



October 26-28, 2020

# Maternal & Infant Health in the Digital World:

*Patient-Centered Care During COVID and Beyond*

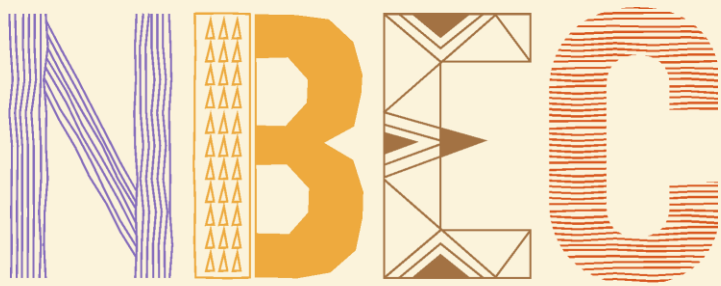
**VIRTUAL CONFERENCE**

[hmhbga.org/event/beyondcovid2020](https://hmhbga.org/event/beyondcovid2020)

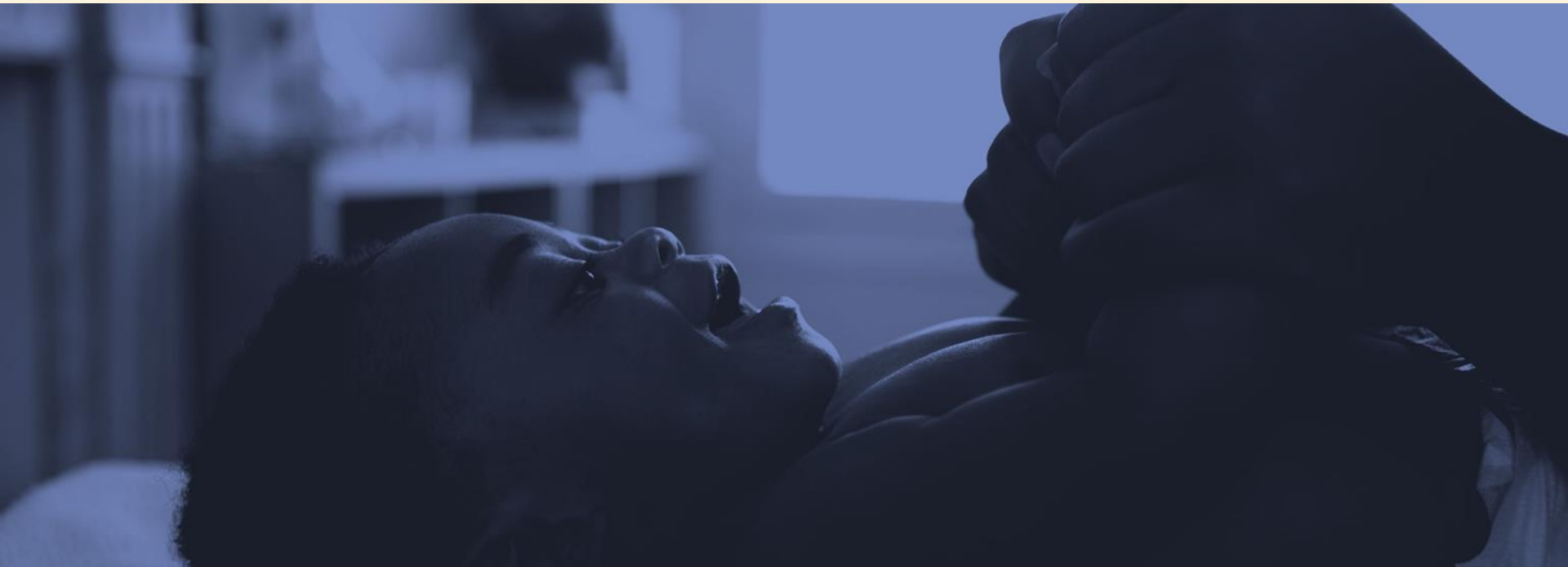
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NATIONAL BIRTH EQUITY COLLABORATIVE



**Lessons from the National Birth Equity Collaborative**  
46th Annual Meeting and Conference for HMHBGA  
Joia Crear-Perry, MD, FACOG

# Mission

NBEC creates solutions that optimize Black maternal and infant health through training, policy advocacy, research and community centered collaboration.

# Vision

All Black mothers and babies thrive.

