

# Addressing Ableism in Medicine

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By Alicia Wong, MD, MPH, MA

# 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

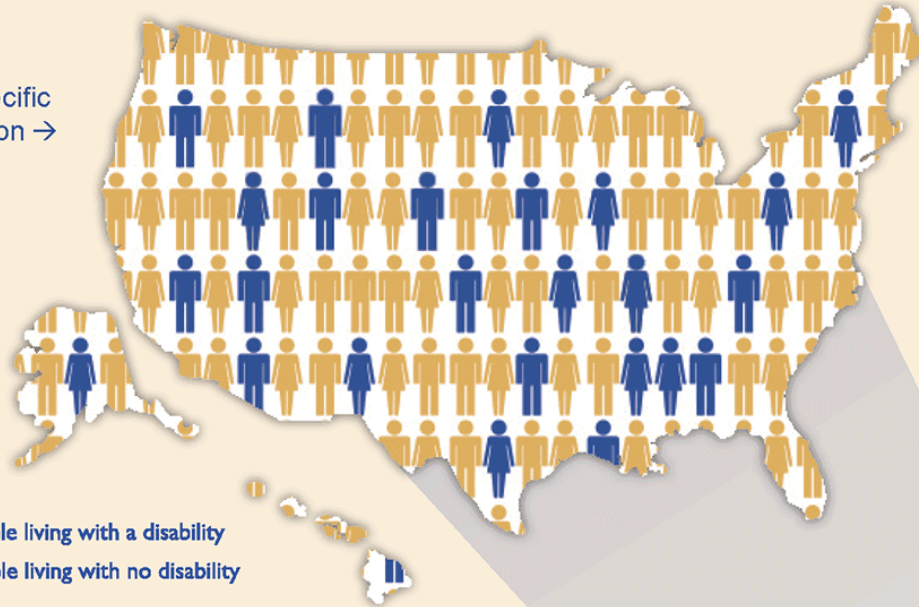


ACCESS



61 million adults in the United States live with a disability

Click for  
state-specific  
information →



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

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



# ABLEISM

a·ble·ism \ 'ābə-li-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.

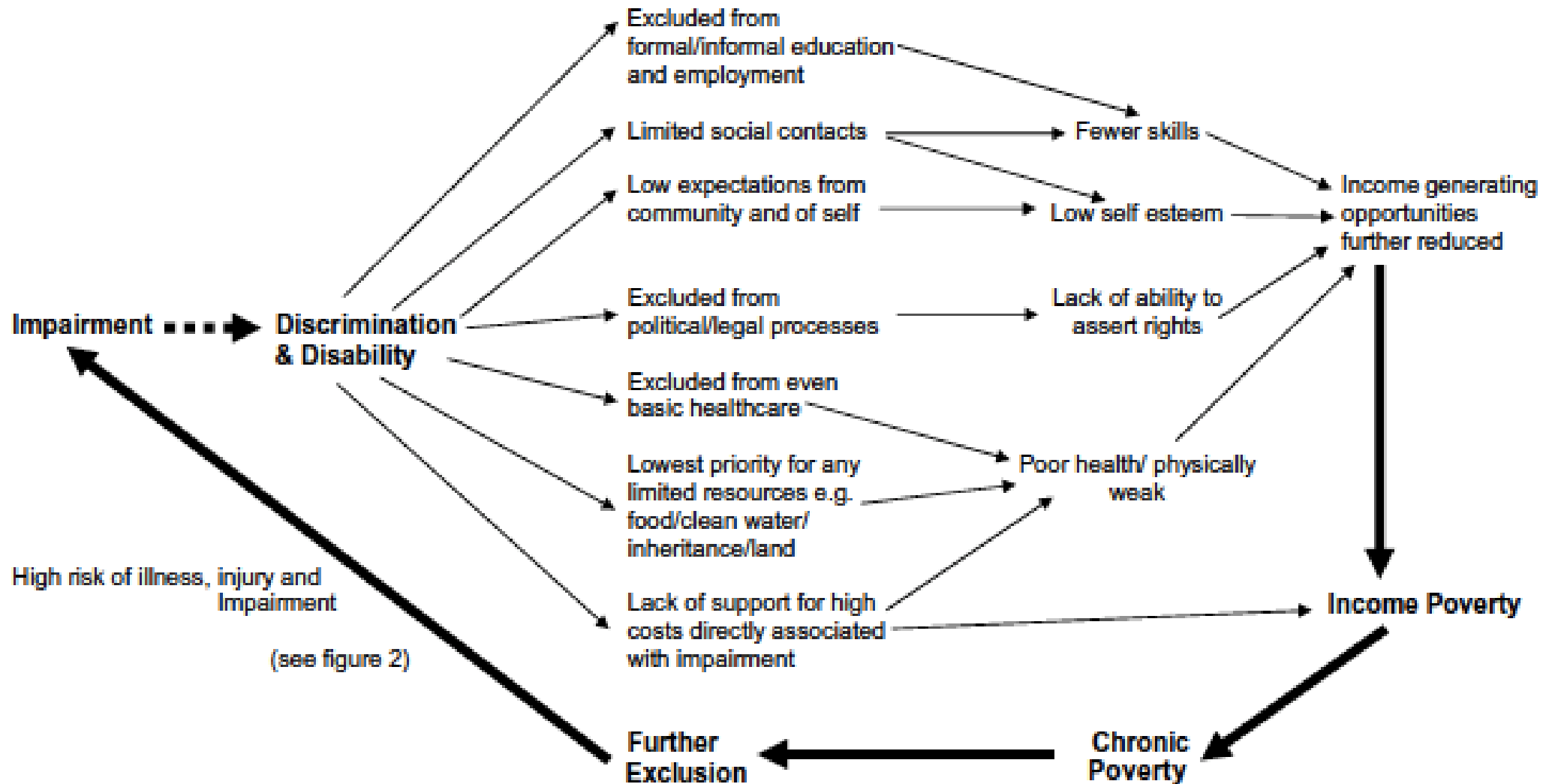
a working definition by Talila "TL" Lewis\*; updated January 2021

