REPRODUCTIVE JUSTICE AND ENVIRONMENTAL JUSTICE CONVENING



Summary and key takeaways from the December 2021 interdisciplinary convening





On December 10, 2021, Columbia University's Global Health Justice and Governance Program (GHJG) in partnership with SisterSong Women of Color Reproductive Justice Collective and Women with a Vision hosted an interdisciplinary convening on reproductive and environmental justice in the U.S. The meeting, held in New Orleans months after Hurricane Ida and the day Mississippi versus Jackson was argued at the Supreme Court, was historic. More than 40 researchers, community-based activists, and donors convened to discuss the connections between environmental justice and reproductive justice and how advocates and scientists can be better aligned to improve health outcomes. The discussion focused on maternal mortality and preterm birth in Louisiana and Mississippi among Black and Brown women—states with the worst records of maternal and infant outcomes in the nation—to ask why environmental drivers of these glaringly bad trends are understudied and discounted.

Maternal and infant health outcomes in Louisiana, Mississippi, and the U.S. overall, 2018-2019

Indicator	Louisiana	Mississippi	U.S. Overall
Maternal	<u>25.2</u> per 100,000	<u>22.6</u> per 100,000	<u>17.4</u> per 100,000
Mortality Rate ¹	live births	live births	live births
Infant	<u>8.1</u> per 1,000	<u>9.1</u> per 1,000	<u>5.6</u> per 1,000
Mortality Rate ²	live births	live births	live births
Preterm Birth	<u>13.12</u>	<u>14.58</u>	<u>10.23</u>
Rate⁵	National rank: 2nd	National rank: 1st	
Low Birthweight	<u>10.8</u>	<u>12.3</u>	<u>8.31</u>
Rate ⁴	National rank: 2nd	National rank: 1st	

¹ Maternal deaths include deaths of women while pregnant or within 42 days of termination of pregnancy, irrespective of the duration and the site of the pregnancy, from any cause related to or aggravated by the pregnancy or its management, but not from accidental or incidental causes.

2 The number of infant deaths (death of an infant before his or her first birthday) per 1,000 live births.

³ Percentage of babies born prior to 37 weeks of pregnancy (gestation).

⁴ Percentage of babies born weighing less than 2,500 grams or 5 lbs. 8 oz.

This document provides highlights from that discussion including preliminary suggestions for future areas of focus. Details of the individual panels are provided in Appendix I; suggestions from breakout groups are provided in Appendix II; and a full list of participants is provided in Appendix III. We gratefully acknowledge the support of the Charles and Lynn Schusterman Family Philanthropies and the David and Lucile Packard Foundation.

REPRODUCTIVE JUSTICE IS ENVIRONMENTAL JUSTICE

Participants were clear that environmental justice is reproductive justice: both terms encompass the other, but more strategic work can and should be done bridging the two movements. The reproductive justice framework⁵ incorporates environmental justice because it addresses intersections of race, gender, class, sexual orientation, and gender identity with the historical and contemporary impacts of economics, politics, and culture in specific locations and situations. Black and Brown researchers and community-based activists gave examples of how their reproductive justice work had been undermined by white activists and donors who prioritize piecemeal solutions to abortion or contraceptive access and fail to address structural racism driving high rates of environmental exposures that disproportionately affect Black and Brown communities and birthing people.

STRUCTURAL RACISM IN RESEARCH INSTITUTIONS AND RESEARCH AGENDAS

Embedded legacies of structural racism directly affect what research is funded, who leads it, and whether policymakers consider it credible. Participants described National Institutes of Health (NIH) proposal processes that systematically prioritize studies of individual risk factors and behaviors over studies of structural factors affecting health outcomes. These selection processes may rely on biased review panels that discount evidence generated by communitybased participatory research models and disadvantage Black and Brown researchers, who due to legacies of structural racism—have a smaller pool of senior Black and Brown researchers to partner with on large cohort studies.

Gatekeeping is replicated within higher education institutions and academic publishing houses that frequently reject evidence-based research on the impact of racism on health. A <u>2021 study of leading medical journals</u> found that less than one percent of articles published between January 1990 and December 2020 directly referred to racism; of these, 90 percent were opinion pieces. Gatekeeping to filter out research on structural racism reinforces existing policies and clinical practices that contribute to poor health outcomes and undermines the professional advancement of Black and Brown researchers working on these issues.



We are battling a system that judges us and does not allow us to push forward the science that addresses the root causes.

- anonymous quote from a researcher in attendance

REPRODUCTIVE JUSTICE AND CLIMATE CHANGE PLANNING

Existing climate change plans fail to address the needs of birthing bodies, as demonstrated by an October 2020 <u>review</u> of more than 100 emergency preparedness documents from 18 cities that found pregnancy mentioned only three times—although concerns about pets were mentioned 37 times. Legacies of redlining, criminalization, and other aspects of structural racism make Black and Brown communities exceptionally vulnerable to climate impacts, and solutions that fail to take these disparities into account risk exacerbating them. Participants described challenges in securing medical care after Hurricane Ida for patients who lacked broadband to use telehealth solutions, for those with opioid use disorder whose methadone treatment was disrupted, and for those dependent on Louisiana Medicaid coverage that did not guarantee them coverage in other states.

