

# Addressing Ableism in Medicine

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By Alicia Wong, MD, MPH

# What is Disability?

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- According to the Americans with Disabilities Act (ADA), a person with a disability is an individual with a **“physical or mental impairment that substantially limits one or more major life activities”**.
  - This is a legal definition



# What is Disability?

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1. Do you have difficulty seeing, even if wearing glasses?
2. Do you have difficulty hearing, even if using a hearing aid?
3. Do you have difficulty walking or climbing steps?
4. Do you have difficulty remembering or concentrating?
5. Do you have difficulty with self-care, such as washing all over or dressing?
6. Using your usual (customary) language, do you have difficulty communicating (for example, understanding or being understood by others)?

Each question has four types of response, designed to capture the full spectrum of functioning, from mild to severe: no difficulty, some difficulty, a lot of difficulty and unable to do it at all.

# Disability Impacts **ALL of US**

COMMUNITIES



HEALTH

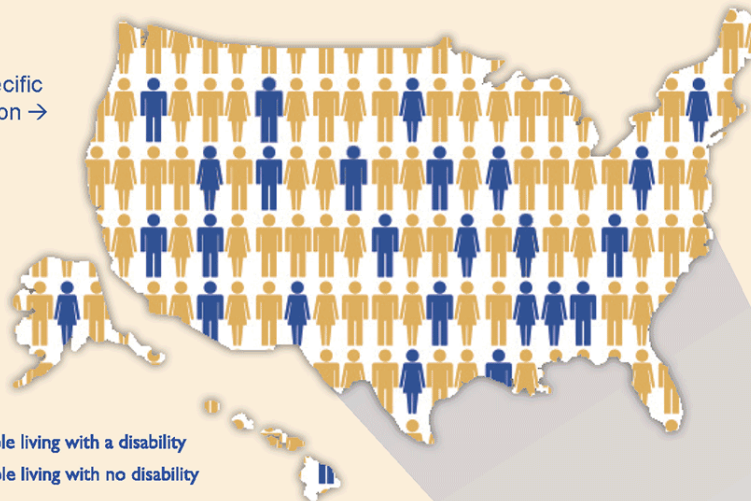


ACCESS



**61 million** adults in the United States live with a disability

Click for  
state-specific  
information →



**26%** of adults in  
the United States  
have some type  
of disability  
(1 in 4)

The percentage of people  
living with disabilities is  
highest in the South





# ABLEISM

a·ble·ism \ 'ābə-ĭi-zəm \  
noun

A system that places value on people's bodies and minds based on societally constructed ideas of normality, intelligence, excellence, desirability, and productivity.

These constructed ideas are deeply rooted in anti-Blackness, eugenics, misogyny, colonialism, imperialism and capitalism.

This form of systemic oppression leads to people and society determining who is valuable and worthy based on a person's language, appearance, religion and/or their ability to satisfactorily [re]produce, excel and "behave."

You do not have to be disabled to experience ableism.

