



Disability Rights Education & Defense Fund

# **Health Disparities at the Intersection of Disability, Race, Ethnicity and Gender**

Mary Lou Breslin ~ November 2019

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Disability Rights Education & Defense Fund

National law and policy center since 1979--  
Dedicated to protecting and advancing disability  
civil and human rights through legal advocacy,  
training, education, and public policy and  
legislative development

# Overview

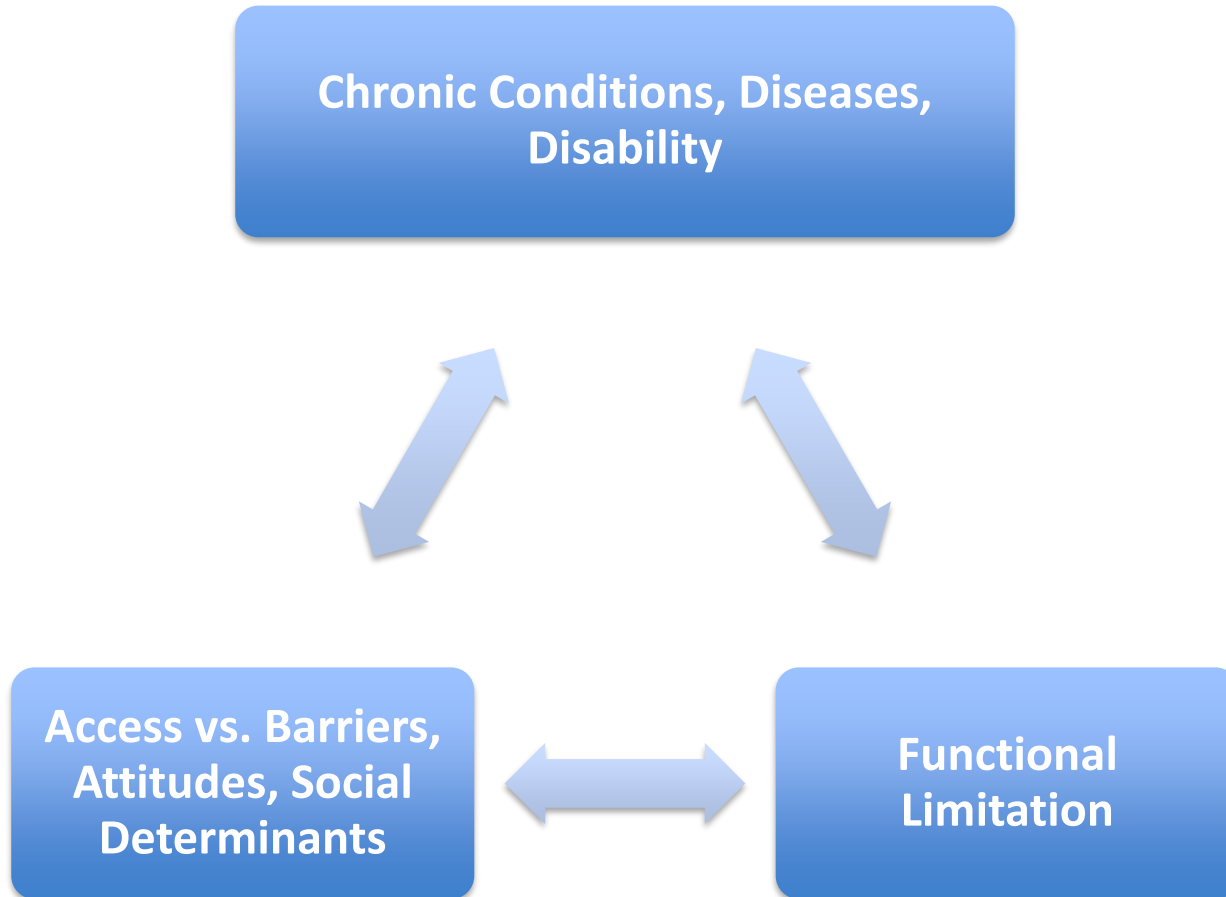
- Defining disability
- Demographics
- Health and healthcare disparities/intersections with race, ethnicity, gender
- Social determinants of health
- Research
  - Access to primary care physician offices in California
- Some progress
- Policy and advocacy recommendations

# Defining Disability

- World Health Organization (WHO) Definition-  
-2001

Disability is a dynamic interaction between health conditions (diseases, disorders, injuries, traumas, etc.) and contextual factors, including environmental and personal attributes.

