



Advancing NIH Research on the Health of Women: A 2021 Conference

Root Causes of Maternal Health Outcomes and the Path to Research Justice

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Mission

NBEC creates global solutions that optimize Black maternal, infant, sexual and reproductive well-being. We shift systems and culture through training, research, technical assistance, policy, advocacy and community-centered collaboration.

Values

We stand on our values of Radical Joy, reproductive and sexual freedom, Black Lives, sisterhood, anti-racism, power, and Black Feminism/Womanism

Vision

Our vision is that all Black mamas and babies thrive

Reproductive Oppression Timeline



- **1619-1719:** The condition of the mother, bodily autonomy
- **1720-1820:** Reproducing Oppression; Ban of Trans-Atlantic Slave Trade
- **1821- 1921:** Enhanced focus on reproductive capacity
- **1922- 2021:** Birth Control, Blame-Eugenics & Sterilization

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.

Everything is a *thing* with a history & set of *relations*

“...understanding anything in our everyday requires that we know something about HOW it arose & developed & how it fits into the larger context or system of which it is a part.”

– Bertell Ollman in *Dialectical Investigations* (1993:11)

It is important to note that when we speak of SYSTEMS & INSTITUTIONS we are still talking about people, collectively organized in a way that is based on a particular set of rules & relations.



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.)

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

Race vs. Racism

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

Levels of Racism

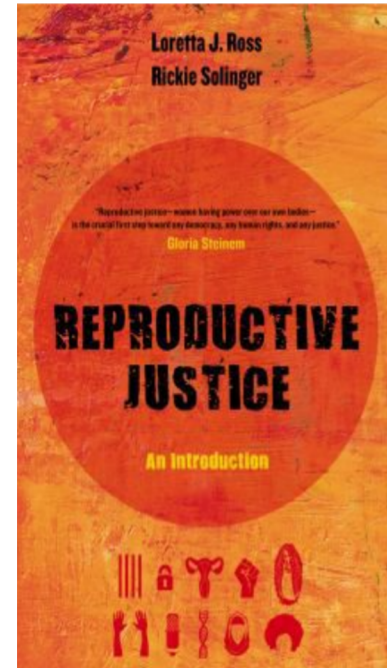
- **Institutionalized racism**- the structures, policies, practices and norms resulting in differential access to the goods, services and opportunities of societies by race.
- **Personally mediated** - the biases and differential assumptions about the abilities, motives and intentions of others by race.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

-- Camara Jones, MD, PhD, Past President APHA

Reproductive Justice

What is Reproductive Justice?

- Developed in 1994 by the Women of African Descent for Reproductive Justice, the concept acknowledges the conditions that dictate women and people's reproductive outcomes.
- Reproductive Justice affirms that all individuals have the human right:
 - Decide if/when they will have a child and the conditions under which they will give birth.
 - **Parent the children they already have with the necessary social supports in safe environments and healthy communities, and without fear of violence from individuals or the government.**
 - The right to bodily autonomy



Operationalizing Reproductive Justice



Research Injustice

What is research injustice?

