Improving Outcomes
for People with Disabilities Series

Contextual and Conceptual Frameworks on Disability

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Excellence in Developmental Disabilities
Leadership Education in Neurodevelopmental
and related Disabilities

Disclosures

I am a salaried faculty member of Cincinnati Children's Hospital Medical Center. The majority of my work is funded by the Administration in Community Living under HHS (HHS-2017-ACL-AOD-DDUC-0195). I am also funded as the Principal Investigator for a Project of National Significance (90DNHC0001). Lastly, I am a member of the PCORI Board of Governors. I do not foresee a conflict of interest with these roles and what I share today.

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- Professor/Researcher
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CENTER FOR DIGNITY IN HEALTHCARE FOR PEOPLE WITH DISABILITIES

Agenda

Today we'll learn to think and talk about disability differently than you may have before.

01

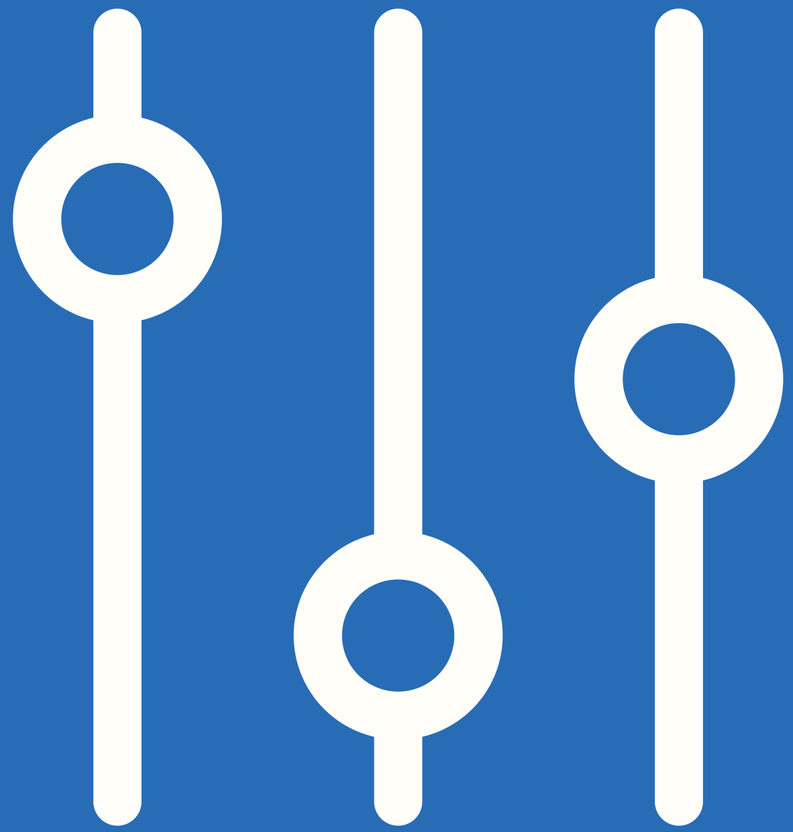
Define the relationship between ableism and inequitable healthcare

02

Review a basic timeline of disability rights

03

Reflect on how your thoughts and behaviors can be anti-ableist



Level setting with our Language

WHAT ARE ATTITUDES?

Attitudes are relatively stable mental positions held towards ideas, objects, or people. They are a combination of beliefs, feelings, and past experiences. Attitudes can predict behaviors.

Negative attitudes → **Stigma** → **Exclusion and discrimination**

Attidudes don't only exist in our heads

WHAT IS ABLEISM?

Discrimination against people with disabilities. Ableism is the belief that life with a disability is less valuable, meaningful, or important compared to nondisabled people.

