

U.S. COMMISSION ON CIVIL RIGHTS

The U.S. Commission on Civil Rights is an independent, bipartisan agency established by Congress in 1957. It is directed to:

- Investigate complaints alleging that citizens are being deprived of their right to vote by reason of their race, color, religion, sex, age, disability, or national origin, or by reason of fraudulent practices.
- Study and collect information relating to discrimination or a denial of equal protection of the laws under the Constitution because of race, color, religion, sex, age, disability, or national origin, or in the administration of justice.
- Appraise federal laws and policies with respect to discrimination or denial of equal protection of the laws because of race, color, religion, sex, age, disability, or national origin, or in the administration of justice.
- Serve as a national clearinghouse for information in respect to discrimination or denial of equal protection of the laws because of race, color, religion, sex, age, disability, or national origin.
- Submit reports, findings, and recommendations to the President and Congress.
- Issue public service announcements to discourage discrimination or denial of equal protection of the laws.1

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Racial Disparities in Maternal Health

U.S. Commission on Civil Rights 2021 Statutory Enforcement Report

Issued pursuant to 42 U.S.C. § 1975a(c)



UNITED STATES COMMISSION ON CIVIL RIGHTS

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Letter of Transmittal

September 15, 2021

President Joseph R. Biden, Jr. Vice President Kamala D. Harris Speaker of the House Nancy Pelosi

On behalf of the United States Commission on Civil Rights ("the Commission"), I am pleased to transmit our annual statutory report, *Racial Disparities in Maternal Health*. The report is also available in full on the Commission's website at www.usccr.gov.

The report evaluates the federal government's role in addressing racial disparities in maternal health. In order to inform our report, the Commission held a virtual briefing in November 2020. The Commission heard from panelists that included government officials, service providers, and women with lived experience, including pregnancy and in some cases direct experience with discrimination in healthcare. The Commission also received written testimony from the panelists and comments from members of the public during an open public comment period in the month following the briefing. The Commission conducted independent research, examining studies by experts in the field and reviewed data about disparities in maternal health outcomes. Finally, the Commission assessed three states as case studies in how federal-state partnerships and state-level programs can address disparities in maternal health outcomes and improve access to, and quality of maternal healthcare.

Taken together, the information the Commission reviewed underscores the many contributing factors to racial disparities in maternal health and outcomes. These disparities have become more severe over the last thirty years, with the rates of Black maternal mortality increasing since with 1990s. Social determinants of health, access and quality of healthcare, and bias all play a significant role in outcomes. Crucially, even controlling for wealth and education levels does not eliminate the disparity in outcomes. As attention of these disparities increases, so does the focus on the stark statistical disparities by decisionmakers and the public. Currently, data show that the large majority of maternal deaths are preventable, increasing the urgency for reliable, consistent statistical data. There are several proposed responses to these disparities which our report explores.

Testimony received by the Commission shows the federal government can play an influential role in reducing racial disparities in maternal health outcomes. Improving access to quality maternity care for women is critical, including preconception and inter-conception care to manage chronic illness and optimize health; prenatal care; delivery care; and postpartum care for 12 months post-delivery, all of which is necessary for improving pregnancy-outcomes. This includes efforts to expand medical insurance coverage to allow women access to medical care throughout the stages of pregnancy and beyond by protecting the Affordable Care Act, by Medicaid expansion, and by the extension of Medicaid coverage for women 12 months postpartum. At the federal level, the Chair notes, efforts can be made to improve hospital quality, particularly for women of color if maternal health disparities are to be eliminated. Improvements in safety culture are linked with improved maternal health outcomes. One recommendation for improving safety in maternal healthcare is to implement standardized care practices across hospitals and health systems and to standardize data collection systems.

We at the Commission are pleased to share our views, informed by careful research and investigation as well as civil rights expertise, to help ensure that all Americans enjoy civil rights protections to which we are entitled.

For the Commission,

norma V. Cantu

Norma V. Cantu

Chair

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This report was produced under the direction and with the contribution of Marik Xavier-Brier, Ph.D., the Commission's Office of Civil Rights Evaluation (OCRE) Director. Civil Rights Analyst Nicholas Bair, Esq. and Social Scientist Sarale Sewell, M.A.* performed principal research and writing. Former OCRE Director Kathy Culliton Gonzalez, Esq,* provided oversight of the entire project, OCRE Social Scientists Julie Grieco, Ph.D., Gerald Fosten, Ph.D., provided valuable data analysis, research, and drafting assistance.

Commissioners and Special Assistants Alec Deull, Alexander Heideman, John Mashburn, Carissa Mulder, Amy Royce, Rukku Singla*, Juana Silverio, Thomas Simuel, and Irena Vidulovic conducted research, edited, and examined the report.

With the assistance of Attorney-Advisors Sheryl Cozart and Pilar Velasquez McLaughlin, and Office of General Counsel intern, William Hinton, the Commission's General Counsel David Ganz reviewed and approved the report for legal sufficiency.

OCRE interns Diego Alvarez (J.D. Candidate 2022, Harvard University Law School) and Caitlyn Tierney (B.A. Candidate 2023, Virginia Tech) also offered valuable research assistance. Commissioner legal interns Ryan Kelley (J.D. Candidate 2021, George Washington University Law School) and Samantha Pepperl (J.D. Candidate 2021, Georgetown University Law Center) offered valuable research assistance.

The Colorado and South Dakota State Advisory Committees to the U.S. Commission on Civil Rights also collected and provided testimony on related civil rights issues within their respective jurisdictions.

^{*}Employee is no longer with the Commission at the time of publication.



Racial Disparities in Maternal Health

Panelists¹

Panel 1: Policy and Legislation:

U.S. Representative Ayanna Pressley (MA-07)

Jennifer E. Moore, Ph.D., R.N., F.A.A.N. – Founding Executive Director, Institute for Medicaid Innovation

Shanna Cox, M.S.P.H – Associate Director for Science, Division of Reproductive Health, Center for Disease Control and Prevention

Shannon Dowler, M.D. - Chief Medical Officer, North Carolina Medicaid

Garth Graham, M.D., M.P.H. – Former Deputy Assistant Secretary for Minority Health, Department of Health and Human Services

Panel 2: Service Providers/Private Organizations:

Angela Doyinsola Aina, M.P.H. – Co-Founding Executive Director, Black Mamas Matter Alliance

Joia Adele Crear-Perry, M.D., F.A.C.O.G. – Founder and President, National Birth Equity Collaborative

Taraneh Shirazian, M.D., F.A.C.O.G. – President and Medical Director, Saving Mothers; Associate Professor of OBGYN, Director of Global Women's Health, NYU Langone Health **Mauricio Leone, M.P.A.** – Chief Operating Officer and Senior Director, Obria Group

Panel 3: Lived Experience:

Chanel Porchia-Albert – Board Member, March for Moms; Founder, Ancient Song Doula Services

Nan Strauss – Managing Director, Policy, Advocacy & Grantmaking, Every Mother Counts Jennifer Jacoby – Federal Policy Counsel, U.S. Policy and Advocacy Program, Center for Reproductive Rights

Nicolle L. Gonzales, B.S.N., R.N., M.S.N., C.N.M. – Executive Director and Founder, Changing Women Initiative

¹ The transcript from the briefing and panelists' written submissions can be found at https://www.usccr.gov/pubs/briefing-reports/2020-11-13-Racial-Disparities-in-Maternal-Health.php.

Panel 4: Written Testimony from Experts:

Elizabeth Howell, M.D., M.P.P. – Chair, Department of Obstetrics and Gynecology, Perelman School of Medicine, University of Pennsylvania

Jonathan Webb, M.B.A., M.P.H. – Chief Executive Officer, Association of Maternal & Child Health Programs

Juanita Chinn, Ph.D. – Program Director, Population Dynamics Branch, Division of Extramural Research, Eunice Kennedy Shriver National Institute of Child Health and Human Development, National Institutes of Health

Melanie Rouse, Ph.D. – Maternal Mortality Projects Manager, Division of Death Prevention, Office of the Chief Medical Examiner, Virginia Department of Health

Ndidiamaka Amutah-Onukagha – Ph.D., M.P.H., Associate Professor of Public Health and Community Medicine, Tufts University School of Medicine



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EXECUTIVE SUMMARY AND INTRODUCTION

Historically, maternal mortality has been used as a key indicator of the overall health of a population, both in the U.S. and internationally, for the following reasons:

[Maternal mortality] is a reflection of the whole national health system and represents the outcome of its cons and pros along with its other characteristics such as intersectoral collaboration, transparency and disparities. Beyond these, it can also illustrate even the sociocultural, political and economic philosophy of a society.²

Over the past two decades, the U.S. maternal mortality rate has not improved while maternal mortality rates have decreased for other regions of the world.³ Furthermore, the rate at which women in the U.S. experience short-term or long-term negative health consequences due to unexpected outcomes of pregnancy or childbirth has also steadily increased over the past few decades, with nearly 50,000 women in the U.S. experiencing these health consequences in 2014.⁴

Significant racial and ethnic disparities persist in both the rate of women in the U.S. who die due to complications of pregnancy or delivery and the rate that women experience negative health consequences due to unexpected pregnancy or childbirth outcomes.⁵ For the purpose of this report, a health disparity is defined as follows:

[A] particular type of health difference that is closely linked with economic, social, or environmental disadvantage. Health disparities adversely affect groups of people who have systematically experienced greater social or economic obstacles to health based on their racial or ethnic group, religion, socioeconomic status, gender, mental health,

² Sajedinejad, S., Majdzadeh, R., Vedadhir, A., Tabatabaei, M. G., & Mohammad, K., "Maternal mortality: a cross-sectional study in global health," *Globalization and Health*, Vol. 11, No. 4. (Feb. 12, 2015). https://doi.org/10.1186/s12992-015-0087-y; *see also*, Donna L. Hoyert, Ph.D., Sayeedha F.G. Uddin, M.D., M.P.H., and Arialdi M. Miniño, M.P.H., "Evaluation of the Pregnancy Status Checkbox on the Identification of Maternal Deaths," *National Vital Statistics Reports*, Vol. 69, No. 1 (Jan. 30, 2020): 1 (stating that maternal mortality is used as a key indicator of overall health of a population).

³ World Health Organization, Trends in Maternal Mortality: 2000 to 2017, Estimates by WHO, UNICEF, UNFPA, World Bank Group, and the United Nations Population Division. Geneva: 2019, p. 41, Table 4.3., https://www.unfpa.org/sites/default/files/pub-pdf/Maternal_mortality_report.pdf; Marian F. MacDorman, Ph.D., Eugene Declercq, Ph.D., Howard Cabral, Ph.D., and Christine Morton, Ph.D., "Is the United States Maternal Mortality Rate Increasing? Disentangling Trends From Measurement Issues," Obstet Gynecol, Vol. 128, No. 3 (September 2016): 447-455, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5001799/; Nina Martin and Renee Montagne, "U.S. Has The Worst Rate of Maternal Deaths in the Developed World," NPR.org, May 12, 2017, https://www.npr.org/2017/05/12/528098789/u-s-has-the-worst-rate-of-maternal-deaths-in-the-developed-world.

⁴ Centers for Disease Control and Prevention, "Severe Maternal Morbidity in the United States," https://www.cdc.gov/reproductivehealth/maternalinfanthealth/severematernalmorbidity.html.

⁵ Centers for Disease Control and Prevention, "Racial/Ethnic Disparities in Pregnancy-Related Deaths — United States, 2007–2016," *Morbidity and Mortality Weekly Report*, Vol. 68, No. 35 (Sep. 6, 2019): 762, https://www.cdc.gov/mmwr/volumes/68/wr/mm6835a3. https://www.cdc.gov/mmwr/volumes/68/wr/mm6835a3 w.

cognitive, sensory, or physical disability, sexual orientation, geographic location, or other characteristics historically linked to discrimination or exclusion.⁶

Compared to any other racial or ethnic group,⁷ Black⁸ women experience the highest rates of nearly all of Centers for Disease Control and Prevention's (CDC) severe maternal morbidity⁹ indicators.¹⁰ Black women in the U.S. are 3 to 4 times more likely to die from pregnancy-related complications than White¹¹ women in the U.S., and Native American¹² women are more than 2 times more likely to die from pregnancy-related complications than White women in the U.S.¹³ Pregnancy-related mortality is also slightly elevated for Asian women (a 1.1 disparity ratio),¹⁴ and for Hispanic women in some geographic areas.¹⁵ Moreover, the risk of pregnancy-related death is so elevated for Black women in certain regions of the U.S. that it is comparable to the

⁶ U.S. Department of Health and Human Services, The Secretary's Advisory Committee on National Health Promotion and Disease Prevention Objectives for 2020, *Phase I Report: Recommendations for the Framework and Format of Healthy People 2020*, Developing Healthy People 2020, p. 28, https://www.healthypeople.gov/sites/default/files/PhaseI 0.pdf.

⁷ Elizabeth A. Howell, MD, MPP, "Reducing Disparities in Severe Maternal Morbidity and Mortality," *U.S. National Library of Medicine, National Institutes of Health*, June 2018, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5915910/.

⁸ This report utilizes the term "Black" to refer to non-Hispanic/Latina Black/African American women (unless otherwise stated).

⁹ Centers for Disease Control and Prevention, "Severe Maternal Morbidity in the United States," https://www.cdc.gov/reproductivehealth/maternalinfanthealth/severematernalmorbidity.html. (The Centers for Disease Control and Prevention defines maternal morbidity as the "physical and psychologic conditions that result from or are aggravated by pregnancy and have an adverse effect on a woman's health," and the most severe complications of pregnancy are referred to as severe maternal morbidity." CDC indicates that severe maternal morbidity "includes unexpected outcomes of labor and delivery that result in significant short- or long-term consequences to a woman's health.").

¹⁰ Centers for Disease Control and Prevention, "How Does CDC Identify Severe Maternal Morbidity?," https://www.cdc.gov/reproductivehealth/maternalinfanthealth/smm/severe-morbidity-ICD.htm (Maternal morbidity is the "physical and psychologic conditions that result from or are aggravated by pregnancy and have an adverse effect on a woman's health," and the most severe complications of pregnancy are referred to as "severe maternal morbidity").

¹¹ This report utilizes the term "White" to refer to non-Hispanic/Latina White/Caucasian women (unless otherwise stated).

¹² This report utilizes the term "Native American" to refer to non-Hispanic/Latina American Indian/Alaska Native women (unless otherwise stated).

¹³ Centers for Disease Control and Prevention, "Racial/Ethnic Disparities in Pregnancy-Related Deaths — United States, 2007–2016," *Morbidity and Mortality Weekly Report*, Vol. 68, No. 35 (Sep. 6, 2019): 763, https://www.cdc.gov/mmwr/volumes/68/wr/mm6835a3.htm?s_cid=mm6835a3_w; Elizabeth A. Howell, MD, MPP, "Reducing Disparities in Severe Maternal Morbidity and Mortality," *U.S. National Library of Medicine, National Institutes of Health*, June 2018, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5915910/.

¹⁴ See Centers for Disease Control and Prevention, "Racial/Ethnic Disparities in Pregnancy-Related Deaths — United States, 2007–2016," Morbidity and Mortality Weekly Report, Vol. 68, No. 35 (Sep. 6, 2019): 763, https://www.cdc.gov/mmwr/volumes/68/wr/mm6835a3_htm?s_cid=mm6835a3_w.

¹⁵ Elizabeth A. Howell, MD, MPP, Natalia N. Egorova, PhD, MPH, Teresa Janevic, PhD, MPH, Amy Balbierz, MPH, Jennifer Zeitlin, DSc, MA, and Paul L. Hebert, PhD, "Severe Maternal Morbidity Among Hispanic Women in New York City: Investigation of Health Disparities," *American Journal of Obstetrics & Gynecology*, Vol. 139, No. 2 (February 2017): 285-294, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5380443/

rate of pregnancy-related deaths¹⁶ in some developing countries.¹⁷ This racial disparity has not improved in decades,¹⁸ and is also seen in other middle to high-income countries with multiethnic populations.¹⁹ According to the World Health Organization (WHO), the U.S. maternal mortality ratio ranked 56th in the world in 2017.²⁰ According to the National Center for Health Statistics (NCHS), in 2018, the maternal mortality rate in the U.S. was 17.4 maternal deaths per 100,000 live births, with 658 women dying of maternal causes.²¹ In 2019, the maternal mortality rate in the U.S. was 20.1 maternal deaths per 100,000 live births, with 754 women dying of maternal causes.²²

Racial disparities in U.S. maternal mortality rates exist for a variety of reasons, but one notable reason is due to differences in the quality of care that women of color receive as compared to White women.²³ Research shows that approximately 3 out of 5 pregnancy-related deaths are preventable preventability does not differ by race,²⁴ yet Black women giving birth are dying at

¹⁶ Centers for Disease Control and Prevention, "Pregnancy Mortality Surveillance System," https://www.cdc.gov/reproductivehealth/maternal-mortality/pregnancy-mortality-surveillance-system.htm. The Centers for Disease Control and Prevention (CDC) defines pregnancy-related death as "the death of a woman while pregnant or within 1 year of the end of a pregnancy –regardless of the outcome, duration or site of the pregnancy-from any cause related to or aggravated by the pregnancy or its management, but not from accidental or incidental causes." Ibid.

¹⁷ Elizabeth A. Howell, MD, MPP, "Reducing Disparities in Severe Maternal Morbidity and Mortality," *U.S. National Library of Medicine, National Institutes of Health*, June 2018, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5915910/.

¹⁸ Centers for Disease Control and Prevention, National Center for Health Statistics, *Maternal Mortality and Related Concepts*, Series 3, No. 33, February 2007, pp. 8-9, https://www.cdc.gov/nchs/data/series/sr_03/sr03_033.pdf.

¹⁹ Maria J. Small, Terrence K. Allen, Haywood L. Brown, "Global disparities in maternal morbidity and mortality," *Semin Perinatol.*, Vol. 41, No. 5 (August 2017): 318-322, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5608036/ (this journal article specifically examines the United States and Brazil as two countries "with the largest populations of African descent brought to the Americas primarily through the transatlantic slave trade." The U.S. and Brazil experience similar racial disparities in maternal mortality and morbidity).

²⁰ World Health Organization, "Maternal Mortality Ratio (per 100 000 live births) Year 2017," https://app.powerbi.com/view?r=eyJrIjoiNTI4ZDc2N2EtMGM5NC00NjUyLTgwYjAtNmM3YzVjYWFlYzZhIiwidCI6ImY2MTBjMGI3LWJkMjQtNGIzOS04MTBiLTNkYzI4MGFmYjU5MCIsImMiOjh9 (accessed 3/26/2020).

²¹ Centers for Disease Control, National Center for Health Statistics, "First Data Released on Maternal Mortality in Over a Decade," Jan. 30, 2020, https://www.cdc.gov/nchs/pressroom/nchs_press_releases/2020/202001_MMR.htm. ²² Centers for Disease Control, National Center for Health Statistics, "Maternal Mortality Rates in the United States, 2019" Mar. 23, 2021, https://www.cdc.gov/nchs/data/hestat/maternal-mortality-2021/maternal-mortality-2021.htm.

²³ Amy Metcalfe, James Wick, and Paul Ronksley, "Racial Disparities in Comorbidity and Severe Maternal Morbidity/Mortality in the United States: an Analysis of Temporal Trends," *Acta Obstetricia et Gynecologica Scandinavica*, No. 97 (2018), 94, https://obgyn.onlinelibrary.wiley.com/doi/pdf/10.1111/aogs.13245.

²⁴ Emily E. Petersen, MD; Nicole L. Davis, PhD; David Goodman, PhD; Shanna Cox, MSPH; Nikki Mayes; Emily Johnston, MPH; Carla Syverson, MSN; Kristi Seed; Carrie K. Shapiro-Mendoza, PhD; William M. Callaghan, MD; Wanda Barfield, MD, "Vital Signs: Pregnancy-Related Deaths, United States, 2011–2015, and Strategies for Prevention, 13 States, 2013–2017," *Morbidity and Mortality Weekly Report*, Centers for Disease Control and Protection, Vol. 68, No. 18 (May 10, 2019): 423, https://www.cdc.gov/mmwr/volumes/68/wr/pdfs/mm6818e1-H.pdf; Centers for Disease Control and Prevention, "Pregnancy-Related Deaths: Data from 14 U.S. Maternal Mortality Review Committees, 2008-2017," https://www.cdc.gov/reproductivehealth/maternal-mortality/erase-mm/mmr-data-brief.html.

staggering rates.²⁵ Dr. Joia Crear-Perry, Founder and President of the National Birth Equity Collaborative, testified to the Commission about some of the causes of racial disparities in maternal health outcomes, writing that:

We know the root causes of poor maternal health—racism and gender oppression inside of healthcare systems and every other facet of society. Women of color are more likely to experience a comorbid illness and report being unfairly treated within healthcare settings based on their race or ethnicity. The inequities that Black women face have become even more urgent as the pandemic and civil unrests show the many ways racism can kill, whether from COVID, police brutality or hemorrhaging during childbirth.²⁶

Each year, nearly 700 women in the U.S. die due to complications of pregnancy or delivery either during their pregnancy or within one year of the end of their pregnancy.²⁷ A woman today is "50 [percent] more likely to die in childbirth than her own mother was."²⁸ During the Commission's briefing in November 2020, Associate Director for Science in the Division of Reproductive Health at the Centers for Disease Control and Prevention Shanna Cox testified that:

[T]he pregnancy-related mortality ratio in the U.S. is not decreasing, and given these deaths are largely preventable, these numbers are absolutely unacceptable. Considerable racial disparities exist, with Black and Native women two to three times more likely to die from pregnancy-related complications than White women.²⁹

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²⁵ Emily E. Petersen, MD, Nicole L. Davis, PhD, David Goodman, PhD, Shanna Cox, MSPH, Carla Syverson, MSN, Kristi Seed, Carrie Shapiro-Mendoza, PhD, William M. Callaghan, MD, Wanda Barfield, MD, "Racial/Ethnic Disparities in Pregnancy-Related Deaths — United States, 2007–2016," *Morbidity and Mortality Weekly Report*, Centers for Disease Control and Protection, Vol. 68, No. 35 (Sep. 6, 2019): 762-765, https://www.cdc.gov/mmwr/volumes/68/wr/pdfs/mm6835a3-H.pdf.

²⁶ Joia Adele Crear-Perry, M.D., F.A.C.O.G., Founder and President, National Birth Equity Collaborative, Written Statement for the Maternal Health Briefing before the U.S. Comm'n on Civil Rights, Nov. 13, 2020, at 1 (hereinafter "Crear-Perry Statement").

²⁷ Emily E. Petersen, MD, Nicole L. Davis, PhD, David Goodman, PhD, Shanna Cox, MSPH, Carla Syverson, MSN, Kristi Seed, Carrie Shapiro-Mendoza, PhD, William M. Callaghan, MD, Wanda Barfield, MD, "Racial/Ethnic Disparities in Pregnancy-Related Deaths — United States, 2007–2016," *Morbidity and Mortality Weekly Report*, Centers for Disease Control and Protection, Vol. 68, No. 35 (Sep. 6, 2019): 762,

https://www.cdc.gov/mmwr/volumes/68/wr/pdfs/mm6835a3-H.pdf; Shanna Cox, Associate Director for Science, Division of Reproductive Health, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention, Written Statement for the Racial Disparities in Maternal Health Briefing before the U.S. Commission on Civil Rights, November 2020, at 1 (hereinafter Cox Statement).