# Interaction of Functional Limitation with Environmental Factors



# Diagnostic to Functional Definition of Disability\*

- *Shifting from a diagnostic to a functional definition allows disability to be disentangled conceptually from poor health and supports the view that people can have a disability and be healthy.*
- *It allows observed differences in health status to be examined as potential health disparities and allows health disparities to be seen as stemming from disparities in access to healthcare*

# **Disability Demographics**

# Disability Demographics (2015)\*

- About 40 million people of all ages, races, gender identities reported a disability.\*
- Disproportionately represented among some racial and ethnic groups
- Growing in numbers as the population ages and with technological advances in care

\*American Community Survey (2015)



# Disability Demographics

## Disability, Race and Ethnicity (2015)\*

- Disability prevalence is highest among American Indians and Alaskan Natives at 17.9 percent
- 13.8 percent for African Americans
- 10.7 percent for non-Hispanic whites
- 8.7 percent for Hispanics/Latinos
- 6.9 percent of Asian Americans

\*American Community Survey (2015)

# Disability Demographics

## Complex Activity Limitations

- Complex activity limitation among people with disabilities
  - Complex activity limitation is captured through four measures:
    - any limitations in social or leisure activities
    - any difficulty or inability to work
    - self-care limitation
    - and an overall combination measure
- People with complex activity limitations face greatest healthcare barriers

# Disability Demographics

## Complex Activity Limitations by Race, Ethnicity, Gender\*

- 14% of adults living in US have complex activity limitation
- Complex activity limitation by race/ethnicity:
  - African Americans/blacks – 17.5%
  - Non-Hispanic whites – 15.5%
  - Hispanic/Latino – 10.0%
- Disability more common among women than men

# Disability Demographics in the Future

- Growing in numbers as the population ages and with technological advances in care
- **49.8 percent of people over age 75 report disability (2015)\***
- 88.5 million or 20% of the total population will be people 65 and older by 2050
- 25.4 percent of people age 65 - 74 report disability (2015)\*

# **Disability, Health and Health Care Disparities**

# Setting the Stage for Recognizing Disability as a Bona Fide Disparities Population

- HHS—Advisory Committee on Minority Health—  
July, 2011
  - “By every measure, persons with disabilities disproportionately and inequitably experience morbidity and mortality associated with unmet health care needs in every sphere. [Members of certain racial and ethnic groups] with disabilities are doubly burdened by their [racial and ethnic] status.”
- Healthy People 2020—identified health disparities

# Disability, Health and Health Care Disparities

## Healthy People 2020

- People with disabilities are more likely to:
  - Experience difficulties or delays in getting the health care they need
  - Not have had an annual dental visit
  - Not engage in fitness activities
  - Have high blood pressure

# Disability, Health and Health Care Disparities (2015)

- Disabled individuals age 18 and over are more likely to smoke (23.4 percent) than adults without disabilities (14.9 percent)\*
- Disabled individuals age 18 and over are more likely to be obese (39.9 percent) than adults without disabilities (25.4 percent)\*



# Disability, Health and Health Care Disparities

- Three out of five people with serious mental illness die 25 years earlier than other individuals, from preventable, co-occurring chronic disease#
- Disabled people on Medicare die from lung cancer at higher rates^

# Compounded Disparities

# Women with Disabilities Health and Health Care Disparities

- Women with disabilities are more likely to:
  - Not have had a mammogram in the past 2 years
  - Not have had a cervical cancer test within the past 3 years

