Access to Health Care for People with Disabilities

ELIZABETH PENDO
Kellye Y. Testy Professor of Law
Senior Associate Dean for Academic Affairs
University of Washington School of Law
ependo@uw.edu | Faculty Profile

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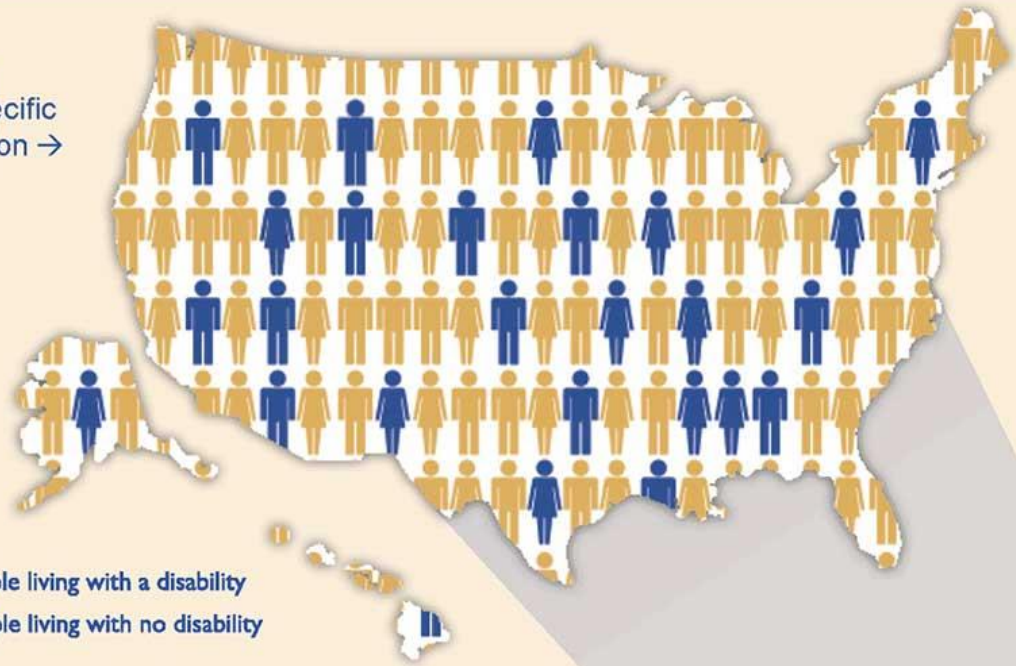
Disability Impacts ALL of US

COMMUNITIES HEALTH ACCESS

61 million adults in the United States live with a disability

Click for state-specific information →



People living with a disability

People living with no disability

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

Living With Disabilities

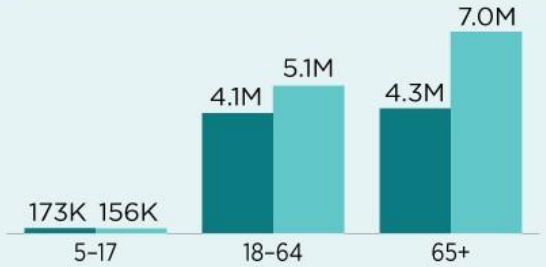
Number of Americans With a Disability by Age, Sex, and Disability Type

Male Female

K = Thousands M = Millions

HEARING difficulty

AMBULATORY difficulty



VISION difficulty

SELF-CARE difficulty

COGNITIVE difficulty

INDEPENDENT LIVING difficulty

* Data not collected for this age group.

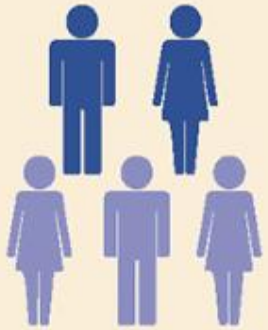
United States® Census Bureau

U.S. Department of Commerce
U.S. CENSUS BUREAU
census.gov

Source: 2019 American Community Survey, 1-year estimates, <www.census.gov/programs-surveys/acs>

Disability is especially common in these groups:

2 in 5 adults age 65 years and older have a disability



1 in 4 women have a disability

2 in 5 Non-Hispanic American Indians/ Alaska Natives have a disability

Social Determinants of Health

- lower levels of education
- lower rates of employment among those seeking jobs
- higher rates of poverty and food insecurity
- problems finding safe, affordable, and accessible housing and transportation
- higher likelihood of being victims of crime