ABLEISM AS A SMOG

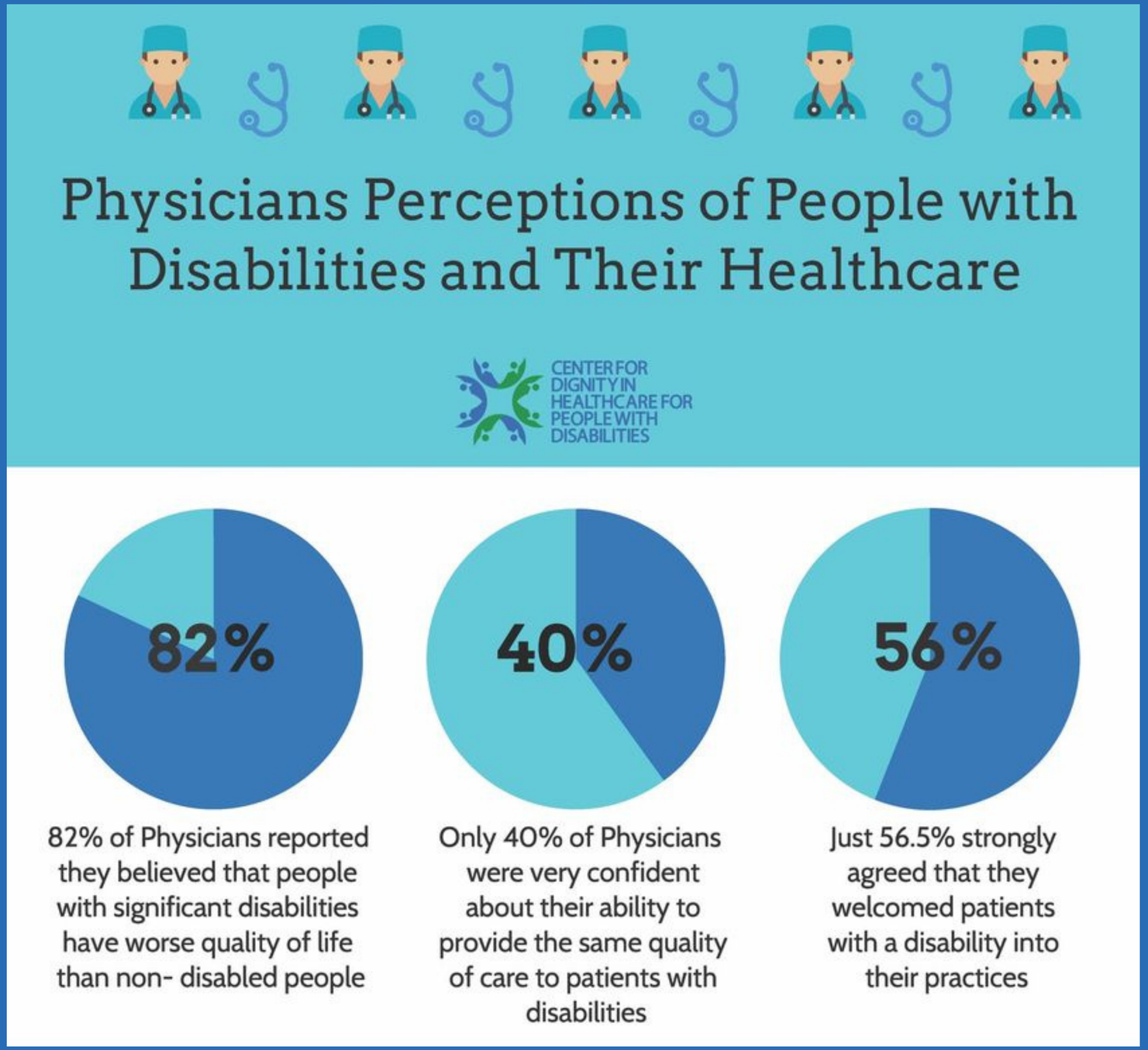
WHAT ARE SOME EXAMPLES OF ABLEISM IN HEALTHCARE?

Research Update

Research on Physicians Perceptions and Knowledge about Disability Equity

- More than 30 years after the Americans with Disabilities Act was enacted
- Iezzoni and colleagues have published high impact research in *Health Affairs*
- 714 practicing US physicians were surveyed
- Responses indicated bias about quality of life and little knowledge about the ADA

Iezzoni et al., 2021 and 2022



Iezzoni et al., 2021

US Physicians' Knowledge about ADA

35.8%

Reported knowing "little or nothing" about the ADA

71.2%

Answered incorrectly about who determines reasonable accommodations

20.5%

Answered incorrectly about who pays for reasonable accommodations

Iezzoni et al., 2022

Highlights from National Council on Disability's Health Equity Framework

- Designating people with disabilities as a Special Medically Underserved Population (SMUP) under the Public Health Services Act
- Requiring comprehensive clinical-care curricula in all U.S. medical, nursing, and other health care professional schools
- Requiring use of accessible medical and diagnostive equipment
- Improving data collection concerning health care for people with disabilities across lifespan

National Council on Disability

Policy Framework

Health Equity Framework for People with Disabilities

February 2022

Purpose

This Policy Brief provides rationale for the need of an all-of-government approac to achieve health equity in the United States and our territories for the largest unrecognized minority group in this country, the 64 million+ people with disabilities, and sets forth a framework to achieve health equity for all people with disabilities. Disability is a natural part of the human condition, which occur across all age, gender, racial, ethnic, language and social groups.