# Women with Disabilities

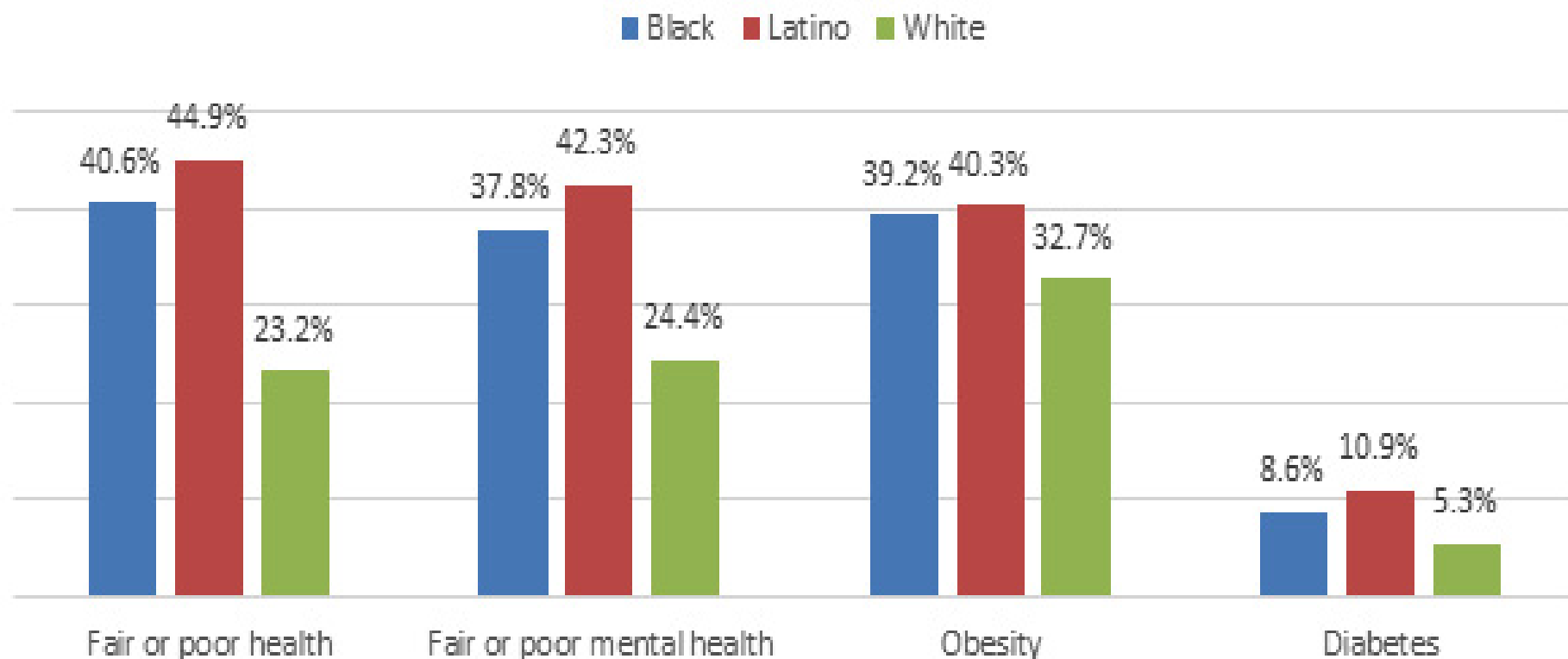
## Health and Health Care Disparities

- Women with disabilities\*
  - Are an unrecognized cancer disparities population
  - Experience well documented barriers to breast cancer screening
  - Have higher death rates from breast cancer
- One study found that women with significant disabilities were 56% less likely to receive mammograms than their nondisabled peers, regardless of age
- They remain largely absent from cancer disparities agendas

# Race and Ethnicity Health and Healthcare Disparities\*

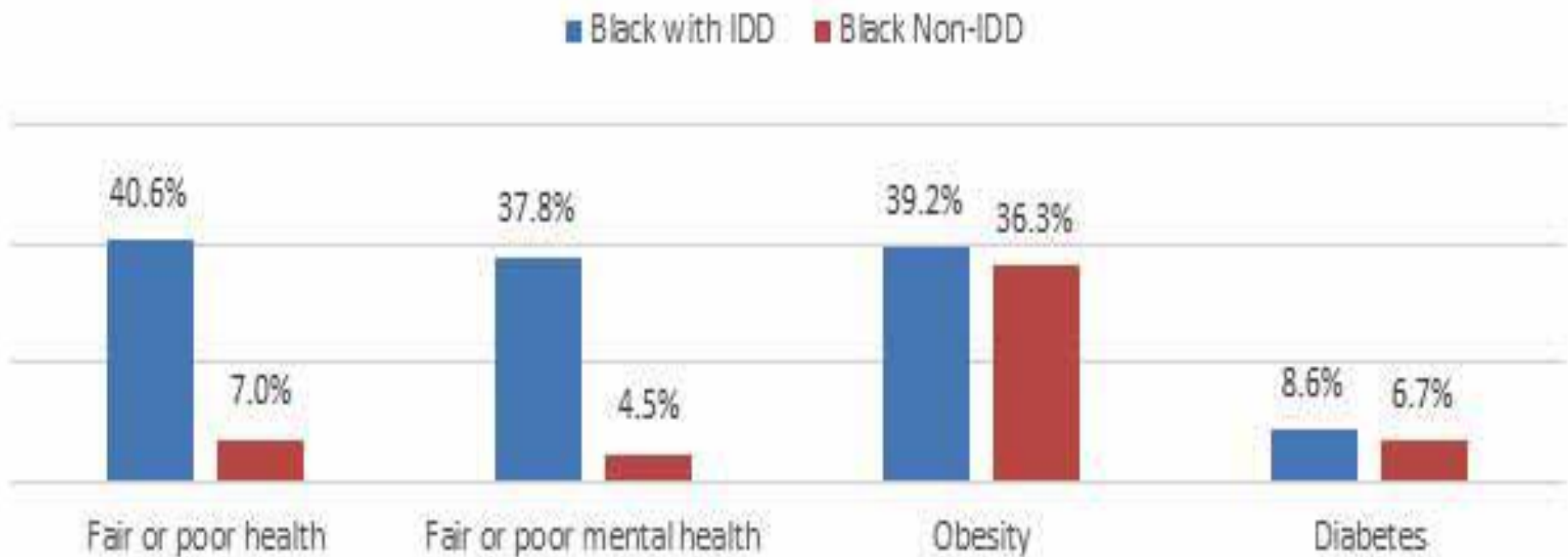
- Consistent with long-standing evidence of racial and ethnic differences in the general population
  - Black and Latino adults with intellectual and developmental disabilities were significantly more likely to be in fair or poor health and mental health than White adults with intellectual and developmental disabilities