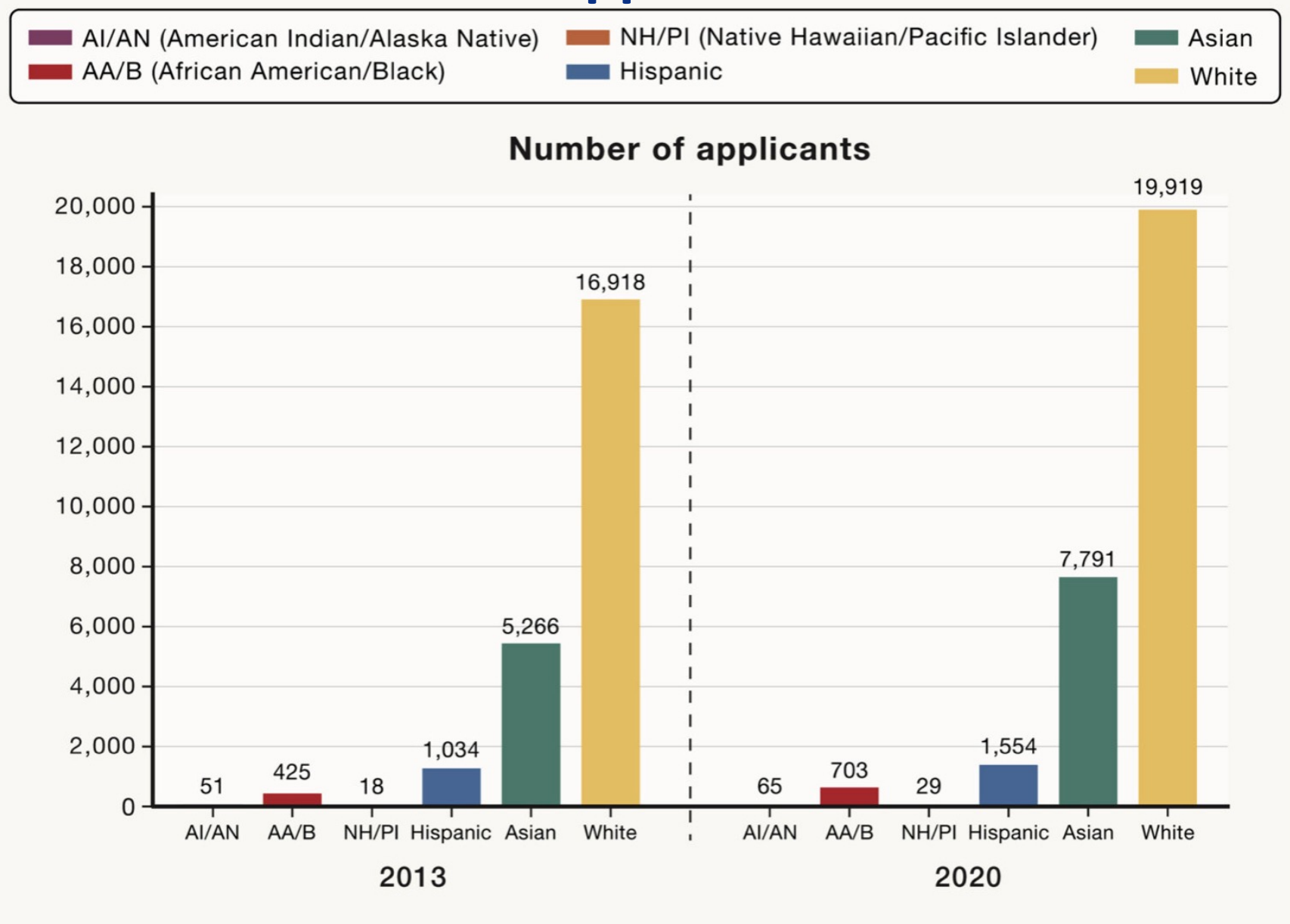
- Research injustice is a situation where community voices and experiences are dismissed, ignored or information is inaccessible due to:
 - Jargon
 - Money
 - Lack of translations narratives exclude or misrepresent community experiences
 - Communities lacking control over the production, documentation, possession, and dissemination of their own data or stories

