Health Equity Rounds

Department of Pediatrics Grand Rounds

June 20, 2024

Pediatrics Grand Rounds

Text: 608-260-7097

Code: HOSVOF

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UNIVERSITY OF WISCONSIN
SCHOOL OF MEDICINE AND PUBLIC HEALTH

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School of Medicine and Public Health
UNIVERSITY OF WISCONSIN–MADISON

Conflict of Interest

The planners and speakers of this CE activity have no relevant financial relationships with ineligible companies to disclose.

The speakers do not intend to discuss any unlabeled or unapproved use of drugs or devices.

Please take a moment at the end of the session to complete your evaluation.

Thank you!

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Health Equity is the opportunity for everyone to attain their full health potential.

Goals of Health Equity Rounds

- Identify and analyze the effects of implicit bias and structural racism in clinical scenarios.
- Describe the historical context and present-day role of structural racism and its impact on the health care system.
- Employ evidence-based tools to recognize and mitigate personally held implicit biases.
- Use newly learned strategies to combat structural racism at the institutional level and reduce the impact of implicit bias on patient care and interprofessional relationships.

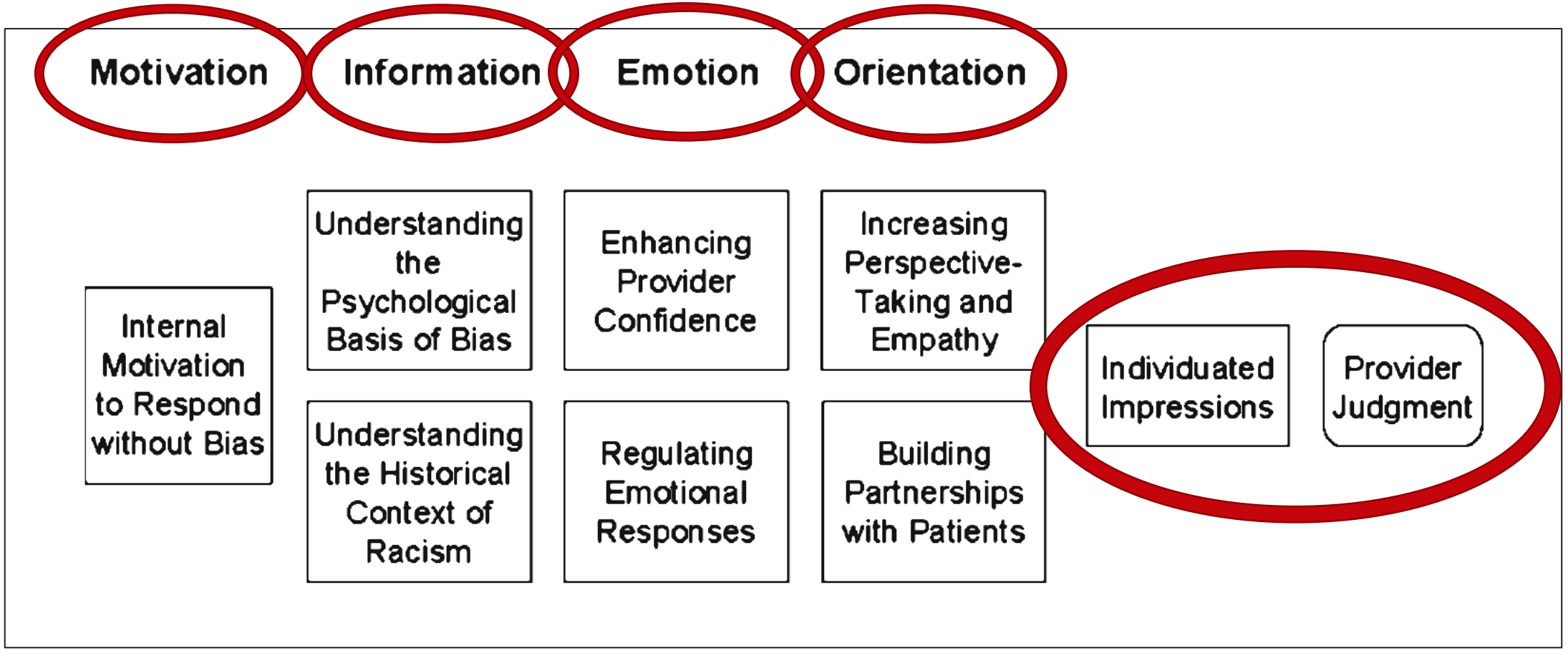
What is Health Equity Rounds?