Health and Health Care Disparities

- Higher rates of chronic conditions
- More likely to go without needed care
- Lower rates of preventative care, including high-value cancer screenings
- Lower rates of care related to sexuality and reproduction
- Lower quality pre-natal care

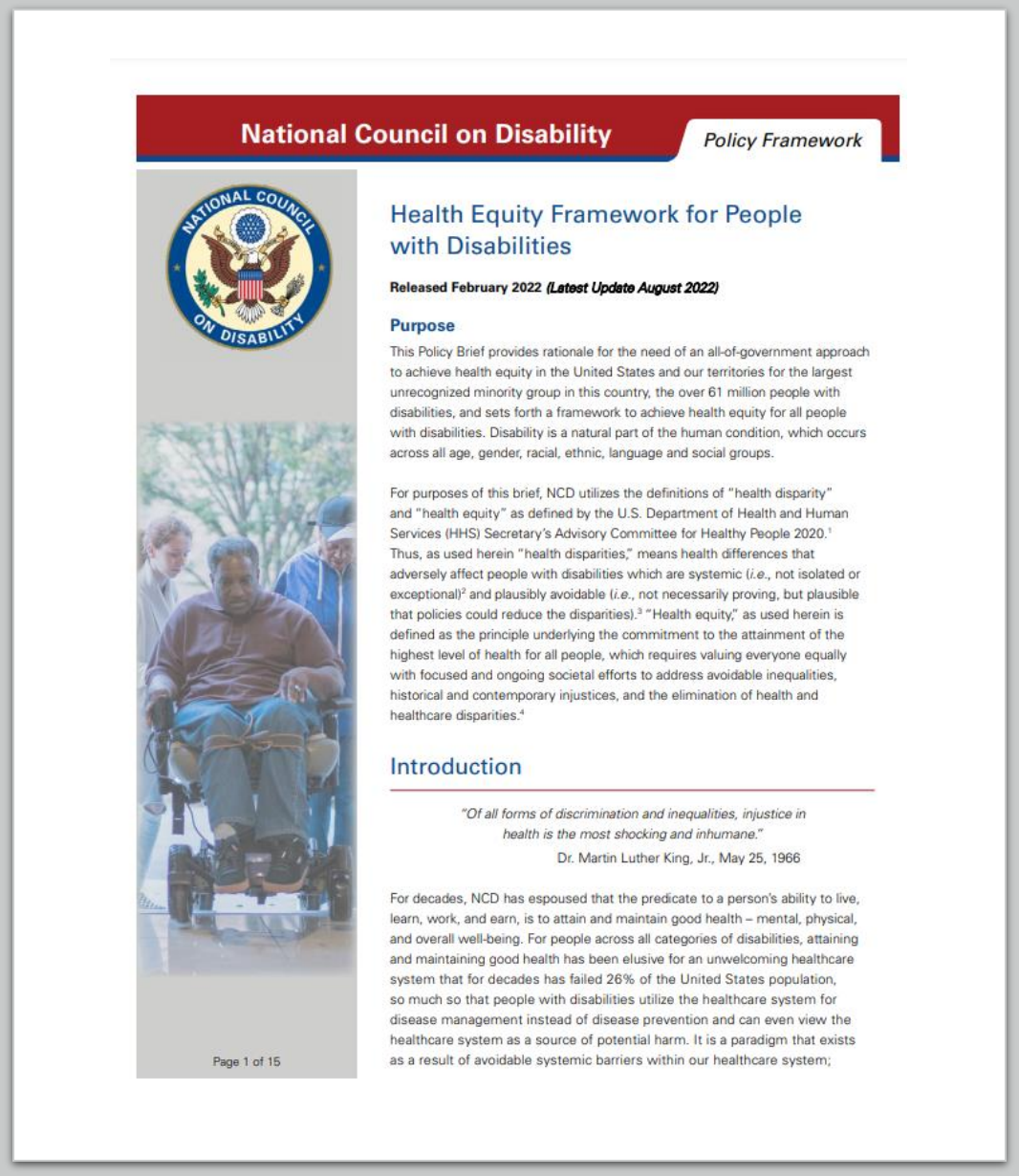
Barriers to Health Care

- Health insurance
- Transportation
- Communication barriers and lack of accommodations
- Physical barriers in offices and facilities
- Inaccessible medical equipment
- Stereotypes about disability

5 Core Components

1. PWD as Special Medically Underserved Population
2. PWD as a Health Disparities Population
3. Comprehensive disability clinical-care curricula
4. Accessible medical diagnostic equipment
5. Improved data collection

38 Add'l Components



National Council on Disability — *Policy Framework*

Health Equity Framework for People with Disabilities

Released February 2022 ***(Latest Update August 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.[1] Thus, as used herein "health disparities," means health differences that adversely affect people with disabilities which are systemic (*i.e.*, not isolated or exceptional)[2] and plausibly avoidable (*i.e.*, not necessarily proving, but plausible that policies could reduce the disparities).[3] "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.[4]

Introduction

"Of all forms of discrimination and inequalities, injustice in health is the most shocking and inhumane."

