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Data Collection and Identification of Disability Status: Necessary Tools to Improve Care Access and Reduce Health Care Disparities for People with Disabilities

Tara Lagu, MD, MPH
Professor of Medicine and Medical Social Sciences
Director, Center for Health Services and Outcomes Research

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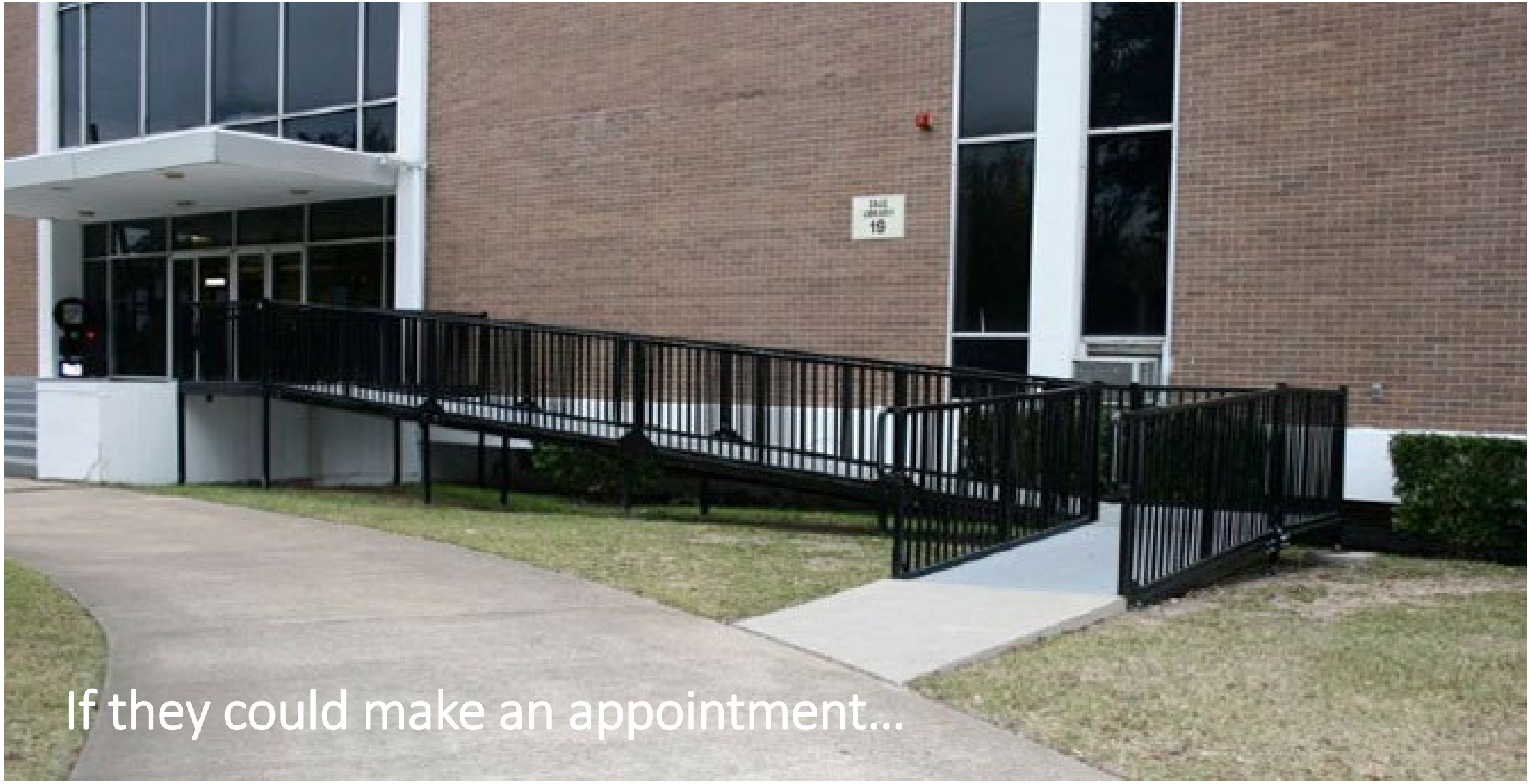
No disclosures.

