Disability Justice in Healthcare: Promoting Anti-Ableism in Medical Settings

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Disclosures

- Dr. Andrews is the author of the book Disability as Diversity and receives royalties from its sales; this book will be cited during this presentation.
- This presentation is entirely independent from Dr. Andrews' employment with the Veterans Health Administration and the opinions expressed in this presentation in no way reflect those of the VHA or the federal government.

Learning Objectives

1. Recognize how ableism can operate implicitly and subtly.
2. Name two types of microaggressions toward people with disabilities.
3. Describe one anti-ableist practice to promote culturally competent healthcare.

Brief Introduction

- I proudly identify as a Disabled amputee woman
- Pronouns: (she/her/hers)
- Located in Austin, TX

Disability as Diversity

- Disability included in most professional and medical definitions of diversity
  - But rarely is disability integrated or included in discussions around diversity
- Disability is often viewed through the medical model as an individual problem rather as a diverse social, political, and cultural experience
- Too often the focus of disability is restricted to the requirements of the ADA, such as accessibility issues.
  - These aspects of the disability experience are only part of a much greater cultural context

(Andrews, 2019)

Disability as Diversity

- Too often, disability is conceptualized as a health outcome to be avoided rather than a distinct sociopolitical and cultural group whose health is overlooked.
- Although health status and disability are concepts that can overlap, when they are used synonymously, efforts at health promotion and disease prevention for disabled people are undermined.

Disability as Health Disparity

- Health Disparities
  - Differences in health outcomes at the population level
  - Linked to a history of social, economic, or environmental disadvantages
  - Regarded as avoidable
- As a group, people with disabilities fare far worse than their nondisabled counterparts across a broad range of health indicators and social determinants of health

Social Determinants of Health

- Social determinants of health directly influence the health status of disabled people, increasing morbidity and mortality rates.
- Poorer social determinants of health for disability include decreased income, housing and transportation problems, and social isolation.
- Compared to persons without disabilities, persons with disabilities are more likely to be unemployed and live in poverty
  - Despite this, people with disabilities incur much higher health care costs than their nondisabled peers.
- Disabled patients are more likely than non-disabled people to report low satisfaction with their health care.

(Frier et al., 2018)

Social Determinants of Health

- Other structural & systemic biases experienced by persons with disabilities include
  - Lack of professional training and competency of providers
  - Poor access to usable and adapted or specialized examination and diagnostic equipment, as well as effective communication
  - Lack of or inaccurate health knowledge and education
- Exclusion from public health and biomedical research studies
  - Unintended consequence of oversight: overprotective attitudes toward those at risk for exploitation

(National Council on Disability, 2009; Pendo, 2008)

Disability & Health

- Adults with disabilities are 2.5 times more likely to report skipping or delaying health care because of cost
- Women with mobility limitations are less likely to be current in mammograms and Pap tests.
- Some also have higher rates of newly diagnosed diabetes
- Percentages of cardiovascular disease are 3 to 4 times higher
- Although they have higher rates of chronic diseases than the general population, adults with disabilities are significantly less likely to receive preventive care.
  - As an illustration, people with cognitive limitations are up to 5 times more likely to have diabetes than the general population

(National Council on Disability, 2009; Pendo, 2008)

Disability & Health

- Disability status is as great or greater a risk for unintentional injury than age, sex or gender, race, or education.
- People with disabilities are 1.5 times more likely to be victims of nonfatal violent crimes than people with no disability
- More than twice as likely to report rape or sexual assault compared with people without a disability.
- Women are victimized more often
- People with cognitive disabilities have the highest rates of violent victimization.
- Both men and women with disabilities are at significantly increased risk for intimate partner violence

(National Council on Disability, 2009; Pendo, 2008)

Ableism in Health Care – Clinical Encounters

- Adults with disabilities are more likely to have had a clinical encounter where the health provider did *not*:
  - Listen carefully to them
  - Explain things in a way they could understand
  - Show respect for what they had to say
  - Spend enough time listening to them

(Smith, 2009)

Ableism in Health Care – Provider Knowledge

- Research demonstrates that healthcare providers are often unsure how to interact with and treat disabled patients and feel uncomfortable
- Yet rarely are attitude or knowledge issues considered or addressed.
- Disabled patients consistently report provider discomfort and negative attitudes, lack of provider skill or knowledge, misinformation about disability, inappropriate assumptions about their needs, and communication breakdowns.

(Iezzoni & Long-Bellil, 2012; Sharby et al., 2015)

Ableism in Health Care - Attitudes

- Attitudes of physicians and other health care providers toward persons with disabilities are as negative (or worse) than those of the general public (National Council on Disability, 2009; Pendo, 2008).
- The difference between health care providers and persons with disabilities in evaluating life with disability is striking.
  - Survey of attitudes of emergency care providers, only 18% health care providers believed they would be glad to be alive with a severe spinal cord injury, compared to 92% of persons with a high spinal cord injury who reported they were glad to be alive (Gerhart et al., 1994).