²⁸ Jackie Marchildon, "Racial Bias in Health Care Is Killing Mothers Around the World," Global Citizen, May 10, 2019, https://www.globalcitizen.org/en/content/racial-inequalities-maternal-mortality-rates/.

²⁹ Shanna Cox, testimony, Racial Disparities in Maternal Health Briefing Before the U.S. Comm'n on Civil Rights, Washington, DC, Nov. 13, 2020, transcript, p. 32 (hereinafter cited as Maternal Health Briefing).

According to some sources, approximately 60 percent of maternal deaths are preventable.³⁰ Significant racial and ethnic disparities persist in both the mortality rate of women in the U.S. who die due to complications during pregnancy or delivery as well as in the rate that women experience significant negative health consequences due to unexpected pregnancy or childbirth outcomes.³¹ Black³² women experience the highest rates of nearly all of the Centers for Disease Control and Prevention's (CDC) severe maternal morbidity³³ indicators,³⁴ higher than any other racial or ethnic group.³⁵

During the November 2020 briefing, the Commission heard from panelists that included government officials, service providers, and women with lived experience, including pregnancy and in some cases direct experience with discrimination in healthcare. The Commission also received written testimony from the panelists and comments from members of the public during an open public comment period in the month following the briefing. The Commission conducted independent research, examining studies by experts in the field and reviewed data about disparities in maternal health outcomes. Finally, the Commission assessed three states as case studies in how federal-state partnerships and state-level programs can address disparities in maternal health outcomes and improve access to, and quality of maternal healthcare.

Taken together, the information the Commission reviewed underscores the many contributing factors to racial disparities in maternal health and outcomes. These disparities have become more severe over the last thirty years, with the rates of Black maternal mortality increasing since with 1990s. Social determinants of health, access and quality of healthcare, and bias all play a significant role in outcomes. Crucially, even controlling for wealth and education levels does not eliminate the disparity in outcomes. As attention and awareness of these disparities increases, so

³⁰ Emily E. Petersen, MD; Nicole L. Davis, PhD; David Goodman, PhD; Shanna Cox, MSPH; Nikki Mayes; Emily Johnston, MPH; Carla Syverson, MSN; Kristi Seed; Carrie K. Shapiro-Mendoza, PhD; William M. Callaghan, MD; Wanda Barfield, MD, "Vital Signs: Pregnancy-Related Deaths, United States, 2011–2015, and Strategies for Prevention, 13 States, 2013–2017," *Morbidity and Mortality Weekly Report*, Centers for Disease Control and Protection, Vol. 68, No. 18 (May 10, 2019): 423, https://www.cdc.gov/mmwr/volumes/68/wr/pdfs/mm6818e1-H.pdf.

³¹ Centers for Disease Control and Prevention, "Racial/Ethnic Disparities in Pregnancy-Related Deaths — United States, 2007–2016," *Morbidity and Mortality Weekly Report*, Vol. 68, No. 35 (Sep. 6, 2019): 762, https://www.cdc.gov/mmwr/volumes/68/wr/mm6835a3.htm?s_cid=mm6835a3_w.

³² This report utilizes the term "Black" to refer to non-Hispanic/Latina Black/African American women (unless otherwise stated).

³³ Centers for Disease Control and Prevention, "Severe Maternal Morbidity in the United States," https://www.cdc.gov/reproductivehealth/maternalinfanthealth/severematernalmorbidity.html. The Centers for Disease Control and Prevention defines severe maternal morbidity as "unexpected outcomes of labor and delivery that result in significant short- or long-term consequences to a woman's health."

³⁴ Centers for Disease Control and Prevention, "How Does CDC Identify Severe Maternal Morbidity?," https://www.cdc.gov/reproductivehealth/maternalinfanthealth/smm/severe-morbidity-ICD.htm.

³⁵ Elizabeth A. Howell, MD, MPP, "Reducing Disparities in Severe Maternal Morbidity and Mortality," *U.S. National Library of Medicine, National Institutes of Health*, June 2018, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5915910/.

does the focus on the stark statistical disparities by decision makers and the public. Currently, data shows that the large majority of maternal deaths are preventable, increasing the urgency for reliable, consistent statistical data. There are a range of proposed responses to these disparities; we explore just a few of them here.

Chapter 1 summarizes key data regarding racial disparities in maternal deaths. Currently, the federal government uses two main measures to track maternal mortality within the United States. The first is the CDC's measure of "pregnancy-related deaths" defined as the death of a woman while pregnant or within one year of the end of a pregnancy from any cause related to or aggravated by the pregnancy or its management. The second is the National Vital Statistics System, the official mechanism of the National Center for Health Statistics for collecting and disseminating vital statistics and the official source for U.S. maternal mortality statistics for international, state, and demographic comparisons. The National Center for Health Statistics uses the World Health Organization's definition of "maternal mortality" or "maternal deaths," defined as "deaths of women while pregnant or within 42 days of being pregnant, from any cause related to or aggravated by the pregnancy or its management, but not from accidental or incidental causes."

According to CDC data, the maternal mortality rate in the United States has not improved over the past 30 years.³⁹ The pregnancy-related mortality ratio in 1987 was 7.2 pregnancy-related deaths per 100,000 live births as compared to 16.9 deaths per 100,000 live births in 2016.⁴⁰ Data from the National Center for Health Statistics also shows that the maternal mortality rate has more than doubled over the last three decades.⁴¹ Moreover, the rates of these losses are much

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³⁶ Centers for Disease Control and Prevention, "Pregnancy Mortality Surveillance System," https://www.cdc.gov/reproductivehealth/maternal-mortality/pregnancy-mortality-surveillance-system.htm#ratio.

³⁷ Lauren M. Rossen, Ph.D., M.S., Lindsay S. Womack, Ph.D., M.P.H., Donna L. Hoyert, Ph.D., Robert N. Anderson,

Ph.D., and Sayeedha F.G. Uddin, M.D., M.P.H., "The Impact of the Pregnancy Checkbox and Misclassification on Maternal Mortality Trends in the United States, 1999–2017," *National Center for Health Statistics, Vital and Health Statistics*, Series 3, No. 44 (January 2020): 1, https://www.cdc.gov/nchs/data/series/sr_03/sr03_044-508.pdf; Centers for Disease Control and Prevention, National Center for Health Statistics, "National Vital Statistics System," https://www.cdc.gov/nchs/nvss/index.htm.

³⁸ Donna L. Hoyert, Ph.D., and Arialdi M. Miniño, M.P.H., "Maternal Mortality in the United States: Changes in Coding, Publication, and Data Release, 2018," *National Vital Statistics Reports*, Vol. 69, No. 2 (Jan. 30, 2020): 1, https://www.cdc.gov/nchs/data/nvsr/nvsr69/nvsr69 02-508.pdf.

³⁹ Centers for Disease Control and Prevention, "First Data Released on Maternal Mortality in Over a Decade," Jan. 30, 2020, https://www.cdc.gov/nchs/pressroom/nchs_press_releases/2020/202001_MMR.htm.

⁴⁰ Ibid.

⁴¹ Centers for Disease Control, National Center for Health Statistics, "First Data Released on Maternal Mortality in Over a Decade," Jan. 30, 2020, https://www.cdc.gov/nchs/pressroom/nchs_press_releases/2020/202001_MMR.htm; Emily E. Petersen, MD, Nicole L. Davis, PhD, David Goodman, PhD, Shanna Cox, MSPH, Carla Syverson, MSN, Kristi Seed, Carrie Shapiro-Mendoza, PhD, William M. Callaghan, MD, Wanda Barfield, MD, "Racial/Ethnic Disparities in Pregnancy-Related Deaths — United States, 2007–2016," *Morbidity and Mortality Weekly Report*, Centers for Disease Control and Protection, Vol. 68, No. 35 (Sep. 6, 2019): 762-765, https://www.cdc.gov/mmwr/volumes/68/wr/pdfs/mm6835a3-H.pdf.

higher among Black women, and data show some disparities for other women of color, particularly Native American women. ⁴² A 2020 Commonwealth Fund report comparing the maternal mortality rate of the U.S. to ten other developed nations found that the U.S. maternal mortality rate of 17.4 in 2018 was double the rate of the next closest country. ⁴³ In fact, according to the American College of Obstetrics and Gynecology the United States is the only developed country with a rising maternal death rate, and for every maternal death in the United States, there are approximately 100 women who experience severe maternal morbidity, or a "near miss."

Chapter 2 of this report examines the possible reasons for racial disparities in maternal health outcomes in the United States and how these disparities impact women of color. The Centers for Disease Control and Prevention states that inequities in the social determinants of health, such as poverty and healthcare access, affect ethnic and racial minority groups and influence a wide range of health and quality-of-life outcomes and risks.⁴⁵ According to the Office of Disease Prevention and Health Promotion of the Department of Health and Human Services (HHS) as well as extensive public health research, addressing social determinants of health is necessary for improving health and reducing health disparities,⁴⁶ including racial disparities in maternal health.⁴⁷

Some of the potential drivers of racial disparities in maternal mortality rates may include variation in hospital quality, underlying chronic conditions, access to risk-appropriate/quality care, and the impacts of structural and implicit biases on health.⁴⁸ Well-documented evidence from the federal government and other sources such as the American Medical Association

⁴² See infra notes 166-177.

⁴³ Roosa Tikkanen, Munira Z. Gunja, Molly FitzGerald, and Laurie Zephyrin, *Maternal Mortality and Maternity Care in the United States Compared to 10 Other Developed Countries*, THE COMMONWEALTH FUND (Nov. 18, 2020) https://www.commonwealthfund.org/publications/issue-briefs/2020/nov/maternal-mortality-maternity-care-us-compared-10-countries (last accessed Feb. 10, 2021) (the comparator nations were Australia, Canada, France, Germany, the Netherlands, New Zealand, Norway, Sweden, Switzerland, and the United Kingdom) (France had the second highest maternal mortality rate of the countries studied at 8.7 deaths per 100,000 live births).

⁴⁴ American College of Obstetrics and Gynecology Public Comment, December 14th, 2020

⁴⁵ Centers for Disease Control and Prevention, Coronavirus Disease 2019 (COVID-19), Health Equity Considerations and Racial and Ethnic Minority Groups, updated July 24, 2020, https://www.cdc.gov/coronavirus/2019-ncov/community/health-equity/race-ethnicity.html.

⁴⁶ Office of Disease Prevention and Health Promotion, HealthyPeople.gov, "Social Determinants of Health," https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-of-health; Samantha Artiga and Elizabeth Hinton, "Issue Brief: Beyond Health Care: The Role of Social Determinants in Promoting Health and Health Equity," Henry J. Kaiser Foundation, May 10, 2018, p. 2, https://www.kff.org/disparities-policy/issue-brief/beyond-health-care-the-role-of-social-determinants-in-promoting-health-and-health-equity/.

⁴⁷ See infra notes 445-450.

⁴⁸ Shanna Cox, Associate Director for Science, Division of Reproductive Health, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention, Written Statement for the *Racial Disparities in Maternal Health Briefing* before the U.S. Comm'n on Civil Rights, Nov. 13, 2020, at 4-5 (hereinafter "Cox Statement").

indicates that people of color have reduced access to quality health care services. ⁴⁹ For example, women of color are less likely than White women to have access to quality maternal healthcare, including family planning, preconception care, prenatal care, and postpartum care. ⁵⁰ Black women have the highest uninsured rates among all women, are more likely to have chronic health conditions that are risk factors for maternal death, and are less likely to get care for disease prevention and management. ⁵¹ Research also indicates that implicit biases affect how providers treat patients of color, including women of color seeking maternal health services. ⁵² Nevertheless, some contend that the underlying causes for disparities in maternal health are lack of prenatal education. ⁵³ CDC data indicates, however, that racial and ethnic disparities were present at all education levels, ⁵⁴ and that there are sizeable disparities between Black women with college education as compared to White women with less than a high school diploma. ⁵⁵

Maternal mortality and morbidity have wide-ranging impacts on families and communities. Research shows that the loss of a mother can have a multi-generational ripple effect, with negative physical, economic, social, and emotional consequences for her family years into the future.⁵⁶ In some cases, pregnancy complications may have an impact on the health of the infant.⁵⁷ Other family members are left to take on childcare responsibilities as well as provide

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⁴⁹ U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality, *National Healthcare Quality and Disparities Report 2018*. September 2019.

https://www.ahrq.gov/sites/default/files/wysiwyg/research/findings/nhqrdr/2018qdr-final.pdf; E. Richard Brown, PhD, Victoria D. Ojeda, MPH, Roberta Wyn, PhD, Rebecka Levan, MPH, Racial and Ethnic Disparities in Access to Health Insurance and Health Care, UCLA Center for Health Policy Research and the Henry J. Kaiser Family Foundation, April 2000, p. xi, https://www.kff.org/wp-content/uploads/2013/01/racial-and-ethnic-disparities-in-access-to-health-insurance-and-health-care-report.pdf; American College of Physicians, Position Paper: Racial and Ethnic Disparities in Health Care, April 2010, pp. 1-2.

https://www.acponline.org/acp_policy/policies/racial_ethnic_disparities_2010.pdf; Samantha Artiga, Kendal Orgera, and Olivia Pham, "Disparities in Health and Health Care: Five Key Questions and Answers," Mar. 4, 2020, https://www.kff.org/disparities-policy/issue-brief/disparities-in-health-and-health-care-five-key-questions-and-answers/; Alan Nelson, MD, "Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care," Journal of the National Medical Association, Vol. 94, No. 8 (August 2002): 666-668, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2594273/pdf/jnma00325-0024.pdf.

⁵⁰ Center for Reproductive Rights, "Research Overview of Maternal Mortality and Morbidity in the United States," p. 4,

https://www.reproductiverights.org/sites/crr.civicactions.net/files/documents/USPA_MH_TO_ResearchBrief_Final_5.16.pdf.

⁵¹ Ibid.

⁵² See infra notes 340-387.

⁵³ See e.g., Mauricio Leone, Chief Operating Officer, Obria Group, written statement for the *Racial Disparities in Maternal Health* Briefing before the U.S. Comm'n on Civil Rights, Nov. 13, 2020, pp. 2-4 (hereinafter "Leone Statement").

⁵⁴ See infra, Figure 1.6.

⁵⁵ See infra notes 186-187.

⁵⁶ Suellen Miller and José M Belizán, "The true cost of maternal death: individual tragedy impacts family, community and nations," *Reproductive Health*, Vol. 12, No. 56 (2015): 1-4, https://link.springer.com/content/pdf/10.1186/s12978-015-0046-3.pdf.

⁵⁷ Ibid.

financially for a child, and may experience lost income due to the death of the mother, as well as potential debt due to hospital bills, funeral costs, etc. 58

Chapter 3 evaluates the federal government's role in addressing racial disparities in maternal health. In addition to the federal Department of Health and Human Service's civil rights enforcement function, there are several programs in the Department charged with serving the public around maternal health disparities. Some departmental offices also have specific duties based on their statutory and regulatory mandates that include assisting vulnerable individuals or combatting health disparities. Some departmental offices also have specific duties based on their statutory and regulatory mandates that include assisting vulnerable individuals or combatting health disparities. For instance, For instance, HHS' administers grant programs for maternal and child health, while the Centers for Medicare and Medicaid Services (CMS), which runs the federal Medicaid health insurance program was the source of payment for 42.3 percent of all births in 2018, and data shows that CMS plays a significant role in insuring women of color. Additionally, the CDC, HHS' Office of Minority Health, the Office of Population Affairs, and several Institutes within the National Institutes of Health (NIH), including the Eunice Kennedy Shriver National Institute of Child Health and Human Development, administer programs that seek to improve maternal health outcomes and reduce racial disparities.

Data collection and research are vital to improving maternal health outcomes and eliminating disparities in maternal mortality and severe maternal morbidity. The creation of the federal Pregnancy Mortality Surveillance System in 1986 helped to fill gaps in maternal mortality surveillance by providing more clinical information about causes of maternal deaths. While vital records data on maternal mortality have faced challenges in accuracy, there have been other efforts to enhance data collection on maternal mortality and severe maternal morbidity through the work of Maternal Mortality Review Committees and the development of the Maternal Mortality Review Information Application, which helps standardize data for better information sharing. Additionally, the Pregnancy Risk Assessment Monitoring System, a project of the CDC and state health departments, collects "state-specific, population-based data

⁵⁸ Ibid., 2; Ben Schwartz, "A new normal: How families and fathers are affected by maternal mortality," *Contemporary OB/GYN*, Sep. 12, 2018, https://www.contemporaryobgyn.net/article/new-normal-how-families-and-fathers-are-affected-maternal-mortality; U.S. Department of Labor, Women's Bureau, Labor Force Participation Rate by Sex, Race and Hispanic Ethnicity, 2016 Annual Averages, https://www.dol.gov/agencies/wb/data/latest-annual-data/labor-force-participation-rates.

⁵⁹ See U.S. Comm'n on Civil Rights, *Are Rights a Reality? Evaluating Federal Civil Rights Enforcement*, pp. 195-198 (Nov. 21, 2019) (discussing the statutory and regulatory authority of the Dep't of Health and Human Services' Office of Civil Rights) https://www.usccr.gov/pubs/2019/11-21-Are-Rights-a-Reality.pdf.

⁶⁰ National Center for Health Statistics, Division of Vital Statistics, "Births: Final Data for 2018," *National Vital Statistics Reports*, Vol. 68, No. 13 (Nov. 27, 2019): p. 2, https://www.cdc.gov/nchs/data/nvsr/nvsr68/nvsr68_13-508.pdf; see also infra note 330.

⁶¹ See infra notes 92-96, and Table 1.1.

⁶² See infra notes 129-139, Table 1.1.

⁶³ See infra notes 573-576, and 598-601.

on maternal attitudes and experiences before, during, and shortly after pregnancy," and covers about 83 percent of births.⁶⁴

Public health researchers and other stakeholders agree that a multi-faceted approach is needed to improve maternal health outcomes and the quality of care for all women, and to eliminate racial disparities. Steps to improve maternal health outcomes are discussed in detail in Chapter 3 including improving data collection, expanding research, improving access to maternal healthcare, improving the quality of maternal healthcare, addressing racial bias in maternal healthcare, and implementing an equity framework for research, planning, and evaluation. 65

Chapter 4 examines several states in which new policies are being developed to gather information about trends and possible best practices to reduce racial disparities in maternal health. The three states studied—Georgia, New Jersey and North Carolina are geographically and racially diverse. In recent years, these three states have received millions of dollars in federal funding to reduce maternal mortalities, including for a variety of programs designed to reduce racial disparities in maternal mortalities. The state programs and their results are analyzed herein.

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⁶⁴ Centers for Disease Control and Prevention, "What is PRAMS?" https://www.cdc.gov/prams/index.htm.

⁶⁵ See infra, notes 743-786 (Recommendations for eliminating racial disparities and improving maternal health outcomes).

⁶⁶ See infra notes 787-1080 (Chapter 4).

⁶⁷ See infra notes 787-907 (Georgia section).

⁶⁸ See infra notes 908-987 (New Jersey section).

⁶⁹ See infra notes 989-1068 (North Carolina section).

CHAPTER 1: KEY MATERNAL DISPARITY DATA OVERVIEW

There are severe and increasing racial disparities in maternal health, mortality and pregnancy-related outcomes. These disparities have continued to grow over several decades, despite the advances in medical and reproductive sciences. In testimony to the Commission, Shanna Cox, Associate Director for Science, Division of Reproductive Health, National Center for Chronic Disease Prevention and Health Promotion at the Centers for Disease Control and Prevention, provided key data about racial disparities in maternal health in the United States.⁷⁰

The American College of Obstetricians and Gynecologists submitted a public comment to the Commission that also explained these disparities, writing:

It is unacceptable that in a country as well-resourced as the U.S. that pregnant women and new mothers are dying of preventable causes. It is especially abhorrent that people of color are disproportionately affected by this crisis. There are a number of complex factors that contribute to racial inequities and disparities in maternal health outcomes. Nationally supported and coordinated data collection efforts are critical to address these factors and move towards our goal of eliminating preventable maternal deaths.⁷¹

Data collection and reporting is another challenge when evaluating potential causes of maternal health disparities. Nicolle Gonzales, Medical Director and Founder of the Changing Woman Initiative, testified to the Commission about some of the deficiencies in data collection regarding Native American women, writing:

Not only do Native American women experience disproportionately higher maternal mortality rates then white or Hispanic women, they are portrayed in the data like it is there fault for not accessing prenatal care in the first trimester, or that they have higher rates of obesity and diabetes —when needed services, education, access to clean water, healthy foods, and adequately funded services are lacking, across the nations. Our maternal health crises is not just a single issue problem, it is intersectional and multigenerational.⁷²

71 American College of Obstetricians a

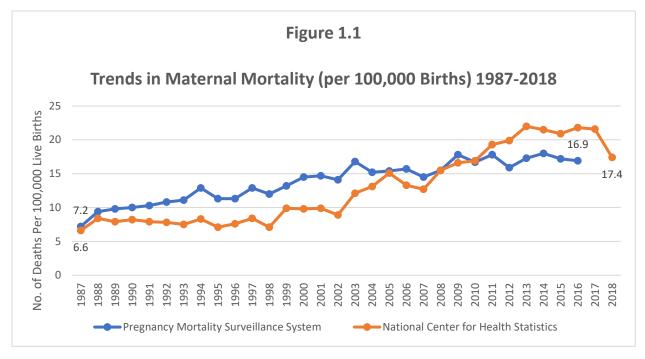
⁷⁰ See generally, Cox Statement, at 1-5.

⁷¹ American College of Obstetricians and Gynecologists, Public Comment for the *Racial Disparities in Maternal Health Briefing* before the U.S. Comm'n on Civil Rights, p. 17 (Dec. 14, 2020) (on file).

⁷² Nicolle L. Gonzales, B.S.N., R.N., M.S.N., C.N.M., Medical Director and Founder, Changing Woman Initiative, Written Statement for the *Racial Disparities in Maternal Health Briefing* before the U.S. Comm'n on Civil Rights, Nov. 13, 2020, at 3 (hereinafter "Gonzales Statement").

Data Regarding Maternal Death in the U.S.

The maternal mortality rate in the U.S. has not improved over the past three decades.⁷³ Figure 1.1 shows the trend in maternal mortality over time, through data from Pregnancy Mortality Surveillance System (in blue) from 1987 through 2016, and data from National Center for Health Statistics (in orange) from 1987 through 2018.



Source: Centers for Disease Control and Prevention, "Pregnancy Mortality Surveillance System," https://www.cdc.gov/reproductivehealth/maternal-mortality/pregnancy-mortality-surveillance-system.htm#ratio;; Centers for Disease Control and Prevention, *Maternal Mortality and Related Concepts*, Vital and Health Statistics, Series 3, No. 33, February 2007, https://www.cdc.gov/nchs/data/series/sr-03/sr03-033.pdf; Lauren M. Rossen, Ph.D., M.S., Lindsay S. Womack, Ph.D., M.P.H., Donna L. Hoyert, Ph.D., Robert N. Anderson, Ph.D., and Sayeedha F.G. Uddin, M.D., M.P.H., "The Impact of the Pregnancy Checkbox and Misclassification on Maternal Mortality Trends in the United States, 1999–2017," *National Center for Health Statistics, Vital and Health Statistics*, Series 3, No. 44, January 2020, p. 30, Table III, https://www.cdc.gov/nchs/data/series/sr-03/sr03-044-508.pdf.