Figure 1: Percentages of Health Outcomes by Ethnicity among Adults with IDD



Haleigh M. Scott and Susan M. Haverkamp (2014) Race and Health Disparities in Adults With Intellectual and Developmental Disabilities Living in the United States. *Intellectual and Developmental Disabilities*: December 2014, Vol. 52, No. 6, pp. 409-418. <https://doi.org/10.1352/1934-9556-52.6.409>

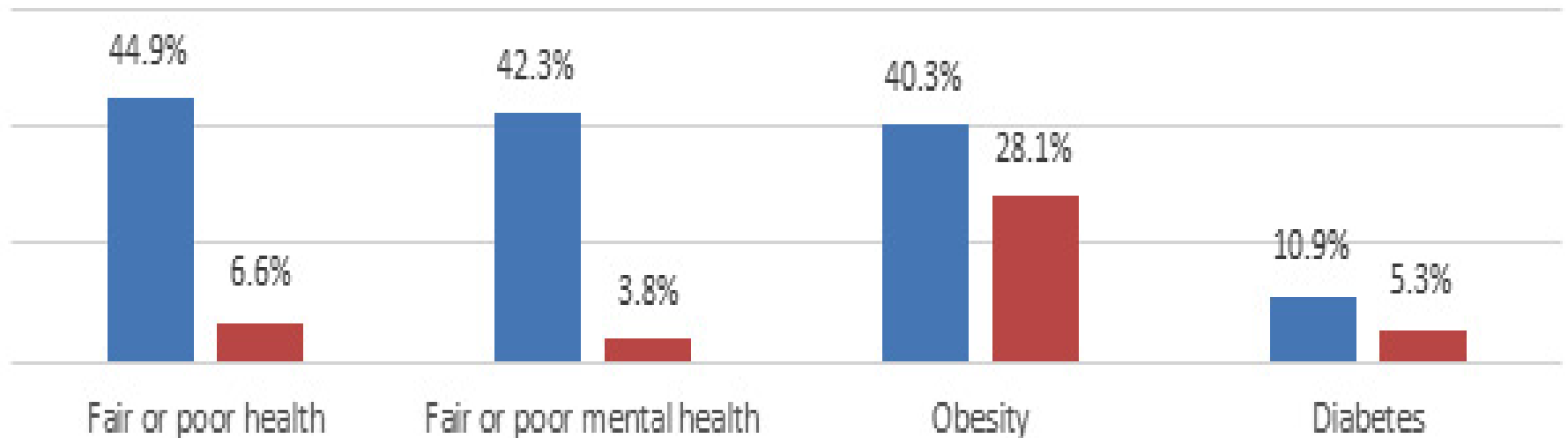
Figure 2: Percentages of Health Outcomes between Black Adults with and without IDD



Haleigh M. Scott and Susan M. Haverkamp (2014) Race and Health Disparities in Adults With Intellectual and Developmental Disabilities Living in the United States. *Intellectual and Developmental Disabilities*: December 2014, Vol. 52, No. 6, pp. 409-418. <https://doi.org/10.1352/1934-9556-52.6.409>

Figure 3: Percentages of Health Outcomes between Latino Adults with and without IDD

■ Latino with IDD ■ Latino Non-IDD



Haleigh M. Scott and Susan M. Havercamp (2014) Race and Health Disparities in Adults With Intellectual and Developmental Disabilities Living in the United States. *Intellectual and Developmental Disabilities*: December 2014, Vol. 52, No. 6, pp. 409-418. <https://doi.org/10.1352/1934-9556-52.6.409>



# Race and Ethnicity Health and Healthcare Disparities

- Women with IDD
  - African-American/black women w/ IDD were significantly and substantially less likely to have received a mammogram during a 2 year period compared to white women with intellectual disabilities (51% of Af. Amer./76% of white women)
- Deaf African American and Hispanics/Latinos significantly less likely to have had a mammogram than deaf whites (43.5% compared with 69.8%)