REPRODUCTIVE JUSTICE AND MEDICAL EDUCATION AND PRACTICE

Educational institutions are failing to educate new medical professionals on social determinants of health and to create a robust pipeline of Black and Brown medical personnel. Maternal and infant health outcomes improve when provider and patient are culturally congruent, yet <u>currently</u> Black and Latinx providers each account for less than six percent of all active medical providers in the U.S. and Indigenous providers only 0.4 percent. Add to that medical training that conditions all providers "to think about race as a biological condition and not a social construct" and the result is care teams that lack the training and lived experience to provide respectful care to their racialized patients.

DONOR FUNDING PRACTICES

Too many donors lack trust in local organizations, either pressuring them to reframe their strategies and work processes to fit donor priorities and processes or bypassing them entirely to fund large, white-led organizations that are disconnected from Black and Brown communities. Local organizations are then called in to "fix" what white-led organizations get wrong while receiving only a fraction of the resources allocated to the larger white organizations. These funding and administrative hurdles sap the energy and effectiveness of Black and Brown organizations and leaders, forcing them to do more with less.

THE ROLE OF CORPORATIONS

Much like the tobacco industry in the past, chemical industry actors influence research agendas and decisions of key institutions from national research and regulatory bodies down to local government development agencies. Industry has the resources to be present at all relevant environmental exposure policy and research discussions and to fund publications and lobbying that promote its positions. Participants said one result is that institutions such as the EPA can come to see those actors as their primary audience.

THE ROLE OF ALLIES

Participants emphasized that white allies need to redress how their actions and omissions support structural racism and need to take on a greater share of the risk in calling out inequities. White researchers must be more transparent about their own practices and listen to and stand with—not in front of—Black, Brown and Indigenous researchers and activists. White allies with technical skills in scientific research, litigation, and advocacy should view their role as assistance and partnership, not leadership.



DISRUPTING STRUCTURAL RACISM WITHIN RESEARCH AND DONOR INSTITUTIONS

- Advocate for changes in NIH staffing, funding priorities, and processes to adopt a holistic approach to reproductive health that prioritizes structural determinants of health; recognizes and elevates Black and Brown research expertise; and values evidence generated by community-led participatory research.
- Analyze the NIH structure and funding mechanisms to identify and shift structural barriers to complex research that analyzes aggregate environmental and socioeconomic exposures and identifies the role of environmental exposures in sexual and reproductive health.
- Document and call out corporate capture of research and regulatory institutions.
- Shift private donor practices to prioritize intersectional approaches to reproductive health within a reproductive justice framework; listen to, support, and elevate community-based leadership and strategies.
- Support Black and Brown leadership pipelines and organizations, including support for solidarity and learning networks and exchanges.
- **Support data sovereignty** for individuals and communities where research is taking place.

SUPPORT PLACE-BASED VOTER MOBILIZATION AND LEGAL AND POLICY ADVOCACY

- **Support local-led strategies** that target state, district, and municipal levels of government and build local power.
- **Recognize the tremendous risks local organizations take** when calling out White Supremacist structures and support them to design and implement strategies to address those risks.
- **Support learning networks** linking organizations working in Louisiana, Mississippi, Texas, and Georgia.

APPENDIX I: THE PANELS



PANEL I: HEALTH OUTCOMES: MATERNAL MORTALITY AND PRETERM BIRTH IN LOUISIANA AND MISSISSIPPI

All roads lead to reproductive justice... Reproductive justice gives us the frame to organize and not just talk about intersectionality in theory but about what that looks like in practice.

– Monica Simpson

As we waited for SCOTUS to rule on the challenge to Texas' SB 8, **Moderator Monica Simpson** (**SisterSong**) kicked off the session by asking each panelist for one thing they are excited about working on, then moved on to a discussion of the state of the field at the state level, in the South, and nationally, before asking what was being left out of discussions of maternal health.

EXCITING WORK

Veronica Gillispie-Bell, MD, MAS, FACOG (Louisiana Perinatal Quality Collaborative)

highlighted the December 7th first ever White House Maternal Day of Action Summit as an opportunity to center Black and Brown birthing persons' experiences. The Summit provided a platform for Black and Brown providers to highlight why cultural congruency is so important to better maternal and infant health outcomes. "Currently Black providers only account for 5.3 percent of all providers, Latinx make up 5.4 percent, and Indigenous providers less than one percent," she said. "If we know there are improved outcomes when there is concordance of race, where does that leave our families of color?"

Deon Haywood (Women with a Vision) spoke about planning for a post-Roe v. Wade world and the inevitable criminalization of women that would follow. "We are being strategic for how we move forward after Roe is gone. Is it through media? How do we get our contraceptive guide printed, how do I get them across the state of Louisiana? How will we do grassroots organizing for people who are not on social media?" "I don't have the privilege to think about only one issue," she said. "I have to think about all of it."