a working definition by Talila "TL" Lewis\*; updated January 2021

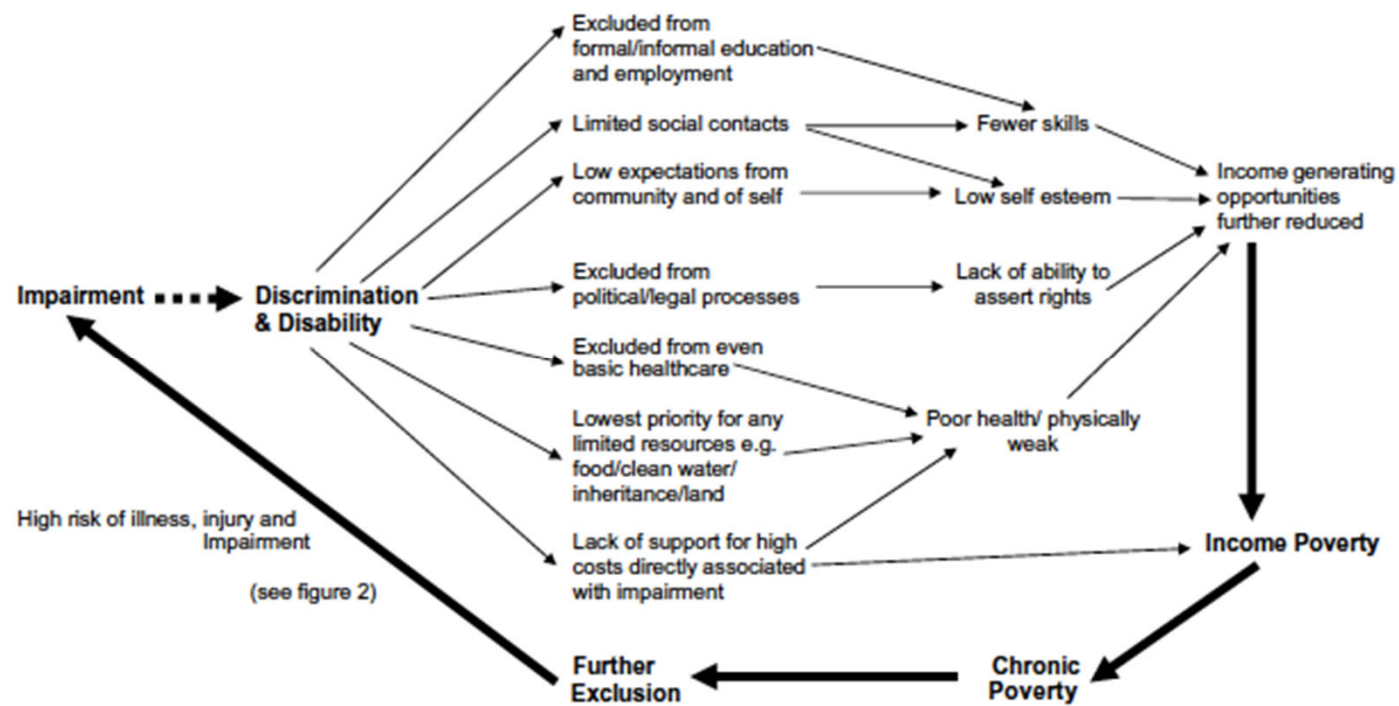
\*developed in community with Disabled Black & other negatively racialized people, especially Dustin Gibson

**“One cannot be antiracist while still being ableist [...] because I think for many