*The Pregnancy Mortality Surveillance System numbers are reported using both the CDC's definition of pregnancy-related deaths: "the death of a woman while pregnant or within [one] year of the end of a pregnancy—regardless of the outcome, duration or site of the pregnancy—from any cause related to or aggravated by the pregnancy or its management, but not from accidental or incidental causes;" The NCHS numbers are reported using the WHO's definition of maternal mortality: "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."

The pregnancy-related mortality ratio (reported from PMSS data) in 1987 was 7.2 pregnancy-related deaths per 100,000 live births as compared to 17.3 deaths per 100,000 live births in

⁷³ Centers for Disease Control and Prevention, "First Data Released on Maternal Mortality in Over a Decade," Jan. 30, 2020, https://www.cdc.gov/nchs/pressroom/nchs_press_releases/2020/202001_MMR.htm.

2017.⁷⁴ As previously mentioned, National Center for Health Statistics data differs slightly, showing that the maternal mortality rate in 1987 was 6.6 deaths per 100,000 live births as compared to 17.4 in 2018, showing a higher estimated increase of 163 percent.⁷⁵ Both data sets show a high increase in maternal mortality over time.

The federal government uses two main measures to track maternal mortality within the United States. One measurement used is the Centers for Disease Control and Prevention (CDC) Pregnancy Mortality Surveillance System, defines "pregnancy-related deaths" as "the death of a woman while pregnant or within [one] year of the end of a pregnancy—regardless of the outcome, duration or site of the pregnancy—from any cause related to or aggravated by the pregnancy or its management, but not from accidental or incidental causes."⁷⁶ Another measurement used is the CDC's National Vital Statistics System, which is the official mechanism of National Center for Health Statistics for collecting and disseminating vital statistics. The official source for U.S. maternal mortality statistics for international, state, and demographic comparisons,⁷⁷ uses the World Health Organization's definition of "maternal mortality" or "maternal deaths," which is defined as "deaths of women while pregnant or within 42 days of being pregnant, from any cause related to or aggravated by the pregnancy or its management, but not from accidental or incidental causes."⁷⁸ Additionally, "[t]he classification of deaths involving pregnancy, childbirth and puerperium specifically excludes external causes (i.e., accidents, homicides, and suicides) as incidental," and excludes late maternal deaths (occurring between 43 days and 1 year of death) from this definition.⁷⁹

⁷⁴ Centers for Disease Control and Prevention, "Pregnancy Mortality Surveillance System," Nov. 25, 2020, https://www.cdc.gov/reproductivehealth/maternal-mortality/pregnancy-mortality-surveillance-system.htm#trends (last accessed Mar. 2, 2021).

⁷⁵ Lauren M. Rossen, Ph.D., M.S., Lindsay S. Womack, Ph.D., M.P.H., Donna L. Hoyert, Ph.D., Robert N. Anderson, Ph.D., and Sayeedha F.G. Uddin, M.D., M.P.H., "The Impact of the Pregnancy Checkbox and Misclassification on Maternal Mortality Trends in the United States, 1999–2017," *National Center for Health Statistics, Vital and Health Statistics*, Series 3, No. 44, January 2020, p. 30, Table III, https://www.cdc.gov/nchs/data/series/sr 03/sr03 044-508.pdf.

⁷⁶ Centers for Disease Control and Prevention, "Pregnancy Mortality Surveillance System," https://www.cdc.gov/reproductivehealth/maternal-mortality/pregnancy-mortality-surveillance-system.htm#ratio.

⁷⁷ Lauren M. Rossen, Ph.D., M.S., Lindsay S. Womack, Ph.D., M.P.H., Donna L. Hoyert, Ph.D., Robert N. Anderson, Ph.D., and Sayeedha F.G. Uddin, M.D., M.P.H., "The Impact of the Pregnancy Checkbox and Misclassification on Maternal Mortality Trends in the United States, 1999–2017," *National Center for Health Statistics, Vital and Health Statistics*, Series 3, No. 44 (January 2020): 1,

https://www.edo.gov/pebs/dota/series/gr. 03/gr03, 044, 508 pdf. Centers for Disease Central and Prevention, National Center for Disease Central and Prevention and Prevention and Prevention of Center for Disease Central and Prevention and Prevention

https://www.cdc.gov/nchs/data/series/sr_03/sr03_044-508.pdf; Centers for Disease Control and Prevention, National Center for Health Statistics, "National Vital Statistics System," https://www.cdc.gov/nchs/nvss/index.htm.

⁷⁸ Donna L. Hoyert, Ph.D., and Arialdi M. Miniño, M.P.H., "Maternal Mortality in the United States: Changes in Coding, Publication, and Data Release, 2018," *National Vital Statistics Reports*, Vol. 69, No. 2 (Jan. 30, 2020): 1, https://www.cdc.gov/nchs/data/nvsr/nvsr69/nvsr69 02-508.pdf.

⁷⁹ Ibid.

The National Center for Health Statistics, however, only includes deaths occurring within 42 days postpartum..⁸⁰ Although the CDC recognizes that many women die as a result of pregnancy beyond the 42-day cutoff (as per the WHO definition), 81 the National Center for Health Statistics only includes deaths occurring within 42 days postpartum.⁸² To fill these data gaps about maternal deaths in the U.S., 83 the CDC established the Pregnancy Mortality Surveillance System (PMSS)in 1986, as the second national source. It uses either death certificates with a checkbox that identifies a relationship between the death and a pregnancy, or death certificates that have a linked birth or fetal death certificate registered in the year preceding death to produce a pregnancy-related maternal mortality ratio.⁸⁴ The Pregnancy Mortality Surveillance System requests death certificate data, along with any birth or fetal death certificates that match to a death certificate, from 52 vital statistics reporting areas, including all 50 states, New York City, and Washington, D.C., which is summarized and reviewed by epidemiologists to determine if the death is pregnancy-related, and then the cause of death. 85 Representing the CDC, Shanna Cox explained to the Commission that "the [Pregnancy Mortality Surveillance System] also allows [the CDC] to look at patterns in pregnancy-related deaths that happen each year in the United States."86 See Table 1.1 for a comparison of the Pregnancy Mortality Surveillance System and National Center for Health Statistics systems of data collection.

Table 1.1 National Sources of Maternal Mortality Information

	National Center for Health Statistics	Pregnancy Mortality Surveillance System
Data Source	Death certificates	Death certificates linked to fetal death and birth certificates
Time Frame	During pregnancy – 42 days postpartum	During pregnancy – 365 days postpartum
Source of Classification	Maternal death	-Pregnancy-associated death -Pregnancy-related death -Pregnancy-associated, but not related death*
Measure	Maternal mortality rate = # of maternal deaths per 100,000 live births	Pregnancy-related mortality ratio = # of pregnancy-related deaths per 100,000 live births
Purpose	Show national trends and provide a	Analyze clinical factors associated with

⁸⁰ Hoyert DL. Maternal mortality and related concepts. Vital Health Stat 3. 2007 Feb;(33):1-13.

⁸¹ Cox Statement, at 1.

⁸² Hoyert DL. Maternal mortality and related concepts. Vital Health Stat 3. 2007 Feb;(33):1-13.

⁸³ Centers for Disease Control and Prevention, "Pregnancy Mortality Surveillance System," https://www.cdc.gov/reproductivehealth/maternal-mortality/pregnancy-mortality-surveillance-system.htm.

⁸⁴ CDC Foundation, *Building U.S. Capacity to Review and Prevent Maternal Deaths: Report from Nine Maternal Mortality Review Committees*, 2018, p. 9; *see also*, Cox Statement at 1, https://www.cdcfoundation.org/sites/default/files/files/ReportfromNineMMRCs.pdf.

⁸⁵ Cox Statement at 1.

⁸⁶ Cox Statement at 2.

	National Center for Health Statistics	Pregnancy Mortality Surveillance System
	basis for international comparison	deaths, publish information that may lead to prevention strategies
Strengths	 Best source of historical data (back to 1900) Reliable basis for international comparison Based on readily available data (death certificates) 	Most clinically relevant national measure of the burden of maternal deaths
Challenges	- Constrained by ICD-10 codes - Lacks sufficient detail to inform prevention strategies	 Constrained by information available on death and birth certificates Lacks detailed information on contributors to deaths

Source: CDC Foundation, *Building U.S. Capacity to Review and Prevent Maternal Deaths: Report from Nine Maternal Mortality Review Committees*, 2018, p. 9,

 $\underline{https://www.cdcfoundation.org/sites/default/files/files/ReportfromNineMMRCs.pdf.}$

The website *Review to Action*, which serves as a resource for preventing maternal mortality, explains three common categories in which definitions of maternal mortality are grouped: (1) pregnancy-associated death; (2) pregnancy-associated, but not related death; and (3) pregnancy-related death.⁸⁷ It also offers the following commonly used definitions of each:

- Pregnancy-associated death The death of a woman while pregnant or within one year of the termination of pregnancy, regardless of the cause. These deaths make up the universe of maternal mortality; within that universe are pregnancy-related deaths and pregnancy-associated, but not related deaths;;
- Pregnancy-associated, but not related death The death of a woman during pregnancy or within one year of the end of pregnancy, from a cause that is not related to pregnancy (e.g., a pregnant woman dies in an earthquake); and
- Pregnancy-related death The death of a woman during pregnancy or within one year of the end of pregnancy, from a pregnancy complication, a chain of events initiated by pregnancy, or the aggravation of an unrelated condition by the physiologic effects of pregnancy.⁸⁸

Rates of maternal mortality, regardless of which definition of maternal mortality is utilized, are typically measured by a ratio that calculates the number of "maternal deaths," or "pregnancy-related deaths" per 100,000 live births.⁸⁹

88 Ibid.

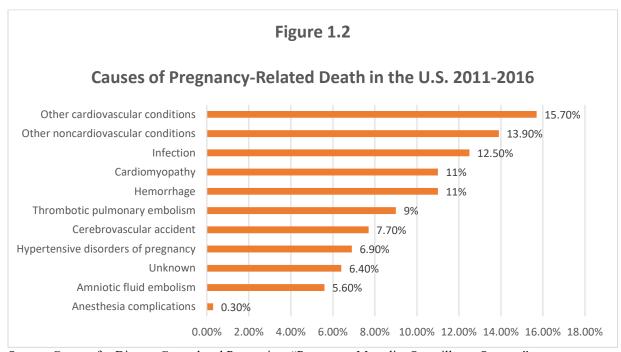
^{*} See Review to Action, "Definitions," https://reviewtoaction.org/learn/definitions.

⁸⁷ Ibid.

⁸⁹ Ibid; *see also* Centers for Disease Control and Prevention, "Pregnancy Mortality Surveillance System," https://www.cdc.gov/reproductivehealth/maternal-mortality/pregnancy-mortality-surveillance-system.htm#ratio; *see*

Risk Factors

There are a variety of risk factors that lead to pregnancy-related deaths in the U.S. Research has shown that pregnant women in the United States who have chronic health conditions such as hypertension, diabetes, and heart disease may be at higher risk for pregnancy complications. From 2011-2016, cardiovascular conditions were responsible for more than a third of pregnancy-related deaths (see Figure 1.2). 91



Source: Centers for Disease Control and Prevention, "Pregnancy Mortality Surveillance System," https://www.cdc.gov/reproductivehealth/maternal-mortality/pregnancy-mortality-surveillance-system.htm#ratio.

also World Health Organization, "Maternal Mortality Ratio (per 100,000 live births)," https://www.who.int/data/gho/indicator-metadata-registry/imr-details/26.

⁹⁰ Centers for Disease Control and Prevention, "Pregnancy Mortality Surveillance System," https://www.cdc.gov/reproductivehealth/maternal-mortality/pregnancy-mortality-surveillance-system.htm#ratio;
Kuklina EV, Ayala C, Callaghan WM. Hypertensive disorders and severe obstetric morbidity in the United States: 1998–2006. Obstet Gynecol. 2009; 113:1299–1306; Admon LK, Winkelman TNA, Moniz MH, Davis MM, Heisler M, Dalton VK. Disparities in chronic conditions among women hospitalized for delivery in the United States, 2005–2014. Obstet Gynecol. 2017;130(6):1319–1326; Albrecht SS, Kuklina EV, Bansil P, et al. Diabetes trends among delivery hospitalizations in the United States, 1994–2004. Diabetes Care. 2010; 33:768–773; Correa A, Bardenheier B, Elixhauser A, Geiss LS, Gregg E. Trends in prevalence of diabetes among delivery hospitalizations, United States, 1993–2009. Matern Child Health J. 2015;19(3):635–642; Deputy NP, Kim SY, Conrey EJ, Bullard KM. Prevalence and changes in preexisting diabetes and gestational diabetes among women who had a live birth—United States, 2012–2016. MMWR Morb Mortal Wkly Rep. 2018; 67:1201–1207; Kuklina EV, Callaghan WM. Chronic heart disease and severe obstetric morbidity among hospitalizations for pregnancy in the USA: 1995–2006. Br J Obstet Gynaecol. 2011; 118:345–352; Lima FV, Yang J, Xu J, Stergiopoulos K. National trends and in-hospital outcomes in pregnant women with heart disease in the United States. Am J Cardiol. 2017;119(10):1694–1700.
⁹¹ Centers for Disease Control and Prevention, "Pregnancy Mortality Surveillance System,"

https://www.cdc.gov/reproductivehealth/maternal-mortality/pregnancy-mortality-surveillance-system.htm#ratio.

Pregnancy complications are health problems that occur during pregnancy and can affect the health of both the mother and the child. Prese complications can occur as a result of the pregnancy, and/or from pre-existing health problems prior to the pregnancy. Pregnancy complications can include both physical and mental conditions and can range from mild discomforts to severe and potentially life-threatening illnesses. Pregnancy categories of common pregnancy complications and pre-existing issues which can affect pregnancy.

Table 1.3 Pre-Existing Conditions Affecting Pregnancy and Common Pregnancy Complications

Health Problems Before Pregnancy	Asthma, Depression, Diabetes, Eating Disorders, Epilepsy, High Blood Pressure, HIV, Migraines, Obesity/Weight Gain, Sexually Transmitted Infections (STIs), Thyroid Disease, Uterine Fibroids
Health Problems During Pregnancy	Anemia, Depression, Ectopic Pregnancy, Fetal Problems, Gestational Diabetes, High Blood Pressure (Pregnancy-Related), Hyperemesis Gravidarum, Miscarriage, Placenta Previa, Placental Abruption, Preeclampsia, Preterm Labor
Infections During Pregnancy	Bacterial Vaginosis, Cytomegalovirus, Group B Strep, Hepatitis B Virus, Influenza, Listeriosis, Parvovirus B19, Sexually Transmitted Infections (STIs), Toxoplasmosis, Urinary Tract Infection (UTI), Yeast Infection

Source: U.S. Department of Health and Human Services, Office on Women's Health, "Pregnancy Complications," https://www.womenshealth.gov/pregnancy/youre-pregnant-now-what/pregnancy-complications.

As noted in Table 1.3, depression is a common mental health problem that can occur during or after pregnancy. Approximately 1 in 9 women experience symptoms of postpartum depression, and the rate of pregnant women diagnosed with depression at delivery increased seven times from 2000 to 2015. Depression during or after pregnancy is generally treatable, seven times from 2000 to 2015.

⁹² Centers for Disease Control and Prevention, "Pregnancy Complications," https://www.cdc.gov/reproductivehealth/maternalinfanthealth/pregnancy-complications.html.

⁹³ Ibid.

⁹⁴ Ibid.

⁹⁵ See also Centers for Disease Control and Prevention, "Depression During and After Pregnancy," https://www.cdc.gov/reproductivehealth/features/maternal-depression/index.html.

⁹⁶ Ibid.; Jean Y. Ko, PhD, Karilynn M. Rockhill, MPH1, Van T. Tong, MPH, Brian Morrow, Sherry L. Farr, PhD, "Trends in Postpartum Depressive Symptoms — 27 States, 2004, 2008, and 2012," *Morbidity and Mortality Weekly Report*, Vol. 66, No. 6 (Feb. 17, 2017): 153-158,

 $[\]underline{\text{https://www.cdc.gov/mmwr/volumes/66/wr/mm6606a1.htm?s_cid=mm6606a1_w}.$

⁹⁷ Centers for Disease Control and Prevention, "Depression During and After Pregnancy," https://www.cdc.gov/reproductivehealth/features/maternal-depression/index.html; Haight, Sarah C. MPH, Byatt, Nancy DO, MS, Moore Simas, Tiffany A. MD, MPH, Robbins, Cheryl L. PhD, MS, Ko, Jean Y. PhD, "Recorded"

yet approximately 60 percent of U.S. pregnant and nonpregnant women of reproductive age with depressive symptoms do not receive a clinical diagnosis and approximately 50 percent of women in the same group with a diagnosis do not receive treatment.⁹⁹

Examining pregnancy-related deaths from 2011-2015, the CDC reported that 31 percent occurred during pregnancy, 36 percent occurred during delivery or during the week following delivery, and 33 percent occurred from 1-week to 1-year postpartum. During the same time period, the pregnancy-related mortality rate was highest among women aged 35 and older, a concerning data point as the average age of first time mothers in the U.S. has increased to 26 in 2018, up from an average age of 21 in 1972. In 2018, the maternal mortality rate for women aged 40 and older (81.9 deaths per 100,000 live births) was approximately 8 times that for women under age 25 (10.6 deaths per 100,000 live births).

A number of psychosocial and environmental risk factors are associated with maternal mental health conditions, such as chronic stressors like racism and poverty; lack of access to insurance, transportation, and providers; substance use disorder; chronic disease; obesity; unplanned pregnancy; delay or failure to seek prenatal care; social isolation and lack of social support; childcare-associated stress; homelessness; or exposure to violence and trauma. Angela D. Aina of the Black Mommas Matter Alliance addressed some of the risk factors in her written testimony to the Commission, writing:

Diagnoses of Depression During Delivery Hospitalizations in the United States, 2000–2015," *American Journal of Obstetrics and Gynecology*, Vol. 133, No. 6 (June 2019): 1216-1223,

 $\underline{https://journals.lww.com/greenjournal/Citation/2019/06000/Recorded_Diagnoses_of_Depression_During_Delivery.} \\ \underline{20.aspx}.$

⁹⁸ Centers for Disease Control and Prevention, "Depression During and After Pregnancy," https://www.cdc.gov/reproductivehealth/features/maternal-depression/index.html.

⁹⁹ Jean Y. Ko, PhD, Karilynn M. Rockhill, MPH1, Van T. Tong, MPH, Brian Morrow, Sherry L. Farr, PhD, "Trends in Postpartum Depressive Symptoms — 27 States, 2004, 2008, and 2012," *Morbidity and Mortality Weekly Report*, Vol. 66, No. 6 (Feb. 17, 2017): 153-158,

https://www.cdc.gov/mmwr/volumes/66/wr/mm6606a1.htm?s cid=mm6606a1 w.

¹⁰⁰ Centers for Disease Control and Prevention, "Pregnancy-related deaths," https://www.cdc.gov/vitalsigns/maternal-deaths/index.html.

¹⁰¹ Emily E. Petersen, MD; Nicole L. Davis, PhD; David Goodman, PhD; Shanna Cox, MSPH; Nikki Mayes; Emily Johnston, MPH; Carla Syverson, MSN; Kristi Seed; Carrie K. Shapiro-Mendoza, PhD; William M. Callaghan, MD; Wanda Barfield, MD, "Vital Signs: Pregnancy-Related Deaths, United States, 2011–2015, and Strategies for Prevention, 13 States, 2013–2017," 424; Quoctrung Bui and Claire Cain Miller, *The Age That Women Have*

Babies: How a Gap Divides America, THE NEW YORK TIMES (Aug. 4, 2018) https://www.nytimes.com/interactive/2018/08/04/upshot/up-birth-age-gap.html.

¹⁰² Centers for Disease Control and Prevention, National Center for Health Statistics, "First Data Released on Maternal Mortality in Over a Decade," Jan. 30, 2020,

https://www.cdc.gov/nchs/pressroom/nchs press releases/2020/202001 MMR.htm.

¹⁰³ CDC Foundation, Building U.S. Capacity to Review and Prevent Maternal Deaths: Report from Nine Maternal *Mortality Review Committees*, 2018, p. 37,

https://www.cdcfoundation.org/sites/default/files/files/ReportfromNineMMRCs.pdf.

Lack of accountability for preventable pregnancy related deaths in hospital settings, mistreatment of pregnant and birthing people, limitations to quality healthcare and telehealth services, pervasive acts of reproductive coercion, and neglect during labor in hospital settings, are all contributors of maternal health inequities experienced by Black women and birthing people. ¹⁰⁴

Mental health conditions serve as an underlying factor that can result in injury or death from suicide, accidental deaths, or deaths due to homicide, which makes the association between mental health and maternal mortality complex. One publication from fourteen Maternal Mortality Review Committees reported that mental health conditions were a leading underlying cause of pregnancy-related death in the U.S. in some regions of the U.S. from 2009-2017. Research suggests that suicidal ideation occurs more often among pregnant women than among the general population. Suicide most commonly occurs in the late postpartum period with one 15-year study of women in Ontario, Canada finding that suicide often occurs within 9 to 12 months postpartum among women with higher rates of prior mental illness than women living postpartum. In addition, substance abuse can lead to increased risk of suicide or unintentional overdose, and "[t]reatment for substance use disorder during pregnancy involves a complex

¹⁰⁴ Angela Doyinsola Aina, M.P.H., Co-Founder and Executive Director, Black Mamas Matter Alliance, Written Statement for the *Racial Disparities in Maternal Health Briefing* before the U.S. Comm'n on Civil Rights, Nov. 13, 2020, at 1-2 (hereinafter "Aina Statement").

¹⁰⁵ CDC Foundation, Report from Maternal Mortality Review Committees: A View Into Their Critical Role, p. 32, https://www.cdcfoundation.org/sites/default/files/upload/pdf/MMRIAReport.pdf; CDC Foundation, Building U.S. Capacity to Review and Prevent Maternal Deaths: Report from Nine Maternal Mortality Review Committees, 2018, p. 37,

https://www.cdcfoundation.org/sites/default/files/files/ReportfromNineMMRCs.pdf.

¹⁰⁶ Centers for Disease Control and Prevention, "Pregnancy-Related Deaths: Data from 14 U.S. Maternal Mortality Review Committees, 2008-2017," https://www.cdc.gov/reproductivehealth/maternal-mortality/erase-mm/mmr-data-brief.html.

¹⁰⁷ CDC Foundation, Building U.S. Capacity to Review and Prevent Maternal Deaths: Report from Nine Maternal *Mortality Review Committees*, 2018, p. 38,

https://www.cdcfoundation.org/sites/default/files/files/ReportfromNineMMRCs.pdf; Bizu Gelaye, PhD, MPH, Sandhya Kajeepeta, MSc, and Michelle A. Williams, ScD, "Suicidal Ideation in Pregnancy: An Epidemiologic Review," *Arch Womens Ment Health*, Vol. 19, No. 5 (October 2016): 741-751, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5023474/.

