

History of Disability – Part 2

05-499/899 Fall 2024

Celebrating Accessibility

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

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Administrivia

- HW2 due Wednesday, Sept 11, 11:59pm
- HW3 will be released Tuesday, Sept 17

The Enlightenment (18th century)

- Critiqued established religions
- Emphasized 'rational' science
- Promoted social progress
- Secular, rational self-interest philosophy started to dominate thoughts about how to run a nation-state.

Social Darwinism

- Built on evolutionary theories of Charles Darwin
 - Human groups and races are subject to the same laws of natural selection as plants and animals.
- Life in human society is a struggle for existence ruled by survival of the fittest.
 - The weak are diminished and their cultures delimited while the strong grow in power and cultural influence over the weak.
- Used to justify imperialist, colonialist, and racist policies.
- This morphed into the Eugenics movement

Eugenics Movement

- Disabled people were unable or unwilling to compete for employment in the factory system.
- Medical profession segregated them from the community into institutions and long-stay hospitals.
- Disabled people were thus a 'burden' to the state.
- In 1930s and 1940s, Nazis systematically murdered thousands of disabled people.
 - In 1938 in Vienna, Austria, Hans Asperger was the first to characterize [autism](#).
 - [He also classified some as "uneducable," leading to their later murder at a euthanasia facility.](#)

Era of Institutionalization

Letchworth Village – Thiells, NY

Housed mentally and physically disabled people since 1911.

Also did research into the cause of intellectual developmental disabilities.

Geraldo Rivera did an expose in 1972 that exposed overcrowded, dirty, and neglectful conditions.

Spurred reforms that closed institutions across the country.

Letchworth Village shut down in 1996.



Independent Living Movement

- Disability Rights Movement in 1960s and 1970s.
 1. All human life, regardless of the nature, complexity and/or severity of impairment is of equal worth.
 2. Anyone whatever the nature, complexity and/or severity of their impairment has the capacity to make choices and should be enabled to make those choices.
 3. People who are disabled by societal responses to any form of accredited impairment – physical, sensory or cognitive – have the right to exercise control over their lives
 4. People with perceived impairments and labelled 'disabled' have the right to participate fully in all areas, economic, political and cultural, of mainstream community living on a par with non-disabled peers

Independent Living

- Philosophy and movement of people with disabilities who work for self-determination, equal opportunities, and self-respect.
- They demand the same choices and control in everyday lives that non-disabled people take for granted.
- They want to grow up within their families, go to the local school, use the same bus as their neighbors, work in jobs related to their education and interests, and start families of their own.
- They are the best experts on their needs, the solutions they want, to be in charge of their own lives, and to speak for themselves.

Centers for Independent Living

Self-help organizations controlled and run by disabled people themselves.

In early 1970s, Berkeley students with disabilities, inspired by Ed Robers (first iron lung user to enroll at UC Berkeley), poured cement to create the first makeshift ramp to a curb.

In 1972, under pressure from the "Rolling Quads," the first disabled student led campus organization in the USA, Berkeley installed the first official curb cut on Telegraph Ave.



UN Convention on the Rights of Persons with Disabilities (2006)

Promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

1. Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
2. Non-discrimination;
3. Full and effective participation and inclusion in society;
4. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
5. Equality of opportunity;
6. Accessibility;
7. Equality between men and women;
8. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

Disability Justice

- Developed by queer, BIPOC, disabled artists ([Sins Invalid](#))
- Their manifesto includes many principles that influence disability HCI today.

Intersectionality

- Coined by Kimberlé Crenshaw in 1989
 - Described the experience of black women, who experience both racism and sexism.
- “We are many things, and they all impact us.”
- There are multiple disabled people, with varied identities, including multiply-disabled people.
 - Each unique identity contributes to one’s shared and differing experiences.

