Submission to the U.S. Commission on Civil Rights
Briefing on Maternal Health Disparities
Washington, D.C.
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Dear Commissioners:

My name is Jennifer Jacoby and I am a Federal Policy Counsel at the Center for Reproductive Rights. On behalf of the Center for Reproductive Rights, I respectfully submit the following testimony to the U.S. Commission on Civil Rights.

The United States is experiencing a maternal health crisis which disproportionately impacts Black and Indigenous women. With the highest maternal mortality ratio in the developed world, the U.S. is one of only thirteen countries where maternal mortality is on the rise.\(^1\) Black women are nearly four times more likely than white women to suffer a maternal death,\(^2\) and twice as likely to suffer maternal morbidity.\(^3\) Indigenous women are two and a half times more likely than white women to die from a maternal death.\(^4\) The majority of U.S. maternal deaths are preventable.\(^5\) In the U.S., racial and ethnic disparities in health are closely linked to social and economic inequalities, reflecting systemic obstacles to health that harm women of color especially. Factors such as poverty, lack of access to health care, and exposure to racism all undermine health and contribute to the disproportionately high number of maternal deaths among Black and Indigenous women.\(^6\)

Despite these troubling maternal health outcomes, the United States does not adequately prioritize or monitor maternal deaths. The lack of systematically collected maternal mortality

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3. Id.


and morbidity data precludes comparisons across states and regions and undermines accountability for preventable maternal deaths and injuries.\(^7\)

Maternal health is further undermined by a lack of social supports and basic health care services for those who cannot afford to pay for them. Rather than expanding access to such resources, recent progress has been under attack. In particular, many low-income uninsured people whom the ACA was intended to cover have fallen through the cracks because they live in states that have opted out of Medicaid expansion.\(^8\)

As a result, millions of people lack access to basic primary care and critical sexual and reproductive health care services that support healthy pregnancies and births, exacerbating racial and economic disparities.\(^9\)

Further, reports are already indicating that the COVID-19 pandemic is putting an additional strain on the health care system and exacerbating the underlying maternal health crisis facing Black and Indigenous birthing people.\(^10\)

In the sections that follow, I will: (1) discuss the real-life impacts of racial bias and discrimination in U.S. maternal health care, (2) describe the U.S. government’s obligations to promote the human rights of all birthing people and where it has fallen short, (3) discuss the role of the federal government in addressing the maternal health crisis and (4) share key federal policy recommendations.

Since 1992, the Center for Reproductive Rights has used the power of law to advance reproductive rights as fundamental human rights worldwide. Our litigation and advocacy over the past 26 years have expanded access to reproductive health care around the nation and the world. We envision a world where every person participates with dignity as an equal member of

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\(^7\) MMR Map, REVIEW TO ACTION http://www.reviewtoaction.org/content/mmr-map (last visited Sept. 25, 2019).


society, regardless of gender; where every woman is free to decide whether or when to have children and whether or when to get married; where access to quality reproductive health care is guaranteed; and where every woman can make these decisions free from coercion or discrimination.

The Center for Reproductive Rights’ Maternal Health & Rights Initiative promotes the human rights of pregnant, birthing, and postpartum people in the United States. Harnessing the power of law, policy, and strategic advocacy, the Initiative seeks to improve access to safe and respectful maternity care for all who need it, and to ensure that all people have an opportunity to attain the highest standard of maternal health possible for themselves. The Initiative seeks government accountability for discrimination and inequalities in U.S. maternal health, and it provides advocates, lawmakers, and leaders with human rights-based advocacy tools that they can use to catalyze policy change.

I. Lived Experience

Black mothers are dying or experiencing severe pregnancy complications at a disproportionate rate in the United States, not because there is something biologically different about them but because of the effects of structural racism in our society and our health care system. Unfortunately, my own close call while giving birth to my daughter is not a unique experience, not even within my own family.