people who are indeed striving to be antiracist, they may not realize the ways in which they’re still being prevented from moving along on this journey due to their unacknowledged or unrecognized ableism”**

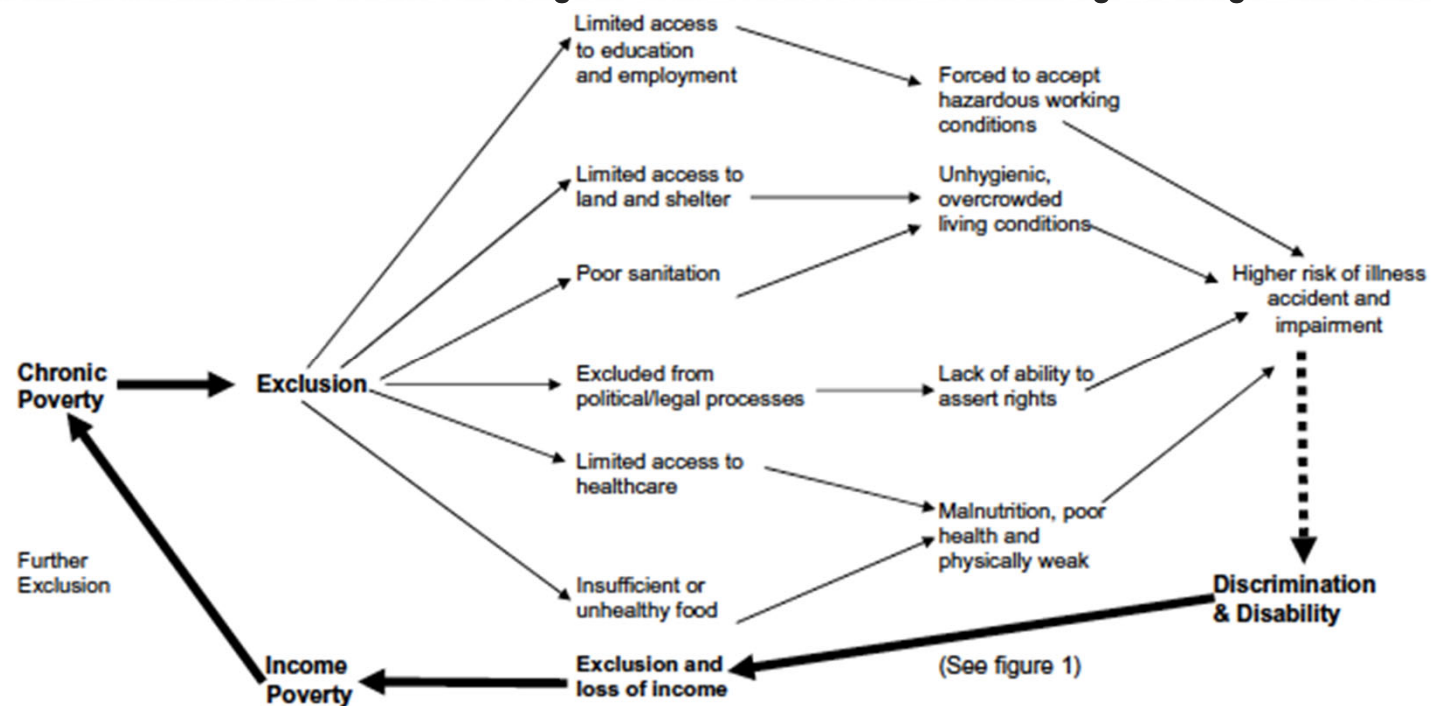
–Dr. Ibram X. Kendi, *Be Antiracist with Ibram X Kendi*