Dr. Martin Luther King, Jr., May 25, 1966

For decades, NCD has espoused that the predicate to a person's ability to live, learn, work, and earn, is to attain and maintain good health – mental, physical, and overall well-being. For people across all categories of disabilities, attaining and maintaining good health has been elusive for an unwelcoming healthcare system that for decades has failed 26% of the United States population, so much so that people with disabilities utilize the healthcare system for disease management instead of disease prevention and can even view the healthcare system as a source of potential harm. It is a paradigm that exists as a result of avoidable systemic barriers within our healthcare system;

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6 Health Disparities

1. Disability data gaps
2. Accessible communication
3. Physical access to care
4. Disability competence training
5. Home and Community Based Services
6. Nondiscriminatory private health insurance benefit design

DISABILITY

By Lisa I. Iezzoni, Michael M. McKee, Michelle A. Meade, Megan A. Morris, and Elizabeth Pendo

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OVERVIEW

Have Almost Fifty Years Of Disability Civil Rights Laws Achieved Equitable Care?

ABSTRACT **For almost fifty years, federal civil rights laws such as Section 504 of the Rehabilitation Act of 1973, the Americans with Disabilities Act (ADA) of 1990 and the ADA Amendments Act of 2008, and Section 1557 and other provisions of the 2010 Patient Protection and Affordable Care Act have prohibited discrimination against Americans with disabilities, including in health care. Despite these laws, disabled Americans continue to experience disparities in health and health care, from preventive care to home and community-based services. In its 2022 *Health Equity Framework for People with Disabilities*, the National Council on Disability highlighted some of these disparities and recommended remedies. To explore these concerns, this article examines disability inequities and potential solutions within six areas. It concludes by recommending the ratification of the 2006 United Nations Convention on the Rights of Persons with Disabilities to reinvigorate US efforts to maximize the health and dignity of disabled Americans and support their full participation in the community.**

Lisa I. Iezzoni (liezzoni@mgh.harvard.edu), Harvard University and Massachusetts General Hospital, Boston, Massachusetts.

Michael M. McKee, University of Michigan, Ann Arbor, Michigan.

Michelle A. Meade, University of Michigan, Ann Arbor.

Megan A. Morris, University of Colorado, Aurora, Colorado.

Elizabeth Pendo, Saint Louis University, St. Louis, Missouri.

In its February 2022 *Health Equity Framework for People with Disabilities*, the National Council on Disability (NCD) called for "an all-of-government approach to achieve health equity...for the largest unrecognized minority group in this country, the over 61 million people with disabilities."[1] The NCD summarizes diverse and persistent disparities in health and health care affecting Americans with disabilities, noting that systemic barriers within US health care cause these shortfalls. Advancing equity for people with disabilities, it asserts, therefore requires fundamental changes and ongoing societal commitments across all public and private health care sectors.[1]

The enduring health and health care disparities disadvantaging Americans with disabilities[2] are discouraging, given the nearly half-century of civil rights laws intended to achieve equity for disabled people. Section 504 of the Rehabilitation Act of 1973 requires that programs receiving federal funds, including Medicare and Medicaid, ensure equitable access for disabled Americans. The Americans with Disabilities Act (ADA) of 1990 and the ADA Amendments Act of 2008, which clarified definitions of *disability*, extended these civil rights protections to other public and private settings and services. Section 1557 of the 2010 Patient Protection and Affordable Care Act (ACA) amended Section 504 of the Rehabilitation Act and several other statutes to provide additional protections against disability discrimination in health care services. Nevertheless, disabled Americans experience disparities and inadequate services across the health care continuum, from preventive care to home and community-based services.[1,2]

This article highlights six areas with persistent health and health care inequities for disabled Americans and suggests potential remedies: disability data gaps, accessible communi-

Disability Laws

- Section 504 of the Rehabilitation Act of 1973, which requires programs receiving federal funds to ensure equal access for disabled people
- The Americans with Disabilities Act of 1990 (ADA) ,and 2008 ADA Amendments Act which clarified definitions of disability, extends these civil rights protections to other public and private settings and services
- Section 1557 of the 2010 Patient Protection and Affordable Care Act (ACA), which amends Section 504 of the Rehabilitation Act to provide additional protections against disability discrimination in certain health care services and programs

Definition of Disability

(A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual;

(B) a record of such an impairment; or

(C) being regarded as having such an impairment"

regardless of whether the individual actually has the impairment.