Leadership of those most impacted

- “Nothing about us, without us”
- Center disabled people in *all* parts of your work.
 - Not just customers of your products or participants in your studies.
 - Center disabled people in the design phase.
 - Center disabled people when conceiving of your projects!
 - Bring on disabled people as leaders in your projects.
- The alternative is to develop solutions for people who don’t want them, or worse, inadvertently discriminate against the very people you intend to help.

Anti-capitalist Politics

- Resist conforming to “normative” levels of productivity in a capitalist culture.
- A disabled person’s worth is not dependent on what and how much they can produce.

Recognizing Wholeness

- Disabled people are not just their disabilities, impairments, or tasks they have difficulty performing.
- They are **whole** people, with rich thoughts, senses, emotions, speech, interests, and quirks.

Interdependence

- “No one is actually independent; we are all actually **interdependent**. The difference between the needs that many disabled people have and the needs of people who are not labeled as disabled is that non-disabled people have had their dependencies normalized.” – Ki’tay Davidson
- Could “independence” be misrepresentative or even harmful? – Bennett (2018)

Critical Disability Theory

- The world is built for non-disabled people.
- Its structures are systemically ableist.
- To make meaningful progress for people with disabilities, we must critically examine our society's norms, question their origin and intent, and remake them.
- This can be liberating for people with disabilities and simultaneously *very* uncomfortable for people without disabilities.
- We go through this process together.

Celebrating Disability

- One of the most pernicious barriers to disability is the social stigma against those with the disability label.
 - Disability is not inherently “less than.”
- Pride in disability promotes a positive and inclusive story
 - Encompasses the diverse experiences of individuals.
- Acknowledge disability as an integral part of our reality, not an exception.
- Tackling this means going straight to the heart of the societal problem: discrimination.
- We flip the burden of adaption to the **non-disabled** and exhort them to change to be inclusive of everyone.

Discussion of Readings

- Discussion Leader: Samantha Lee
- 1. Cynthia L. Bennett, Erin Brady, and Stacy M. Branham. 2018. [Interdependence as a Frame for Assistive Technology Research and Design Download Interdependence as a Frame for Assistive Technology Research and Design](#). In Proceedings of the 20th International ACM SIGACCESS Conference on Computers and Accessibility (ASSETS '18). Association for Computing Machinery, New York, NY, USA, 161–173. <https://doi.org/10.1145/3234695.3236348>.
- 2. Jampel, C. (2018). [Intersections of disability justice, racial justice and environmental justice Download Intersections of disability justice, racial justice and environmental justice](#). Environmental Sociology, 4(1), 122–135. <https://doi.org/10.1080/23251042.2018.1424497>.
- 3. Excerpts from the movie "[Crip Camp](#)"
 - Protest movement to start disability rights: 39:03 - 50:02
 - Judy Heumann schooling government officials: 1:29:50 - 1:36:07

An HCI and Design Perspective

Before the 1990s...

- 1960s: many people who were blind brought in to be programmers, then start to be phased out
- 1970s: computers begin to have more visual interfaces and increase in keyboarding
- This cycle of growth led to people being pushed out of gainful employment and positioned accessibility as overcoming a deficit
 - Remember the medical model

In the late 1990s - Shift toward Universal design

- Ronald Mace (an architect) coined the phrase Universal Design
- In 1997 - Seven Principles proposed with guidelines
 - <https://www.udinstitute.org/principles>

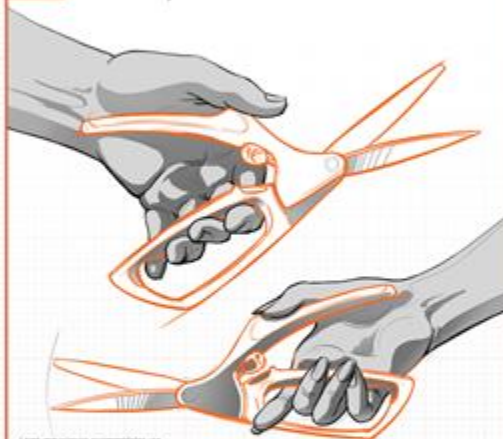
The Principles of Universal Design



1 Equitable Use
The design is useful and marketable to people with diverse abilities.

The design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design.

