Northwestern Medicine®
Feinberg School of Medicine

Transdisciplinary Approaches to Mitigate Persistent Inequities in Quality and Outcomes of Health Care for People with Disabilities

Carol Haywood, PhD, OTR/L
Research Assistant Professor of Medical Social Sciences
Center for Health Services and Outcomes Research,
Institute for Public Health and Medicine

June 24, 2024

No disclosures.

Acknowledgements

- **Northwestern University**: Tara Lagu, Andrew Berry, Jissell Torres, Tiwalade Adekunle, Allison Kannam, Tracey Singer, G Bajaj, Samantha Schroth, Lauren Leviton, Christene DeJong, Cindy Barnard, Carolyn Schafer, David Cella, Rinad Beidas, Susan Magasi (UIC), IPHAM, and CHSOR
- **Northwestern Medicine**: Kevin O'Leary, Ariana King, Erin Slade-Smith, Diana Xu, Lyndsay Gant, Julia Samolczyk
- **University of Colorado**: Megan Morris
- **Harvard, MGH**: Lisa Iezzoni
- **Lurie Children's Hospital**: Carolyn Foster
- **SRALab**: Allison Kessler, Leslie Rydberg

Learning Objectives

01

Describe barriers for people with mobility-related disabilities to access health care.

02

Describe what is known about physician attitudes relating to care for people with disabilities, including the role of bias and systematic constraints to providing care.

03

Determine strategies to increase accessibility of health care for people with disabilities.

People with Disability (PWD)

- >67 million Americans[1]
- Physical, intellectual, visual, communication, mental health
- Not a monolith
- Intersectional

1. Varadaraj et al. (2021) doi:10.1001/jamanetworkopen.2021.30358

Spectrum of Disability

- Invisible – Visible
- Co-occurring (~30 million people report >1 disability type[1])
- Stable, fluctuating, progressive
- Acute, chronic
- Can impact anyone at any time

1. Varadaraj et al. (2021) doi:10.1001/jamanetworkopen.2021.30358

Disability is not a brave struggle or “courage in the face of adversity.” Disability is an art. It’s an ingenious way to live.

– Neil Marcus, Disability Visibility

Person-First, Identity-First…

- Person-first language positions the person before the disability:

  “a person with tetraplegia” “a person with autism”

- Identity first language positions disability as the primary identifier:

  “a tetraplegic” “an autistic person”

Just ask.

Legislation to Protect Rights of PWD

1973

Rehabilitation Act, Section 504

Prohibits discrimination against PWD in federally-funded programs and services.

1990

Americans with Disabilities Act (ADA)

Titles II and III: require provision of health care services with reasonable accommodations.

2008

ADA Amendments Act

Strengthened laws for nondiscrimination.

2010

Affordable Care Act, Section 1557

Strengthened protections for PWD.

Legislation to Protect Rights of PWD

Rehabilitation Act, Section 504

Prohibits discrimination against PWD in federally-funded programs and services.

ADA Amendment

Strengthened l…

Persistent inequities in health care for PWD

Americans with Disabilities Act (ADA)

Titles II and III: require provision of health care services with reasonable accommodations.

2008

2010

Affordable Care Act, Section 1557

Strengthened protections for PWD.

A “Disparity Population”

- Higher rates of chronic disease; lower rates of primary/preventive care[1]
  —People with physical disabilities have higher odds of unmet medical (75%), dental (57%), and prescription med (85%) needs[2]
- Fare poorly “on virtually all measures of social determinants” [3]
- Meet criteria for disparity population[3]
- CDC, HHS, AHRQ, and NIH recognize disability as a disparity population

1. Iezzoni et al., 2021, doi:10.1097/MLR.0000000000001449
2. Mahmoudi & Meade, 2015, doi: 10.1016/j.dhjo.2014.08.007
3. Krahn et al., 2015, doi: 10.2105/AJPH.2014.302182

Tuesday, September 26, 2023

NIH designates people with disabilities as a population with health disparities

Designation, new research program and update to NIH mission are actions to ensure inclusion of people with disabilities.

Today, Eliseo J. Pérez-Stable, M.D., director of the National Institute on Minority Health and Health Disparities (NIMHD), designated people with disabilities as a population with health disparities for research supported by the National Institutes of Health. The decision was made in consultation with Robert Otto Valdez, Ph.D., the director of the Agency for Healthcare Research and Quality, after careful consideration of a report pdf delivered by an NIMHD advisory council, input from the disability community and a review of the science and evidence. A report pdf issued in December 2022 by the Advisory Committee to the (NIH) Director (ACD), informed by the work of the Subgroup on Individuals with Disabilities, explored similar issues faced by people with disabilities. The designation is one of several steps NIH is taking to address health disparities faced by people with disabilities and ensure their representation in NIH research.

"This designation recognizes the importance and need for research advances to improve our understanding of the complexities leading to disparate health outcomes and multilevel interventions," said Dr. Pérez-Stable. "Toward this effort, NIMHD and other NIH institutes launched a new research program to better understand the health disparities faced by people with disabilities who are also part of other populations designated as having health disparities."

Institute/Center

NIH Office of the Director (OD

National Institute on Minority Health and Health Disparities (NIMHD)

Contact

NIH News Media Branch
301-496-5787

NIMHD Press Team
301-402-1366

Connect with Us

Subscribe to news release

RSS Feed

Taken from: Centers for Disease Control and Prevention. Disability and Health Data System (DHDS) [Internet]. [updated 2022 May; cited 2022 December 12]. Available from: http://dhds.cdc.gov

Academic and Clinical Background

BA in Psychology	Master of Occupational Therapy	PhD, Occupational Science
2008	2009	2018

