Disability and U.S Policy



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- **Teaching**: Public and Global Health, Community Health Assessment, Violence Prevention, Problems in Global Health, Social Justice, Ethics and Health Policy, Anti-racist Service learning.

- **Research & Work**: I collaborate with communities in USA and Africa in bringing Equity, Antiracism and Social Justice lens in teaching, research and program activities.

- **Positionality**: Intermittent and unseen disability that may affect reflexivity and passion for systemic advocacy to improve lives of persons with all disability types.



Halema Salim, BS-PHGH

Background: Public Health-Global Health graduate from the University of Washington, with interests in advocacy, health equity, and social justice.

Passionate about culturally responsive work addressing the social determinants of health, language barriers in healthcare, food insecurity, and access to resources for underserved communities.

Research & Work: Medical interpretation for Afghan refugee and immigrant populations, West African community hypertension research, leading inclusive youth programs, and board member at the Mukilteo Community Garden.

Positionality: Closely connected to the disability community, especially children with Autism and their families, and committed to advocacy that centers dignity and systems built to include everyone.



Outline

- Basic Definitions
- Historical Context
- Epidemiology of Disability
- Framework for Progress: Humanist and Intersectionality
- Disability policies: history, progress and gaps
- Q and A



Key Definitions

A disability is any condition of the body or mind (impairment) that makes it harder for a person with the condition to do certain activities (activity limitation) and to interact with the world around them (participation restrictions)

CDC

WHO

"Disability inclusion" refers to the **meaningful participation** of persons with disabilities in all their diversity, and the promotion and mainstreaming of their rights into the work of the health sector, in compliance with the Convention on the Rights of Persons with Disabilities

Key Definitions

A **person with a disability** as someone who has a physical or mental impairment that substantially limits one or more major life activities- ADA

Disability is the inability to engage in any substantial gainful activity (SGA) due to a medically determinable physical or mental impairment. The impairment must be expected to result in death or last for at least 12 months- SSA

Key Definitions: Ableism

The “oppression, prejudice, stereotyping, or discrimination against disabled people on the basis of actual or presumed disability”.

The belief that people are superior or inferior, have better quality of life, or have lives more valuable or worth living on the basis of actual or perceived disability.



Lydia X.Z Brown-
Disability Rights Advocate
& Scholar

Key Definitions: Policy

Policy is a law, regulation, procedure, administrative action, incentive, or voluntary practice of governments and other institutions.

-CDC

Policies decide who gets access, protection, and resources.

US Policy- Historical

- **The Immigration Act (1882):** prohibited entry into the U.S. for people labeled as “lunatic,” “idiot,” or anyone considered unable to care for themselves without becoming a “public charge.”

- **The Alien Immigration Act (1903)** expanded exclusion to “insane persons, epileptics, and persons who have been insane within five years previous; persons who have had two or more attacks of insanity at any time previously

US Policy- Historical

- **The Immigration Act (1907)** further expanded exclusion from the US people with "intellectual /developmental disability, cognitive impairments , suffering from tuberculosis, and people "certified" by an immigration official "as being mentally or physically defective," among other categories.
- **The Immigration Act (1917)** further excluded people who experienced just one "attack" of insanity and people with "chronic alcoholism" and "constitutional psychopathic inferiority," such as pathological liars, persons with abnormal sex instincts or people perceived as having undesirability behavioral conditions

US Policy- Historical: Eugenics, Race, & Disability

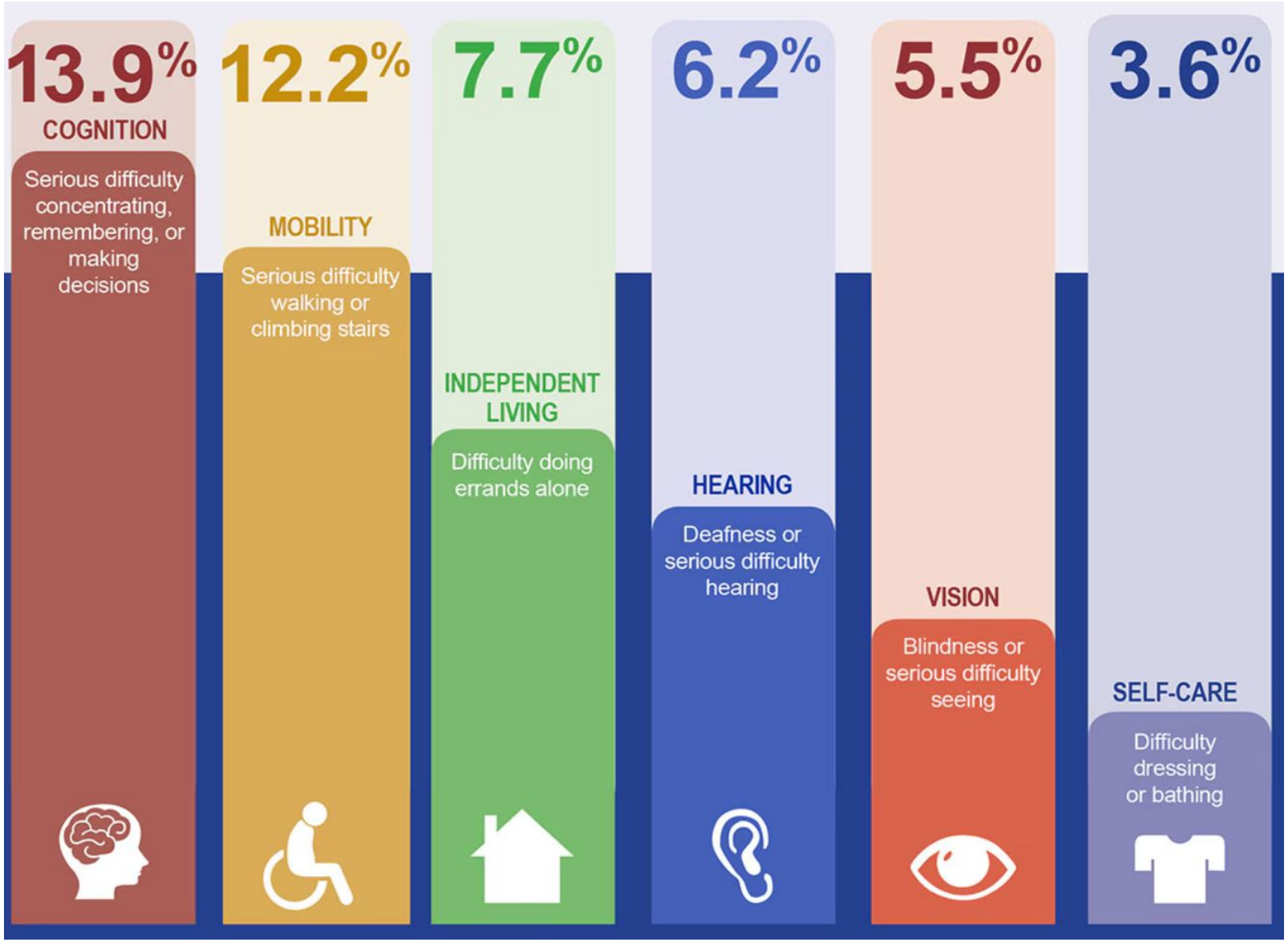
- **Eugenics:** Pseudoscience claiming society could be improved by stopping people seen as “unfit” from having children, which heavily included low-income people of color, immigrants, and **individuals with disabilities.**
- **Buck v. Bell (1927):** the Supreme Court allowed states to forcibly sterilize people considered “unfit” to procreate or “feebleminded”. Over 70,000 Americans were sterilized under these laws.