2 Flexibility in Use
The design accommodates a wide range of individual preferences and abilities.



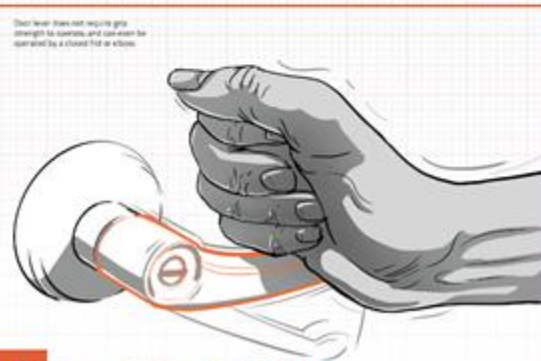
3 Simple and Intuitive Use
Use of the design is easy to understand, regardless of the user's experience, knowledge, language skills, or education level.



5 Tolerance for Error
The design minimizes hazards and the adverse consequences of accidental or unintended actions.



4 Perceptible Information
The design communicates necessary information effectively to the user, regardless of ambient conditions or the user's sensory abilities.



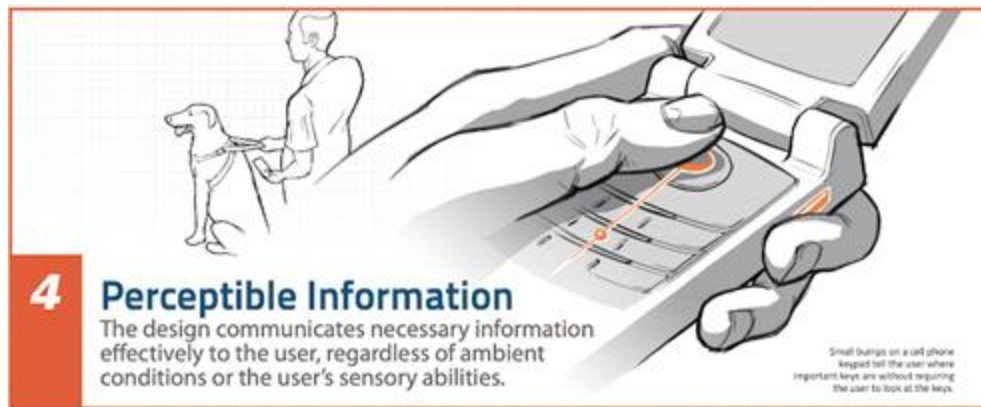
6 Low Physical Effort
The design can be used efficiently and comfortably and with a minimum of fatigue.



7 Size and Space for Approach and Use
Appropriate size and space is provided for approach, reach, manipulation, and use regardless of user's body size, posture, or mobility.

An example: Perceptible Information

The design communicates necessary information effectively to the user, regardless of ambient conditions or the user's sensory abilities.



Guidelines:

- Use different modes (pictorial, verbal, tactile) for redundant presentation of essential information.
- Provide adequate contrast between essential information and its surroundings.
- Maximize "legibility" of essential information.
- Differentiate elements in ways that can be described (i.e., make it easy to give instructions or directions).
- Provide compatibility with a variety of techniques or devices used by people with sensory limitations.

Participation Activity

1. Pair up with a neighbor.
2. Write your names down on a sheet of paper.
3. Recall the 7 Universal Design Principles:
 - Equitable Use, Flexibility in Use, Simple and Intuitive Use, Perceptible Information, Tolerance for Error, Low Physical Effort, Size and Space for Approach and Use
4. Identify how *curbcuts* satisfy two principles of universal design.
5. Identify how *speech recognition* satisfies two different principles of universal design.
6. Let's discuss.
7. Turn in your paper before you leave class.