¹⁰⁸ CDC Foundation, Building U.S. Capacity to Review and Prevent Maternal Deaths: Report from Nine Maternal *Mortality Review Committees*, 2018, p. 38,

https://www.cdcfoundation.org/sites/default/files/files/ReportfromNineMMRCs.pdf; Wallace, M.E., Hoyert, D., Williams, C., & Mendola, P., "Pregnancy-associated homicide and suicide in

³⁷ US states with enhanced pregnancy surveillance," *Obstetrics & Gynecology*, Vol. 215 No. 3 (2016): 364.e1-364.e10, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5003645/.

¹⁰⁹ Sophie Grigoriadis, Andrew S. Wilton, Paul A. Kurdyak, Anne E. Rhodes, Emily H. VonderPorten, Anthony Levitt, Amy Cheung, Simone N. Vigod, *Perinatal suicide in Ontario, Canada: a 15-year population-based study*, CMAJ (Aug. 28, 2017),), https://www.cmaj.ca/content/cmaj/189/34/E1085.full.pdf.

¹¹⁰ Ibid.; Bolton, J., Cox, B., Clara, I., & Sareen, J., Use of alcohol and drugs to self-medicate anxiety disorders in a nationally representative sample, The Journal of nervous and mental disease, Vol. 194, No. 11 (November 2006): 818-825,

assessment of risk related not only to pregnancy, but also to interactions with other treatments of comorbid conditions, such as antidepressants."¹¹¹

The CDC defines maternal morbidity as the "physical and psychologic conditions that result from or are aggravated by pregnancy and have an adverse effect on a woman's health," and the most severe complications of pregnancy are referred to as "severe maternal morbidity." The CDC indicates that severe maternal morbidity "includes unexpected outcomes of labor and delivery that result in significant short- or long-term [negative] consequences to a woman's health." Each year, more than 50,000 women in the U.S. experience severe maternal morbidity, and those numbers have been steadily increasing. While a combination of factors is likely responsible for the increase in severe maternal morbidity in the U.S., the CDC has documented that factors such as maternal age, pre-pregnancy obesity, preexisting chronic medical conditions, and caesarean deliveries are also contributing factors. 115

The CDC identifies severe maternal morbidity using hospital discharge data and International Classification of Diseases (ICD) diagnosis and procedure codes. ¹¹⁶ There are currently 21 indicators (with corresponding ICD codes) used to identify delivery hospitalizations with severe maternal morbidity. ¹¹⁷ Blood transfusions account for a significant proportion of severe maternal

https://journals.lww.com/jonmd/Abstract/2006/11000/Use_of_Alcohol_and_Drugs_to_Self_Medicate_Anxiety.2.as px.

¹¹¹ CDC Foundation, Building U.S. Capacity to Review and Prevent Maternal Deaths: Report from Nine Maternal *Mortality Review Committees*, 2018, p. 38,

https://www.cdcfoundation.org/sites/default/files/files/ReportfromNineMMRCs.pdf.

In 2005, the U.S. Food and Drug Administration published an advisory warning of a potential association between the use of selective serotonin reuptake inhibitors (SSRIs), a type of antidepressant, among pregnant women and birth defects in infants. Over the years, recent meta-analyses and systematic reviews have reached conflicting conclusions, leading to uncertainty about the safety of antidepressant use in pregnancy.

Jennita Reefhuis, Owen Devine, Jan M. Friedman, Carol Louik, and Margaret A. Honein, "Specific SSRIs and birth defects: Bayesian analysis to interpret new data in the context of previous reports," *BMJ*, Vol. 351 (Jul. 2015), https://www.bmj.com/content/351/bmj.h3190; see also Centers for Disease Control and Prevention, "Link Between Depression Treatments and Birth Defects,"

https://www.cdc.gov/pregnancy/meds/treatingfortwo/features/ssrisandbirthdefects.html (accessed Sept. 15, 2020).

112 Centers for Disease Control and Prevention, "Pregnancy Complications,"

https://www.cdc.gov/reproductivehealth/maternalinfanthealth/pregnancy-complications.html.

¹¹³ Centers for Disease Control and Prevention, "Severe Maternal Morbidity in the United States," https://www.cdc.gov/reproductivehealth/maternalinfanthealth/severematernalmorbidity.html.

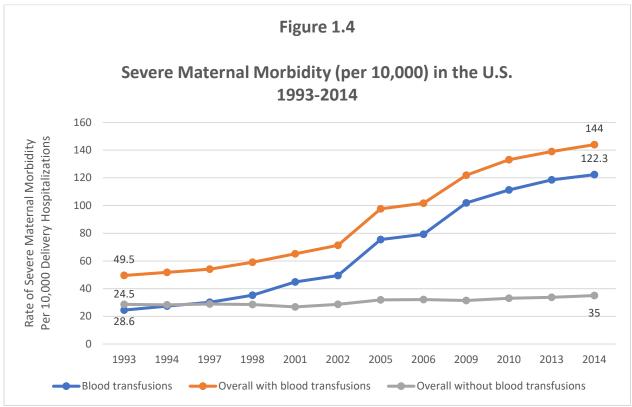
114 Ibid.

¹¹⁵ Ibid.

116 Ibid.

117 Centers for Disease Control and Prevention, "How Does CDC Identify Severe Maternal Morbidity?," https://www.cdc.gov/reproductivehealth/maternalinfanthealth/smm/severe-morbidity-ICD.htm.

morbidity events.¹¹⁸ Figure 1.4 displays the rate of severe maternal morbidity in the U.S. from 1993-2014 with and without blood transfusions.



Source: Centers for Disease Control and Prevention, "Rates in Severe Morbidity Indicators per 10,000 Delivery Hospitalizations, 1993–2014," https://www.cdc.gov/reproductivehealth/maternalinfanthealth/smm/rates-severe-morbidity-indicator.htm.

The overall rate of severe maternal morbidity (measured per 10,000 delivery hospitalizations) increased from 49.5 in 1993 to 144.0 per 10,0000 in 2014, which is nearly a 200 percent increase or nearly triple the total of women impacted over the course of a decade. Among women who did not receive blood transfusions, the rate of severe maternal morbidity increased from 28.6 in 1993 to 35.0 per 10,000 in 2014, a roughly 20 percent increase.

¹¹⁸ Centers for Disease Control and Prevention, "Rates in Severe Morbidity Indicators per 10,000 Delivery Hospitalizations, 1993–2014," https://www.cdc.gov/reproductivehealth/maternalinfanthealth/smm/rates-severe-morbidity-indicator.htm. CDC indicates that the overall rate of severe maternal morbidity increase has been mostly driven by the increase in blood transfusions. *See also* William M. Callaghan, MD, MPH, Andrea P. MacKay, MSPH, Cynthia J. Berg, MD, MPH, "Identification of severe maternal morbidity during delivery hospitalizations, United States, 1991-2003," *American Journal of Obstetrics & Gynecology*, Vol. 199, No. 2 (August 2008): 133.e1-133.e8, https://www.sciencedirect.com/science/article/abs/pii/S0002937807023320.

¹¹⁹ Centers for Disease Control and Prevention, "Rates in Severe Morbidity Indicators per 10,000 Delivery Hospitalizations, 1993–2014," https://www.cdc.gov/reproductivehealth/maternalinfanthealth/smm/rates-severe-morbidity-indicator.htm.

¹²⁰ Ibid.

The American College of Obstetricians and Gynecologists (ACOG) has acknowledged that severe maternal morbidity, or "near misses" are associated with a high rate of preventability, and that without identification and treatment of preventable maternal morbidity, maternal mortality can occur. ¹²¹ Similarly, ACOG states that maternal mortality also has a high rate of preventability. ¹²² There are various commonalities among women who survive severe maternal morbidity and those who die from similar complications. ¹²³ The WHO has developed a "near miss" framework for understanding and classifying "the similarities, the differences and the relationship between women who died and those who survived life-threatening conditions [that can] provide a more complete assessment of quality in maternal health care." ¹²⁴

The federal government has faced challenges to identify and report maternal deaths;; however, the CDC has made recent improvements in data collection. For example, while the National Center for Health Statistics recently reported national maternal mortality statistics for 2018, it had not published a national maternal mortality rate for over a decade due to challenges with correctly identifying and reporting maternal mortality data. In 2016, the Journal of Obstetrics and Gynecology published a study declaring that it was "an international embarrassment" that the U.S. has not been able to provide a national mortality rate to international data repositories since 2007, citing underfunding to state and national vital statistics systems. Passed on independent data analysis, the study reported a much higher maternal mortality rate than reported by the National Center for Health Statistics in the U.S., finding a rate of 23.8 deaths per 100,000

¹²¹ American College of Obstetricians and Gynecologists, "Severe Maternal Morbidity: Screening and Review," Obstetric Care Consensus, No. 5, September 2016, p. 8, https://www.acog.org/clinical/clinical-guidance/obstetric-care-consensus/articles/2016/09/severe-maternal-morbidity-screening-and-review.

¹²² Ibid.

World Health Organization, "The WHO Near-Miss Approach,"
 https://www.who.int/reproductivehealth/topics/maternal_perinatal/nmconcept/en/.
 Ibid.

¹²⁵ Centers for Disease Control and Prevention, National Center for Health Statistics, *First Data Released on Maternal Mortality in Over a Decade*, Jan. 30, 2020,

https://www.cdc.gov/nchs/pressroom/nchs_press_releases/2020/202001_MMR.htm; see generally, Cox Statement at 1-3.

¹²⁶ Centers for Disease Control and Prevention, National Center for Health Statistics, "First Data Released on Maternal Mortality in Over a Decade," Jan. 30, 2020,

https://www.cdc.gov/nchs/pressroom/nchs_press_releases/2020/202001_MMR.htm.

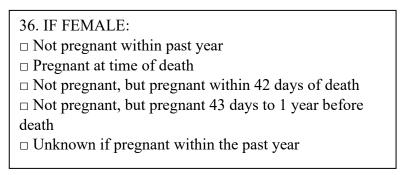
¹²⁷ Marian F. MacDorman, PhD, Eugene Declercq, PhD, Howard Cabral, PhD, and Christine Morton, PhD, "Recent Increases in the U.S. Maternal Mortality Rate Disentangling Trends From Measurement Issues," *Obstet Gynecol*, Vol. 128, No. 3 (September 2016): 8,

http://d279m997dpfwgl.cloudfront.net/wp/2016/08/MacDormanM.USMatMort.OBGYN_.2016.online.pdf. See also Donna L. Hoyert, Ph.D., and Arialdi M. Miniño, M.P.H., "Maternal Mortality in the United States: Changes in Coding, Publication, and Data Release, 2018," National Vital Statistics Reports, Vol. 69, No. 2 (Jan. 30, 2020): 1, https://www.cdc.gov/nchs/data/nvsr/nvsr69/nvsr69-02-508.pdf.

live births in 2014, and also finding a 26.6 percent increase from the 2000 rate of 18.8 deaths per 100,000 live births, and significant racial disparities in maternal mortality rates. ¹²⁸

Official statistics regarding maternal deaths are obtained from information on death certificates completed by physicians, coroners, or medical examiners and reported to the states. ¹²⁹ In 2003, the National Center for Health Statistics recommended that all states add a standardized pregnancy "checkbox" item to the U.S. Standard Certificate of Death to improve the identification and address the underreporting of maternal deaths, ¹³⁰ according to the definition used by the National Center for Health Statistics ¹³¹— see Figure 1.5.

Figure 1.5 Pregnancy Checkbox Item Addition to U.S. Standard Certificate of Death



Source: Donna L. Hoyert, Ph.D., Sayeedha F.G. Uddin, M.D., M.P.H., Arialdi M. Miniño, M.P.H., "Evaluation of the Pregnancy Status Checkbox on the Identification of Maternal Deaths," *National Vital Statistics Reports*, Vol. 69, No. 1 (Jan. 30, 2020): 2, https://www.cdc.gov/nchs/data/nvsr/nvsr69/nvsr69 01-508.pdf.

Implementation of the pregnancy checkbox resulted in the identification of a significantly greater number of maternal deaths using that data—nearly three times greater than the number of identified maternal deaths without use of the checkbox data. ¹³²

By 2018, all states had implemented a version of the checkbox on their death certificates and the National Center for Health Statistics resumed publication of the U.S. maternal mortality rate. ¹³³

¹²⁸ The study included 48 states and the District of Columbia but excluded California and Texas which were analyzed separately. Ibid., 1, 5.

¹²⁹ Centers for Disease Control, National Center for Health Statistics, "First Data Released on Maternal Mortality in Over a Decade," Jan. 30, 2020, https://www.cdc.gov/nchs/pressroom/nchs press releases/2020/202001 MMR.htm.

¹³⁰ Ibid; Donna L. Hoyert, Ph.D., and Arialdi M. Miniño, M.P.H., "Maternal Mortality in the United States: Changes in Coding, Publication, and Data Release, 2018," *National Vital Statistics Reports*, Vol. 69, No. 2 (Jan. 30, 2020): 1, https://www.cdc.gov/nchs/data/nvsr/nvsr69/nvsr69 02-508.pdf.

¹³¹ See supra note 78.

¹³² Donna L. Hoyert, Ph.D., Sayeedha F.G. Uddin, M.D., M.P.H., Arialdi M. Miniño, M.P.H., "Evaluation of the Pregnancy Status Checkbox on the Identification of Maternal Deaths," *National Vital Statistics Reports*, Vol. 69, No. 1 (Jan. 30, 2020): 1, https://www.cdc.gov/nchs/data/nvsr/nvsr69/nvsr69 01-508.pdf.

¹³³ Donna L. Hoyert, Ph.D., and Arialdi M. Miniño, M.P.H., "Maternal Mortality in the United States: Changes in

The American College of Obstetricians and Gynecologists wrote to the Commission about the status of data collection after the widespread adoption of the pregnancy checkbox, stating:

Although the [National Center for Health Statistics], in partnership with the states, has improved the accuracy of the data collected from U.S. death certificates by including the standardized pregnancy status checkbox, it is important to recognize that misclassification of pregnancy status and other challenges with vital statistics data still exist. Continued improvement in tracking all data events—including accounting for maternal deaths up to 12 months postpartum and deaths from suicide and substance use disorder—is still needed.¹³⁴

Identifying cases of severe maternal morbidity can be challenging. To date there is no existing consensus definition as to what conditions should represent severe maternal morbidity among healthcare professionals. According to the American College of Obstetricians and Gynecologists and the Society for Maternal-Fetal Medicine, severe maternal morbidity "is not always reported and may not be well coded in, or otherwise readily extracted from, record systems," and "[d]efinitions of severe maternal morbidity that rely on diagnosis codes, such as the Centers for Disease Control and Prevention's definition, may miss cases, have a relatively low positive predictive value (0.40) and, at a practical level, may be difficult for facilities to operationalize." Additionally, the American College of Obstetricians and Gynecologists and the Society for Maternal-Fetal Medicine recommend that facilities have a screening process in place to detect cases of severe maternal morbidity, with the Society for Maternal-Fetal Medicine specifically recommending the use of two screening criteria: 1) transfusion with four or more units of blood and 2) admission of a pregnant or postpartum woman to an intensive care unit, as these criteria have "high sensitivity and specificity for identifying women with severe morbidity and a high positive predictive value (0.85) for identifying severe maternal morbidity." They

Coding, Publication, and Data Release, 2018," *National Vital Statistics Reports*, Vol. 69, No. 2 (Jan. 30, 2020): 1, https://www.cdc.gov/nchs/data/nvsr/nvsr69/nvsr69-02-508.pdf.

¹³⁴ American College of Obstetricians and Gynecologists, Public Comment for the *Racial Disparities in Maternal Health Briefing* before the U.S. Comm'n on Civil Rights, p. 5.

¹³⁵ Sarah K. Kilpatrick, MD, PhD and Jeffrey L. Ecker, MD, American College of Obstetricians and Gynecologists and the Society for Maternal–Fetal Medicine, "Severe Maternal Morbidity: Screening and Review," *American Journal of Obstetrics and Gynecology*, Vol. 215, No. 3 (September 2016): B18, https://www.ajog.org/action/showPdf?pii=S0002-9378%2816%2930523-3.

¹³⁶ Ibid.

¹³⁷ Ibid; *See also* Elliott K. Main, MD, Anisha Abreo, MPH, Jennifer McNulty, MD, William Gilbert, MD, Colleen, McNally, MD, Debra Poeltler, PhD, Katarina Lanner-Cusin, MD, Douglas Fenton, MD, Theresa, Gipps, MD, Kathryn Melsop, MS, Naomi Greene, PhD, Jeffrey B. Gould, MD, MPH, Sarah Kilpatrick, PhD, MD, "Measuring Severe Maternal Morbidity: Validation of Potential Measures," *American Journal of Obstetrics and Gynecology*, Vol. 214, No. 5 (May 2016): 643.e1-643.e10,

https://www.sciencedirect.com/science/article/abs/pii/S0002937815022978.

¹³⁸ Sarah K. Kilpatrick, MD, PhD and Jeffrey L. Ecker, MD, American College of Obstetricians and Gynecologists and the Society for Maternal–Fetal Medicine, "Severe Maternal Morbidity: Screening and Review," *American*

both recommend that facilities review all cases that meet at least one of the criteria to properly characterize the events and determine if the event was potentially avoidable, but acknowledge that not every case that meets the criteria will represent preventable severe maternal morbidity, which "underscores the importance of reviewing each 'screen positive' case to identify those with true morbidity and, especially, those that may be deemed upon review to have been potentially avoidable." ¹³⁹

Data Collection and Research

Data collection and research are one part of a comprehensive approach to improving maternal health outcomes and eliminating disparities in maternal mortality and severe maternal morbidity. Associate Professor at Tufts University School of Medicine, noted in her written testimony to the Commission that the fact that approximately 60 percent of pregnancy-related deaths are preventable shows the need for improved data collection efforts to better understand how to reduce maternal mortality and morbidity. With regard to data collection on maternal mortality and severe maternal morbidity, the creation of the Pregnancy Mortality Surveillance System helped to fill gaps in the National Center for Health Statistics vital records data by providing more clinical information about causes of maternal deaths. While vital records data on maternal mortality has faced challenges in accuracy, there have been other efforts to enhance data collection on maternal mortality and severe maternal morbidity through the work of Maternal Mortality Review Committees and the development of the Maternal Mortality Review Information Application, which helps standardize data for better information sharing. Additionally, the Pregnancy Risk Assessment

Journal of Obstetrics and Gynecology, Vol. 215, No. 3 (September 2016): B18, https://www.ajog.org/action/showPdf?pii=S0002-9378%2816%2930523-3.

¹³⁹ Ibid. See also Elliott K. Main, MD, Anisha Abreo, MPH, Jennifer McNulty, MD, William Gilbert, MD, Colleen, McNally, MD, Debra Poeltler, PhD, Katarina Lanner-Cusin, MD, Douglas Fenton, MD, Theresa, Gipps, MD, Kathryn Melsop, MS, Naomi Greene, PhD, Jeffrey B. Gould, MD, MPH, Sarah Kilpatrick, PhD, MD, "Measuring Severe Maternal Morbidity: Validation of Potential Measures," *American Journal of Obstetrics and Gynecology*, Vol. 214, No. 5 (May 2016): 643.e1-643.e10,

https://www.sciencedirect.com/science/article/abs/pii/S0002937815022978; Stacie E. Geller, Deborah Rosenberg, Suzanne Cox, Monique Brown, Louise Simonson, Sarah Kilpatrick, "A Scoring System Identified Near-Miss Maternal Morbidity During Pregnancy," *Journal of Clinical Epidemiology*, Vol. 57, No. 7 (July 2004): 716-720, https://www.sciencedirect.com/science/article/abs/pii/S0895435604000083; Whitney B. You, Suchitra Chandrasekaran, John Sullivan, William Grobman, "Validation of a Scoring System to Identify Women with Near-Miss Maternal Morbidity," *American Journal of Perinatology*, Vol. 30, No. 1 (2013): 21-24, https://www.thiemeconnect.de/products/ejournals/pdf/10.1055/s-0032-1321493.pdf.

¹⁴⁰ See infra notes 141-151(discussing relevant testimony).

¹⁴¹ Ndidiamaka Amutah-Onukagha, Associate Professor, Department of Public Health and Community Medicine, Tufts University School of Medicine, Written Statement for the *Racial Disparities in Maternal Health Briefing* before the U.S. Comm'n on Civil Rights, Nov. 13, 2020 at p. 2 (hereinafter "Amutah-Onukagha Statement").

¹⁴² See supra notes 84-86, and Table 1.1.

¹⁴³ See supra notes 129-139, Table 1.1.

¹⁴⁴ See infra notes 573-576, and 598-601.

Monitoring System, a project of the CDC and state health departments, collects "state-specific, population-based data on maternal attitudes and experiences before, during, and shortly after pregnancy," and covers about 80 percent of births. Pregnancy Risk Assessment Monitoring System data are used to investigate emerging reproductive health issues in order to help state and local governments create programs and policies that help reduce maternal and infant health problems, and can highlight differences in postpartum visit attendance and associated barriers to postpartum care, the content of care and counseling received. In the Commission's 2019 report, *Are Rights Reality? Evaluating Federal Civil Rights Enforcement*, that evaluated 13 federal agencies including the Department of Health and Human Services, the Commission found that research, data collection, and reporting were among seven essential elements for effective civil rights enforcement. In the commission for the content of the content of the commission of the content of the content of the commission found that research, data collection, and reporting were among seven essential elements for effective civil rights enforcement.

Even with recent changes in data collection such as widespread implementation of the pregnancy checkbox, gaps in data collection about women of color persist. The National Indian Health Board wrote to the Commission about failures in data collection, including racial misclassification and small sample sizes when collecting data about American Indian and Alaskan Native populations. 149

They stated, in part:

Racial misclassification and the relatively small population size of AI/AN women have prevented the issue of maternal mortality in Indian Country from gaining national attention. In addition to the PMSS the other national level data source to assess maternal mortality is maintained by the National Center for Health Statistics and relies on death certificate data reported via the National Vital Statistics Survey. However, death certificate race data is often recorded by coroners or medical examiners based on the decedent's appearance, which leads to frequent miscoding and underestimates of health outcomes. Publicly available data on maternal deaths and health outcomes from the Indian Health Service (IHS), the federal agency responsible for providing healthcare services to federally recognized Tribes, is also sparse. While the agency reported no

¹⁴⁵ Centers for Disease Control and Prevention, "What is PRAMS?" https://www.cdc.gov/prams/index.htm.

¹⁴⁷ Cox Statement, at 6.

¹⁴⁸ U.S. Comm'n on Civil Rights, *Are Rights a Reality?*, p. 63, https://www.usccr.gov/pubs/2019/11-21-Are-Rights-a-Reality.pdf, noting that:

Some civil rights enforcement offices (including that of HHS) have statutory responsibility to collect data. In 2002, the Commission found that having sufficient data to identify civil rights violations and determine whether there is compliance with federal civil rights laws is important. Since then, the Commission has repeatedly found that data collection and reporting are essential to effective civil rights enforcement, and that a lack of effective civil rights data collection is problematic.

¹⁴⁶ Ibid.