# Race and Ethnicity Health and Healthcare Disparities

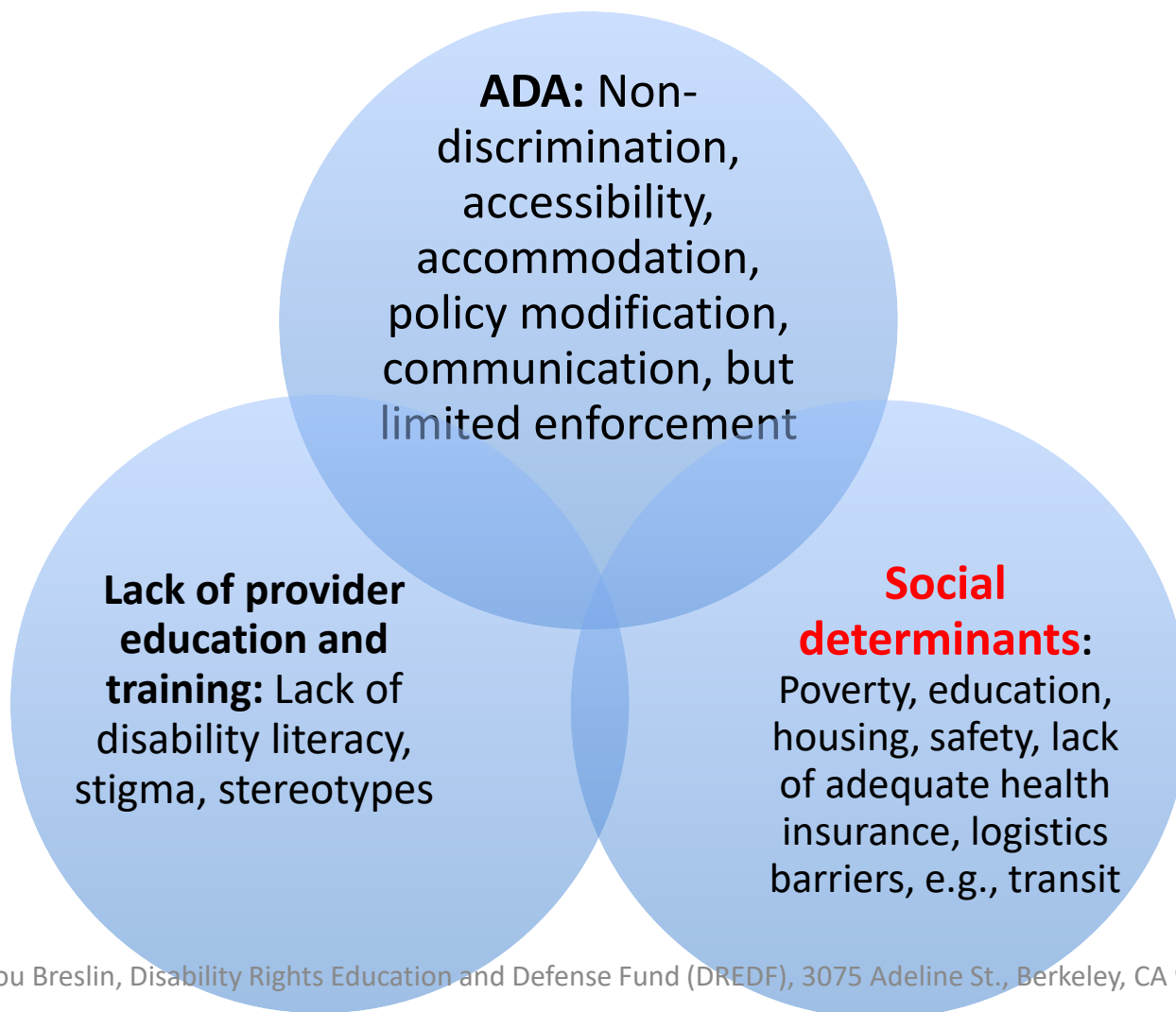
- Efforts to understand specifically how the health care barriers faced by people with disabilities may be compounded by race or ethnicity have been virtually nonexistent
- A 2017 scoping review for NASEM found only one published study that was specifically framed by its authors as an examination of barriers to health care access for people with disabilities who are also members of racial or ethnic groups

# Social Determinants

# Why Disparities? Complex, Intersecting Factors

- Lack of provider training and cultural literacy
  - Cultural competence is widely seen as a foundational pillar for reducing disparities through culturally sensitive and unbiased quality care
- Social determinants
  - Poverty
  - Attitudes, prejudice and stereotypes
  - Physical and programmatic inaccessibility
- Inadequate data collection and research

# Why Disparities? Complex Interaction of Factors that Influence Health Status and Health Outcomes for Disabled People



# Social Determinants



Healthy People 2020 approach to social determinants of health

# Social Determinants

- Healthy People 2020 defines social determinants of health as:

“...conditions in the environments in which people are born, live, learn, work, play, worship, and age that affect a wide range of health, function, and quality of life outcomes and risks.”