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

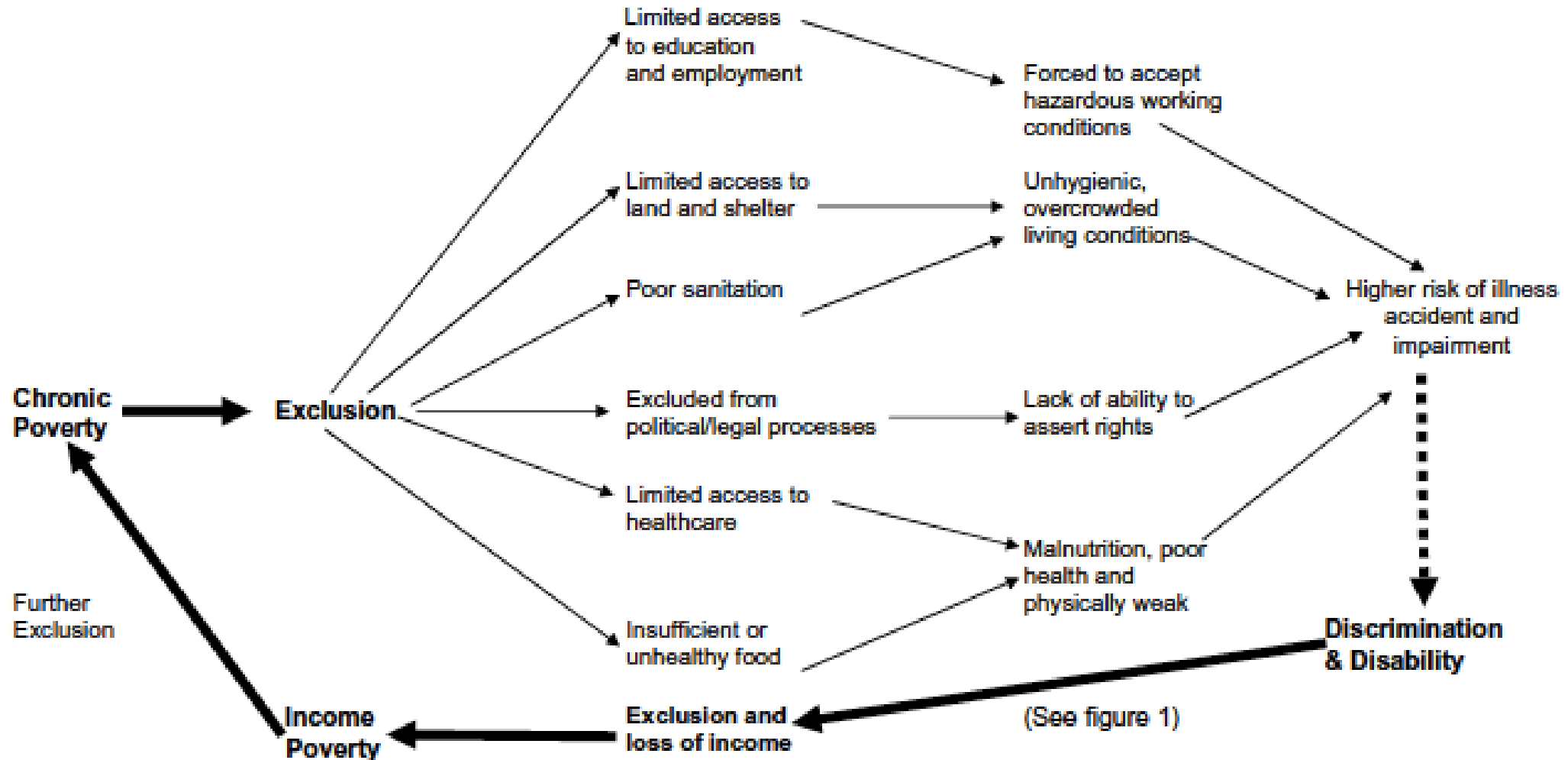
**“One cannot be antiracist while still being ableist [...] because I think for many people who are indeed striving to be antiracist, they may not realize the ways in which they’re still being prevented from moving along on this journey due to their unacknowledged or unrecognized ableism”**