St Ambrose University

Clinical practice: OT Acute inpatient physical rehabilitation

2009-2013

USC University of Southern California

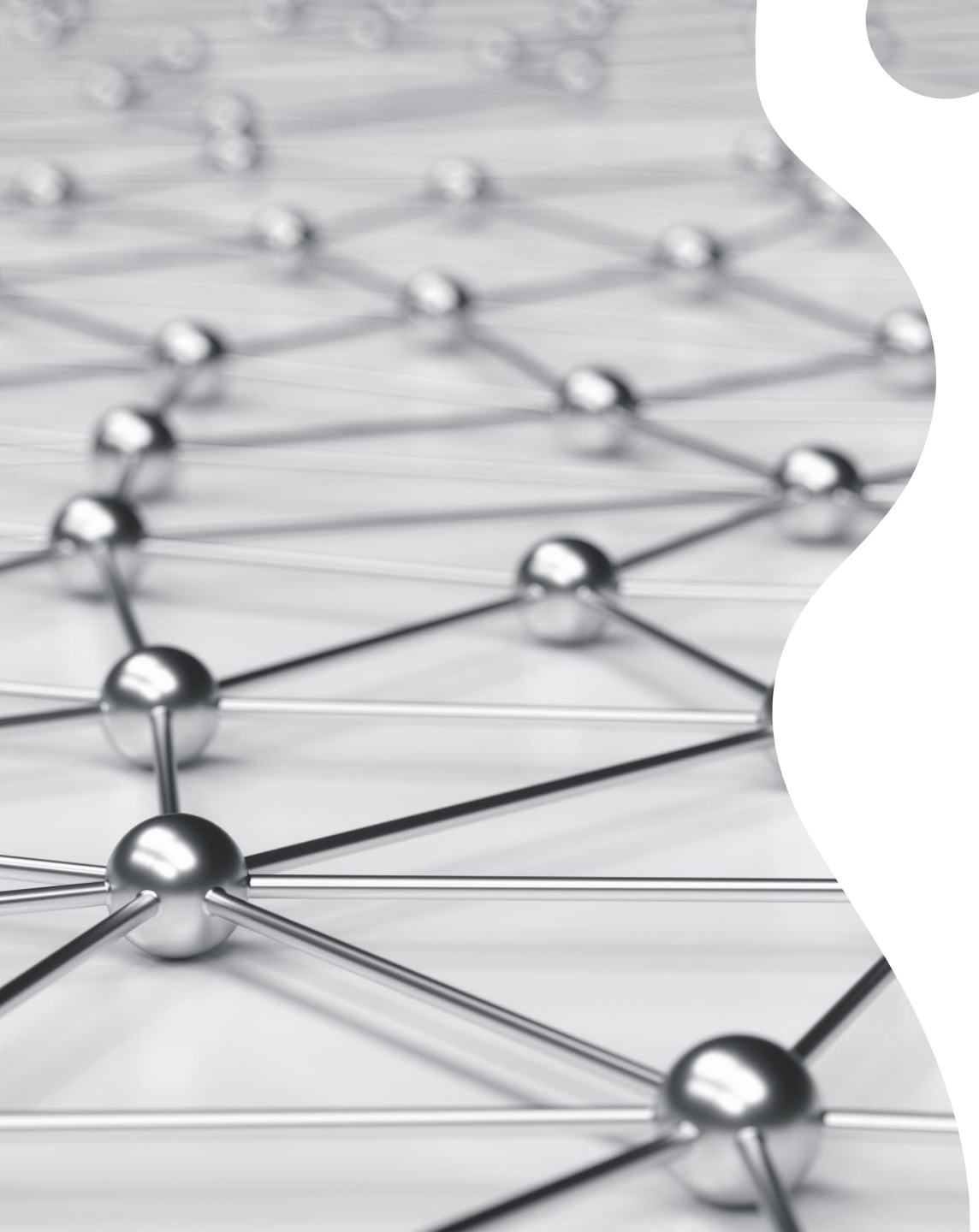
Shirley Ryan AbilityLab

REHABILITATION

REAL WORLD

Northwestern Medicine®
Feinberg School of Medicine

Integrated HSOR Fellowship	Research Assistant Professor
2018-2021	2021-



Occupational Science

- Holistic study of human activities (“occupations”) and their influence on health
- Transdisciplinary
- Applied through occupational therapy practice

Research Foci

A Qualitative Study of Caregiving for Adolescents and Young Adults With Spinal Cord Injuries: Lessons From Lived Experiences

Carol Haywood, PhD, OTR/L,[1] Elizabeth Pyatak, PhD, OTR/L, CDE,[2] Natalie Leland, PhD, OTR/L, BCG, FAOTA, FGSA,[3] Benjamin Henwood, PhD,[4] and Mary C. Lawlor, ScD, OTR/L, FAOTA[2]

[1]Northwestern University Feinberg School of Medicine, Chicago, Illinois; [2]University of Southern California, Mrs. T.H. Chan Division of Occupational Science and Occupational Therapy, Los Angeles, California; [3]Department of Occupational Therapy, School of Health

Feature Articles

Understanding lived experiences through multiple perspectives: Caregiving as an exemplar

Carol Haywood & Mary C. Lawlor

Pages 128-139 | Accepted 28 Aug 2018, Published online: 11 Oct 2018

Cite this article https://doi.org/10.1080/14427591.2018.1521738 Check for updates

Health Policy Perspectives

Engaging Patient Stakeholders in Planning, Implementing, and Disseminating Occupational Therapy Research

Carol Haywood, Gabriela Martinez, Elizabeth A. Pyatak, Kristine Carandang

Spinal Cord. 2022 Oct;60(10):888-894. doi: 10.1038/s41393-022-00810-0. Epub 2022 May 17.

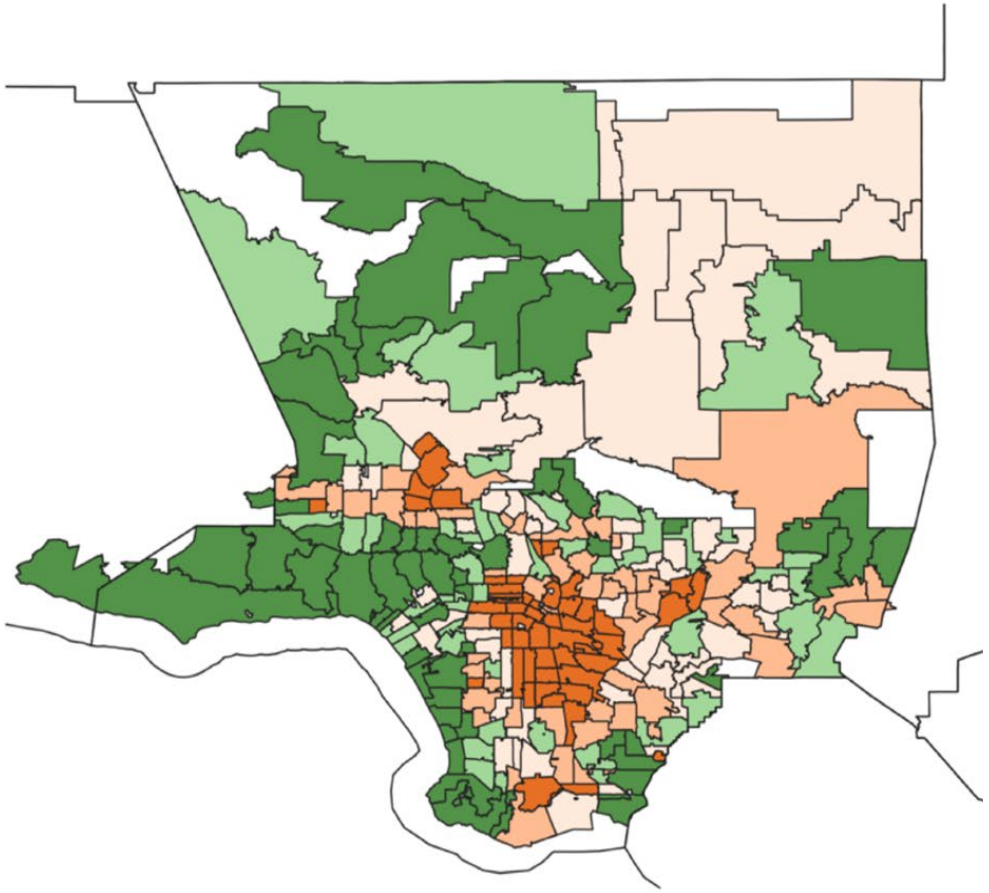
Development of the International Spinal Cord Injury Basic Data Set for informal caregivers

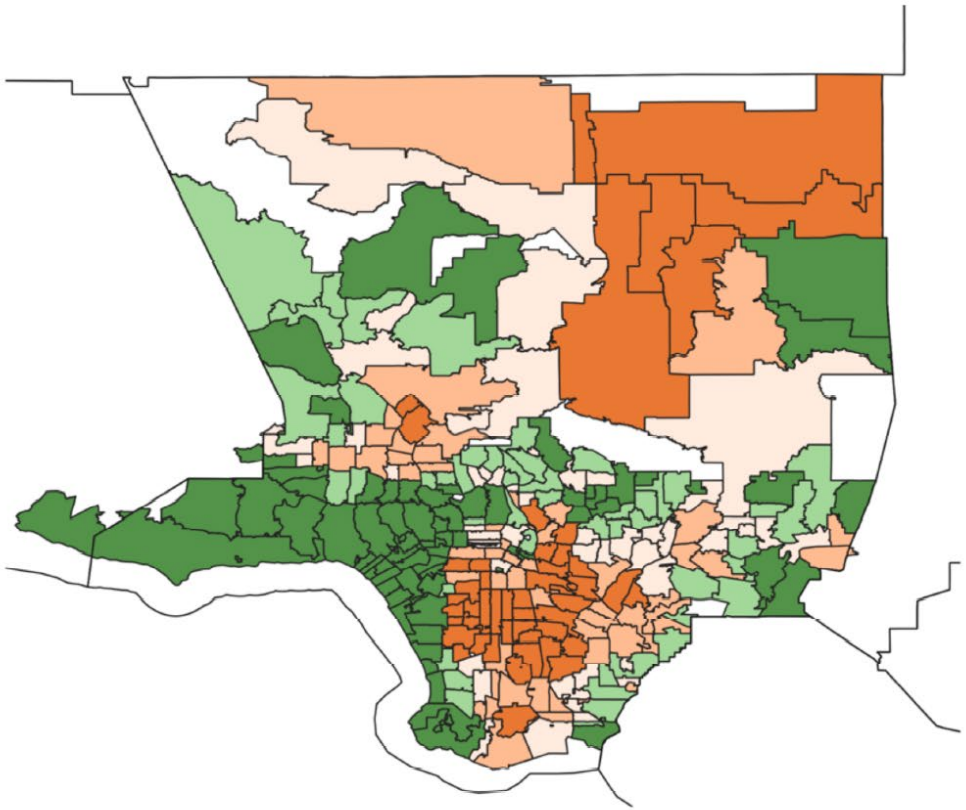
Carol Haywood [1], Rebecca Martin [2], Kathryn Dent [3], M J Mulcahey [4]