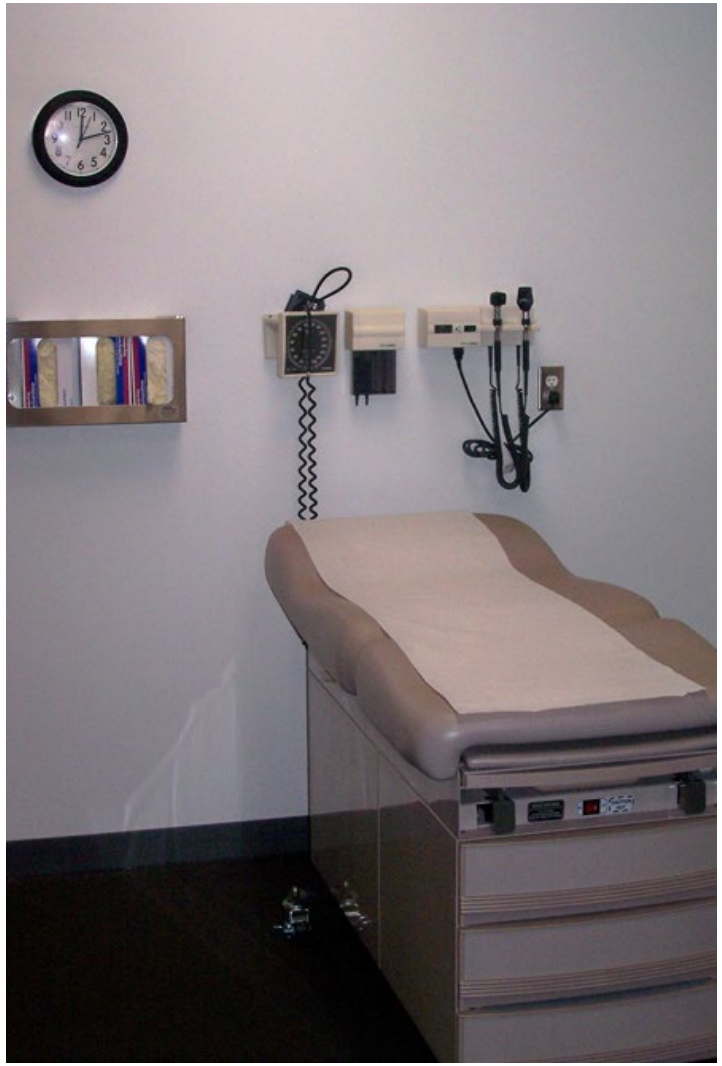
“It’s like discrimination or something…”

Study Design

- Used a deceptive research technique
- Telephone survey where a physician or student attempted to make an appointment for a fictional patient
- No up-front explanation that it was research


If they could make an appointment…

If they could/ would not…



Results

- Of 256 practices, 56 (22%) were inaccessible
  - 9 practices located in inaccessible buildings
  - 47 could not transfer the patient
- Of the remaining 200 accessible practices, 103 planned to “manually” transfer the patient
- Fewer than 10% of practices had height-adjustable tables or lift

Annals of Internal Medicine | ORIGINAL RESEARCH

Access to Subspecialty Care for Patients With Mobility Impairment

A Survey

Tara Lagu, MD, MPH; Nicholas S. Hannon, BS; Michael B. Rothberg, MD, MPH; Annalee S. Wells, DO; K. Laurie Green, MD; McAllister O. Windom, MD, MPH; Katherine R. Dempsey, BA, BS; Penelope S. Pekow, PhD; Jill S. Avrunin, MS; Aaron Chen, BS; and Peter K. Lindenauer, MD, MSc

Background: Adults who use wheelchairs have difficulty accessing physicians and receive less preventive care than their able-bodied counterparts.

Objective: To learn about the accessibility of medical and surgical subspecialist practices for patients with mobility impairment.

Design: A telephone survey was used to try to make an appointment for a fictional patient who was obese and hemiparetic, used a wheelchair, and could not self-transfer from chair to examination table.

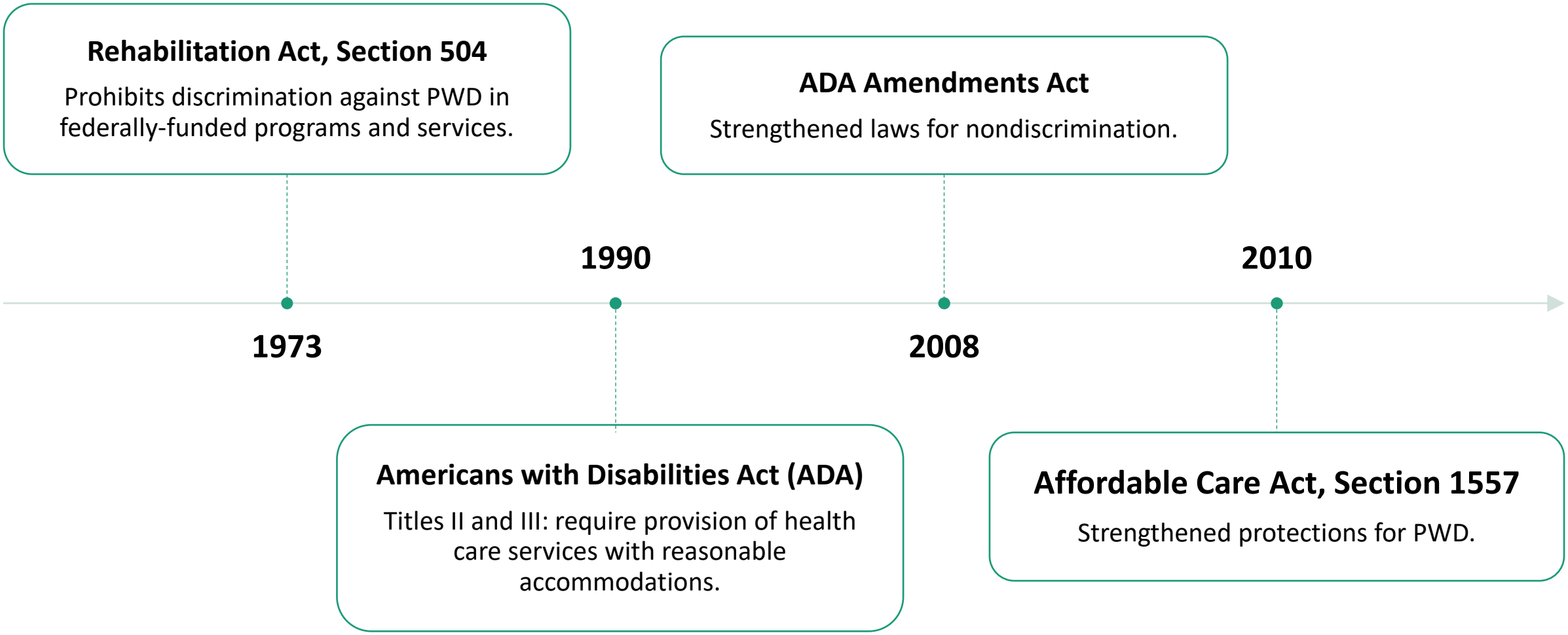
Setting: 256 endocrinology, gynecology, orthopedic surgery, rheumatology, urology, ophthalmology, otolaryngology, and psychiatry practices in 4 U.S. cities.