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

# Disability → Poverty Cycle

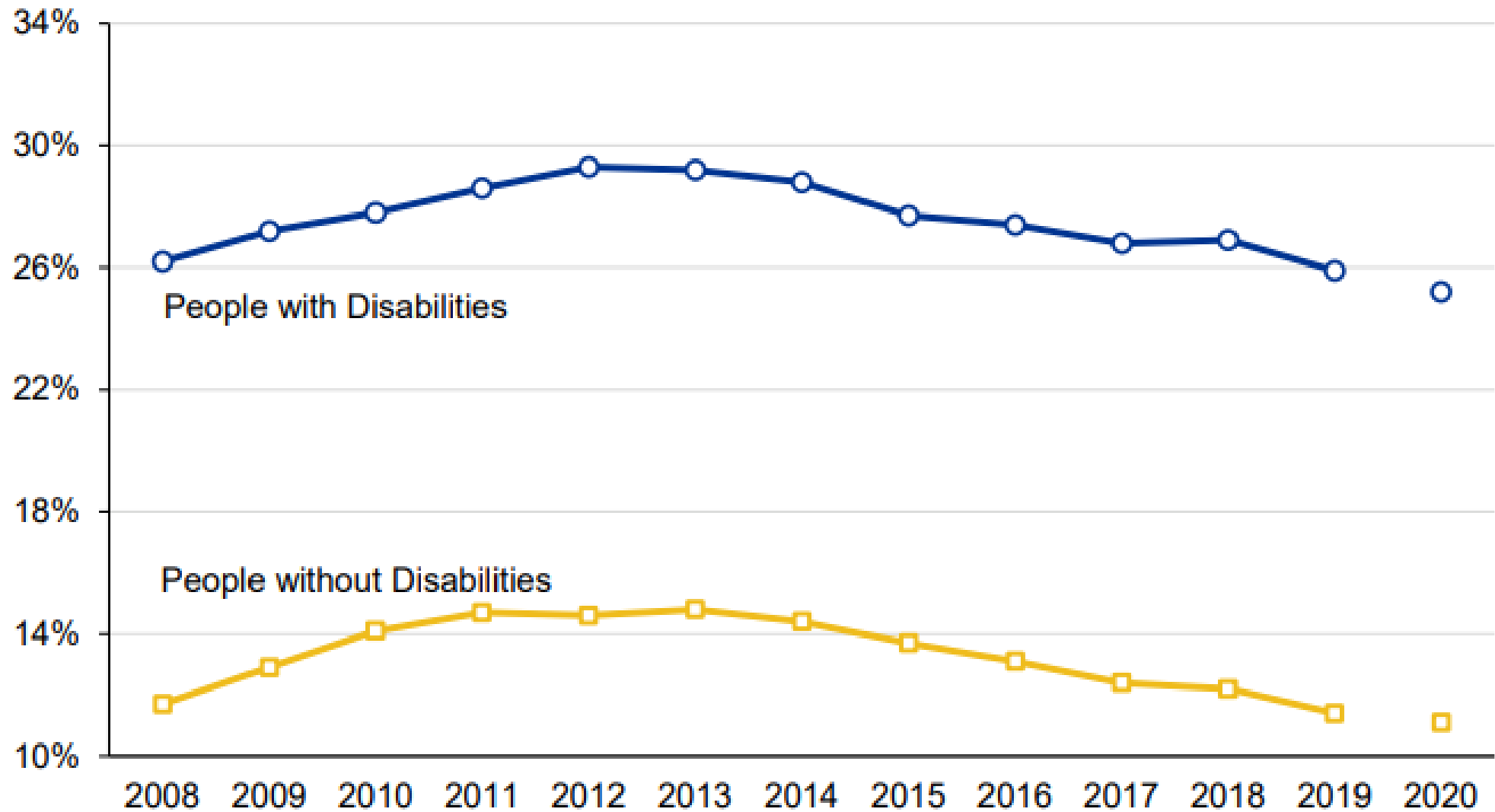


# Poverty → Disability Cycle

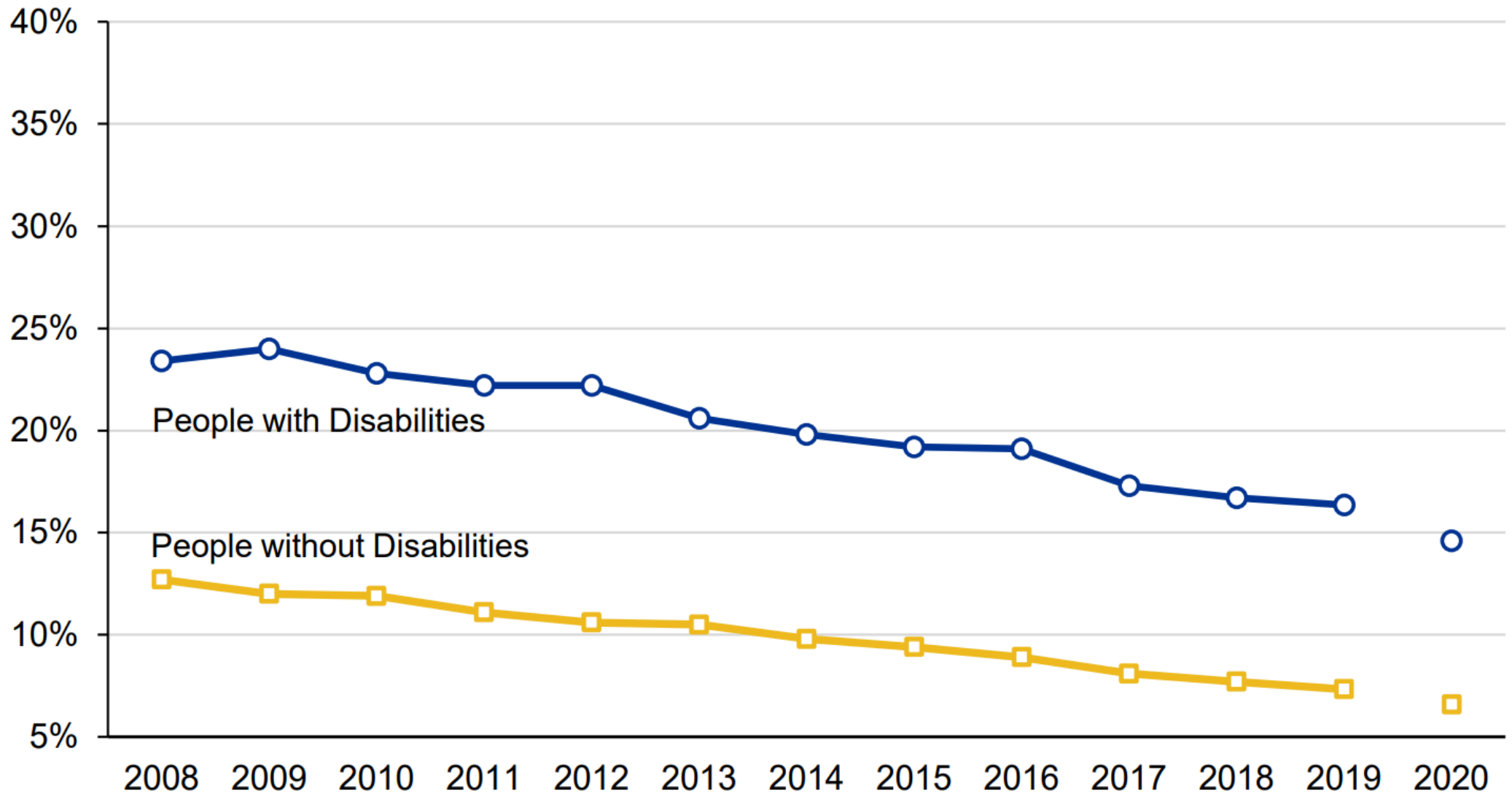




**Figure 7. Poverty Rate**

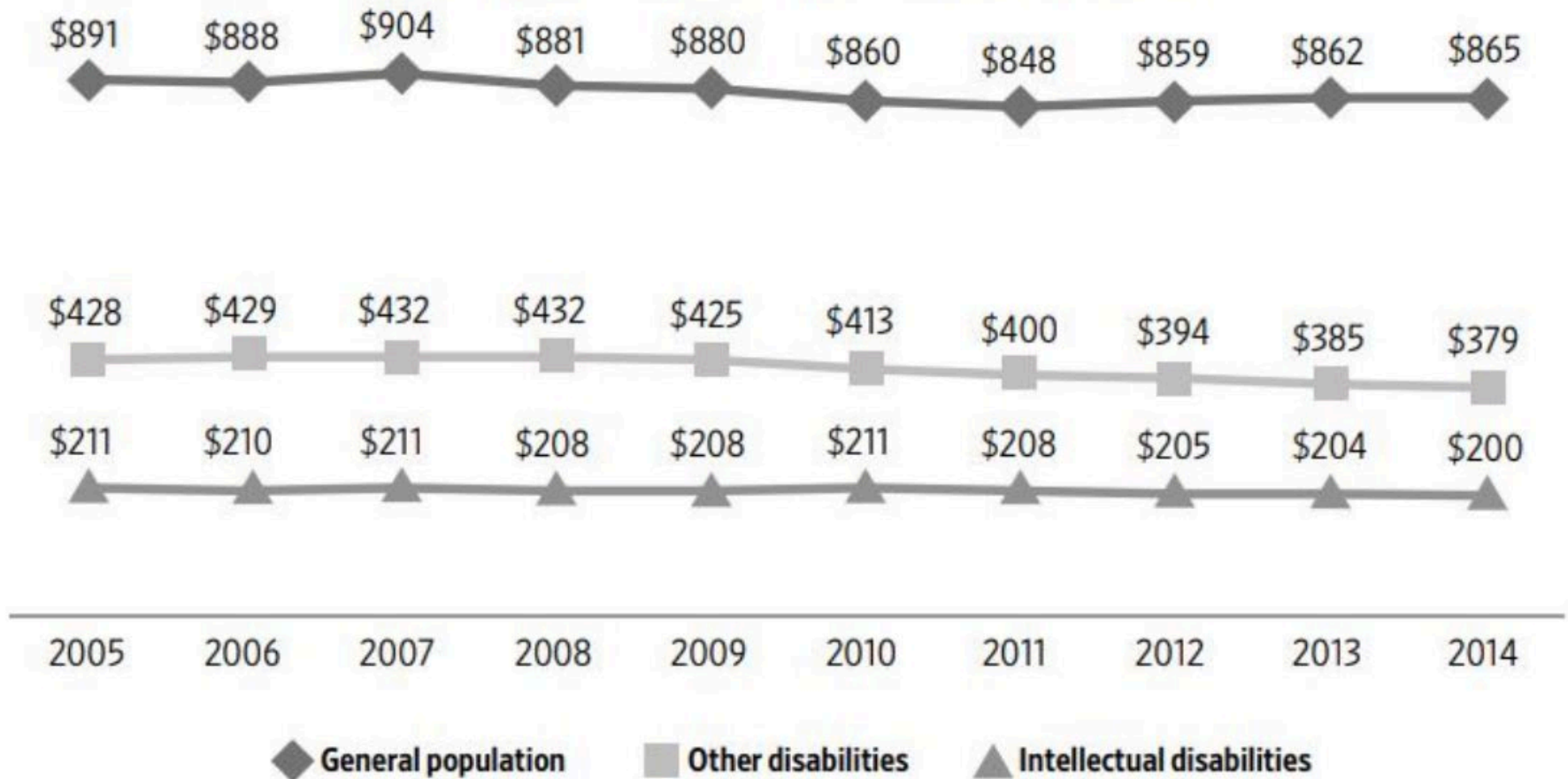


