviant: behavior or appearance that is outside the social norm. What is considered deviant varies from culture to culture. Often the real deviancy is in the eye of the beholder.

Group Discussion:

How Have Disability Stereotypes Affected You?



What To Do About Disability Stereotypes?

- Group discussion: What Is Your Role?
- Society reinforces the erroneous concept that people with disabilities are inherently inferior to people without disabilities by attempting to restrict or confine people with disabilities to roles which are considered socially inferior, such as sick person, weak person, non-contributing person.”
- Society often seems comfortable with us only when we stay where society would like to put us, in these socially less-than roles.

Strengths That Result From Living with Disability

Give some examples of “Strengths” that result from living your life to the fullest as a person with a disability



“Handicapped” vs. “Disability”

- The term “**handicapped**” connotes the negative image of a person on the street corner with a “handy cap” in hand, begging for money. This term is outdated -- “**disability**” is the preferred term. Avoid using the term “handicapped” in any context, including signs.
- This preference is reflected in federal, state and local legislation.
- *The ADA was not called the “Americans with Handicaps Act” -- the term “handicap” does not appear anywhere in the ADA.*

“Handicapped” vs. “Disability”

- The word “**disability**” means the lack of ability or power. A disability can mean that a person may do something differently as compared to a person who does not have a disability, but with equal participation and equal results.

Terminology

- Use “People First” Language – *People First, Disability Second.* This encourages the use of **positive language**. Put the person *first* in thought and word and emphasize a person’s *abilities* instead of limitations.
- *Examples:*
 - “Tom, the blind man, is a teacher.” (negative)
 - “Tom is a teacher. He is also a person with a disability.”
 - “Tom, the teacher, is blind.”
 - “Tom is a teacher.”

Terminology

- Having a disability does not define a person. Don't refer to a person's disability unless it is important or relevant.
- People with disabilities are **people** who *happen* to have **disabilities**. It is more positive to say "**person with a disability**," rather than "disabled person."
- ❖ *Please note some people prefer **identity first** language, as they view their disability as part of their identity. A person's preference should always be taken into account when writing and/or talking about a person and their disability. However, if you aren't sure, and if you can't ask the person and/or cannot be certain of the person's preference, use person-first language.*

Confined to a Wheelchair?

Wheelchair Bound?

- When you hear these phrases ... what kind of mental picture do you get? A person chained to the chair?
- People use wheelchairs and/or scooters to **increase** their mobility. Wheelchairs are **mobility aids**. For many people, a wheelchair means **freedom** and allows people to **participate in society**.
- Many people who use wheelchairs can walk but may use a wheelchair to conserve energy or to travel faster.
- More acceptable: “**person who uses a wheelchair**”; “**wheelchair user**”.



Disability: Invisible Or Visible



Some More On Language Etiquette...

Some words and phrases to avoid:

- Handicapped
- Wheelchair bound/Confined to a wheelchair
- Crippled
- Retarded
- Deaf-mute
- Physically challenged
- Differently abled
- Special needs
- Special/ Brave/ Inspiration/ Courageous suffer (a person isn't necessarily in pain)
- Patient (most people with disabilities are not sick)

***Get away from words that mean dependency, confinement, and suffering.
Be straightforward.***

Some More On Language Etiquette...

Some Preferred Phrases:

- **"Accessible parking space"** instead of "handicapped parking space" or "disabled parking space"
- **"Accessible restroom"** instead of "handicapped restroom"
- **"Accessible bathroom stall"** instead of "handicapped bathroom stall"