Results: Of 256 practices, 56 (22%) reported that they could not accommodate the patient, 9 (4%) reported that the building was inaccessible, 47 (18%) reported inability to transfer a patient from a wheelchair to an examination table, and 22 (9%) reported use of height-adjustable tables or a lift for transfer. Gynecology was the subspecialty with the highest rate of inaccessible practices (44%).

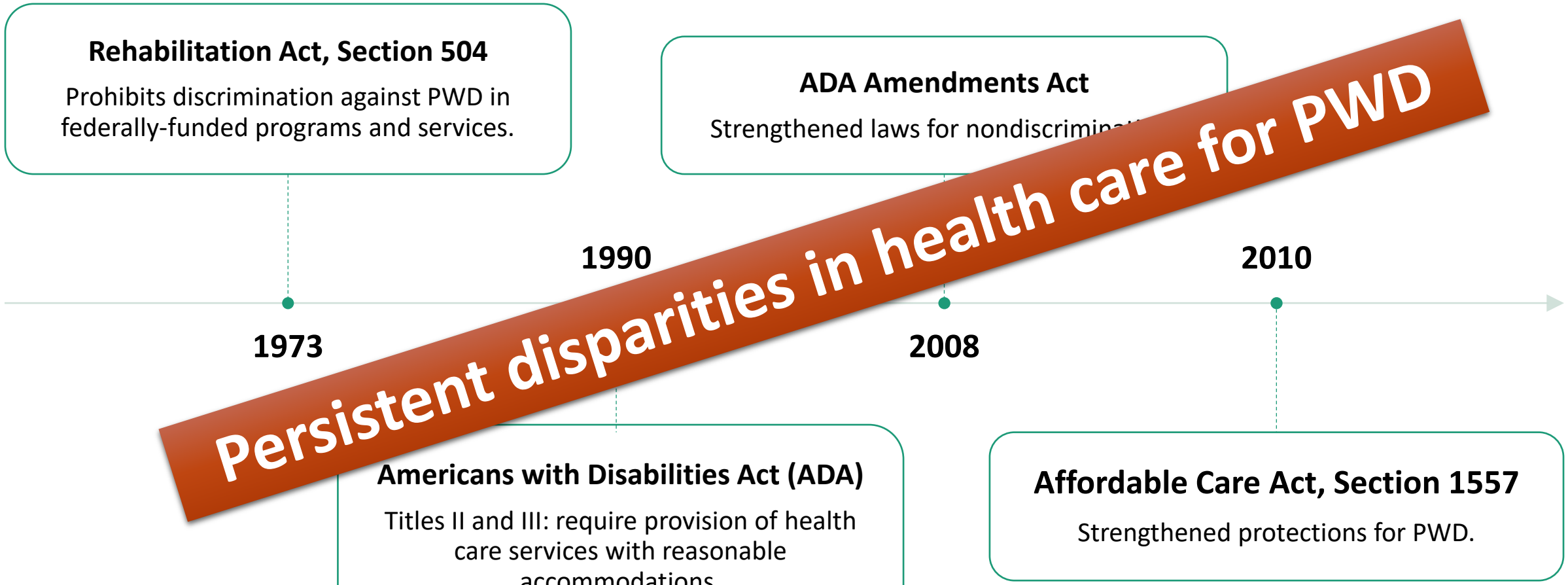
Limitation: Small numbers of practices in 8 subspecialties in 4 cities and use of a fictional patient with obesity and hemiparesis limit generalizability.

Conclusion: Many subspecialists could not accommodate a patient with mobility impairment because they could not transfer the patient to an examination table. Better awareness among providers about the requirements of the Americans with Disabilities Act and the standards of care for patients in wheelchairs is needed.

Legislation to Protect Rights of PWD



Legislation to Protect Rights of PWD



“It’s Knowledge. Let’s Educate Our Workforce”

The NEW ENGLAND JOURNAL of MEDICINE

SOUNDING BOARD

The Axes of Access — Improving Care for Patients with Disabilities

Tara Lagu, M.D., M.P.H., Lisa I. Iezzoni, M.D., and Peter K. Lindenauer, M.D.