I am the daughter of a Black mother and white, Jewish father, born and raised in New York City. I am also a mother to my 19-month old daughter. Thirty-two years ago, while pregnant with me, my mother nearly lost her life. I fared only slightly better – born 3 pounds 10 ounces with a short stint in the neonatal intensive care unit. Toward the end of her pregnancy, my mother presented with symptoms of preeclampsia. At each prenatal visit, both she and my father expressed concerns about her rapid weight gain and physical discomfort. Each time, they were told to go home. During these conversations, it became clear to my parents that my mother’s care team relied on assumptions about her swollen appearance that were largely based on racial stereotypes. To them she was likely always overweight. Despite my parents’ protests, her providers had already made up their minds about their Black patient. Moreover, the providers were preoccupied with my mother’s marriage to my white father. The combination of discrimination, disrespect, and distraction almost killed her.

19 months ago, I shared in this unfortunate family tradition. I bore my mother’s symptoms, which also went undetected. I was told to go home. I fought to be admitted to the hospital early. I was blamed for my condition. I laid with a monitor across my swollen belly and was provided

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oxygen on and off for days as they tried to induce labor. I ultimately landed in surgery and had a caesarean section that most likely could have been prevented. For days, my mother watched helplessly by my side as history repeated itself.

We did nothing wrong. In fact, my mother and I over two different time periods did the exact same thing. We advocated for ourselves, had access to top doctors, good insurance, and sufficient means. But our circumstances were no match for racial bias.

We were the lucky ones. Sadly, many families like ours have experienced much worse.

II. Legal Obligations to Help Prevent Maternal Deaths and Eliminate Racial Disparities in Maternal Health Outcomes

Experiences like those I described above have occurred over and over again for decades. Meanwhile, the U.S. government has yet to mount an adequate response to the maternal health crisis disproportionately impacting Black, Brown, and Indigenous people. In this section, I will address the U.S. government’s obligations with respect to maternal health and assess its shortcomings using a human rights perspective. Reliance on international human rights standards is necessary in this context. While there is overlap between human rights, which are universal and interconnected, and U.S. civil rights, our domestic civil rights laws have thus far not protected Black and Indigenous women from inequalities in maternal health outcomes and care. However, international treaty monitoring bodies and other UN experts have assessed the U.S. human rights record on maternal health and have made recommendations with respect to its international human rights obligations.

Sexual and reproductive rights are fundamental human rights. All pregnant and birthing people have the right to safe and respectful maternal health care, free from discrimination, coercion, and violence. To align with international human right standards, maternal health care must be available, physically, economically, and culturally accessible, medically and ethically acceptable, and of good quality. The U.S. has a duty to protect, respect, and fulfill human rights related to maternal health. Indeed, preventable maternal health harms – including death, morbidity, disrespect, and abuse – are recognized human rights violations that the government has an obligation to address.

The U.S. has failed to meet its obligations in this regard. Racial disparities in U.S. maternal health outcomes reflect the ongoing, systemic devaluation of Black, Brown, and Indigenous peoples’ lives. Many experience violations of their human rights on the basis of multiple, often overlapping identities, as well as real or perceived characteristics, including gender, race, ethnicity, disability, health status, class, sexual orientation, age, immigration status, and geographic location. Eliminating disproportionate risks that marginalized people face while forming families is an essential component of a broader struggle for racial justice and civil rights. Because structural, institutional, and interpersonal racism – of the kind my family experienced – constrain the lives and choices of people of color, new policies that advance both reproductive
freedom and racial justice are necessary to alleviate the long-term impact of racism on maternal health outcomes.

International treaty monitoring bodies and other UN Special Procedures have made the following recommendations to the U.S. with respect to these maternal health obligations:

In its 2014 review of the United States, the Committee on the Elimination of Racial Discrimination expressed concern with high maternal and infant mortality rates among African American communities. The Committee recommended that the United States ensure effective access to affordable and adequate health-care services; eliminate racial disparities in the field of sexual and reproductive health and standardize data collection on maternal and infant deaths; and improve monitoring and accountability mechanisms for preventable maternal mortality, including at the state level.

