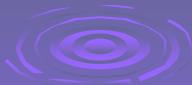




# Women and Disabilities

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# Introduction

- About one out of every 10 women has a disability that affects daily living
- Disability itself is often seen as “illness” – not simply a way of being
- Women experience unique burdens of disability

“We learn to understand disability as something that is wrong with someone, as an exceptional and escapable calamity rather than as what is perhaps the most universal of human experiences”.

Garland-Thompson 2005

# Definition

Disability- ‘ a physical or mental impairment that substantially limits one or more major life activities’ (ADA, 1992)

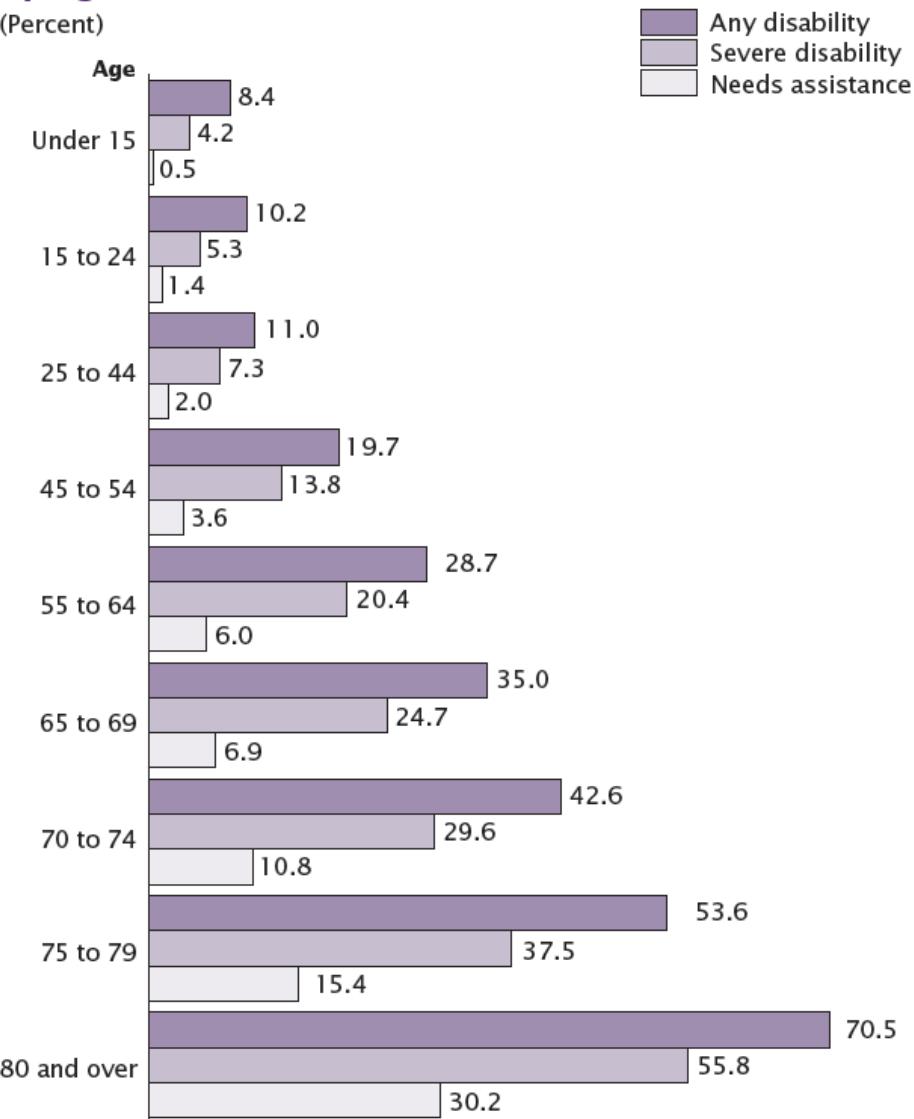
## US legal definition

“inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to last or has lasted for a continuous period of not less than 12 months”

# People with Disabilities/Disabled People

- Over 26% of adults in the US reported having a disability (CDC)
- Even larger percent than reported
- Language: Person First vs. Identity First
  - Will use interchangeably to honor the variety of people's identities

Figure 2.  
**Disability Prevalence and the Need for Assistance  
by Age: 2010**



Note: The need for assistance with activities of daily living was not asked of children under 6 years.

Source: U.S. Census Bureau, Survey of Income and Program Participation, May–August 2010.

# Intersections of gender, poverty, ability, race/Ethnicity

- Severely disabled- more likely to live in poverty (26% vs 8% non-disabled)
- More women with disabilities (28 vs 23 million)
- 19% white Americans, 20% black Americans, 14% Latino and Asian-American

# Ableism

- ❖ Overarching act of prejudice and/or discrimination against people with disabilities and the devaluation of disability (Hehir, 2002)
- ❖ "...deeply rooted beliefs about health, productivity, beauty and the value of human life, perpetuated by the public and private media, combined to create an environment that is often hostile to those whose physical, mental, cognitive, and sensory abilities fall outside of the scope of what is currently defined as socially acceptable." (Rauscher and McClintock, 1996, p. 198)
- ❖ Non-disabled individuals hold unearned social privilege over those who are disabled (Pease, 2010)

# Types of disability



# Disabilities

- Acquired vs. congenital
- Visible vs. non-apparent
- Short-term vs. long term
- Concurrent
- Chronic pain/illness



# Disability Movement

- Historical trends
- 1970's times of change –Berkeley
  - Ed Roberts
- Independent Living
- 1988 Gallaudet University



# Americans with Disabilities Act

- 1990 (amended in 2009)  
“Let the shameful wall of exclusion finally come tumbling down” – GHW Bush 1990
- Civil rights law protects against discrimination for a disability
- Case by case determination
- Employment, public and private facilities
- Defines disability as "...a physical or mental impairment that substantially limits a major life activity.“