**Figure 3. Percent with Less High School Diploma**



# 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.



LISTEN FOR FREE

SUPPORT US

# The Overlooked Reality of Police Violence Against Disabled Black Americans

▶ LISTEN

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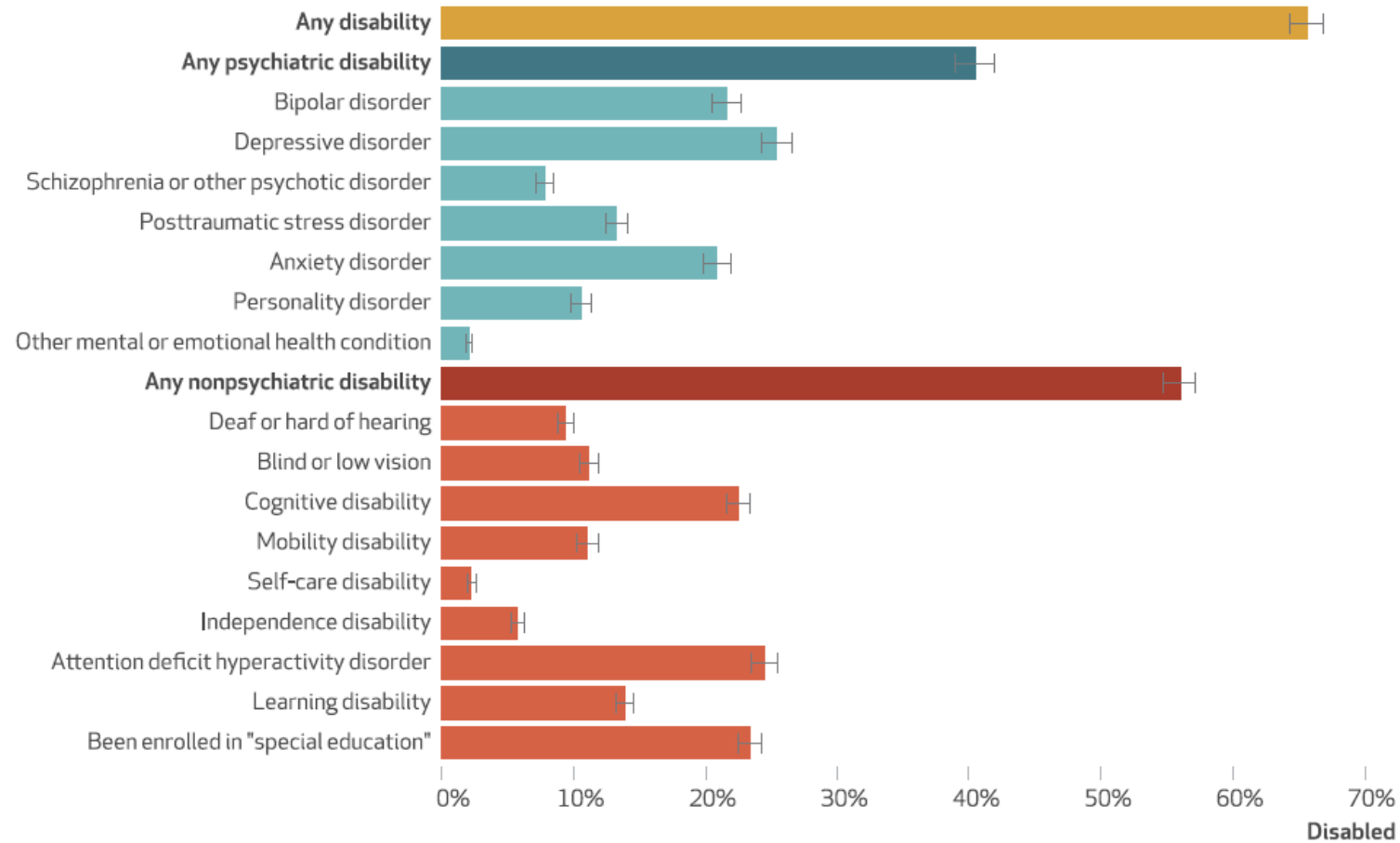
June 15, 2020

