

Using data to advance health equity for people with disabilities

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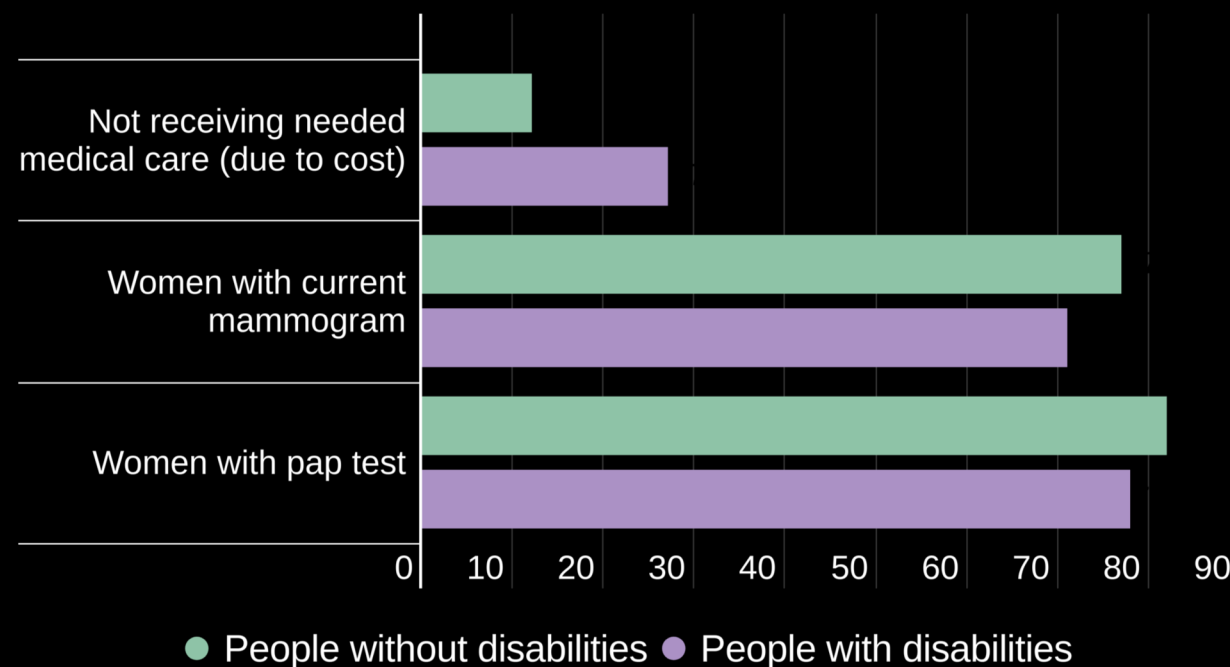
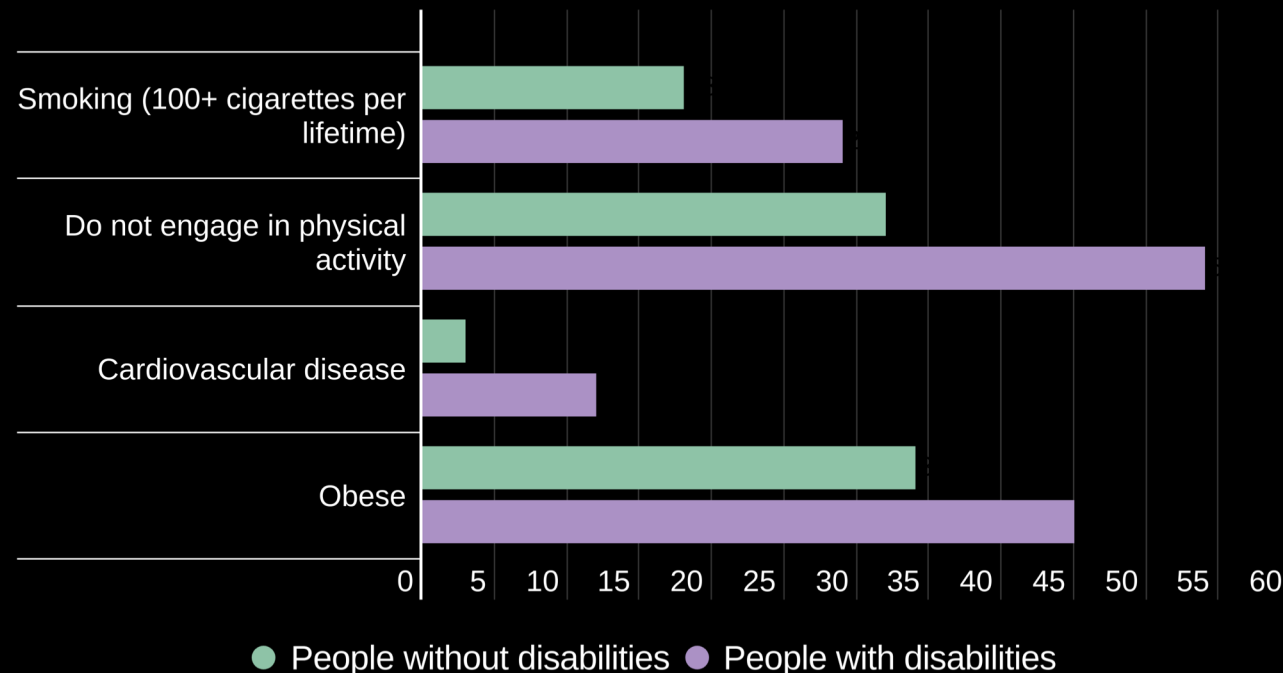
Johns Hopkins School of Nursing