After its 2015 visit to the United States, the UN Working Group on discrimination against women in law and practice recommended that the U.S. address racial disparities in maternal health. Similarly, at the conclusion of its 2016 U.S. visit, the UN Working Group of Experts on People of African Descent noted that racial discrimination has a negative impact on Black women’s ability to maintain good health and recommended that the United States prioritize policies and programs to reduce maternal mortality for Black women.

At the conclusion of his 2017 visit to the United States, the UN Special Rapporteur on Extreme Poverty noted concern that the U.S. has the highest maternal mortality rate among wealthy countries, and that Black women are three to four times more likely to die from child birth.

In 2019, the UN Special Rapporteur on Violence Against Women expressed concern about instances of obstetric violence reported in the U.S.

Despite this record of concern, the U.S. has not implemented these recommendations.

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12 Committee on the Elimination of Racial Discrimination (CERD), Concluding Observations—United States of America, para. 15, UN Doc. CERD/C/USA/CO/7-9 (Sept. 25, 2014).
13 Id.
17 Special Rapporteur on violence against women, its causes and consequences, A human rights-based approach to mistreatment and violence against women in reproductive health services with a focus on childbirth and obstetric violence, para. 35, U.N. Doc. A/74/137 (July 11, 2019).
III. The Role of the Federal Government

The U.S. government has human rights obligations in the area of maternal health, and the federal government must play a critical role in addressing the crisis. While the federal government has issued multiple policies, programs, and campaigns related to this issue, there is still a need for lawmakers to directly address racial disparities in birth outcomes and proactively ensure access to safe and respectful maternal health care for all people.

A. Congress

Over the past few years, this issue has garnered significant attention from Congress. For example, in the 115th Congress approximately 25 bills were introduced on maternal health. Two bills became law. Of these, the Preventing Maternal Deaths Act of 2018 is most notable. This law authorized the Centers for Disease Control and Prevention (“CDC”) to support state and tribal maternal mortality review committees, which collect, analyze, and report specified data relating to maternal deaths. While this advancement in support for data collection is important, bills that would comprehensively address the root causes of the crisis (e.g., ensure access to high-quality, culturally congruent care for all birthing people) have yet to become law.

However, during the 115th Congress, Congresswoman Alma Adams (D-NC-12) and Congresswoman Lauren Underwood (D-IL-14) founded the Black Maternal Health Caucus. The Black Maternal Health Caucus is uniquely organized around the goals of elevating the crisis within Congress and the advancement of policy solutions to improve maternal health outcomes and end racial disparities. With 53 founding members, the Caucus has grown to one of the largest bipartisan caucuses in Congress, with over 100 members as of January 2020.

In the 116th Congress interest on this issue persists and a commitment to ending racial disparities in maternal health outcomes is more apparent. However, such bills have yet to pass both chambers. During this time, the Black Maternal Health Week Resolution was reintroduced by Congresswoman Alma Adams (D-NC-12) and Senator Kamala Harris (D-CA), which designated April 11-17, 2020 as Black Maternal Health Week to raise awareness about the U.S. maternal health crisis. Also, Congresswoman Deb Haaland (D-NM-1) introduced the nation’s first Native Maternal Health Resolution, which sought to shed light on the maternal health crisis disproportionately impacting Indigenous people in the United States. In March, members of the Black Maternal Health Caucus and Senator Kamala Harris (D-CA) introduced a comprehensive nine bill package called, the Black Maternal Health Momnibus Act of 2020, which I explain in greater detail below.

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This summer, Congresswoman Lauren Underwood (D-IL-14) and Senator Elizabeth Warren (D-MA) introduced the Maternal Health Pandemic Response Act of 2020, which with respect to the ongoing COVID-19 pandemic would improve data collection and research, ensure the inclusion of pregnant people in vaccine and therapeutic development, improve public health education, and take steps to create federal recommendations on respectful care.\(^{22}\)

Most recently, the U.S. House of Representatives passed the Helping Medicaid Offer Maternity Services (“MOMS”) Act of 2020, which would allow states to extend Medicaid coverage up to one year postpartum.\(^{23}\)

Next congress, a bicameral, bipartisan commitment to passing these bills is urgently needed.