¹⁴⁹ National Indian Health Board, Public Comment for the *Racial Disparities in Maternal Health Briefing* before the U.S. Comm'n on Civil Rights, Dec. 13, 2020, p. 2, (available at https://www.usccr.gov/pubs/briefing-reports/2020-11-13-Racial-Disparities-in-Maternal-Health.php).

maternal deaths from 2016- 2018, these numbers reflect the less than 10 percent of AI/AN births that occur at an HIS facility, with an increasing number of births occurring elsewhere. These data limitations severely hinder any efforts to understand and support the health of AI/AN women. ¹⁵⁰

Research is also vital to improving maternal health outcomes and eliminating disparities in maternal mortality and severe maternal morbidity. In her written testimony before the Commission, Juanita Chinn, Program Director in the Population Dynamics Branch of the National Institutes of Health, where she manages programs on the Demography of Health, Mortality, and Population Composition, noted that "[r]esearch is critical in developing an evidence base on how institutional policies impact the racial and socioeconomic disparities observed in maternal mortality," and this evidence base "documents the pervasive disparities and identifies opportunities for informed intervention and prevention." ¹⁵¹

In addition to funding its other maternal health programs, the Health Resources and Services Administration awarded a total of \$1.2 million for six research projects related to maternal health in 2018. In 2019, the National Institutes of Health (NIH) spent approximately \$334 million on maternal health research. NIH has a total of 27 institutes and centers, several of which support research on maternal health. The Eunice Kennedy Shriver National Institute on Child Health and Human Development (National Institute of Child Health and Human Development), which is authorized to conduct research on maternal health, alone funded about 60 percent of maternal health research projects in 2019, although 20 other NIH institutes and centers supported maternal health research as well.

In its 2020 strategic plan, the National Institute of Child Health and Human Development identified maternal health as a research priority, including the development of indicators to threats to maternal health during pregnancy to help understand how pregnancy-related conditions contribute to maternal mortality and severe maternal morbidity and how they can be

¹⁵⁰ National Indian Health Board, Public Comment, December 2020, Page 2

¹⁵¹ Juanita Chinn, Program Director, Population Dynamics Branch, Division of Extramural Research, Eunice Kennedy Shriver National Institute of Child Health and Human Development, National Institutes of Health, Written Statement for the *Racial Disparities in Maternal Health Briefing* before the U.S. Comm'n on Civil Rights, Nov. 13, 2020, at 5 (hereinafter "Chinn Statement").

¹⁵² Government Accountability Office, *Trends in Pregnancy-Related Deaths and Federal Efforts to Reduce Them*, GAO-20-248, March 2020, p. 43, https://www.gao.gov/assets/710/705331.pdf.

¹⁵³ Chinn Statement, at 1.

¹⁵⁴ 42 U.S.C. § 281 (d).

¹⁵⁵ Chinn Statement, at 1.

¹⁵⁶ 42 U.S.C § 285g.

¹⁵⁷ Chinn Statement, at 1.

prevented. 158 In addition, the National Institute of Child Health and Human Development has identified health disparities as a cross-cutting issue of prioritization, noting that:

Pervasive disparities exist in the health of racial/ethnic, rural, low-resource, sexual and gender minority, and other underrepresented populations. Understanding the contribution of social, economic, structural, and regional factors is vital to advancing preventive, diagnostic, and intervention efforts. These factors are particularly important in maternal health and mortality, birth outcomes, infant mortality, child development, and exposure to trauma and injury. Improving approaches in populations that experience specific cultural, social, or access issues will be an emphasis across the research themes. 159

Some NIH-funded research projects focusing on racial disparities in maternal health include:

- A study to identify and correct problems in data collection and coding of maternal deaths, which should produce more accurate maternal mortality estimates, and ultimately provide a more accurate identification of at-risk populations and a greater understanding of racial and ethnic disparities; 160
- Continuing research to help understand the drivers of racial disparities in severe maternal morbidity, looking further than just clinical risk factors by examining social determinants of health, including hospital quality, access to quality care, culturally and linguistically appropriate services, and institutional policies and practices; ¹⁶¹
- An examination of hospital quality to understand why racial and ethnic minorities are giving birth in lower quality hospitals and hospitals with higher rates of severe maternal morbidity; 162

¹⁵⁹ Ibid., 8.

¹⁵⁸ Eunice Kennedy Shriver National Institute on Child Health and Human Development, Strategic Plan 2020, p. 19, https://www.nichd.nih.gov/sites/default/files/2019-09/NICHD Strategic Plan.pdf.

¹⁶⁰ Chinn Statement, at 3; see also NIH Reporter, "Methodological Issues in Maternal Mortality Research, https://projectreporter.nih.gov/project_info_description.cfm?aid=9789688&icde=49163138&ddparam=&ddvalue=& ddsub=&cr=2&scb=default&cs=ASC&pball=.

¹⁶¹ Chinn Statement, at 4; see also see also NIH Reporter, "Understanding Severe Maternal Morbidity: Predictors, Trends, and Disparities,"

https://projectreporter.nih.gov/project_info_description.cfm?aid=9327774&icde=49165908&ddparam=&ddvalue=& ddsub=&cr=2&scb=default&cs=ASC&pball=; Stephanie A. Leonard, PhD, Elliot K. Main, MD, Karen A. Scott, MD, MPH, Jochen Profit, MD, MPH, and Suzan L. Carmichael, PhD, "Racial and Ethnic Disparities in Severe Maternal Morbidity Prevalence and Trends," Annals of Epidemiology, Vol. 33 (May 2019): 30-36, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6502679/; Stephanie A. Leonard, PhD, Elliot K. Main, MD, and Suzan L. Carmichael, PhD, "The Contribution of Maternal Characteristics and Cesarean Delivery to an Increasing Trend of Severe Maternal Morbidity," BMC Pregnancy Childbirth, Vol. 19 (2019): 16, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6327483/.

¹⁶² Chinn Statement, at 4; see also E.A. Howell and J. Zeitlin, "Improving Hospital Quality to Reduce Disparities in Severe Maternal Morbidity and Mortality," Semin Perinatol, Vol. 41, No. 5 (August 2017): 266-272, https://www.ncbi.nlm.nih.gov/pubmed/28735811; Howell EA, Egorova NN, Janevic T, Brodman M, Balbierz A, Zeitlin J, Hebert PL, "Race and Ethnicity, Medical Insurance, and Within-Hospital Severe Maternal Morbidity Disparities," Obstetrics and Gynecology, Vol. 135, No. 2 (February 2020): 285-293, https://www.ncbi.nlm.nih.gov/pubmed/31923076.

- A study to examine factors associated with maternal mortality, such as income inequality, structural racism, residential segregation, and how state-level policies can impact incidences of maternal mortality, specifically by race and socioeconomic status; 163
- Research to examine pregnancy-associated homicide—an understudied leading cause of death during pregnancy and postpartum—exploring whether "failure to identify and address factors underlying pregnancy-associated homicide with perpetuate racial inequality in mortality during pregnancy and postpartum;" and to identify whether social contexts in which women live, such as income inequality, structural racism, community violence, and spatial social polarization, increase risk for pregnancy-associated mortality and pregnancy-associated homicide. 165

HHS' Office on Women's Health has recently engaged in a national partnership with Premier, Inc. to leverage maternal health data and performance improvement to scale advancements in care for mothers and infants across the nation. The partnership will utilize data representative of 25 percent of U.S. hospital inpatient discharges, to analyze the risk factors affecting maternal morbidity and mortality — such as racial and ethnic disparities, rising maternal age, socioeconomic factors and comorbidities. In addition, the partnership will unite a cohort of at least 200 hospitals to join a data-driven Perinatal Collaborative. Standardized, evidence-based practices and care bundles will be implemented with members of the collaborative, measuring outcomes to identify and scale the most effective practices.

Racial Disparities in Maternal Death Rates

Significant racial and ethnic disparities exist in the number of pregnancy-related deaths of women across the U.S (see Figure 1.6). ¹⁶⁶ These racial disparities have the greatest impact upon

¹⁶³ Chinn Statement, at 4.

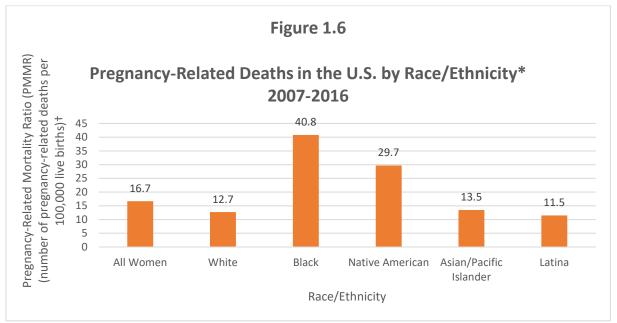
¹⁶⁴ Ibid., 5.

¹⁶⁵ Ibid., 5; see also NIH Reporter, "Pregnancy-associated mortality," <a href="https://projectreporter.nih.gov/project-info-description.cfm?aid=9770920&icde=49166161&ddparam=&ddvalue=&ddval

ddsub=&cr=2&scb=default&cs=ASC&pball=; Maeve E. Wallace, PhD; Joia Crear-Perry, MD; Pooja K. Mehta, MD; et al., "Homicide During Pregnancy and the Postpartum Period in Louisiana, 2016-2017," *JAMA Pediatr.*, Vol. 174, No. 4 (February 2020): 387-388, https://jamanetwork.com/journals/jamapediatrics/article-abstract/2760408; Maeve E. Wallace, PhD, Donna Hoyert, PhD, Corrine Williams, ScD, and Pauline Mendola, PhD, "Pregnancy-Associated Homicide and Suicide in 37 US States with Enhanced Pregnancy Surveillance," *American Journal of Obstetrics and Gynecology*, Vol. 215, No. 3 (September 2016): 364.e1-364.e10, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5003645/.

¹⁶⁶ Emily E. Petersen, MD, Nicole L. Davis, PhD, David Goodman, PhD, Shanna Cox, MSPH, Carla Syverson, MSN, Kristi Seed, Carrie Shapiro-Mendoza, PhD, William M. Callaghan, MD, Wanda Barfield, MD, "Racial/Ethnic Disparities in Pregnancy-Related Deaths — United States, 2007–2016," *Morbidity and Mortality Weekly Report*, Centers for Disease Control and Protection, Vol. 68, No. 35 (Sep. 6, 2019): 762-765, https://www.cdc.gov/mmwr/volumes/68/wr/pdfs/mm6835a3-H.pdf.

Black women and impact Black women of all ages and education levels and persist across time. 167



Source: Emily E. Petersen, MD, Nicole L. Davis, PhD, David Goodman, PhD, Shanna Cox, MSPH, Carla Syverson, MSN, Kristi Seed, Carrie Shapiro-Mendoza, PhD, William M. Callaghan, MD, Wanda Barfield, MD, "Racial/Ethnic Disparities in Pregnancy-Related Deaths — United States, 2007–2016," *Morbidity and Mortality Weekly Report*, Centers for Disease Control and Protection, Vol. 68, No. 35 (Sep. 6, 2019): 763, https://www.cdc.gov/mmwr/volumes/68/wr/pdfs/mm6835a3-H.pdf.

*Black, White, Native American, and A/PI were non-Latina; Latina women might be of any race; 25 pregnancy-related deaths with unknown race/ethnicity were included in the total analyses but not presented in an individual column.

†These numbers are reported using the CDC's definition of pregnancy-related deaths: "the death of a woman while pregnant or within [one] year of the end of a pregnancy—regardless of the outcome, duration or site of the pregnancy—from any cause related to or aggravated by the pregnancy or its management, but not from accidental or incidental causes."

During 2007-2016, the pregnancy-related mortality ratio for all U.S. women was 16.7 deaths per 100,000 live births. ¹⁶⁸ The pregnancy-related mortality ratio for White women during those years was 12.7 deaths per 100,000 live births. ¹⁶⁹ In contrast, the pregnancy-related mortality ratio for Black women during those years was 40.8 deaths per 100,000 live births, which is 3.2 times that of White women. ¹⁷⁰ The pregnancy-related mortality ratio for Native American women during that time was 29.7 deaths per 100,000 live births, which is 2.3 times that of White women. ¹⁷¹

¹⁶⁸ Ibid.

¹⁶⁷ Ibid.

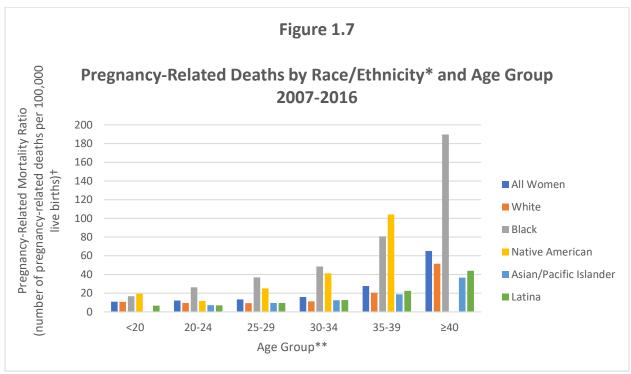
¹⁶⁹ Ibid.

¹⁷⁰ Ibid.

¹⁷¹ Ibid.

The pregnancy-related mortality ratios for Asian/Pacific Islander women and Latinas during that time were 13.5 and 11.5 deaths per 100,000 live births respectively, which was 1.1 and 0.9 times that of White women, respectively. Additionally, some studies have found greater disparities compared to White women among Latinas in certain geographic areas. 173

Figure 1.7 shows that during 2007-2016, pregnancy-related mortality ratios generally increased with maternal age across all racial and ethnic groups. As Figure 1.7 illustrates, although maternal age is increasing, the racial disparities are still apparent, especially among Black women over 40. The researchers note that there was insufficient sample size to provide estimates for Native American women over 40.



Source: Emily E. Petersen, MD, Nicole L. Davis, PhD, David Goodman, PhD, Shanna Cox, MSPH, Carla Syverson, MSN, Kristi Seed, Carrie Shapiro-Mendoza, PhD, William M. Callaghan, MD, Wanda Barfield, MD, "Racial/Ethnic Disparities in Pregnancy-Related Deaths — United States, 2007–2016," *Morbidity and Mortality Weekly Report*, Centers for Disease Control and Protection, Vol. 68, No. 35 (Sep. 6, 2019): 763, https://www.cdc.gov/mmwr/volumes/68/wr/pdfs/mm6835a3-H.pdf.

¹⁷² Ibid.

¹⁷³See, Washington State Dep't of Health, Washington State Maternal Mortality Reivew Panel: Maternal Deaths 2014-2016, (Oct. 2019) https://www.doh.wa.gov/Portals/1/Documents/Pubs/141-010-
https://www.doh.wa.gov/Portals/1/Documents/Pubs/141-01

¹⁷⁴ See supra note 101 (discussing increasing average maternal age in the U.S.).

¹⁷⁵ *Id*.

*Black, White, Native American, and A/PI were non-Latina; Latina women might be of any race; 25 pregnancy-related deaths with unknown race/ethnicity were included in the total analyses but not presented in an individual column.

**Two pregnancy-related deaths with unknown age were excluded from age analyses. Data was omitted from certain categories due to fewer than 10 deaths, potentially causing calculated ratios to be unreliable.

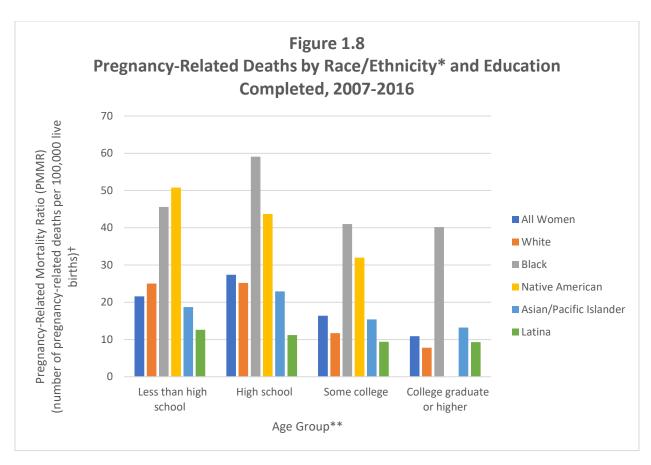
†These numbers are reported using the CDC's definition of pregnancy-related deaths: "the death of a woman while pregnant or within [one] year of the end of a pregnancy—regardless of the outcome, duration or site of the pregnancy—from any cause related to or aggravated by the pregnancy or its management, but not from accidental or incidental causes."

Examining pregnancy-related deaths among age groups, the greatest racial disparities from 2007-2016 were seen among Native American women aged 35-39, for whom the pregnancy-related mortality ratio was 5.1 times higher for Native American women than White women; followed by Black women aged 30-34, for whom the pregnancy-related mortality ratio was 4.3 times higher for Black women than White women. ¹⁷⁶

Additionally, these racial disparities persisted across all education levels; however, the sample size to provide estimates for Native American women were not sufficient at the college graduate or higher education level.

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¹⁷⁶ Emily E. Petersen, MD, Nicole L. Davis, PhD, David Goodman, PhD, Shanna Cox, MSPH, Carla Syverson, MSN, Kristi Seed, Carrie Shapiro-Mendoza, PhD, William M. Callaghan, MD, Wanda Barfield, MD, "Racial/Ethnic Disparities in Pregnancy-Related Deaths — United States, 2007–2016," *Morbidity and Mortality Weekly Report*, Centers for Disease Control and Protection, Vol. 68, No. 35 (Sep. 6, 2019): 763, https://www.cdc.gov/mmwr/volumes/68/wr/pdfs/mm6835a3-H.pdf.



Source: Emily E. Petersen, MD, Nicole L. Davis, PhD, David Goodman, PhD, Shanna Cox, MSPH, Carla Syverson, MSN, Kristi Seed, Carrie Shapiro-Mendoza, PhD, William M. Callaghan, MD, Wanda Barfield, MD, "Racial/Ethnic Disparities in Pregnancy-Related Deaths — United States, 2007–2016," *Morbidity and Mortality Weekly Report*, Centers for Disease Control and Protection, Vol. 68, No. 35 (Sep. 6, 2019): 763, https://www.cdc.gov/mmwr/volumes/68/wr/pdfs/mm6835a3-H.pdf.

*Black, White, Native American, and A/PI were non-Latina; Latina women might be of any race; 25 pregnancy-related deaths with unknown race/ethnicity were included in the total analyses but not presented in an individual column.

**687 pregnancy-related deaths with unknown educational levels were excluded from education analyses. Data was omitted from certain categories due to fewer than 10 deaths, potentially causing calculated ratios to be unreliable. †These numbers are reported using the CDC's definition of pregnancy-related deaths: "the death of a woman while pregnant or within [one] year of the end of a pregnancy—regardless of the outcome, duration or site of the pregnancy—from any cause related to or aggravated by the pregnancy or its management, but not from accidental or incidental causes."

Regarding pregnancy-related deaths broken out by education, the greatest racial disparities from 2007-2016 were found among Black women who had obtained college degrees or who had completed some college, with mortality ratios of 5.2 times and 3.5 times higher for Black women than that of White women, respectively. Researchers also noted that there was a "sizeable" disparity in the 2007-2016 pregnancy-related mortality ratio seen among Black

¹⁷⁷ Ibid.

women who had completed college degrees and White women with less than a high school diploma, where the rate was 1.6 times higher for Black women who had completed a higher level of education, which the CDC researchers posited may be due to differences in access to care, quality of care, prevalence of chronic diseases, and systemic racism in the healthcare system. ¹⁷⁸

The CDC has reported that "[c]ardiomyopathy, thrombotic pulmonary embolism, and hypertensive disorders of pregnancy contributed to a significantly higher proportion of pregnancy-related deaths among black women than among white women," and "[h]emorrhage and hypertensive disorders of pregnancy contributed to a higher proportion of pregnancy-related deaths among [Native American] women than among white women." (see Table 1.9)¹⁷⁹

Table 1.9 Cause-Specific Pregnancy-Related Death, by Race/Ethnicity, 2007-2016 (Proportionate cause of death by race/ethnicity* No. (%) attributed to each cause)

Cause of Death	White	Black	Native American	Asian/ Pacific Islander	Latina	Total Deaths
Hemorrhage	250 (9.1%)	237 (9.7%)	23 (19.7%)†	66 (19.5%) [†]	173 (15.8%) [†]	752 (11.1%)
Infection	418 (15.2%)	235 (9.7%)§	10 (8.5%)§	51 (15.0%)	183 (16.7%)	900 (13.3%)
Amniotic fluid embolism	147 (5.3%)	106 (4.4%)	3 (2.6%)	51 (15.0%) [†]	58 (5.3%)	365 (5.4%)
Thrombotic pulmonary or other embolism	246 (8.9%)	265 (10.9%) [†]	9 (7.7%)	11 (3.2%)§	88 (8.0%)	624 (9.2%)
Hypertensive disorders of pregnancy	184 (6.7%)	200 (8.2%) [†]	15 (12.8%)†	21 (6.2%)	106 (9.7%)†	528 (7.8%)
Anesthesia complications	7 (0.3%)	14 (0.6%)	0 (0.0%)	3 (0.9%)	6 (0.5%)	30 (0.4%)
Cerebrovascular accidents	207 (7.5%)	148 (6.1%)§	6 (5.1%)	37 (10.9%)†	92 (8.4%)	490 (7.2%)
Cardiomyopathy	288 (10.4%)	345 (14.2%) [†]	17 (14.5%)	21 (6.2%)§	75 (6.8%)§	748 (11.1%)
Other cardiovascular conditions	465 (16.9%)	393 (16.2%)	13 (11.1%)	38 (11.2%)§	124 (11.3%)§	1,035 (15.3%)
Other noncardiovascular medical conditions	384 (13.9%)	343 (14.1%)	16 (13.7%)	26 (7.7%)§	130 (11.9%)	903 (13.3%)

¹⁷⁸ Ibid., 763-64.

¹⁷⁹ Ibid., 763.

Cause of Death	White	Black	Native American	Asian/ Pacific Islander	Latina	Total Deaths
Unknown	160 (5.8%)	146 (6.0%)	5 (4.3%)	14 (4.1%)	61 (5.6%)	390 (5.8%)
Total	2,756	2,432	117	339	1,096	6,765

Source: Emily E. Petersen, MD, Nicole L. Davis, PhD, David Goodman, PhD, Shanna Cox, MSPH, Carla Syverson, MSN, Kristi Seed, Carrie Shapiro-Mendoza, PhD, William M. Callaghan, MD, Wanda Barfield, MD, "Racial/Ethnic Disparities in Pregnancy-Related Deaths — United States, 2007–2016," *Morbidity and Mortality Weekly Report*, Centers for Disease Control and Protection, Vol. 68, No. 35 (Sep. 6, 2019): 763, https://www.cdc.gov/mmwr/volumes/68/wr/pdfs/mm6835a3-H.pdf.

- * Black, White, Native American, and A/PI women were non-Latina; Latina women could be of any race.
- † Significantly higher proportion of pregnancy-related deaths compared with that among White women, p<0.05.
- § Significantly lower proportion of pregnancy-related deaths compared with that among White women, p<0.05.
- ¶ Twenty-five pregnancy-related deaths with unknown race/ethnicity were included in the total but not elsewhere in the table.