National Physician Survey

- In a survey of 714 practicing US physicians nationwide
  - 82.4 % reported that people with significant disability have worse quality of life than nondisabled people.
  - Only 40.7 % of physicians were very confident about their ability to provide the same quality of care to patients with disability
  - Just 56.5 % strongly agreed that they welcomed patients with disability into their practices
  - 18.1% percent strongly agreed that the health care system often treats these patients unfairly

(Iezzoni et al, 2021)

Medical System – Medical Model

- Medical establishment based on the medical model of disability
- Providers often harbor fixed and fundamentally flawed assumptions about disability.
- Assumptions continuously reinforced by the medical model of disability in which they have been trained and operate
- Often directly at odds with how disability communities understand the meaning of disability and with how disabled people experience their own lives.
- Medical experts have inaccurate perception of the quality of life of disabled people
  - Systematically rate the quality of life lower than the average non-disabled person does

(Peña-Guzmán & Reynolds, 2019)

History of Ableism in Health Care

- The United States has a long history of excluding and mistreating persons with disabilities.
  - Segregation and stigmatization; institutionalization
- Relies on resources that were not designed with disabled people in mind
- Medical information is wholly insufficient to understand the lived experience of person with a particular impairment
- Disability experience saturated with social, cultural, political, and historical complexities

Distrust of Medical Institution

- Health care providers are part of an institution with a long and dark history concerning disability.
- Historically, medicine has played a central role in the construction of disability as both spectacle and tragedy, as something to be gawked at and pitied.
- The disability community tends to distrust the medical establishment and its historically pathological understanding of disability
- As part of the ‘medical industrial complex,’ medical education is deeply implicated in the history of ableism and other forms of oppression

(Peña-Guzmán & Reynolds, 2019)

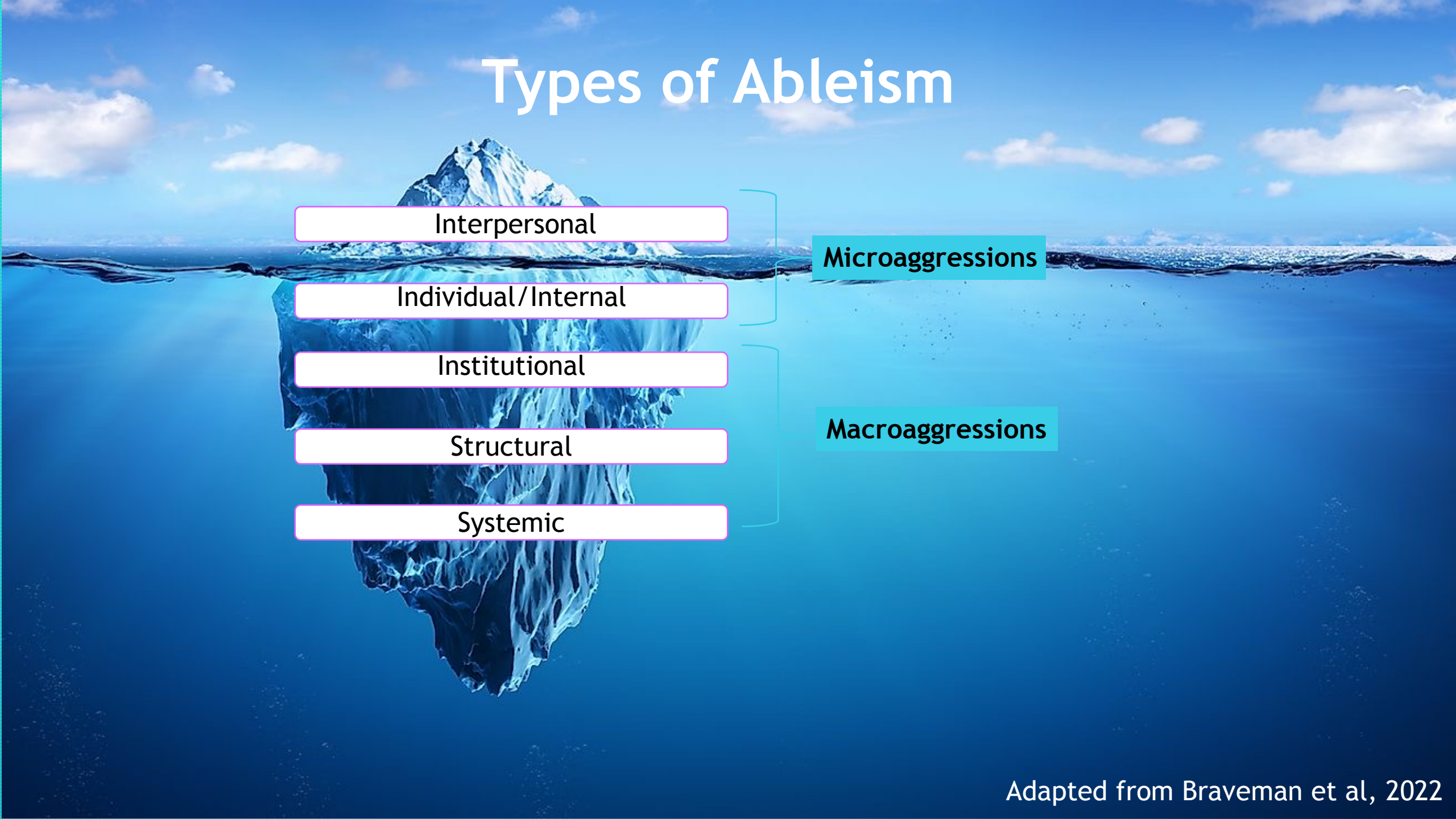
Attitudes and Ableism

What is Ableism?