Johns Hopkins Bloomberg School of Public Health

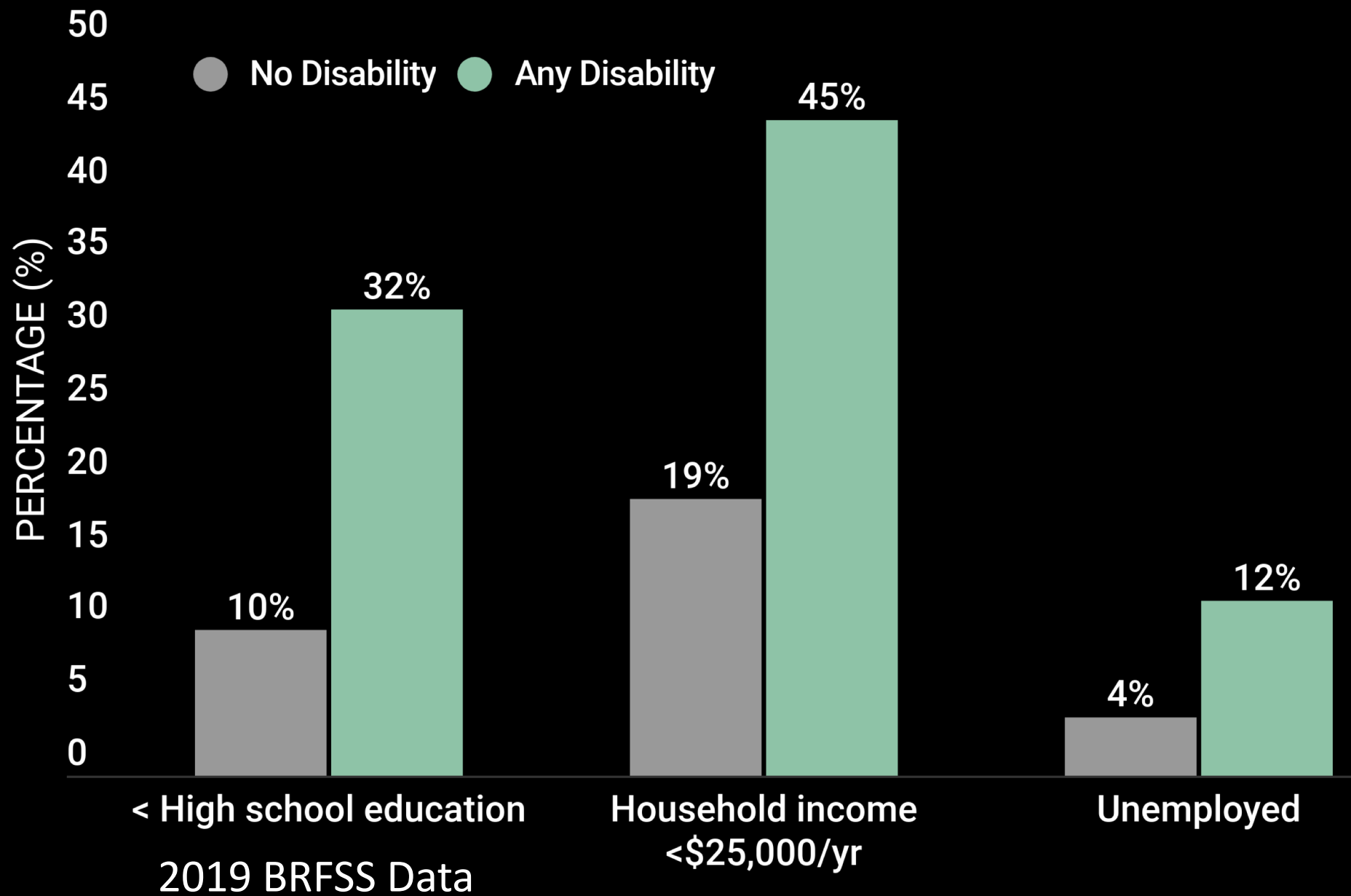
Johns Hopkins School of Medicine

People with disabilities face health disparities

Krahn et al. AJPH. 2015.