Kelly Davis, MPA (National Birth Equity Collaborative)* loved that Reproductive Justice provides a framework to tear down patriarchal, heteronormative, racist systems while building alternatives. "The thing I am excited to tear down the most in 2022 is the idea that long-acting contraceptives are an evidence-based solution for poverty and climate change. That is a lie, it is a damn lie, and it is a damn racist lie. The thing I am most excited about building is supporting all the beautiful Black women and queer folks that are reinterpreting, reimagining what farming and community growing looks like in service of mamas, babies, and just healing."

THE CONTEXT FOR REPRODUCTIVE AND ENVIRONMENTAL JUSTICE WORK

Ms. Simpson then asked Ms. Haywood to describe the **current situation in Louisiana**, which is still recovering from Hurricane Ida, a category 4 storm that made landfall in August 2021. Ms. Haywood described how the government's focus on criminalization rather than building infrastructure had resulted in flooding even in areas that had never flooded before. "The fact that our state doesn't have a plan in place and policies in place to employ, care, and service the needs of our people tells you where we are." She connected the fight for safe abortion to the broader fight against structural racism, and the future of Louisiana to that of Mississippi and Texas. "So the fight becomes how to fight for environmental justice, maternal health, and climate change in a state that is first and last in everything... Most people think abortion is the issue, but if you understand reproductive justice you will understand that this will affect families, it will affect the mental health of people in our state. When Roe goes we aren't just talking about not being able to walk into an abortion clinic. There are some people in our government that don't want anyone to have birth control. They don't care if you don't have housing." Even so she has seen community activism beginning to move the needle and some people at the state level beginning to listen, but she expects it to be a hard fight.

Ms. Davis spoke to **the landscape for the US as a whole**, calling out the environmental movement's failure to advocate for Black birthing people. "Climate change advocacy, research, and programs have really centered white male bodies," she said. The Collaborative's joint review of more than 100 emergency preparedness documents from 18 cities mentioned pregnancy only three times while pets were mentioned 37 times. "We had Haitian asylum seekers entering the country after two disastrous earthquakes in ten years and yet the climate change community...did not mobilize," she said. "We have communities in Louisiana and Mississippi where a preponderance of Black people live that don't even have access to potable water *every day* and we know that pregnant folks need water."

Dr. Gillispie-Bell provided insights on **health system failings**, saying "As a provider during Hurricane Ida, [we] not only don't have a plan for infrastructure, we don't have any kind of plan... We don't think about how our displaced patients will reach care." <u>Forty percent</u> of people in Louisiana have state Medicaid, which doesn't guarantee them access to care if they evacuate to Texas, leaving her to scramble to call her networks to try to get them services. Telehealth helped for those who could access broadband, but "all these things we are developing as solutions are solutions for the majority, and we risk making our disparity gaps worse because in rural areas and even some urban areas we don't have some infrastructure we need for these solutions to work." She also urged us to not focus too narrowly on medical causes of maternal mortality and what we need to do in hospitals. "The three leading causes of maternal mortality in Louisiana from our 2018 review are substance use disorders, motor vehicle collisions, and homicides... We have to look at social determinants of health and environmental [factors] are part of that." She described social determinants as "like a tree and every branch is a different determinant of health...but what matters is where your tree is planted. If you are from New Orleans and your tree is planted on St. Charles Avenue your outcomes look really different than if it is planted in the Lower 9th or even New Orleans East."

ELEVATING WHAT IS MISSING FROM THE CONVERSATION

Ms. Simpson asked what was missing from the conversation about maternal health, including the parts that we aren't hearing or that people fear to say aloud.

Ms. Davis called out the **failure to address Black birthing people's needs holistically**. "Black women are not body parts. Our medical system reduces people to body parts." Using a substance abuse example, she contrasted standards of care for white heroin users who get long-term buprenorphine prescriptions with those for Black people with substance abuse disorders, who have to go daily to a clinic to receive methadone, which impacts their ability to work, care for children, or shelter in place. She also criticized those who present midwives and doulas as the *sole* solution to the maternal mortality crisis. "How can a doctor deal with homicide? If we think of just a clinical solution we never get to how Black women move through the world... For marginalized people, race manifests through place and place is your environment... We need to flip the script to say that what is happening in clinical situations is the result of environmental degradation."

Explaining that many **people** "don't recognize the White Supremacy we have been living under," Ms. Haywood described the scene after Hurricane Ida for those who "stayed because no one prepared us to leave...[another part of an] infrastructure issue of how we get our people out safely." She recounted seeing women she knew who were struggling with mental health issues without clothes on because the hurricane had destabilized them; people whose once unsafe housing was now actively dangerous; long lines of women with babies on their hips trying to buy diapers and food because the hurricane had destroyed what they had stored. "The reason [emergency planners and the State] can't acknowledge this is because they are so used to policing Black and Brown people with an anti-Black mindset." What takes place in the criminal justice system is replicated in the health care system, she said. "We are only seen as people to be policed, people to be thrown away, and people to ignore... Our biggest problem is that those with the biggest budgets and loudest mouths are anti-Black. White Supremacy centered every single system we have in this country which is why we are in the situation we are in." Calling out "the good white women... [who] only ever wanted to talk about abortion access" and rejected reproductive justice, she called for work to "chip away at *every* system that oppresses our people," saying "We cannot afford to have siloed conversations in 2022."