- Case-based educational presentation
- Opportunity to review objectively
- Intervention that will enable participants to recognize and act on identified health inequities

Ground Rules

- All participants should participate freely and respectfully.
- Providers involved were acting in what they felt to be in the patient's best interest.
- Patient and provider team confidentiality is important.
- Lean into discomfort.

Conceptual Model



Burgess D, van Ryn M, Dovidio J, Saha S. Reducing racial bias among health care providers: lessons from social-cognitive psychology. J Gen Intern Med, 2007 Jun

Learning Objectives

Upon completion of this educational activity, members of the healthcare team will be able to:

1. Examine the history of disability and the evolution of the disability rights and disability justice movements.
2. Define ableism and ability-based privilege and the impact this oppressive system has on healthcare.
3. Identify ableist language and culture in our society and in medicine.
4. Increase knowledge on ways to interrupt ableism and apply disability-conscious best practices.

Vignette

Case

- Teenage female who uses a wheelchair presents with her parent for a well child check. They arrive 10 minutes after the appointment time because all the accessible parking spaces were full in the parking lot.
- During check-in the Medical Assistant asks the parent how much the child weighs. The parent says, “I don’t know” and asks if there is a wheelchair scale they can use. The MA replies “There is, but we would have to go down the hall and you are already late.”
- The provider enters the room and greets the parent. The provider compliments the parent on the “cute” outfit the patient is wearing.
- The provider asks the parent how things have been going for the patient. The parent attempts to involve the child in the discussion but the provider continues asking the parent questions.
- The provider reviews the Wisconsin Immunization Registry and comments that the child is listed as due for HPV vaccine, but that vaccine “doesn’t really apply” to the patient.

Presentation

An Introduction to Ableism and its Impacts on Medicine

SMPH/UW Health Diversity, Equity & Inclusion

Patty Cisneros Prevo
she/her
Program Manager
Diversity, Equity & Inclusion
pcisnerosprevo@uwhealth.org

Role Overview

- Serve as a DEI business partner and link between the SMPH/UW Health DEI Office and the Department of Medicine and the Carbone Cancer Center
- Ensure DOM/UWCCC receive the necessary support from the DEI Office for the intentional implementation of all SMPH/UW Health DEI strategic priorities
- Engage with DOM/UWCCC leaders to achieve outcomes related to DEI initiatives
- Chair DOM DEI Committee and UWCCC Diverse Workforce and Equity Transformation Committee (DWETC)

My Background

PERSONAL
- 1996 Acquired spinal cord injury

SPORT
- 1996 Introduced to wheelchair basketball by physical therapist
- 1997 Introduced to collegiate wheelchair basketball and the Paralympic Games
- 1999 Named to Team USA
- To date- 3x Paralympian, 2x gold medalist & captain of Team USA

ADVOCACY
- Appointed to the Congressional Commission on the State of the Olympics & Paralympics
- Author of *Tenacious: Fifteen Adventures Alongside Disabled Athletes*
- Advocate and consultant on disability

Collaboration & Appreciation

We wish to express our deepest appreciation to the following individuals for support with this content:

Mari Magler, Director, at the University of Wisconsin-Madison McBurney Disability Resource Center

Ruben Mota, University of Wisconsin-Madison Americans with Disabilities Act (ADA) Coordinator

The University of Wisconsin-Madison Committee on Disability Access & Inclusion (CDAI)

Disclaimer

By understanding the experiences of people with disabilities we can empathize better and create a more inclusive environment that allows all people, including disabled people, the agency to reach their goals and participate fully in society.