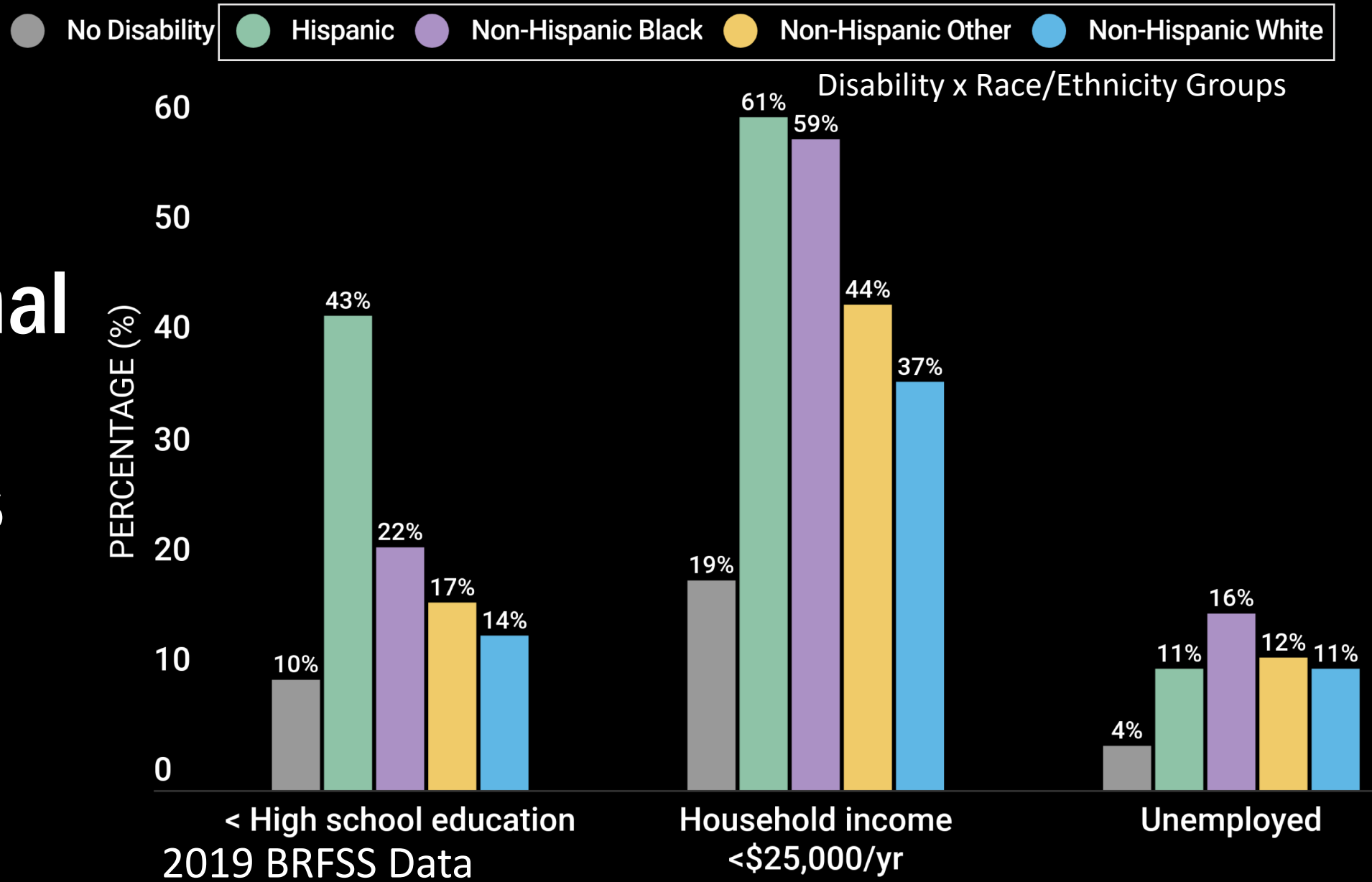


Disability Inequities



Varadaraj et al. JAMA Netw Open. 2021.

Intersectional Disability Inequities