Objective 3

Understanding Independent Living History and Philosophy

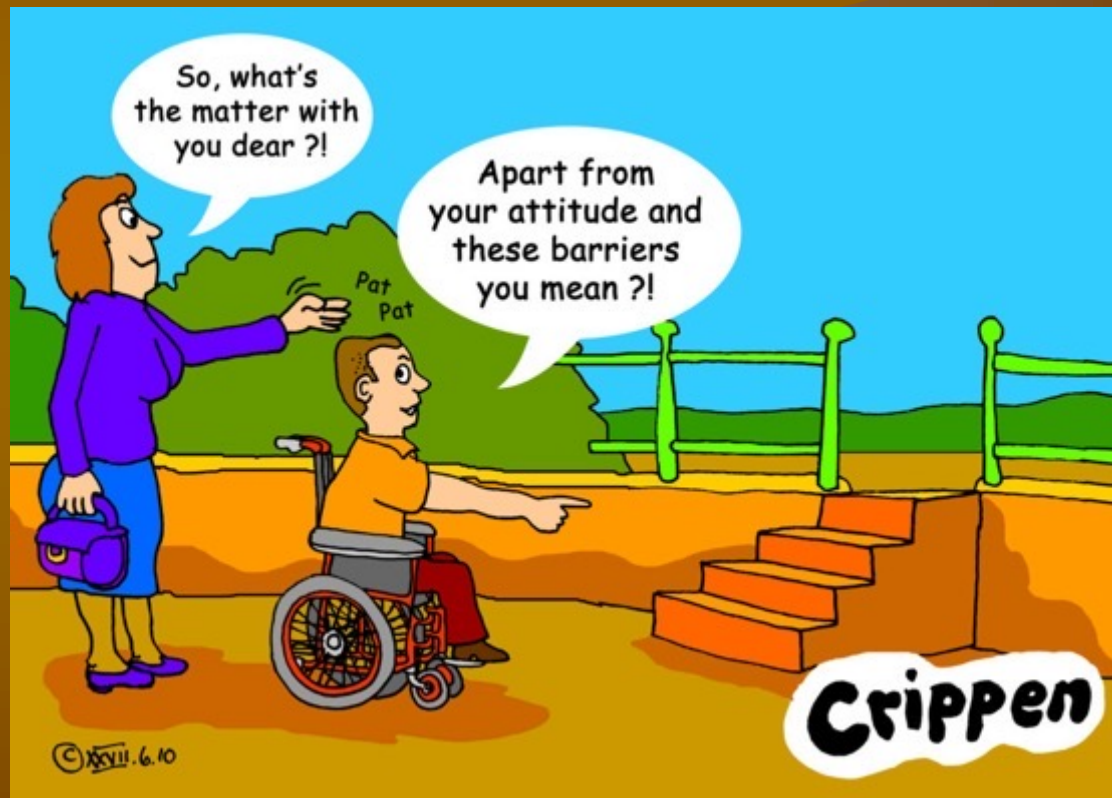


Independent Living Philosophy

- A Movement
- A Civil Rights Movement
- A Social Movement



Social Movements

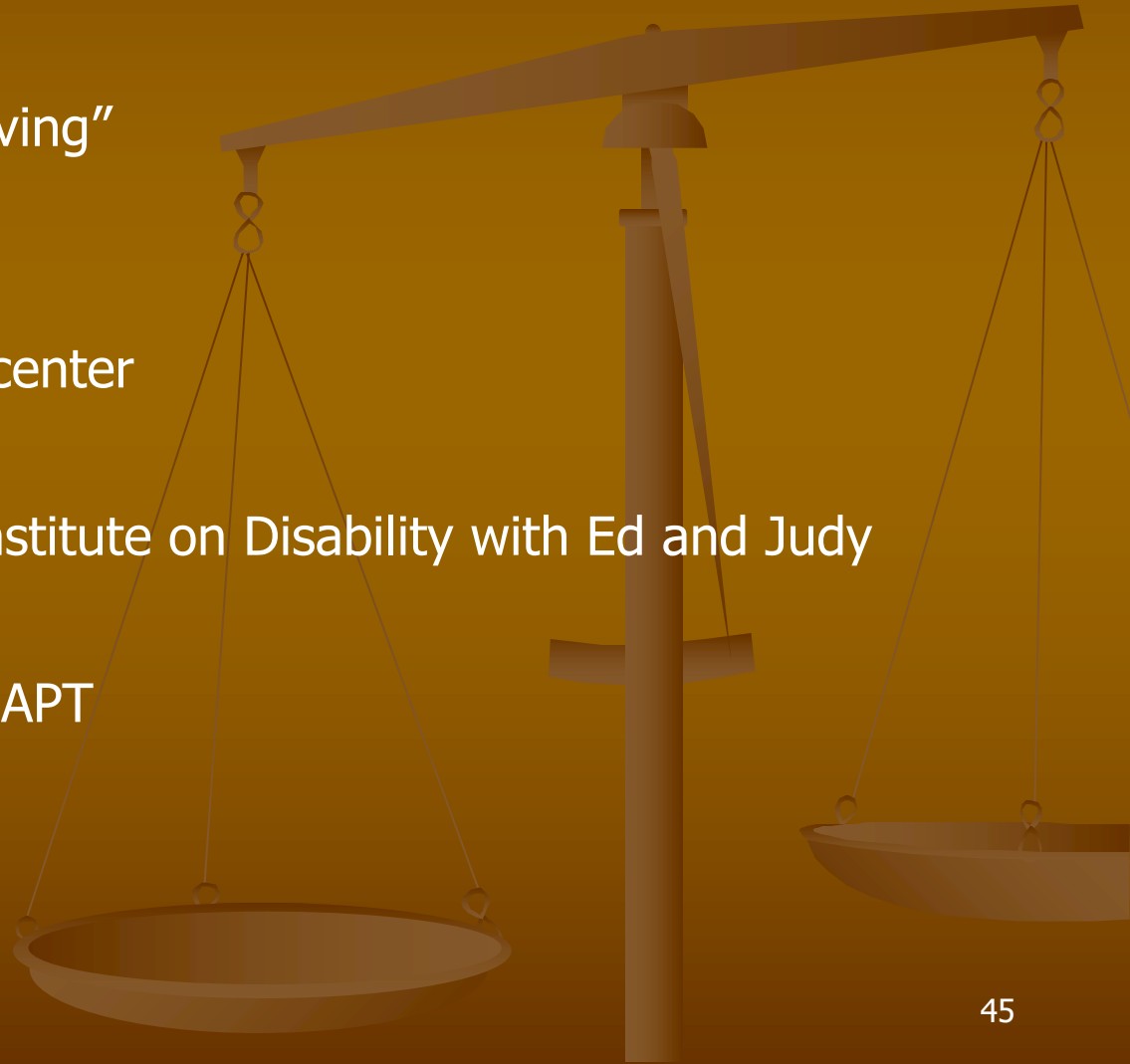


Deinstitutionalization

- An attempt to move people, primarily those with developmental disabilities, out of institutions and back into their home communities.
- When the process of deinstitutionalization began in the 1960's, some people with significant disabilities were released from inevitable life sentences in nursing homes and other institutions, which created for the first time in history an opportunity, an imperative, for people with disabilities to live free and independent lives. From this, a community and a culture with history, values, and an objective were born.
- The IL Movement focused on supporting these individuals.

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 the National Council on Independent Living, NCIL
- 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, IRLU
 - Directed preparation of the original ADA legislation and its introduction in Congress.
- Liz Savage and Pat Wright, "Mothers of the ADA"

Ohio's CILs



The Ability Center



The Center
for Disability
Empowerment




**Tri-County Independent
Living Center, Inc.**

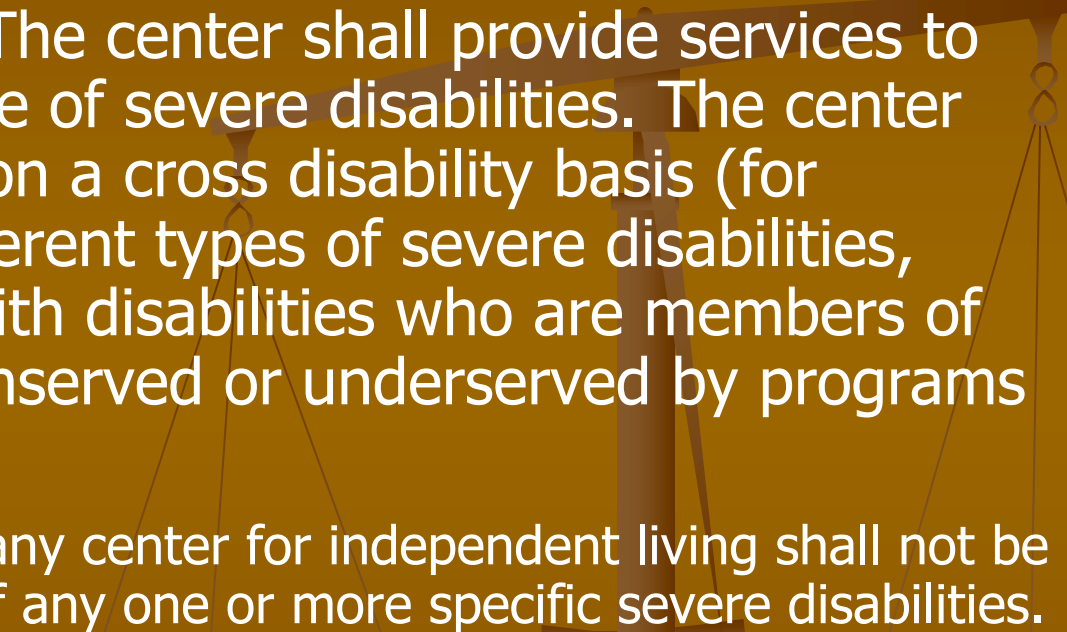
Independent
Living Center of
North Central
Ohio



Standards for Independent Living Centers

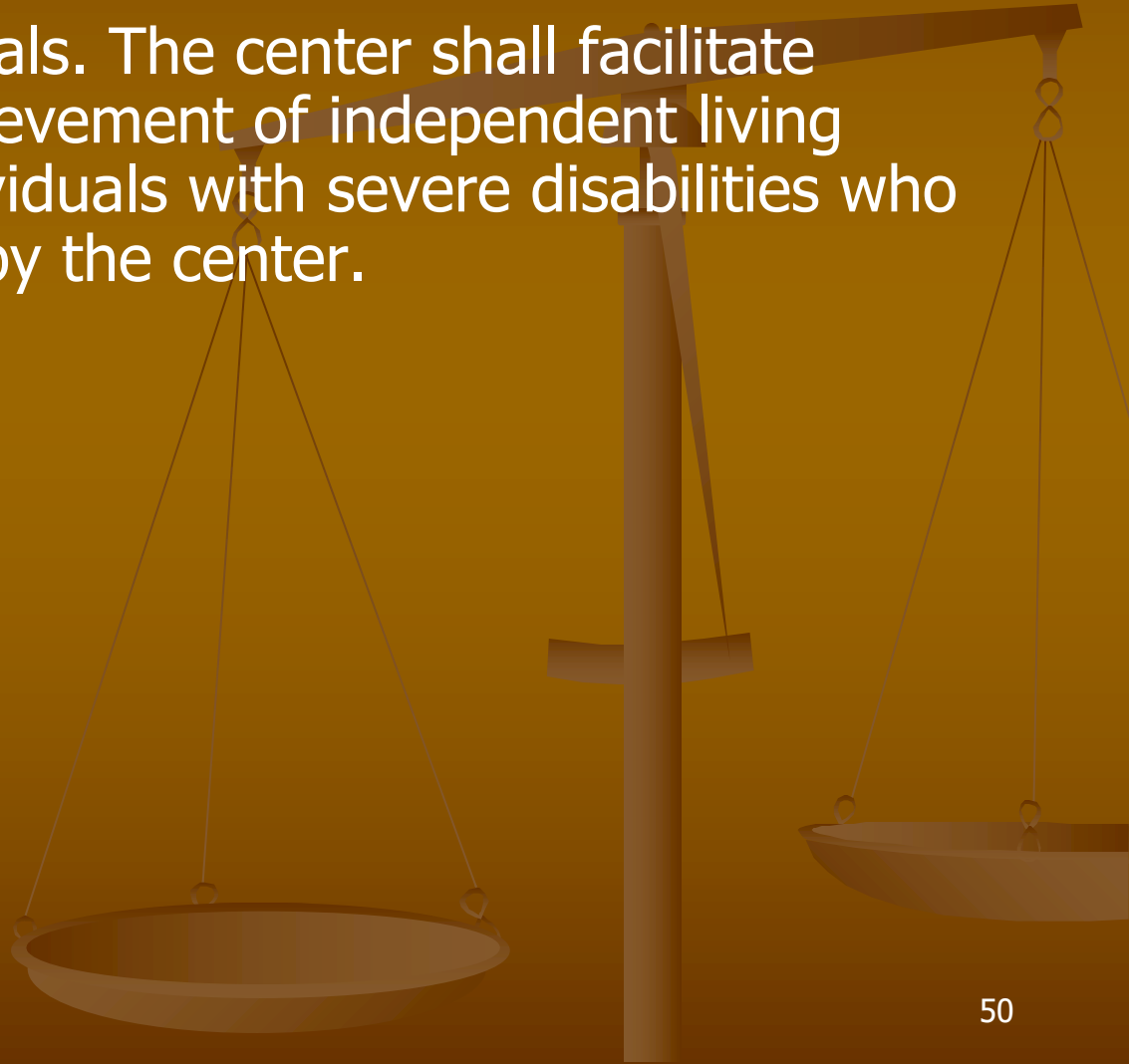
- 
- (1) Philosophy. The center shall promote and practice the independent living philosophy of:
- (A) Consumer control of the center regarding decision making, service delivery, management, and establishment of the policy and direction of the center;
 - (B) Self-help and self-advocacy;
 - (C) Development 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.

