The Historical and Contemporary Context of Medical Distrust and What It Will Take to Repair

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Who am I?
A bit about me professionally.

• Serving as the inaugural Director of the Office of Health Equity since October of 2021.
• Vice-Chair of the Governor’s Health Equity Council
• Consultant to government, non-government organizations and the private sector
• Researcher for Race to Equity/Kids Forward
• Doctorate in Sociology
  o Trained in quantitative and qualitative methods
    ▪ Randomized Control Trials (RCTs), quasi-experimental designs and other inferential statistical methods
    ▪ Ethnography and comparative historical techniques
...and Personally

Wisconsin Department of Health Services
Setting the Stage
Clinical Trials Composition

• According to the Food and Drug Administration (FDA), in 2020, among clinical trial participants for approved molecular entities and therapeutic biologics:
  o 75% self-identified as white (vs 61.6% of US population)
  o 8% self-identified as Black or African American (vs 12.4% of US population)
  o 11% self-identified as Hispanic (vs 18.7% of US population)
  o 6% self-identified as Asian (vs 6% of US population)
Why Care About Diversity in Clinical Trial Participation?

- Genes
- Age
- Weight
- Height
- Environment
- Social Determinants
  - Race and Ethnicity
Race has been built into medical practice

- Belief that race is biological has shaped healthcare practice and healthcare inequities. Examples include:
  - kidney functioning tests, anemia cut offs in pregnancy, and bone density tests
What is race?
Human Genetic Variation and Categories of Race

• Race has no biological foundation.

• Study: The Apportionment of Human Diversity
  ○ Evolutionary biologist Richard Lewontin’s (1972) work.
  ○ Tested how much human genetic variation can be attributed to “racial” groupings.
  ○ Only 6 percent of genetic variation in humans can be attributed.
Genetic Variation Between Individuals

• Race fails to explain a significant amount of human genetic variation.
• Variation between any two individuals is very small.
  o One single nucleotide polymorphism (SNP)
    ▪ A single letter change in our DNA, per 1000.
• Racial categorization could only explain 6 percent of the variation found in 1 in 1000 SNPs.
Genetic Variation Within Categories of Race
Genetic variation can be greater within “race” than it is between “races.”
• Two individuals within a “race” will be more genetically dissimilar from each other than from an individual from a different “race.”
So, what is race then?

“Race is a culturally structured systematic definition of a way of looking at perceiving and interpreting reality.” – Social Anthropologist Dr. Audrey Smedley

• Race is a fluid, political and social construct.
• Race was created and has been used to establish social hierarchies by dividing human populations into groups.
Social and Structural Determinants of Health

Social determinants of health (SDOH) are the conditions in the environments where people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks.
The Context of Healthcare Distrust
Trust in US institutions is on the decline.
- This includes institutional experts.
The Undefeated and Kaiser Family Foundation (KFF) Poll

Generally speaking, how often do you think our health care system treats people unfairly based on their race or ethnic background?

- **Black**
  - 2%
  - 7%
  - 31%
- **Hispanic**
  - 33%
  - 16%
- **White**
  - 30%
  - 10%

Generally speaking, how often do you think our health care system treats people unfairly based on their race or ethnic background?

- **Black**
  - 5%
  - 20%
  - 33%
- **Hispanic**
  - 29%
- **White**
  - 27%
  - 16%

Generally speaking, how often do you think our health care system treats people unfairly based on their race or ethnic background?

- **Black**
  - 3%
  - 10%
  - 31%
- **Hispanic**
  - 16%
- **White**
  - 21%
  - 33%
The Undefeated and Kaiser Family Foundation (KFF) Poll

Was there a time in the last twelve months when you felt you were treated unfairly in the following places because of your racial or ethnic background?

**POLL**

**AT YOUR PLACE OF WORK**
- **Black**: 26%
- **Hispanic**: 17%
- **White**: 13%

**IN A STORE WHERE YOU WERE SHOPPING**
- **Black**: 40%
- **Hispanic**: 24%
- **White**: 10%

**IN DEALINGS WITH THE POLICE, SUCH AS TRAFFIC INCIDENTS**
- **Black**: 26%
- **Hispanic**: 18%
- **White**: 4%

**WHILE GETTING HEALTH CARE FOR YOURSELF OR A FAMILY MEMBER**
- **Black**: 20%
- **Hispanic**: 5%
- **White**: 5%
The Undefeated and Kaiser Family Foundation (KFF) Poll
Historic and Contemporary Drivers of Distrust
Abuse, Mistreatment and Exploitation in Healthcare

Sterilization rates per 1000 institutionalized patients

In the first half of the twentieth century, approximately 20,000 people — many of them Latino — were forcibly sterilized in California.