It was Friday afternoon, and I had promised my patient's family that I would discharge her. Despite trying all day to make a follow-up appointment with the appropriate subspecialist, I could not find a practice within 50 miles of her home that could accommodate a patient who used a wheelchair. After I explained the situation and apologized, the patient said to me, "You know, Doctor, it's like discrimination or something."

The statement of the patient in the vignette is supported by a growing body of evidence that persons with disabilities confront barriers when attempting to access the health care system.[1-7] Although the 1990 Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act require that health care providers provide "full and equal access to care for persons with disabilities,"[8,9] research has shown that patients with disabilities may be transferred in an unsafe manner onto examination tables and other

[a height-adjustable table] and I'll refer you." — Patient who uses a wheelchair.[10]

Physically accessible health care environments are free of physical barriers to care. This includes access to elevators, ramps, parking, doorways, bathrooms, and medical diagnostic equipment, such as examination tables, weight scales, and radiographic and ophthalmologic equipment. Previous research has emphasized that universal accessibility is about "more than ramps."[11] The inability to enter a building is rarely the reason that patients cannot be accommodated.[4] Inaccessible equipment is a far more common barrier. In one study of outpatient settings that evaluated access for a patient who could not transfer independently, 20% of subspecialty practices refused to book an appointment because they were unable to transfer the patient to an examination table.[4] Manufacturers of examination tables and

Physical Access

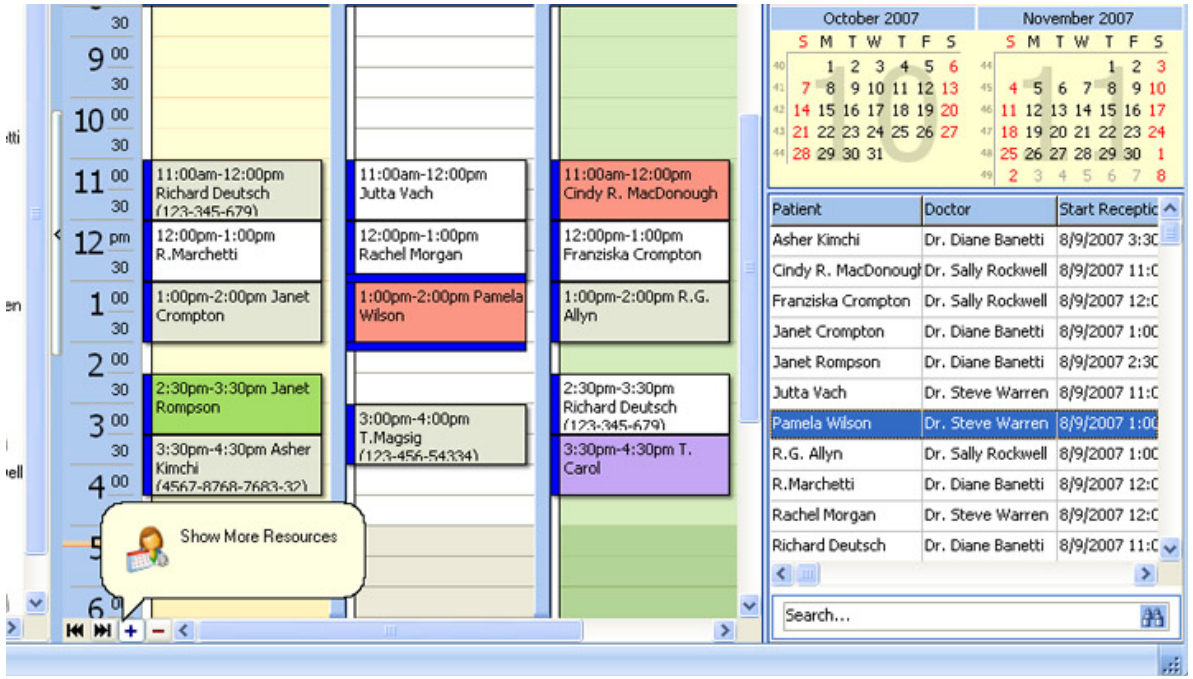
- Room next to exam table for wheelchair
- Adjustable height table
- Space to allow transfers
- Accessible route in and out

Communication Access

- Providers and patient work together to identify alternative communication methods for patients with disabilities
- Large print forms
  - —Web, email, text
  - —Telecommunication device for the deaf (TDD)
  - —Sign language interpreters

Programmatic Access

Universal accessibility of scheduling, staffing, and other administrative resources.



Programmatic Access

- When patient makes an appointment, the system alerts the receptionist (“flags”)
- Room with the accessible table is reserved for her appointment time
- Trained staff are also alerted prior to patient’s arrival

“It’s Equipment. Let’s Get Clinicians the Right Tools.”

Is it about tables?