## CONSIDER THIS:

- Some research suggests medical care responsible for only 10 – 15% of health outcomes
- 85 – 90% derived from social and physical environments\*

\* Braverman & Gottlieb, 2014, Sederer, 2015

# Social Determinants

## Poverty

- Disability is both a fundamental cause and consequence of income poverty
- Half of all working age adults experiencing income poverty have a disability
- **Income poverty rate for PWD is over 2 times higher than gen. pop. (30.5% vs. 12%)**



# Social Determinants

## Housing

- Inadequate and unaffordable housing is an important health indicator for both people of color and people with disabilities
  - Increases risk of housing insecurity and homelessness
  - Poor health outcomes are associated with substantial disparities in housing, lack of housing mobility, and housing discrimination
  - People with disabilities are more likely to live in substandard housing that present health hazards such as pests, physical damage, or rodent infestations than those who do not have disabilities, even controlling for income\*

# Social Determinants

## Homelessness\*

### A National Snapshot

- Chronically homeless:
  - 2017 – 369,081 total homeless individuals living emergency shelters, transitional housing, on the streets or in places not meant for human habitation
  - 86,962 or 24% were chronically homeless
- A person is considered chronically homeless if they have a disability and if they have been continuously homeless for one year or more or have experienced at least four episodes of homelessness adding up to at least 12 months in the last three years.

# Social Determinants

## Disability and Homelessness

### Alameda County

- An estimated 42 percent of the 8,000 people who are homeless at any given time in Alameda County have a disability\*
- Some 68 percent of the 2,000 people who annually experience homelessness in Berkeley are disabled, according to a city report\*\*
  - having a disability of any kind increased the likelihood that someone would remain homeless by 733 percent

# Social Determinants

## Provider Attitudes

### Race, Ethncity, Disability\*

#### Race, ethnicity

- Implicit bias (unconscious belief) and explicit bias
- Clinical bias, stereotyping
  - Associated with race-based disparities in treatment
- Research shows that physicians provide less info., spend less time w/ AA/Black patients

#### Disability

- Perceptions elicit pity, compassion, disgust and anxiety; disability bias reported to be moderate to strong
- Negative attitudes reported by med., nursing students, physicians and nurses, other health professionals
- Misperception of life with a disability

# Social Determinants

## Impact of Attitudes on Patient Care

- Communication
  - Breakdowns across disability types
    - Too little time spent with patient
    - Loss of trust, fear of certain providers
- Diagnostic overshadowing
  - Clinicians lack skills to distinguish clinical problem from disability; disability overshadows
- Providing quality, age-appropriate care
  - Patient might be regarded as childlike; breast and cervical cancer screening neglected for woman

# Social Determinants

## Impact of Attitudes on Ethical Decision Making

- Disability is a battleground for many bioethics issues
  - Devaluation of the lives of people with disabilities perpetuates unequal access to medical care, including life-saving care
  - Biases have serious and deadly consequences
  - Health care providers' subjective judgments about whether a patient's life is "worth living" often influences their decisions regarding whether to withdraw or withhold medical care

# Social Determinants

## Impact of Attitudes on Ethical Decision Making

- A provider suggested a woman in her 50s with DD only visit once a year as, “She’s lived a good life - once a year is fine.”
- A provider while delivering her child, said about the mother, “Well, the Deaf woman should tie her tubes so she doesn’t get pregnant again.”
- “Patients with intellectual disabilities do not feel pain and therefore do not need anesthesia.”

# National Council on Disability

## Bioethics and Disability Report Series

- Organ Transplant Discrimination Against People with Disabilities
- The Danger of Assisted Suicide Law
- Genetic Testing and the Rush to Perfection
- Quality-Adjusted Life Years and the Devaluation of Life with a Disability
- Medical Futility and Disability Bias

<https://dredf.org/federal-disability-agency-publishes-series-of-reports-on-bioethics-and-disability/>