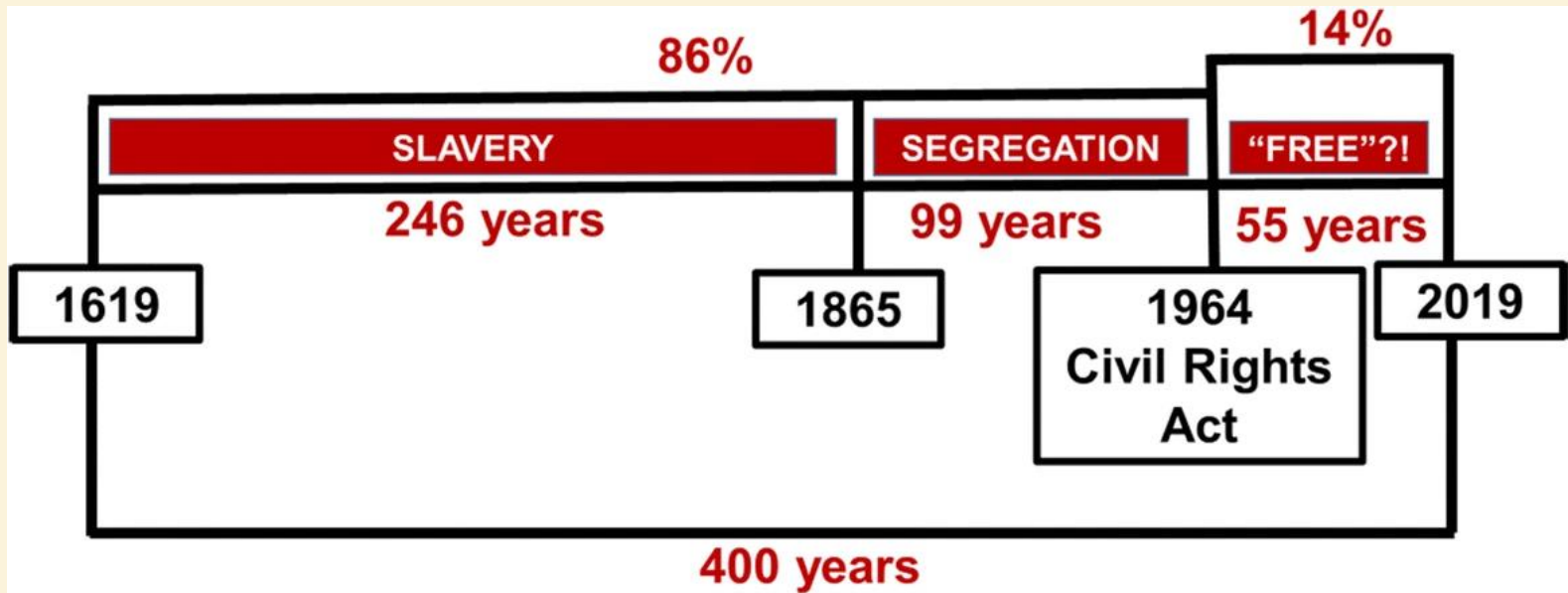


NATIONAL BIRTH EQUITY COLLABORATIVE

*Core Values:*

*Leadership, Freedom, Wellness,  
Black Lives, Sisterhood*

# Timeline of African American Experience



Sealy-Jefferson, S. *et al.*

**86% of the Black experience has been under explicit racial oppression.**

**100% of the U.S. Black experience has been in struggle for humanity and equality.**

# Human Rights – The Global Standard

## Article 2.

**Everyone** is entitled to all the rights and freedoms set forth in this Declaration, **without distinction of any kind**, such as race, color, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.

## Article 3.

**Everyone has the right to life**, liberty and security of person

## Article 25.

(1) Everyone has the right to a **standard of living adequate for the health and well-being of himself and of his family**, including food, clothing, housing and medical care and necessary social services

(2) Motherhood and childhood are **entitled** to special care and assistance. All children, whether born in or out of wedlock, shall enjoy the same protection.

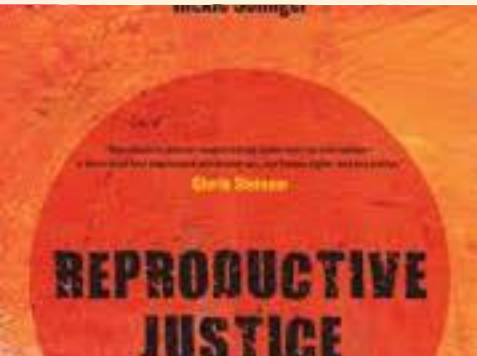
# Reproductive Justice

**The human right to maintain personal bodily autonomy, have children, not have children, and parent the children we have in safe and sustainable communities.**

-Loretta Ross

## **We must...**

- Analyze power systems
- Address intersecting oppressions
- Center the most marginalized
- Join together across issues and identities



## birth equity (*noun*):

1. The assurance of the conditions of optimal births for all people with a willingness to address racial and social inequities in a sustained effort.

Joia Crear-Perry, MD  
*National Birth Equity Collaborative*

# pregnancy wellbeing (*noun*):

1. Rooted in Reproductive Justice, asserts that regardless of access to knowledge, power or wealth, all birthing people are supported by government and health systems to be physically and mentally well through their pregnancy.