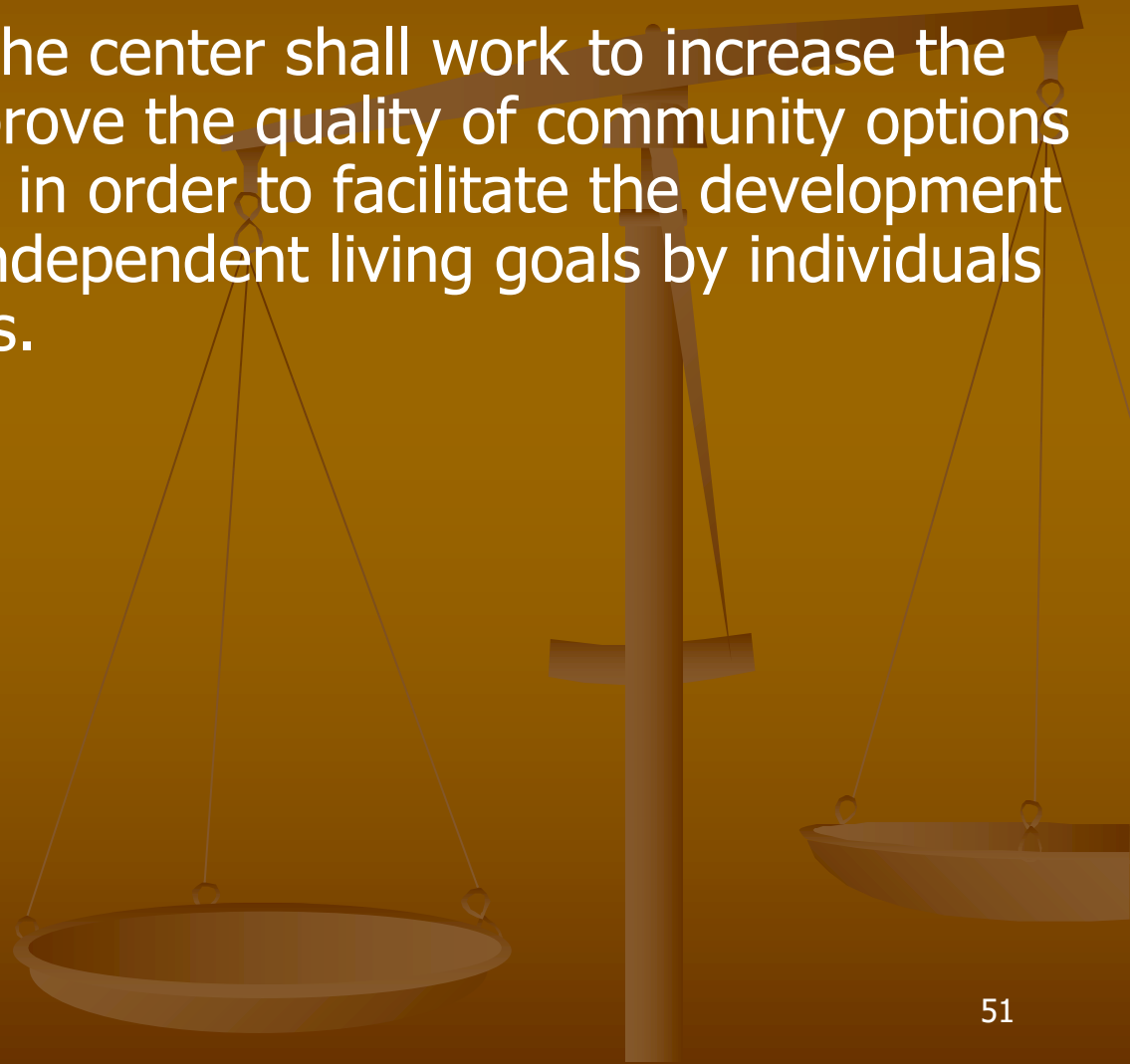
Develop Goals for Independent Living

- (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.