Chart: The Conversation, CC-BY-ND • Source: California Eugenic Sterilization Dataset, University of Michigan • Get the data
# Entrenched Health Disparities

## Infant Birth and Mortality Outcomes in Wisconsin, 2020

<table>
<thead>
<tr>
<th></th>
<th>Black (Non-Hispanic)</th>
<th>White (Non-Hispanic)</th>
<th>Risk ratio (Black vs. White)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low birthweight, %</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Premature born</td>
<td>X (12.8)</td>
<td>12 (8.6)</td>
<td>1.49</td>
</tr>
<tr>
<td>Birth rate per 1,000</td>
<td>8th grade or less</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Some high school</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>High school graduate/GED</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Some college</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>College graduate</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Postgraduate</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Missing</td>
<td></td>
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</tr>
</tbody>
</table>

*Birth rate received Women, Infants, and Children Program during pregnancy*


An "X" indicates a value that is less than 5 (but more than zero) and has been suppressed to protect confidentiality. A period (.) indicates there are zero cases in that cell.
Entrenched Health Disparities
Entrenched Health Disparities

[Graphs showing age-adjusted death rate and years of potential life lost by race and ethnicity from 1990 to 2020]

# Diversity in Healthcare

## Racial/Ethnic Distribution of Health Care Workers

<table>
<thead>
<tr>
<th>Occupation</th>
<th>White</th>
<th>Black</th>
<th>Hispanic</th>
<th>Asian</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>All Health Care Workers</td>
<td>60%</td>
<td>13%</td>
<td>16%</td>
<td>7%</td>
<td>3%</td>
</tr>
<tr>
<td>Aides and Personal Care Workers</td>
<td>45%</td>
<td>18%</td>
<td>29%</td>
<td>6%</td>
<td>3%</td>
</tr>
<tr>
<td>Direct Contact Support Workers</td>
<td>53%</td>
<td>17%</td>
<td>22%</td>
<td>5%</td>
<td>3%</td>
</tr>
<tr>
<td>Health Care Providers</td>
<td>67%</td>
<td>10%</td>
<td>10%</td>
<td>10%</td>
<td>3%</td>
</tr>
</tbody>
</table>

**Total and Select Occupations, 2019**

- **Gender Diversity**: Less than 30% of physicians in the following fields are female:
  - Obstetrics and Gynecology
  - Neurological Surgery
  - Pediatrics
  - Thoracic Surgery

- **Racial and Ethnic Diversity**: Only 36% of US physicians are female.

- **Socioeconomic Diversity**: Of all US physicians:
  - 17% work in areas with high poverty
  - 6% work in areas with low poverty
  - 56% work in areas with medium poverty

*Wisconsin Department of Health Services*
What can we do?
Long-term Goals

- Identifying and implementing strategies that diversify healthcare, public health, and clinical/academic workforces.
- Address the social and structural determinants of health, eliminate health disparities and improve overall population health.
- Build/re-build public trust in healthcare systems and medical/biomedical research.
Strategies to Build Trust

• Establish research/practice governance structures that brings underrepresented groups into study development implementation and dissemination.
  
  o **Examples:**
    - **Carbone Cancer Center’s Community Advocacy Boards (CAB)** – Cancer Health Disparities Initiative
    - **Community Advisors on Research Design and Strategies (CARDS)** – Wisconsin Network for Research Support (WINRS)
    - **Dane County Health Council** and the **Black Maternal Child Health Alliance**
Strategies to Build Trust

• Invest in, and partner with, researchers from underrepresented groups from the start of a potential project and through every phase.
  o **Children, Families and Schools Study** – *Can FAST Build Social Capital Among Low-Income, Urban Latino Families?*
    ▪ National Institute of Child Health and Human Development (NICHD) Grant
    ▪ 5-year study
    ▪ 3000+ Families, 52 Schools, 2 School Districts
Strategies to Build Trust

• Provide scientifically accurate training and professional development on race and health and cultural humility to healthcare professionals and researchers.
  - Examples:
    - Dr. Tiffany Green – Race in US Obstetrics and Gynecology
    - Beverly Hutcherson – Courses on biology, race, epigenetics
Final Thoughts
In Summation

• Race is not a biology.
  o Is race the best way of capturing the variation of concern?

• Contemporary distrust is a function of historic and contemporary experiences with medical research, healthcare systems and health outcomes.

• Ultimately, addressing distrust requires addressing power imbalances as well as the drivers and outcomes of these imbalances.
In Summation, cont.

• In the meantime, strategies that support the co-development and leadership of research with members of underrepresented groups, or groups of interest can create localized structures of trust.

• Improving experiences with healthcare providers and systems will go along way to improve trust.
THANK YOU