For purposes of this brief, NCD utilizes the definitions of "health disparity" and "health equity" as defined by the U.S. Department of Health and Human Services (HHS) Secretary's Advisory Committee for Healthy People 2020.[1] Thus, as used herein "health disparities" means health differences that adversely affect people with disabilities which are systemic (i.e., not isolated or exceptional)[2] and plausibly avoidable (i.e., not necessarily proving, but plausible that policies could reduce the disparities).[3] "Health equity" as used herein is defined as the principle underlying the commitment to the attainment of the highest level of health for all people, which requires valuing everyone equally with focused and ongoing societal efforts to address avoidable inequalities, historical and contemporary injustices, and the elimination of health and healthcare disparities."

Introduction

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

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

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

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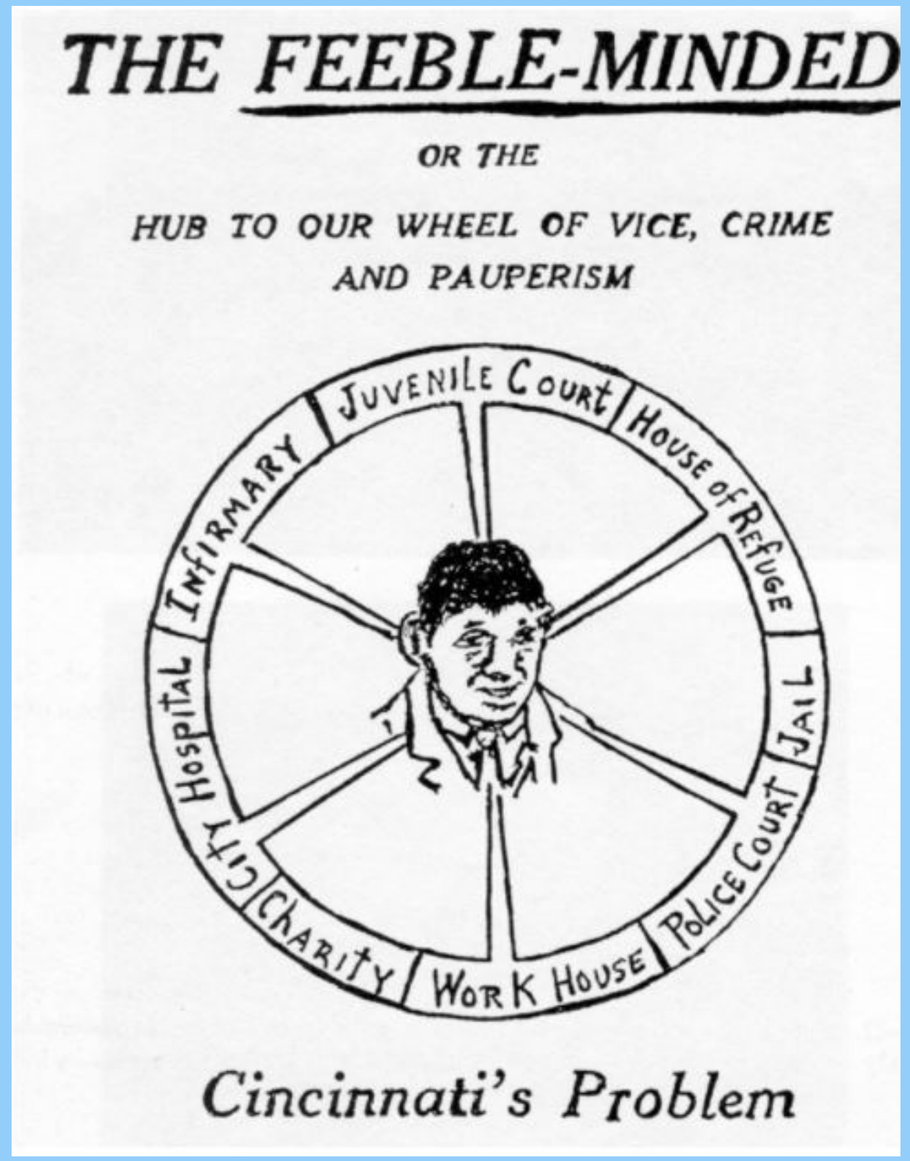
Conceptual Frameworks: Disability Models in Healthcare

Disability models

- are human-made frameworks
- reflect history/context
- guide society in their treatment of people with disabilities



Moral Model of Disability

The oldest model provides the basis for segregation. Disability may be associated with sin and shame.