Affiliations + expand

PMID: 35581401 PMCID: PMC9110939 DOI: 10.1038/s41393-022-00810-0

Free PMC article





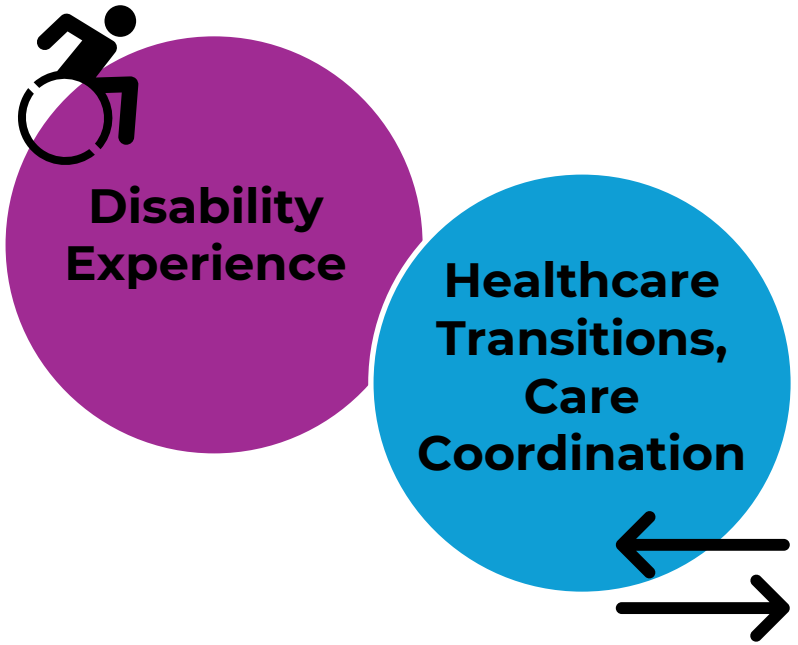
Barriers to Accessing Healthcare
- Lowest Vulnerability
- Low Vulnerability
- Moderate Vulnerability
- High Vulnerability
- Highest Vulnerability

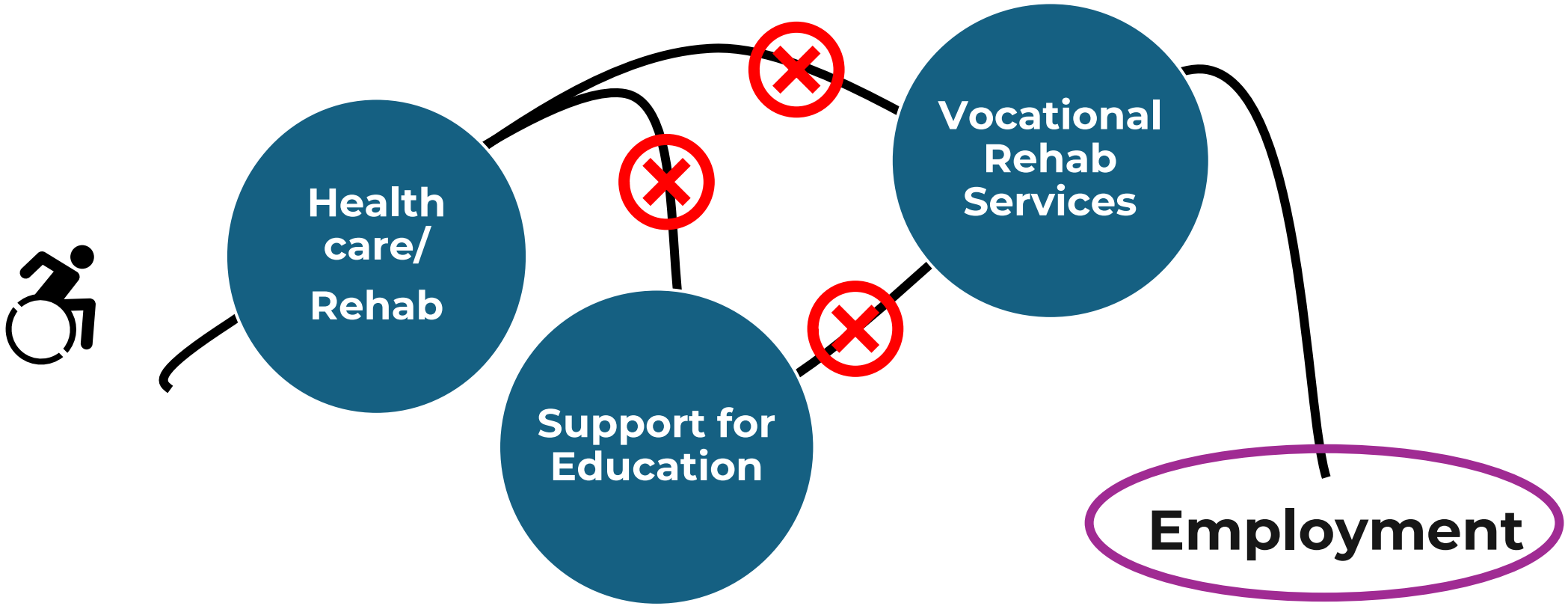
Pre-existing Health Vulnerablity
- Lowest Vulnerability
- Low Vulnerability
- Moderate Vulnerability
- High Vulnerability
- Highest Vulnerability