Varadaraj et al. JAMA Netw Open. 2021.



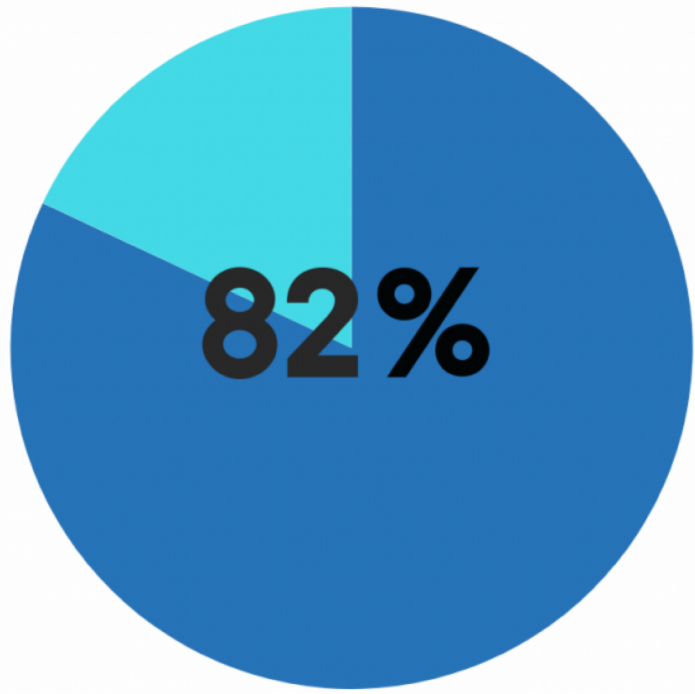
Root causes of disability inequities:

- Ableism
- Inaccessibility

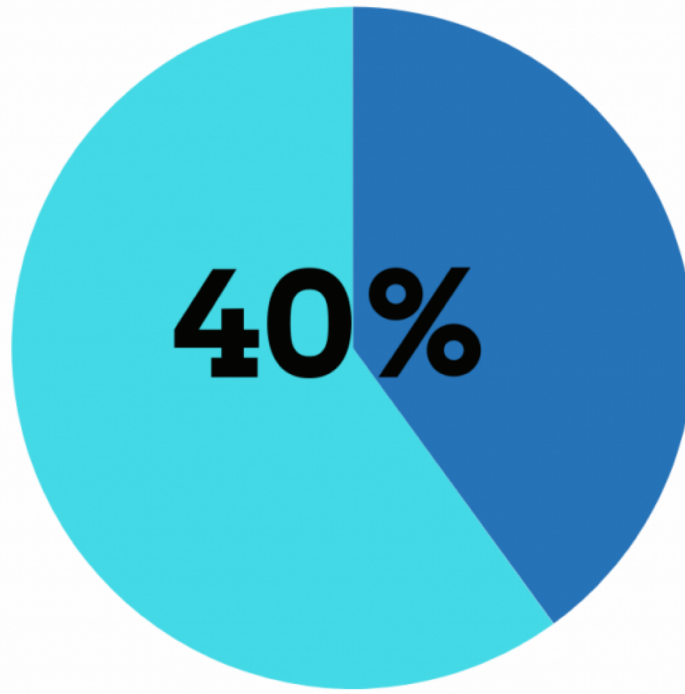
**Ableism
threatens
health
equity**

**“Ableism is rooted in
the assumption that
non-disabled people
are the ideal.”**

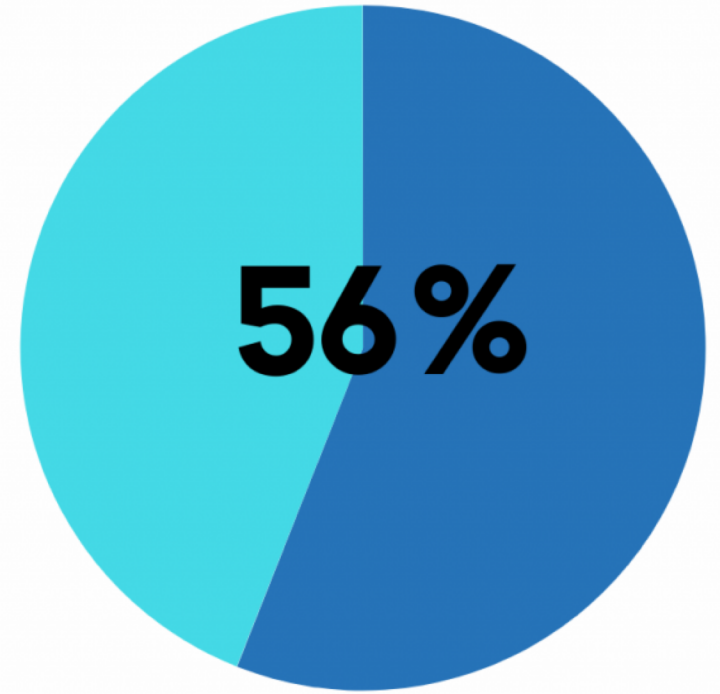
**- Amanda Morris and Chris Alcantara
Are You Ableist. Washington
Post. April 12, 2023.**



82% of Physicians reported they believed that people with significant disabilities have worse quality of life than non-disabled people



Only 40% of Physicians were very confident about their ability to provide the same quality of care to patients with disabilities



Just 56.5% strongly agreed that they welcomed patients with a disability into their practices

Slide created by:



Accessibility is everyone's responsibility

- **Barriers to information, interactions, services, programs, facilities, and environments**
- **Access must be of equivalent ease of use**

“Some doctors said their office scales could not accommodate wheelchairs, so they had told patients to go to a supermarket, a grain elevator, a cattle processing plant or a zoo to be weighed...”

Lagu et al. Health Aff. 2022.

The New York Times

These Doctors Admit They Don't Want Patients With Disabilities

When granted anonymity in focus groups, physicians let their guards down and shared opinions consistent with experiences of many people with disabilities.