42 U.S.C. § 12102 (2)

Health Care Programs and Services

- No exclusion of people with disabilities
- Physical access to health care services and facilities, including accessible spaces and the removal of barriers
- Effective communication, including auxiliary aids and services such as the provision of sign language interpreters or materials in alternative formats
- Reasonable modification of policies, practices, and procedures when necessary to accommodate individual needs
- Integrated settings

At the Top of the Covid-19 Curve, How Do Hospitals Decide Who Gets Treatment?

Guidelines that could determine which coronavirus patients get prioritized for lifesaving care vary by state, involving factors such as age, health problems, pregnancy and cognitive abilities.

A ward for coronavirus patients in Brooklyn this week. Victor J. Blue for The New York Times

HHS Office for Civil Rights in Action

March 28, 2020

BULLETIN: Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19)

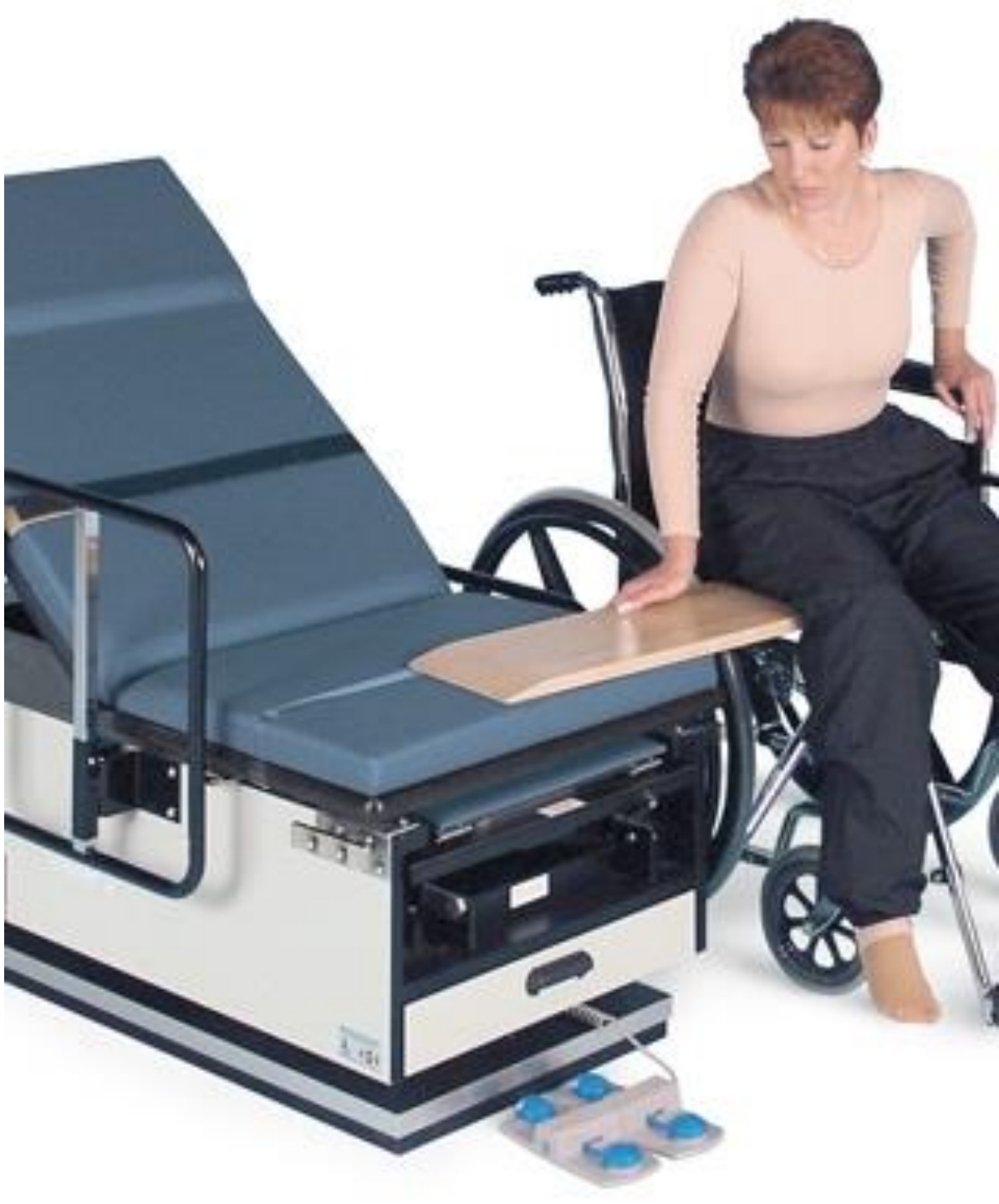
In light of the Public Health Emergency concerning the coronavirus disease 2019 (COVID-19), the Office for Civil Rights (OCR) at the U.S. Department of Health and Human Services (HHS) is providing this bulletin to ensure that entities covered by civil rights authorities keep in mind their obligations under laws and regulations that prohibit discrimination on the basis of race, color, national origin, disability, age, sex, and exercise of conscience and religion in HHS-funded programs.[1]