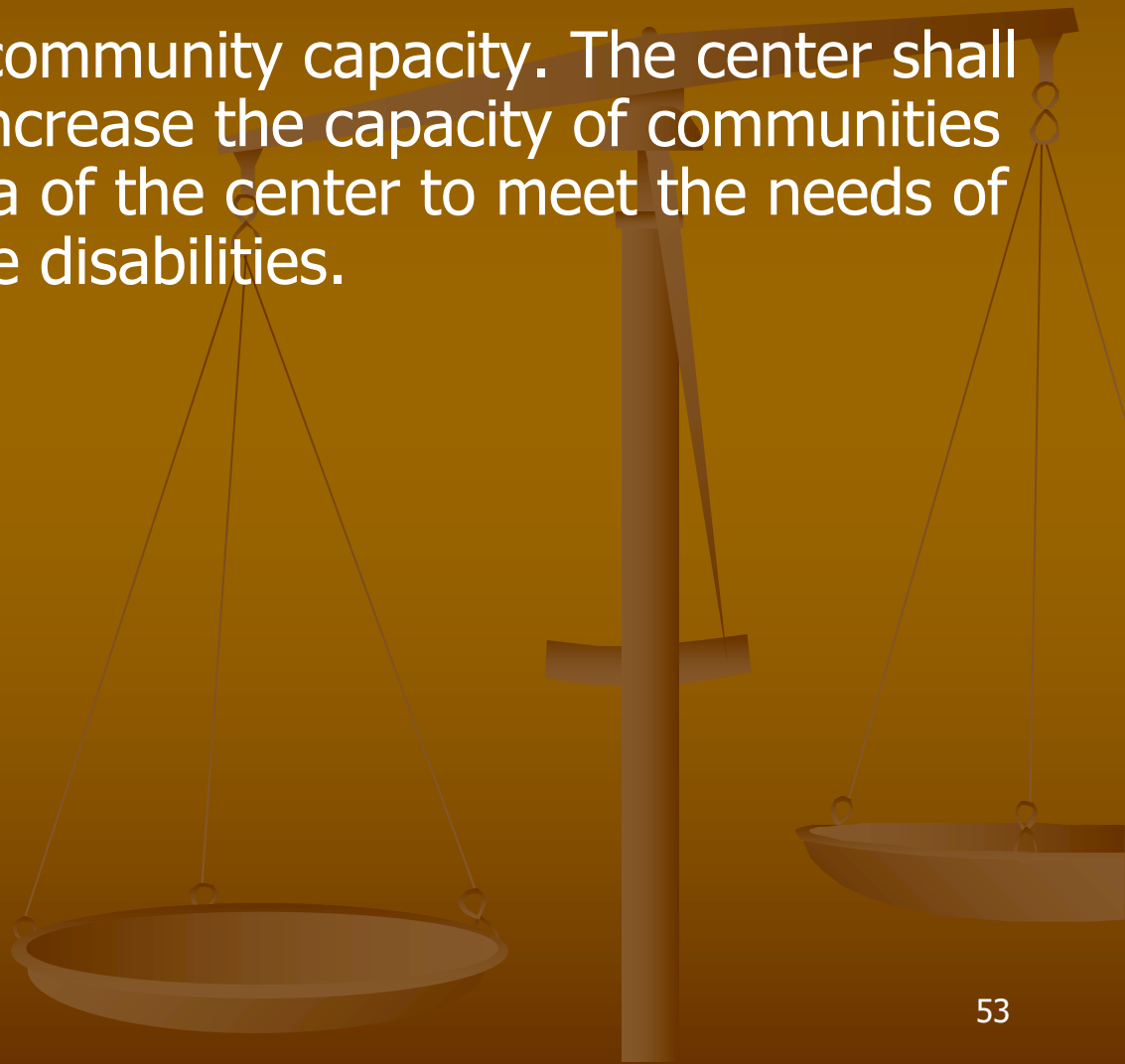
Provide Core Services

(5) Independent living core services. The center shall provide independent living core services and, as appropriate, a combination of any other independent living services.

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

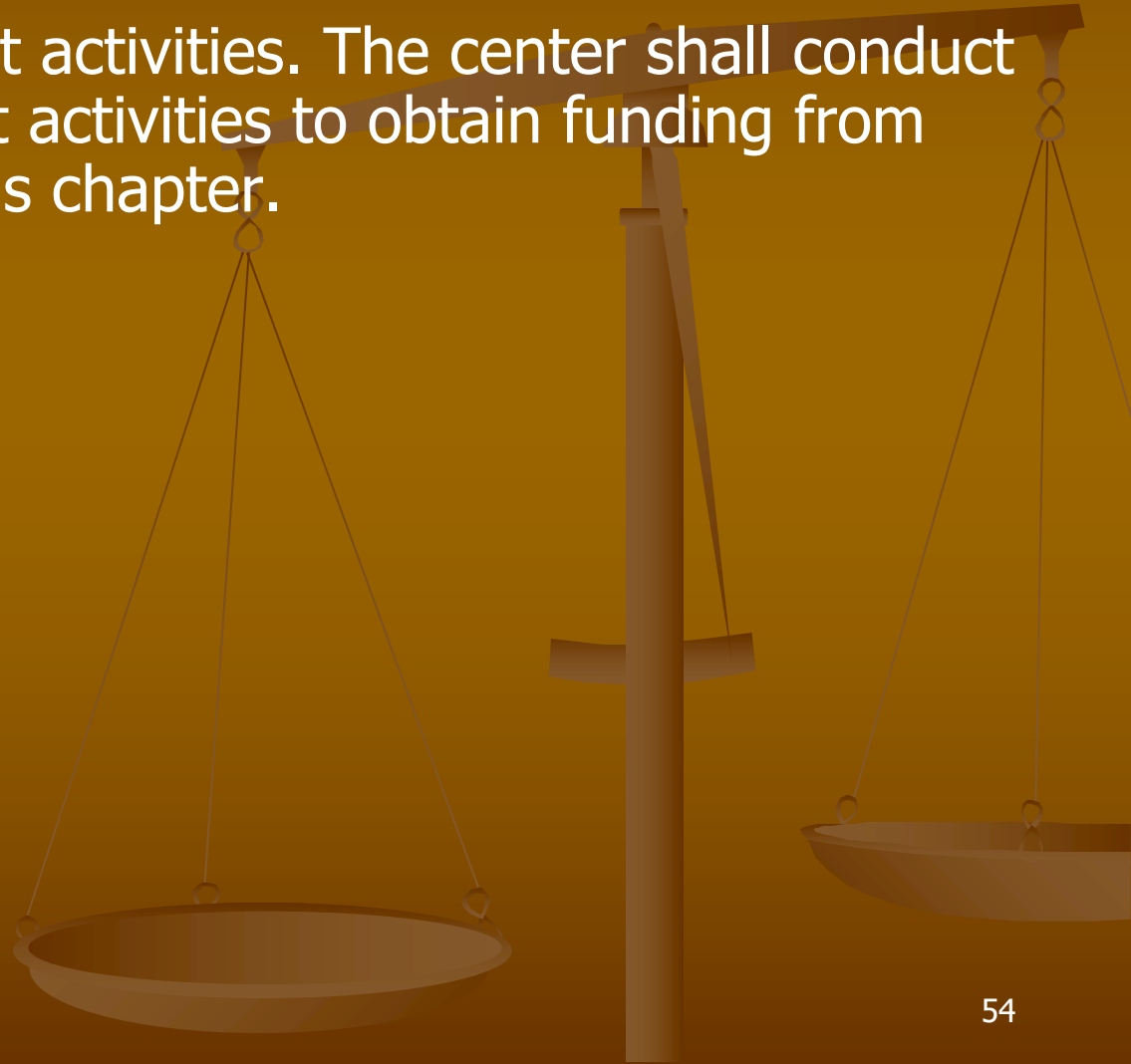
Increase Community Capacity

- (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.