Dr. Gillispie-Bell called for **greater emphasis on maternal respectful care**, which requires both expanding the number of Black and Brown people on care teams and changing how medicine is taught. "There is a level of trust that comes when you see someone who looks like you... We have a shared cultural experience and those things are missing from the health care system because we don't have diversity in the health care team." Medicine as currently taught undermines respectful care because "we are conditioned early on to think about race as a biological condition and not a social construct," she said. As a result, "we don't see individuals, we see representatives of a particular race, ethnicity, gender. We have to revamp our medical education."



Both Dr. Gillispie-Bell and Ms. Haywood called out how **medical and criminal systems in** Louisiana use the language of compliance to control and erase Black and Brown people. In medicine, "non-compliance" is a cover for failing to engage with the patient holistically and results in punitive denial of care. In the justice system, it is used to exclude women from diversion programs by setting conditions for attendance that are impossible for them to meet, such as timing that conflicts with school pick-ups and work commitments.



Participants highlighted the need for all actors to be more strategic in the work they prioritize. This includes more work to "reorient people to their voice and their power." Funders need to step out of their silos and to understand that reproductive justice requires an intersectional approach and mutual respect. Scientists also need to be more responsive to priorities identified by groups working at the community level. "I should be able to call a scientist to say, Hey can you work with me about what we see now, not what we saw 15 years ago," one community leader said.

PANEL II: SCIENTIFIC EVIDENCE

The thing that's most important to me about racial disparities is that they are preventable differences.

- Jasmine Miller-Kleinhenz, PhD



Moderator Dr. Micaela Martinez (Emory University and Columbia University Mailman School of Public Health) asked Dr. Woodruff to provide an overview of the science to date on environmental impacts on maternal and infant health. Drs. Headen, Wallace and Miller-Kleinhenz then shared insights from their research, and finally Dr. Boyles described how the National Institute of Environmental Health Sciences addresses reproductive health in calls for proposals.

Tracey Woodruff, PhD, MPH (Department of Obstetrics, Gynecology, and Reproductive Sciences, University of California San Francisco)

Dr. Woodruff described the ubiquitous nature of toxic chemicals in the U.S., and their disproportionate impact on Black, Brown, and Indigenous communities. There has been little improvement in reducing these exposures despite recent amendments to the <u>Toxic Substances</u> <u>Control Act</u>. While there is very little data on the extent of chemical exposures, growing evidence shows that even small exposures to toxic chemicals during pregnancy can trigger adverse health consequences. How can we use science **now** to reduce harms, and not wait until we have all the data?

Every year, the U.S. produces about 30,000 pounds of chemicals per person; Dr. Woodruff's studies have found ubiquitous exposure of pregnant people to more than 43 different industrial chemicals, many with serious health hazards. These chemicals can make it more likely for the pregnant person to get an illness and can interact with other pregnancy related physiological changes that increase risk of breast cancer, gestational diabetes, and pre-eclampsia, among other conditions.

These exposures mean babies are born "pre-polluted," with chemicals in their bodies, and her studies have found significant links between prenatal exposures and health harms to children, like loss of IQ. Dr. Woodruff referenced July 2021 <u>American College of Obstetricians and Gynecologists Clinical Guidance</u> citing evidence that in the United States, individuals in communities of color are more likely to live in counties with the highest levels of outdoor air pollution and to be exposed to a variety of indoor pollutants, including lead, allergens, and pesticides, than white populations. These exposures can be exacerbated by injustice, racism, poverty, neighborhood quality, housing quality, psychosocial stress, and nutritional status. Add to this occupational exposures, especially in occupations associated with toxic chemical exposures. These include agriculture (pesticides), manufacturing (organic solvents and heavy metals), dry cleaning (solvents), custodial



and cleaning services (organic solvents), beauty salons (solvents and phthalates), and health care (biologics and radiation).

Individuals with occupational exposure to toxic chemicals are additionally vulnerable to adverse reproductive health outcomes because of the risk of higher exposures in the workplace. For example, levels of organophosphate pesticides and phthalates (often used in plastics) measured in occupationally-exposed populations are far greater than levels measured in the general population. Immigrant populations working low-wage labor disproportionately work in occupations associated with a hazardous workplace environment in relation to toxic chemical exposures.

A 2009 <u>report</u> by the National Academy of Sciences underscores that the effects of low-dose exposure to an environmental contaminant may be quite different based on characteristics such as the underlying health status of the population and the presence of additional or background environmental exposure.

Irene Headen, PhD, MS (Department of Community Health and Prevention, Drexel Dornsife School of Public Health)



Dr. Headen challenged us to shift our research paradigm to reimagine from a Black American perspective how we achieve Black reproductive health. Black women cannot be reduced to numbers: the huge declines since 1935 in maternal and infant mortality "have come at the cost of extremely exacerbating racial inequities in these outcomes," as evidenced in the growing ratio of Black to white mortality across both outcomes.