In this time of emergency, the laudable goal of providing care quickly and efficiently must be guided by the fundamental principles of fairness, equality, and compassion that animate our civil rights laws. This is particularly true with respect to the treatment of persons with disabilities during medical emergencies as they possess the same dignity and worth as everyone else.

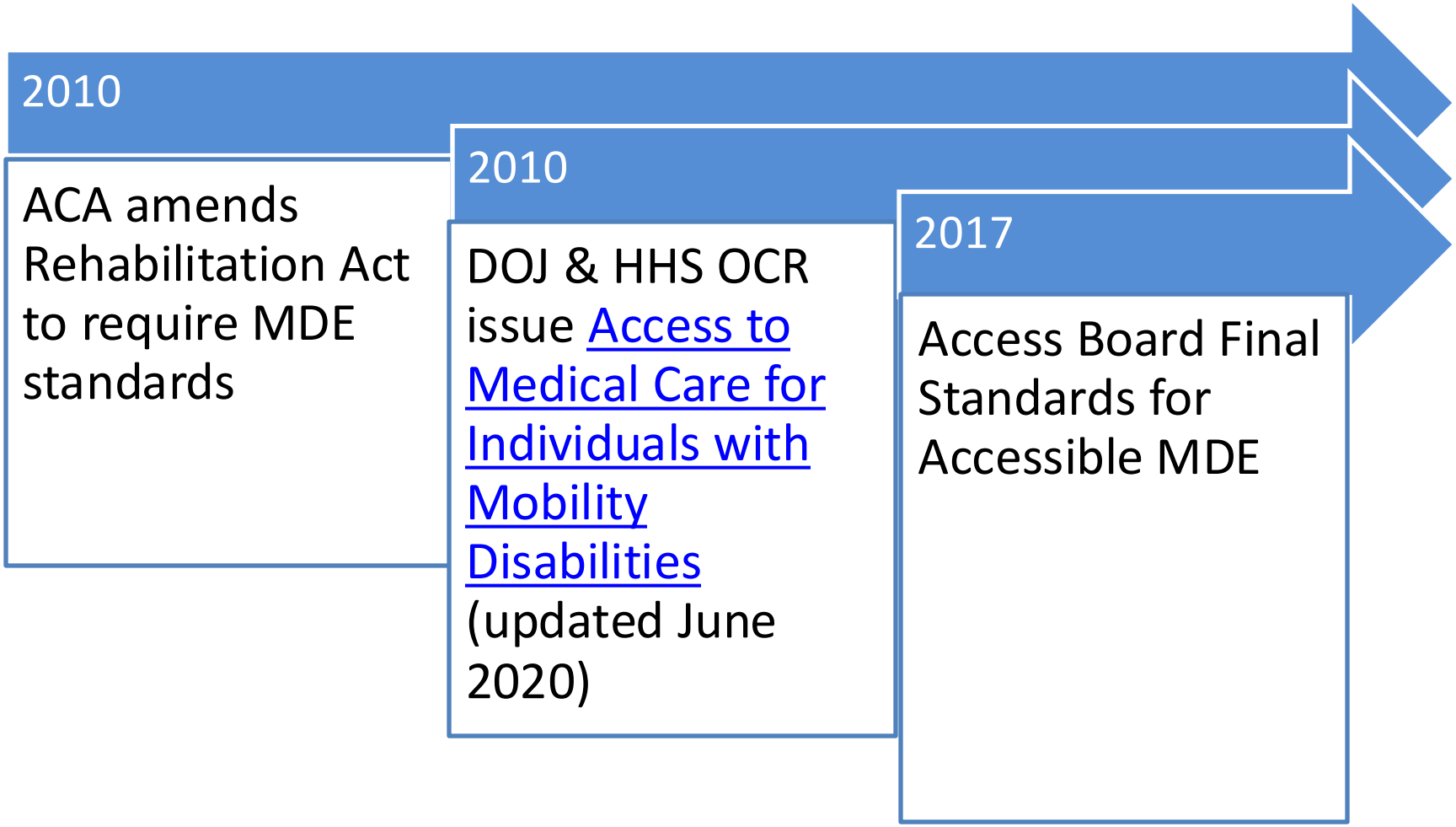
The Office for Civil Rights enforces Section 1557 of the Affordable Care Act and Section 504 of the Rehabilitation Act which prohibit discrimination on the basis of disability in HHS funded health programs or activities. These laws, like other civil rights statutes OCR enforces, remain in effect. As such, persons with disabilities should not be denied medical care on the basis of stereotypes, assessments of quality of life, or judgments about a person's relative "worth" based on the presence or absence of disabilities. Decisions by covered entities concerning whether an individual is a candidate for treatment should be based on an individualized assessment of the patient based on the best available objective medical evidence.