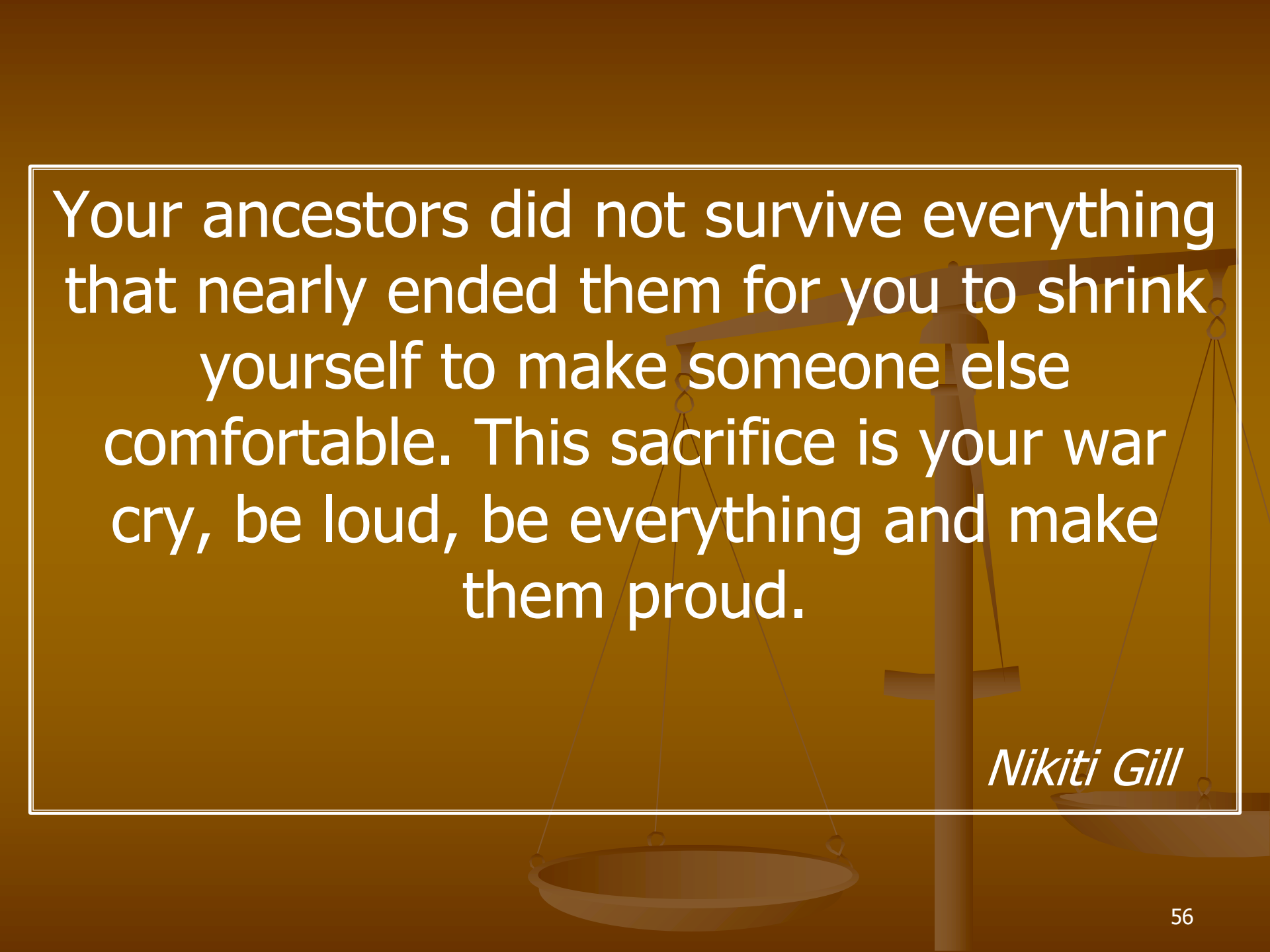
Conduct Resource Development

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



Objective 4

How to Become Involved with Advocacy,
Grassroots Advocacy and Community
Organizing and Understanding Disability Pride



Your ancestors did not survive everything
that nearly ended them for you to shrink
yourself to make someone else
comfortable. This sacrifice is your war
cry, be loud, be everything and make
them proud.

Nikiti Gill

Forms of Activism

- Writing Letter(s)
- Demonstration
- Marches
- Organizing
- Speeches/Lectures/Academia
- Scholarship/Art/Music/Poetry/Literature
- Civil Disobedience



Principles of Advocacy

- Clarity of purpose
- Safeguard
- Confidentiality
- Equality and Diversity
- Empowerment
- Putting people first



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

- 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 people with disabilities.
- The term arose in the broader civil rights movements of the 1960s and 1970s and is part of the disability rights movement.

From Wikipedia, the free encyclopedia

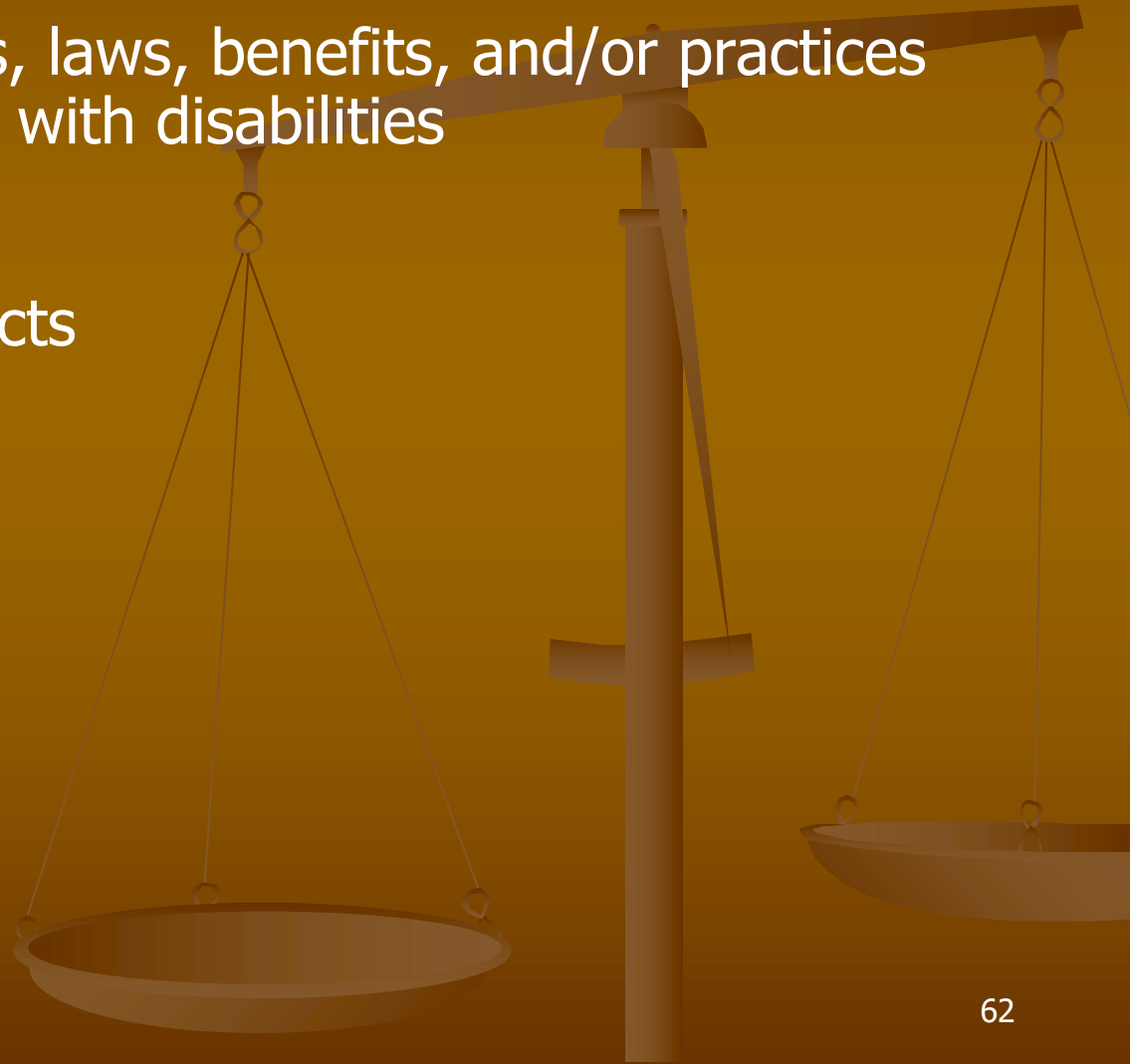
What is Self-Advocacy?



- 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





Johnny Crescendo's "Pride."



"Disability Pride represents a rejection of the notion that our physical, sensory, mental, and cognitive differences from the non-disabled standard are wrong or bad in any way, and is a statement of our self-acceptance, dignity and pride.

It is a public expression of our belief that our disabilities are a natural part of human diversity, a celebration of our heritage and culture, and a validation of our experience.

Disability Pride is an integral part of movement building, and a direct challenge to systemic ableism and stigmatizing definitions of disability.

It is a militant act of self-definition, a purposive valuing of that which is socially devalued, and an attempt to untangle ourselves from the complex matrix of negative beliefs, attitudes, and feelings that grow from the dominant group's assumption that there is something inherently wrong with our disabilities and identity."

Sarah Triano

Disability Pride

- Disability pride equals personal liberation from handicapism (myths and stereotypes accepted about disability).
- It is an awareness and analysis of our experience.
- It is a positive view of ourselves.
- People with disabilities who acknowledge their disability view themselves as perhaps different but not inferior.
- Disability is an integral, important, and valid part of who they are, and they view disability as a natural occurrence of the human condition.

Disability Pride *Continued*

- They do not apologize for having a disability. They are proud of who they are and do not experience regular feelings of self-hate and self-depreciation.
- This sense of pride does not develop over night, it evolves over time.
- Some days, feeling that sense of strength and pride is a struggle.
- Networking and being with peers with disabilities who feel good about themselves can help to reinforce the pride.