Los Angeles, CA

Ong et al., 2021
DOI: 10.3390/ijerph18094829

Research Foci





Research Article

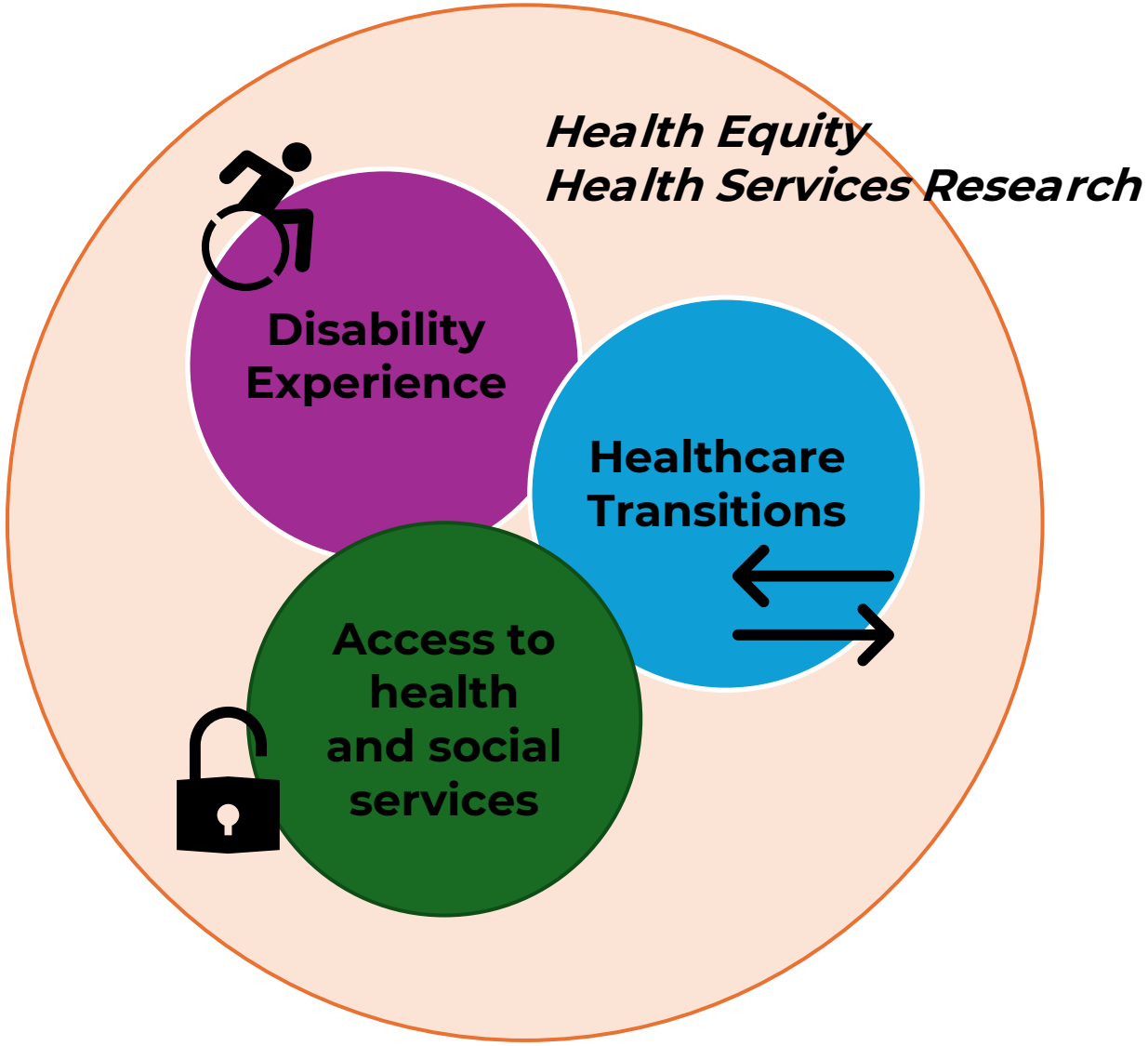
Understanding vocational rehabilitation service access among adolescents and young adults in foster care

Carol Haywood, Judy Havlicek, Vanessa V. Klodnick & Lucy A. Bilaver

Pages 497-516 | Received 29 Oct 2021, Accepted 30 Mar 2022, Published online: 17 Apr 2022

Research Foci

Research Foci



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

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

The Hypothetical Patient

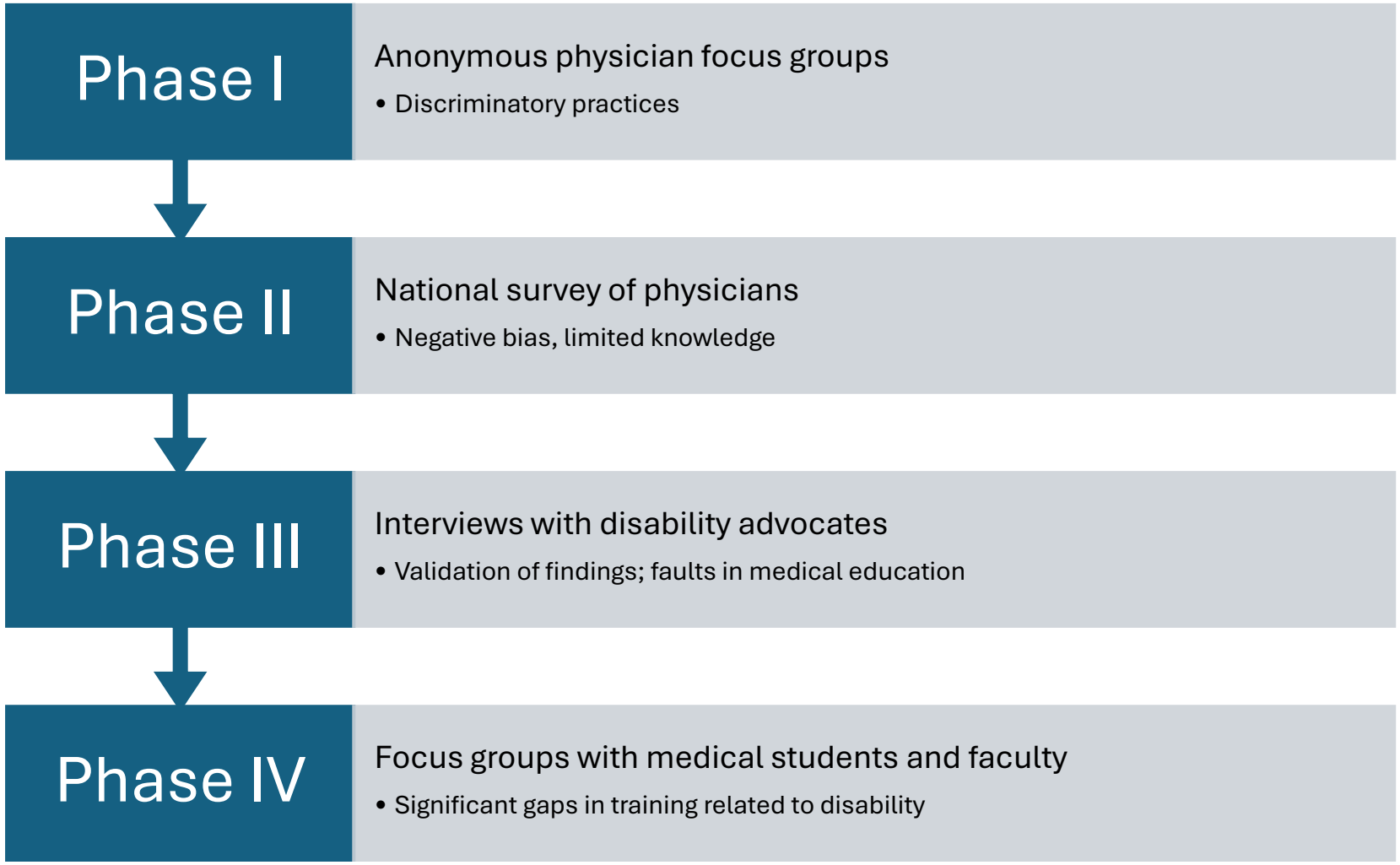
- Woman, hemiparetic due to a stroke
- Unable to bear weight, could not transfer
- 99 Kg
- Standardized script included chief complaint and medical history specific to subspecialty
- Clinical scenarios chosen by a group of internists through an iterative process

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 (unsafe)
- <10% of practices had height-adjustable tables or lifts

Physician attitudes relating to care for PWD

(R01HD091211-01A1, PI: Iezzoni)



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 Americans with Disabilities Act

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.