Joia Crear-Perry, MD  
*National Birth Equity Collaborative*



# reproductive wellbeing (*noun*):

1. All people have the information, services, and support they need to have control over their bodies and to make their own decisions related to sexuality and reproduction throughout their lives

Joia Crear-Perry, MD  
*National Birth Equity Collaborative*

# Indicator ≠ Framework

## Indicator

Indicator is a datapoint

- Measurement limited by current reality
- A product of our past understanding of public health and science
- Systems are more apt to adhere to specific prescribed indicators than to determine alternatives

## Framework

A framework is a vision

- Expands understanding of current reality
- Allows freedom to explore language of indicators
- Exploration of alternatives to traditional data collection & application
- Questions historical construction health systems



# Root Causes and Social Determinants of Health

# Root Causes

Institutional Racism

Class Oppression

Gender Discrimination and Exploitation

LABOR MARKETS

TAX POLICY

Power and Wealth Imbalance

HOUSING POLICY

EDUCATION SYSTEMS

GLOBALIZATION & DEREGULATION

SOCIAL SAFETY NET

SOCIAL NETWORKS

Safe Affordable Housing

Job Security

Social Determinants of Health

Living Wage

Quality Education

Transportation

Availability of Food

Social Connection & Safety

Psychosocial Stress / Unhealthy Behaviors

Disparity in the Distribution of Disease, Illness, and Wellbeing

Adapted by MPHI from R. Hofrichter, *Tackling Health Inequities Through Public Health Practice*.

# What are “Social Determinants of Health”?

*“The social determinants of health are the conditions in which people are born, grow, live, work, and age.*

These circumstances are shaped by the distribution of money, power, and resources at the global, national, and local levels.

Examples of resources include employment, housing, education, health care, public safety, and food access.”

## Racism as a SDOH

Racism affects health both directly (i.e., via chronic stress) and indirectly (i.e., via race-based discrimination across multiple systems which creates differential access to high-quality schools, safe neighborhoods, good jobs, and quality healthcare, in other words, by shaping SDOH.)

# Social Construction of Race

A photograph of two women sitting at a table in a cafe or office setting. The woman on the left is wearing glasses and a patterned top, looking towards the woman on the right. The woman on the right is wearing a dark top and is holding a card, looking down at it. On the table, there is a coffee cup, a tablet, and some papers. The background shows a window with a grid pattern and a railing. The entire image has a blue tint.

# Anthropological Approaches Demonstrate

- Race is real, and it matters in society, but not how racists think it does.
- Race is not a genetic cluster nor a population.
- Race is not biology, but racism has biological effects
- Social constructs are real for those who hold them

**RACE**

≠

**ETHNIC GROUP**

≠

**POPULATION**

≠

**ANCESTRY**

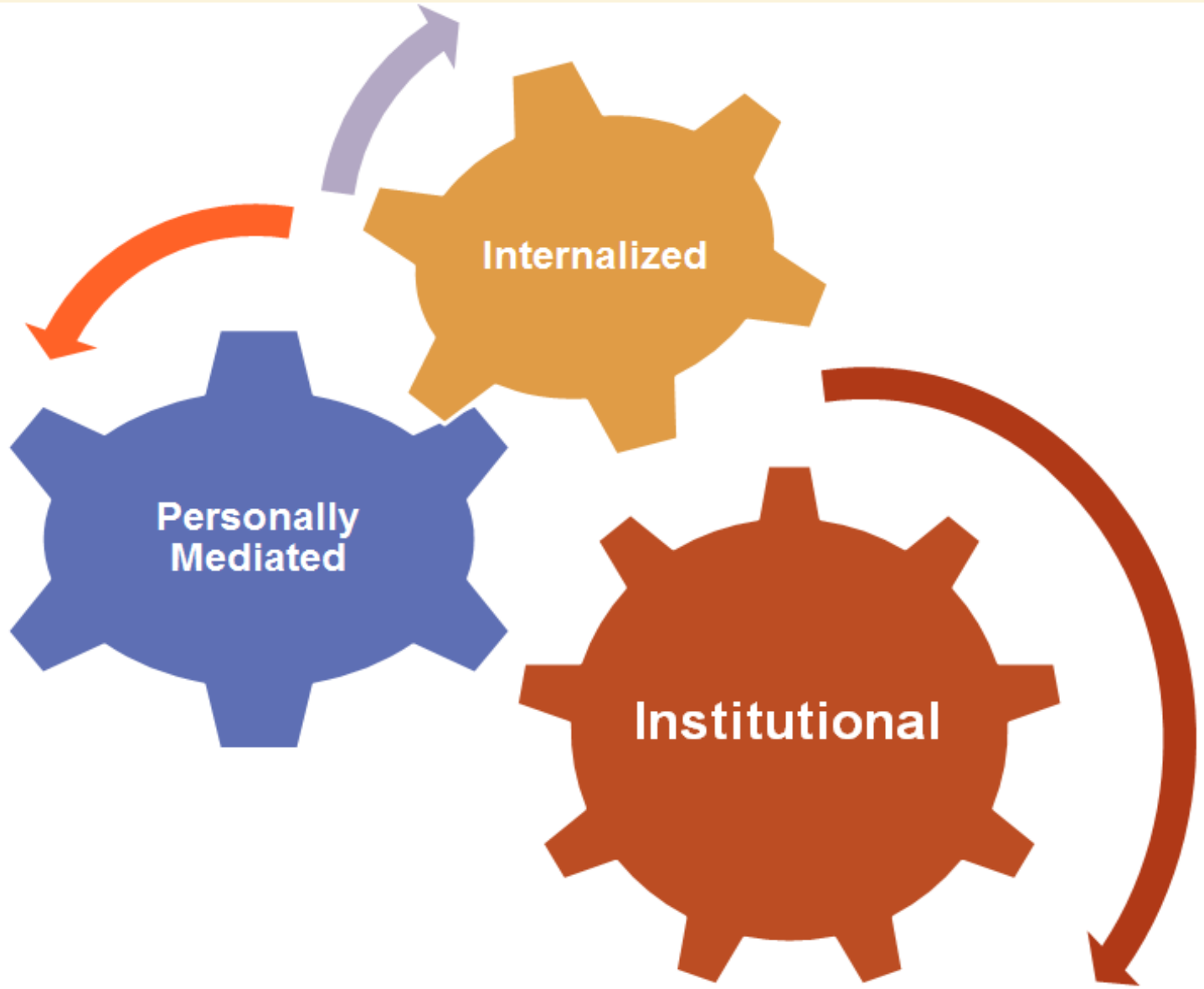
These are four different ways to describe, conceptualize and discuss human variation... and cannot be used interchangeably