Laws Require Physical Accessible Care

But long delay in adopting specific legal standards for accessible medical diagnostic equipment



ACA Requires Standards for MDE



New Regulations for MDE in 2024

- May 9, 2024 – new final rule updating regulations for Section 504 (read fact sheet)
- August 9, 2024 – new final rule updating regulations for ADA Title II (read fact sheet)

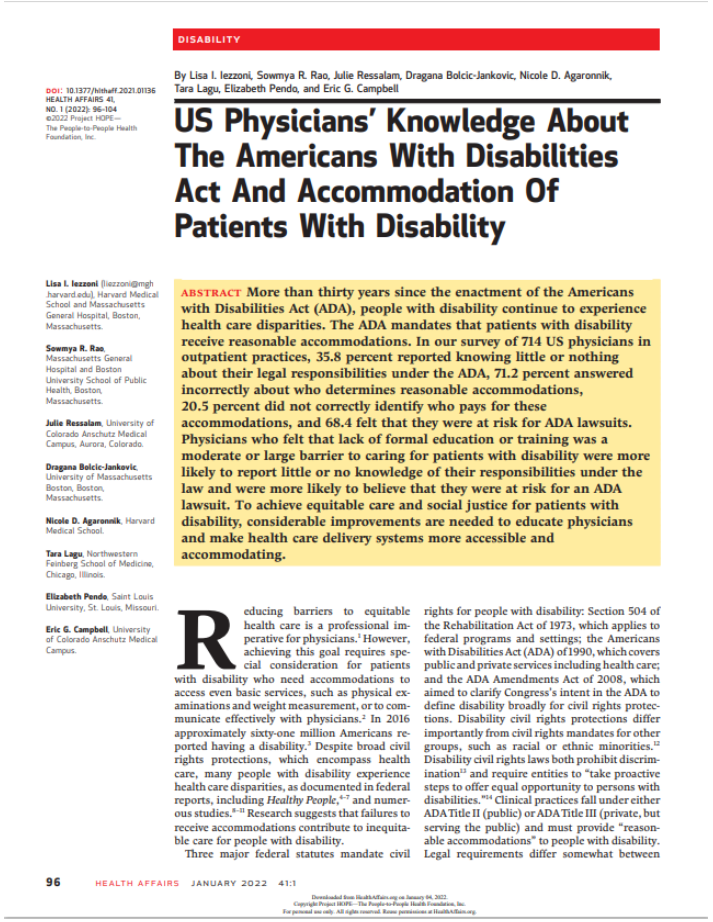
ADA Title II Requirements

- By August 9, 2026, any state or local government entity that uses an examination table must purchase, lease, or otherwise acquire at least one examination table that meets the MDE Standards, unless the entity already has one.
- By August 9, 2026, any state or local government entity that uses a weight scale must purchase, lease, or otherwise acquire at least one weight scale that meets the MDE Standards, unless the entity already has one.

- The rule requires state and local government entities to ensure that their staff can successfully operate accessible MDE, assist with transfers and positioning of individuals with disabilities, and carry out the rule's requirements for existing MDE.
- At all times when services are provided to the public, state and local government entities are expected to have staff who can operate accessible MDE.
- Often, the most effective way for state and local government entities to ensure that their staff can successfully operate accessible MDE is to provide staff training on the use of accessible MDE.