- 400 patients with disability seen in primary care clinics with and without height-adjustable examination tables.
- General perceptions of quality of care and whether or not they were examined

It’s not about tables

- No difference in perceived quality of care or use of physical examination in clinics with and without height-adjustable examination tables

Use of Accessible Examination Tables in the Primary Care Setting: A Survey of Physical Evaluations and Patient Attitudes

Megan A. Morris, PhD, MPH, CCC-SLP[1,2,3], Allysha C. Maragh-Bass, PhD, MPH[3], Joan M. Griffin, PhD[1,2], Lila J. Finney Rutten, PhD[1,2], Tara Lagu, MD[4,5,6], and Sean Phelan, PhD[2]

[1]Mayo Clinic Robert D. and Patricia E. Kern Center for the Science of Health Care Delivery, Rochester, MN, USA; [2]Department of Health Sciences Research, Mayo Clinic, Rochester, MN, USA; [3]Center for Surgery and Public Health, Brigham and Women’s Hospital, Boston, MA, USA; [4]Center for Quality of Care Research, Baystate Medical Center, Springfield, MA, USA; [5]Department of Medicine, Tufts University School of Medicine, Boston, MA, USA; [6]Division of Hospital Medicine, Baystate Medical Center, Springfield, MA, USA.

BACKGROUND: Accessible diagnostic equipment, including height-adjustable examination tables, is necessary to accommodate patients with disabilities. Studies demonstrate that only a minority of clinics provide accessible equipment. For clinics with this equipment, no studies have examined the use of such equipment in routine clinical care.

OBJECTIVE: In primary care clinics with and without height-adjustable examination tables, we compared the frequency and variation in physical evaluations on examination tables and patients’ perceptions of quality care.

DESIGN: Survey administered to patients at two primary care clinics in Rochester, MN, in 2015. One clinic had height-adjustable examination tables in every exam room; the other clinic had none.

PATIENTS: A total of 399 English-speaking adult primary care patients (61% participation).

MAIN MEASURES: Participants were asked whether they were physically evaluated on a table during their clinical encounter. In addition, they completed two subscales of the Patient Perception of Quality of Care survey: Percep-

J Gen Intern Med 32(12):1342–8
DOI: 10.1007/s11606-017-4155-2

INTRODUCTION

According to the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act of 1973, healthcare organizations must ensure equal access to healthcare services and facilities for patients with disabilities, including reasonable modifications when necessary.[1,2] Despite this legislation, multiple studies have found that patients with mobility impairments receive less preventive care and fewer examinations than patients without disabilities. This disparity has been attributed, in part, to inaccessible medical environments.[3–17] The Department of Justice (DoJ), which is charged with enforcing the ADA (under Title II for public entities and Title III for public accommodations), recommends that when pa-

“Maybe It’s Attitudes?”

RESEARCH ARTICLE | DISABILITY

HEALTH AFFAIRS > VOL. 40, NO. 2: VITAL DIRECTIONS, QUALITY & MORE

Physicians' Perceptions Of People With Disability And Their Health Care

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

AFFILIATIONS

PUBLISHED: **FEBRUARY 2021**

https://doi.org/10.1377/hlthaff.2020.01452

Physician Perceptions of PWD

- Survey of 714 practicing physicians across the United States
- 57% strongly agreed they welcomed PWD into their practices
- 41% were very confident in their ability to provide the same quality of care to their patients with and without disabilities
- 36% reported knowing little or nothing about their legal responsibilities under the ADA

Iezzoni et al. (2021) doi: 10.1377/hlthaff.2020.01452

By Tara Lagu, Carol Haywood, Kimberly Reimold, Christene DeJong, Robin Walker Sterling, and Lisa I. Iezzoni

'I Am Not The Doctor For You': Physicians' Attitudes About Caring For People With Disabilities

DOI: 10.1377/hlthaff.2022.00475
HEALTH AFFAIRS 41,
NO. 10 (2022): 1387–1395

ABSTRACT **People with disabilities face barriers when attempting to gain access to health care settings. Using qualitative analysis of three physician focus groups, we identified physical, communication, knowledge, structural, and attitudinal barriers to care for people with disabilities. Physicians reported feeling overwhelmed by the demands of practicing medicine in general and the requirements of the Americans with Disabilities Act of 1990 specifically; in particular, they felt that they were inadequately reimbursed for accommodations. Some physicians reported that because of these concerns, they attempted to discharge people with disabilities from their practices. Increasing health care access for people with disabilities will require increasing the accessibility of space and the availability of proper equipment, improving the education of clinicians about the care of people with disabilities, and removing structural barriers in the health care delivery system. Our findings also suggest that physicians' bias and general reluctance to care for people with disabilities play a role in perpetuating the health care disparities they experience.**

Tara Lagu (Tara.lagu@northwestern.edu), Northwestern University, Chicago, Illinois.

Carol Haywood, Northwestern University.