# Disability → Poverty Cycle

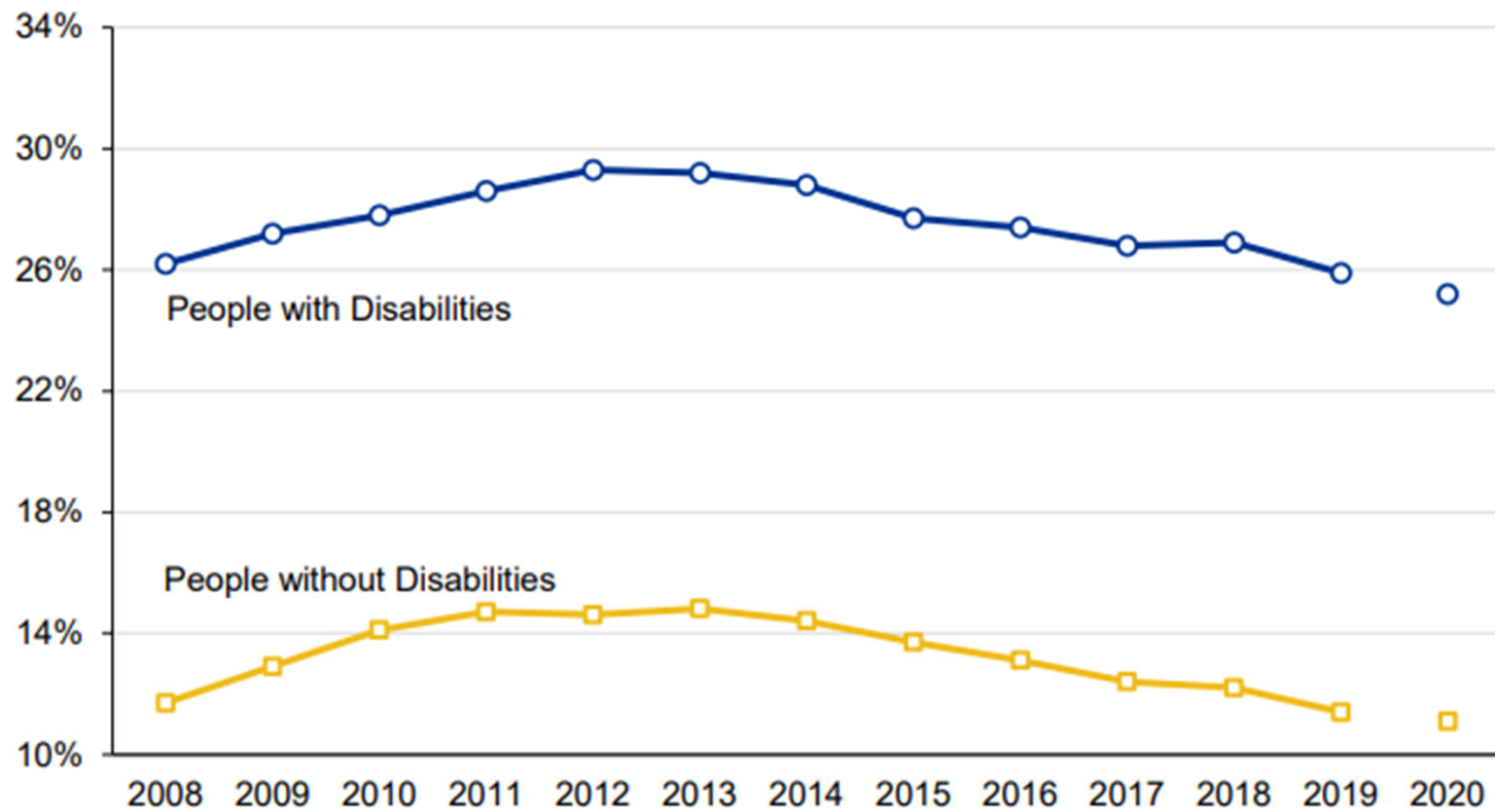


# Poverty → Disability Cycle

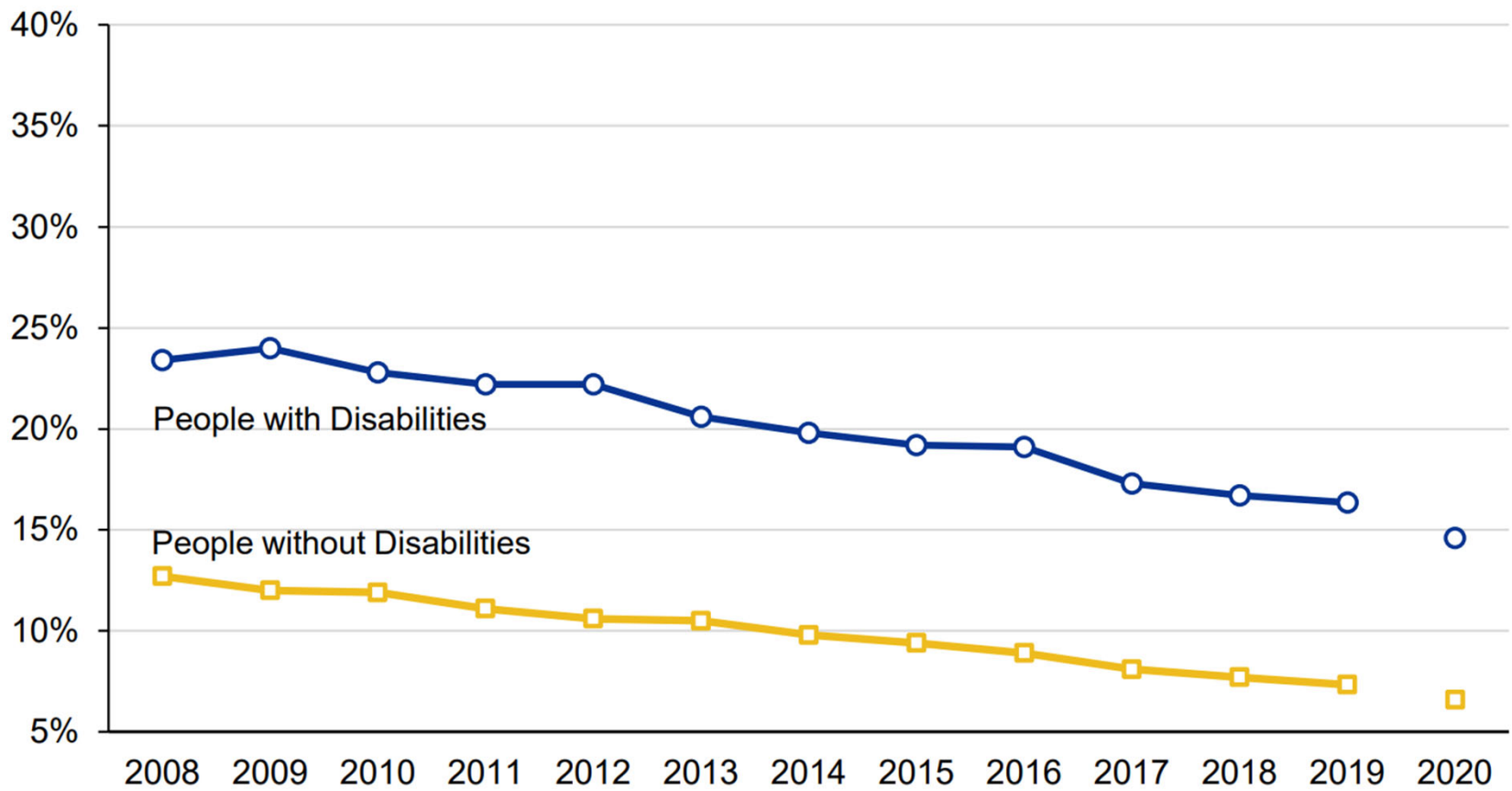




**Figure 7. Poverty Rate**



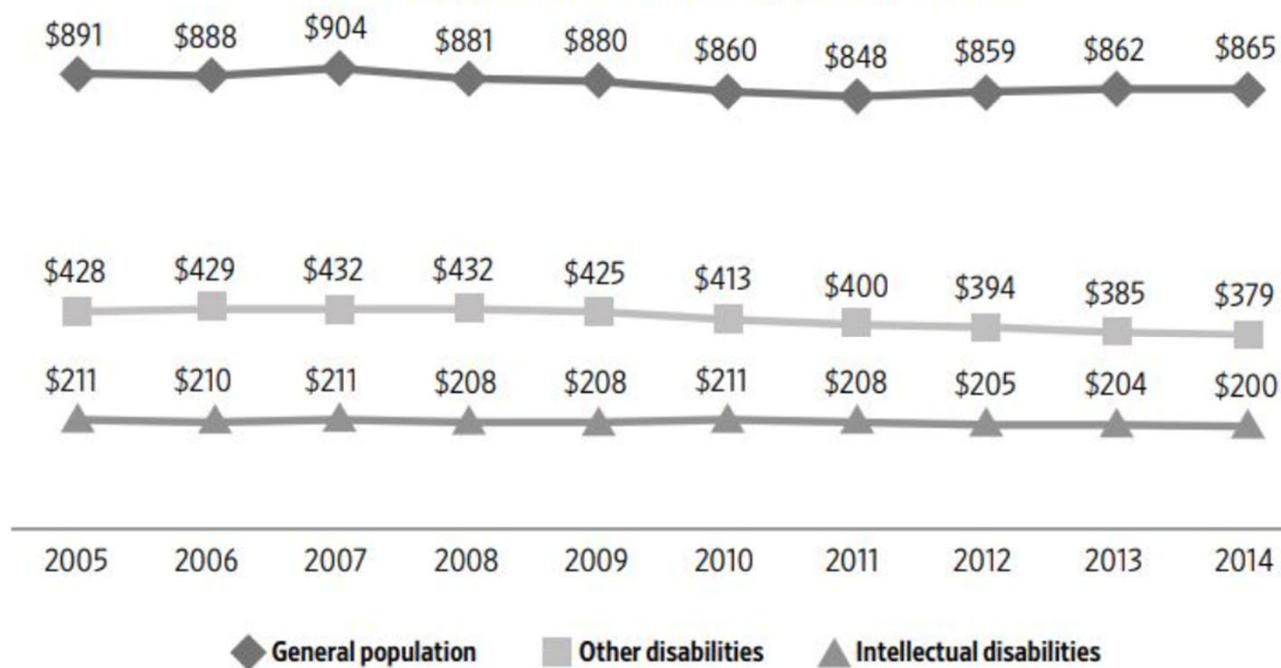
**Figure 3. Percent with Less High School Diploma**





# Subminimum Wage

Figure 6. Trends in Weekly Wages (in 2014 Dollars)\*



\* Earnings of the general population were computed by dividing the annual wages of civilians, ages 16–64, by 52 weeks, using data from the American Community Survey.