# Social Construction of Disability

- Environment causing disability, not impairment
- Focuses on social and political responsibility for change
- Challenges what is normal
- Challenges deficit model instead of lost potential
- Needs to incorporate lived experience

# poetry

➤ <https://www.youtube.com/watch?v=yq7kg6qAMiq>

“The Dogs” by Ella Mae Lentz

# Narratives of disability

- Biomedical- physiological failures that demand normalization through technology or medicine
- Sentimental – pity or lessons in suffering for ‘non-disabled’
- Overcoming- disability must be overcompensated for
- Catastrophe – incites courage or defeats

# Feminist disability studies

- Disability- a cultural interpretation of human variation
  - Not inherent inferiority
  - A pathology to cure
  - An undesirable trait to eliminate

# Feminist disability studies

social category- not biological

System of exclusions that stigmatize human differences

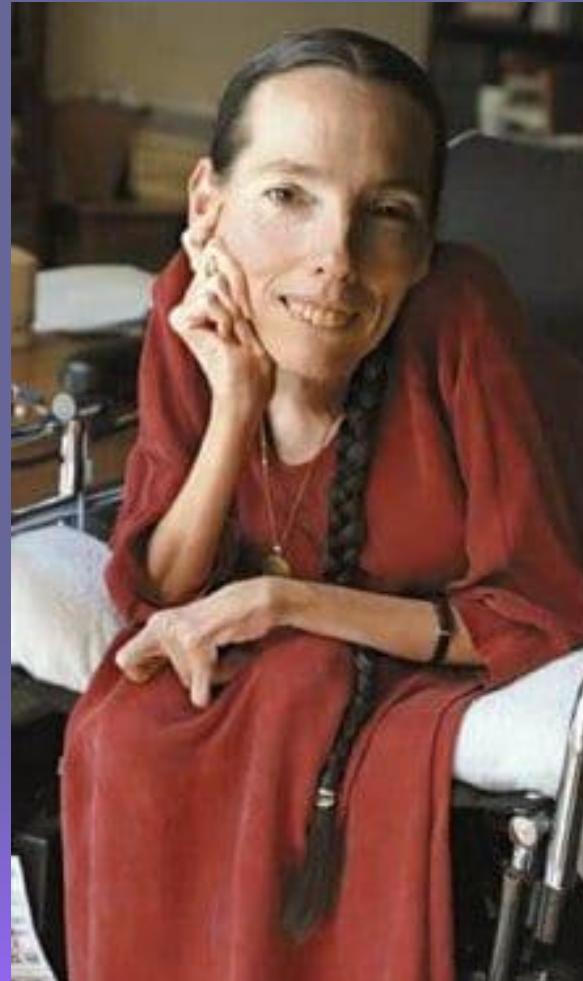
Uncovers communities and identities

Reveals discriminating attitudes and practices

Disability as an effect of power relations

# “Should I have been killed at birth?”

“We take constraints that no one would choose and build rich and satisfying lives within them. We enjoy pleasures other people enjoy, and pleasures peculiarly our own.”



# Harriet McBryde Johnson

- \*\* <https://www.youtube.com/watch?v=PcLmfSaRPGk>
- <https://www.youtube.com/watch?v=Fjzen4CUe68>



Not Dead Yet is a national, grassroots disability rights group that opposes legalization of assisted suicide and euthanasia as deadly forms of discrimination against old, ill and disabled people.

Not Dead Yet helps organize and articulate opposition to these practices based on secular social justice arguments. Not Dead Yet demands the equal protection of the law for the targets of so called “mercy killing” whose lives are seen as worth-less.

# Reproduction

- Problematic history of eugenics
  - Associated with strong racist and ableist underpinnings
  - First coined in reference to people who are deaf more likely to partner with a deaf person
  - Social decision of what is normal
  - Examples of coerced/forced sterilization in US

# Eugenic sterilizations



## 1927 Supreme Court Buck v Bell

- “3 generations of feeble-mindedness is enough” Justice Oliver Wendell Holmes
- Gave wide permission to involuntarily sterilize women for range of issues
- Last sterilizations under this law- 1979

# Pregnancy

- choice to do prenatal testing for disabilities
  - Down's Syndrome
  - Spina bifida
  - SMA, Cystic fibrosis, Tay-Sachs
- ‘Choice’ to give birth to a child with a disability
  - Advancing technology makes early prenatal detection of more congenital disabilities possible

# Expansion of prenatal diagnoses

- Genetic counselors
- Preparation for parenting
- Decision for terminating pregnancy

# Parenting

- Unique maternity care needs
- Who should be a parent?
- *some* (but not *all*) mothers with disabilities may need more assistance with childcare than their non-disabled neighbors

# Caregivers

- Formal and informal caregivers
  - Family members, hired staff
  - Institutional settings and home
- Majority are women
- Very poorly paid (2015 law for homecare to pay at least minimum wage and overtime)
- Health care benefits

# Disability as a desired label?

ADA limitations

New disease diagnoses “diseases that you have to fight to get”

Fibromyalgia

Chronic Fatigue Syndrome

Multiple Chemical Sensitivity

# Autoimmune disorders: fibromyalgia

- Diagnosis of elimination
- 2-5% population
- 9:1 women to men ratio
- Chronic pain, exhaustion,
- Much more widely diagnosed AFTER patented medication (Lyrica) developed
- Public education vs marketing

# Take home messages

- Ongoing tension between non-disabled society and persons with disabilities
  - How do we change structural barriers and opinions?
- Ask, don't just assume...
- Need perspective of people with disabilities in order to learn
- Ask questions