A blue-tinted photograph of two women smiling and looking down at a baby. The woman on the right is smiling broadly with her eyes closed, and the woman on the left is also smiling and looking down. The baby is in the foreground, partially visible. The text "Racism- Not Race" is overlaid in white in the center of the image.

Racism- Not Race

# Levels of Racism



- **Institutionalized racism**- the structures, policies, practices and norms resulting in differential access to the goods, services and opportunities of societies by race.
- **Personally mediated** - the biases and differential assumptions about the abilities, motives and intentions of others by race.
- **Internalized racism** - the acceptance and entitlement of negative messages by the stigmatized and non stigmatized groups.

-Camara Jones, MD, PhD, Past President APHA

# Finding the Roots of Inequities

Black mothers who are college-educated fare worse than women of all other races who never finished high school.

Obese women of all races have better birth outcomes than black women who are of normal weight.

Black women in the wealthiest neighborhoods do worse than white, Hispanic and Asian mothers in the poorest ones.

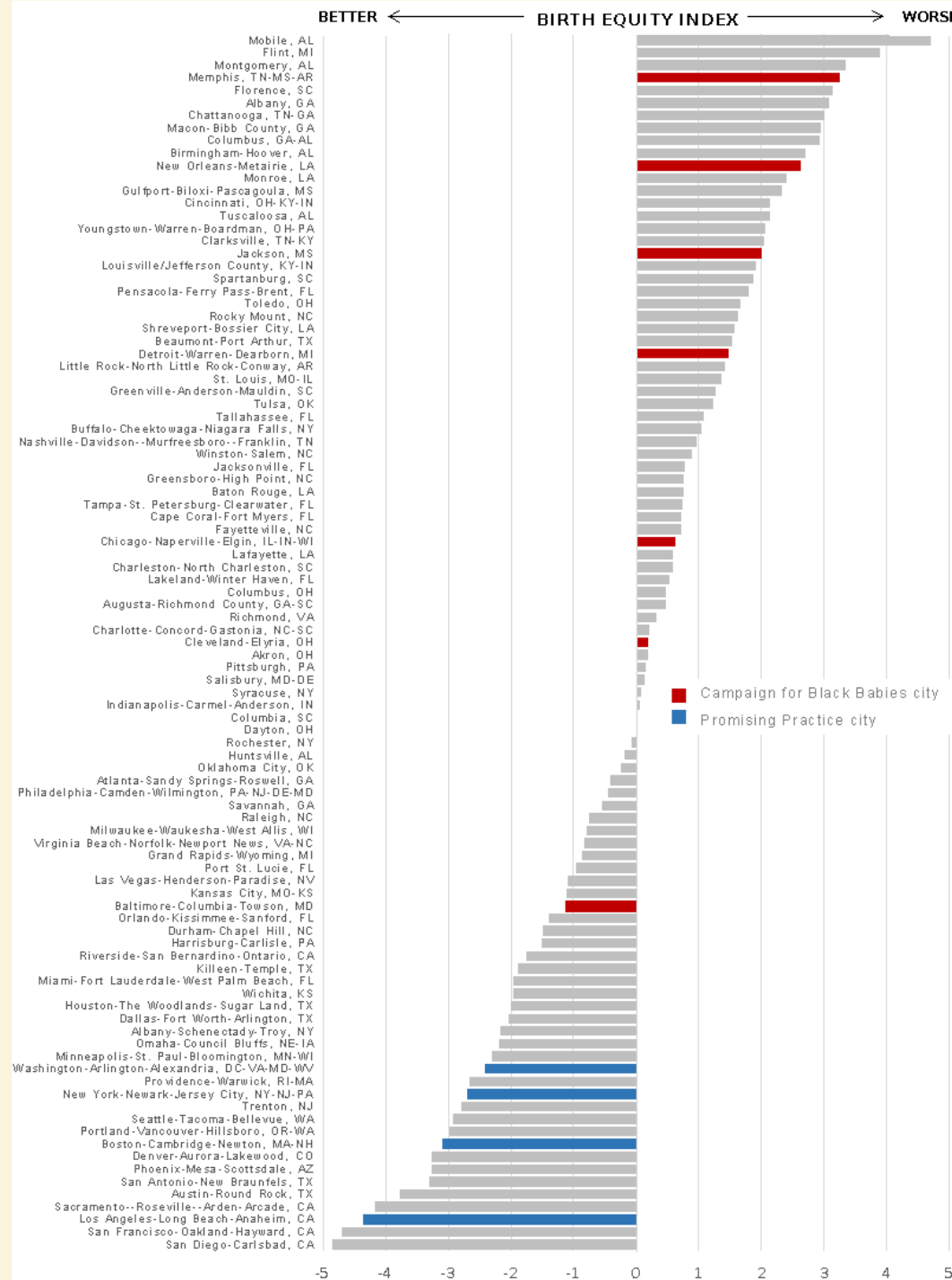
African American women who initiated prenatal care in the first trimester still had higher rates of infant mortality than non-Hispanic white women with late or no prenatal care.