- Ableism is a system of prejudice and discrimination that devalues and excludes people with disabilities
  - Disability stigma
  - Prejudicial attitudes and discriminatory behavior toward disabled people
  - Harmful attitudes toward people with disabilities
  - Analogous to racism, sexism, etc.
- Like other forms of oppression, ableism operates at different levels: (1) interpersonal, (2) individual and internal, (3) institutional, (4) structural, and (5) systemic

(Powell et al, 2022)

Types of Ableism



Adapted from Braveman et al, 2022

Types of Attitudes

- Myths and stereotypes common in contemporary cultural and media portrayals
- Biases and prejudice have resulted in institutionalized oppression
- Cumulative effect of such harmful attitudes
- Ableism often operates subtly and unconsciously
- People unable to recognize the effects of their negative attitudes because they are unaware they are prejudiced in the first place

(Andrews, 2019)

Attitudes

Explicit

- Conscience
- Expressed outwardly

Implicit

- Not always known to the person holding them
  - subconscious
- Ingrained
- Can be subtle

Implicit biases **can be reduced** through recognizing them and reducing or "managing" them, so we can control the likelihood that these biases will affect our behavior.

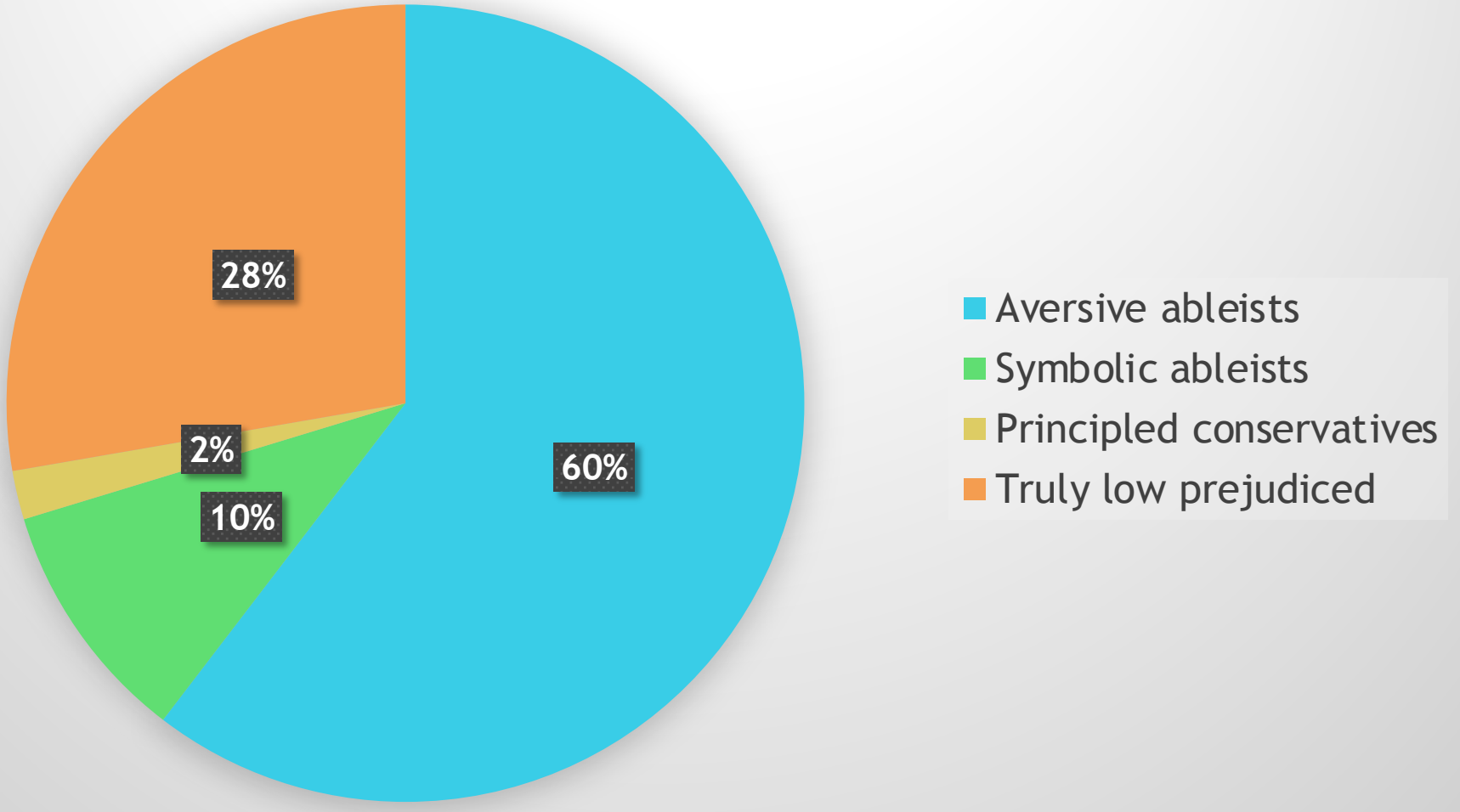
(Friedman, 2019; VanPuymbrouck et al., 2020;; Nosek et al, 2007)

Attitudes

- Implicit Association Test Research
  - Attitudes toward disability among the most biased
  - Family members have lower explicit bias but same implicit bias
  - Disabled people themselves have less explicit and implicit biased attitudes but still moderately prefer nondisabled people
  - Women tend to feel more favorably toward people with disabilities than men
  - As education increases, explicit bias decreases but implicit bias increases
  - Health care providers generally not cognizant of own disability biases
    - Aversive ableists, having low explicit prejudice and high implicit prejudice