Effective Communication

- 35.8% of physicians reported knowing little or nothing about their legal responsibilities under the ADA
- 71.2% of physicians had incorrect understanding of who determines reasonable accommodations (decisions require collaboration between patients and clinicians)



DISABILITY

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By Lisa I. Iezzoni, Sowmya R. Rao, Julie Ressalam, Dragana Bolcic-Jankovic, Nicole D. Agaronnik, Tara Lagu, Elizabeth Pendo, and Eric G. Campbell

US Physicians' Knowledge About The Americans With Disabilities Act And Accommodation Of Patients With Disability

Lisa I. Iezzoni (liezzoni@mgh.harvard.edu), Harvard Medical School and Massachusetts General Hospital, Boston, Massachusetts.

Sowmya R. Rao, Massachusetts General Hospital and Boston University School of Public Health, Boston, Massachusetts.

Julie Ressalam, University of Colorado Anschutz Medical Campus, Aurora, Colorado.

Dragana Bolcic-Jankovic, University of Massachusetts Boston, Boston, Massachusetts.

Nicole D. Agaronnik, Harvard Medical School.

Tara Lagu, Northwestern Feinberg School of Medicine, Chicago, Illinois.

Elizabeth Pendo, Saint Louis University, St. Louis, Missouri.

Eric G. Campbell, University of Colorado Anschutz Medical Campus.

ABSTRACT **More than thirty years since the enactment of the Americans with Disabilities Act (ADA), people with disability continue to experience health care disparities. The ADA mandates that patients with disability receive reasonable accommodations. In our survey of 714 US physicians in outpatient practices, 35.8 percent reported knowing little or nothing about their legal responsibilities under the ADA, 71.2 percent answered incorrectly about who determines reasonable accommodations, 20.5 percent did not correctly identify who pays for these accommodations, and 68.4 felt that they were at risk for ADA lawsuits. Physicians who felt that lack of formal education or training was a moderate or large barrier to caring for patients with disability were more likely to report little or no knowledge of their responsibilities under the law and were more likely to believe that they were at risk for an ADA lawsuit. To achieve equitable care and social justice for patients with disability, considerable improvements are needed to educate physicians and make health care delivery systems more accessible and accommodating.**

Reducing barriers to equitable health care is a professional imperative for physicians.[1] However, achieving this goal requires special consideration for patients with disability who need accommodations to access even basic services, such as physical examinations and weight measurement, or to communicate effectively with physicians.[2] In 2016 approximately sixty-one million Americans reported having a disability.[3] Despite broad civil rights protections, which encompass health care, many people with disability experience health care disparities, as documented in federal reports, including *Healthy People*,[4–7] and numerous studies.[8–11] Research suggests that failures to receive accommodations contribute to inequitable care for people with disability.

Three major federal statutes mandate civil rights for people with disability: Section 504 of the Rehabilitation Act of 1973, which applies to federal programs and settings; the Americans with Disabilities Act (ADA) of 1990, which covers public and private services including health care; and the ADA Amendments Act of 2008, which aimed to clarify Congress's intent in the ADA to define disability broadly for civil rights protections. Disability civil rights protections differ importantly from civil rights mandates for other groups, such as racial or ethnic minorities.[12] Disability civil rights laws both prohibit discrimination[13] and require entities to "take proactive steps to offer equal opportunity to persons with disabilities."[14] Clinical practices fall under either ADA Title II (public) or ADA Title III (private, but serving the public) and must provide "reasonable accommodations" to people with disability. Legal requirements differ somewhat between

Olmstead v. L.C. ex rel. Zimring (Sup. Ct. 1999)

Can a state choose to provide services to individuals with disabilities in a segregated or institutional setting, as opposed to an appropriate community-based setting?

Left to right: Sue Jamieson, the attorney that brought the Olmstead case to the Supreme Court; Elaine Wilson and Lois Curtis, prevailing plaintiffs

Image from https://www.disability.state.mn.us/2018/06/22/mcd-celebrates-19th-anniversary-of-the-olmstead-decision/