B. Federal Agencies

At the same time, generally three operating divisions within the U.S. Department of Health and Human Services (“HHS”), have aimed to raise awareness on maternal health issues and/or provided funding for maternal health initiatives: the CDC, the National Institute of Health (“NIH”), and the Health Resources and Services Administration (“HRSA”).\(^{24}\) While important, these programs and initiatives do not specifically focus on addressing racial disparities in maternal health care. Instead, these programs tend to focus on data collection efforts and public health education around pregnancy.

The CDC has multiple initiatives ranging from safe medication use during pregnancy to detecting the effects of new health threats, like COVID-19, on pregnant mothers and babies.\(^{25}\) With respect to data collection, the CDC has made 24 awards, supporting 25 states for its Enhancing Reviews and Surveillance to Eliminate Maternal Mortality (“ERASE MM”) Program. This funding directly supports agencies and organizations that coordinate and manage Maternal Mortality Review Committees (“MMRCs”) to identify, review, and characterize maternal deaths; and identify prevention opportunities.


\(^{24}\) The Indian Health Service (“IHS”) is an agency within the Department of Health and Human Services, with 12 Area Offices managing care in regions around the country and offices dedicated to managing and liaising with tribes that have chosen to self-govern their healthcare systems and urban Indian programs. IHS also maintains as subject matter based offices providing support to IHS-run facilities and tribe-run facilities. Healthcare services include maternity care but the funds for such contracted care are limited, however, and many gaps remain between the services needed by Indigenous peoples and those provided by IHS. We are not aware of IHS maternal health specific-campaigns and initiatives.

In a significant shift toward acknowledging racism as a root cause and capturing racial bias and discrimination data, the CDC’s Working Group on Capturing Bias through MMRCs recently added three new contributing factors to the CDC’s Maternal Mortality Review Information Application (“MMRIA”) committee decisions form. The MMRIA is a key data collection tool in the maternal death review and recommendation development process. The three new contributing factors are: discrimination, interpersonal racism, and structural racism.26

The CDC’s Pregnancy Risk Assessment Monitoring System (“PRAMS”) collects state-specific, population-based data on maternal experiences before, during, and shortly after pregnancy. Currently, the PRAMs survey does not include a standard set of questions to capture experiences of discrimination, disrespect, and abuse in maternal health care.

The CDC’s Reproductive Health Division recently launched a new campaign this fall, called “Hear Her.” The campaign seeks to raise awareness of potentially life-threatening warning signs during and after pregnancy and improve communication between patients and their healthcare providers.

Notably, in 2008, the NIH’s National Institute of Child Health and Development (“NICHD”) created the National Child and Maternal Health Education Program (“NCMHEP”). This program has focused on medication use during pregnancy, education for plus-size pregnant women, maternal mental health, among other initiatives. Most recently, the NIH launched the IMPROVE Initiative to Prevent Maternal Mortality and Morbidity to support research on how to reduce preventable maternal deaths, improve health for women before, during, and after delivery, and promote health equity in the United States.

HRSA provides health care to people who are geographically isolated, and/or economically or medically vulnerable, including pregnant people. HRSA’s Maternal and Child Health Bureau (“the Bureau”) administers programs, supports research, and invests in workforce training to ensure the health and well-being of mothers and families. In partnership with states and communities, the Bureau supports health care and public health services for an estimated 55 million people nationwide.