(Friedman, 2019; VanPuymbrouck et al., 2020; Nosek et al., 2007)

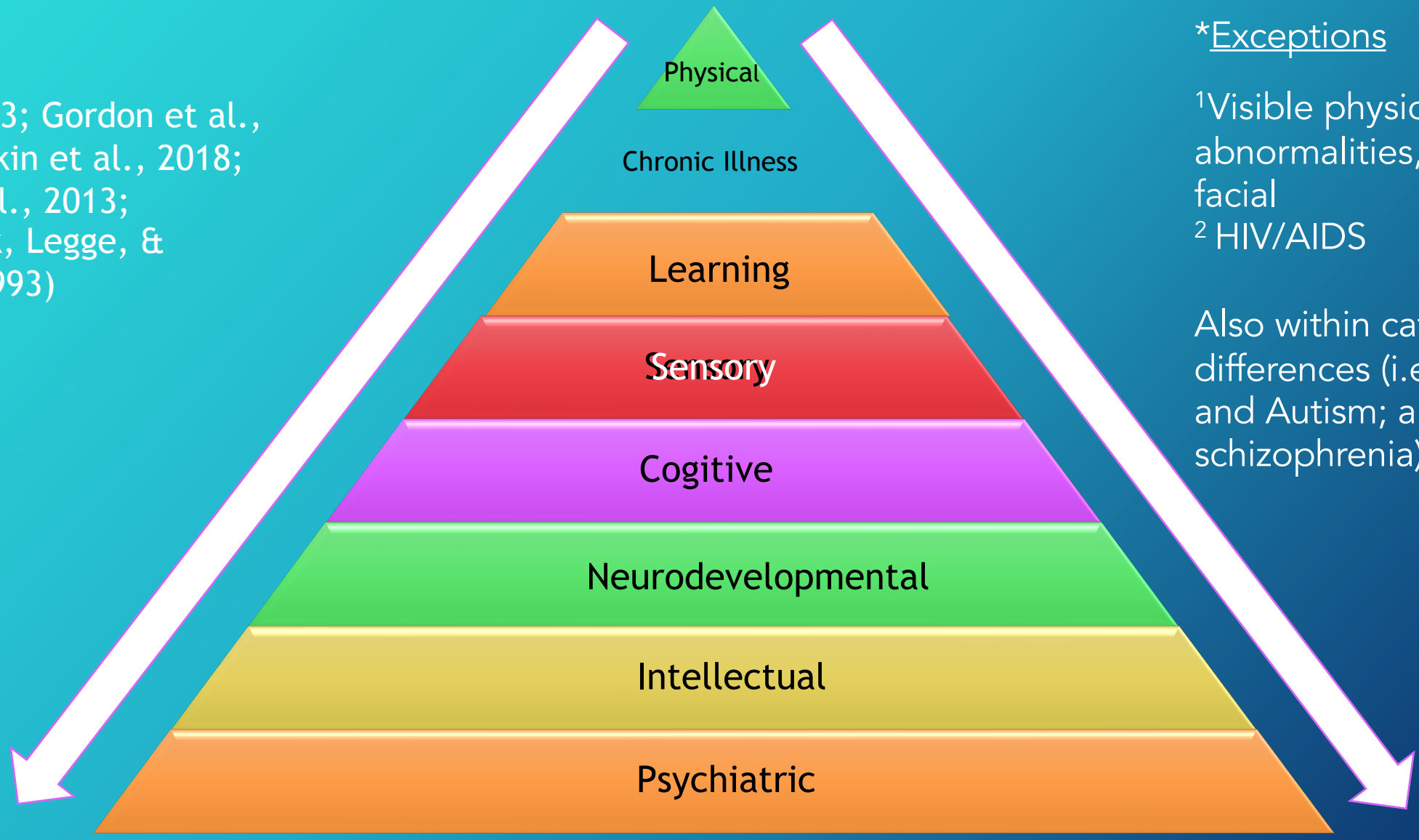
Prejudice Styles of Health Care Providers



(VanPuymbrouck, Friedman, & Feldner, 2020)

Hierarchy of Disability Stigma and Ableism

(Deal, 2003; Gordon et al., 2004; Huskin et al., 2018; Morin et al., 2013; Westbrook, Legge, & Pennay, 1993)