These kinds of guidelines are good for understanding some of the general requirements for our designs, but not necessarily how to apply them well.

This Era of Checklists and Guidelines

- From this point on accessibility is really dominated by reliance on checklists
- Generally at this point for HCI it was widely accepted that:
 - Specific guidelines are good for evaluation, but bad for design
 - General guidelines are good for awareness but also bad for design
 - Conformance to a guideline doesn't necessarily mean that any individual will be able to use the technology
- Here is where we really see the emergence of user-centered approaches

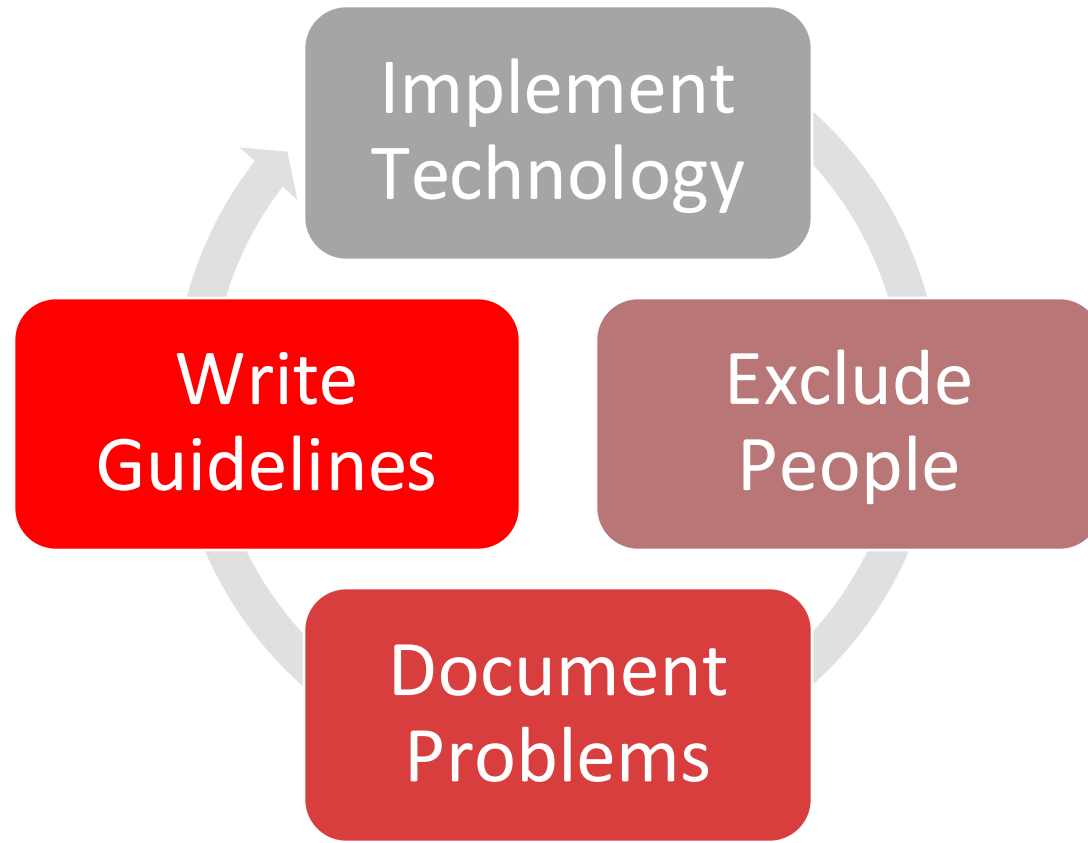
Web Content Accessibility Guidelines (WCAG)

- Proposed in 1999 starts to work toward making change on the Web
- Although well received, they weren't perfect, and when evaluated they fell a bit short
- WCAG 2.0 released in 2008 to respond to updated context
- WCAG 3.0 is about to be released.
- We'll go into this more a bit later

What's Going On?