We can understand why this is the case by looking at the legacies of structural racism embedded in place across different geographic scales. We see this in states with the largest increases in maternal mortality, and at the micro level, in neighborhoods with histories of redlining where we see consistent associations of poor birth outcomes among Black birthing people.

She argues that more than just place, we need to understand that, as scholar Ruha Benjamin discusses in her book, *Race After Technology*, "racism is a far-reaching technology that (re)produces the constrained context of Black communities." "We need to understand the Black birthing body as not only a site where racism is experienced, but a site upon which racist policies are created that then perpetuate across societies to create broad-based, embedded racism." Addressing this requires us to reimagine research to center Black voices. This means adopting <u>principles of research that engage with and respect Black mamas</u> to produce actionable evidence to dismantle racism and promote maternal health.

Maeve Wallace, PhD (Tulane University School of Public Health and Tropical Medicine)

Dr. Wallace highlighted the impact of geography, income inequality, and state policies in producing Louisiana's vast disparities in maternal health outcomes. Nationally, "Louisiana is always last or fighting for last with Mississippi on maternal health outcomes," she noted. In <u>2016</u>, for example, Louisiana had 77.6 pregnancy-related deaths per 100,000 live births compared to 21.8 deaths nationally; by <u>2018</u> that number had risen to 92.5 deaths, a devastating increase from Louisiana's 2011 rate of 9.7 deaths.

Within Louisiana, Black women have double the maternal mortality rate of white women, with non-Hispanic Black birthing people accounting for 58 percent of maternal deaths in 2018, while making up only 37 percent of all births. In contrast, non-Hispanic white birthing people accounted for 38 percent of maternal deaths, although they make up 58 percent of total births. That means 145.3 Black deaths per 100 live births.

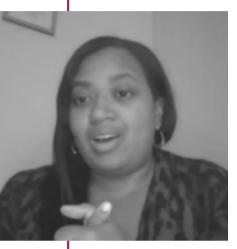
Decades of research focused on individual and clinical factors associated with maternal mortality have not reversed these trends. We need to look at the features that shape the places where women are born, live, work, and play; the historical and contemporary policies that shape those places; and the structure and functioning of our society that dictates the distribution of power and resources across people and places. In short, we need to look at structural racism, class, and gender oppression.



One of the challenges of this work is measurement: how do we quantify structural racism? It is hard to measure stress in an individual or a neighborhood. Another is identifying causal pathways between these huge, multifaceted, intersecting forces and reproductive health outcomes. Can we draw on environmental epidemiology to think about measuring physical environment as markers of structural racism, about measuring physical environmental exposures as causal pathways linking racial residential segregation, income inequality, violence, and policy to individual physical risk of death?

Jasmine Miller-Kleinhenz, PhD (Department of Epidemiology, Emory University Rollins School of Public Health)

Dr. Miller-Kleinhenz noted a growing interest among biological researchers in exploring how what goes on "above the skin" affects health outcomes, especially those factors upstream from social determinants of health. The CDC's declaration this year that racism is a public health crisis has helped in leveraging resources for certain kinds of studies, especially biological studies. Her research group looks at the impact of redlining.⁶Redlining occurs so far upstream that it serves as a useful proxy for a range of factors such as housing, education, physical work environment, health care, nutrition, green space, physical activity, financial stress, and temperature.



In Metro Atlanta, her research group has found a <u>60% increase</u> in breast cancer mortality for women who live in redlined areas. Women in these areas were four times more likely to be non-Hispanic Black, and patients at the time of diagnosis were more likely to have advanced types of breast cancer. Dr. Miller-Kleinhenz's research asks what biological pathways connect redlining and breast cancer and focuses on the role changes in the epigenome have in affecting what cancer-associated genes are expressed or repressed. Her research has found associations between redlining and increased DNA methylation, with the majority of those epigenomic changes in genes implicated in carcinogenesis. She also found that women living in redlined areas were biologically five years older than their chronological age, and almost seven years older when adjusted for both age and race. This accelerated biological aging may help explain a wide range of health disparities for conditions affected by aging.

These epigenomic changes have far reaching consequences because they affect not only individual women, but also their fetuses and through their fetuses, any future grandchildren.

Abee Boyles, PhD (National Institute of Environmental Health Sciences)

Dr. Boyles explained how the National Institutes of Health addresses structural racism, speaking from her experience leading the Breast Cancer and Environmental Research Program. She said that most of her portfolio is unsolicited proposals, and she and her colleagues are able to fund proposals that "review well," but that "we do know that questions of social determinants of health and health disparities at the NIH-wide level don't review as well." She acknowledged structural racism within the NIH processes, noting that applications from Black Principal Investigators are less likely to score as well in review and that one of the drivers of this gap may be due to proposals that are really focused on the questions that affect their communities.