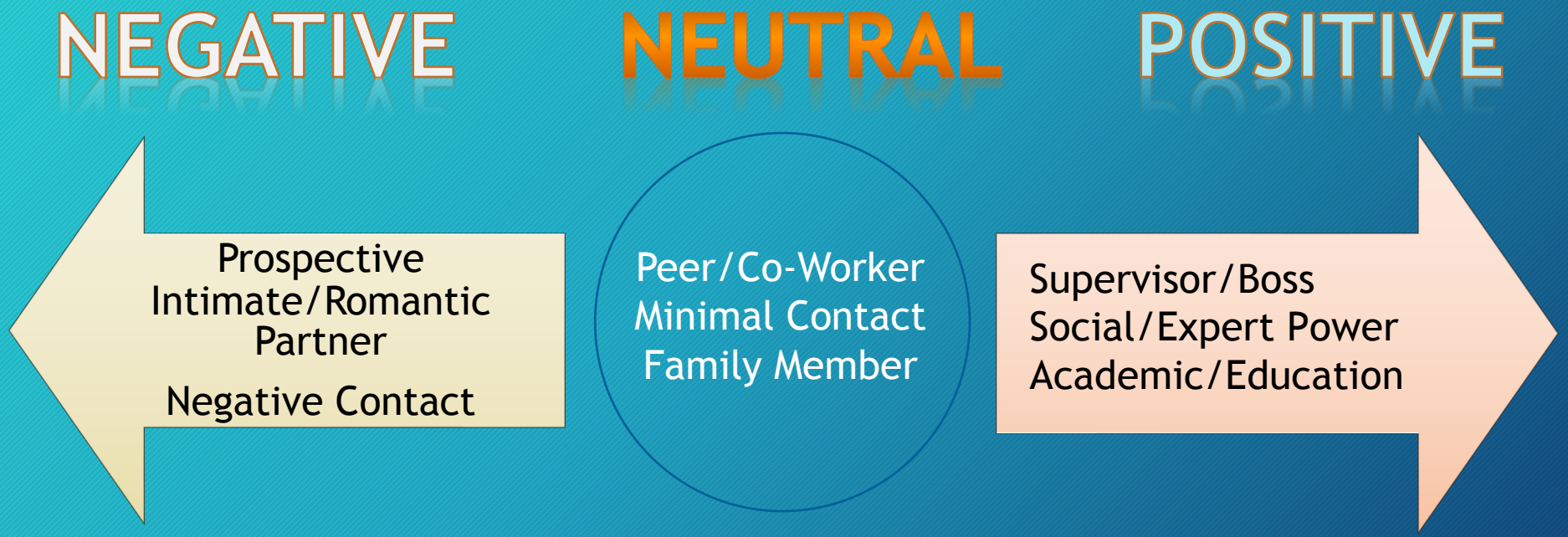


*Exceptions

[1]Visible physical abnormalities, especially facial
[2] HIV/AIDS

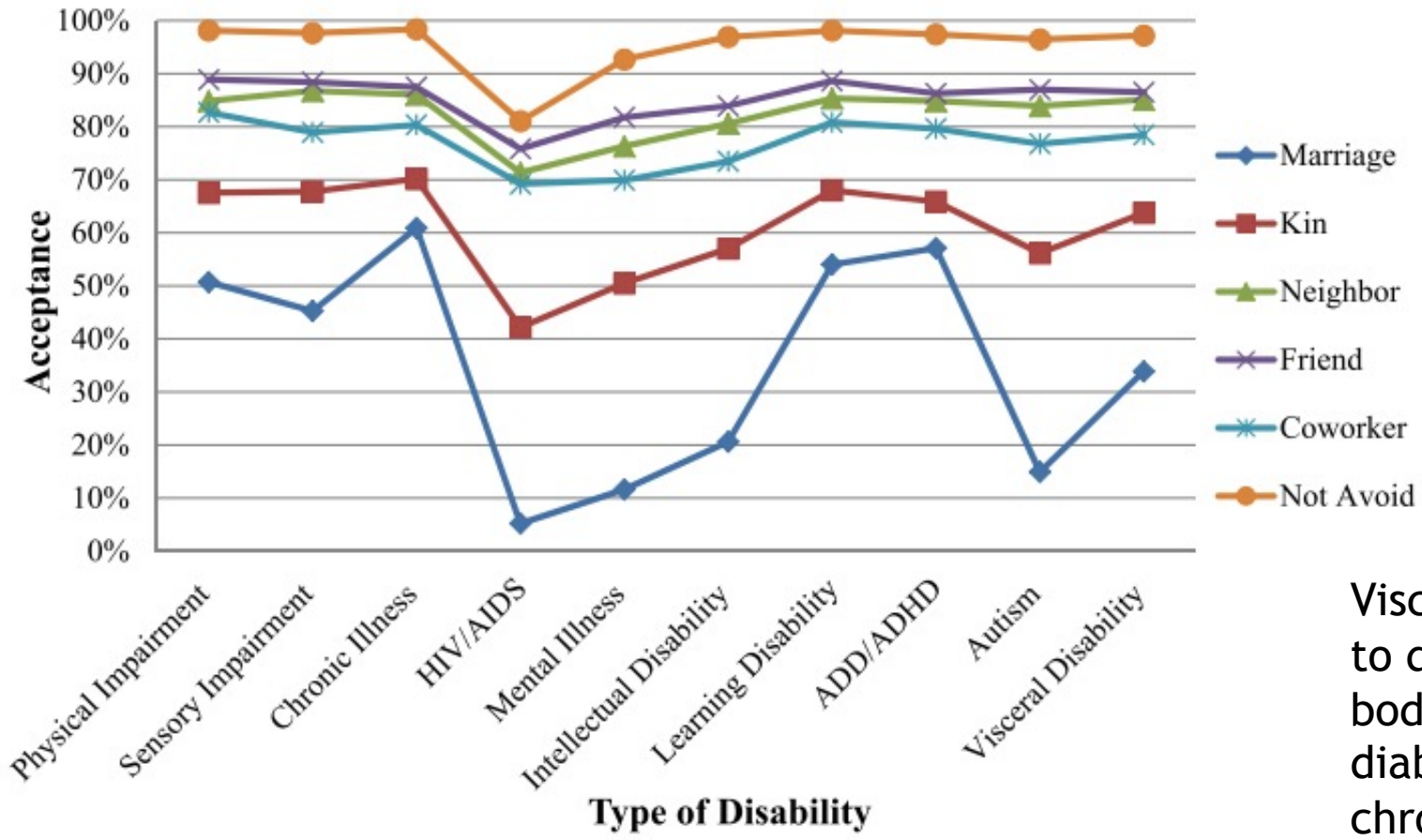
Also within category differences (i.e., ADHD and Autism; anxiety and schizophrenia)