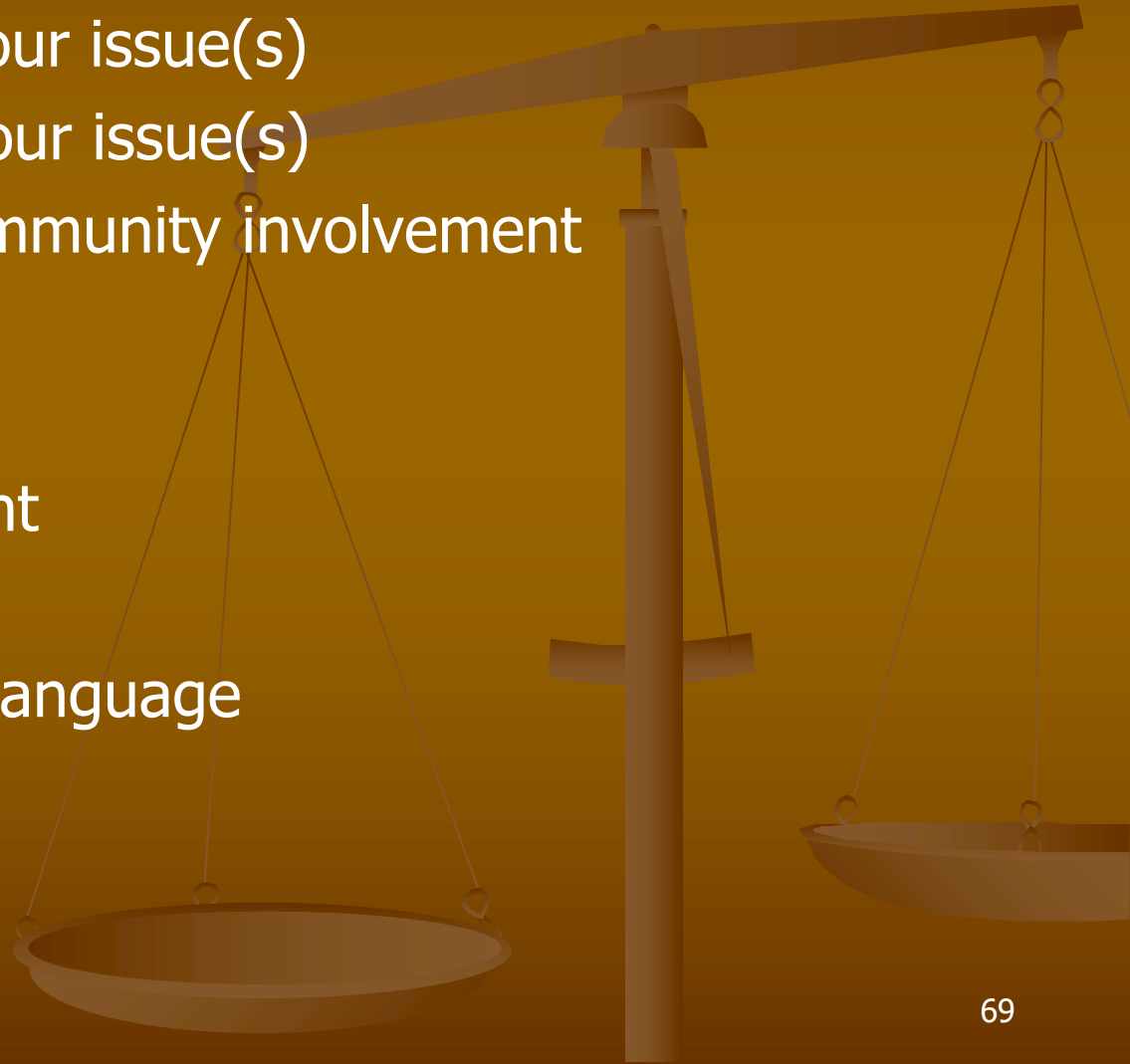
**Before you can lead,
you must first learn to
follow**

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

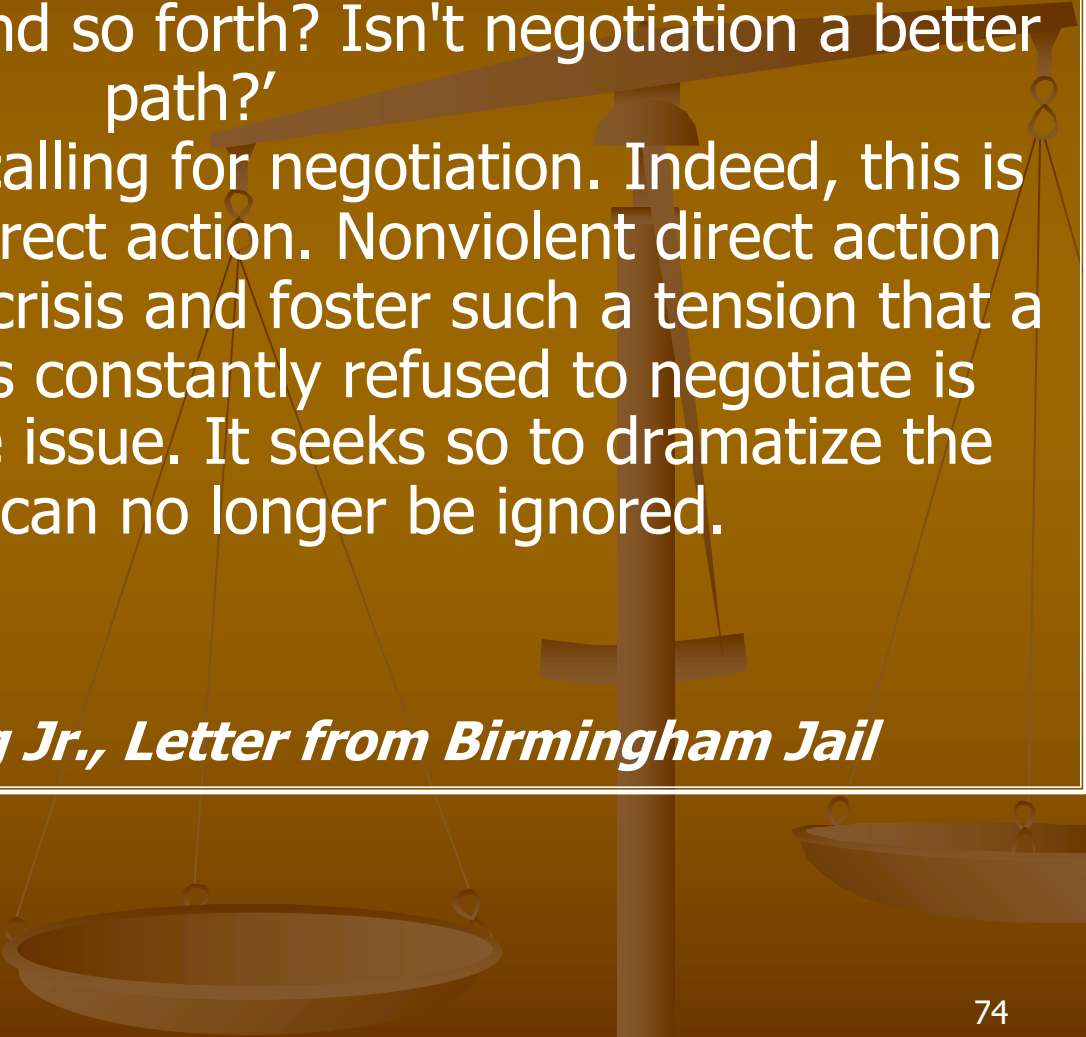




ADAPT

- 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





You may well ask: 'Why direct action?
Why sit-ins, marches and so forth? Isn't negotiation a better
path?'

You are quite right in calling for negotiation. Indeed, this is the very purpose of direct action. Nonviolent direct action seeks to create such a crisis and foster such a tension that a community which has constantly refused to negotiate is forced to confront the issue. It seeks so to dramatize the issue that it can no longer be ignored.