- Each time we adjust the guidelines we have new problems emerge
- We are playing a constant game of catch up

The current model resembles this



Causes major
implementation lag

In the Mid-Late 2000s UX has emerged

- Power argues that just as accessibility is trying to catch up to this implementation and conceptual lag in design, HCI and the rest of the world are acknowledging UX, usability, and the importance of context and lived experience.

Power, C., Cairns, P., & Barlet, M. (2018). Inclusion in the third wave: access to experience. *New Directions in Third Wave Human-Computer Interaction: Volume 1-Technologies*, 163-181.

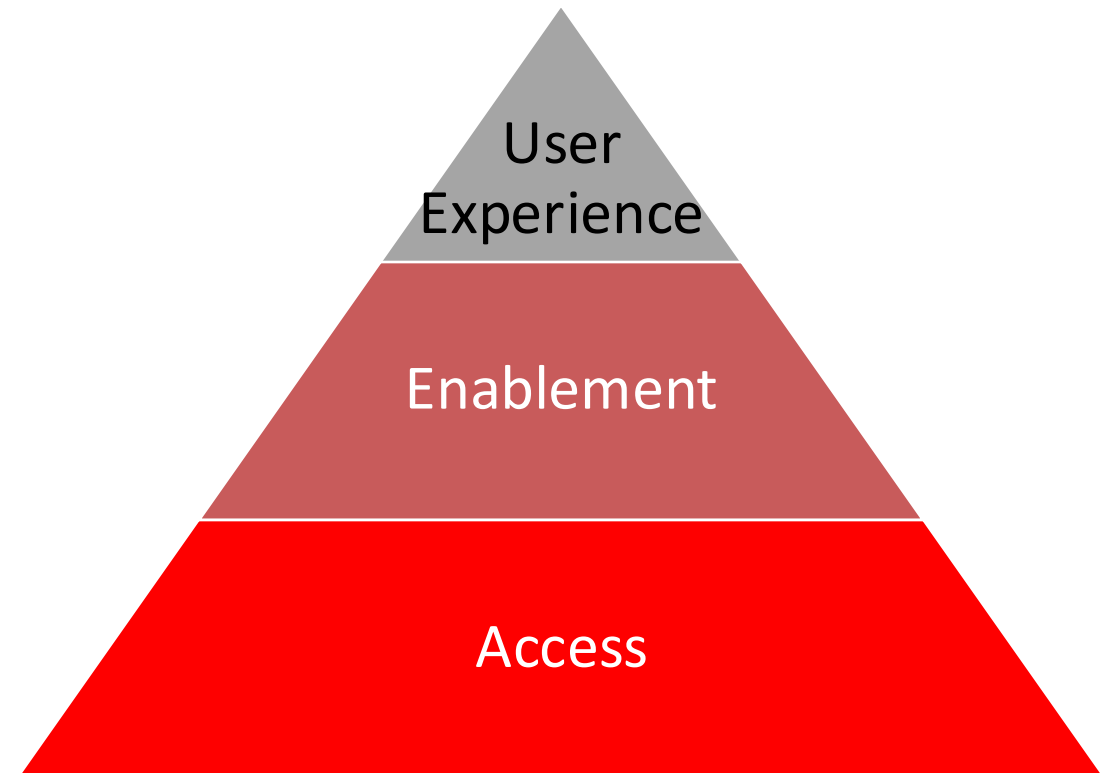
Accessible User Experiences

- “We need a shift in the way we design such that we move beyond the deficits model to the way people want to interact and the experiences people want to have with their technologies...that are free from the barriers imposed by the mismatch between their disability and the technology”

Access to Experience

In the third wave:

- We need to overcome deficits in getting information in and out of the machine
- Ensure that people can achieve their goals by getting them around the interaction cycle
- Ensure that people are having the experience they want to have



As we continue to push the boundaries of user
experience,

Accessibility and inclusion
cannot be an afterthought.

Next time: Assistive Technologies