

Disability Advocacy

05-499/899 Fall 2024

Celebrating Accessibility

<https://cmu-05-499.github.io>

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Adminstrivia

- Project Pitches will take the entire class, Tues Oct 8.
 - Let's go over the [requirements](#).
- Let's welcome ITI Assistive Technologies as our final partner organization to introduce themselves.

Disability Evolution



Where are we now?

- Disability Pride
 - Initially, a victory celebration for the passage of Section 504 and the ADA
 - “It’s so important for our people to show the world we are proud of who and what we are.” – Eric von Schmetterling
 - But it became a movement

What does Disability Pride mean?

- Accomplishments
- Shared, cultural identity
- Rejection of shame
- Rejection of embarrassment
- Rejection of dishonor
- Rejection that body-minds are broken
- Refusal to cover up your disability

Difficulty in Being Proud

- Is it more difficult to be proud of your disability
 - if it is invisible?
 - if you weren't born with it?
 - if you haven't been discriminated against because of it?

Disability Advocacy

- Standing up for what you believe is right.
- What are those rights?
 - The right to live.
 - The right to exist.
 - The right to speak on your own behalf.
 - The right to equality.

Many origins for disability advocacy

- Self-advocacy
- Parent and guardian advocacy
- Charity
- Research
- Medical
- Legal
- Government
- Service Providers

Let's Take a Tour

- Sight
- Hearing
- Speech
- Mobility
- Cognition
- Chronic Illness

Disabilities All-Up

Organization	Mission	Founded By	Year
American Association of People with Disabilities	Full civil rights for over 60 million Americans with disabilities	Disabled People	1995
American Coalition of Citizens with Disabilities	Demonstrations to pass Section 504 of the Rehabilitation Act of 1973	Disabled People	1975
Commission on Disability Rights	Promote the ABA's commitment to justice and the rule of law for people with mental, physical, and sensory disabilities, and to promote their full and equal participation in the legal profession.	?	1973
Easterseals	Lead the way to full equity, inclusion, and access through life-changing disability and community services.	Charity	1919
Center for Independent Living (founded: disabled people)	People with disabilities have the same rights, options, choices, and equal opportunities as anybody else.	Disabled People	1972

Disabilities All-Up

Organization	Mission	Founded By	Year
National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR)	Generate new knowledge and to promote its effective use to improve the abilities of individuals with disabilities to perform activities of their choice in the community, and to expand society's capacity to provide full opportunities and accommodations for its citizens with disabilities.	Government Department	1978
National Association for Rare Disorders	Helping those who battle and care for rare disease feel seen, heard, supported and connected.	Parents of People with Disabilities	1983
A Place for Us (founded by disabled students)	Connecting and empowering students with disabilities and their allies to be disability activists and succeed in higher education.	Disabled Students	?
Western Pennsylvania Disability History and Action Consortium	Preserve history of people with disabilities struggle to attain human and civil rights.	Institutions and Advocacy Organizations	2015
AstroAccess	Make spaces more accessible	People with Disabilities	2021

Sight

- National Federation of the Blind (1940)
 - founded by Blind/visually impaired people
- American Council of the Blind (1960s)
 - founded by Blind/visually impaired people
- American Foundation for the Blind (1921)
 - founded as a charity but advised by Helen Keller
- Western PA School for Blind Children (1885)
 - founded as a charity
- Lighthouse Guild (1905)
 - founded as a charity
- Library of Accessible Media for Pennsylvanians (LAMP) (1882)
 - founded by doctors and specialists
- Pennsylvania Association for the Blind (1910)
 - founded as a service provider
- Guide Dogs for the Blind (1942)
 - founded as a service provider
- IBSA International Blind Sports Federation (1981)
 - founded as a consortium of organizations

Sight (Research/Medical)

- National Eye Institute (1968) founded by Congress
- American Glaucoma Society (1985) founded by doctors
- Glaucoma Research Foundation (1978) founded by doctors
- Macular Degeneration Association
- Discovery Eye Foundation (1970) founded by parents of a person with visual impairments
- Foundation Fighting Blindness (1971)
 - founded by visually impaired people and their families
 - Retina International (1978) focuses on research

National Federation of the Blind



- We advance the lives of our members and all blind people in the United States. The National Federation of the Blind knows that blindness is not the characteristic that defines you or your future. Every day we raise the expectations of blind people, because low expectations create obstacles between blind people and our dreams. Our collective power, determination, and diversity achieve the aspirations of all blind people.
- The National Federation of the Blind is the oldest and largest nationwide organization of blind Americans, founded in 1940.

Library of Accessible Media for Pennsylvanians (LAMP)

- Reading For All
 - The Library of Accessible Media for Pennsylvanians (LAMP) is a program funded through the Pennsylvania Office of Commonwealth Libraries and Administered throughout the state of Pennsylvania by Carnegie Library of Pittsburgh and the Free Library of Philadelphia.
- LAMP circulates over 1.5 million titles in accessible formats like digital, digital download, Braille, print/Braille, large-print and Audio described DVDs to Pennsylvanians.