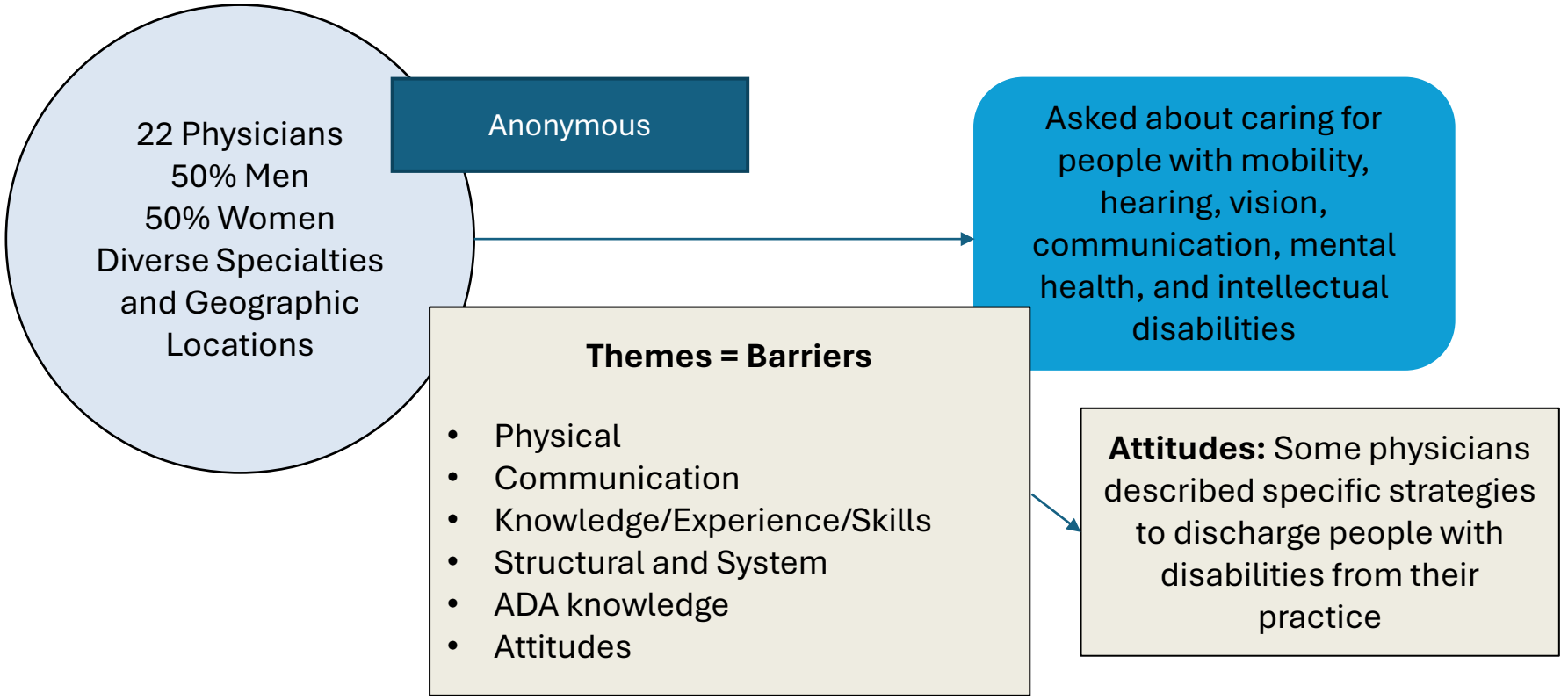
Kimberly Reimold, University of Massachusetts, Worcester, Massachusetts.

Christene DeJong, Baystate Health, Springfield, Massachusetts.

Robin Walker Sterling, Northwestern University.

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

Focus Groups



Physical Barriers

"Our medical assistants just write 'wheelchair, w/c' and the weights don't get checked until someone makes a big deal about it."

Communication Barriers

"Most of my patients have hearing aids that are not working. It's just better to use paper and pen."

Knowledge Barriers

"I don't even know [how to care for people with disabilities]. I'm not qualified."

Bias in Structures and Systems

"Seeing patients at a 15-minute clip is absolutely ridiculous. To…see a patient with disability in those timeframes is unreasonable and unacceptable…"

Gaps in Knowledge of the ADA

"I truthfully think the [ADA] 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…You just don't want to deal with them…"

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.'"

Physicians make discretionary choices.

- Physicians have the right to exercise discretion.
- Physicians do not have the right to discriminate.
- Identifying intent is difficult.
- The ADA is enforced through lawsuits.

Many physicians in our study were overwhelmed – demonstrating the problems with our health care system.

Our findings suggest that physician attitudes and bias play a role in perpetuating disability disparities.

able·ism

/ˈābəˌlizəm/ noun

A system of assigning value to people's bodies and minds based on societally constructed ideas of normalcy, productivity, desirability, intelligence, excellence, and fitness. These constructed ideas are deeply rooted in eugenics, anti-Blackness, misogyny, colonialism, imperialism, and capitalism.

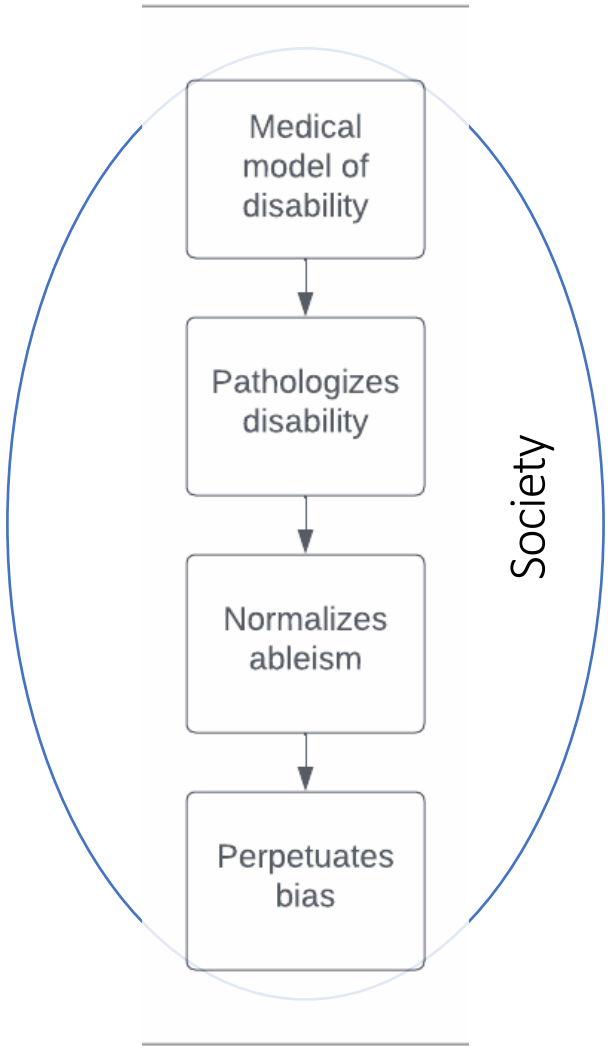
This systemic oppression leads to people and society determining people's value based on their culture, age, language, appearance, religion, birth or living place, "health/wellness", and/or their ability to satisfactorily re/produce, "excel" and "behave."

You do not have to be disabled to experience ableism.

working definition by @TalilaLewis, updated January 2022, developed in community with disabled Black/negatively racialized folk, especially @NotThreeFifths. Read more: bit.ly/ableism2022

Q: What is the role of medical education in shaping physician attitudes in care for PWD?

- Focus groups (3, all virtual)
- Probes:
  - How is disability taught in medical education?
  - What strategies may be used to advance disability-competent care through medical education?
- Recorded, transcribed, coded w/ constant comparative method
  - Deductive and inductive coding scheme



The Hidden Curriculum:

- PWD are neglected and problematized in the curriculum
- Bias against trainees with disabilities
- Ill-prepared for clinical care

If we want to make changes, we have to be able to measure them.

PROMIS Measures

- Self/parent-reported measures of global, physical, mental, and social health
- Center patient voices to improve health care

Participation in Health Care for People with Mobility-Related Disability (PwMD)

1: Generate conceptual model of participation in health care for PwMD through identification of principal factors that affect ability to participate and satisfaction with participation in health care.

H: The conceptual model will include overlapping personal, activity, and environmental factors (e.g., built, social, policy).

2: Develop item bank for a novel PROM of participation in health care for PwMD.