Disclaimer: I understand disability is not a monolith. Every person's experience with disability can be very different and nuanced. I am sharing general definitions of disability and action items in interrupting ableism.

Disability

Disability

To inform ourselves on the variety and nature of diversity within disabilities, the table below features high-level categories of disabilities with examples and links to detailed descriptions.

Disability type	Examples
Visual Disabilities	Blind, low vision, color blindness
Auditory Disabilities	Deaf, hard of hearing
Motor Disabilities	paralysis, cerebral palsy (CP), facial muscular impairments
Cognitive Disabilities	learning disabilities, traumatic brain injury (TBI), attention deficit disorder (ADD), autism, dementia
Mental Health Conditions	bipolar, depression, anxiety, post-traumatic stress disorder (PTSD), schizophrenia

Non-apparent disabilities

Disabilities aren't always immediately apparent, or even visible, to others. Apparent disabilities can sometimes be accepted or normalized in certain settings while non-apparent disabilities can be stigmatized, sometimes questioning the validity of the disability.

History

Disability History

Pre- and Early Colonial Period

- Indigenous North America – before 1492
  - Most communities did not have a word for disability
  - Indigenous focus was on harmony between body, spirit, and mind
- Colonial Communities – 1492 – 1700
  - Bodily variations not significant if can work
  - Community care expected for cognitive/mental disabilities

Approaching Independence

- Late Colonial Era – 1700 – 1776
  - Asylums only used as a last resort
  - Disability was used to legitimize slavery
- Creating Citizens – 1776 – 1865
  - Shift from religious to medical explanation
  - Disability-specific institutions emerge

Civil War & Industrialization

- Institutionalization of Disability – 1865 – 1890
  - Adaptive devices; first wheelchair patent
  - Civil War pension system
- The Progressive Era – 1890 – 1927
  - Disability as moral defect; rise of eugenics
  - 1916 polio epidemic saw children removed from their homes

Approaching Civil Rights

- Pre-Civil Rights Era – 1927 – 1968
  - "We don't want tin cups, we want jobs"
  - Activists began to fight ableism; understand intersectionality
- Rights and Rights Denied – 1968 – present
  - Disability rights movement energized and inspired by civil rights movement

Nielsen, Kim E. A Disability History of the United States. Beacon Press, 2012 Oct

Activism

Disability Rights

- Independent living movement focused on:
  - Self-determination
  - Community living
  - Removal of societal barriers
- Independent living activists began addressing architectural, employment, and transportation barriers

Ed Roberts, Bradley Lomax, and Judy Heumann

Disability Justice

- "Disability Justice was built because the Disability Rights Movement and Disability Studies do not inherently centralize the needs and experiences of folks experiencing intersectional oppression, such as disabled people of color, immigrants with disabilities, queers with disabilities, trans and gender non-conforming people with disabilities, people with disabilities who are houseless, people with disabilities who are incarcerated, people with disabilities who have had their ancestral lands stolen, amongst others."
- 10 Principles of Disability Justice

Patty Berne, Mia Mingus, and Stacey Milbern

Nielsen, Kim E. A Disability History of the United States. Beacon Press, 2012 Oct

Sins Invalid. https://www.sinsinvalid.org/

Ableism

What is ableism?

The act of prejudice or discrimination against people with disabilities and/or the devaluation of disability.

Kattari, S.K. Examining Ableism in Higher Education through Social Dominance Theory and Social Learning Theory. Innov High Educ 40, 2015 Feb

Working Definition of Ableism

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 that 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.