 Give this article    1.2K





Disability Data

A key component to advancing
health equity

Who counts depends on who is counted

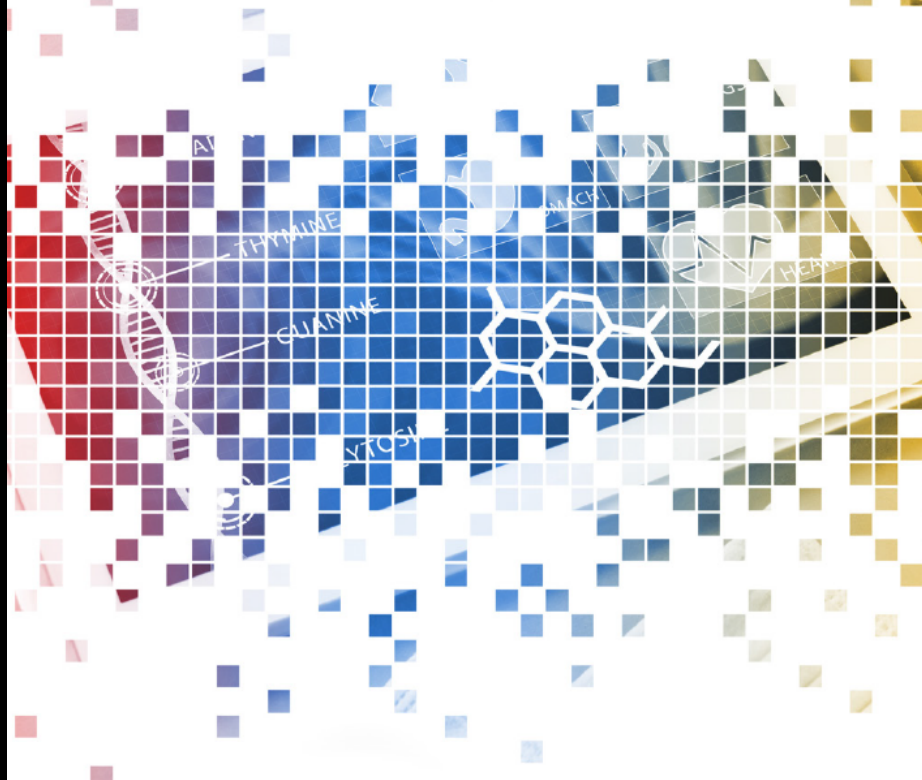
Unlike race, ethnicity, gender, and age, disability data are not routinely collected as part of demographic information





United States Core Data for Interoperability

VERSION 3 (JULY 2022)



Office of the National Coordinator
for Health Information Technology

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Health Care Equity Requires Standardized Disability Data In The EHR

[Megan A. Morris](#), [Silvia Yee](#), [Mary Lou Breslin](#), [Mark Savage](#),
[Bonnielin K. Swenor](#)

OCTOBER 27, 2022

10.1377/forefront.20221026.83825



DREDF

Disability Rights Education & Defense Fund

**Viewing disability
as a demographic,
and not a health
outcome.**

FIRST OPINION

The next Census could undercount the number of disabled Americans by 20 million

By Bonnielin Swenor and Scott Landes Nov. 27, 2023

STAT



Landes and Swenor. STAT News. 2023.