# The Overlooked Reality of Police Violence Against Disabled Black Americans

► LISTEN



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June 15, 2020

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# Our Legal Obligations

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# The Rehabilitation Act of 1973

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- Prohibits employers from discriminating against qualified individuals with disabilities in job application procedures, hiring, firing, advancement, compensation, job training, and other terms and conditions of employment including a request for a reasonable accommodation.
- Section 504 protects students with disabilities from discrimination by public schools, and by any college, trade school, or private school that gets federal funding



# Americans with Disabilities Act of 1990

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- ADA extends Section 504's protections to employers and to public spaces
- Civil rights protections
- Protects people with disabilities from discrimination by the government, schools, employers, and anyone who offers goods and services to the public

# Affordable Care Act of 2010

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- Section 1557 of the Affordable Care Act of 2010 prohibits discrimination on the ground of race, color, national origin, sex, age, or disability in certain health programs and activities
- Applies to any health program or activity, any part of which receives funding from the Department of Health and Human Services (HHS), such as hospitals that accept Medicare or doctors who receive Medicaid payments



# Health Inequities and Ableism in Medicine

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# Disability and Healthcare **ACCESS**



Healthcare access barriers for working-age adults include

**1 in 3**

adults with disabilities  
(18-44 years)

do not have a  
**usual healthcare  
provider**



**1 in 3**

adults with disabilities  
(18-44 years)

have an **unmet  
healthcare need  
because of cost**  
in the past year



**1 in 4**

adults with disabilities  
(45-64 years)

did not have a  
**routine check-up**  
in the past year







## Health Disparities by Disability Status

Health Care Access	Disability % (SE)	No disability % (SE)
Breast cancer screening (women 50-74 years, NHIS 2015)	65.8% (2.483)	72.2% (1.287)
Use of oral health care system in past year (2 years+, MEPS 2013)	37.1% (1.959)	44.4% (0.570)
Health Behaviors		
Meeting physical activity guidelines (18 years+, NHIS 2015)	9.6% (1.010)	23.6% (0.534)
Healthy weight (20 years+, NHANES 2013-14)	23.2% (1.886)	29.5% (0.955)
Current cigarette smokers (18 years+, NHIS 2015)	28.0% (1.547)	13.7% (0.409)



SOURCES: National Health Interview Survey (NHIS), CDC/NCHS;  
Medical Expenditure Panel Survey (MEPS), AHRO;  
National Health and Nutrition Examination Survey (NHANES), CDC/NCHS.

**Objs. C-17, OH-7, PA-2.4,  
NWS-8, TU-1.1**

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## DISABILITY

By Lisa I. Iezzoni, Sowmya R. Rao, Julie Ressler, Dragana Bolcic-Jankovic, Nicole D. Agaronnik, Karen Donelan, Tara Lagu, and Eric G. Campbell

# Physicians' Perceptions Of People With Disability And Their Health Care

**ABSTRACT** More than sixty-one million Americans have disabilities, and increasing evidence documents that they experience health care disparities. Although many factors likely contribute to these disparities, one little-studied but potential cause involves physicians' perceptions of people with disability. In our survey of 714 practicing US physicians nationwide, 82.4 percent reported that people with significant disability have worse quality of life than nondisabled people. Only 40.7 percent of physicians were very confident about their ability to provide the same quality of care to patients with disability, just 56.5 percent strongly agreed that they welcomed patients with disability into their practices, and 18.1 percent strongly agreed that the health care system often treats these patients unfairly. More than thirty years after the Americans with Disabilities Act of 1990 was enacted, these findings about physicians' perceptions of this population raise questions about ensuring equitable care to people with disability. Potentially biased views among physicians could contribute to persistent health care disparities affecting people with disability.