US Policy- Historical: Eugenics, Race, & Disability

- **Disability labels were used to justify racism:** in 1851, Dr. Samuel A. Cartwright invented Drapetomania, a fake mental illness to explain why enslaved people ran away
- **Forced sterilization fell hardest on women of color:** Black, Latina, and Native American women were sterilized without consent, some as recently as the 1970s. Forced sterilizations continue today in the incarceral system that disproportionately affects persons of color and disability

Types of Disabilities:

- Cognition
- Mobility
- Independent Living
- Hearing
- Vision
- Self-Care



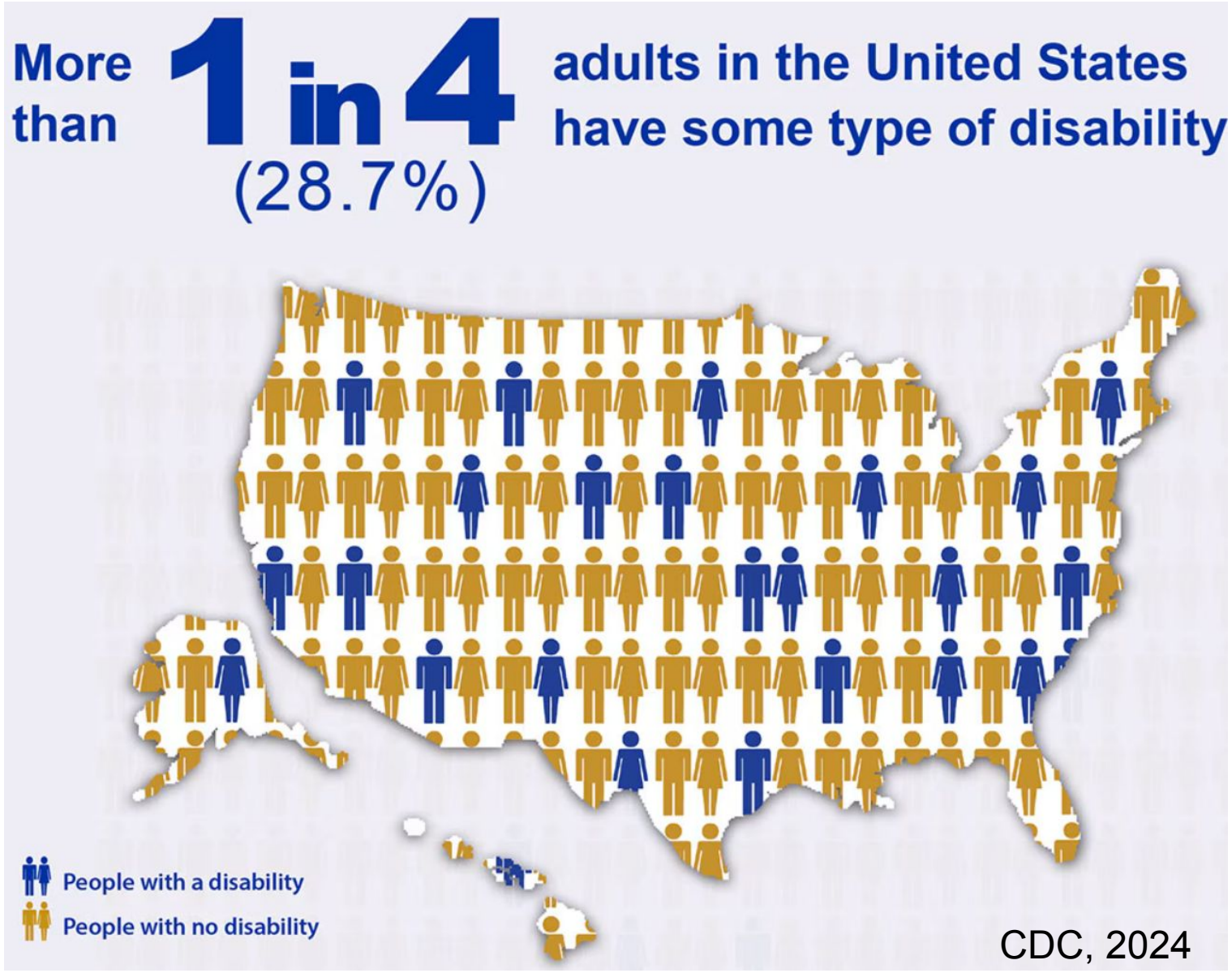
CDC, 2024

Epidemiology

~1.3 billion people or 16% or 1 in 6 of the global population currently experience significant disability.