# Birth Equity Index

Data tool to identify significant social determinants

- A comprehensive set (50+) of social determinant indicators were selected to broadly define health and opportunities for better health within the social and physical environment of 20 US metro areas with some of the highest black infant mortality rates in the country. We identified those that were at least marginally associated with black infant mortality rates including:*

  - prevalence of smoking and obesity among adult residents
  - number of poor physical and mental health days experienced by residents
  - percentage of residents with limited access to healthy foods
  - rates of homicide and jail admissions
  - air pollution
  - racial residential segregation (isolation)
  - rates of unemployment and low education among NH black residents
  - income inequality between black and white households
- We used data-reduction techniques to combine values of these indicators into an overall index of black infant mortality social determinants, with higher values representing worse health conditions.*



# Campaign for Black Babies

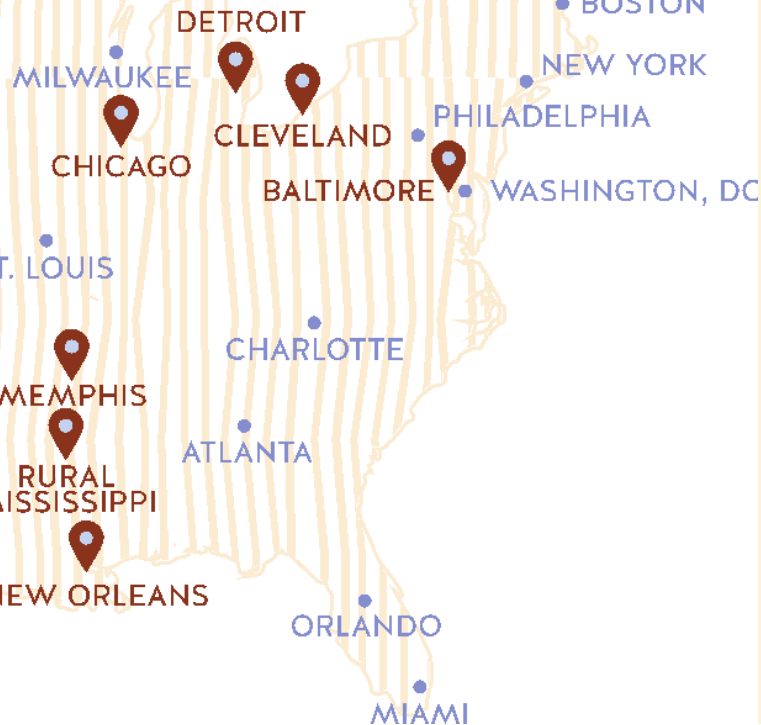
- **CITIES WITH HIGHEST BLACK INFANT DEATHS**

\*1 in 4 black infant deaths occur in these places.

- **CITIES WITH ACTIVE CAMPAIGNS FOR BLACK BABIES**

\*Meeting our 5-year and 10-year goals in all 20 places means saving 3,000+ babies.





• LOS ANGELES



## “Look at the Whole Me”: A Mixed-Methods Examination of Black Infant Mortality in the US through Women’s Lived Experiences and Community Context

Maeve E. Wallace <sup>1,2,\*</sup>, Carmen Green <sup>2</sup>, Lisa Richardson <sup>2,3</sup>, Katherine Theall <sup>1,2</sup> and Joia Crear-Perry <sup>2</sup>

# Physician–patient racial concordance and disparities in birthing mortality for newborns

 Brad N. Greenwood,  Rachel R. Hardeman,  Laura Huang, and  Aaron Sojourner

PNAS September 1, 2020 117 (35) 21194-21200; first published August 17, 2020

<https://doi.org/10.1073/pnas.1913405117>

- Patient-physician racial concordance has beneficial health outcomes.
- In the United States the infant mortality rate for Black newborns is 3x that for White newborns.
- Found that newborn-physician racial concordance associated with drastic improvement in Black infant mortality, even more for complicated births and hospitals that deliver more Black babies.
  - Black babies cared for by Black physician caused the infant mortality rate to be halved.