Dr. Boyles said one way for NIH to address this was through calls for proposals in specific areas to target these concerns, and pointed to a 2019 call on <u>Pregnancy as a Vulnerable Time Period for</u> <u>Women's Health</u> and a 2017 call on <u>Environmental influences on Placental Origins of Development</u> as funding some research on environmental impacts on Black women's reproductive health. She also encouraged researchers to propose environmental and reproductive health research in calls where those connections were not prioritized. This includes the area of climate change, a Biden Administration priority area and thus a growing NIH area of interest. NIH does not expect to receive its budget until February 2022, but her expectation is that some of an expected \$100 million for climate change could include funding for reproductive health, and also that there could be ways for community partners to benefit from the Biden Administration's <u>Justice40</u> interagency initiative, although the latter is not a funded program.

She called for more emphasis on research at the community level, especially around climate change, and for better networks of people sharing local solutions with other communities.

DISCUSSION

THE IMPACT OF STRUCTURAL RACISM ON WHAT RESEARCH IS FUNDED AND PUBLISHED

Participants recounted the extensive barriers they face in obtaining NIH funding for research on Black, Indigenous, People of Color (BIPOC) birthing people's reproductive health and pushed back on Dr. Boyle's suggestion that they could benefit from increased NIH funding for climate change in the absence of meaningful action to address structural racism within the NIH.

Several participants called for fundamental changes in the NIH request for proposals (RFP) review process to address bias in who qualifies as an expert, what is needed to review a grant, and what is considered rigorous. "Too often it is a group of old white men sitting in a room evaluating grants that are community engaged, amplifying community solutions, but they are working from such an embedded personal and institutional perspective that is rooted in white supremacy and so the way they talk about 'the rigor' of those projects puts it in an automatic sideline so that the expertise needed to review those projects is not in the room," one researcher noted. Other participants called out the damaging effects of the additional barriers they face as BIPOC researchers when publishing their work, a dearth of senior level Black and Brown Pls to partner with on larger RFPs, and the lack of RFPs prioritizing Black and Brown leadership in research affecting their communities. "I can make it to the [review] room but when I get to the room I need some help to be lifted to compete against white Pls who have had the opportunity across their education to run these big cohort studies," said one. A white participant noted that her efforts to partner with BIPOC researchers had been hampered by NIH restrictions on having a community-based co-Pl.

Participants highlighted the broader failure in the NIH and within the larger field to address structural drivers. "The NIH is very focused on individuals and what "you" did to influence your health and not what the system did to influence your health," one said. Another cited a recent review of the top four medical journals that found that only one percent of papers published said the word or talked about racism; of these, 90 percent were opinion pieces. "We are battling a system that judges us and does not allow us to push forward the science that addresses the root causes." Participants said this was often reflected in more barriers to publication than white colleagues face, and limited support when navigating institutions with embedded White Supremacy.

ROLE OF CORPORATIONS

A participant gave examples of how chemical industry actors shape research agendas and decisions of key institutions such as the Environmental Protection Agency (EPA), so that these institutions come to see those actors as their primary audience. The industry has the resources to go to every conference and to fund publications that promote its positions and in doing so influences how scientists assess what is important.

POSSIBLE PATHS FORWARD

Participants discussed what they needed from allies, and how they are changing their own research and teaching practices to disrupt norms of whiteness in their fields. They described efforts to be more transparent about their own research processes and to recognize the indoctrination perpetuated within Western scientific methods. For academics, this meant also being open with students about the biases in the rules of the game they are learning and also holding white colleagues to the same standards of transparency in their research processes. The discussion acknowledged the heavy burden playing this role creates and highlighted the need for support from others in their fields. "As people of color, women of color, queer people of color, it is important for us to have allies and accomplices in this. It is a risk for us emotionally, physically, and professionally to call out these inequities. We are battling this at all levels and it takes a physical, spiritual, emotional, and cultural cost and it takes allies and accomplices to stand with us – not in front of us – in these battles. It needs to happen now. People are literally dyina. We can't wait."

One participant suggested that the pending appointment of a new NIH director provided an opportunity to push for some of the changes discussed and encouraged other participants to lobby members of Congress to raise questions about how the NIH spends its money and evaluates proposals.

PANEL III: ADVOCACY AND WAYS FORWARD



66 Can you imagine a world where we were heard? If you simply saw me as me and did not try to erase my Blackness? That would be a beautiful space. - Deon Haywood



Moderator Terry McGovern (Columbia University Mailman School of Public Health)

launched the panel by recalling how in the 1980s women of color living with HIV had identified that HIV looked different in their cases and mobilized to expand the definition of HIV to capture those differences, resulting in a 500 percent increase in the number of women of color gualifying for HIV treatment and programs. They did this by auditing the science, looking at who was in those studies, talking about the failure to look at converging epidemics, organizing across many different kinds of people using lawsuits and movement-building. As the previous panel had shown, science is NOT objective, and we need to make demands on what the science is and who gets funded.