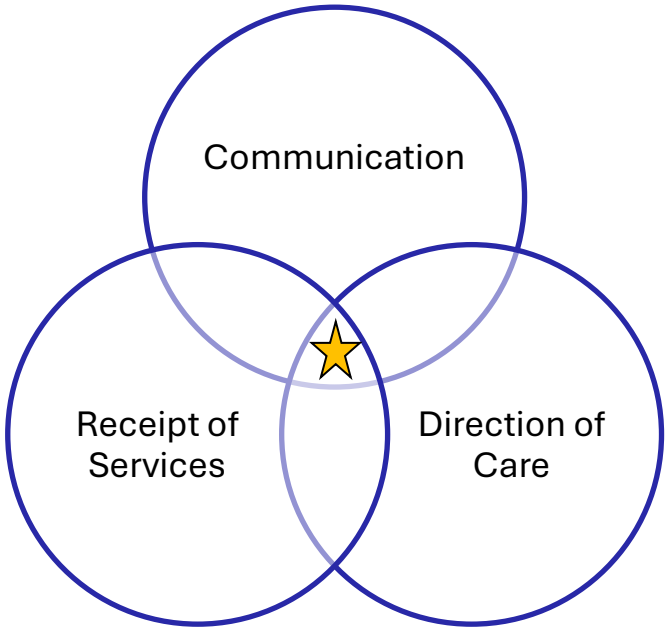
Methods

- Qualitative interviews (concept elicitation)
- Eligibility: ≥18 years, self-identified mobility-related disability, living in the community in Illinois, English speaking fluency
- Purposive sampling for maximum variation
- Community research partnership (Advisory Board)

Demographic and Disability Characteristics

	N(20)	%
Gender		
Female	11	55%
Male	7	35%
Non-binary	2	10%
Race and Ethnicity		
American Indian or Alaska native	0	0%
Asian	2	10%
Black or African American	3	15%
Hispanic or Latino	3	15%
Native Hawaiian or other Pacific Islander	0	0%
White (non-Hispanic or Latino)	11	55%
Other	0	0%
Prefer not to answer	1	5%
Annual Household Income		
Under $15,000	3	15%
$15,000 - $24,999	3	15%
$25,000 - $34,999	1	5%
$35,000 - $49,999	1	5%
$50,000 - $74,999	2	10%
$75,000 - $99,999	3	15%
$100,000 and over	1	5%
I do not know	2	10%
I prefer not to answer	4	20%
Screening survey: Disability		
Use an assistive device to move around in my environment	19	95%
Walking on smooth surfaces	16	80%
Walking on uneven surfaces	19	95%
Climbing stairs	17	85%
Reaching	6	30%
Getting up from the ground to stand	19	95%
Holding a utensil or other small object	4	20%
None of the above	1	5%
Screening survey: Barriers to health care		
Had trouble getting health care services that I needed in the past	18	90%
Physical access	14	70%
Communication	4	20%
Procedural or financial	8	40%
Other	4	20%
Geographic Residence		
City	9	45%
Suburban Area	8	40%
Rural	3	15%

Participation in Health Care Encounters



I'd have some rather urgent issues every now and then. She would give me her opinion on what she thinks we need to do next. I, of course, always had my own opinions. Then, we would fight it out. But in a good way. That's what I feel like we're participating in. She'd hear my way. I'd hear her way, and then sometimes we'd meet in the middle. Sometimes I'd go her way, or I wouldn't. But then, the next time, we were all good again. I don't know. I just felt like she listened to me, and I listened to her.

Participation = Engagement?

Patient Activation Measure

Health Care Engagement Measure

Failures in Policy

[My attempt for primary care] was abysmal. So, I tried yet another new one. I made it very clear when I made the appointment that I wanted a physical since no one has ever looked at me at all, and I have some pending surgery coming up and I want to make sure I'm okay. And I made it very clear that I wanted a physical- and a real physical, not a Medicare physical. And as soon as I went there, I knew it wasn't going to work out. First of all, the room was basically too small for me, so they had to move a bunch of chairs out of the way. And then I look at this table that's 10 feet high in the air, I'm like, ‘Hmm, this isn't going to happen today.’

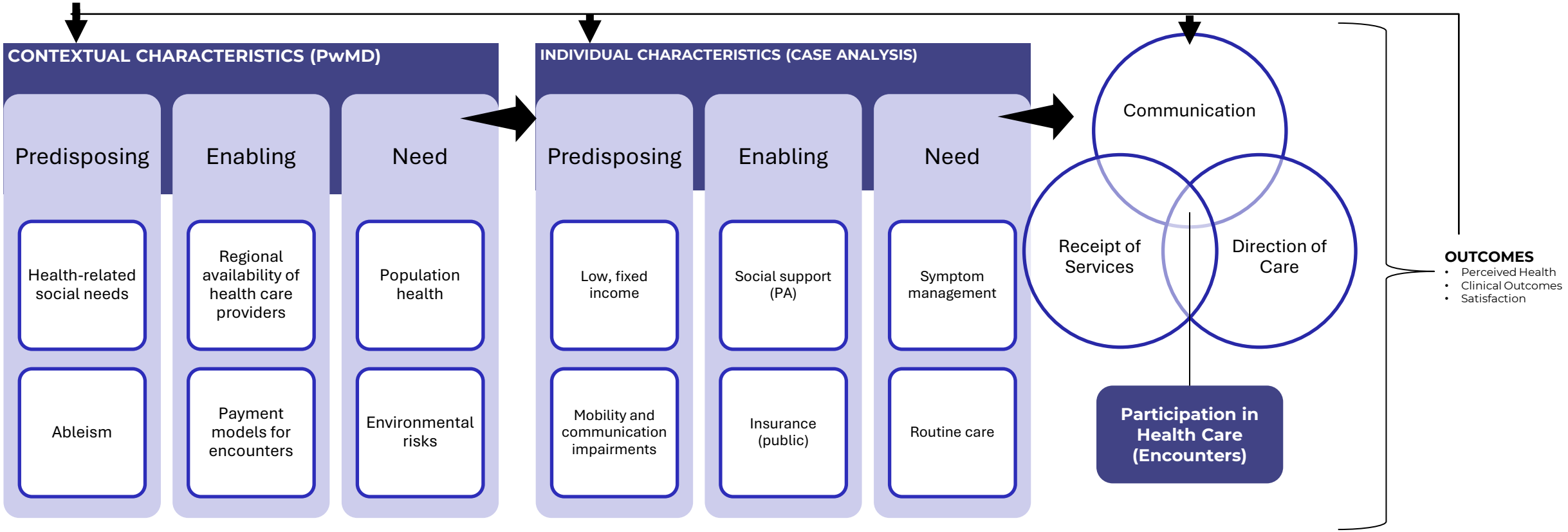
So, I thought, ‘Well, okay, maybe she can pivot and figure out how to do it from the chair rather than on a table.’ So, she starts doing the whole Medicare BS physical, which is garbage, which I would not waste garage parking fees on that. And I said, ‘No, no, no, I'm sorry. You misunderstood. I am here for a real physical.’ She goes, ‘That's what I'm doing.’ And I said, ‘No, you're not. Drawing hands on a clock is not a real physical… That's not what I'm looking for.’ She goes, ‘I'm required to do this by Medicare.’…

And then I did say… what kind of bad intestinal problems I've been having. And she goes, ‘Yeah, we can talk about that next year when you come back.’ I'm like, ‘All right, well first of all, I'm not coming back. Secondly, I'll be dead if I wait a year or so. I don't think so.’

Providers and Clinics Unprepared to Care for PwMD

So, you know when you go to the doctor and somebody shoves you in a room and they close the door and then the doctor knocks on the door and, "Hi, I am Dr. Joe Blow"? Well, you should see their face when they see how you're sitting there [in a wheelchair], right?
It's like, "Woo. Nobody warned me on that one."

Applying Andersen's Behavioral Model of Health Services Use



Andersen & Davidson, 2007

Conclusions and Implications

- Access to health care services is a primary driver of participation in health care for PwMD.
- Many barriers to participation in health care for PwMD are modifiable.
- Routine assessment of **patient-reported participation** in health care may serve as an essential indicator of patient support needs to advance health care access (e.g., disability-related accommodations).

