

# Kate M. Nicholson, J.D.

## Position:

Executive Director, National Pain Advocacy Center.

## No conflicts, but in full disclosure:

Member, NIH Interagency Pain Research Coordinating Committee (IPRCC)

Subject Matter Expert, National Advisory Neurological Disorders and Stroke Council (NANDSC)

Board Member, NIH PURPOSE

Association Partner, NIH HEAL CONNECTIONS

Appointed Member, CDC Opioid Workgroup (past)

Member, IASP Global Advocacy Working Group

Member, USASP Advocacy Committee

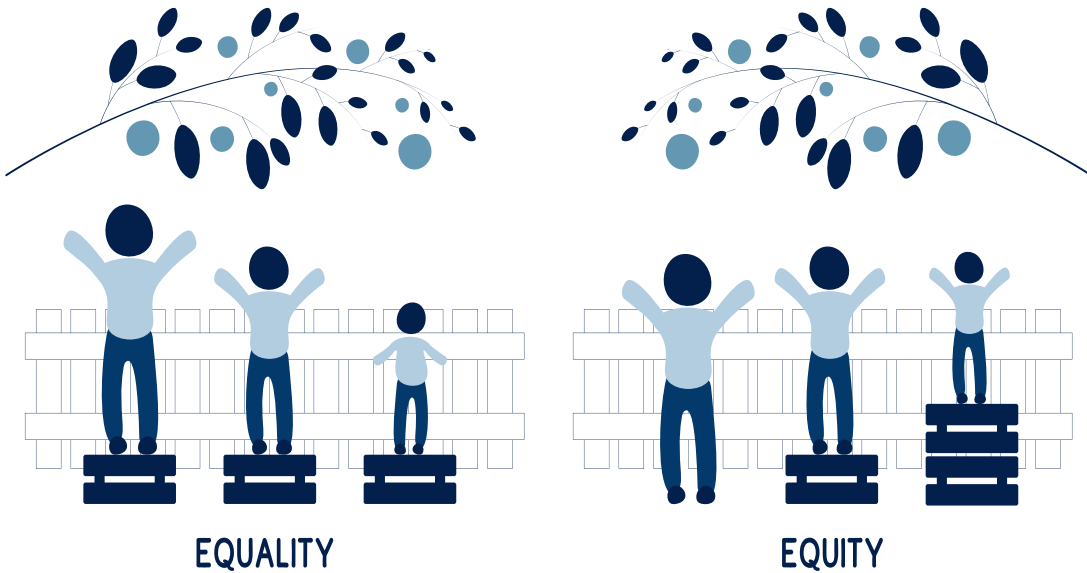
## OUR VISION

We envision a world in which pain is treated equitably and effectively, so that **all people in pain can lead full and productive lives.**



# Equity

**Equity ≠ Equality.** Equity may require treating people differently for a level playing field.



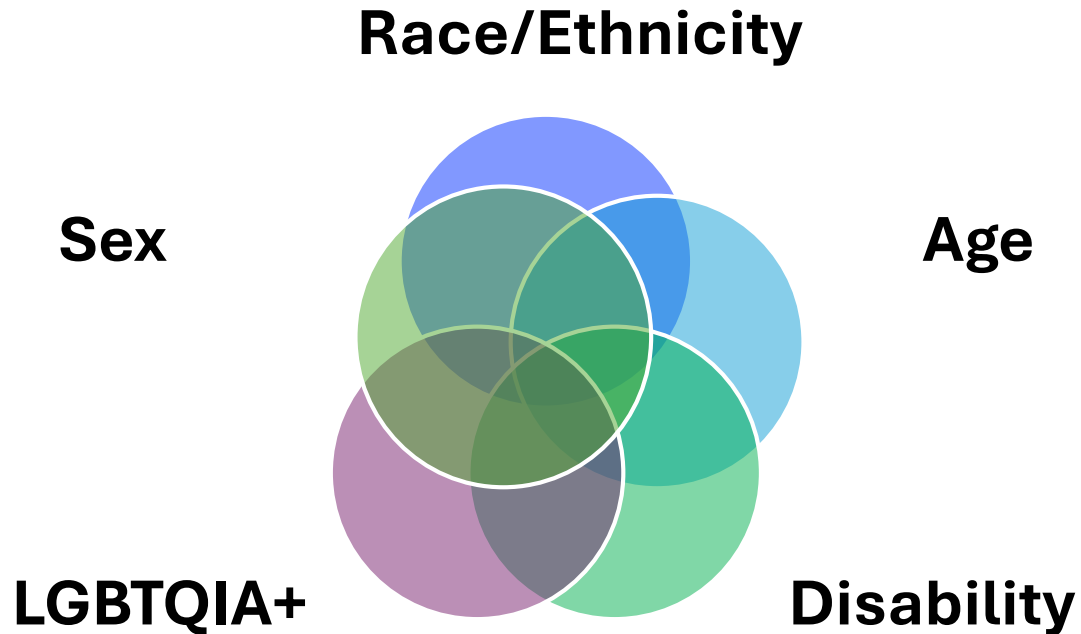
**Disparities:** *avoidable* differences in health status among groups.