~80% of persons with disabilities living in low and middle income countries (LMICs) where health services are already limited

~61 million US adults live with a disability



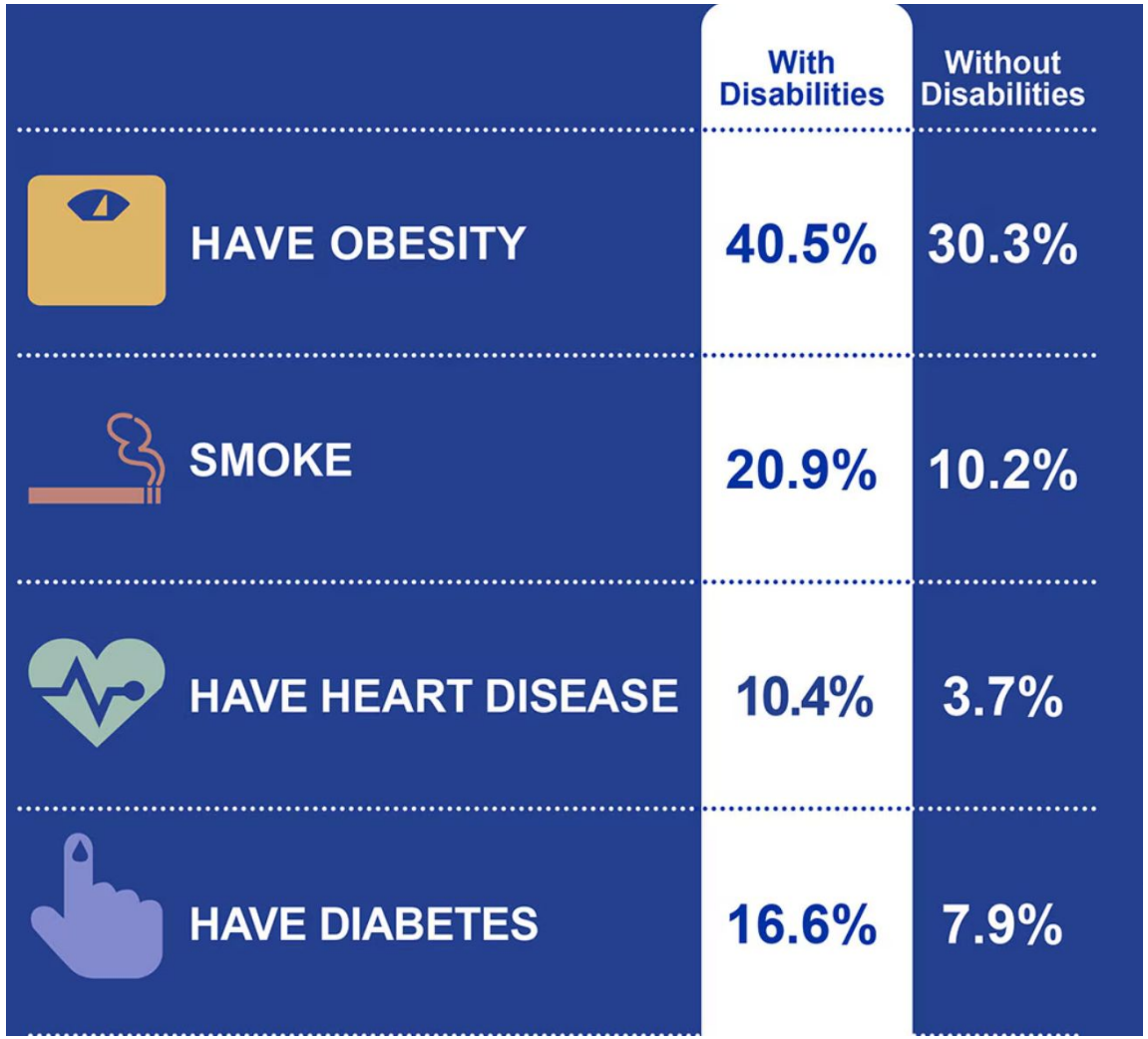
Epidemiology

People with disabilities may die up to 20 years earlier than those without disabilities.