There are a few rare cultural exceptions that worshipped disability as a positive sign from a higher being.

Charity Model of Disability

This model depicts people with disabilities as victims of their circumstances deserving of pity.

It is highly successful for fundraising and thus, hard to eliminate.

Medical model of disability

Problems or symptoms are within the individuals. If the individual is "cured", symptoms resolve.

The is the model currently most understood and utilized by most of society.

Restoring dignity and humanizing medical images to reduce bias

www.positiveexposure.org

Social model of disability

Society is the diabling factor. Attitudes and remaining environmental barriers are the problem.

The social model places the "burden" of disability outside of the individual.

What does NOT predict health disparities?

Cultural or minority model of disability

Disability is an embodied experience that is influenced by identity and sociopolitical context.

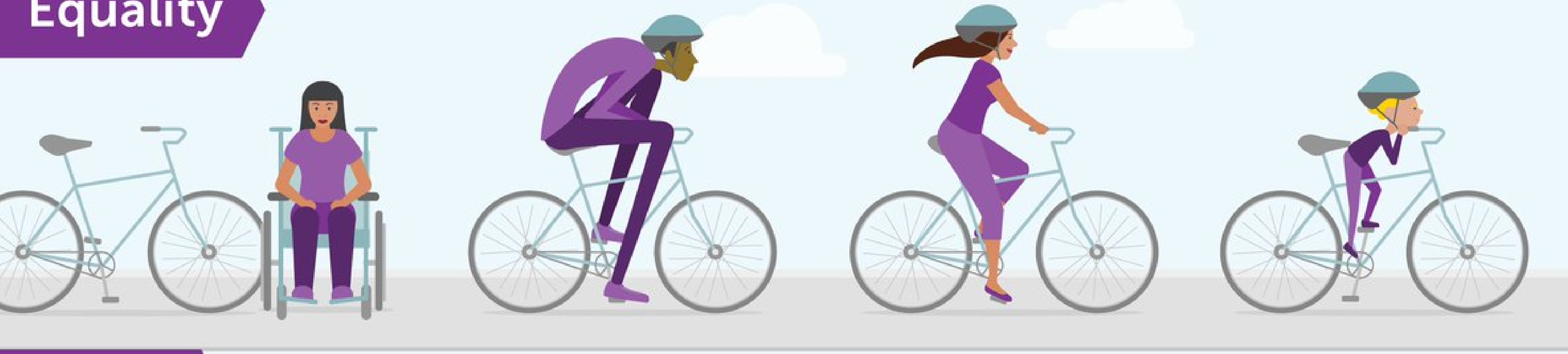
There are other modern models, including functional, biopsychosocial, sociopolitical.

Equitable framing of disability

WHAT IS EQUITY?

Equity means everyone has a fair and just opportunity. This means removing obstacles and these may vary from person to person.