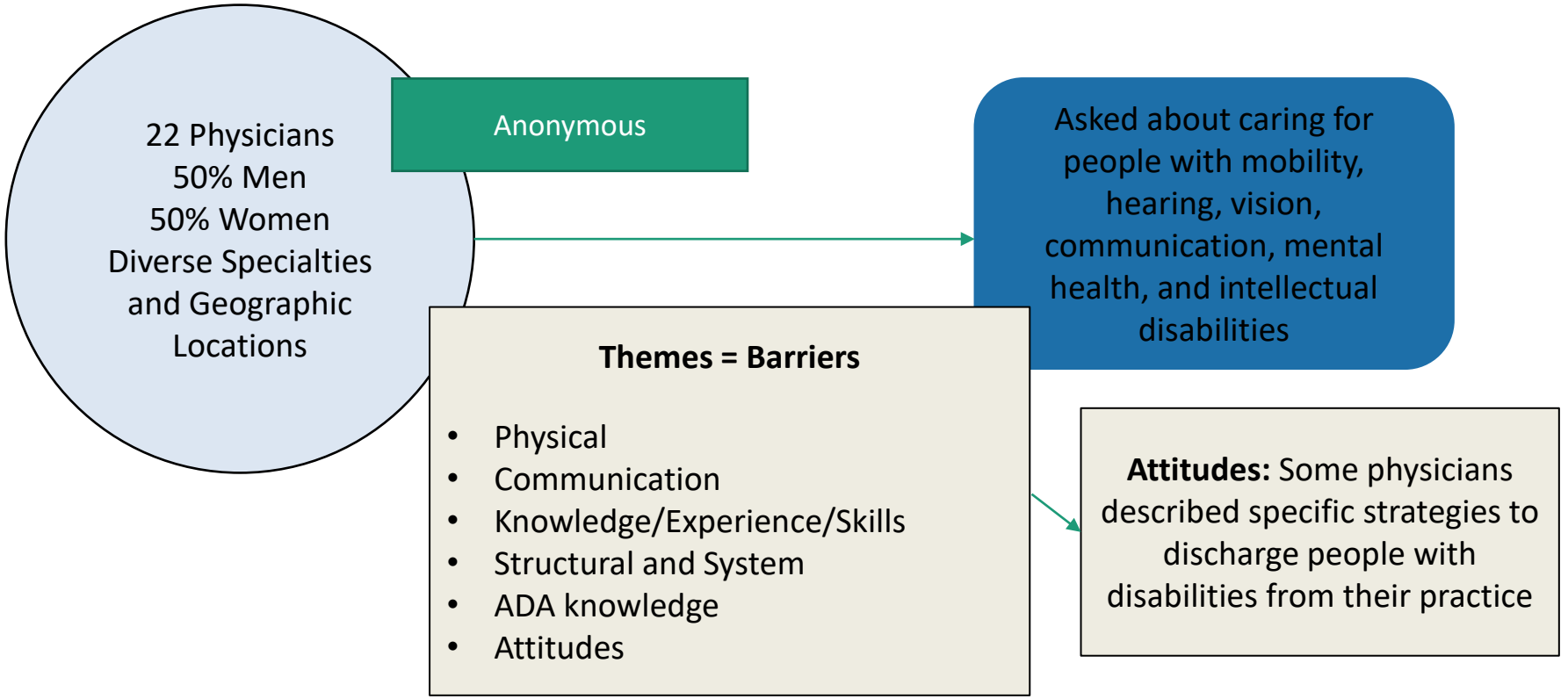
Kimberly Reimold, University of Massachusetts, Worcester, Massachusetts.

Christene DeJong, Baystate Health, Springfield, Massachusetts.

Robin Walker Sterling, Northwestern University.

Lisa I. Iezzoni, Harvard University and Massachusetts General Hospital, Boston, Massachusetts.

Focus Groups



Attitudes: *Statements about Denying Care*

"I have actually thought about it a lot because in a sense we are kind [of] in a powerless position to deny care. …My solution is to say, 'I no longer take new patients.'"

Attitudes: *Statements about Denying Care*

"[I say] 'I think you need a lot more care, and I am not the doctor for you.'"

Disparities in Health Care Access and Quality

- Limited access to care and substandard quality of care [1]
- Higher rates of chronic disease; lower rates of primary/preventive care [2]