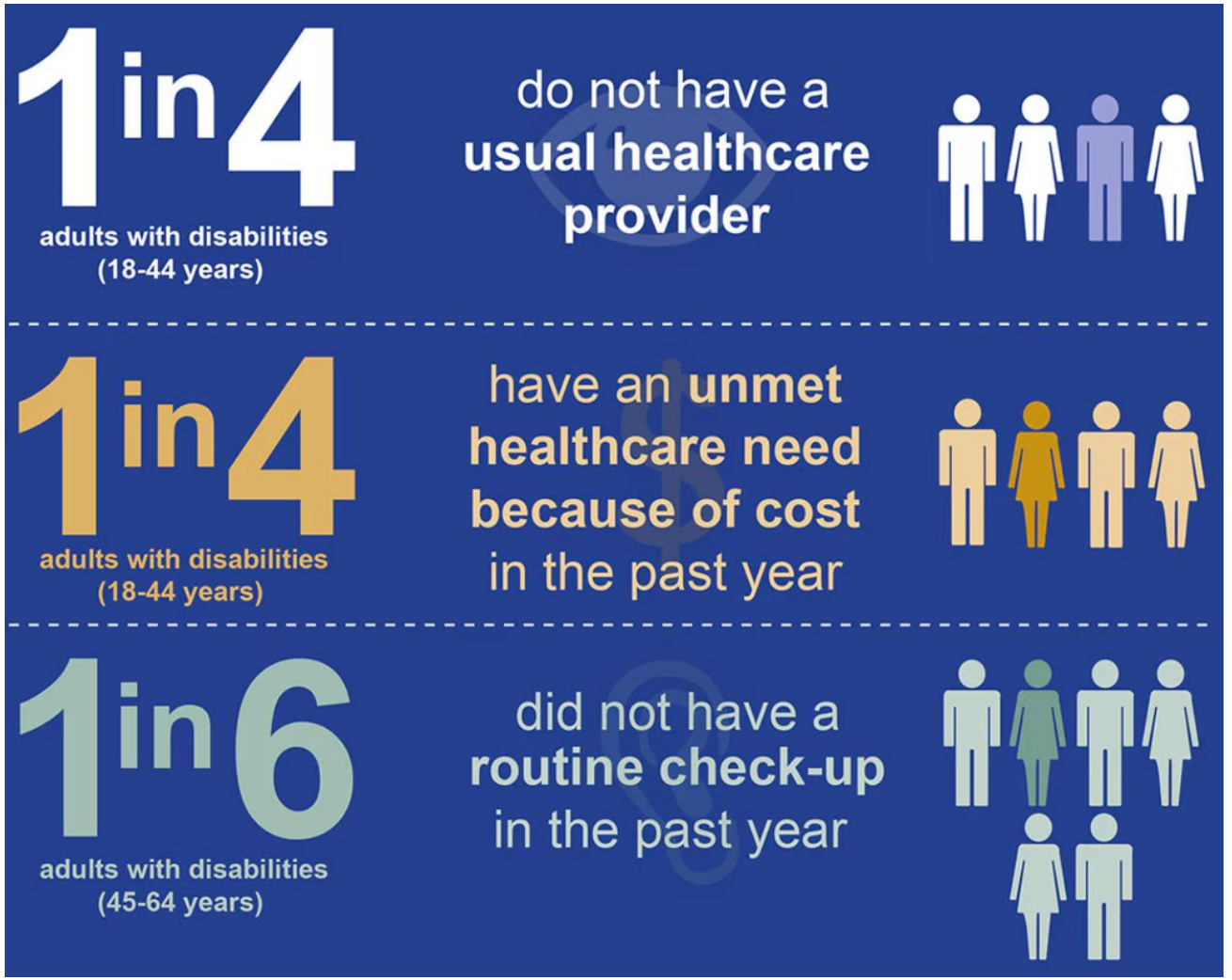
Many health disparities are driven not by the disability itself, but by preventable and unjust social factors.

What are some unfair or unjust factors you can think about?

Adults with disabilities are more likely to:



Health care gaps for people with disabilities



CDC, 2024

Unfair societal factors harming People with disability



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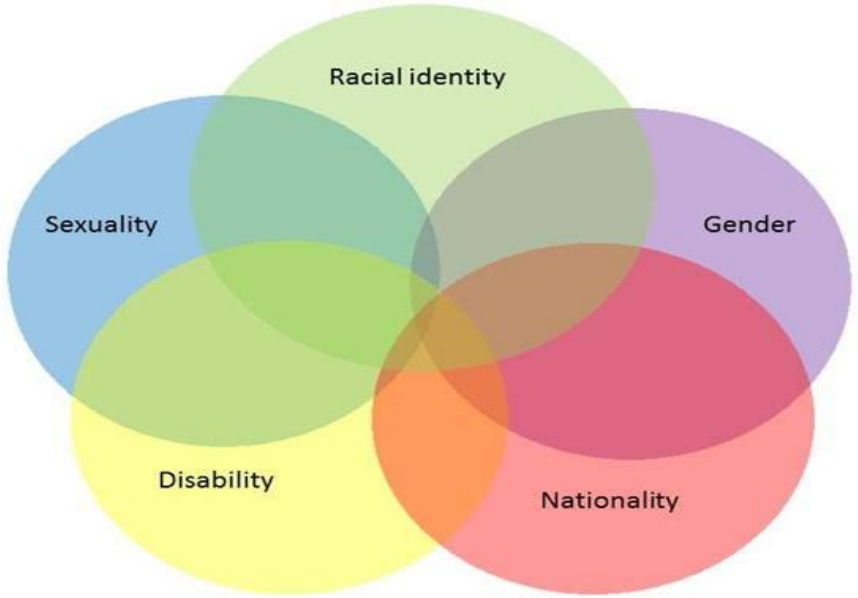
- **Health system barriers**: Physical, transport and financial barriers to healthcare access; lack of trained providers; poor HCW attitude [1,2]
- **Laws and policies**: favors dehumanizing of PwD and taking away their autonomy, civil and human rights, Eugenics, immigration, Institutional care, and underinsurance [2,3]
- **Research Discrimination**: underestimation, incomplete data and overreach [4]
- **Poor communication access**: incomplete and negative healthcare experiences; misinformed or under informed healthcare education or inaccessible format [2, 5]
- **Overall, there is a culture of Societal Ableism and devaluation of person with disabilities**

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2. Matin, B. K., Williamson, H. J., Karyani, A. K., Rezaei, S., Soofi, M., & Soltani, S. (2021). Barriers in access to healthcare for women with disabilities: a systematic review in qualitative studies. *BMC Women S Health*, *21*(1), 44. https://doi.org/10.1186/s12905-021-01189-5
3. Landes, S. D., Swenor, B. K., Hall, J. P., & Forber-Pratt, A. J. (2025). Disability data: a case study in research limitation transparency. *Health Affairs Scholar*, *3*(11), qxaf205. https://doi.org/10.1093/haschl/qxaf205
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5. Sharby, N., Martire, K., & Iversen, M. (2015). Decreasing Health Disparities for People with Disabilities through Improved Communication Strategies and Awareness. *International Journal of Environmental*

Intersectionality

- Disability intersects with other marginalized identities, which can increase health inequities. People who are poor, women, Black, or LGBTQ+ may face compounded discrimination when they also have a disability.
- For example, women with disabilities are 2–4 times more likely to experience intimate partner violence than women without disabilities [1].