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UPDATES

MENU

CORONAVIRUS AND INEQUALITY

Published — April 8, 2020

## STATE POLICIES MAY SEND PEOPLE WITH DISABILITIES TO THE BACK OF THE LINE FOR VENTILATORS

Jayson Naana, a biotech technician with Cure Biomedical, tests ventilator functionality at Bloom Energy in Sunnyvale, Calif. (Beth LaBerge/KQED via AP, Pool)

INVESTIGATIONS

## Oregon Hospitals Didn't Have Shortages. So Why Were Disabled People Denied Care?

December 21, 2020 · 3:21 PM ET



JOSEPH SHAPIRO



7-Minute Listen

+ PLAYLIST



## People With High-Risk Disabilities Feel Left Out By California's Vaccine System

March 9, 2021 · 2:59 PM ET

Heard on [All Things Considered](#)

ADWOA GYIMAH-BREMPONG



3-Minute Listen

+ PLAYLIST





# TENNCARE ELIGIBILITY 101

WHAT DETERMINES WHO IS ELIGIBLE FOR MEDICAID IN TENNESSEE?

First, an individual must fall into one of the categories covered by TennCare.

Next, an individual must then meet household income limits specific to that category.



CHILDREN

250% of the federal poverty level (FPL)



PREGNANT WOMEN

NEWBORNS OF MEDICAID-ELIGIBLE WOMEN (ages 0-1): no income limit



PARENTS AND CARETAKER RELATIVES OF DEPENDENT CHILDREN

~80-101% FPL\*

TRANSITIONAL COVERAGE: 185% FPL



INDIVIDUALS WITH DISABILITIES AND INDIVIDUALS 65+

75% FPL



INDIVIDUALS IN NEED OF CARE TRADITIONALLY PROVIDED IN NURSING HOMES

225% FPL

100% FPL  
(about \$20,400 for a household of 3 in 2017)

200% FPL  
(about \$40,800 for a household of 3 in 2017)

\*Parent/caretaker eligibility depends on monthly income and family size.

Note: This information is not all-inclusive. Consult the Tennessee Division of Health Care Finance and Administration for comprehensive eligibility information.

THE SYCAMORE INSTITUTE | [SycamoreInstituteTN.org](http://SycamoreInstituteTN.org)



# Health First Colorado Buy-In Program For Working Adults With Disabilities

The Health First Colorado Buy-In Program for Working Adults with Disabilities lets adults with a disability who qualify to "buy-into" Health First Colorado (Colorado's Medicaid Program). If you work and earn too much to qualify for Health First Colorado you may qualify. If you qualify, you pay a monthly premium. Your monthly premium is based on your gross monthly earned and unearned income after any applicable disregards.

## Who qualifies?

- You must be between 16 or older,
- You must be employed,
- You must have a qualifying disability, either through Social Security or the State Disability Determination vendor, even if you are 65 or older. The [Social Security Administration \(SSA\) listings](#) describe what disabilities qualify, and
- Your income after disregards must be below 450% of the Federal Poverty Level (FPL). For example, you can earn about \$10,279 a month and qualify. You may have additional income that is disregarded.
- Applicants should always complete the [Health First Colorado Application](#) to find out if their income qualifies.

You are not required to apply for SSA disability. If you do not have a current disability determination from the Social Security Administration, fill out the [Health First Colorado Disability Application](#) and on the [How To Apply page](#). We will determine if you qualify using the [Social Security Administration \(SSA\) listings](#), without regard to your substantial gainful activity or your ability to work.



# What Can We Do?

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# We Must Be Anti-Ableist

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1. Learn about disability history and disability culture
2. Educate yourself and others on issues faced by the disability community
3. Become aware of barriers to access and equity
4. Work to eradicate barriers that create an inequitable experience
5. Follow the social model of disability
6. Challenge the representation of people with disabilities by non-disabled people
7. Avoid and call out inspiration porn
8. Recognize that people with disabilities are experts at developing workarounds for their disabilities
9. Follow identity-first language when requested, and people-first language otherwise



# We Must Practice and Teach Disability Accessible Care

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- Address curricular gaps with intentional course design
- Use disability inclusive language
- If someone comes into clinic recently discharged from acute rehab, what do we want to make sure we do and ask?
- If we transition people from pediatric complex care clinic, what are our responsibilities in that transition? How do we provide ongoing care?
- As people with disabilities get older, what do we have to think about?
  - Changes in guardianship and living situation as caregivers age
  - Contraception and reproductive health
  - Pregnancy and parenting
- Policies and social programs – Day programs, Medicaid waivers, Medicaid Buy-In, transportation options
- DME, Rehab services, bowel and bladder management, wound care
- Accessible exam rooms and equipment, hospital and clinic policies,
- Staff training – transfers, communication, cultural competency