NIH's Plan to Confront Research Injustice

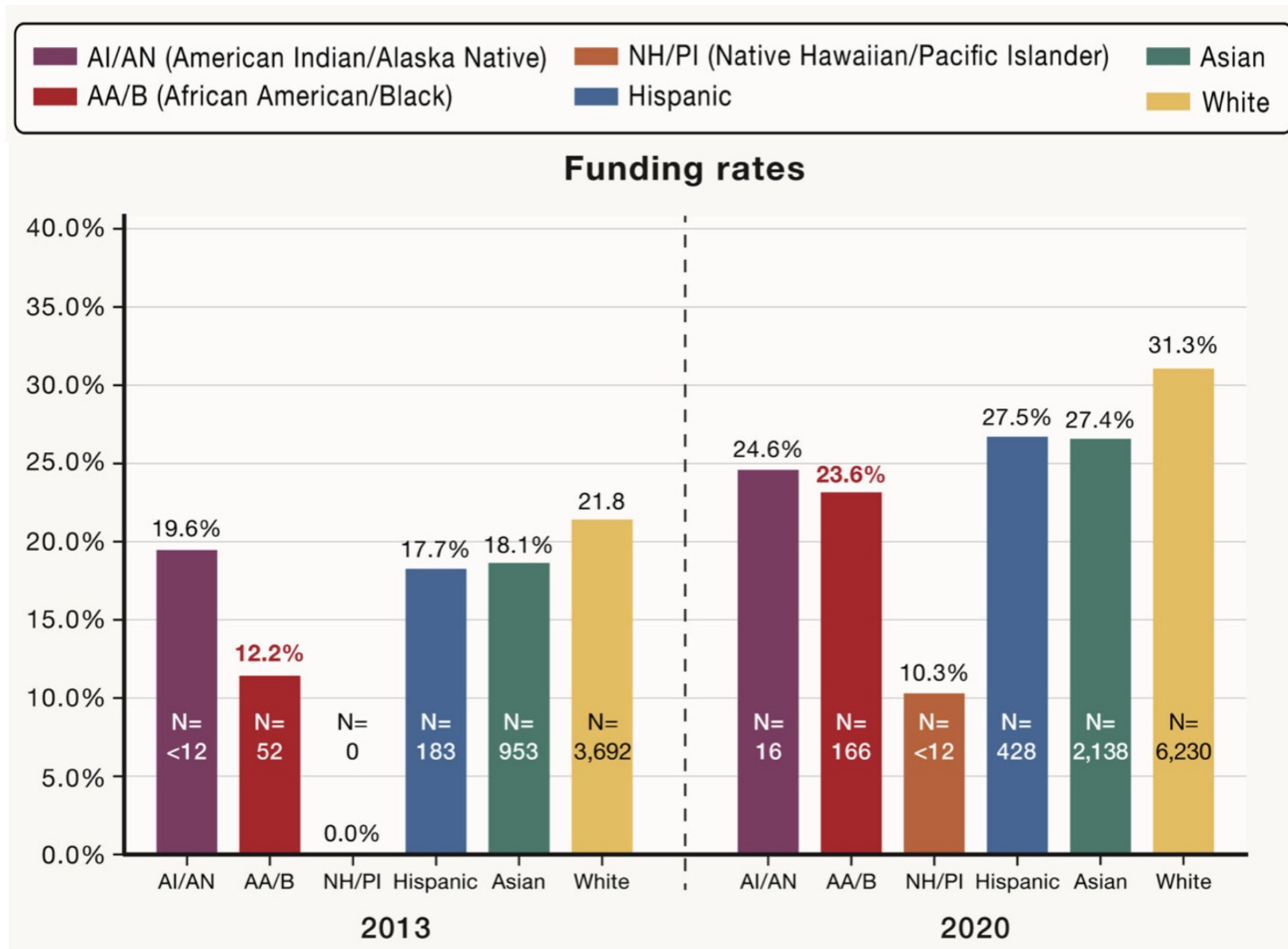
- June, 2021, NIH Director, Francis Collins released his plan intended to eliminate a big gap in grants awarded to white and minority scientists and boost funding for research on health disparities
- Programming to recruit, mentor, and retain researchers from underrepresented racial and ethnic groups, and appoint diversity and inclusion officers at each of its 27 institutes and centers.
- NIH leaders plan to spend \$60 million on projects aimed at reducing health disparities and another \$30 million to study and address the impact of structural racism and discrimination on minority health. This new funding is meant to help address the funding gap

McFarling, U. (2021). NIH releases a plan to confront structural racism. Critics say it's not enough. Taffe, M. A., & Gilpin, N. W. (2021). Racial inequity in grant funding from the US National Institutes of Health. *eLife*, 10, e65697. <https://doi.org/10.7554/eLife.65697>

Disparities in NIH RO1 Grant Applications



Disparities in NIH RO1 Funding



Major Assumptions of Current Research

1. There are no solutions or interventions for improved Black maternal health that Black women themselves do not already possess
2. The “shame and blame” narratives that dominate much of the discourse about data on Black Mamas is not insightful or helpful and perpetuates a dangerous myth that White people serve as a default standard for the rest of the population
3. The current conduct of research—specifically the dissociation of social and clinical determinants of health—is both problematic and unethical

Gaps in current research

- There is a lack of consideration of structural factors leads to systematic underestimation or misappraisal of Black maternal clinical risk factors
 - Disregard for structural factors increases risk to poorer health outcomes
- Compounding structural determinants of health are proposed fixes to so-called “health disparities” that focus on quality improvement without equity
- Centered on individuals that fail to acknowledge that structures of power are often out of reach for marginalized communities
- This issues are reinforced by silos that exist in the provision of clinical health services where much of the research that drives interventions for improved health outcomes is conducted

Structural factors include: Access to health insurance, transportation, childcare, housing, education, food insecurity, carceral involvement, and other social determinants have been described and associated with poorer health outcomes

Current unaddressed ethical issues

- Lack of informed consent
- Lack of acknowledgment or compensation for scientific awards and discoveries
- Explicit coercion of communities of color and inflicted harm
- Criminalization of pregnant people and punitive uses of various contraceptive methods, and involuntary sterilization