1. Dunkle, K., et al., *Disability and violence against women and girls*. 2018, UKaid: London.

Intersectionality: Health emergencies

- Often hit harder during crises due to overlapping disadvantages. [1]
- During COVID-19, many were isolated from society, with reports of overmedication, sedation, confinement, and instances of self-harm. [1]
- During Covid, persons with intellectual disabilities experienced higher mortality rates.[2,3]
- Less likely to receive intensive care when needed. [3]

1. Brennan, C.S., *Disability Rights During the Pandemic: A Global Report on Findings of the COVID-19 Disability Rights Monitor*. 2020, COVID-19 Disability Rights Monitor.
2. Williamson, E.J., et al., *Risks of COVID-19 hospital admission and death for people with learning disability: population based cohort study using the OpenSAFELY platform.* BMJ, 2021. 374: p. n1592.
3. Baksh, R.A., et al., *Understanding inequalities in COVID-19 outcomes following hospital admission for people with intellectual disability compared to the general population: a matched cohort study in the UK.* BMJ Open, 2021. 11(10): p. e052482.

Intersectionality: SDGs & Disability Inclusion

- The Sustainable Development Goals (SDGs) cannot be achieved without including people with disabilities; as disability intersects with poverty, gender, and other inequalities that shape access
- Disability inclusion" refers to the meaningful participation of persons with disabilities and the promotion and Inclusion of their rights into the work of the health sector, in compliance with the Convention on the Rights of Persons with Disabilities- WHO.



Health for All includes Persons with Disability

- Universal health coverage cannot be achieved unless people with disabilities have equal access to quality health services
- Investing in disability-inclusive health care pays off economically: For every US$1 spent on making prevention and treatment of noncommunicable diseases (like heart disease or diabetes) accessible and inclusive, about US$10 is gained in benefits.
- Improving population health through clean air and water, road safety, child nutrition, and preventing violence against women requires public health measures that are inclusive of the needs, skills, and capacities of people with disabilities.

Rehabilitation Act (1973)

Section 504:prohibits disability-based discrimination in any program or organization that receives federal funding. It requires that services be available, accessible, delivered fairly, and that employment practices and administrative operations do not exclude or disadvantage people with disabilities.

Cannot deny access to spaces as a result of physical barriers. Cannot deny employment opportunities, including hiring, promotion, training, and fringe benefits, for which they are otherwise entitled or qualified.

Americans with Disabilities Act (1990)

The Americans with Disabilities Act (1990), banned discrimination based on disability in employment, government services and public accommodations.

People with disabilities were demanding access to everyday things so they can live their lives. The ADA was important in framing for Americans to understand disability **as a civil rights issue not health.**

Americans with Disabilities Act Amendment (2008)

ADA was amended to ADAA to provide" clear and comprehensive national mandate" for the elimination of discrimination, and "clear, strong, consistent, enforceable standards addressing discrimination" of Americans with disability

ADAA broadened the definition of disability such that being a person with disability is more inclusive. This makes it easier for an individual seeking protection under the ADAA to establish that he or she has a disability on the "basis of" Vs "because of" a disability. **Why is this distinction important**?

ADAA Act 2008 https://www.eeoc.gov/statutes/ada-amendments-act-2008

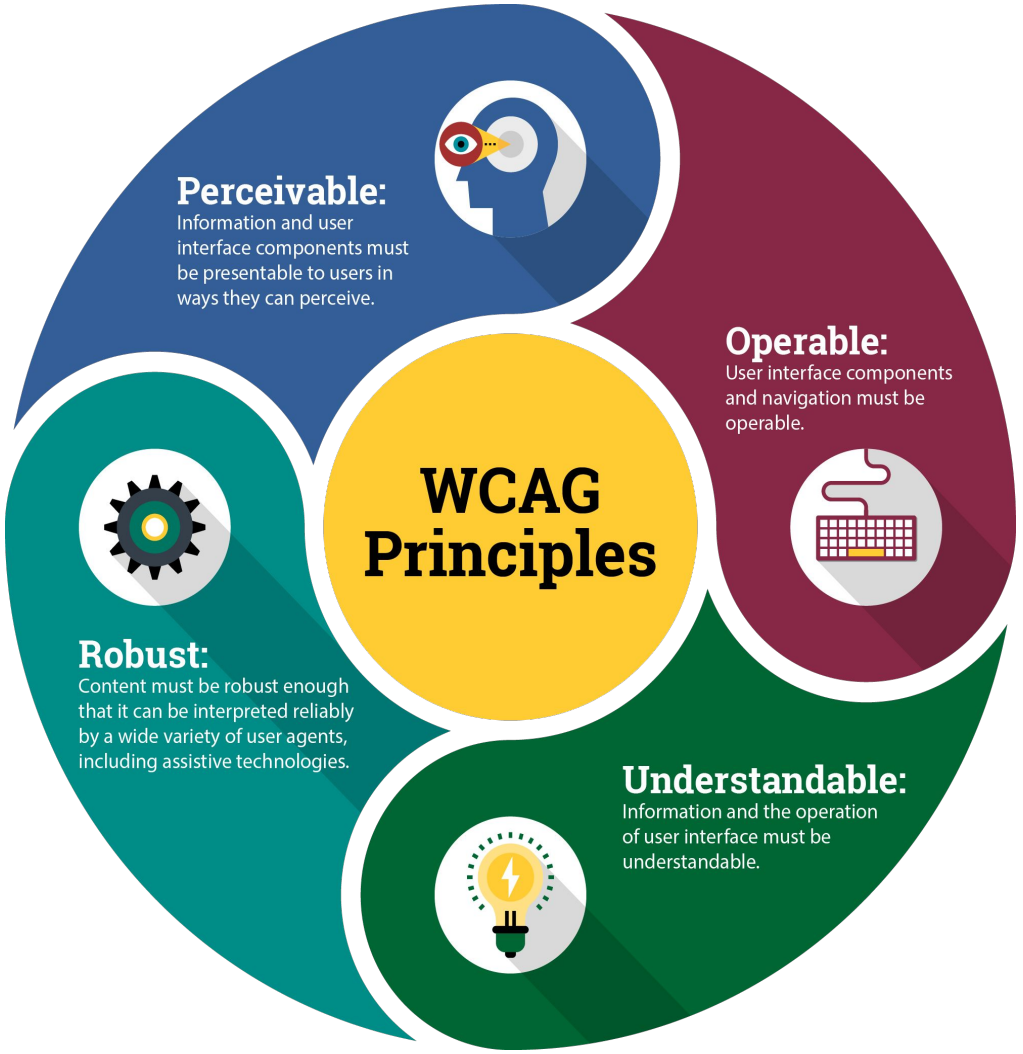
Patient Protection & Affordable Care Act (2010)