Additionally, Asian/Pacific Islander women and Latinas experience a higher proportion of pregnancy-related deaths due to hemorrhages than White women, and Latinas experience a higher proportion of pregnancy-related deaths due to hypertensive disorders of pregnancy than White women. Cardiovascular conditions are the leading cause of pregnancy-related death for both Black and White women; hemorrhage is the leading cause of pregnancy-related death for both Native American women and Asian/Pacific Islander women; and infection is the leading cause of pregnancy-related death for Latinas. ¹⁸⁰

Research has shown that the timing of death among Black and White women did not significantly differ for most periods of time in the pregnancy to post-partum spectrum, with the exception of the period between 43-365 days postpartum (known as the late postpartum period), wherein Black women had a greater proportion of deaths at 14.9 percent compared to 10.2 percent of deaths of White women. ¹⁸¹ The greater proportion of deaths of Black women during the late postpartum period can be attributed to a higher proportion of pregnancy-related deaths of Black women due to cardiomyopathy, ¹⁸² which is a disease of the heart muscle that makes it

¹⁸⁰ U.S. Government Accountability Office, *Maternal Mortality: Trends in Pregnancy-Related Deaths and Federal Efforts to Reduce Them*, GAO-20-248, March 2020, p. 16, https://www.gao.gov/assets/710/705331.pdf.

¹⁸¹ Emily E. Petersen, Nicole L. Davis, David Goodman, Shanna Cox, Nikki Mayes,, Emily Johnston, Carla Syverson, Kristi Seed,, Carrie K. Shapiro-Mendoza, William M. Callaghan, Wanda Barfield, "Vital Signs: Pregnancy-Related Deaths, United States, 2011–2015, and Strategies for Prevention, 13 States, 2013–2017," *Morbidity and Mortality Weekly Report*, Centers for Disease Control and Protection, Vol. 68, No. 18 (May 10, 2019): 425, https://www.cdc.gov/mmwr/volumes/68/wr/pdfs/mm6818e1-H.pdf.

¹⁸² Ibid., 426.

more difficult for the heart to pump blood to the rest of the body. ¹⁸³ Cardiomyopathy is the most common cause of death for all women during the late postpartum period. ¹⁸⁴

For each maternal death, nearly 100 women have experienced severe maternal morbidity, ¹⁸⁵ and those rates are higher for women of color. ¹⁸⁶ Studies report severe maternal morbidity at more than 2 times higher for Black women, ¹⁸⁷ and at nearly 2 times higher for Native American women compared to White women. ¹⁸⁸ The National Indian Health Board noted in a letter to the Commission that "[t]he underfunding of [the Indian Health Service] also affects prenatal care, a vital service that helps to reduce maternal death and morbidity." ¹⁸⁹ Furthermore, the National Indian Health Board explained in its letter to the Commission how the "urbanization of the US medical system" has a disproportionate impact on Native Indian and Native Alaskan women, as 40 percent of all Native Indian and Native Alaskan people live in rural areas. ¹⁹⁰ A study conducted in New York City found that maternal morbidity was 2 times higher for Latinas compared to White women. ¹⁹¹ Black women are more likely to experience comorbid illnesses

¹⁸³ Mayo Clinic, "Cardiomyopathy," https://www.mayoclinic.org/diseases-conditions/cardiomyopathy/symptoms-causes/syc-20370709 (last accessed Sept. 11, 2020).

¹⁸⁴ Emily E. Petersen, Nicole L. Davis, David Goodman, Shanna Cox, Nikki Mayes,, Emily Johnston, Carla Syverson, Kristi Seed,, Carrie K. Shapiro-Mendoza, William M. Callaghan, Wanda Barfield, "Vital Signs: Pregnancy-Related Deaths, United States, 2011–2015, and Strategies for Prevention, 13 States, 2013–2017," *Morbidity and Mortality Weekly Report*, Centers for Disease Control and Protection, Vol. 68, No. 18 (May 10, 2019): 426, https://www.cdc.gov/mmwr/volumes/68/wr/pdfs/mm6818e1-H.pdf.

¹⁸⁵ Centers for Disease Control and Prevention, "Severe Maternal Morbidity in the United States," https://www.cdc.gov/reproductivehealth/maternalinfanthealth/severematernalmorbidity.html; Elizabeth A. Howell, MD, MPP, Professor of Population Health Science & Policy and Obstetrics, Gynecology, and Reproductive Science, Director of the Blavatnik Family Women's Health Research Institute, Ichan School of Medicine at Mt. Siani, Written Statement for the Racial Disparities in Maternal Health Briefing before the U.S. Commission on Civil Rights, Nov. 13, 2020, at 1 (hereinafter "Howell Statement").

¹⁸⁶ Howell Statement, at 1.

¹⁸⁷ Andreea A. Creanga, MD, PhD; Brian T. Bateman, MD, MSc; Elena V. Kuklina, MD, PhD;

William M. Callaghan, MD, MPH, "Racial and ethnic disparities in severe maternal morbidity: a multistate analysis, 2008-2010," *American Journal of Obstetrics & Gynecology*, Vol. 210, No. 5 (May 2014): 435e1, https://www.ajog.org/action/showPdf?pii=S0002-9378%2813%2902153-4; Elizabeth A. Howell, MD, MPP, Natalia Egorova, PhD, MPH, Amy Balbierz, MPH, Jennifer Zeitlin, DSc, MA, and Paul L. Hebert, PhD, "Site of Delivery Contribution to Black-White Severe Maternal Morbidity Disparity," *American Journal of Obstetrics & Gynecology*, Vol. 215, No. 2 (August 2016): 143-152: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4967380/.

¹⁸⁸ Andreea A. Creanga, MD, PhD; Brian T. Bateman, MD, MSc; Elena V. Kuklina, MD, PhD;

William M. Callaghan, MD, MPH, "Racial and ethnic disparities in severe maternal morbidity: a multistate analysis, 2008-2010," *American Journal of Obstetrics & Gynecology*, Vol. 210, No. 5 (May 2014): 435e1, https://www.ajog.org/action/showPdf?pii=S0002-9378%2813%2902153-4.

¹⁸⁹ National Indian Health Board, Public Comment for the *Racial Disparities in Maternal Mortality Briefing* before the U.S. Comm'n on Civil Rights, Dec. 13, 2020, p. 3. ¹⁹⁰ Ibid.

¹⁹¹ Elizabeth A. Howell, MD, MPP, Natalia N. Egorova, PhD, MPH, Teresa Janevic, PhD, MPH, Amy Balbierz, MPH, Jennifer Zeitlin, DSc, MA, and Paul L. Hebert, PhD, "Severe Maternal Morbidity Among Hispanic Women in New York City: Investigation of Health Disparities," *American Journal of Obstetrics & Gynecology*, Vol. 139, No. 2 (February 2017): 285-294, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5380443/. This study also reports that

and pregnancy complications than White women, with higher rates of specific types of hemorrhage, preeclampsia, pregnancy-induced and chronic hypertension, asthma, placental disorders, gestational diabetes, preexisting diabetes, and blood disorders. Women of color, especially Black women, who "develop these conditions at earlier ages, are less likely to have their conditions adequately managed, and more likely to have complications and mortality from these conditions." ¹⁹³

Hispanic women in New York City deliver in higher risk-adjusted severe maternal morbidity hospitals than non-Hispanic white women and suggests that the differences in site of care might contribute to the disparities found.

192 Elizabeth A. Howell, MD, MPP, "Reducing Disparities in Severe Maternal Mortality and Morbidity," *Obstet Gynecol*, Vol. 61, No. 2 (June 2018): 4, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5915910/; Berg, Cynthia J., et al. "Pregnancy-related mortality in the United States, 1991–1997." *Obstetrics & Gynecology*, Vol; 101, No. 2 (2003): 289-296; Howell EA, Egorova NN, Balbierz A, Zeitlin J, Hebert PL. Site of delivery contribution to blackwhite severe maternal morbidity disparity. Am J Obstet Gynecol. 2016 Aug;215(2):143–152; Rathore SS, McMahon MJ. Racial variation in the frequency of intrapartum hemorrhage. Obstet Gynecol. 2001 Feb;97(2):178–183; Bryant AS, Seely EW, Cohen A, Lieberman E. Patterns of pregnancy-related hypertension in black and white women. Hypertens Pregnancy. 2005;24(3):281–290; Carroll KN, Griffin MR, Gebretsadik T, Shintani A, Mitchel E, Hartert TV. Racial differences in asthma morbidity during pregnancy. Obstet Gynecol. 2005 Jul;106(1):66–72; Howell EA, Egorova N, Balbierz A, Zeitlin J, Hebert PL. Black-white differences in severe maternal morbidity and site of care. Am J Obstet Gynecol. 2016;214(1): 122.e121–122.e127.

¹⁹³ Elizabeth A. Howell, MD, MPP, "Reducing Disparities in Severe Maternal Mortality and Morbidity," *Obstet Gynecol*, Vol. 61, No. 2 (June 2018): 4, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5915910/; Beckie TM. Ethnic and racial disparities in hypertension management among women. Semin Perinatol. 2017 Jun 7.

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CHAPTER 2: UNDERSTANDING RACIAL DISPARITIES IN MATERNAL HEALTH, MORBIDITY, AND MORTALITY

As discussed in Chapter 1, overall maternal mortality rates in the United States have worsened during the past 30 years. ¹⁹⁴ A recurring theme in testimony to the Commission emphasized that the causes of racial disparities in maternal mortality in the United States are varied and are not all directly related to the healthcare system. Jonathan Webb, CEO of the Association of Maternal & Child Health Programs provided written testimony to the Commission stating:

[F]or decades, we have looked at race as a factor in determining or predicting potential health outcomes. More recently, research demonstrates that racism and not race is the actual risk factor. The public health community's response to addressing inequities has evolved over time. Several decades ago, we began with looking at the social determinants of health (SDOH) –the conditions in the places where people live, learn, work, and play that have an effect on a wide range of health, quality-of life-risks and outcomes. ¹⁹⁵

Dr. Ndidiamaka Amutah-Onukagha, Associate Professor in the Department of Public Health and Community Medicine at Tufts University School of Medicine, similarly testified to the Commission about "how racism is embedded in the healthcare system" writing: "[w]hile we may not yet know the exact and precise causes of death, we can determine without a doubt that social determinants of health are important proximal causes of maternal mortality." ¹⁹⁶

The Commission received testimony from Shanna Cox of the Centers for Disease Control and Prevention that some of the drivers of these disparities include variation in hospital quality, underlying chronic conditions, access to risk appropriate/quality care, and the impacts of structural racism and implicit bias on health. At this time, research indicates that there are many complex factors that create and perpetuate racial disparities in maternal health. See Cox

¹⁹⁴ Cox Statement, at 1-2; *see also*, Centers for Disease Control and Prevention, *Pregnancy Mortality Surveillance System*, https://www.cdc.gov/reproductivehealth/maternal-mortality/pregnancy-mortality-surveillance-system.htm? Fyregnancy-mortality-surveillance-system.htm#trends (last accessed Dec. 14, 2020).

¹⁹⁵ Jonathan Webb, Chief Executive Officer, Association of Maternal & Child Health Programs, Written Statement for the Racial Disparities in Maternal Health Briefing before the U.S. Comm'n on Civil Rights, Nov. 13, 2020, at 2 (hereinafter "Webb Statement").

¹⁹⁶ Ndidiamaka Amutah-Onukagha, Ph.D., M.P.H., Associate Professor of Public Health and Community Medicine, Tufts University School of Medicine, Written Statement for the Racial Disparities in Maternal Health Briefing before the U.S. Comm'n on Civil Rights, Nov. 13, 2020, at 1-2 (hereinafter "Amutah-Onukagha Statement") (emphasis in original).

¹⁹⁷ Cox Statement, at 4-5.

¹⁹⁸ Ibid., 4; Allison S. Bryant, Ayaba Worjoloh, Aaron B. Caughey, and A. Eugene Washington, "Racial/Ethnic Disparities in Obstetrical Outcomes and Care: Prevalence and Determinants," *American Journal of Obstetrics & Gynecology*, Vol. 202, No. 4 (April 2010): 335-343, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2847630/; Alexis Gadson, MD, Eloho Akpovi, BS, Pooja K. Mehta, MD, MSHP, "Exploring the social determinants of

added that as data collection surrounding this issue improves, data should shed more light on the drivers of racial disparities in maternal mortality and morbidity. 199

Despite the need for more comprehensive and robust data collection on maternal health outcomes, data show that racial disparities in maternal health outcomes have persisted over time. 200 For instance, 2016 CDC data tracking on pregnancy-related deaths showed Black women in the U.S. died from health disparities between 3 to 4 times the rate of White women in the U.S.; and Native American women in the U.S. died at a rate between 2 to 3 times that of White women in the U.S., and these disparities persisted among women with higher levels of education. 201 This rate, however, varied regionally. In New York City, for example, Black women were 12 times more likely to die from pregnancy-related causes than White women; Asian/Pacific Islander women were over 4 times as likely, and Latinas were over 3 times as likely to die from pregnancy-related causes compared with White women. 202 The rates at which women of color experience severe maternal morbidity (based on the CDC's defined indicators such as eclampsia, heart failure, aneurysm, and other conditions occurring during labor and delivery) 203 are also higher than those of White women, with Black and Native American women

racial/ethnic disparities in prenatal care utilization and maternal outcome," *Seminars in Perinatology*, Vol. 41, No. 5 (August 2017): 308-317, https://www.sciencedirect.com/science/article/abs/pii/S0146000517300502?via%3Dihub; Louisiana Department of Health, *Louisiana Maternal Mortality Review Report: 2011-2016*, August 2018, 22, http://ldh.la.gov/assets/oph/Center-PHCH/Center-PH/maternal/2011-2016 MMR Report FINAL.pdf.

There are three commonly used measures of maternal deaths in the United States. While they all capture some aspect of maternal deaths, they are not equivalent.

Pregnancy-associated death: Death while pregnant or within one year of the end of the pregnancy, irrespective of cause.

Pregnancy-related death: Death during pregnancy or within one year of the end of pregnancy from a pregnancy complication, a chain of events initiated by pregnancy, or the aggravation of an unrelated condition by the physiologic effects of pregnancy. Used in the U.S. only, this CDC measure is typically reported as a ratio per 100,000 births.

¹⁹⁹ Ibid., 4.

²⁰⁰ Cox Statement at 1-2; see also, Leone Statement at 1, 3.

²⁰¹ See supra notes 72; 166-176 and Figure 1.6; see also, Centers for Disease Control and Prevention, Racial and Ethnic Disparities Continue in Pregnancy-Related Deaths, (Sept. 5, 2019) https://www.cdc.gov/media/releases/2019/p0905-racial-ethnic-disparities-pregnancy-deaths.html (last accessed Feb. 22, 2021).

²⁰² New York City Department of Health and Mental Hygiene, Bureau of Maternal, Infant and Reproductive Health, *Pregnancy-Associated Mortality: New York City, 2006-2010*, p. 5, https://wwwl.nyc.gov/assets/doh/downloads/pdf/ms/pregnancy-associated-mortality-report.pdf.

²⁰³ The Centers for Disease Control and Prevention defines "severe maternal morbidity" as "unexpected outcomes of labor and delivery that result in significant short- or long-term consequences to a woman's health." *See*, Centers for Disease Control and Prevention, *Severe Maternal Morbidity in the United States*, https://www.cdc.gov/reproductivehealth/maternalinfanthealth/severematernalmorbidity.html#anchor_References (last accessed Dec. 14, 2020); *see also*, Roosa Tikkanen, Munira Z. Gunja, Molly FitzGerald, and Laurie Zephyrin, *Maternal Mortality and Maternity Care in the United States Compared to 10 Other Developed Countries*, THE COMMONWEALTH FUND, (Nov. 18, 2020) https://www.commonwealthfund.org/publications/issue-briefs/2020/nov/maternal-mortality-maternity-care-us-compared-10-countries.

in the U.S. experiencing severe maternal morbidity at approximately double the rate of White women in the U.S..²⁰⁴ Research has shown that approximately 66 percent of pregnancy-related deaths are preventable,²⁰⁵ with some research showing that these events are more preventable in women of color by reducing gaps in access and quality of care for pregnant women of color.²⁰⁶ But overall, data continues to show that women of color are dying at staggering rates compared to White women.²⁰⁷

Dr. Elizabeth Howell, Chair of the Department of Obstetrics and Gynecology at the Perelman School of Medicine at the University of Pennsylvania testified to the Commission that:

By quality of care, I am referring to the care we provide to women before, during, and after pregnancy. I'm not just referring to the care provided by physicians and nurses – their communication skills, their knowledge and decision-making, and their ability to deliver care without bias, I am also talking about the systems in place that make it possible – or difficult—for women to receive evidence-based care—coverage, hospital system policies and practices, resources, staffing, and more. ²⁰⁸

Howell continued, "Black women tend [to] deliver in specific hospitals and those hospitals have worse outcomes for both Black and White pregnant women regardless of patient risk factors." ²⁰⁹

Maternal mortality: Death while pregnant or within 42 days of the end of pregnancy, irrespective of the duration and site of the pregnancy, from any cause related to or aggravated by the pregnancy or its management, but not from accidental or incidental causes. Used by the World Health Organization (WHO) in international comparisons, this measure is reported as a ratio per 100,000 births.

See also, Centers for Disease Control and Prevention, How Does CDC Identify Severe Maternal Morbidity?, https://www.cdc.gov/reproductivehealth/maternalinfanthealth/smm/severe-morbidity-ICD.htm (last accessed Jan. 11, 2021).

Disparities in Pregnancy-Related Deaths — United States, 2007–2016," *Morbidity and Mortality Weekly Report*, Centers for Disease Control and Protection, Vol. 68, No. 35 (Sep. 6, 2019): 762-765,

 $\underline{https://www.cdc.gov/mmwr/volumes/68/wr/pdfs/mm6835a3-H.pdf}.$

²⁰⁴ See supra notes 186-191.

²⁰⁵ Centers for Disease Control and Prevention, "Pregnancy-Related Deaths: Data from 14 U.S. Maternal Mortality Review Committees, 2008-2017," https://www.cdc.gov/reproductivehealth/maternal-mortality/erase-mm/mmr-data-brief.html; Emily E. Petersen, MD; Nicole L. Davis, PhD; David Goodman, PhD; Shanna Cox, MSPH; Nikki Mayes; Emily Johnston, MPH; Carla Syverson, MSN; Kristi Seed; Carrie K. Shapiro-Mendoza, PhD; William M. Callaghan, MD; Wanda Barfield, MD, "Vital Signs: Pregnancy-Related Deaths, United States, 2011–2015, and Strategies for Prevention, 13 States, 2013–2017," *Morbidity and Mortality Weekly Report*, Centers for Disease Control and Protection, Vol. 68, No. 18 (May 10, 2019): 423, https://www.cdc.gov/mmwr/volumes/68/wr/pdfs/mm6818e1-H.pdf.

²⁰⁶ Mehta, Pooja K. MD, MSHP; Kieltyka, Lyn PhD, MPH; Bachhuber, Marcus A. MD, MSHP; Smiles, Dana MPH, MA; Wallace, Maeve PhD, MPH; Zapata, Amy MPH; Gee, Rebekah E. MD, MPH, "Racial Inequities in Preventable Pregnancy-Related Deaths in Louisiana, 2011–2016," *Obstetrics and Gynecology*, Vol. 135, No. 2 (February 2020): 276-283, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7299502/; Howell Statement, 1.

²⁰⁷ Emily E. Petersen, MD, Nicole L. Davis, PhD, David Goodman, PhD, Shanna Cox, MSPH, Carla Syverson, MSN, Kristi Seed, Carrie Shapiro-Mendoza, PhD, William M. Callaghan, MD, Wanda Barfield, MD, "Racial/Ethnic Disposition in Programs of Page 1981 and Page 1981 and

²⁰⁸ Howell Statement at 1-2.

²⁰⁹ Ibid., 2.

Factors Impacting Racial Disparities in Maternal Health

As discussed above, there are range of factors contributing to racial disparities in maternal health and heightening the understanding and increasing focus on the nature and contributing role/s of each is essential. These factors include the social determinants of health, equal access and quality to care, and bias and implicit bias in the healthcare system.

Social Determinants of Health and Maternal Health Outcomes

While health outcomes are influenced by a number of factors, research has shown that health behaviors (e.g., smoking, diet, and exercise) and social/environmental factors (e.g., access to/quality of education, healthcare, housing, work, transportation, etc.) have the biggest impact upon health outcomes. State-based research shows a connection between social determinants of health and location, and women who live in areas or neighborhoods without access to reliable transportation, healthy and affordable groceries, and safe public spaces for recreation and fitness are more likely to suffer from poor maternal health outcomes than women who live in areas with access to these resources. Additionally, analysis of county-level data collected by the CDC shows residential racial segregation of Black Americans has historically been one of the leading causes of U.S. racial socioeconomic inequality, and played a significant role in perpetuating racial disparities in health.

The Centers for Disease Control and Prevention states that inequities in the social determinants of health, such as poverty and healthcare access, affect ethnic and racial minority groups and

²¹⁰ Ibid.; *See also* Gopal K. Singh, Mohammad Siahpush, and Michael D. Kogan, "Neighborhood Socioeconomic Conditions, Built Environments, and Childhood Obesity," Health Affairs 29, no. 3 (March 2010):503-512, doi: 10.1377/hlthaff.2009.0730; Vincent J. Felitti et al., "Relationship of Childhood Abuse and Household Dysfunction to Many of the Leading Causes of Death in Adults: The Adverse Childhood Experiences (ACE) Study," American Journal of Preventive Medicine 14, no. 4 (May 1998): 245–258; Raj Chetty et al., "Where is the Land of Opportunity? The Geography of Intergenerational Mobility in the United States," The Quarterly Journal of Economics 129, no. 4 (Sept. 14, 2014): 1553-1623, doi: 10.1093/qje/qju022.

²¹¹ Review to Action, *Building U.S. Capacity to Review and Prevent Maternal Deaths: A Report from Nine Maternal Mortality Review Committees*, 2018, p. 47, https://www.cdcfoundation.org/sites/default/files/files/ReportfromNineMMRCs.pdf.

²¹² Ioana Popescu, Erin Duffy, Joshua Mendelsohn, and José J. Escarce, "Racial residential segregation, socioeconomic disparities, and the White-Black survival gap," *PLoS ONE*, Vol. 13 No. 2 (Feb. 23, 2018) https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0193222; David R. Williams and Pamela Braboy Jackson, "Social Sources Of Racial Disparities In Health," *Health Affairs*, Vol. 24, No. 2, (March/April 2005), https://www.healthaffairs.org/doi/full/10.1377/hlthaff.24.2.325; David R. Williams, Ph.D., M.P.H., and Chiquita Collins, Ph.D., "Racial Residential Segregation: A Fundamental Cause of Racial Disparities in Health," *Public Health Reports*, Vol. 116 No. 5, 404-16 (Sep./Oct. 2001) https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1497358/pdf/12042604.pdf.

influence a wide range of health and quality-of-life outcomes and risks.²¹³ According to the federal Office of Disease Prevention and Health Promotion of the Department of Health and Human Services as well as extensive public health research, addressing social determinants of health is necessary for improving health and reducing health disparities,²¹⁴ including racial disparities in maternal health.²¹⁵ The Office of Disease Prevention and Health Promotion houses HealthyPeople.gov, an extensive public health initiative that they describe as follows:

Healthy People identifies public health priorities to help individuals, organizations, and communities across the United States improve health and well-being. Healthy People 2030, the initiative's fifth iteration, builds on knowledge gained over the first 4 decades. ²¹⁶

HealthyPeople.gov defines social determinants of health as "conditions in the environments in which people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks." These social, economic, and physical "conditions" (also referred to as "place") affect people's patterns of social engagement and their sense of security and well-being. Access to resources such as affordable housing, quality education, public safety, availability of healthy foods, local emergency/health services, and a healthy environment can all have a significant impact on health outcomes. ²¹⁹

According to the National Academies of Science, Engineering, and Medicine, it is important to acknowledge that race and ethnicity are salient factors when examining health inequity:

Race and ethnicity are socially constructed categories that have tangible effects on the lives of individuals who are defined by how one perceives one's self and how one is perceived by others. It is important to acknowledge the social construction (i.e., created

²¹³ Centers for Disease Control and Prevention, Coronavirus Disease 2019 (COVID-19), Health Equity Considerations and Racial and Ethnic Minority Groups, updated July 24, 2020, https://www.cdc.gov/coronavirus/2019-ncov/community/health-equity/race-ethnicity.html.