PLACEHOLDER

Pay Gaps

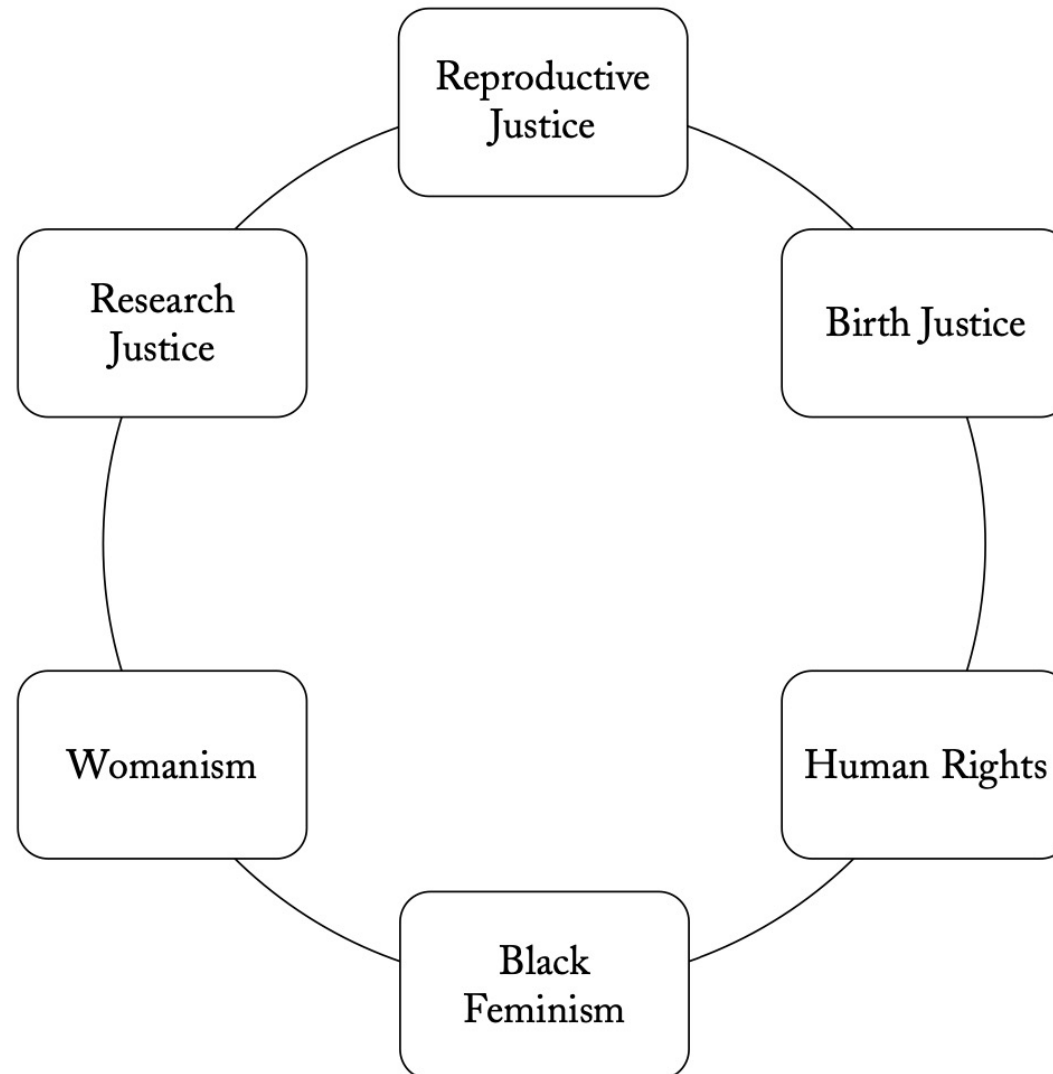
Funding

Trickle-down effect

Low representation of Black scientist, researchers

REFERENCE

BMMA Research Working Group Conceptual Framework



PLACEHOLDER

REFERENCE

Research Reimagined

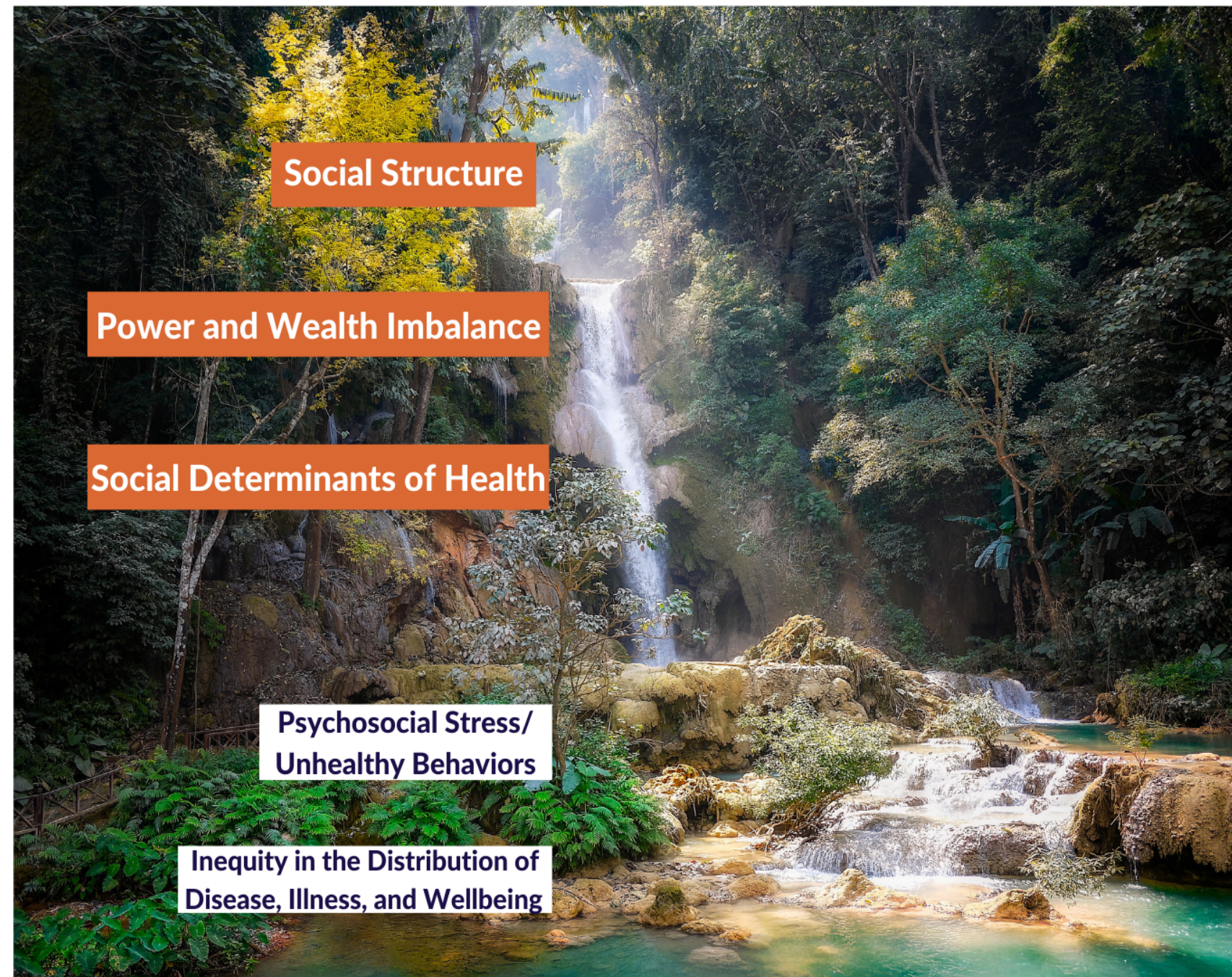
Best Practices and Guidelines for Holistic Care

1. Recognize and respect the rights of Black mamas
2. Understand the historical, sociocultural, political and economic contexts in which Black mamas live their lives
3. Invest in Black women as researchers
4. Fund and conduct ethical research that benefits Black mamas
5. Honor and commit to community engagement through the entire research process
6. Include health equity and social justice as key themes in research with Black mamas

Policy/Advocacy

Downstream vs. Upstream

Goal: Aim for **Upstream** Interventions



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.

Policy Change Examples

- Leverage nurses and other staff to **assist in culture-shift to collaborative care** (assessments, referrals, relationship building)
- Influence partner organizations to prioritize racial equity in their work
- Trainings and workshops for staff to develop more cultural competence and manage implicit bias **in response to maternal experiences of racism**
- Work with community action teams to improve city-wide transportation infrastructure **in response to data and maternal experience** (signage, bike lanes, crossing guards, bus schedules, etc)
- Lead community action teams to activate against federal threats to Medicaid and public health infrastructure through the ACA, **in response to overall disinvestment in health and safety**
- **Educate the community** on opioid abuse and its impact on family health. **Lead a city-wide advocacy campaign** to direct funds towards the issue



Thank you!



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