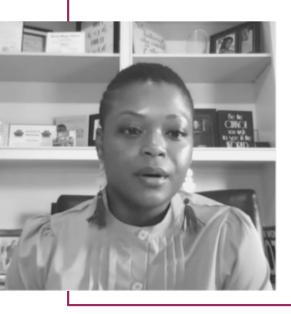


Sharon Lavigne (RISE St. James) described RISE's organizing to oppose new chemical factories in St. James Parish, an already heavily polluted, largely Black community in Louisiana. She launched RISE St. James in October 2018 when she learned that Formosa Plastics would be building a \$9.4 billion plastics complex in her neighborhood. The plant had been approved by the governor without input from the community. Despite threats, Ms. Lavigne <u>mobilized a national campaign</u> that halted the plant's construction. Its combination of grassroots organizing, coalition building, litigation, and advocacy with the EPA and politicians has been called "<u>a master class in campaigning for Environmental Justice</u>." RISE is also mobilizing to reverse the parish's approval of a new South Louisiana Methanol plant that would be located next to the Fifth District's only park, and is looking into a class action lawsuit against other plants in the district.

Michelle Colón (SHERo, Sisters Helping Every Woman Rise

and Organize) began by calling out the artificial distinction academia has created between reproductive justice and environmental justice, saying in her experience environmental justice has never been separate, and has always been part of Black women surviving. She stressed the importance of grassroots organizing and intergenerational conversations to build community, given examples from their work bring together cis-gender and transgender and non-binary community members. "Money [for activities] is all good, but what is the point if you don't have the actual people you are helping on your team." Calling Mississippi a Post-Roe society ("When you are in a state with only one clinic and it also provides services for your sister states of Louisiana, Tennessee, and Alabama.... [w]hen people have to travel 100 miles one way to a health care facility, that is a Post-Roe society."), she urged greater focus on voting rights. "You can't talk about attacks on abortion rights if you aren't going to take on attacks on voting rights."





Nakeitra Burse, DrPH (Six Dimensions) recounted how the loss of close family members to maternal complications had shown her the depth of the structural nature of the challenges Black women face; despite their education, health insurance, and family rallying around them, "they couldn't escape the system." Her organization combines work that gives women tools to advocate for themselves with data analysis and advocacy. "When we look at some of this data we see why the data is not objective, we see the flaws in the data, and so it is not just community-driven work, but how can we hold researchers accountable for the work they are doing."



Deon Haywood (Women with a Vision) explained how WWAV had evolved to add legal and policy advocacy to their initial focus on the needs of Black women living with HIV who were ignored by early programs focused on gay white males. WWAV began in the 1980s with work on women's health promotion, HIV/AIDS education, and harm reduction and quickly saw the need to work on interconnected issues such as housing and childcare. After Hurricane Katrina, they realized they needed to look at policy from a local, state, and national level, and to expand community work with sex workers. At that time, the government was repurposing a 200-year-old law criminalizing "crimes against nature" to target Black women on the street as a way to increase funding for policing. This is a felony offense that in Louisiana can result in a 20-year sentence and is recorded on your ID as a sex offender, which can preclude you from jobs that require a background check. "At that moment we decided that we were going to have to fight differently, to talk about policy, about how all these things fall under the reproductive justice framework by weaving a story about how the criminalization of sex work and Black women puts these women at risk of HIV." They worked with the people most affected, and with Bill Quigley and the Center for Reproductive Rights to fight the law. "Those lawyers just wanted to be lawyers, they didn't want to be in the spotlight and they said, 'Deon, we are following you. If you work with people who aren't willing to follow you, don't work with them because they aren't there for you.' And we won, and then in another few months another law was passed that allowed us to petition to remove people from the sex offender registry and we removed 800 people and continue to do so. Since then they have sponsored other bills around decriminalization; they haven't won, but it has changed how people talk about sex work and how they understand what it means to stand with this population." Lastly, Ms. Haywood pushed back against funders and government officials who attempt to constrain how Black women organize by forcing them to exclude family members from their organization's staff. "I see a lot in the South that we are building leaders - our families. We see freedom and liberation in our lives through the people directly connected to us... Trust Black women. Trust us to know our lives, to know what is happening. Don't come to me with your research because you read a book and decided we are so good to study... My commitment is not to you, the commitment is to community."

DISCUSSION

Ms. McGovern asked panelists for ways to move forward differently in a world where science is not objective, industry has penetrated the NIH and everywhere else, and White Supremacy feeds all of it.



ENGAGEMENT WITH SCIENTIFIC RESEARCH

Panelists diverged on what role they saw for research, from those who saw it of limited value to those who argued that greater strategic engagement with journals could help shift research agendas and drive funding to more effective interventions. Dr. Burse called for more efforts to ensure that her and other organizations' work on the ground is reflected in scientific journals, and that researchers who come in from out of state are accountable to communities and not exploitative. The similarities between Mississippi and Louisiana create opportunities for approaches working in one state to be replicated in the other, she noted. Lack of academic credentials should not be a barrier to this: "We can find people to help us write the science," she said. Ms. Colón questioned the value of grassroots organizations engaging with a research framework that doesn't serve them and called on participants to "get away from this tired ass bureaucratic, patriarchal, racist model... Why are we using the slave master's tools? When you are doing grassroots social justice work I don't need to see another study - I live it and I see the people in our communities." Citing the de facto exclusion of migrants from a recent study due to fears of immigration detention, she questioned the value of studies that didn't even include the people her organization strives to help. Ms. Haywood called for truly equitable participatory research. "Don't be writing anything about WWAV if you did not ask me and if WWAV is not a principal like you... We are doing the work and I want people to operate from a place of joining me not trying to jump ahead of me, not trying to write about me and then get your money and your research and then tell me you got \$600,000 to do this project and we got \$5,000 for you.