Andrews' Continuum of Social Proximity



(Andrews, 2019; Based on findings from Chen, Brodwin, Cardoso, & Chan, 2002; Hergenrather & Rhodes, 2007; Hunt & Hunt, 2000; Miller, Chen, Glover-Graf, & Kranz, 2009; Shannon, Tansey, & Schoen, 2009)

Huskin et al., 2018



Visceral disability refers to diseases affecting the body's organs; such as diabetes mellitus, chronic liver disease

Disability Stigma

- The most stigmatized disabilities tend to be those that are most visible, those that involve mental functioning, and those for which a person is seen as responsible
- Blame
  - People tend to blame individuals more for unfavorable outcomes perceived as “controllable”
  - Need to perceive the world as a just place (just world belief)
  - Disabilities perceived as having a mental or behavioral component (e.g., substance use disorders) were rated as more controllable vs. those believed to be physical (e.g., amputation)
- Congenital disability is more stigmatized than acquired disability
  - People assume that these disabilities are
    - Genetically determined natural kinds (i.e., biological)
    - Fundamentally different (i.e., discrete)
    - Permanent (i.e., immutable)
    - Influences the person’s traits (i.e., informative)

Andrews' Catastrophize-Sensationalize Continuum

- Negative
  - Dependent
  - Vulnerable
  - Pitiful
  - Incompetent

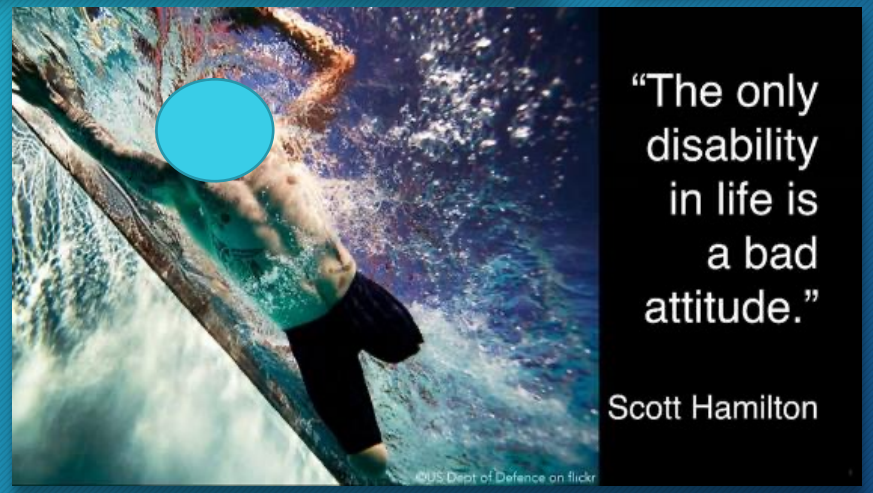
Positive AND negative stereotypes diminish the person's individuality and DEHUMANIZE – both can be harmful

- Overly-Positive
  - Inspirational
  - Courageous
  - Hero
  - Superhuman

Inspiration Porn

Images of disabled people with sentimental or motivational statements attached that “have the dual function of making the nondisabled feel better about themselves while simultaneously holding the average disabled person to an impossibly high standard”

- Stella Young



INSPIRATION PORN

Includes:

- Praising disabled people and calling them inspirational for carrying out daily or mundane tasks
- Praising them for “overcoming” their disabilities
- Heaping praise on non-disabled people for “helping” a disabled person.

“No amount of smiling at a flight of stairs ever turned it into a ramp”

- the late, great Stella Young

Types of Attitudes

- Microaggressions
  - A statement, action, or incident regarded as an instance of indirect, subtle, or unintentional discrimination against members of a marginalized group such as a racial or ethnic minority.
  - Microaggressions are the everyday slights, insults, put-downs, invalidations and offensive behaviors that people of marginalized groups experience in daily interactions with (usually) well-intentioned people who may be unaware of their impact.
  - Microaggressions are reflections of implicit bias or prejudicial beliefs and attitudes (usually) beyond the level of conscious awareness.

Sue et al., 2007

Types of Microaggressions

- Microassaults
  - Conscious, direct statements or actions intended to hurt a person (e.g., name calling).
- Microinsults
  - Unconscious and characterized as remarks or actions that intentionally or unintentionally convey rudeness or insensitivity (e.g., telling jokes based on stereotypes).
- Microinvalidations
  - Usually, unconscious comments and behaviors that discount, exclude, negate or contradict the thoughts, feelings or lived experience of a person (e.g., denying existence of discrimination).
- Nonverbal Microaggression
  - Microaggressions don’t have to be verbal; can be actions or conveyed through body language.