“System” Level Challenges to Tackle!

- Accommodations (e.g., height adjustable tables) are often not present
- Physicians and staff may be biased against people with disability
- Disability is not taught in medical school or residency
- Disability is not part of hospital or clinic orientation or training
- Disability and related accommodation needs are not consistently documented in medical records or scheduling systems

Building Tools for Equity…

Disability status and accommodation needs in the EHR

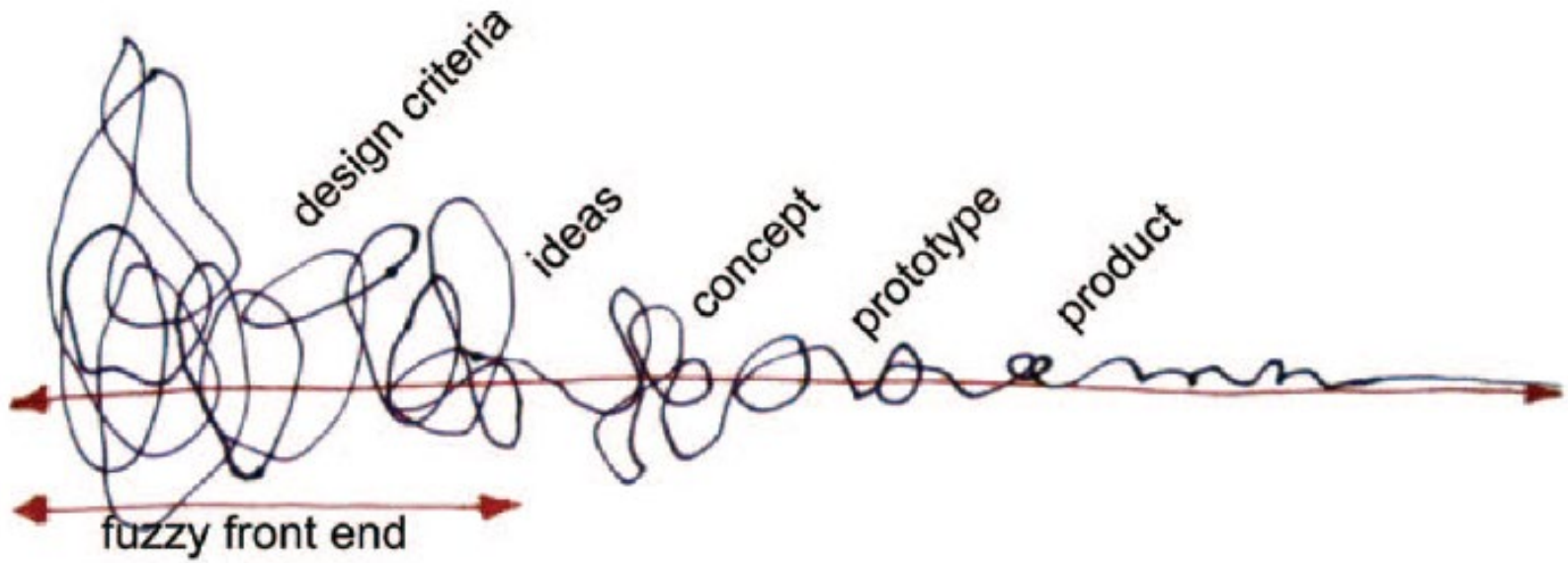
- PI: Megan Morris (University of Colorado); Site PI: Lagu; Co-I: Haywood
- Funding: NIDCD (09/22 – 06/27)
- Primary focus on communication-related disabilities

Patient-facing tools to report disability and accommodation needs

- PI: Haywood; Mentors/Collaborators: Morris & Lagu
- Funding: Craig H. Neilsen Foundation (05/24 – 04/26)
- Primary focus on mobility-related disabilities

Background

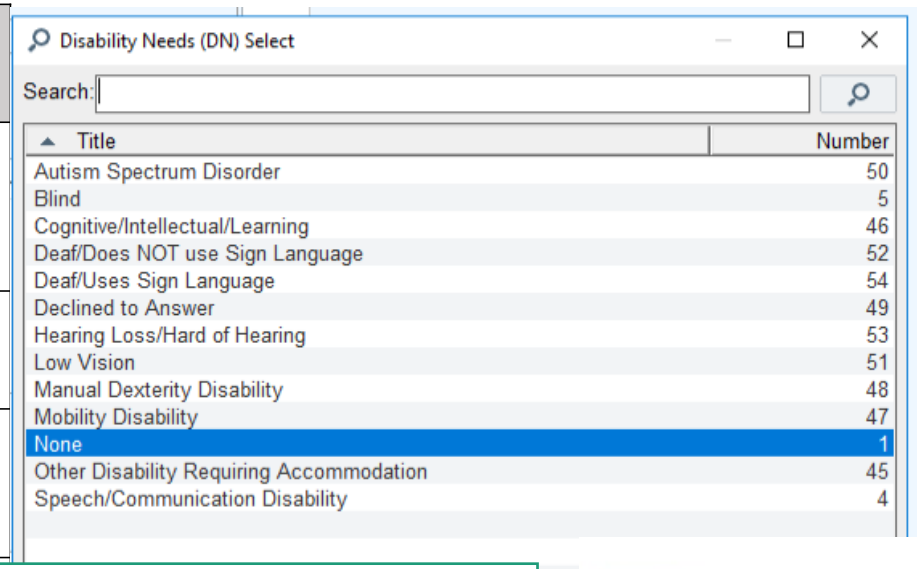
- Health care organizations are required by multiple federal laws (e.g., ADA, ACA) to provide disability accommodations to patients with disabilities
  - *BUT:* Organizations/providers often do not know who has a disability
- The DOJ has outlined requirements for health care organizations to routinely collect disability status
- In July 2022, the Office for the National Coordinator for Health Information Technology (ONC) released requirements for all EHRs to include standard disability data elements
- As of November 2022, Epic Foundation include the standard disability data elements, but not the modules or tools to support collection and documentation