Ability-based Privilege

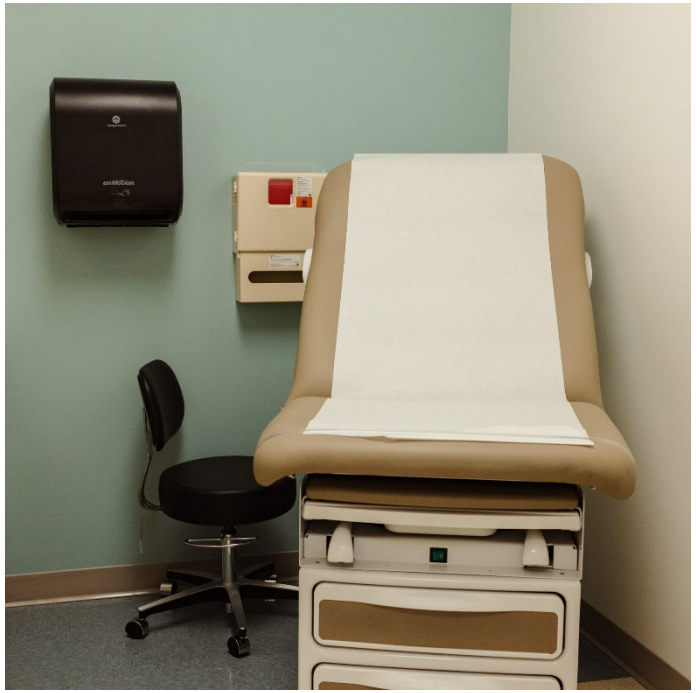
A set of unearned privileges held by people without disabilities.

Kattari, S.K. Examining Ableism in Higher Education through Social Dominance Theory and Social Learning Theory. Innov High Educ 40, 2015 Feb

Everyday Ableism

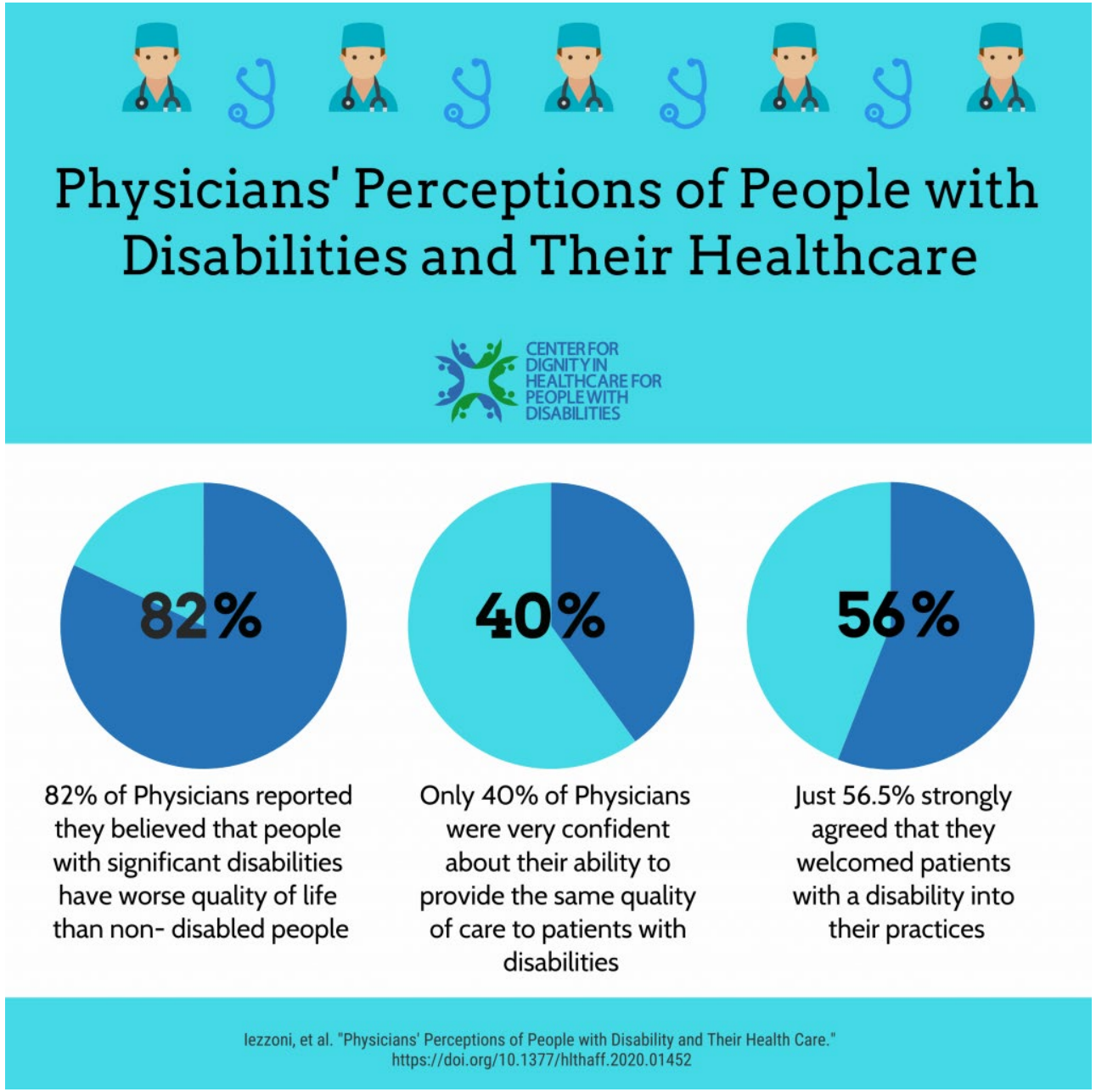
Ableism appears when we fail to design inclusively. Examples of everyday situations where ableism leads to making decisions without considering inclusion:

- Holding appointments in inaccessible spaces
- Producing videos without captions
- Creating inaccessible websites
- Refusing to provide accommodations



Ableism & Healthcare

Ableism in Healthcare



Iezzoni, et al. Physicians' Perceptions of People with Disability and their Health Care. 2021 Feb. http://doi.org/10.1377/hlthaff.2020.01452

THE PRACTICE OF MEDICINE

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

Barriers to Caring for People with Disabilities
Physical accommodations
Communication accommodations
Knowledge, experience, and skills
Structural barriers
Attitudes toward people with disabilities
Knowledge of the ADA

Many physicians expressed explicit bias toward people with disabilities.

Lagu T, et al. *Health Affairs*, 2022.

Themes illustrating barriers to caring for disabled people:

- **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.*
- **Communication accommodations**
  - *I use paper and pen. And most of my patients have hearing aids that are not working…*
- **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**
  - *I have, like, 18 pages of [disability] documentation—of which 1 paragraph is essential and necessary for me to care for the patient.*
- **Attitude toward people with disabilities**
  - *We've gotten to a point in society where a lot of people are wanting some form of accommodations, and a lot are illegitimate. They want their pet peacock on the airplane and whatnot, and it makes it very difficult.*
- **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…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.*

Lagu, Tara, Haywood, Carol, Reimold, Kimberley, DeJong, Christene, Sterling, Robin Walker, and Iezzoni, Lisa I. 'I Am Not The Doctor for You': Physicians' Attitudes About Caring For People With Disabilities, 2022 Oct

“Nominated and Appointed” – PICU provider attitudes towards their care of medically complex, neurologically impaired children

PICU providers’ experiences:

- Witness CMC with NI as a growing population
- Experience tension with the “traditional perception” of their work
- Need to adapt to and find meaning in caring for CMC with NI and their families
- Feel ambivalence and mixed emotions when caring for CMC with NI

Bleed EJ, et al. “Nominated and Appointed” – PICU provider attitudes towards their care of medically complex, neurologically impaired children. PAS abstract presentation, 2023.

Americans with Disabilities Act (ADA)

- Civil rights law that prohibits discrimination on the basis of disability.
- Ensures ***reasonable*** accommodations to individuals with disabilities.

Burden of Proof

People with disabilities often need to prove their disabled status to be determined eligible for a variety of services and accommodations for:

- Disability income
- Accessible housing
- Transportation
- Education (K-12- higher education)
- Employment

Ableist Language

Harmful to mental health community	Negative attribution of disability	Outdated language
psycho	Deaf and dumb	hearing-impaired
insane	Turn a blind eye to…	visually-impaired
crazy	What? Are you Deaf/Blind?	