Equality



Equity

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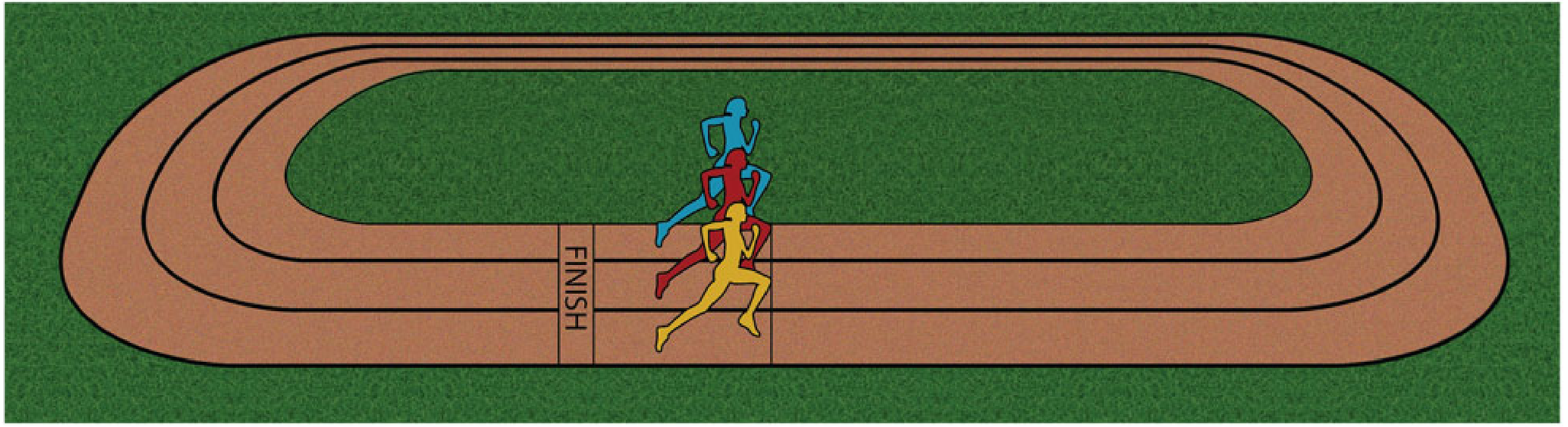
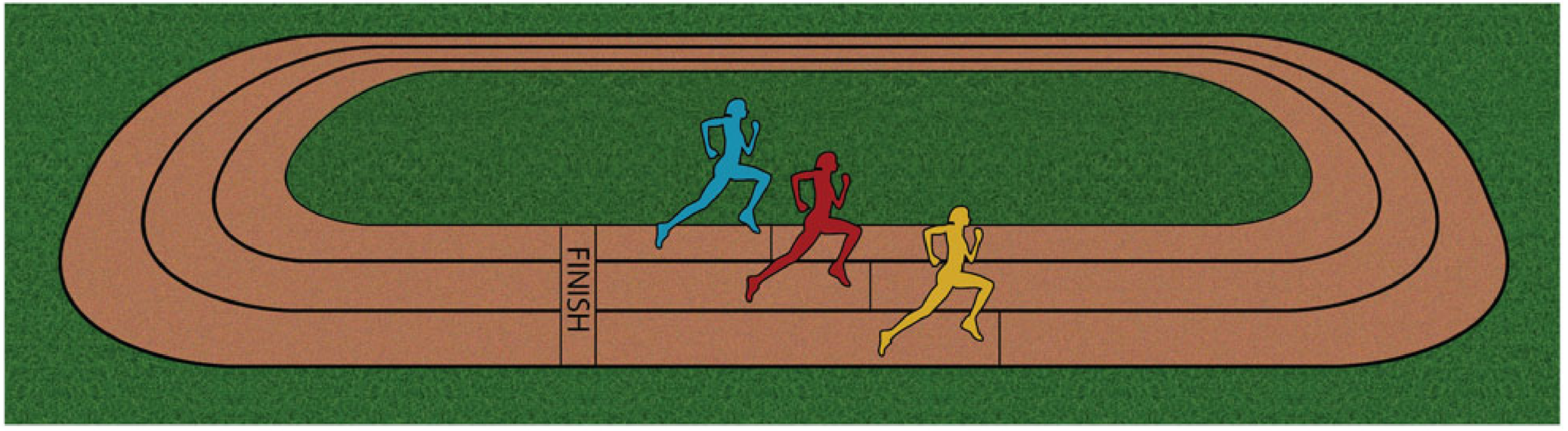


EQUALITY



EQUITY

Framework for Change: Patient-Centered Outcomes (PCOR)

Ensures voices of patients are heard in what is valued in healthcare.

Facilitates communication between provider and patients

Helps to identify what are the most important research questions

Facilitates a better understanding of how disability impacts healthcare

ABLEISM AS A WEED IN THE SIDEWALK

Anti-ableism dismantles ableism at its roots.

FRAMEWORK FOR CHANGE: DISABILITY JUSTICE

Disabled people of the global majority-Black and brown people-share common ground in confronting ableism and racism. All bodies have power and strengths **not despite disability but because of it.** Our community is strong through our interdepdence.

10 principles of disability justice by Sins Invalid

Key Takeaways

- It is not enough to strive not to be ableist. We must be anti-ableist.
- The way we frame or conceptualize disability impacts our attitudes and the outcomes of people with disabilities.
- Reconceptualizing disability includes disability justice and centering people with disabilities in health equity efforts.

Let's discuss.
Comments.
Questions.

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