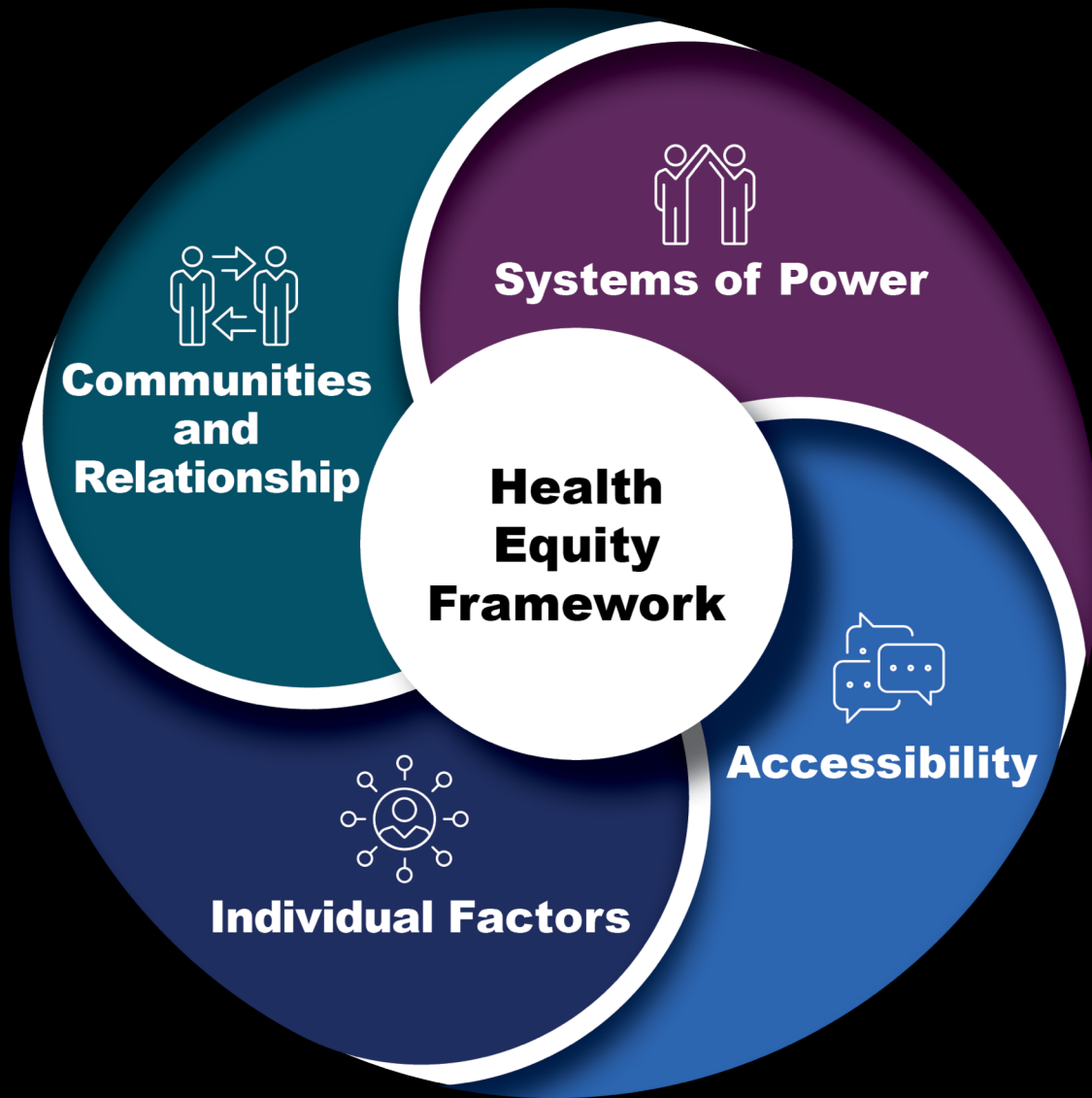
Disability Data in All Places Policy

- Intersectionality
- Inequity
- Interoperability
- Inclusion





**Health equity and
disability
determination**



Disability Health Equity

Health equity is influenced
by people and environments

SPHERE	 INDIVIDUALS	 RELATIONSHIPS	 SYSTEMS OF POWER	 ACCESSIBILITY
DEFINITION	Factors impacting people's response to their environment	Support structures and personal interactions	Policies, procedures, and processes	Design of environments, information, activities, etc
EXAMPLES	• Educational opportunity • Disability tax	• Provider bias • Compounding discrimination	• Medical record requirements • Disability data inequities	• Inaccessible forms • Transit barriers