The Bureau aims to improve women’s health before, during, and after pregnancy, the quality and safety of maternity care, and systems of maternity care. Primarily, the Bureau supports states and jurisdictions through the Title V Maternal and Child Health Block Grant, which is one of the largest federal block grant programs and is a key source of support for promoting and improving the health and well-being of families. While Title V funds many important programs, only a small portion of these funds are typically dedicated to care and support for pregnant and postpartum people. HRSA also aims to achieve its mission through other programs, such as Healthy Start, which includes providing standardized interventions and supports, and the

IV. Key Recommendations on Federal Policy

While there are many bills and agency-led campaigns and initiatives on maternal health, more must be done to effectively address the discrimination, disrespect, and abuse many Black, Brown, and Indigenous birthing people experience. Indeed, policy initiatives must center the experiences and leadership of the people directly impacted by poor maternal health outcomes and related violations of their human rights. Lawmakers must engage community leaders in authentic collaborations, and policies must respond directly to the needs prioritized by the most affected communities. At the same time, the work of eliminating poor outcomes, disparities, and human rights abuses in the field of maternal health belongs to everyone, including the federal government. Below, are a few key recommendations that would advance federal maternal health policy.

The Black Maternal Health Momnibus Act of 2020 (“the Momnibus”), referenced above, is an example of legislation, which implements human rights standards. In the development of each individual bill, lawmakers met with Black, Brown, and Indigenous advocates from the outset and meaningfully consulted with them throughout the drafting and introduction process. As a result, this nine bill package led by Congresswoman Lauren Underwood (D-IL-14), Congresswoman Alma Adams (D-NC-12), Senator Kamala Harris (D-CA), and members of the Black Maternal Health Caucus aims to fill gaps in existing legislation to comprehensively address each dimension of the crisis. If passed, the Momnibus would:

1. Make critical investments in social determinants of health that influence maternal health outcomes, like housing, transportation, and nutrition.

2. Provide funding to community-based organizations that are working to improve maternal health outcomes for Black women.

3. Comprehensively study the unique maternal health risks facing women veterans and invest in Veterans Affairs (“VA”) maternity care coordination.

4. Grow and diversify the perinatal workforce to ensure that every mom in America receives maternity care and support from people she can trust.

5. Improve data collection processes and quality measures to better understand the causes of the maternal health crisis in the United States and inform solutions to address it.

6. Invest in maternal mental health care and substance use disorder treatments.

7. Improve maternal health care and support for incarcerated women.

8. Invest in digital tools like telehealth to improve maternal health outcomes in underserved areas.
9. Promote innovative payment models to incentivize high-quality maternity care and continuity of health insurance coverage from pregnancy through labor and delivery and up to 1 year postpartum.\textsuperscript{27}

In addition, to passing legislation like the Momnibus there are a number of agency actions that should be implemented to directly address racial disparities in birth outcomes. The following are a few key initiatives:

1. Establish an Interagency Taskforce and issue regulations to encourage the development of a culture of equity, dignity, respect, and empowerment in health care systems, whereby accountability mechanisms are encouraged and implemented across systems to address discriminatory care, disrespect, mistreatment, and abuse of pregnant individuals based on race, age, sex (including gender identity and sexual orientation), immigration status, insurance coverage, perceived socioeconomic status, and other factors.

2. HHS should issue regulations establishing a minimum threshold for maternity care that specifically defines which services health plans must provide to ensure comprehensive, equitable pregnancy care coverage.

3. The administration should use every mechanism at its disposal to encourage states to extend Medicaid and CHIP coverage up to 12 months postpartum, including by issuing guidance and encouraging states to submit section 1115 waivers, while ensuring continued Maintenance of Effort (“MOE”).

4. The Centers for Medicare and Medicaid Services (“CMS”) should promote Medicaid coverage of doula support and provide guidance to the states on how best to set up an efficient and effective Medicaid coverage program for doula care that helps build a culturally competent doula workforce, reimburses doulas with a living wage, and gives specific guidance to state agencies on reimbursement mechanisms, billing codes, and ensuring network adequacy and access for all managed care enrollees.

V. Conclusion

On behalf of the Center for Reproductive Rights, I deeply appreciate the opportunity to submit this testimony to the Commission. We commend you for your commitment to examining this critical issue. If you have any questions please contact me at JJacoby@reprorights.org.

Sincerely,

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