Ableism in Health Care (Interpersonal)

- Differential treatment justified by misplaced sympathy/pity
  - Treating patients with disabilities as incompetent or unable to make their own decisions because of their disabilities
  - Helplessness/Infantilization microaggression: Occurs when people frantically try to help disabled people
    - Provider moves a chair away without asking (patient using wheelchair planned to transfer)

(Keller & Galgay, 2010; Olkin et al 2019; Peña-Guzmán & Reynolds, 2019)

Ableism in Health Care (Interpersonal)

- Second Class Citizen microaggression
  - Occurs when a disabled person's right to equality is denied because they are considered to be bothersome, expensive, and a waste of time, effort and resources
  - Patient with COVID-19 denied treatment because doctors deemed his quality of life with brain and spinal cord injuries as "nonexistent."
- Denial of Disability Experience microaggression
  - Occurs when disability related experiences are minimized or denied
  - "I don't think of you as disabled"
- Denial of Reality of Symptoms microaggression
  - Tendency to assume that a disabled individual's symptoms are a manifestation of psychological concerns: "It's probably nothing"

(Keller & Galgay, 2010; Olkin et al 2019; Peña-Guzmán & Reynolds, 2019)

Ableism in Health Care (Interpersonal)

- Discount testimony concerning the specific reason for presenting, over-focusing instead on their impairment and tying diagnosis solely to it
  - Denial of personal identity microaggression
  - Occurs when any aspect of a person's identity other than disability is ignored or denied
  - Clinician: "I'm going to see the SCI in room 423"
- Professionally trained "experts" about disability, which they may have no lived experience (many nondisabled clinicians)

(Keller & Galgay, 2010; Olkin et al 2019; Peña-Guzmán & Reynolds, 2019)

Ableism in Health Care (Interpersonal)

- Removing entire categories or resources from a communicative space because the disability erroneously renders topics categorically inapplicable.
  - Examples: disabled sexuality, parenting
- De-sexualization microaggression
  - Occurs when the sexuality and sexual being is denied
  - Example: Provider never asks about sexual or reproductive health issues or plans

(Keller & Galgay, 2010; Olkin et al 2019; Peña-Guzmán & Reynolds, 2019)

Ableism in Health Care (Interpersonal)

- Over-inquisitiveness on the part of providers about disability status and a cascade of assumptions about patients with disabilities
  - Important distinction between “need to know” and “want to know” questions.
  - The first category refers to questions that providers should ask; the second, to those they tend to ask out of ignorance and curiosity
- Denial of privacy microaggression: Occurs when personal information is required about a disability
  - Someone unnecessarily asking “what happened to you?”

(Keller & Galgay, 2010; Olkin et al 2019; Peña-Guzmán & Reynolds, 2019)

Ableism in Health Care (Interpersonal)

- Spread effect microaggression
  - Occurs when other expectations about a person are assumed due to one specific disability
  - Provider speaks very loudly to blind patient
- Secondary gain microaggression
  - Occurs when a person expects to feel good or be praised for doing something for a disabled person
  - "You're such an amazing person to dedicate your life to helping the disabled – those poor people!"

(Keller & Galgay, 2010; Olkin et al 2019; Peña-Guzmán & Reynolds, 2019)

Ableism in Health Care (Interpersonal)

- Management of Interpersonal Affect microaggression
  - Occurs when the onus placed on disabled people to manage their discomfort.
  - Disabled patient reassures provider, “it’s okay” that the exam table doesn’t raise or lower for transfers.
- Blame microaggression
  - Occurs when disabled people are directly or indirectly held responsible for their disabilities
  - “Were you driving drunk?”
  - “Did you smoke?”

(Keller & Galgay, 2010; Olkin et al 2019; Peña-Guzmán & Reynolds,

Ableism in Health Care (Interpersonal)

- Overconfidence in expert status, being less likely to:
  - Question first intuitions
  - Request further diagnostic tests
  - Entertain alternative hypotheses
  - Consider referring to other specialists
  - Get a second opinion
  - Reflect more critically about social conditions and determinates of health

(Keller & Galgay, 2010; Olkin et al 2019; Peña-Guzmán & Reynolds,

Ableism in Health Care (Institutional)

- Institutional ableism is discrimination against people with disabilities within an organization's policies and practices
- Examples:
  - Local crisis care policies for medical rationing
  - Organ transplant criteria
  - Convoluted processes for requesting reasonable accommodations
  - Difficulty obtaining culturally appropriate communication (i.e., ASL interpreters)
  - Lack of accessible communication or educational materials

(Powell et al, 2022)

Ableism in Health Care (Structural)

- Emphasizes the roles of structures
- Ableism *across* institutions, in laws, policies, and entrenched norms
- Creates disparities in life outcomes for people with disabilities compared with people without disabilities
- For example:
  - State's crisis care standards for medical rationing
  - Lack of education and training on disability
  - Discriminatory pay laws, marriage laws
  - Lack of affordable accessible housing

(Braveman et al, 2022)

Ableism in Health Care (Systemic)

- Emphasizes the involvement of whole systems, and often all systems
  - For example, political, legal, economic, health care, school, and criminal justice systems including the structures that uphold the systems
- Pervasively and deeply embedded in and throughout systems, laws, written or unwritten policies, entrenched practices
- Established beliefs and attitudes that produce, condone, and perpetuate widespread unfair treatment
- Reflects both ongoing and historical injustices
- Examples: Disabled poverty, unemployment, mortality rate, for-profit medical systems, health care disparities

(Braveman et al, 2022)