Martin Luther King Jr., Letter from Birmingham Jail

The Reverend Wade Blank, 1940-1993

- Pittsburgh, PA
- College, Conservative
- Accused of being a racist
- Selma, Alabama with Dr. Martin Luther King, Jr.
- *He about the stark oppression, which occurred against people considered to be outside the "mainstream" of our "civilized" society*
- Presbyterian Minister and War on Poverty Field Organizer, Canton OH



The Reverend Wade Blank, *continued*

- December 1971 – Heritage House, Denver Colorado
- *Youth Wing, an orderly, then an assistant administrator*
- 1974 – Wade got fired
- *Institutional services and living arrangements were at odds with the pursuit of personal liberties and life with dignity.*
- 1974 – Atlantis Community is Born

Liberated Community

A society where human beings could live in equality and develop the power to effect change

Confrontation Works

It takes society's fears – those fears we're always trying to dispel in disability awareness workshops – and turns them to a new use...



ADAPT - American Disabled for Accessible Public Transit

Founded July 5-6, 1978

Wade and nineteen disabled activists held a public transit bus "hostage" on the corner of Broadway and Colfax in Denver, Colorado. ADAPT eventually mushroomed into the nation's first grassroots, disability rights, activist organization.

For seven years ADAPT blocked buses in cities across the US to demonstrate the need for access to public transit. Many went to jail for the right to ride.

In the spring of 1990, the Secretary of Transportation, Sam Skinner, finally issued regulations mandating lifts on buses. These regulations implemented a law passed in 1970-the Urban Mass Transit Act-which required lifts on new buses. The transit industry had successfully blocked implementation of this part of the law for twenty years, until ADAPT changed their minds and the minds of the nation.

ADAPT played a major role in gaining passage of the Americans with Disabilities Act, ADA, particularly in ADA's stringent requirements relating to accessible transit, and its being seen as a civil rights law. Passage of this bill has meant victory for ADAPT in our struggle for lifts on buses.



ADAPT - American Disabled for Attendant Programs Today

In 1990, after passage of the Americans With Disabilities Act (ADA), ADAPT shifted its vision toward a national system of community-based personal assistance services and the end of the apartheid-type system of segregating people with disabilities by imprisoning them in institutions against their will. The fight for a national policy of attendant services and the end of institutionalization continues to this day.

Nationally ADAPT focuses on promoting services in the community instead of warehousing people with disabilities in institutions and nursing homes. Attendant services (help with things like eating, dressing, toileting, moving from wheelchair to bed, etc.) are the cornerstone to community-based services for people with severe disabilities.



Some - mostly those that didn't know him - have said that Wade's methods were "extreme."

They said that civil disobedience in the eighties and nineties is "passe," "obsolete," "inappropriate." The same kinds of things were said about Washington, Jefferson, Gandhi and Martin Luther King.

What is extreme, what is inappropriate is millions of human beings living with less dignity than we accord to our pet dogs and cats.

What is inappropriate is American citizens imprisoned without due process of law in oppressive institutions and rat-infested back rooms.

What is inappropriate is people with disabilities living and begging in the streets.

What is inappropriate, what is unspeakably immoral, is a society that cannot be bothered to make the simple changes necessary to give its own children the opportunity of full humanity.

Justin Dart

The `Built Environment' Often Causes the Real

- Many people with disabilities view their disability as problems with the environment rather than problems with their own body. It is the environment which frequently causes the real disability.
- Disability does not have to be about self-hatred and self-blame. Often it is not the disability which limits activities as much as the architectural barriers. The built environment limits participation, productivity, integration, independence, and equality.

Examples

- If a person with a disability is offered a job that cannot be accepted because it is located on the second floor of a building without an elevator, the real problem is that there is no elevator.
- When a person cannot attend school or a training program because there are no ramps or curb cuts, no interpreters, brail or taped material, the real problem is that there is no physical and communication access to education.
- The real problem is often the environment!

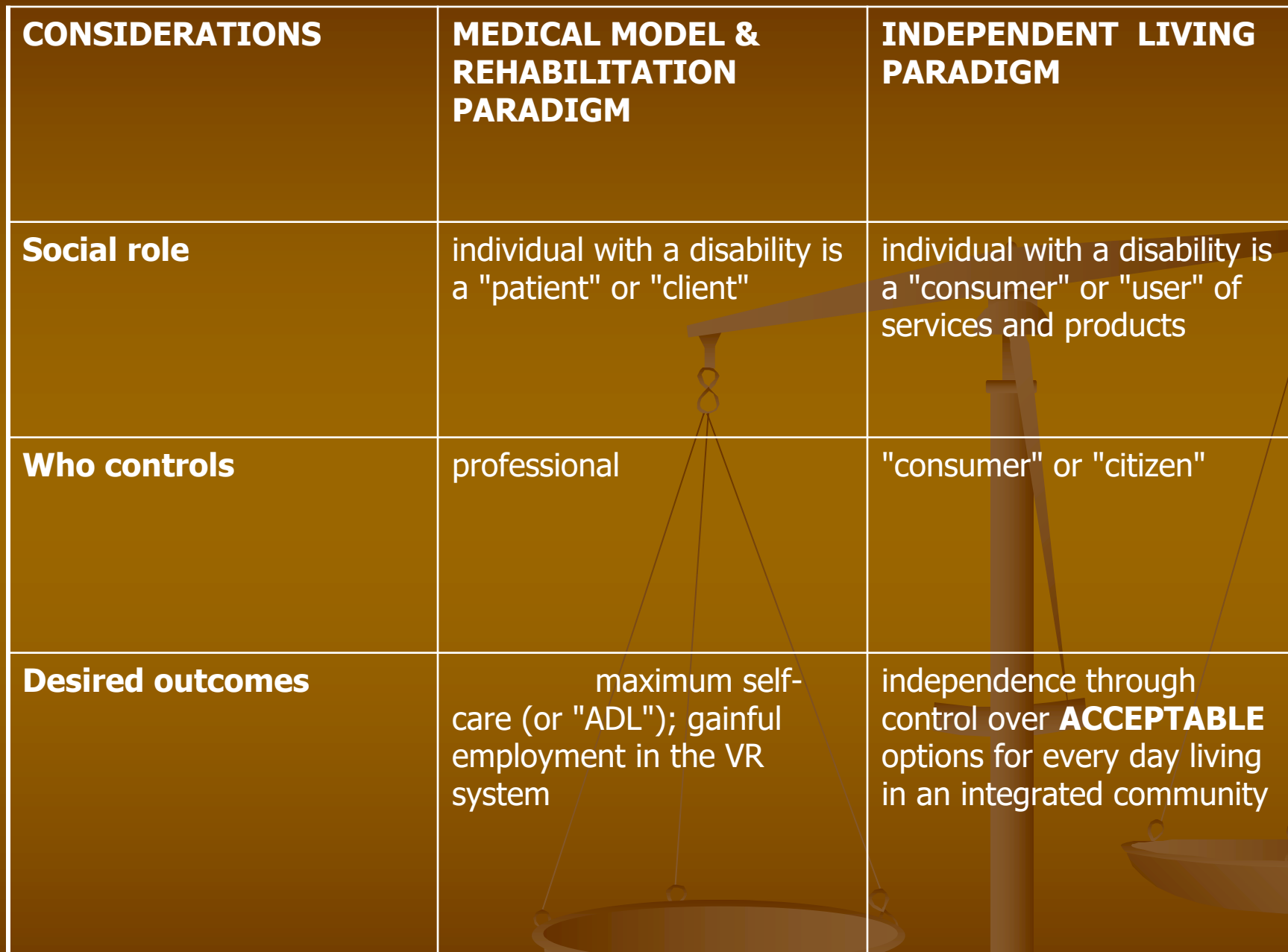
Disability-Related Public Policy Transition



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

Independent Living And Traditional Paradigms

CONSIDERATIONS	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 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 removal 2. advocacy 3. self-help 4. peer role models and counseling 5. consumer control over options and service



CONSIDERATIONS	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

Thank You!