A blue-tinted photograph of a woman smiling and holding a baby, with another person looking on. The image is overlaid with a semi-transparent blue filter. The text "Policies and Perinatal Health" is centered in white.

# Policies and Perinatal Health



# Racial Health Inequities: Individual vs. Collective Accountability

**“Racially discriminatory policies have usually sprung from economic, political, and cultural self-interests, self-interests that are constantly changing.”**

- Politicians seek political self-interest.
- Capitalists seek increased profit margins.
- Cultural professionals seek professional advancement.



— Ibram X. Kendi, *Stamped from the Beginning: The Definitive History of Racist Ideas in America*

# Racially Biased Narratives and Policy

## Black Crack/Cocaine Narrative

- Illicit drug use among white women at the time was equally prevalent
- Connoted careless Black motherhood in inner-city America
- “Crack babies” considered biologically inferior, eventual super-predators, and a longterm burden on fed. Assistance & service programs
- Pregnant drug users were convicted as killers, drug dealers and child abusers
- Mass incarceration of Black mothers through random drug tests, leveraging child removal and incarceration

## White Opioid Narrative

- White women are America’s sisters and daughters
- Opioids are an “epidemic of despair” for Middle America
- Considered a disease, not a moral failing
- No conclusions made about prenatal opioid use or future of exposed babies
- Public health response through special funding (\$45 Billion) in fed. health care bill that threatened Medicaid (frontline insurance responder)
- Southern states that led in criminalizing black women are softening punitive policies for addicted mothers

# Lessons Learned from Substance Abuse

Dr. Claire Cole debunked the “crack baby” term with scientific data, determining effects of poverty are a bigger driver of poor long-term developmental outcomes than drug abuse itself

**Understanding community context and humanizing the victims of drug addiction allowed for...**

“Fetal/Neonatal Abstinence Syndrome” recognized over “Crack Babies”

Aid funding instead of increased criminal justice budgets



**Data**  
- **Voice**  

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**Poor Policy**

# COVID-19 and Maternal Health Outcomes

- Black Americans are disproportionately dying from COVID-19
  - effects of discriminatory policing and work practices, barriers to healthcare access, and a lack of health coverage, housing segregation, lack of educational and employment opportunities, implicit bias in healthcare
- COVID-19 has had an overwhelming impact on Black maternal health outcomes
  - restricting patients from seeking prenatal and postnatal care due to concerns or fear of exposure
    - lead to provider missing underlying symptoms
  - limit/restrict number of people in the delivery room
    - mothers have to choose between their partner, midwife, or doula

# Police Violence and Birth Outcomes

- Black people are disproportionately impacted by police violence
- The trauma of police violence creates stress and adds to the allostatic load and weathering, contributing to Black maternal mortality
  - allostatic load: the damaging biological effects of overexposure to stress hormones
  - weathering: the ongoing stress of racism results in higher levels of disease and biological aging in Black people
- 2016 study found police killings of unarmed Black people substantially decreased the birth weight and gestational age of Black infants residing nearby
- The immediate and long-range trauma police brutality causes is deadly

A photograph of a family in a hospital bed, overlaid with a blue tint. A man is leaning over a woman and a baby, kissing the baby's forehead. The woman is smiling and looking at the baby. The word "Opportunities" is written in white text across the center of the image.

Opportunities

# Racial Equity Lens

The health care system alone isn't equipped to overcome the inequities driven by income, language, education or racism

## **Racial Equity Lens**

- Centers place, environment and social determinants
- Addresses aggravated risk for specific local challenges
- Addresses intergenerational and cumulative effects of structural racism on health

# Useful Resources

## Racial Equity Analysis

- What?
- Why care?
- Now what?

## Root Cause Analysis

- Identify systems vulnerabilities that impact patient safety and outcomes
- Identify measurable systems-based corrective actions
- Ensure follow-through and implementation
- Ensure that leadership at all levels of the organization participate and hold staff accountable for RCAs

## 5 Whys Exercise

- ❖ Identify an event or pattern that concerns staff
- ❖ Identify tangible and intangible structures that are contributing to results
- ❖ Brainstorm implications for action

**How can you better apply existing tools in your daily work?**



# Birth Equity Agenda

**Five critical measures for ensuring that the United States has the proper infrastructure and resources in place to achieve equitable maternal health outcomes.**

1. Reproductive health and autonomy are promoted and protected at the highest levels of government.
2. Health is a government priority and a recognized right.
3. Individual and institutions are held accountable for discrimination that leads to disparate health impacts.
4. No maternal death goes unnoticed or uncounted.
5. Government involvement in reproductive health may not intrude on reproductive freedom, agency, and autonomy.