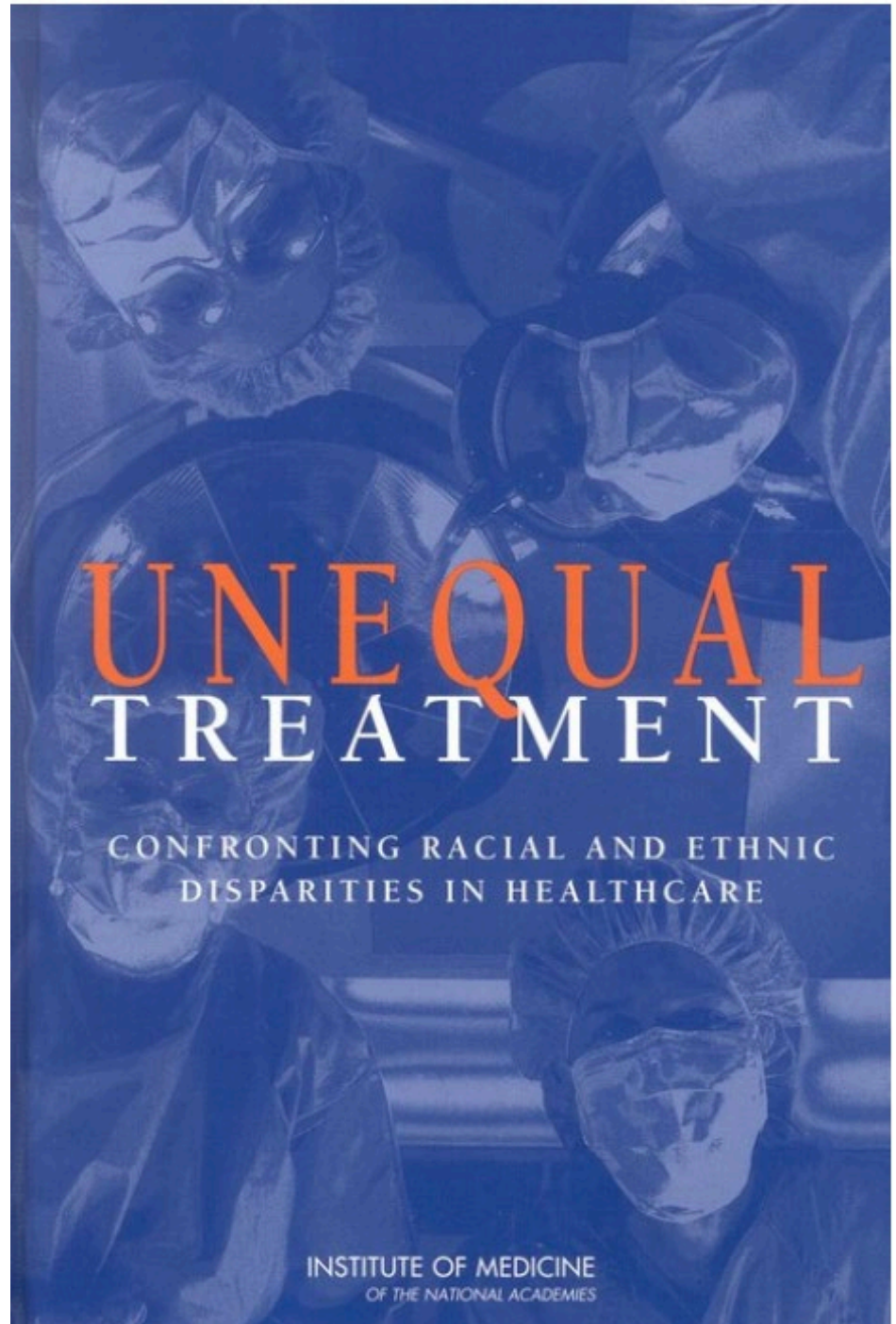
1. Lagu et al., 2013, doi: 10.7326/0003-4819-158-6-201303190-00003
2. Iezzoni et al., 2021, doi:10.1097/MLR.0000000000001449

“Oh. It’s Ableism.”

A List of Structural Barriers to Understanding and Addressing Disability Disparities (all are highly related to data collection and use of the electronic record):

1. No federal and few state mandates for data collection about disability

- Race and ethnicity data collection first authorized under Title VI of the Civil Rights Act of 1964; but data collection about race/ethnicity is woven into the fabric of hundreds of laws, policies, and procedures within and beyond HHS
- There is no corresponding example for disability


UNEQUAL
TREATMENT
CONFRONTING RACIAL AND ETHNIC
DISPARITIES IN HEALTHCARE
INSTITUTE OF MEDICINE
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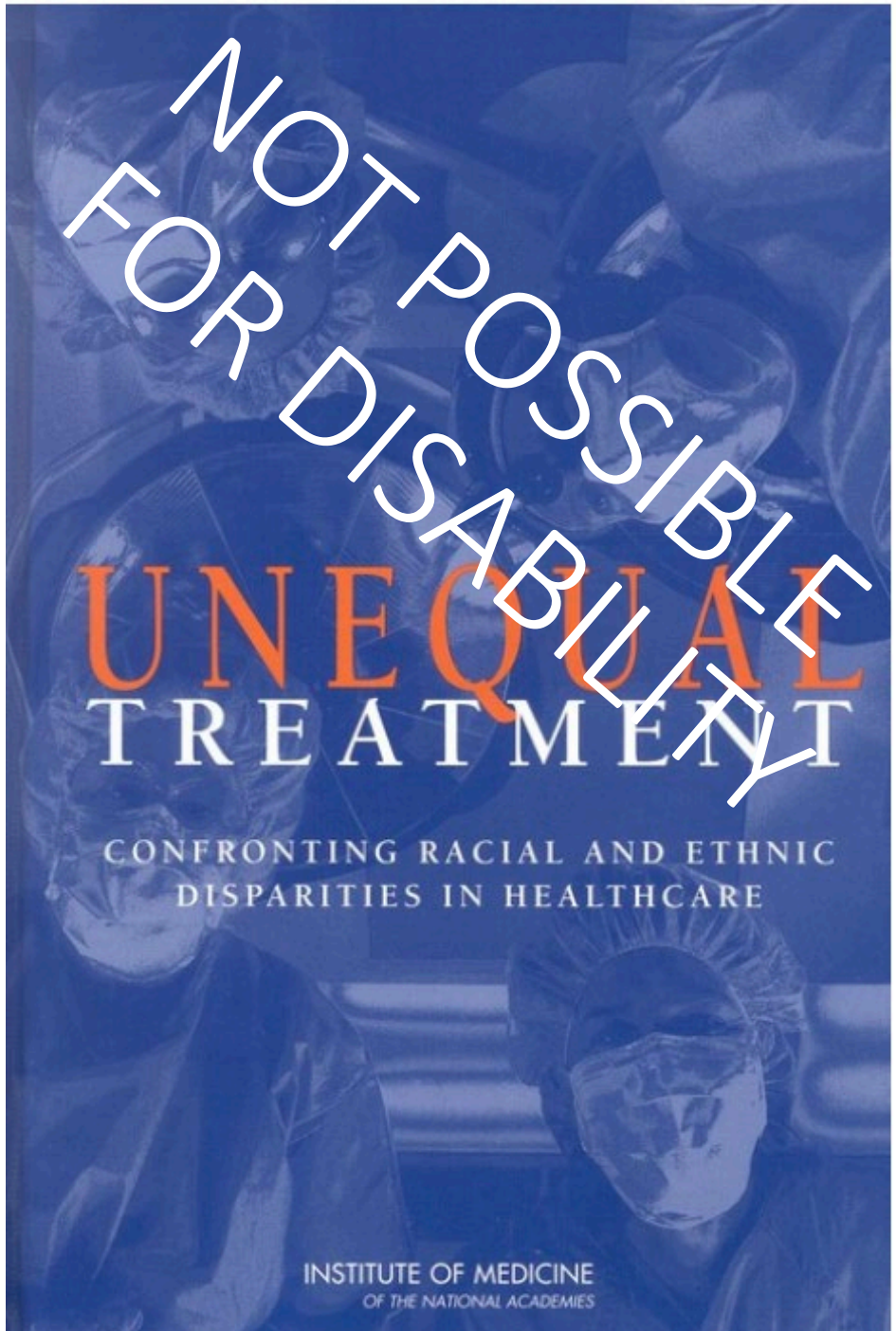
NOT POSSIBLE FOR DISABILITY
UNEQUAL TREATMENT
CONFRONTING RACIAL AND ETHNIC DISPARITIES IN HEALTHCARE
INSTITUTE OF MEDICINE
OF THE NATIONAL ACADEMIES