Integration Mandate

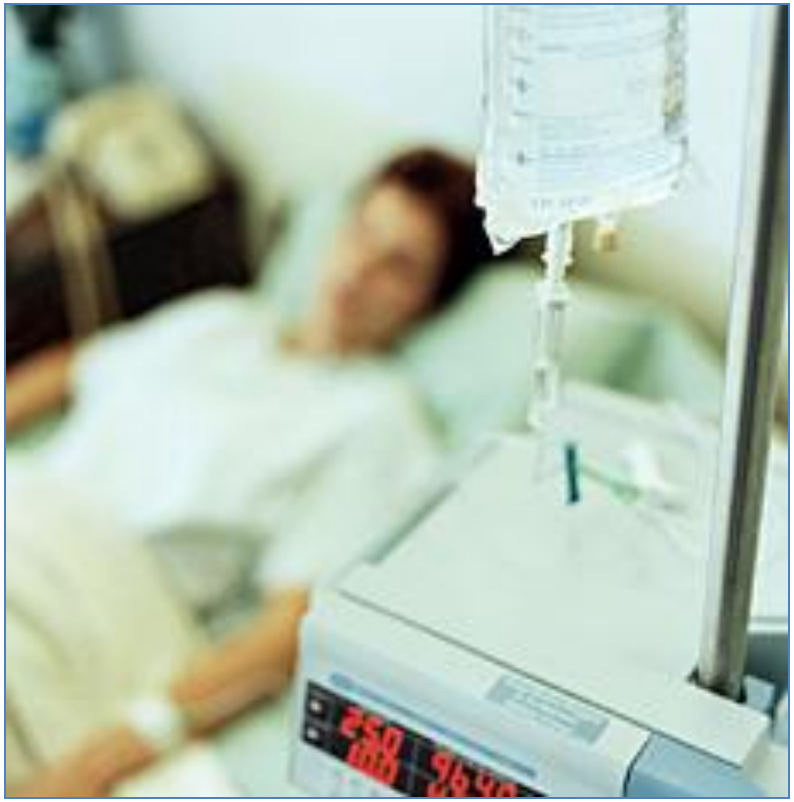
Public entities are required to "administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities."

The "most integrated setting" is one that "enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible . . . ."-

28 C.F.R. § 35.130(d)

Alexander v. Choate (Sup. Ct. 1985)

Can states make decisions with a disparate impact on people with disabilities, such as a reduction of the number of inpatient days covered by Medicaid program?



Theories of Discrimination

A plaintiff alleging disparate treatment must show that the covered entity intentionally treated them differently than others because of a protected characteristic

A plaintiff alleging disparate impact must show that a facially neutral policy or practice falls more harshly on a protected group (but not discriminatory intent)

Affordable Care Act

- Insurance reforms, e.g. no exclusion of pre-existing conditions
- Essential health benefits requirements include habilitative and rehabilitative services, mental health /SUD services
- Section 1557

2024 Section 1557 Final Rule*

- Reinstates application to health insurance and provides clear nondiscrimination standards for the industry
- Applies to all HHS-administered health programs and activities (e.g. Centers for Medicare & Medicaid Services)
- Protects LGBTQI+ patients from discrimination and clarifies prohibition on sex discrimination
- Requires providers to take steps to identify and mitigate discrimination when they use patient care decision support tools, including clinical algorithms
- Applies to telehealth services
- **Requires Section 1557 policies and staff training**

*See a full summary of the 2024 rule at https://www.hhs.gov/civil-rights/for-individuals/section-1557/1557-fact-sheet/index.html. The 2016 Rule, 2020 Rule, and subsequent legal developments are summarized in the background section of the 2022 proposed rule. See 87 Fed. Reg. 47824, at 47825-47828.

How to report

- HHS (Section 504, Section 1557), here
- DOJ (ADA Title II & 3), here
- Hospital grievance process
- The Joint Commission
- State health department
- State antidiscrimination agency

Additional information here, https://www.hrc.org/resources/what-to-do-if-you-experience-discrimination

Additional Resources

- Elizabeth Pendo and Lisa I. Iezzoni, *The Role of Law and Policy in Achieving Healthy People's Disability and Health Goals around Access to Health Care, Activities Promoting Health and Wellness, Independent Living and Participation, and Collecting Data in the United States*. Rockville (MD). HHS, ODPHP (Mar. 12, 2020)
- National Council on Disability, Framework to End Health Disparities of People with Disabilities, (Feb. 2022, updated May 2023)
- Lisa I. Iezzoni, et. al, *Have Almost 50 Years of Disability Civil Rights Laws Achieved Equitable Care?*, 41(10) Health Affairs 1371 (Oct. 2022
- Lisa I. Iezzoni, et al. *U.S. Physicians Knowledge About the Americans with Disabilities Act and Accommodation of Patients with Disability*, 41(1) Health Affairs 96 (2022)
- Gloria L. Krahn, Deborah Klein Walker & Rosaly Correa-De-Araujo, Persons With Disabilities as an Unrecognized Health Disparity Population, 105 Am. J. Public Health S198–S206 (2015)