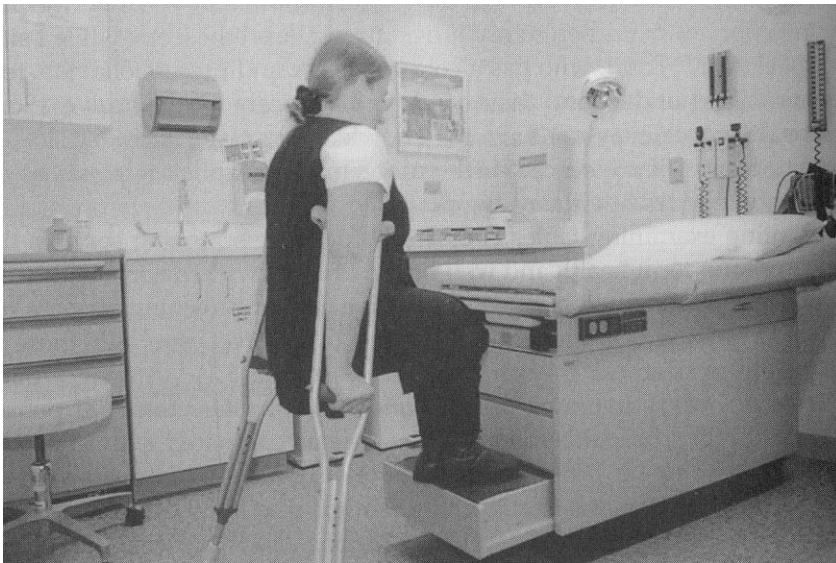
# Social Determinants Healthcare Physical and Services Barriers

- Physical barriers
- Lack of accommodations (communication assistance)
- Inaccessible medical and diagnostic equipment
  - Exam tables
  - Weight scales
  - Mammography equipment
- Inflexible policies, e.g., short exam time

# Physical Barriers and Solutions

- Lack of accessible exam equipment such as exam tables

## Problem



## Solution



# Physical Barriers and Solutions

- Inaccessible equipment such as weight scales

***Problem***



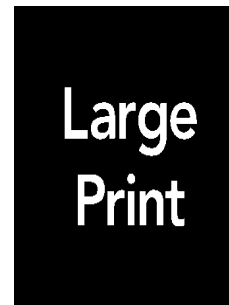
***Solution***



# Communication Barriers and Solutions

- Communicating effectively using the right tools for people with problems seeing, hearing, thinking, remembering, learning and understanding

- Braille
- Large print
- Digital text
- Audio



# Communication Barriers and Solutions

- Communicating effectively using the right tools for people with problems seeing, hearing, thinking, and understanding

## Sign Language interpreters

**ASL** -- a visual-gestural language used by millions of Americans of all ages. ASL is a rich and complete language that has a different grammatical structure than the English language



# Healthcare Stories



# Research

- Annals of Internal Medicine--2013: review of 256 specialty practices
- DREDF/Syracuse University analysis of 3998 California Medicaid primary care practices



# Research on Attitudinal and Physical Barriers to Care\*

- Annals of Internal Medicine--2013: review of 256 specialty practices:
  - 56 (22%) reported that they could not accommodate the patient
  - 9 (4%) reported that the building was inaccessible
  - 47 (18%) reported the inability to transfer a patient from a wheelchair to an examination table
  - Only 22 (9%) reported the use of height-adjustable tables or a lift for transfer
  - Gynecology is the subspecialty with the highest rate of inaccessible practices (44%)

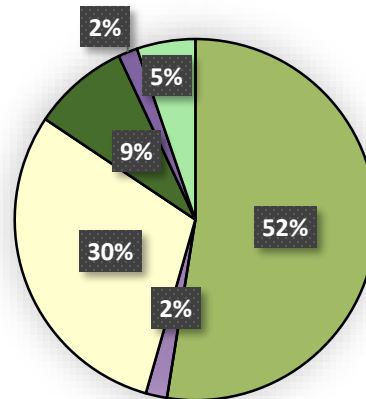
# **DREDF/Syracuse Univ. Study: Access/3998 Medicaid Primary Care Practices in California 2013 – 2016**

- Managed Care Health Plans survey PCP offices when new provider joins plan and every 3 years thereafter
  - 86 question survey based on 2011 ADAAG
  - Plus accessible exam tables and weight scales

# DREDF/Syracuse Univ. Study: Access/3998 Medicaid Primary Care Practices in California 2013 - 2016

- Unduplicated audits from 5 California Medicaid managed care plans, 2013-2016
- Unit of analysis: primary care practice *office*, which may house a single physician or a group practice
- Each practice is a separate observation

Mudrick, Nancy R., Swagger, LeeAnn, and Breslin, Mary Lou. "Equal Care: Accessibility of Health Care Settings for People with Disabilities Across Two Time Periods." Presentation, Society for Social Work and Research Annual Conference, Washington, DC, January 14, 2018