²¹⁴ Office of Disease Prevention and Health Promotion, HealthyPeople.gov, "Social Determinants of Health," https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-of-health, (last accessed Apr. 5, 2021); Samantha Artiga and Elizabeth Hinton, "Issue Brief: Beyond Health Care: The Role of Social Determinants in Promoting Health and Health Equity," Henry J. Kaiser Foundation, May 10, 2018, p. 2, https://www.kff.org/disparities-policy/issue-brief/beyond-health-care-the-role-of-social-determinants-in-promoting-health-and-health-equity/.

²¹⁵ Office of Disease Prevention and Health Promotion, HealthyPeople.gov, "Discrimination," https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-health/interventions-resources/discrimination, (last accessed Apr. 5, 2021).

²¹⁶ U.S. Dep't of Health and Human Services, "About Healthy People 2030" https://health.gov/healthypeople/about, (last accessed Apr. 5, 2021).

²¹⁷ Office of Disease Prevention and Health Promotion, HealthyPeople.gov, "Social Determinants of Health," https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-of-health;; see infra notes.

²¹⁸ Ibid.

²¹⁹ Ibid.

from prevailing social perceptions, historical policies, and practices) of the concepts of race and ethnicity because it has implications for how measures of race have been used and changed over time. Furthermore, the concept of race is complex, with a rich history of scientific and philosophical debate as to the nature of race. Racial and ethnic disparities are arguably the most obstinate inequities in health over time, despite the many strides that have been made to improve health in the United States. Moreover, race and ethnicity are extremely salient factors when examining health inequity. Therefore, solutions for health equity need to take into account the social, political, and historical context of race and ethnicity in this country. ²²⁰

The American College of Obstetricians and Gynecologists also submitted testimony on this point to the Commission, writing:

It is well established, and [the American College of Obstetricians and Gynecologists'] guidance affirms that, social determinants of health, including systemic racism, are responsible for a large proportion of health inequities that exist in the U.S. It is estimated that social and structural factors account for more than one-third of total deaths in the U.S. per year, and evidence suggests that addressing social needs of individuals' results in improve overall health.²²¹

In a public comment submitted to the Commission, the National Women's Law Center wrote that higher quality care is the solution to racial disparities and the "[d]iscrimination and bias [that] manifest at every point in our healthcare system" results in preventable pregnancy-related deaths. The Colorado Advisory to the Commission described the connection between socioeconomic disadvantage and higher maternal mortality statewide, stating, "[P]eople who earn less than \$15,000 per year constitute forty-five percent of maternal death in Colorado while being only twenty-six percent of the population. This could be due to a lack of access to care due to high costs or other overlapping factors. ²²³"

The Henry J. Kaiser Family Foundation used the following framework in a recent report for understanding social determinants of health (See Table 2.1):

²²² Dorianne G. Mason, Director of Health Equity, National Women's Law Center, Public Comment for the *Racial Disparities in Maternal Health Briefing* before the U.S. Comm'n on Civil Rights, Dec. 14, 2021, p. 2.

²²⁰ The National Academies of Sciences, Engineering, and Medicine, *Communities in Action: Pathways to Health Equity*, Washington, DC: The National Academies Press, p. 58, https://www.ncbi.nlm.nih.gov/books/NBK425848/pdf/Bookshelf NBK425848.pdf.

²²¹ American College of Obstetricians and Gynecologists, Public Comment, pp. 6-7.

²²³ Advisory Memorandum on Maternal Mortality and Fetal/Infant Mortality, Colorado Advisory Committee to the U.S. Commission on Civil Rights, September 22, 2020, at 3, https://www.usccr.gov/files/2020-10-05-CO-Advisory-Memorandum-Maternal-Mortality-and-Fetal-Infant-Mortality.pdf.

Economic Neighborhood Education Food Community **Health Care** and Physical **Stability** and Social System **Environment** Context Literacy Social **Employment** Housing Hunger Health integration coverage Transportation Provider Income Language Access Support systems availability to healthy options **Expenses** Safety Early Community Provider childhood engagement linguistic and education cultural competency Debt Parks Vocational Discrimination Quality of care training Medical Bills **Playgrounds** Stress Higher Education Support Walkability Zip code/geography

Table 2.1 Social Determinants of Health

Source: Samantha Artiga and Elizabeth Hinton, "Issue Brief: Beyond Health Care: The Role of Social Determinants in Promoting Health and Health Equity," Henry J. Kaiser Foundation, May 10, 2018, p. 2, https://www.kff.org/disparities-policy/issue-brief/beyond-health-care-the-role-of-social-determinants-in-promotinghealth-and-health-equity/. Information adapted by the Commission.

In the U.S., many racial disparities in health can be linked to disparities in socioeconomic disadvantage.²²⁴ These systemic obstacles correlate with data showing that Black women face the highest risk of poor maternal health outcomes compared with any other racial or ethnic group.²²⁵ For example, nearly half of all Black women grow up in households that are in the bottom fifth of the income distribution as compared to 14 percent of White women, and approximately 35 percent of Black women remain in the bottom fifth of the income distribution as individual adults as compared to 29 percent of White women.²²⁶ These socioeconomic differences can also lead to disparities in health outcomes of women of color. Overall, people of color are more likely to suffer from a chronic disease than the general population, with Black

²²⁴ Center for Reproductive Rights, "Research Overview of Maternal Mortality and Morbidity in the United States,"

https://www.reproductiverights.org/sites/crr.civicactions.net/files/documents/USPA MH TO ResearchBrief Final 5.16.pdf.

²²⁵ Ibid., 2.

²²⁶ Scott Winship, Richard V. Reeves, and Katherine Guyot, "The inheritance of black poverty: It's all about the men," Brookings, Mar. 22, 2018, https://www.brookings.edu/research/the-inheritance-of-black-poverty-its-all-aboutthe-men/.

individuals experiencing the largest disparity with 48 percent of adults reporting chronic illness as compared to 39 percent of the overall population of the U.S.²²⁷ CDC studies have found that chronic disease may be a contributing factor to maternal mortality,²²⁸ and some chronic illnesses that can lead to pregnancy complications are more prevalent among people of color. For example, Native Americans are more than twice as likely and Black people are nearly 1.5 times as likely to have diabetes as White individuals, which can increase risk of maternal mortality.²²⁹

Additionally, data show that Black women experience infertility, unintended pregnancy, preterm birth, and fetal death at a higher rate than other women of all races and ethnicities (see Table 2.2).²³⁰ Rates of preterm birth are elevated for Native American and Latinas as compared to White women, and rates of unintended pregnancy are elevated for Latinas as compared to White women.²³¹ Noting the racial disparity of unintended pregnancy rates for Black and Latina women as compared to White women, there is a link between unintended pregnancies and adverse perinatal outcomes, including maternal depression (although a link between unintended pregnancies and severe maternal morbidity needs further study).²³²

Table 2.2 Select Examples of Disparities in Obstetric and Gynecological Health

Disparities in Health Outcomes	Native American	Asian	Black	Latina	White
Infertility in the past 12 mos (% of women)	N/A	10	12	9	7
Unintended pregnancy (% of pregnancies)	N/A	N/A	69	56	42

²²⁷ "Health Disparities: A Case for Closing the Gap," HealthReform.gov, *1, https://smhs.gwu.edu/rodhaminstitute/sites/rodhaminstitute/files/HCReform%20-%20Disparities%20Report.pdf.

 $\underline{https://www.cdc.gov/reproductive health/maternal infanthealth/severe maternal morbidity.html \#anchor_References}$

²²⁸ Please reference notes 5 and 6 and corresponding text:

²²⁹ Ibid., 17; *see*, Cheryl L Robbins, Lauren B Zapata, Sherry L Farr, Charlan D Kroelinger, Brian Morrow, Indu Ahluwalia, Denise V D'Angelo, Danielle Barradas, Shanna Cox, David Goodman, Letitia Williams, Violanda Grigorescu, and Wanda D Barfield, "Core state preconception health indicators - pregnancy risk assessment monitoring system and behavioral risk factor surveillance system, 2009," *MMWR Surveill Summ*. Vol. 25, No. 63, (Apr. 2014) https://pubmed.ncbi.nlm.nih.gov/24759729/.

²³⁰ The American College of Obstetricians and Gynecologists, "Racial and Ethnic Disparities in Obstetrics and Gynecology," Committee Opinion No. 649, December 2015 (reaffirmed 2018), p. 2, https://www.acog.org/-media/project/acog/acogorg/clinical/files/committee-opinion/articles/2015/12/racial-and-ethnic-disparities-in-obstetrics-and-gynecology.pdf.

²³¹ Kramer MR, Strahan AE, Preslar J, Zaharatos J, St Pierre A, Grant JE, Davis NL, Goodman DA, Callaghan WM. Changing the conversation: applying a health equity framework to maternal mortality reviews. Am J Obstet Gynecol. 2019 Dec;221(6):609.e1-609.e9. doi: 10.1016/j.ajog.2019.08.057. Epub 2019 Sep 6. PMID: 31499056..

²³² Elizabeth A. Howell, MD, MPP, "Reducing Disparities in Severe Maternal Mortality and Morbidity," *Obstet Gynecol*, Vol. 61, No. 2 (June 2018): 4, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5915910/; Abajobir AA, Maravilla JC, Alati R, Najman JM. A systematic review and meta-analysis of the association between unintended pregnancy and perinatal depression. Journal of Affective Disorders. 2016 Mar 01;192:56–63.

Preterm birth (% of live births)	13	10	17	12	10
Fetal death (/1000 live births + fetal deaths)	N/A	N/A	11	5	5

Source: The American College of Obstetricians and Gynecologists, "Racial and Ethnic Disparities in Obstetrics and Gynecology," Committee Opinion No. 649, December 2015 (reaffirmed 2018), p. 2, https://www.acog.org/-/media/project/acog/acogorg/clinical/files/committee-opinion/articles/2015/12/racial-and-ethnic-disparities-in-obstetrics-and-gynecology.pdf.

Disparities in the exposure to stress over time may also contribute to chronic health problems that can impact health during pregnancy.²³³ Recent research by the American Psychiatric Association (APA) found that there are significant racial and socioeconomic disparities in self-reported stress, where Black and Latinx individuals report higher levels of stress than White respondents.²³⁴ There are also disparities in exposure to threats to safety and financial security, for example, violence and barriers to occupational advancement.²³⁵ Furthermore, there are disparities in access to resources (personal, social, educational, and material), and "[w]ithout sufficient resources, even minor demands are stressful."²³⁶ The APA also found that racial/ethnic minorities also report higher exposure to discrimination, which "compounds these effects by increasing threat exposure and creating barriers to the development of the resources needed to respond to these threats."²³⁷

Access and Quality of Care

Well-documented evidence from the federal government and other sources such as the American Medical Association indicates that people of color have reduced access to quality health care services. ²³⁸ In their 2018 *National Healthcare Quality and Disparities Report*, the Department of

²³³ American Psychological Association, Stress and Health Disparities: Contexts, Mechanisms, and Interventions Among Racial/Ethnic Minority and Low Socioeconomic Status Populations, 2017, p. 1, https://www.apa.org/pi/health-disparities/resources/stress-report.pdf.

²³⁴ Ibid.

²³⁵ Ibid.

²³⁶ Ibid.

²³⁷ Ibid.

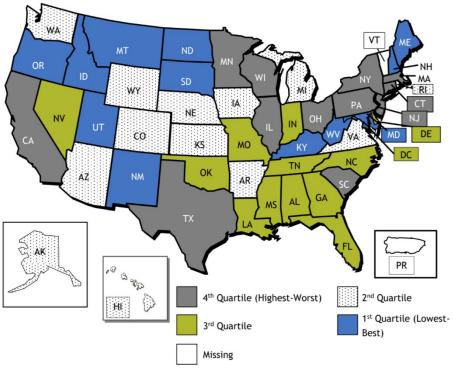
²³⁸ U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality, *National Healthcare Quality and Disparities Report 2018*, September 2019,

https://www.ahrq.gov/sites/default/files/wysiwyg/research/findings/nhqrdr/2018qdr-final.pdf; E. Richard Brown, PhD, Victoria D. Ojeda, MPH, Roberta Wyn, PhD, Rebecka Levan, MPH, Racial and Ethnic Disparities in Access to Health Insurance and Health Care, UCLA Center for Health Policy Research and the Henry J. Kaiser Family Foundation, April 2000, p. xi, https://www.kff.org/wp-content/uploads/2013/01/racial-and-ethnic-disparities-in-access-to-health-insurance-and-health-care-report.pdf; American College of Physicians, Position Paper: Racial and Ethnic Disparities in Health Care, April 2010, pp. 1-2,

https://www.acponline.org/acp_policy/policies/racial_ethnic_disparities_2010.pdf; Samantha Artiga, Kendal Orgera, and Olivia Pham, "Disparities in Health and Health Care: Five Key Questions and Answers," Mar. 4, 2020, https://www.kff.org/disparities-policy/issue-brief/disparities-in-health-and-health-care-five-key-questions-and-answers/; Alan Nelson, MD, "Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care,"

Health and Human Services' Agency for Healthcare Research and Quality found that these disparities vary by state, which may indicate correlation with state policies, as displayed in Figure 2.3.²³⁹

Figure 2.3 Average Differences in Quality of Care for Black, Hispanic, and Asian individuals compared with White individuals, by State, 2015-2017



Source: U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality, *National Healthcare Quality and Disparities Report 2018*, September 2019, https://www.ahrq.gov/sites/default/files/wysiwyg/research/findings/nhqrdr/2018qdr-final.pdf

National data suggests women of color are more likely to experience barriers to access of quality maternal healthcare than White women, due to a lower likelihood of health insurance coverage. Lack of access to insurance coverage, in addition to poor communication with woman of color by providers, can cause barriers in accessing quality maternal healthcare, including family planning, preconception care, prenatal care, and postpartum care²⁴⁰. Uninsured rates experienced

Journal of the National Medical Association, Vol. 94, No. 8 (August 2002): 666-668, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2594273/pdf/jnma00325-0024.pdf.

²³⁹ U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality, *National Healthcare Quality and Disparities Report 2018*, September 2019, https://www.ahrq.gov/sites/default/files/wysiwyg/research/findings/nhqrdr/2018qdr-final.pdf

²⁴⁰ Jennifer Jacoby, Response to USCCR Follow-Up Questions for the Racial Disparities in Maternal Health Briefing, Jan. 8, 2021, at 1-2, (on file) (hereinafter "Jacoby Response"); Center for Reproductive Rights, "Research Overview of Maternal Mortality and Morbidity in the United States," p. 4,

by black women are amongst the highest; additionally, Black women are more likely at higher risk of chronic health conditions that are factors for maternal death, and are less likely to receive care for disease prevention and management.²⁴¹ In addition, Black women also experience disparate rates of unintended pregnancy (potentially attributable to structural phenomenon like provider bias, i.e. provider suggesting different treatments to black patients than white patients)²⁴², which affect access to the benefits of preconception care. These rates put Black women at higher risk of complications during pregnancy and, in turn, poorer maternal health outcomes.²⁴³

Preconception and interconception²⁴⁴ care aims to raise the level of wellness among women of childbearing age, prior to pregnancy,²⁴⁵ and has been linked to improved maternal health outcomes.²⁴⁶ This is particularly important for women of color, as they are often at higher risk than White women for preconception risk factors.²⁴⁷ One study, *Racial and Ethnic Disparities in Preconception Risk Factors and Preconception Care*, found that Native American women and Black women were most likely to have multiple preconception risk factors, such as at-risk drinking, smoking, obesity, or mental distress.²⁴⁸ Access to preconception care has been found to

https://www.reproductiverights.org/sites/crr.civicactions.net/files/documents/USPA_MH_TO_ResearchBrief_Final_5.16.pdf; Elizabeth A. Howell, *Reducing Disparities in Severe Maternal Morbidity and Mortality*, 61(2) CLIN. OBSTET. GYNECOL. 387, 390-91 (2018), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5915910/ ("Several recent investigations have found that racial and ethnic minority women deliver in different and lower quality hospitals than whites").

²⁴¹ Ibid.

²⁴²Christine Dehlendorf et. al., *Racial/Ethnic Disparities In Contraceptive Use: Variation By Age And Women's Reproductive Experiences*, 210(6) Am. J. OBSTET. GYNECOL. 526.e1,526.e1-9 (2014), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4303233/

²⁴³Elizabeth A. Howell, *Reducing Disparities in Severe Maternal Morbidity and Mortality*, 61(2) CLIN. OBSTET. GYNECOL. 387, 390-91 (2018), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5915910/.

²⁴⁴ Interconception refers to the time between the end of one pregnancy and the conception of the next pregnancy; *see*, Denise D'Angelo, M.P.H., Letitia Williams, M.P.H., Brian Morrow, M.A., Shanna Cox, M.S.P.H., Norma Harris, Ph.D., Leslie Harrison, M.P.H., Samuel F. Posner, Ph.D., Jessie Richardson Hood, M.P.H., Lauren Zapata, Ph.D., "Preconception and Interconception Health Status of Women Who Recently Gave Birth to a Live-Born Infant --- Pregnancy Risk Assessment Monitoring System (PRAMS), United States, 26 Reporting Areas, 2004" Division of Reproductive Health, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention, MMWR Surveillance Summaries, Dec. 14, 2007, https://www.cdc.gov/mmwr/preview/mmwrhtml/ss5610a1.htm.

²⁴⁵ March of Dimes, *Toward Improving the Outcome of Pregnancy III*, December 2010, p. 46, https://www.marchofdimes.org/toward-improving-the-outcome-of-pregnancy-iii.pdf.

²⁴⁶ Centers for Disease Control and Prevention, Recommendations to Improve Preconception Health and Health Care --- United States: A Report of the CDC/ATSDR Preconception Care Work Group and the Select Panel on Preconception Care, https://www.cdc.gov/mmwr/preview/mmwrhtml/rr5506a1.htm; HealthyPeople.gov, "Maternal, Infant, and Child Health," https://www.healthypeople.gov/2020/topics-objectives/topic/maternal-infant-and-child-health?topicid=26.

²⁴⁷ Clark H. Denny, R. Louise Floyd, Patricia P. Green, Donald K. Hayes, "Racial and Ethnic Disparities in Preconception Risk Factors and Preconception Care," *Journal of Women's Health*, Vol. 21, No. 7 (July 2012): 720, https://pdfs.semanticscholar.org/7227/02edd5a54df2e67802e63b8934de2f6a9e2c.pdf. ²⁴⁸ Ibid., 722.

be particularly critical to reducing racial disparities in maternal healthcare between Black and White women.²⁴⁹

Women receiving no prenatal care are 3 to 4 times more likely to have a pregnancy-related death than women who receive prenatal care.²⁵⁰ While there is still much to be learned about the content and quality of prenatal care and its relationship to maternal health, 251 it is generally accepted among medical professionals that regular prenatal care is important for improving and maintaining a healthy pregnancy and reducing the risk of pregnancy complications.²⁵² Research shows that there is a link between reduced numbers of prenatal visits and poor pregnancy outcomes (e.g., low birthweight, preterm birth, infant mortality), ²⁵³ and some research links fewer prenatal visits to maternal mortality or severe maternal morbidity.²⁵⁴ Access to maternal fetal medicine subspecialists has also been linked to improved health outcomes among pregnant women with chronic illness and pregnancy-related complications, ²⁵⁵ and less frequent visits

²⁴⁹ Association of Maternal & Child Health Programs, "Opportunities and Strategies for Improving Preconception Health through Health Reform," March 2015, p. 1, http://www.amchp.org/Transformation-Station/Documents/AMCHP%20Preconception%20Issue%20Brief.pdf.

²⁵⁰ Maternal Health Task Force at the Harvard Chan School, "Maternal Health in the United States," https://www.mhtf.org/topics/maternal-health-in-the-united-states/; "Maternal Mortality in the United States: a Human Rights Failure," Contraception, No. 83 (2011): 189, https://www.contraceptionjournal.org/article/S0010-7824(10)00685-2/pdf.

²⁵¹ Rebecca A. Gourevitch Alex Friedman Peahl Margaret McConnell Neel Shah, "Understanding The Impact Of Prenatal Care: Improving Metrics, Data, And Evaluation," *Health Affairs*, Feb. 26, 2020, https://www.healthaffairs.org/do/10.1377/hblog20200221.833522/full/.

²⁵² Eunice Kennedy Shriver National Institute of Child Health and Human Development, "What is Prenatal Care and Why is it Important?," https://www.nichd.nih.gov/health/topics/pregnancy/conditioninfo/prenatalcare#:~:text=Pre%2DPregnancy%20and%20prenatal%20care,the%20risk%20of%20pregnancy%20complications...

²⁵³ Elizabeth A. Howell, MD, MPP, "Reducing Disparities in Severe Maternal Mortality and Morbidity," Obstet Gynecol, Vol. 61, No. 2 (June 2018): 4, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5915910/; Cox RG, Zhang L, Zotti ME, Graham J, "Prenatal care utilization in Mississippi: racial disparities and implications for unfavorable birth outcomes," Matern Child Health J., Vol. 15, No. 7 (October 2011) 931-942; Till SR, Everetts D, Haas DM, "Incentives for increasing prenatal care use by women in order to improve maternal and neonatal outcomes," Cochrane Database Syst Rev., Vol. 12 (December 2015): CD009916

²⁵⁴ Elizabeth A. Howell, MD, MPP, "Reducing Disparities in Severe Maternal Mortality and Morbidity," Obstet Gynecol, Vol. 61, No. 2 (June 2018): 4, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5915910/; Howell EA, Egorova NN, Balbierz A, Zeitlin J, Hebert PL, "Site of delivery contribution to black-white severe maternal morbidity disparity," Am J Obstet Gynecol, Vol. 215, No. 2 (August 2016): 143-152,

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4967380/; Howell EA, Egorova NN, Janevic T, Balbierz A, Zeitlin J, Hebert PL, "Severe Maternal Morbidity Among Hispanic Women in New York City: Investigation of Health Disparities," Obstet Gynecol Vol. 129 (2017):285-94.