LAMP History

- 19th century: Home Teaching Society for the Blind (Philadelphia). They read books to blind people.
- 20th century: Carnegie Library of Pittsburgh and Free Library of Philadelphia provided Braille services to blind readers. In 1934, they recorded the first audiobooks.
- 1950s: Braille library moved to Philadelphia. Pittsburgh focused on audiobooks on cassette tape.
- 2005-2015: Moved to digital audiobooks.
- 2018: Download-on-demand digital audiobooks introduced.

National Eye Institute



- Founded in 1968 by Congress to protect and prolong vision of all Americans.
- As part of the federal government's National Institutes of Health, the mission of the National Eye Institute is to “conduct and support research, training, health information dissemination, and other programs with respect to blinding eye diseases, visual disorders, mechanisms of visual function, preservation of sight, and the special health problems and requirements of the blind.”

Hearing

- Gallaudet University (1864)
 - A bilingual, diverse, multicultural institution of higher education that ensures the intellectual and professional advancement of deaf and hard of hearing individuals through American Sign Language (ASL) and English.
- National Association of the Deaf (1880) founded by Deaf people
 - Promote the right of the American deaf community to use sign language, to congregate on issues important to them, and to have its interests represented at the national level.
- Hearing Loss Association of America (1979) founded by a hard of hearing person for self-help for hard of hearing people
- USA Deaf Sports Federation (1950s)
 - National governing body of deaf sport organizations in the United States. Its purpose is to regulate the rules of competition for affiliated organizations, facilitate the participation of US teams in international deaf competitions, and promote human rights and equity through sports.

National Association of the Deaf

- Established in 1880, the National Association of the Deaf (NAD) is the nation's premier civil rights organization of, by and for deaf and hard of hearing individuals in the United States of America.
- The mission of the National Association of the Deaf is to preserve, protect and promote the civil, human and linguistic rights of Deaf, DeafBlind, DeafDisabled, Hard of Hearing, and Late-Deafened people in the USA.



National Association of the Deaf

Speech

- Tourette Association of America
- Tourettes Action
- American Speech-Language-Hearing Association
- American Stroke Association
- National Aphasia Association

Mobility

- Shepherd Center
- US Olympic and Paralympic Committee
- National Spinal Cord Injury Association
- Rehabilitation International
- Special Hockey International
- United Cerebral Palsy
- Move United
- Little People of America
- [Ms. Wheelchair Pennsylvania](#)
- [Access Mob Pittsburgh](#)

Shepherd Center

- Founded in 1975, Shepherd Center, located in Atlanta, Georgia, is a private, not-for-profit hospital specializing in medical treatment, research, and rehabilitation for people with spinal cord injury, brain injury, multiple sclerosis, spine and chronic pain, and other neuromuscular conditions.
- Founded by parents of a son with a spinal cord injury.
- Shepherd's Accessibility User Research Collective (AURC) provides user research services connecting product developers with people with disabilities.

Cognition (Intellectual Disabilities)

- The Arc
- American Association on Intellectual and Developmental Disabilities
- Coleman Foundation
- Special Olympics
- Best Buddies International
- National Down Syndrome Society
- National Down Syndrome Congress
- Down Syndrome International
- Assume that I Can campaign (Down Syndrome)

Cognition: Autism

- Autism Speaks (founded by grandparents)
- Autism Society (founded by parents)
- Autistic Self-Advocacy Network (founded by autistic folks)
- Autistic Women and Non-Binary Network (founded by autistic folks)
- The Els for Autism Foundation (founded by parents)
- International Society for Autism Research (founded by researchers)
- National Autism Association (founded by parents)
- Organization for Autism Research (founded by parents/grandparents)
- USA Interagency Autism Coordinating Committee (founded by US gov federal advisory committee)
- [Autism Connection of Pennsylvania](#) – 1996 – founded by friends and family
- [Pittsburgh Center for Autistic Advocacy](#) (founded by autistic folks)
- [Achieva](#) (founded by service providers)

Chronic Illness

- American Diabetes Association (founded: physicians/researchers)
- Chronic Disease Coalition (founded: patients/families)
- American Cancer Society
- National Multiple Sclerosis Society (founded: family)
- Multiple Sclerosis Association of America
- Muscular Dystrophy Foundation
- Crohns and Colitis Foundation
- Dysautonomia International
- Parkinson's Foundation
- Michael J Fox Foundation
- Davis Phinney Foundation
- American Parkinson Disease Association
- Parkinson Foundation Western Pennsylvania

Discussion Question

- What role should people with disabilities play in advocacy organizations for people with that disability?

ITI Assistive Technologies

- Contact: [Shannan Palma](#)
- Speakers: April and Wesley
- ITI Assistive Technologies Inc. is a group of neurodivergent developers, researchers, designers, and educators making tools for daily life. ITI's vision is to create a world where Autistic/ADHD adults can thrive and contribute their full potential to society through interdependence.
- Project idea:
 - We're interested in having the student team design and build out an interface between our mobile app(s) and existing wearable(s) to help us predict and prevent nervous system dysregulation in real time.