- Contact Us!
 - Lisa Marn, SIL: lmarn@sil-oh.org
 - Maria Matzik, ACIL: maria.matzik@acils.com
 - Maria Sutter, LEAP: msutter@leapinfo.org
- Please join us for our next seminar:
 - **Understanding Advocacy**
 - **February 9, 2023**
 - **2- 4pm EST**
- Many thanks to our interpreter and captionist.
- Resources for the information in this presentation are listed on the slides at the end of this presentation.
- Recordings, transcripts, and copies of the presentation will be available after the series is complete. You'll receive more info by email.

Resources 1

- *29 U.S. Code § 796f–4 - Standards and assurances for centers for independent living.* (n.d.). LII / Legal Information Institute. Retrieved from [29 U.S. Code § 796f–4 - Standards and assurances for centers for independent living](#)
- *A Guide to Disability Rights Laws.* (n.d.). Retrieved from <https://www.ada.gov/cguide.htm>
- *About Independent Living.* (2019, May 30). National Council on Independent Living. <https://ncil.org/about/aboutil/>
- ADL. (2022, May 10). *10 Ways Youth Can Engage in Activism.* Retrieved from <https://www.adl.org/education/resources/tools-and-strategies/10-ways-youth-can-engage-in-activism>
- *Advocacy: inclusion, empowerment and human rights.* (n.d.). Social Care Institute for Excellence (SCIE). Retrieved from <https://www.scie.org.uk/advocacy/commissioning/inclusion>

Resources 2

- Arly. (2020, April 11). *A Brief History of the Disability Rights Movement*. YouTube. <https://www.youtube.com/watch?v=cNYhFDpAHtk>
- *Berkeley and Disability Rights*. (2021, August 25). Mad Lab at Cal. Retrieved from <https://disabilitylab.berkeley.edu/berkeley-and-disability-rights/>
- Carmel, J. (2020, July 22). nytimes.com. *New York Times*. <https://www.nytimes.com/2020/07/22/us/ada-disabilities-act-history.html>
- Disability Community Resource Center. (2018, February 12). *Disability Pride*. Retrieved from <https://www.dcrc.co/advocacy/>
- *Ed Roberts: The Father of Independent Living - FoundSF*. (n.d.). Retrieved from https://www.foundsf.org/index.php?title=Ed_Roberts:_The_Father_of_Independent_Living

Resources 3

- Hayman, B. (2019, September 3). *Independent Living History*. Access Living. Retrieved from <https://www.accessliving.org/newsroom/blog/independent-living-history/>
- *History of Atlantis/ADAPT*. (2021, March 30). Atlantis Community, Inc. <https://atlantiscommunity.org/about-us/history-of-atlantis-adapt/>
- *IL History & Philosophy / Independent Living Research Utilization*. (n.d.). Retrieved October 30, 2022, from <https://www.ilru.org/topics/il-history-philosophy>
- IL NET, an ILRU/NCIL Training and Technical Assistance Project. (2001). *Systems Advocacy: Using Your Power to Effect Change*. https://www.ncsilc.org/wp-content/uploads/2013/03/SystemsAdvocacy_EffectChange.pdf
- Institute for Educational Leadership. (2007). *Disability History Timeline: Resource and Discussion Guide*. National Consortium on Leadership and Disability for Youth. http://www.nclد-youth.info/Downloads/disability_history_timeline.pdf

Resources 4

- Johnson, M. (1989, September/October). The Bargain. *Disability Rag*, 10(5).
- Kailes, J. I. (1993). *Disability Pride: The Interrelationship of Self-Worth, Self-Empowerment, and Disability Culture*.
http://www.jik.com/pubs/Disability_Pride.rtf
- Kailes, J. I. (2010). *Language Is More than a Trivial Concern!*
<http://www.jik.com/pubs/language%20FINAL-L-12.27.10.pdf>
- Lawrence Carter-Long. (2013, January 23). *Disability Activist Ed Roberts on "60 Minutes" with Harry Reasoner*. YouTube.
<https://www.youtube.com/watch?v=ZxidR5SZXxA>
- Longmore, P. K. (2003). *Why I burned my book and other essays on disability*. Temple University Press.
- Longmore, P. K., & Umansky, L. (2001, March 1). *The New Disability History: American Perspectives (The History of Disability, 6)*. New York University Press.

Resources 5

- *March 12, 1990: Disability Rights Activists Make "Capitol Crawl" for the ADA.* (2022, April 19). Zinn Education Project. Retrieved from <https://www.zinnedproject.org/news/tdih/capitol-crawl-for-ADA/>
- Mayerson, A. B. (2021, July 6). *The History of ADA.* Disability Rights Education & Defense Fund. Retrieved from <https://dredf.org/about-us/publications/the-history-of-the-ada/>
- *Moments in Disability History – Disability Social History Project.* (n.d.). Retrieved October 30, 2022, from <https://disabilityhistory.org/moments-in-disability-history/>
- National Council on Disability. (1997, July 26). *Equality of Opportunity: The Making of the Americans with Disabilities Act.* Retrieved from <https://files.eric.ed.gov/fulltext/ED512697.pdf>
- National Organization on Disability. (2022, February 4). *Our History / NOD @ 40.* <https://www.nod.org/about/nod-history/>

Resources 6

- nlas pina1. (2010, October 29). *1993 Disability Pride March in NYC* [Video]. YouTube. Retrieved from <https://www.youtube.com/watch?v=M7OcgdnZejs>
- Oregon SILC. (n.d.). *History and Philosophy of Independent Living*. <https://www.oregon.gov/DHS/SENIORS-DISABILITIES/SILC/Documents/history-philosophy.pdf>
- *Parade Mission*. (n.d.). DISABILITY PRIDE PARADE PARADE. Retrieved from <https://www.disabilityprideparade.org/parade-mission.html>
- *Rehabilitation Act of 1973 (Rehab Act)*. (n.d.). Retrieved from <https://askearn.org/page/the-rehabilitation-act-of-1973-rehab-act>
- *Self-Advocacy: Improve Your Life by Speaking Up*. (n.d.). Retrieved from <https://www.betterup.com/blog/self-advocacy>
- Soken-Huberty, E. (2021, May 3). *5 Types of Activism*. Human Rights Careers. Retrieved from <https://www.humanrightscareers.com/issues/types-of-activism/>

Resources 7

- *Systems Advocacy*. (n.d.). Retrieved from <http://www.headinjury.com/advosystem.html>
- *Timeline of Disability Rights / Resources / Accessibility.com*. (n.d.). Retrieved October 16, 2022, from <https://www.accessibility.com/resources/timeline-of-disability-rights>
- *Types of Advocacy / Center for Excellence in Disabilities*. (n.d.). Retrieved from <https://cedwvu.org/resources/types-of-advocacy/>
- *We will ride! – The Gang of 19*. (2018, November 1). Retrieved from <https://adapt.org/we-will-ride-the-gang-of-19/>
- *"We Will Ride!" The Origin of the Disability Rights Movement in Denver*. (2022, June 13). Denver Public Library History. Retrieved from <https://history.denverlibrary.org/news/we-will-ride-origin-disability-rights-movement-denver-0>

Resources 8

- *What are the 5 principles of advocacy? What are qualities o. (n.d.).* youth4work.com. Retrieved from <https://www.youth4work.com/Talent/Legal-Advocate/Forum/144584-what-are-the-5-principles-of-advocacy-what-are-qualities-of-a-good-advocate>
- *Where We Came From. (n.d.).* Disability Rights Center of Kansas. Retrieved from <https://www.drckansas.org/resource-center/history-of-disability-rights/where-we-came-from-a-brief-history-of-the-disability-rights-movement-and-disability-discrimination>