# Accessibility Summary, Exam Equipment: 2017 data

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%	Elements of exam equipment access
19.1	Has height adjustable exam table that lowers to 17-19 inches
90.8	Height-adjustable exam table has space next to it for wheelchair/scooter for transfer
23.7	Exam table has elements to assist transfer and support a person on the table
5.9	A lift is available to assist staff members with transfer
84.2	Exam room has 60” turning circle for wheelchair/scooter user
10.9	Has a weight scale within the office that accommodates wheelchair/scooter and patient
	<p>Mudrick, Nancy R., Swagger, LeeAnn, and Breslin, Mary Lou. "Equal Care: Accessibility of Health Care Settings for People with Disabilities Across Two Time Periods." Presentation, Society for Social Work and Research Annual Conference, Washington, DC, January 14, 2018.</p>

**Some Progress**

# Some Progress—Federal Agencies

- The Commission on Dental Accreditation (CODA) recently voted to require dental schools to train their students in effective treatment of patients with ID/DD, effective January 1, 2020
- CMS Office of Minority Health: Improving Access to Care for People with Disabilities—videos, patient guide, July 2019
- USDOJ ADA/504 cases
- HHS/CMS, Office of Minority Health – Equity Plan for Improving Quality in Medicare, Sept 2015: Increase physical accessibility of health care facilities

# Some Progress—CDC

- CDC funds
  - State Disability and Health Programs in 19 states
    - Working to improve the health and quality of life among people with mobility limitations and/or intellectual disabilities (ID) through adaptation and implementation of evidence-based strategies in their communities.
  - Two National Centers on Health Promotion for People with Disabilities.
  - The Reaching People with Disabilities through Healthy Communities Project

<https://www.cdc.gov/ncbddd/disabilityandhealth/programs.html>

# Some Progress—DOJ Action

- USDOJ actions: 2006 – 2019 (includes Barrier Free Health Care Initiative)
  - Auxiliary aids and services (ASL/interpreter)—69
  - Modification of policies and practices (includes service animals)—4
  - Architectural barriers—3
  - Denial of care/discrimination (HIV/opioid addition)--20



# **“Core Competencies on Disability for Health Care Education”**

**June 2019**

**Ohio State University**

**Nisonger Center at Wexner Medical Center**

**and**

**Alliance for Disability and Health Care  
Education**

# 10 Guiding Principles and Values

1. People with disabilities should have equitable access to appropriate, accessible, and high quality healthcare.
2. People with disabilities face barriers in accessing effective healthcare that may or may not be associated with their disabilities.
3. Training should be provided for all healthcare providers so that they are able to provide high-quality care to patients with disabilities.

# 10 Guiding Principles and Values

4. Healthcare providers can maximize the quality of life of their patients with disabilities by preventing and treating health conditions.
5. People with disabilities are experts in their own condition, and this expertise should be respected and used to improve healthcare decisions and care.
6. Quality-of-life and treatment goals can only be fully understood from the patient's point of view.

# 10 Guiding Principles and Values

7. Healthcare providers should communicate directly with patients with disabilities, presuming their competence and including them in the decision-making process.
8. Healthcare provider should know under what circumstances caregivers should be included in healthcare encounter and decision-making.
9. Provide the optimal patient experience by creating a respectful, accessible, and welcoming office environment using universal design principles.
10. Appropriately accommodating patients with disabilities is essential for all healthcare providers. Failing to provide equal access to care and accessible diagnostic/screening equipment for people with disabilities should be grounds for disciplinary action.

# Research and Monitoring Gaps

# Gaps in Research and Monitoring

- Need to identify disability status in healthcare reporting tools
- Lack of knowledge about where people with disabilities seek care and the quality, effectiveness and accessibility of that care
- Failure to recognize people with disabilities as an underserved population; integrate disability within broader HHS and public health measures to combat health disparities

# Recommendations

## Healthy People: Science-Based 10-Year Objectives

- Expand the knowledge base and raise awareness about determinants of health for people with disabilities by increasing:
  - The inclusion of disability status in public health data collection efforts across the lifespan
  - The inclusion of people with disabilities in health promotion activities
  - The expansion of disability and health training opportunities for public health and health care professionals

# Advocacy Opportunities

- **Disability and Health Tsar!**
  - Work with managed care organizations to improve accommodations in clinical settings
    - Purchase of accessible medical and diagnostic equipment
    - Create model accommodation policies for clinical providers
  - Work with large providers to embed functional limitation data and accommodations info. for patients in EHR (EPIC, etc.)
  - Advocate for accurate disability data collection that will inform future policies and programs
  - Work with community health leaders to offer disability competency training for clinicians that meets continuing medical ed. requirements



**Thank You!**



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