Ableist Language in Healthcare

Euphemisms	Harmful to cognitive disabilities	Outdated language
disAbled	frequent flyer	wheelchair bound
differently abled	rock/rock garden	lame
physically challenged	vegetable/vegetable patch lame	special needs
creatively abled	idiot	handicapped

Interrupting Ableism

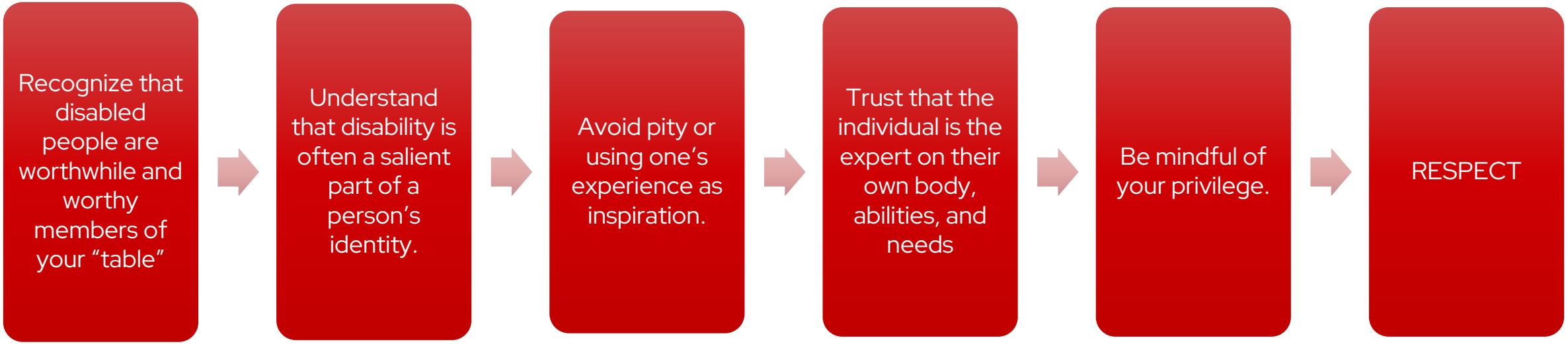
Disability Justice and Anti-ableism Best Practices

Some disability-conscious best practices for patient care include:

- Ask the patient/parent if they feel comfortable with the terms/diagnoses that you use or that they might find in medical documentation.
- Ask the patient and/or ask a caregiver what is the best way to address, communication with, and interact with the patient.
- Be respectful of patient autonomy by avoiding paternalistic pats on the head or other mannerisms, nicknames, or touching that could be demeaning.
- Ask before touching or moving a patient or their wheelchair/mobility device.
- Examine patients with disabilities as close to how you would examine any other patient.
- Children with disabilities deserve the same standard of care as non-disabled children, but often key aspects of child health maintenance are neglected for children with disabilities.
- Ask patients or parents if they have had accessibility issues with your clinic and be prepared to address any issues that you are alerted to.
- Ask health care team members and staff if they are comfortable with the needs of patients with disabilities.
- Ensure all adaptive medical equipment is present and working for those with a disability.

Lunsford, Christopher D., Quirici, Marion. Disability Justice and Anti-ableism for the Pediatric Clinician.

Tips on Practicing Anti-Ableism



Scenario reimagined

- Teenage female who uses a wheelchair presents with her parent for a well child check. They arrive on time because accessible parking spaces were available.
- The MA notes the patient is a wheelchair user and works with a colleague to swap for a bigger room that can better accommodate the patient. During check-in the Medical Assistant states “Let’s pop down the hall to use the wheelchair scale to weigh you.” The MA confirms the weight of the wheelchair and enters an accurately calculated weight for the patient.
- The provider enters the room and greets the patient. She asks how school is going and what activities the teen plans to do this summer.
- The provider reviews the Wisconsin Immunization Registry, notes the patient is due for HPV vaccine, and makes a plan with the patient and parent to administer the vaccine at the end of the visit.
- After obtaining an initial history from the patient, the provider asks the parent to step out of the room per usual routine for adolescent patients.

Thank You!

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