Complicating this…

- Without a data collection mandate, “early adopter” health systems that want to collect information about patients’ disabilities and accommodation needs are DISCOURAGED from doing so because it might reveal gaps in care and failures to provide accommodations that put them at risk for lawsuits
- Further, data collection may also encourage unfavorable comparisons to peer institutions who choose not to “risk” collecting the data
- Without a mandate, few health systems will collect the data voluntarily for all patients. Need federal or state laws, policies, and procedures requiring this data collection.
- Also need to incorporate into hospital and health system accreditation

2. Confusing and Varying Definitions of Disability

- SSA vs. ADA vs. Identity vs…..

ADA

- Protect civil rights (e.g., access to public spaces, goods, and services).
- **Definition is intentionally broad, inclusive.**

SSA

- Determines eligibility for services (e.g., Social Security Disability Insurance).
- **Definition is narrow to limit the number of eligible beneficiaries.**

Complicating this…

- Health systems might be on board with collecting the information for purposes of accommodating patients or bridging gaps in care
- Health systems are less interested in sharing data from their electronic health record if it is for purposes of determining disability for the SSA
- Why? Concerns about gaming, insistence from patients about what does (or does not) get included in the record, and fear of third parties using the data for reasons that are beyond the scope of medical care

3. Attempts to Identify Disability from the Record Alone Not Successful

- More on this in many subsequent presentations
- Attempts to use natural language processing to identify disability from notes did not show good sensitivity or specificity. Data collection is needed.

4. Lack of Standard Questions about Disability and Accommodations

- Existing HHS questions are broad and do not get at disability severity or chronicity
- There are no validated questions about accommodations (and no support to conduct the research to validate these questions).

HHS Data Standard

- Questions established in 2011, after ACA mandate
- Widely used (US Census, Dept of HHS, Dept of Ed, Dept of Justice, Dept of Housing and Urban Dev)

Data Standard for Disability Status

1. *Are you deaf or do you have serious difficulty hearing?*
   a. ___ Yes
   b. ___ No

2. *Are you blind or do you have serious difficulty seeing, even when wearing glasses?*
   a. ___ Yes
   b. ___ No

3. *Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions? (5 years old or older)*
   a. ___ Yes
   b. ___ No

4. *Do you have serious difficulty walking or climbing stairs? (5 years old or older)*
   a. ___ Yes
   b. ___ No

5. *Do you have difficulty dressing or bathing? (5 years old or older)*
   a. ___ Yes
   b. ___ No

6. *Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping? (15 years old or older)*
   a. ___ Yes
   b. ___ No

https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=3&lvlid=53

5. Unclear Buy-In from NIH and other federal agencies that people with disabilities experience disparities

- CDC, HHS, AHRQ, and NIH now all recognize disability as a disparity population
- Willingness to require data collection or fund studies focused on PWD independent of race or other social vulnerabilities, however, remains to be seen
- Catch-22: We don’t have data so can’t “prove” that PWD experience disparities, but don’t have buy-in to mandate data collection or NIH support to conduct research.

What can we do?

Advocate, Legislate, Formulate Policy

- Work with advocacy groups to continue to highlight (and, when possible, address) these structural barriers
- Continue to be outspoken about the issues
- Health systems, EMR vendors, and insurance companies are not the enemy: many want to work with us and try to change from within, and we should take advantage of this
- Conduct research when possible

Conduct Research “on the Margins”

Tools to measure quality of care for PWD (mobility)

Documentation of disability status and accommodation needs

Inpatient and outpatient settings!

Review of technical standards for medical school

Review guidelines for disability-competent care (mobility)

Strategies to implement accommodation supports in primary care (communication and mobility)

Mechanisms of ableism in acute care

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Thank you!

tara.lagu@northwestern.edu

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