- Section 1557 prohibits discrimination in health programs and activities **based on** Race, Color, National origin, Sex, including pregnancy, childbirth, and related medical conditions, Age, **Disability** or sex (including pregnancy, sexual orientation, gender identity, and sex characteristics),in a covered health program or activity.
- Section 1557 prohibits retaliation for filing a discrimination complaint



Disability rights as Civil rights: ADA Title II Digital Accessibility Rule

- **April 2024:** The Department of Justice required state and local governments, including public schools and universities, to make their websites and mobile apps accessible
- **What "accessible" means:** Meeting the WCAG 2.1 Level AA standard, such as captions on videos, image descriptions, and compatibility with screen readers
- **April 2026 update:** Deadlines were pushed back one year
  - Large public entities (50,000+ people): **April 26, 2027**
  - Smaller entities (<50,000 people): **April 26, 2028**
- **Why this matter?**



Why are these Policies harmful?

- In Texas, **H.R 620, ADA Education and Reform Act of 2018,**
- (Sec. 3) Prohibits civil actions based on the failure to remove an architectural barrier to access into an existing public accommodation **unless**:

  (1) the aggrieved person has provided to the owners or operators a written notice specific enough to identify the barrier, and

  (2) the owners or operators fail to provide the person with a written description outlining improvements that will be made to improve the barrier, or they fail to remove the barrier or make substantial progress after providing such a description. The aggrieved person's notice must specify the circumstances under which public accommodation access was denied.

- (Sec. 5) The Judicial Conference of the United States must develop a model program to promote alternative dispute resolution mechanisms to resolve such claims.

Section 1557 of the Patient Protection and Affordable Care Act https://www.hhs.gov/civil-rights/for-individuals/section-1557/index.html

Why are Civil Rights based Policies Considered limited or Problematic in Practice?

1) Implementation gaps: accessibility and enforcement are inconsistent in real life

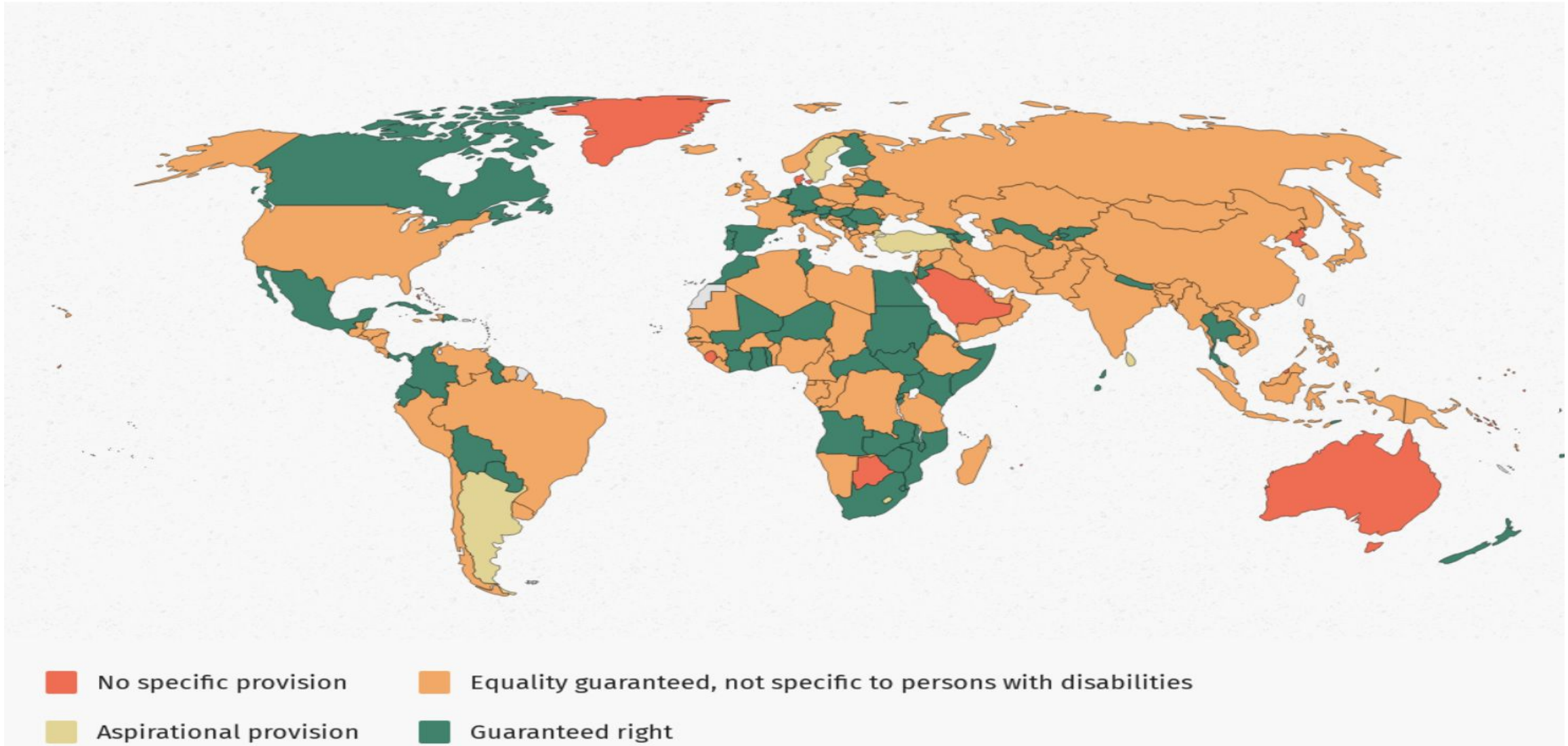
2) Narrow focus on legal compliance: Some systems focus on avoiding lawsuits rather than creating truly inclusive environments