# The Black Maternal Health Momnibus Act of 2020

**Comprehensive federal legislation to address and improve every dimension of the Black maternal health crisis in America.**

- ❖ Social Determinants for Moms Act
- ❖ Kira Johnson Act
- ❖ Protecting Moms Who Served Act
- ❖ Perinatal Workforce Act
- ❖ Data to Save Moms Act
- ❖ Moms MATTER Act
- ❖ Justice for Incarcerated Moms Act
- ❖ Tech to Save Moms Act
- ❖ IMPACT to Save Moms Act

A blue-tinted photograph of two women sitting at a table in what appears to be a cafe or office setting. The woman on the left is wearing glasses and a patterned top, looking towards the woman on the right. The woman on the right is holding a card and looking down at it. On the table are a coffee cup, a tablet, and some papers. The background shows a railing and a window.

# Respectful Maternity Care

“What’s missing from the care of Black women is their centered voice, validation of experience, and freedom to choose and be informed. Black women need **respectful care that is free of implicit and explicit bias.** It is the provider’s responsibility to address those biases. To address the issue of maternal mortality **we need care that originates from and is defined by Black women-led organizations, practitioners, and community members.”**



Jessica Roach, MPH

Black Mamas Matter Alliance (2018). Setting the Standard for Holistic Care of and for Black Women. Retrieved from <https://blackmamasmatter.org/resources/bmma-products/>

# Mothers Voices Driving Birth Equity

National Birth Equity Collaborative  
Funded by the Robert Wood Johnson Foundation

## BACKGROUND

**Women in the US are dying in pregnancy and childbirth at unprecedented rates.**

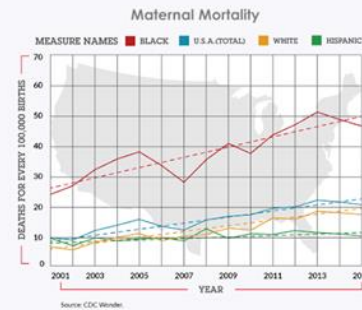
The community closest to the pain and suffering through disparate deaths and complications are Black mothers and birthing people.

Disrupting birthing narratives and care required cultural shifting from mother/individual blame to provider/systems accountability.

Cultural transformation depends the capacity for providers and systems to listen to, understand, and respond to community voices in sharing stories of disrespectful and dismissive care and service gaps.



**Listen to** Black Women  
**Trust** Black Women  
**Respond to** Black Women



NBEC

National Birth Equity Collaborative (NBEC) optimizes Black birth outcomes through training, research, community centered collaboration, and advocacy. NBEC uplifts Black women led organizations, guiding clinicians and researchers to center women, their families and their stories.

ACOG-  
AIM

The American College of Obstetrics and Gynecology (ACOG) is the lead partner in The Alliance for Innovation on Maternal Health (AIM) program. AIM is a national alliance to promote consistent and safe maternity care to reduce maternal mortality and severe maternal morbidity.

## PURPOSE

**To develop and apply a community informed theoretical model in the creation and testing of a participatory patient-reported experience metric (PREM) of mistreatment and discrimination in childbirth.**

There is no metric for patient-reported experience of mistreatment and discrimination in childbirth and pregnancy developed by, for, and with impacted Black communities, mothers, and scholars

## Research & QI Methodologies

Reproductive Justice

Cultural Humility

Research Justice

Systematic analysis and disruption of hierarchy of knowledge construction and power in QI, clinical research, and public health

Prioritization and amplification of community voice and knowledge

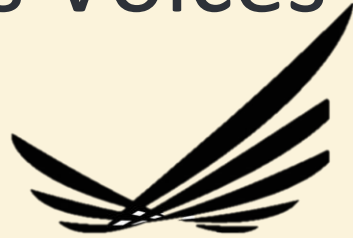
Co-development of shared language, vision, and understanding of respectful and dignified maternity care

Co-creation and testing of best practices that lead to improved listening, shared decision making and trust between Black mothers, clinicians, and health systems

## OBJECTIVES

- Facilitate and sustain opportunities for Black mothers stories to be valued, seen, & heard in semi-structured focus group interviews
- Develop a community informed theoretical model in collaboration with Black mothers/birthing people based on group interviews
- Map existing theoretical constructs onto those identified from Black mothers and CBOs to inform the co-creation and co-testing of a PREM of respect, mistreatment, and discrimination
- Utilize the PREM in systems accountability, quality improvement patient advocacy and interprofessional education

# Mothers Voices Driving Birth Equity



Robert Wood Johnson  
Foundation

Transforming Health &  
Healthcare Systems

“Cultural transformation deepens the capacity for providers and systems to listen to, understand, and respond to community voices in sharing stories of disrespectful and dismissive care and service gaps.”