Share



**EXHIBIT 1**

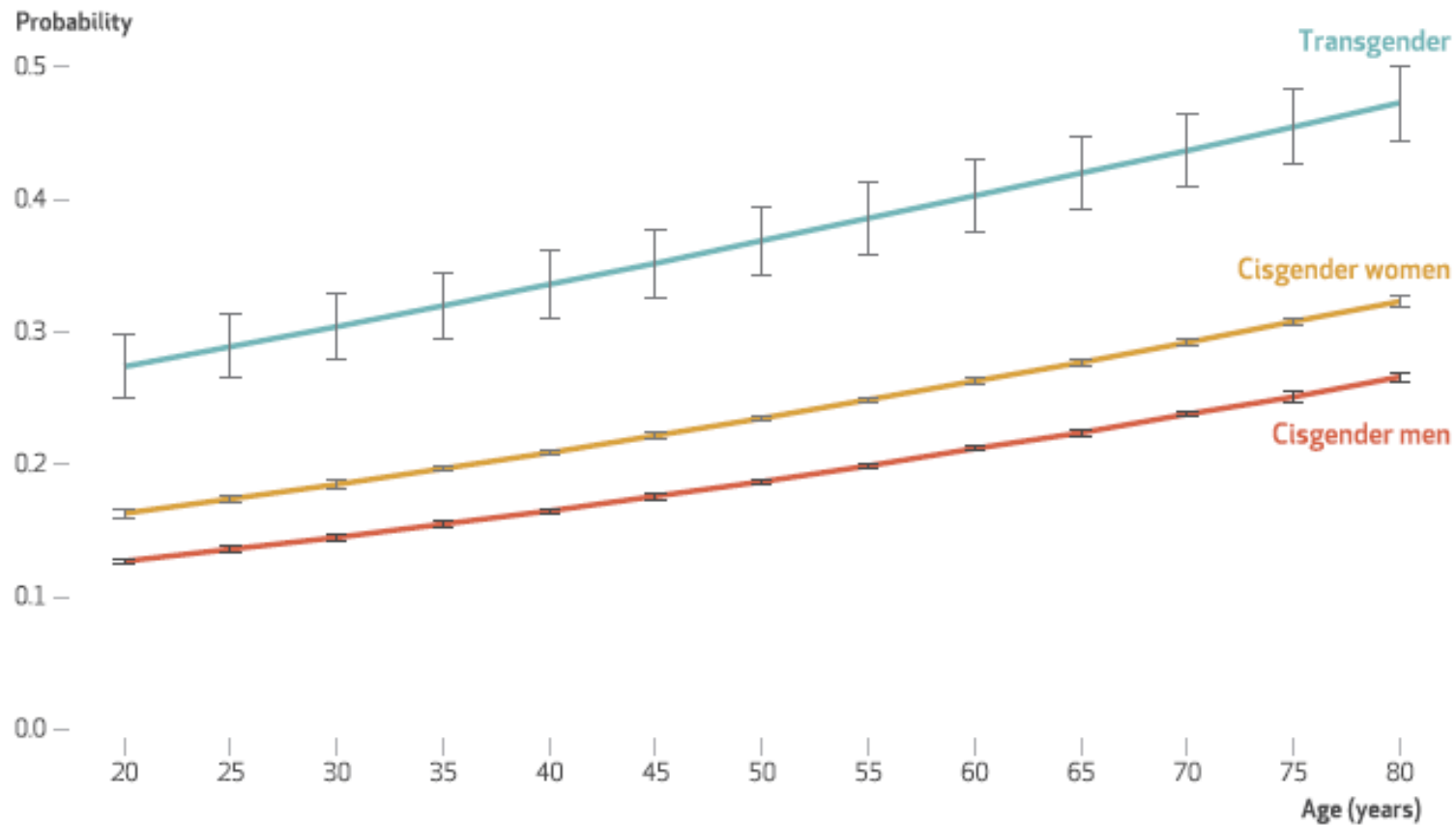
**Disability prevalence among people incarcerated in state or federal prisons in the US, by disability type, 2016**



**SOURCE** Authors' analysis of data from the Bureau of Justice Statistics, Survey of Prison Inmates (SPI), 2016. **NOTES** N = 22,660. Estimates reflect the proportion of people in state and federal prisons who reported various disability types. The "any disability" category includes anyone who reported either a psychiatric or a nonpsychiatric disability. The SPI survey questions are in the appendix (see note 17 in text).

**EXHIBIT 4**

**Adjusted probability of reporting at least one disability among US adults, by age and gender, 2014-20**



**SOURCE** Author's analysis of data from the Behavioral Risk Factor Surveillance System, 2014-20. **NOTES** The probabilities are weighted. Sample sizes are in the exhibit 1 notes. The model controls for continuous age (within age groups), partnership status, racial minority status, sexual orientation, insurance status, employment, annual household income, educational attainment, current smoker status, heavy drinking, and obesity. Whiskers represent 95% confidence intervals. Confidence intervals for cisgender men and women were all 0.004 or less in both directions. Missing data were imputed using chained equations.