3) Ongoing barriers: Physical, social, and communication barriers can still exist despite legal protections

4) Unequal impact: Some groups with intersecting identities (for example, disability and social race disadvantage or poverty) may still face more barriers, linking to intersectionality.

WORLD

Does the constitution explicitly guarantee equality or non-discrimination for persons with disabilities?



Map reflects constitutions in place as of June 2024.

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Where do we go from here? Disability Rights as Human Rights

- The Convention on the Rights of Persons with Disabilities and its Optional Protocol (A/RES/61/106) was adopted on 13 December 2006 at the United Nations
- Frames **Disability rights as human rights,** with an explicit social development dimension. It reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms.
- Signed by President Barack Obama in 2009. Yet to be ratified.



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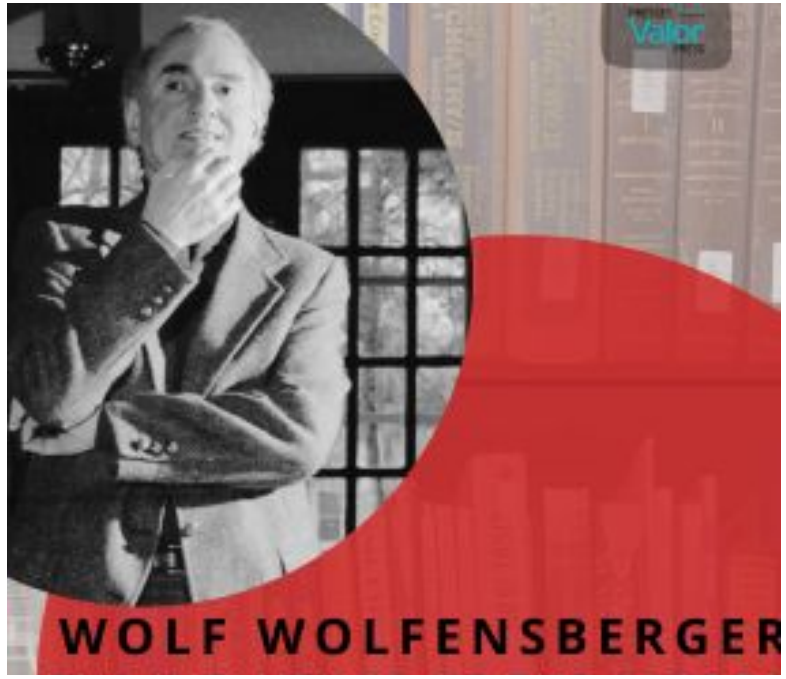
The *WHO Global report on health equity for persons with disabilities*:

- Calls on WHO Member States to take action to advance health equity for persons with disabilities
- Invites civil society, decision makers and all interest holders to collaborate and advocate for the implementation of the recommendations included in the report
- Documents the evidence on health inequities faced by persons with disabilities, and the contributing factors; and,
- Makes evidence-based recommendations for country-level actions to address these gaps.

World Health Organization

Social Role Valorization (SRV)

- Disability has historically been equated with social devaluation.
- **SRV combats devaluation** and is about helping marginalized individuals gain roles in society that are valued and respected.
- By supporting people with disability being in meaningful roles (like employee, student, or volunteer), it promotes inclusion and community participation that reduces stigma and improves quality of life.