# **We Must Document Patients' Disability and Accommodations**

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- No population health data available
- We cannot track clinical outcomes and disparities
- Cannot address intersectional disparities



# We Must Train and Employ Providers With Disabilities

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**“More than 20% of the American population lives with disability, but as few as 2% of practicing physicians do – and the vast majority acquire them after completing training.”**



## Health Equity Framework for People with Disabilities

February 2022

### Purpose

This Policy Brief provides rationale for the need of an all-of-government approach to achieve health equity in the United States and our territories for the largest unrecognized minority group in this country, the over 61 million people with disabilities, and sets forth a framework to achieve health equity for all people with disabilities. Disability is a natural part of the human condition, which occurs across all age, gender, racial, ethnic, language and social groups.

For purposes of this brief, NCD utilizes the definitions of “health disparity” and “health equity” as defined by the U.S. Department of Health and Human Services (HHS) Secretary’s Advisory Committee for Healthy People 2020.<sup>1</sup> Thus, as used herein “health disparities,” means health differences that adversely affect people with disabilities which are systemic (*i.e.*, not isolated or exceptional)<sup>2</sup> and plausibly avoidable (*i.e.*, not necessarily proving, but plausible that policies could reduce the disparities).<sup>3</sup> “Health equity,” as used herein is defined as the principle underlying the commitment to the attainment of the highest level of health for all people, which requires valuing everyone equally with focused and ongoing societal efforts to address avoidable inequalities, historical and contemporary injustices, and the elimination of health and healthcare disparities.<sup>4</sup>



# Resources for Building Cultural Competency

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- Andrews, E. E. (2019). *Disability as Diversity: Developing cultural competence*. Oxford University Press, USA.
- Disability Rights Education & Defense Fund. “Healthcare Access.” Available at: <https://dredf.org/healthcare-access/>
- Disability Visibility Project. Available at: <https://disabilityvisibilityproject.com/>
- Taussig, R. (2020). *Sitting Pretty: The View from My Ordinary Resilient Disabled Body*. Harper One.
- The Heumann Perspective Podcast. Available at: <https://podcasts.apple.com/us/podcast/the-heumann-perspective/id1558688277>
- Wong, A. (Ed.). (2020). *Disability visibility: First-person stories from the twenty-first century*. Vintage.
- Young, Stella. (2014). “I am not your inspiration, thank you very much.” *TED Talk*. Sydney, Australia. Available at: <https://youtu.be/8K9Gg164Bsw>

# Resources for Clinical Care

- 
- National Council on Disability. (2022). “Health Equity Framework.” Available at: <https://ncd.gov/publications/2022/health-equity-framework>
  - World Health Organization. (2011). “World report on disability.” Available at: <https://www.who.int/publications/i/item/9789241564182>
  - University of Michigan Resources, Protocols, Workflow, and Tip Sheets for Providers and Clinical Staff. Available at: <https://disabilityhealth.medicine.umich.edu/clinical/michart-disability-accommodations-tab/resources-protocols-workflow-tip-sheets-providers-clinic-staff>
    - Clinic Checklist at the bottom of the page
  - American Academy of Developmental Medicine & Dentistry (AADMD). Available at <https://www.aadmd.org>
  - Disability Competent Care. Available at: <https://hcpf.colorado.gov/disability-competent-care>
  - Disability Equity Collaborative. Available at: <https://www.disabilityequitycollaborative.org/>
  - Healthcare for Adults with Intellectual and Developmental Disabilities: Toolkit for Primary Care Providers. Available at: <https://iddtoolkit.vkcsites.org/>
  - Primary Care Providers – SCI Healthcare Resources. Available at: <https://asia-spinalinjury.org/primary-care/>
  - “Reproductive Healthcare for Women with Disabilities.” Available at: <https://www.aucd.org/docs/ncbddd/webinar/AUCD%20Presentation%20%206-16.pdf>
  - SUNY Upstate Medical University. Practical Recommendations for Enhancing the Care of Patients with Disability Modules 1-3. Available at: <https://www.upstate.edu/pmr/education/disability/>