# 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

## ADA Amendments Act of 2008

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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

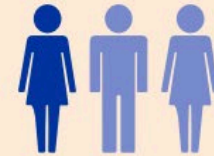


Healthcare access barriers for working-age adults include

**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)

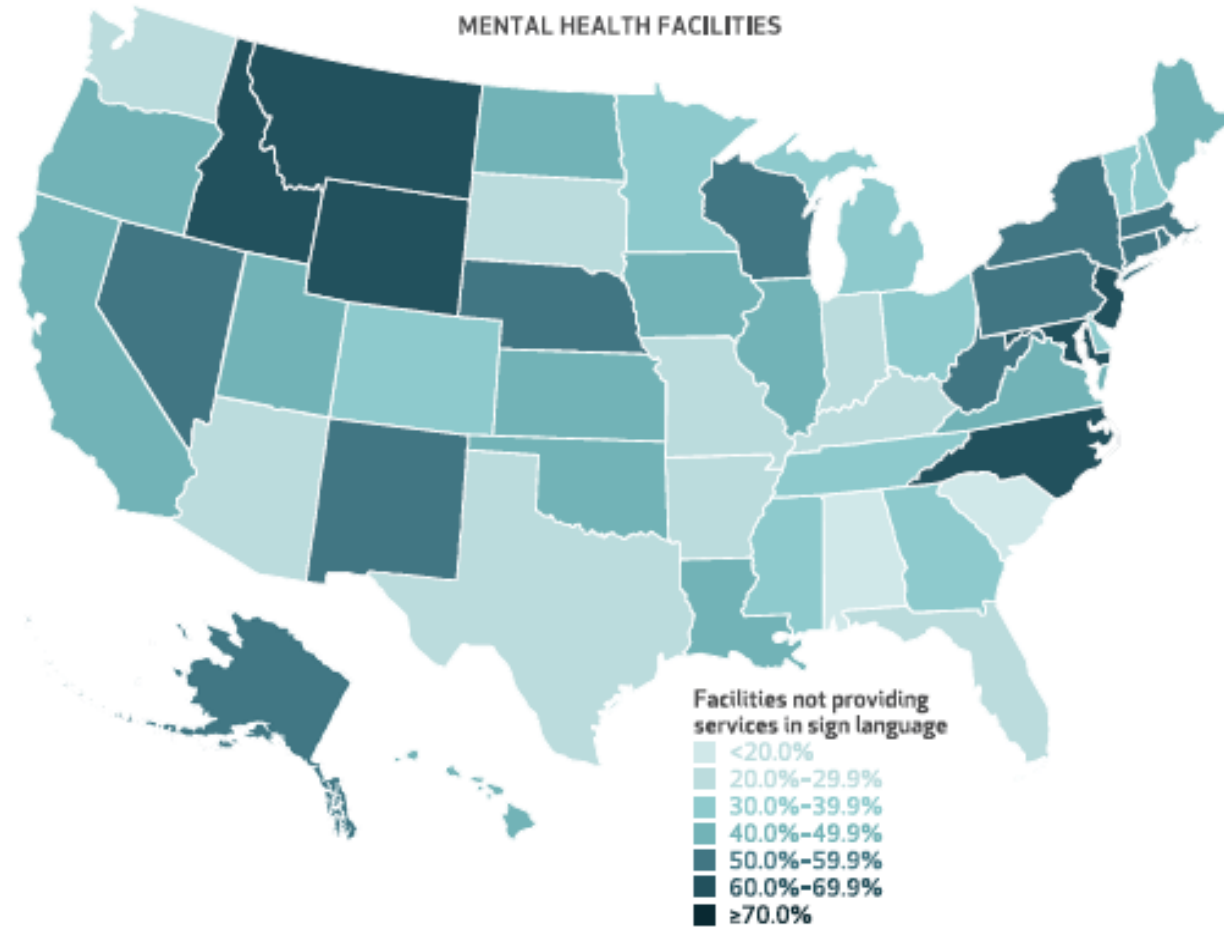


SOURCES: National Health Interview Survey (NHIS), CDC/NCHS;  
 Medical Expenditure Panel Survey (MEPS), AHRQ;  
 National Health and Nutrition Examination Survey (NHANES), CDC/NCHS.

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

**EXHIBIT 2**

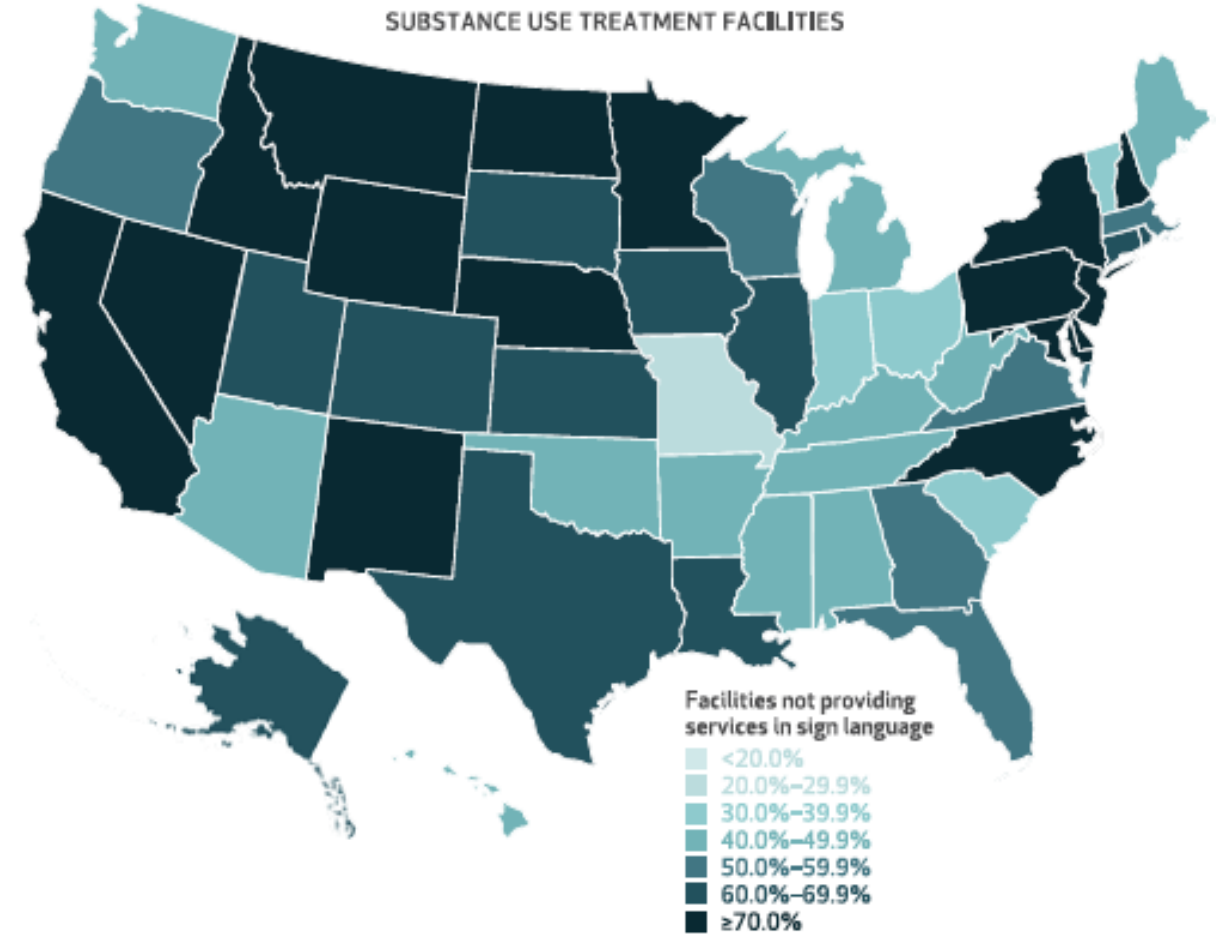
Prevalence of mental health facilities in the US that are covered entities under Section 1557 of the Affordable Care Act but do not provide services in sign language to Deaf and hard-of-hearing patients, 2019