- Dr. Karen Scott

## Participant Characteristics

Black women from U.S. and Africa  
N=50

Mean Age: 32

## Cities

- Atlanta, GA
- Baltimore, MD
- Chicago, IL
- Dallas, TX
- Houston, TX
- Tulsa, OK

# What is Respectful Care?

## Themes

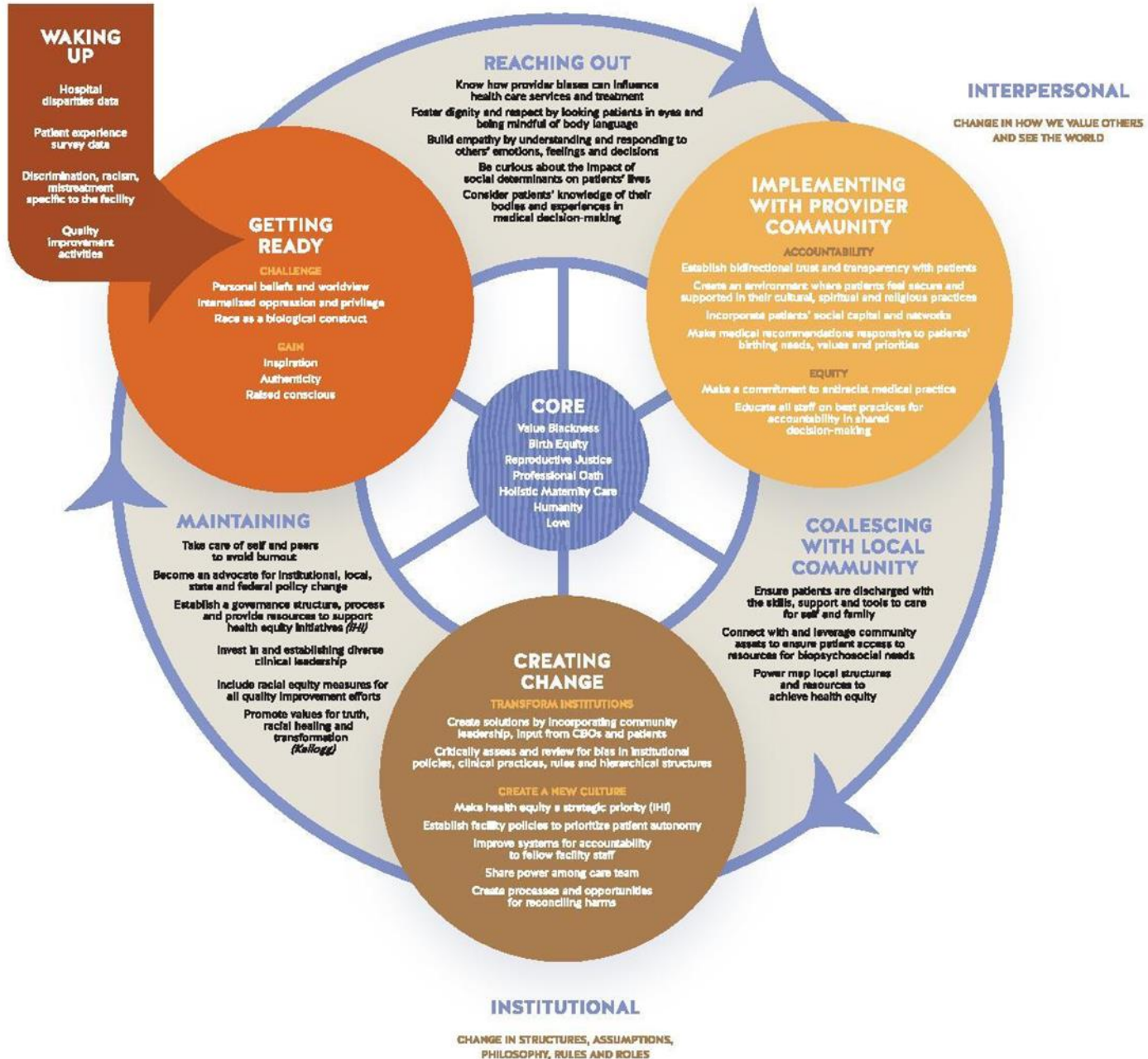
- Accountability
- Equity
- Empathy
- Safety
- Racism
- Trust

## COVID-19 Relevant Themes

- Autonomy
- Communication
- Information
- Medical recommendations
- Transparency
- Social capital and networks

# INTERNALIZED

CHANGE WITHIN THE CORE OF PEOPLE ABOUT  
WHAT THEY BELIEVE ABOUT THEMSELVES





# Holistic Systems of Care

## Setting the Standard for Holistic Care of and for Black Women



Human centered design  
Community engagement

- Trauma informed story sharing
- Community informed advocacy

Mamatoto Village Doula  
Services



Washington D.C.

Ancient Song Doula Services



Brooklyn, New York

# 2019 KINDRED PARTNERS

BMMA Kindred Partners are Black women-led organizations that work with and for Black Mamas operating at the national, state and local levels. Additionally, their work and activities are guided by the birth justice, reproductive justice, and human rights frameworks.



# BMMA's Research Principles





**Segregationists**

**Assimilationists**

**Anti-Racists**

# Thank you



Founder President

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