**Inequities:** *avoidable and unjust* differences in health status & distribution of health resources (policies/structures).

**Social Determinants of Health:** *nonmedical factors* affecting health outcomes. Where people are born, live, work; social, political, environmental & economic forces.

Health Equity: Creating an environment where everyone has an opportunity to thrive.

# Intersectionality



People don't come as Black or Female or Disabled.

Inequities and disadvantages compound at the intersection of identities. (Crenshaw)

When we focus on a category, such as race, we often mythologize a universal experience. Those who fall outside familiar prisms or stereotypes are invisible. (Crenshaw)

Example: We know pain disparately affects people as they age. We know there is bias based on race. There is little research on pain in aging Black men.

# Pain Across the Life Course

We tend to think about treating pain in children and older adults.

But from my lived experience perspective, it's also essential to consider the lifecycle of pain on an individual level.

The same treatments may not be effective for the same person over the course of their pain journey.

People can develop overlapping conditions that complicate things, and conditions can wax and wane or develop different features.



# National Center for Health Statistics

- **Nearly 1 in 4 adults** have chronic pain (up 5.1% from 2021)
- **22.3 million adults have high-impact pain** (up 3.4% from 2021)
- Chronic and high-impact chronic pain
  - are **higher in women**;
  - increase with age**;
  - are **higher in non-urban** areas and
  - reflect racial and ethnic disparities**, with the highest rates among American Indians and Native Alaskans.



















































# Race/Sex Inequities/Disparities

- Women disproportionately suffer chronic + high-impact pain and comorbid conditions causing pain.
- Women are more often disbelieved and under-treated.
- A recent study found significant sex disparities in ER records, with women receiving less pain-relieving medication being less likely to have their pain recorded by nurses.

- Black and Hispanic people report higher levels of pain and worse outcomes;
- But are also less likely to receive medication or receive lower doses and are less likely to be referred to pain management;
- And are subject to provider bias based on false beliefs that they feel pain less intensely. (Hoffmann, KN, et al., Proc Natl Acad. Sci U S A. 2016).

## Sex bias in pain management decisions

Mika Guzikevits , Tom Gordon-Hecker , David Rekhtman ,                                                  

# The Issues are Structural and Social

## Systemic barriers go beyond bias:

- Transportation barriers
- Communication barriers
- Cultural and literacy barriers
- Physical and equipment barriers
- Socio-economic barriers
- Health coverage barriers
- Geographic barriers (care deserts)
- The digital divide

## Social Determinants of Health:

- Where people live
- Where people work,
- How people eat,
- Environmental exposures,
- People's sense of agency,
- People's sense of autonomy,
- People's sense of political power,
- Discrimination, etc.



# Possible Areas of Need

- **Equity as a Cross-Cutting Issue**
  - Ensure diversity of representation in all studies (even those not focused on equity) and gather data on race, sex/gender, disability, LGBTQIA+, SOS, education, zip code, etc., in a contextualized way.
- **Methodologies that Support Multi-Factorial Research**
  - Prioritize methodologies to study the multiple inputs determining health (SDOH, intersectional identities, etc.)
- **Mitigation of Bias**
  - Prioritize standardization and validation of assessment tools (developed with input from diverse PWLE, clinicians, and other interest holders).
  - Determine which training and education modules are most effective in mitigating bias in clinical care. Leverage results to develop protocols and pipelines.



# Possible Needs (cont.)

- Health Equity/Whole Person Interventions

- Consider collaborative research with diverse patients, providers, and community members.
- Encourage pragmatic trials and real-world studies of interventions in health systems with the potential to be effective and scalable.

- Resilience, Self-Efficacy, and Empowerment

- Research the effectiveness of direct-to-consumer education in self-advocacy, self-efficacy, and training in navigating complex health systems for diverse PWLE.
- Resilience research is one approach suited to examining systems (Trans NIH workgroup).

# Possible Needs (cont.)

- **Leverage Technology (while being mindful of the digital divide).**
  - Technology and AI can replicate existing barriers and biases, but they may provide tailored, health-literate, culturally literate translations within EHRs to partners (patients and providers with differing heuristics). The use of zip codes could generate treatment resources to help address care coordination.
  - Leverage telehealth and digital tools while being mindful of security and privacy.
- **Systems-Based Lens**
  - Broadly consider including interest holders in advisory groups, not only diverse PWLE but also health systems administrators, payers, etc.
  - Evaluate the role of payment structures on equitable access to modalities and care.
- **Dissemination and Implementation**
  - Consider both early in all research. Communication is critical to patients, policymakers, etc. Research that isn't implemented fails to reach those in need.