**SOURCE** Authors' analysis of survey data from the 2019 National Mental Health Services Survey administered by the Substance Abuse and Mental Health Services Administration. **NOTES** Puerto Rico not shown because of mapping constraints; its noncompliance level was 39 percent. Map developed using the website Datawrapper.

**EXHIBIT 3**

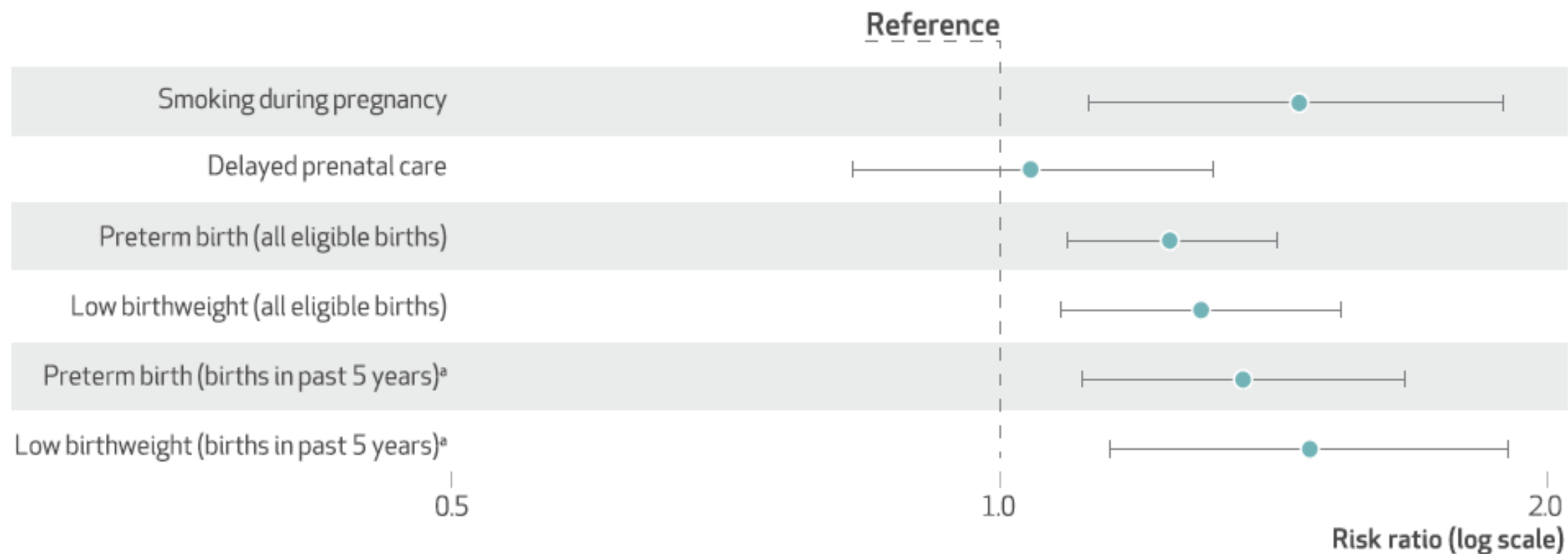
Prevalence of substance use treatment facilities in the US that are covered entities under Section 1557 of the Affordable Care Act but do not provide services in sign language to Deaf and hard-of-hearing patients, 2019



**SOURCE** Authors' analysis of survey data from the 2019 National Survey of Substance Abuse Treatment Services administered by the Substance Abuse and Mental Health Services Administration. **NOTES** Puerto Rico not shown because of mapping constraints; its non-compliance level was 67 percent. Map developed using the website Datawrapper.

### EXHIBIT 3

## Adjusted relative risk of prenatal health risks and adverse pregnancy outcomes for births to women with disabilities who participated in the National Survey of Family Growth between 2011 and 2019



**SOURCE** Authors' analysis of data from the National Survey of Family Growth, 2011–19. **NOTES** Whiskers represent 95% confidence intervals. Data on prenatal care and smoking during pregnancy were only available for births in the past 5 years. Reference category is women without disabilities. <sup>a</sup>Sensitivity analysis results.

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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**Analytic themes illustrating barriers to caring for people with disabilities, with selected responses, from physician focus groups, fall 2018****Themes and selected responses****PHYSICAL ACCOMMODATIONS**

We have issues with power chair or wheelchair patients who couldn't come in the front door; we had to make a ramp in the back entrance of the clinic so they come through the back door.

I think our [medical assistants] just put wheelchair "w/c" and the weights don't get checked until someone makes a big deal about it, and the argument is same: "it's not safe."

**COMMUNICATION ACCOMMODATIONS**

I use paper and pen. And most of my patients have hearing aids that are not working... It's just better to use paper and pen, sometimes it's just better, because with HIPAA, when they're yelling and you are yelling, the whole office can hear you yelling.

**KNOWLEDGE, EXPERIENCE, AND SKILLS**

Durable medical equipment, that's a very big barrier. And not even knowing myself what would be the best kind of care, the best equipment for them, I don't even know, I'm not even qualified.

**STRUCTURAL BARRIERS**

Seeing patients at a 15-minute clip is absolutely ridiculous. To have someone say, well we're still going to see those patients with mild to moderate disability in those timeframes—it's just unreasonable and it's unacceptable to me. But training [to address problems common for people with mild to moderate disability] would help.

I have, like, 18 pages of [disability] documentation—of which 1 paragraph is essential and necessary for me to care for the patient.

Coordination of care becomes a huge challenge and barrier. Our institution is trying to get social workers in our office to do some of this legwork. There's financial and space constraints that limit that, too, but we're looking for solutions to be able help coordinate for care these patients with special needs because they are a unique population that require a unique set of interventions.

