HCI – Disability Studies

Adapted from Oussama Metatla’s Lecture 2024

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Outline

- What is disability studies?
- Models of disability
- Case Study: Technologies for Neurodiverse Social Play

Disclaimer

- Talking about potentially sensitive topics
- Please be respectful and consider others experiences and needs

What is Disability Studies?

- Critical Theory's entrance into HCI
- **User-centeredness**: who are the users of technology and how do they shape design
- In case of disability
  - Bringing in understandings of disability into design
  - Designing to be more inclusive

What is Disability Studies?

- What is [particularly non-disabled people's] assumptions about the experience of disability
  - E.g. Burden?
  - E.g. something in need of assistance?

What is Disability Studies?

https://www.youtube.com/watch?v=4fHGsLuA76w

What is Disability Studies?

- What if we move beyond these assumptions?
- Example: understanding the socio-cultural models of disability
- Can you think of any activities so far that you've done in your degree (maybe in HCI theory, SEP) that have made assumptions about the abilities of users?
  - What are they?
  - What is the potential impact?

What is Disability Studies?

- A field of critical inquiry focused on the lived experience of disabled people, and the societal, medical and intellectual policies and rhetoric concerned with disability (Mankoff et al. 2010)
- Developed in the 80s
- Following disability rights movements that led to a shift:
  - From the individual/rehabilitation model of disability to an independent living model (US)
  - From a medical model of disability to a social model of disability (UK)

Jennifer Mankoff, Gillian R. Hayes, and Devva Kasnitz. 2010. Disability studies as a source of critical inquiry for the field of assistive technology. In Proceedings of the 12th international ACM SIGACCESS conference on Computers and accessibility (ASSETS '10). Association for Computing Machinery, New York, NY, USA, 3–10. https://doi.org/10.1145/1878803.1878807

Distinctions

- **Impairment**: a physical or biological condition of a person

Vs.

- **Disability**: a form of exclusion propagated by society that discriminates against people who are seen as being impaired

Distinctions

- **Key distinctions**: description of disability
- **Person-first**: “a person with a disability” e.g. a person with autism, a person who is blind, a person who is visually impaired
    - Objectifies disability as something that resides within the individual

Vs.

- **Identity-first**: “disabled person” e.g. autistic person, Deaf person, blind person, visually impaired person
    - Disability is a devaluing social process imposed on the individual
    - Positive assertion of identity
- Most communities, particularly autistic and Deaf communities, prefer identity-first language. **However**, always best to ask someone’s personal preference

Models of Disability

- Beyond language: how do we define disability?
  - How is it viewed and understood?
  - How does this impact how we design technology and research?
- Models
  - Social
  - Medical
  - Predicament
  - … others exist!

Medical Model

- Focuses on the physical and functional limitations a person may demonstrate
- Disability is within the individual (often linked to a medical diagnosis)
- Assistive technology ‘fixes’
- Can you think of any examples?

Medical Model

- Can you think of any examples?
  - Screen-readers
  - AAC devices (Augmentative and Alternative Communication device)

Social Model

- Focuses on barriers imposed by social/cultural environment that contribute to disabling a person
- Disability is located in the social environment
- Fixing ‘society,’ attitudes, environment, policies etc.
- Can you think of examples?

Social Model

Critique of models

- Social Model: is the locus of disability truly in society?
  - May be invalidating
- Medical/Social Model
  - Impairment can be a social construct/who defines what is ‘normal’?
  - Should we eliminate disability?
    - Whole communities of individuals with their own language, culture and values (e.g. Deaf community) may no longer exist?
- Both ignore positive aspects of disability experience
  - Pride in one’s own individuality
  - Community/culture

Predicament Model

- The predicament model of disability recognises disability as a complex situation, rather than solely a medical deficit or a social construct
- Complementary to the neurodiversity movement: aims to value that ‘being neurodivergent’ can mean a diversity of things to different people and is highly individual
  - Moving beyond ‘functional’ labels or ‘levels’ of autism

Case Study: Technologies for Neurodiverse Play

Case Study: Technologies for Neurodiverse Play

- Autism typically seen through a deficit-focused medicalised lens
- Play also typically defined using neurotypical norms
- Technologies for autistic children often focus on ‘correcting’ behaviour to appear more neurotypical
  - Often teach masking: reduced self esteem, worse mental health
  - Ignores autistic children’s experiences/natural ways of being

Case Study: Technologies for Neurodiverse Play

- **Double Empathy Problem**: a theory suggesting that social communication difficulties between autistic and non-autistic people are mutual, not a one-sided deficit (Milton 2012)
- Aligned more with the social model of disability

Milton, D. E. M. (2012). On the ontological status of autism: The 'double empathy problem'. *Disability & Society, 27*(6), 883–887. https://doi.org/10.1080/09687599.2012.710008

Case Study: Technologies for Neurodiverse Play

- **ChromaConnect!**
- Device that allowed children to signal their different play ‘modes’
- Overcome challenge of differences in communication styles

Case Study: Technologies for Neurodiverse Play