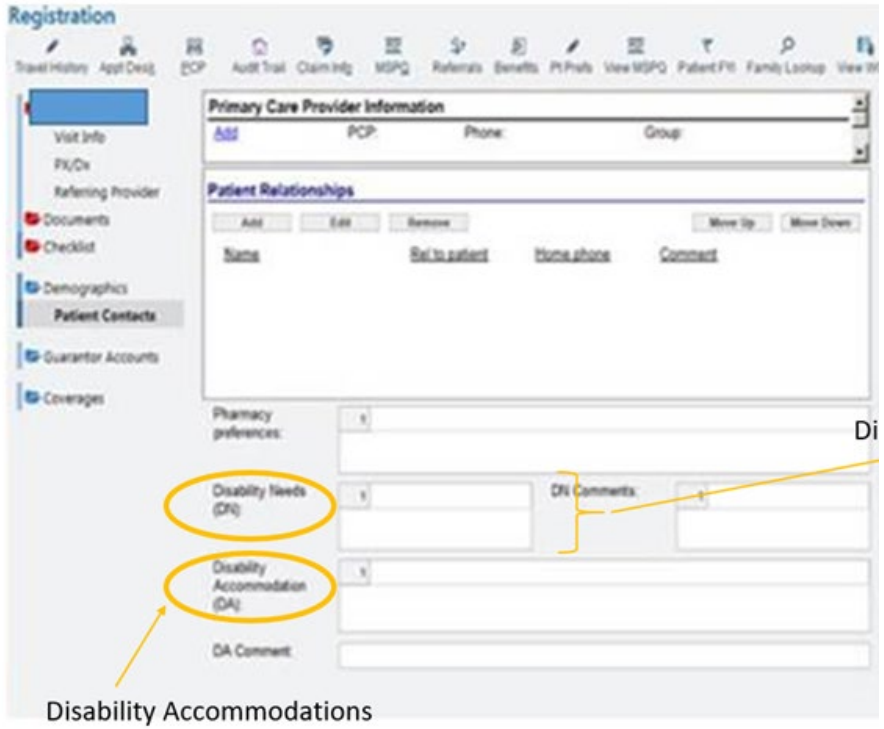
co-designing

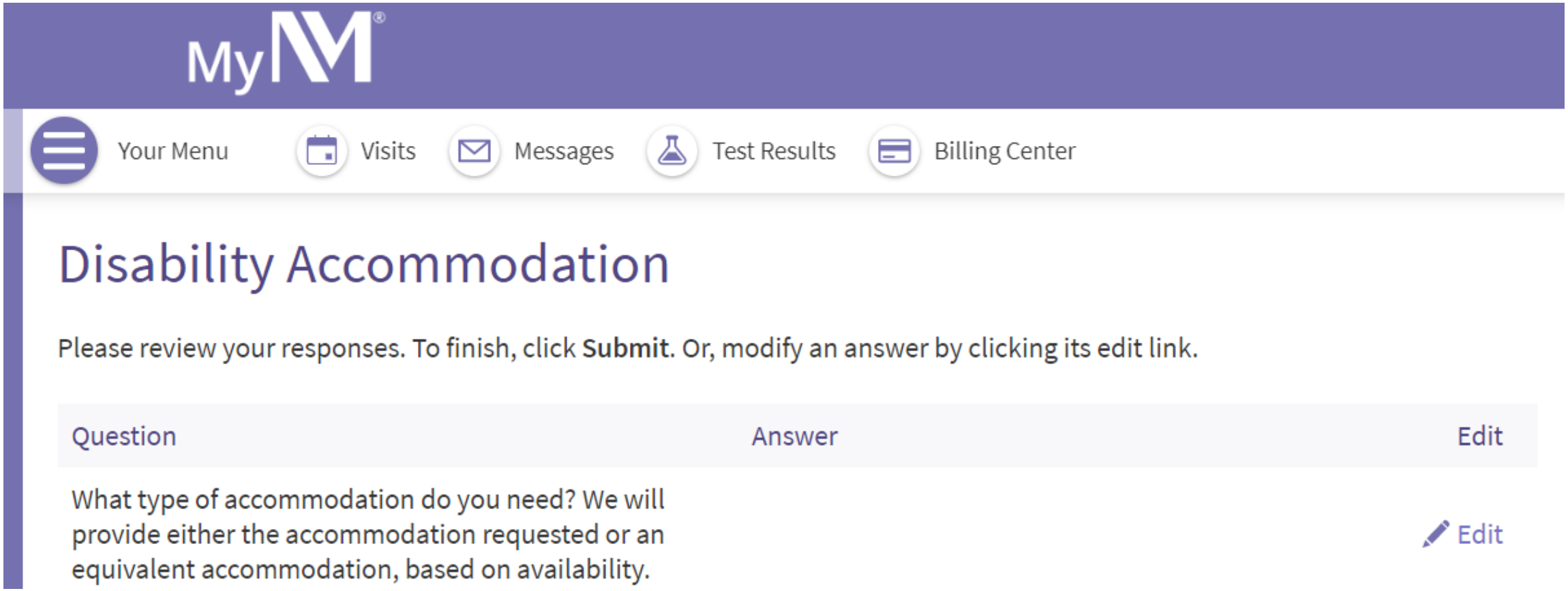
Sanders & Stappers, 2008

Disability Category	Patient-Centered Disability Questionnaire
General Screening	Due to a disability, do you need any additional assistance or accommodations during your visit?
Hearing	Are you deaf, or do you have serious difficulty hearing?
Vision	Are you blind, or do you have serious difficulty seeing, even when wearing glasses?
Cognition	Do you concer
Mobility	Do you climbi
Activities of Daily Living (ADL)	Do you bathing?
Instrumental Activities of Daily Living (IADL)	Do you have difficulty doing errands alone such as visiting a physician's office or shopping?
Communication	Using your usual language, do you have difficulty communicating (for example, understanding or being understood)?



University of Colorado Health System




MyNM
Your Menu
Visits
Messages
Test Results
Billing Center
Disability Accommodation
Please review your responses. To finish, click Submit. Or, modify an answer by clicking its edit link.
Question
Answer
Edit
What type of accommodation do you need? We will provide either the accommodation requested or an equivalent accommodation, based on availability.
Edit

Implementation of Disability-Related Accommodations in Clinical Practices

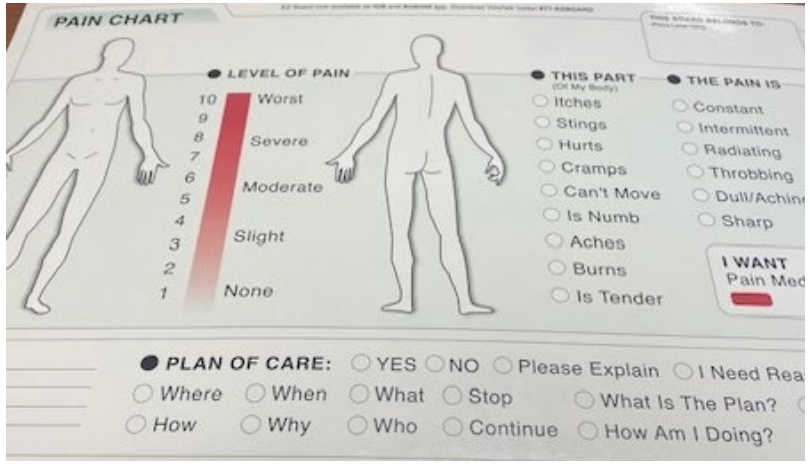
i.e., Response to accommodation requests…

Communication examples:

communication boards, voice amplifiers, CART services, ASL interpreters

Mobility examples:

wheelchair accessible scales, transfer lifts, adjustable heigh exam tables, personal assistance (dressing, transfers)



Standards for 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

Ideal Programmatic Access

- Universal accessibility of scheduling, staffing, and other administrative resources.
- 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 her arrival

Guidelines and Recommendations for Disability-Competent Health Care

	Before an Appointment	During an Appointment	After an Appointment
Physical Access: accessibility of the healthcare environment	-Ensure entrances and walkways are accessible and free of potential barriers (e.g., boxes, equipment).	-Provide wheelchair-accessible scales and adjustable-height exam tables.	-Assess and create accessibility in spaces that PWD experienced trouble navigating through.
Policy / Procedural Access: policies and procedures support accessibility of spaces	-Ask patients about accommodation needs; document in the EHR to prepare for appointment.	-Allow essential caregivers and service animals . -Make care decisions independent of disability status.	-Collect and utilize disability data as an important factor in quality improvement initiatives.
Disability Etiquette: specific to patient interactions	-Discuss procedures, treatments, or other elements of a visit before they are performed.	-If offering assistance, wait until it is accepted before proceeding. -Speak and direct questions to the patient (not companions or personal care attendants).	
Provider Training Needs: what clinicians and staff should know about to care for PWD	-Staff should be trained on accessible equipment use and patient transfers to maximize safety for both staff and patients.	-Awareness of disability bias. -Clinicians should not make assumptions about what a patient may or may not need.	-Clinicians should be trained to support interdisciplinary care coordination for complex conditions.

Occupational Science

Critical Theory

Disability Studies

Health Services Research

Implementation Science

Organizational Change

Communication

Health Equity

User-Centered Design

Documentation Tools

Clinical Care Guidelines

Health Care Access & Quality

Scientific Reports

P/policy Advocacy

Institute of Clinical & Translational Sciences at Washington University in St. Louis. Translational Science Benefits Model website. https://translationalsciencebenefits.wustl.edu. Published February 1, 2019. Accessed June 10, 2024.

Northwestern Medicine®
Feinberg School of Medicine

Thank you!

carol.haywood@northwestern.edu