Sarah Young Bear-Brown
Persons with disabilities have always been here


Harriet Tubman


Helen Keller


TIME
1977
Judith Heumann
Fighting for access
Judy Heumann


Brad Lomax


Tammy Duckworth


Stevie Wonder

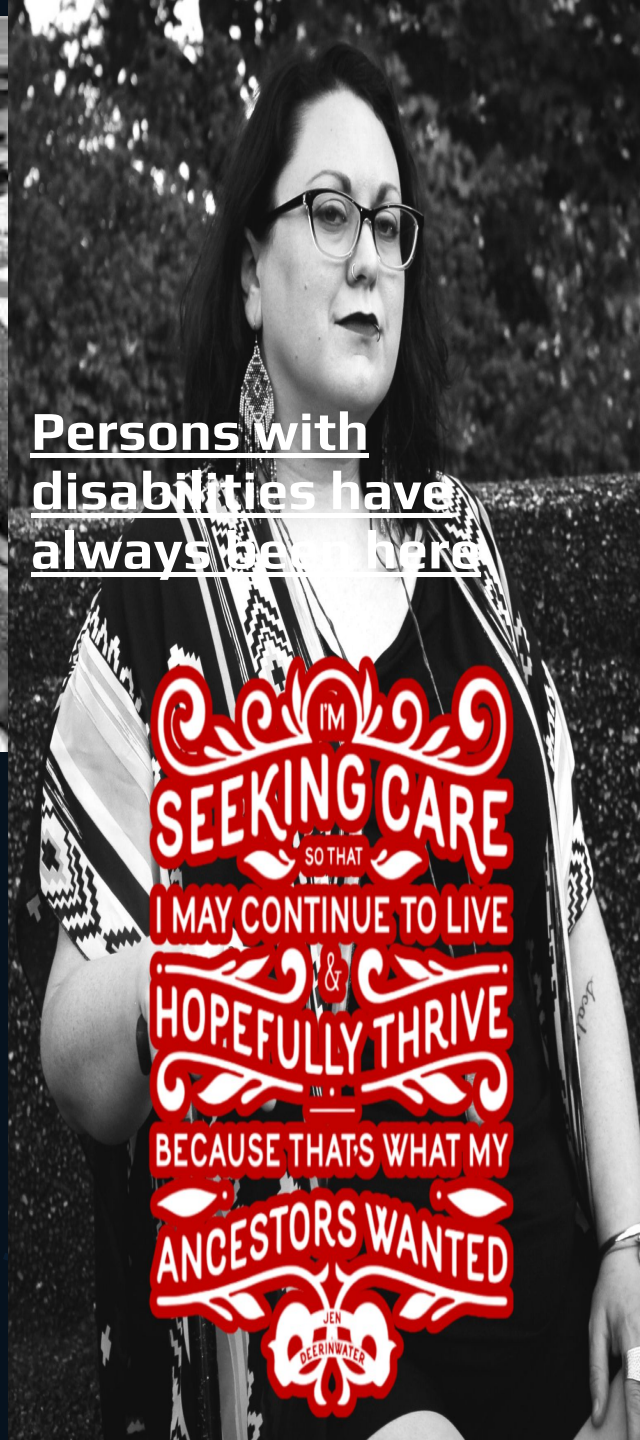

CIVIL RIGHTS FOR DISABLED
Justin Dart

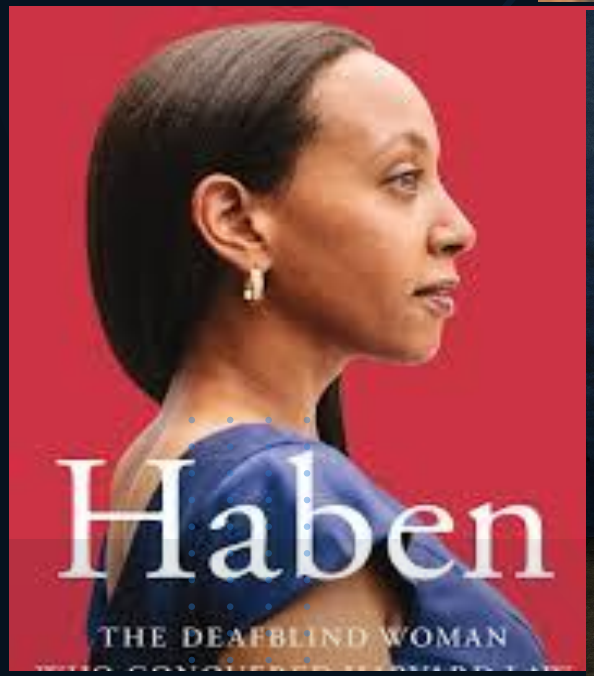

Maya Angelou


Claudia Gordon

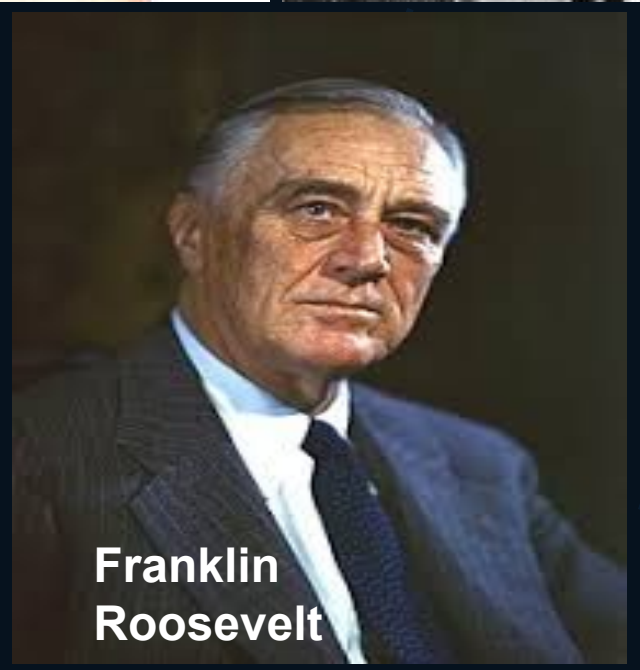

Marlee Martin


Stephen Hawking


Persons with disabilities have always been here
I'M SEEKING CARE
SO THAT
I MAY CONTINUE TO LIVE
&
HOPEFULLY THRIVE
BECAUSE THAT'S WHAT MY
ANCESTORS WANTED
JEN DEERINWATER


Haben
THE DEAFBLIND WOMAN


Frida Kahlo


Franklin Roosevelt

Conclusion

- 1 in 6 persons live with disabilities, 80% live in resource limited settings
- Disability is a target identity. Subject to constant oppression and harm in resource allocation & policy priority
- Since 2000, ~184 countries have passed disability civil rights laws. But without disability been affirmed as a Human Right, we still have a long way to go.



Acknowledgements



- Persons living with disabilities, seen and unseen, who have lived experiences, knowledge and leadership shape this work
- Disability Rights Advocates and Activists in community everywhere

Slidebazaar

NATIVE AMERICAN DISABILITY LAW CENTER