Convening Report

It is about us understanding and navigating systems that we were never meant to be a part of and looking at it differently and strategically in how we move." Ms. McGovern argued that we can't move forward in certain lanes without getting the science better to have the evidence that these environmental exposures are killing women of color and causing preterm births. "All of the litigation we funded after Katrina lost because the science wasn't there. We've just heard a lot about why the science wasn't there – the NIH isn't funding it, the right people aren't funded even in the lanes that are being funded – and without that evidence we have a lot of trouble winning against industry in court." She called for scientists and researchers to see their role much as WWAV's lawyers had: to provide a technical skill and not to presume to speak for anyone.

VOTER MOBILIZATION AND LEGAL AND POLICY ADVOCACY

Ms. Lavigne called for more efforts to engage directly with legislators to change laws and for direct action through service on boards. Valencia Robinson (Mississippi in Action) stressed the need to meet people where they are and be prepared for a long-term, exhausting process. Ms. Haywood described WWAV's approach to integrated voter engagement using canvassers drawn directly from their programs and community. She pushed back on people who say we have to get Black women to vote without recognizing that Black women do vote in large numbers, but that some people need help to "step into their power." "We have trans women and non-binary folk who have never voted who have been in and out of jail but have never been in prison and they don't even know they have the right to vote because they've been told they were in jail," she said. Successful grassroots organizing requires "stepping out of your fear because White Supremacy will cause fear." Citing an arson attack on WWAV and death threats against her personally, she called on participants to "step out of the shadows of what they think we should be doing and do the most all the time."

ENGAGEMENT WITH DONORS

Participants were critical of donors' lack of trust in local organizations, and of pressures to reframe their strategies and work processes to fit donor priorities and processes. Dr. Burse noted that too often "money goes to big or white organizations, and they don't have the reputation or connections to do the work, so they call us in but give us pennies and then at the very last minute we have to pull it off. And we often do it because we want the integrity of the work moving forward but it is not right and it continues to add to the burden that Black women face when we are saving the world... If you trust us with the work you should be able to trust us with the big projects." Ms. Colón urged organizations to decline funding from donors that want to dictate strategy or pressure organizations to cut back on what they work on. "Sometimes being a true ally means just shut the fuck up." Instead, organizations should focus on listening to people in their communities and other communities and build statewide and regional networks.





66 We need to move differently, move together, move forward.



- Deon Haywood

Participants were divided into four groups to reflect on the panel discussions and to identify paths for collaborative work across reproductive justice, environmental justice, and science. The below lists show the set of topics that arose within each group's discussion. We list them here as priority areas for future discussion.

GROUP 1

- Prejudice/racial inequality/racism
- Failing Infrastructure
- Housing Discrimination
- Access to water: e.g. in Mississippi cities lack potable water in homes and water for toilets in schools
- Mental Health
 - Environmental disparities
- Pollution impacting mental health and brain development • Post-partum coverage: e.g. only 60 days in Mississippi although many conditions only emerge later; BBB had pushed
- for 12 months Disconnect between science and policy
- HIV criminalization: Mississippi criminalizes PLWHIV for "exposing" others to saliva, urine, feces even if there is no transmission, it results in a felony but if you don't have HIV it is only a misdemeanor; 80% of new diagnosis are Black people
- Emerging Issues
 - Fibroids and related impacts on hysterectomy, caesarian, and VBAC rates
 - Menopause/peri-menopause
 - Birth control: programs that aim to limit Black births, limits on choice in methods
 - Self-managed abortion in the midst of a pandemic

GROUP 3

- Opportunities to build and strengthen networks and create reservoirs of information on issues not elevated by the mainstream
- More risk-taking by white researchers share the burden
- More progressive representation in government
- Breaking grip of the interlocked tourism and heavy industry interests
- More attention to negative role of Economic Development and Tourism Commissions (e.g. docks built for tourism but used for industry)

GROUP 2

- New models of research that respect community
- Researchers should see themselves as part of community
- Partnerships that add value and are not extractive
- Ways of collecting data/evidence that helps communities express what they already know to be true
- Connecting Black researchers directly to community and support their success so that
- money/opportunities aren't all going to white entities Implementation science: we have the data, now what?
- Getting all the people in a room to connect • resources
- Ask who is missing in the room
- Ask yourself, what is your liberatory lane, it may differ from others

GROUP 4

- Formal recognition that Environmental Justice is **Reproductive Justice**
- Trust and support for community
- Leadership in defining issues based on lived experience
- Data Sovereignty so that that individuals and communities own their data; ownership documented in contracts with researchers
- Support so that individual leaders are not carrying the load alone



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