**ATTITUDES TOWARD PEOPLE WITH DISABILITIES**

We've gotten to a point in society where a lot of people are wanting some form of accommodation and a lot are illegitimate. They want their pet peacock on the airplanes and whatnot, and it makes it very difficult.

We remind the residents that the relationship is with the patient, and the guardian is there facilitating that relationship. But we kind of wanted to keep them focused on the fact that you are dealing with a living breathing human, regardless of the fact that you are communicating everything that needs to be communicated.

**KNOWLEDGE OF THE ADA**

I truthfully think the [Americans with Disabilities] Act makes the disabled person more of a target and doesn't help them but hurts them. Because a lot of us, me personally, are afraid to treat them... so I look at it as not [a] helpful act but I look at it as a hurtful act. Because all of us, even in this discussion, well, we are afraid of this, we're afraid of that... You just don't want to deal with them, and that's what the [ADA] is all about.

I think we're pretty open as sitting ducks for lawsuits if we try to get rid of a patient with disabilities because they can turn around and say that it was discrimination.

CORONAVIRUS AND INEQUALITY

Published — April 8, 2020

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



Jayson Naona, 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



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)

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



PREGNANT WOMEN

195% FPL



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.



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# 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 biopsychosocial 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, lab, pharmacy
- 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 identify disparities
- We cannot identify and address intersectional disparities



## 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>

# 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.”**

**EXHIBIT 1****Percent of surveyed physicians who experienced mistreatment at least once from coworkers or patients during the previous 12 months, by type of mistreatment and disability status, 2019**

Types of mistreatment	Coworkers <sup>a</sup>		Patients	
	Physicians without disabilities	Physicians with disabilities	Physicians without disabilities	Physicians with disabilities
Subjected to offensive sexist remarks	12.1%	27.1%	18.1%	35.8%
Subjected to racially or ethnically offensive remarks	11.8	28.4	21.3	33.3
Subjected to offensive remarks or names related to sexual orientation	5.3	23.1	6.1	22.6
Subjected to offensive remarks or names related to a disability	3.5	28.7	3.8	28.7
Subjected to offensive remarks or names based on your personal beliefs	10.6	24.5	13.5	27.8
Threatened with physical harm	4.8	27.6	22.6	39.9
Physically harmed	1.8	24.6	5.3	26.3
Subjected to unwanted sexual advances	7.5	31.3	16.4	39.9

**SOURCE** Authors' analysis using data from the 2019 National Sample Survey of Physicians, developed by the Association of American Medical Colleges. **NOTES** For physicians without disabilities,  $n = 5,673$ ; for physicians with disabilities,  $n = 178$ . The unweighted count of physicians reporting disability was 169, but after the sampling weights were applied (necessary for proper representation of the study population), the weighted count is 178. The counts do not sum to 6,000 (the size of the data source sample) because in 149 cases, a value was missing for the disability variable. <sup>a</sup>Includes supervisors, other health care professionals, residents, fellows, interns, and other institution employees or staff. Respondents were provided with the ADA Amendments Act of 2008 definition of *disability* (see note 28 in text) and asked, "Do you have a disability as defined by the [Americans with Disabilities Act]?"

“There’s something unsettling about offering accommodations for an ‘exceptional’ body when the entire system surrounding that body is built on the assumption that more and faster and harder and higher is fundamentally, inherently superior. When you applaud your employees only for arbitrary measurement of work – arriving early, leaving late, never taking sick days or time off, or showing up on the weekend – when you always push for more – [...] you do not demonstrate an appreciation for those who have a need, who say no, enforce boundaries, or require flexibility – the very stuff of accommodations masked under different names.”

- Rebekah Taussig, *Sitting Pretty: The View From My Ordinary Resilient Disabled Body*

# Resources at Denver Health

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- Dr. Patricia Meyer: family medicine physician who runs the SCI Clinic at Primary Care Center ([patricia.meyer@dhha.org](mailto:patricia.meyer@dhha.org); 303-602-8270)
- Dr. Alicia Wong: family medicine physician who works at the SCI Clinic at Primary Care Center and sees patients with disabilities ([Alicia.wong@dhha.org](mailto:Alicia.wong@dhha.org); 303-602-8270)
- Dr. Barry Martin: family medicine physician who sees patients at the Down Syndrome Clinic at Pena ([barry.martin@cuanschutz.edu](mailto:barry.martin@cuanschutz.edu))
- Dr. Nicholas Breitnauer: med-peds physician who sees patients at the Down Syndrome Clinic at Pena
- Dr. Vera Staley ([vera.staley@dhha.org](mailto:vera.staley@dhha.org)) : PM&R physician – adult outpatient and inpatient consult
- Dr. Gina Signoracci: Rehab psychologist ([gina.signoracci@dhha.org](mailto:gina.signoracci@dhha.org))
- Billy Morrison: RN manager for the DH SCI Clinics and Down Syndrome Clinics ([billy.Morrison@dhha.org](mailto:billy.Morrison@dhha.org))
- Referral to Primary Care Spinal Cord Injury Clinic
- E-Consult Wound Care or contact Misty (Merrietta) Novak

# Resources at UCH and CHCO

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- Dr. Jessica Solomon Sanders: specialist in neurodevelopmental disabilities at UCH (Central Park Neurology clinic, 720-848-2828)
- Dr. Daniel Wood: urologist at CHCO who sees adults with disabilities and leads transition care for surgery at CHCO
- Dr. Michael Puente: Pediatric Ophthalmologist who started seeing adult patients at UCH and is planned to start seeing patients at DH next year
- Dr. Eleanor Floyd: med/peds specialist in care of adults with medical complexity and developmental disabilities (720-777-3999)
- Dr. Laura Pickler: family medicine doc who runs the GI feeding program at CHCO
- Dr. Cristina Sarmiento: PM&R specialist who is starting a cerebral palsy clinic at UCH (Central Park Foot and Ankle)
- Dr. Barry Martin: family medicine doc who sees adults with developmental disabilities at UCH
- Dr. Laura Pickler: family medicine doc who runs the GI feeding program at CHCO



University of Colorado **Anschutz Medical Campus**

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**Schedule an appointment**

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# Resources for Clinical Care and Policy

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- 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>
- Disability & Health Issues (October 2022). *Health Affairs*: Vol. 41, No 10. Available at <http://www.healthaffairs.org>
- 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/>

# 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/>
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