Anti-ableist practices

To promote disability justice in healthcare

Internal/Individual Strategies

- Self examination is CRUCIAL
- Examine your own preconceptions, biases, beliefs and emotional reactions towards persons with disabilities
  - Take the IAT!
  - Read works by disabled authors about the **lived experience** of disability
  - Learn more about the disability rights movement
  - Watch a movie or documentary about disability and critique the portrayal of disability
- Be thoughtful about use of language
  - Respect individual preferences
- Don't overfocus on the individual – RECOGNIZE SYSTEMIC ABLEISM

(Nario-Redmond, 2019; Kattari et al., 2018)

Internal/Individual Strategies

- Center the perspectives of those who are most impacted by ableism
  - Health care providers should not assume that they know what a patient wants or what type of health care they would like to receive.
  - Many times patients are the experts on their own conditions, thus knowing their own needs quite well.
  - Balance with educating yourself and taking the onus off disabled patients to always educate

Sins Invalid

Interpersonal Strategies

- Work on seeing and treating the whole disabled person with dignity rather than reducing them to medical aspects of disability
  - Recognize that individuals respond to disability in varied ways
  - Don’t assume disability issues are the cause of psychological or other problems

(Nario-Redmond & Kemerling, 2019)

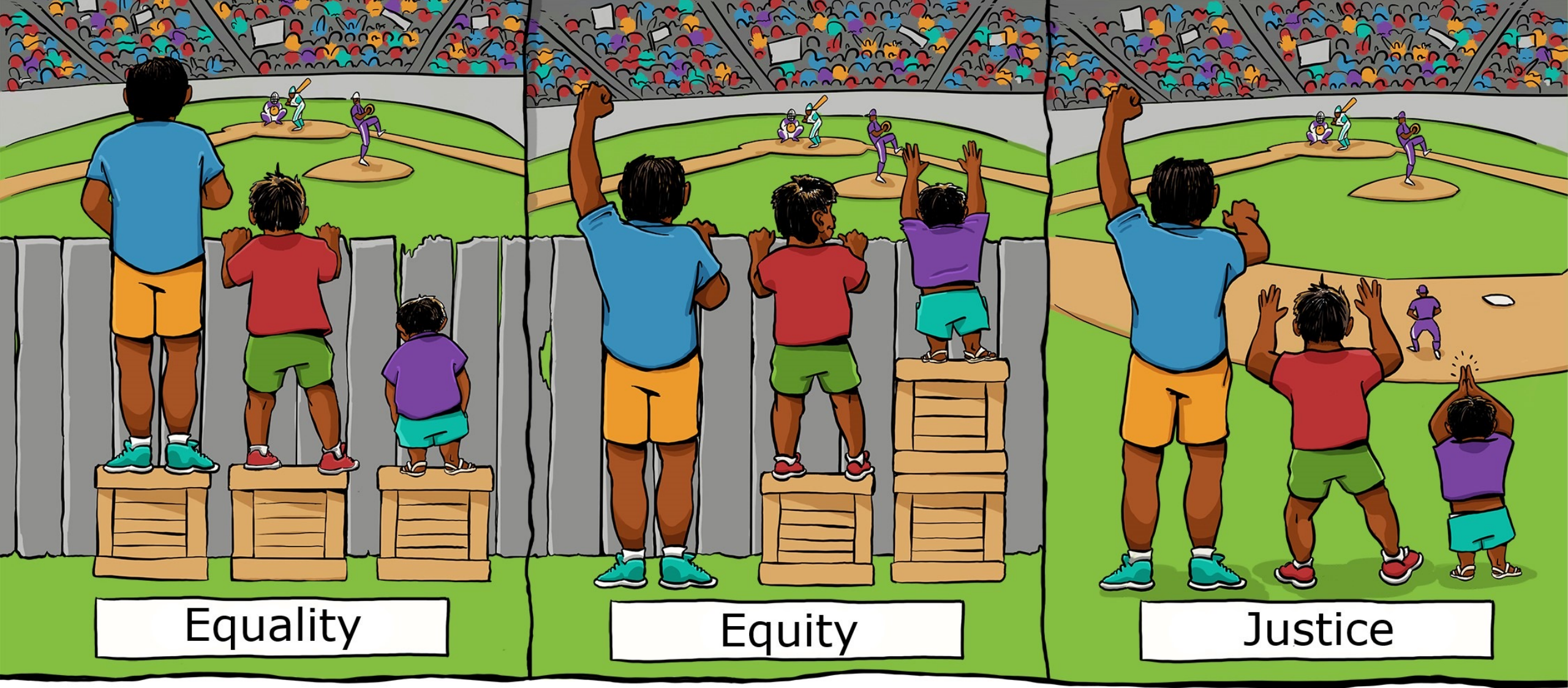
Institutional Strategies

- Examine closely your organization's policies and practices that affect disabled patients
  - For example, crisis care standard for medical rationing; organ transplant criteria
- Provide cultural competence education and training on disability to all health care workers
- Recruit and retain disabled health care providers
  - Remember that it is POWER that changes attitudes.

(Powell et al, 2022)

Structural Strategies

- Identify ableism across institutions that creates disparities for people with disabilities compared with people without disabilities.
- Help explicitly identify this ableism and challenge it
- Strive for universal design and access for all



Everyone Gets Treated Equally

Everyone Gets the Supports They Need (Individualized)

Removal of Systemic Barrier/Cause of Inequity

Center for Story-Based Strategy

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