²⁵⁵ Elizabeth A. Howell, MD, MPP, "Reducing Disparities in Severe Maternal Mortality and Morbidity," Obstet Gynecol, Vol. 61, No. 2 (June 2018): 4, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5915910/; Antony KM, Dildy GA. Postpartum hemorrhage: The role of the Maternal-Fetal Medicine specialist in enhancing quality and patient safety. Semin Perinatol. 2013 Aug 01;37(4):246-256; Safi LM, Tsiaras SV. Update on Valvular Heart Disease in Pregnancy. Current Treatment Options in Cardiovascular Medicine. 2017 Aug 05;19(9):70; D'Alton ME, Bonanno CA, Berkowitz RL, et al. Putting the "M" back in maternal-fetal medicine. Am J Obstet Gynecol. 2013 Jun 01;208(6):442-448.

among women with chronic illness may result in adverse pregnancy outcomes.²⁵⁶ Women of color are statistically less likely than White women to start prenatal care in the first trimester of pregnancy, with Black, Native American, and Native Hawaiian/Pacific Islander women having the lowest percentages (63.6 percent, 59.4 percent, and 54.7 percent, respectively) as compared to White women (79 percent).²⁵⁷

The postpartum period following the end of a pregnancy or "fourth trimester" has also been identified as critically important for the long-term health and wellbeing of a woman who has given birth. Data show that approximately half of all maternal deaths occur during the postpartum period, between 1 day and 1 year following the end of the pregnancy. During this time, a woman is recovering from childbirth; adapting to many physical, social and psychological changes; and facing challenges that often include a lack of sleep, fatigue, pain, stress, increased mental health symptomology, and many others. The American College of Obstetricians and Gynecologists has emphasized the importance of receiving continuous care during this critical time, and has recently updated guidance recommending improved content and frequency of postpartum visits, and among other measures, "[t]o optimize the health of women and infants, postpartum care should be an ongoing process, rather than a single encounter, with services and support tailored to each woman's individual needs." Additionally, postpartum care is particularly important for women with chronic illness, and women who experience poor maternal outcomes are prone to chronic illness later in life. Data and support tailored to chronic illness later in life.

²⁵⁶ Elizabeth A. Howell, MD, MPP, "Reducing Disparities in Severe Maternal Mortality and Morbidity," *Obstet Gynecol*, Vol. 61, No. 2 (June 2018): 4, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5915910/; Eden RD, Penka A, Britt DW, Landsberger EJ, Evans MI. Re-evaluating the role of the MFM specialist: Lead, follow, or get out of the way. The Journal of Maternal-Fetal & Neonatal Medicine. 2005 Jan 01;18(4):253–258.

²⁵⁷ U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, *Child Health USA 2014*, March 2015, p. 76, https://mchb.hrsa.gov/chusa14/dl/chusa14.pdf. ²⁵⁸ American College of Obstetricians and Gynecologists, "Optimizing Postpartum Care," Committee Opinion No. 736, May 2018, https://www.acog.org/clinical/clinical-guidance/committee-opinion/articles/2018/05/optimizing-postpartum-care.

²⁵⁹ Centers for Disease Control and Prevention, "Vital Signs: Pregnancy-Related Deaths, United States, 2011–2015, and Strategies for Prevention, 13 States, 2013–2017," *Morbidity and Mortality Weekly*, Vol. 68, No. 8 (May 10, 2019): 423-429,

https://www.cdc.gov/mmwr/volumes/68/wr/mm6818e1.htm#:~:text=Among%20these%20deaths%2C%2031.3%25%20occurred,hemorrhage%2C%20and%20varied%20by%20timing..

²⁶⁰ Ibid.

²⁶¹ American College of Obstetricians and Gynecologists, "Optimizing Postpartum Care," Committee Opinion No. 736, May 2018, https://www.acog.org/clinical/clinical-guidance/committee-opinion/articles/2018/05/optimizing-postpartum-care.

²⁶² Ibid.

²⁶³ Elizabeth A. Howell, MD, MPP, "Reducing Disparities in Severe Maternal Mortality and Morbidity," *Obstet Gynecol*, Vol. 61, No. 2 (June 2018): 4, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5915910/; see, The American College of Obstetricians and Gynecologists, "Optimizing Postpartum Care," Committee Opinion No. 736, May 2018, https://www.acog.org/-/media/project/acog/acogorg/clinical/files/committee-opinion/articles/2018/05/optimizing-postpartum-care.pdf.

Currently, about 40 percent of women do not attend postpartum visits.²⁶⁴ Mauricio Leone of Obria Group noted in his testimony that lack of education about healthcare options can result in some women delaying or foregoing pre- and postpartum visits to healthcare providers.²⁶⁵

As discussed in Chapter 1, mental health disorders such as depression are common in the postpartum period, ²⁶⁶ and can be underlying factors resulting in maternal deaths from suicide, accidental death, or homicide. ²⁶⁷ Data also show that the proportion of low-income women who seek postpartum care is low, ²⁶⁸ and women who do not seek prenatal care or are late in seeking pregnancy care are less likely to attend a postpartum checkup. ²⁶⁹ Research examining use of postpartum care reports that women receiving financial assistance, reporting two or more moves during their pregnancy, reporting having trouble understanding the provider, and those reporting problems with transportation to their provider were less likely to engage in a postpartum visit. ²⁷⁰ In contrast, women who received an appointment reminder in their preferred language had higher odds of having had a postpartum visit. ²⁷¹ Other reported barriers to postpartum care use include

²⁶⁴ American College of Obstetricians and Gynecologists, "Optimizing Postpartum Care," Committee Opinion No. 736, May 2018, p. e141, https://www.acog.org/-/media/project/acog/acogorg/clinical/files/committee-opinion/articles/2018/05/optimizing-postpartum-care.pdf.

²⁶⁵ Leone Statement at pp. 3-4.

²⁶⁶ See supra notes 106-109.

²⁶⁷ See supra notes 105-111; Moreover, the rate of depression and anxiety among pregnant women has more than doubled during the COVID-19 pandemic.

²⁶⁸ American College of Obstetricians and Gynecologists, "Optimizing Postpartum Care," Committee Opinion No. 736, May 2018, p. e141, https://www.acog.org/-/media/project/acog/acogorg/clinical/files/committee-opinion/articles/2018/05/optimizing-postpartum-care.pdf; De Bocanegra HT, Braughton M, Bradsberry M, Howell M, Logan J, Schwarz EB. Racial and ethnic disparities in postpartum care and contraception in California's Medicaid program. Am J Obstet Gynecol. 2017; Howell EA, Padrón NA, Beane SJ, et al. Delivery and Payment Redesign to Reduce Disparities in High Risk Postpartum Care. Maternal and Child Health Journal. 2017 Mar 01;21(3):432–438, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5380444/.

²⁶⁹ Elizabeth A. Howell, MD, MPP, "Reducing Disparities in Severe Maternal Mortality and Morbidity," *Obstet Gynecol*, Vol. 61, No. 2 (June 2018): 4, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5915910/; Siddiqui R, Bell T, Sangi-Haghpeykar H, Minard C, Levison J. Predictive factors for loss to postpartum follow-up among low income HIV-infected women in Texas. AIDS Patient Care STDS. 2014 May;28(5):248–253, https://pubmed.ncbi.nlm.nih.gov/24720630/.

²⁷⁰ Bryant, Allison S., Jennifer S. Haas, Thomas F. McElrath, and Marie C. McCormick. 2006. "Predictors of Compliance with the Postpartum Visit Among Women Living in Healthy Start Project Areas." Maternal and Child Health Journal 10 (6) (June 29): 511–516,

 $[\]frac{https://dash.harvard.edu/bitstream/handle/1/37136752/eScholarship\%20UC\%20item\%2087t7k7zp\%202.pdf?sequence=3\&isAllowed=y.$

²⁷¹ Bryant, Allison S., Jennifer S. Haas, Thomas F. McElrath, and Marie C. McCormick. 2006. "Predictors of Compliance with the Postpartum Visit Among Women Living in Healthy Start Project Areas." Maternal and Child Health Journal 10 (6) (June 29): 511–516,

 $[\]underline{\text{https://dash.harvard.edu/bitstream/handle/1/37136752/eScholarship\%20UC\%20item\%2087t7k7zp\%202.pdf?sequence=3\&isAllowed=y.}$

feeling fine, being too busy with the baby, lack of childcare, lack of parental leave, or a lack of need.²⁷²

As indicated below, in some cases, access to quality healthcare may be a geographical issue. In rural America, there is a lack of access to quality maternal healthcare as a result of several factors such as hospital and obstetric department closures, workforce shortages, and challenges to the access of care arising from social determinants of health that affect rural mothers.²⁷³ These challenges can result in negative maternal health outcomes, including maternal mortality, severe maternal morbidity, and postpartum depression.²⁷⁴ Native American women and other women of color are disproportionately impacted by these disparities in access to care.²⁷⁵ Forty percent of all Native people live in rural areas and often times have to travel for hours to access a birthing center or hospital.²⁷⁶ Sandra Wilcox, a licensed practical nurse and director of the Maternal and Child Health program for the Rosebud Sioux Tribe, testified to the South Dakota Advisory Committee about the issue of transportation, emphasizing that some Native American women must travel a four and a half hour drive to access prenatal care.²⁷⁷

In Colorado, rural areas see increased maternal mortality. The Colorado Advisory Committee to the Commission explained:

Around twelve percent of Colorado's total population lives in a rural area, yet that same group makes up about eighteen percent of total maternal deaths. This is largely due to the distance people in rural areas must travel and the time it takes to receive care. That results in a delay of access to care that can change a health outcome.²⁷⁸

Melanie Rouse, Maternal Mortality Projects Manager for the Virginia Department of Health's Office of the Chief Medical Examiner noted in her testimony to the Commission that the Medicaid program includes transportation benefits, which may help women in accessing care; Virginia has identified utilization of these benefits as one of the keys to reducing racial

²⁷² DiBari, J. N., Yu, S. M., Chao, S. M., & Lu, M. C. (2014). Use of postpartum care: predictors and barriers. Journal of pregnancy, 2014, 530769. https://doi.org/10.1155/2014/530769, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3945081/.

²⁷³ Centers for Medicare & Medicaid Services, *Improving Access to Maternal Health Care in Rural Communities*, p. 1, https://www.cms.gov/About-CMS/Agency-Information/OMH/equity-initiatives/rural-health/09032019-Maternal-Health-Care-in-Rural-Communities.pdf.

²⁷⁴ Ibid.

²⁷⁵ Ibid.

²⁷⁶ See, National Indian Health Board, Public Comment for the *Racial Disparities in Maternal Mortality Briefing* before the U.S. Comm'n on Civil Rights, Dec. 13, 2020.

²⁷⁷ Sandra Wilcox, Director of the Maternal Child and Health Program for the Rosebud Sioux Tribe, South Dakota State Advisory Committee to the U.S. Comm'n on Civil Rights, *Meeting on Native American Maternal Health Disparities*, Transcript, Jul. 25, 2020, at 9.

²⁷⁸ Advisory Memorandum on Maternal Mortality and Fetal/Infant Mortality, Colorado Advisory Committee to the U.S. Commission on Civil Rights, p. 3 Sept. 22, 2020, https://www.usccr.gov/files/2020-10-05-CO-Advisory-Memorandum-Maternal-Mortality-and-Fetal-Infant-Mortality-pdf

disparities in maternal health outcomes.²⁷⁹ Jennifer Jacoby, Federal Policy Counsel at the Center for Reproductive Rights testified that the federal government has a role in improving the health outcomes of pregnant women and mothers by addressing the social determinants of health, including transportation.²⁸⁰

According to the March of Dimes, more than five million women in the U.S. (in 1,085 counties nationwide) live in "maternity care deserts" that have no hospital with obstetric services or no obstetric providers. 281 While most maternity care deserts are in rural areas, this problem can also occur in urban areas. 282 Nan Strauss of Every Mother Counts testified to the Commission that "[i]n 2016, more than five million women lived in rural and urban counties with neither an obstetrician/gynecologist nor a nurse midwife, nor a hospital with a maternity unit."283 Continuity of care is disrupted when hospitals close in cities, which can cause barriers to accessing prenatal care and obstetric services due to issues of transportation, finding/coordinating new services, and insurance, which can negatively impact low-income neighborhoods (which often overlap with neighborhoods of color). This can exacerbate lack of access to healthcare services for these vulnerable populations. 284 These disparities in access to care can be stark, as Nan Strauss wrote in her testimony that "[n]early one in four Black individuals lives in a provider shortage area, as compared to just over one in seven of their white counterparts."²⁸⁵ The March of Dimes has recommended the regionalization of perinatal care, a strategy to improve both maternal and neonatal outcomes, by closing the geographical gap of services and ensuring that pregnant women receive risk-appropriate care in a facility equipped with the proper resources and healthcare providers.²⁸⁶ Additionally, the American College of Obstetricians and Gynecologists recommends expanding telemedicine or telehealth services as

²⁷⁹ Melanie J. Rouse, Ph.D., Maternal Mortality Projects Manager, Virginia Department of Health's Office of the Chief Medical Examiner, Division of Death Prevention, Written Statement for the Racial Disparities in Maternal Health Briefing before the U.S. Comm'n on Civil Rights, Nov. 13, 2020 at 5 (hereinafter "Rouse Statement").

²⁸³ Nan Strauss, J.D., Managing Director of Policy, Advocacy, and Grantmaking, Every Mother Counts, Written Statement for the *Racial Disparities in Maternal Health Briefing* before the U.S. Comm'n on Civil Rights, Nov. 13, 2020, at 4 (hereinafter "Strauss Statement").

²⁸⁰ Jennifer Jacoby, Federal Policy Counsel, Center for Reproductive Rights, Written Statement for the Racial Disparities in Maternal Health Briefing before the U.S. Comm'n on Civil Rights, Nov. 13, 2020, at 9 (hereinafter "Jacoby Statement").

²⁸¹ March of Dimes, "Nowhere to Go: Maternity Care Deserts Across the U.S.," p. 1, https://www.marchofdimes.org/materials/Nowhere_to_Go_Final.pdf.

²⁸² Ibid.

²⁸⁴ March of Dimes, "Nowhere to Go: Maternity Care Deserts Across the U.S.," p. 3, https://www.marchofdimes.org/materials/Nowhere_to_Go_Final.pdf.

²⁸⁵ Strauss Statement at 5.

²⁸⁶ March of Dimes, "Nowhere to Go: Maternity Care Deserts Across the U.S., p. 9, https://www.marchofdimes.org/materials/Nowhere to Go Final.pdf.

an accessible and cost-effective alternative when in-person healthcare visits are impracticable or unavailable, and has been shown to be effective in rural communities.²⁸⁷

A recent study found that between 2004 and 2014, 179 rural counties in the U.S. lost hospital-based obstetrics services. In 2004, 45 percent of rural counties in the U.S. did not offer any hospital-based obstetrics services, and this increased to 54 percent by 2014, with the most severe impacts in largely Black counties and in states with the strictest Medicaid eligibility requirements. Another study examining access to obstetric care in rural counties found that "Black women were found to be ten times as likely as white women to live in a county that had no in-hospital obstetric services and four times as likely to live in a county where hospital obstetric services had recently closed." ²⁹⁰

People of color are less likely to be insured than White people.²⁹¹ Latinos experience the highest uninsured rate of any racial or ethnic group (at 32 percent uninsured), with Native and Black Americans seeing 27 percent and 21 percent uninsured rates, respectively, compared to 13 percent of White people (who also have the highest rate of private medical insurance coverage and the lowest rates of Medicaid/other public insurance coverage).²⁹² While the Affordable Care Act healthcare mandate served to narrow the gap in insurance coverage and to increase the likelihood of physician visits,²⁹³ there are still persistent racial disparities in access to care.²⁹⁴

²⁸⁷ ACOG Public Comment at 8-9.

²⁸⁸ Katy B. Kozhimannil, PhD, MPA; Peiyin Hung, PhD, MSPH; Carrie Henning-Smith, PhD, MPH, MSW; et al, "Association Between Loss of Hospital-Based Obstetric Services and Birth Outcomes in Rural Counties in the United States," *JAMA*, Vol. 319, No. 12 (2018): 1239-1247, https://jamanetwork.com/journals/jama/fullarticle/2674780.

²⁸⁹ Ibid.; Adriana Gallardo and Nina Martin, "Another Thing Disappearing From Rural America: Maternal Care," *ProPublica*, Sep. 5, 2017, https://www.propublica.org/article/another-thing-disappearing-from-rural-america-maternal-care; *see also* Joia Crear-Perry, Founder and President, National Birth Equity Collaborative, and Board Member, Black Mamas Matter Alliance, Written Statement for the Racial Disparities in Maternal Health Briefing before the U.S. Comm'n on Civil Rights, Nov. 13, 2020, at 7 (hereinafter "Crear-Perry Statement").

²⁹⁰ Strauss Statement at 5; Hung, P.et al. *Access to Obstetric Services In Rural Counties Still Declining, With 9 Percent Losing Services*, 2004–14. Health Affairs, 2017.36(9): 1663–71. Available at: https://doi.org/10.1377/hlthaff.2017.0338;; *see also*, Merkt PT, Kramer MR, Goodman DA, Brantley MD, Barrera CM, Eckhaus L, Petersen EE. Urban-rural differences in pregnancy-related deaths, United States, 2011-2016. Am J Obstet Gynecol. 2021 Feb 25:S0002-9378(21)00144-7. (finding "[p]regnancy-related mortality ratio age disparities increased with rurality."), https://pubmed.ncbi.nlm.nih.gov/33640361/

²⁹¹ The Henry J. Kaiser Family Foundation, "Health Coverage by Race and Ethnicity: The Potential Impact of the Affordable Care Act," March 2013, p. 1, https://www.kff.org/wp-content/uploads/2014/07/8423-health-coverage-by-race-and-ethnicity.pdf.

²⁹² Ibid., 5.

²⁹³ Jie Chen, PhD, Arturo Vargas-Bustamante, PhD, Karoline Mortensen, PhD, and Alexander N. Ortega, PhD, "Racial and Ethnic Disparities in Health Care Access and Utilization Under the Affordable Care Act," *Med Care*, Vol. 54, No. 2 (February 2016): 140-146, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4711386/.

²⁹⁴ Susan L. Hayes, Pamela Riley, M.D., David C. Radley, and Douglas McCarthy, "Reducing Racial and Ethnic Disparities in Access to Care: Has the Affordable Care Act Made a Difference?," Aug. 24, 2017,

Medicaid plays a significant role in insuring people of color, particularly Black, Native American, and Latinx individuals.²⁹⁵ Thirty-two percent of both Black and Native Americans, and 30 percent of Latinx people are insured by Medicaid. ²⁹⁶ A recent study found that Medicaid expansion²⁹⁷ is significantly associated with lower maternal mortality rates, as seen in Medicaid expansion states as compared to states that did not expand Medicaid coverage.²⁹⁸ The results suggest that increased access to insurance coverage and access to postpartum and preconception care can contribute to a lower maternal mortality rate.²⁹⁹ The study also suggests that the expansion of Medicaid is helping to decrease racial disparities in maternal mortality. 300 Prior to Medicaid expansion, only certain low-income individuals were eligible for Medicaid coverage. including the elderly, persons with disabilities, children, pregnant women, and some parents.³⁰¹ States that have expanded Medicaid have extended eligibility to all low-income adults, allowing for healthcare coverage for adult women before pregnancy. 302 Nan Strauss, Managing Director of Policy, Advocacy, and Grantmaking at Every Mother Counts, testified that in states that have not expanded Medicaid, "many women, particularly women of color, are left in the 'coverage gap,' where they earn too much to qualify for Medicaid, but not enough to purchase private health insurance, even with tax subsidies."303 Melanie Rouse, Maternal Mortality Projects Manager in the Virginia Department of Health's Office of the Chief Medical Examiner, testified to the Commission that she expects Virginia's recent Medicaid expansion will "have a positive

 $\underline{https://www.commonwealthfund.org/publications/issue-briefs/2017/aug/reducing-racial-and-ethnic-disparities-access-care-has.}$

²⁹⁵ The Henry J. Kaiser Family Foundation, "Health Coverage by Race and Ethnicity: The Potential Impact of the Affordable Care Act," March 2013, p. 5, https://www.kff.org/wp-content/uploads/2014/07/8423-health-coverage-by-race-and-ethnicity.pdf.

²⁹⁶ Ibid.

²⁹⁷ See "Medicaid expansion and what it means for you," https://www.healthcare.gov/medicaid-chip/medicaid-expansion-and-you/. Medicaid expansion refers to the ability for all individuals in a household to qualify for Medicaid coverage based on household income alone; in states that have not expanded Medicaid, qualification may be based on household income, household size, disability, family status, and other factors (depending on the state). See also The Henry J. Kaiser Family Foundation, "Status of State Medicaid Expansion Decisions: Interactive Map," https://www.kff.org/medicaid/issue-brief/status-of-state-medicaid-expansion-decisions-interactive-map/. Individual states have the option of expanding Medicaid coverage and at present, 37 states (including DC) have adopted Medicaid expansion.

²⁹⁸ Erica L. Eliason, M.P.H., "Adoption of Medicaid Expansion Is Associated with Lower Maternal Mortality," *Women's Health Issues*, Feb. 25, 2020, https://www.whijournal.com/article/S1049-3867(20)30005-0/fulltext.
https://www.whijournal.com/article/S1049-3867(20)30005-0/fulltext.
https://www.whijournal.com/article/S1049-3867(20)30005-0/fulltext.
https://www.whijournal.com/article/S1049-3867(20)30005-0/fulltext.

³⁰⁰ Ibid.

³⁰¹ Kaiser Family Foundation. Who Is Impacted by the Coverage Gap in States That Have Not Adopted the Medicaid Expansion? The Kaiser Commission on Medicaid and the Uninsured, p. 4 (2016), https://www.kff.org/slideshow/who-is-impacted-by-the-coverage-gap-in-states-that-have-not-adopted-the-medicaid-expansion/.

³⁰² Erica L. Eliason, M.P.H., "Adoption of Medicaid Expansion Is Associated with Lower Maternal Mortality," *Women's Health Issues*, Feb. 25, 2020, https://www.whijournal.com/article/S1049-3867(20)30005-0/fulltext.

³⁰³ Strauss Statement, at 5.

impact on maternal and infant health outcomes."³⁰⁴ In addition to expanding Medicaid to a greater population, several experts recommended to the Commission that Medicaid coverage be extended nationwide to last through one year postpartum, beyond the current 60-day coverage requirement. ³⁰⁵ However, a 2004 study noted that even with access to Medicaid, women of color may face disparities in the health services provided, as it found that Black, Latina, and Asian/Pacific Islander women were still less likely than White women to receive patient-initiated pregnancy services (i.e., prenatal services, prescriptions, and screening tests for diseases), discretionary services, and services requiring follow-up care. ³⁰⁶

Currently, Medicaid requires all states to cover pregnant women with incomes up to 138 percent of the federal poverty level; however, many states go above and beyond this threshold and cover women with incomes between 138 percent and 380 percent of the federal poverty level.³⁰⁷ Additionally, Jennifer Moore of the Institute for Medicaid Innovation testified to the Commission that:

The Public Health Services Act Section 2706, within the Affordable Care Act (ACA),³⁰⁸ provides that Medicaid health plans cannot discriminate against any licensed or certified provider, such as a certified nurse-midwife. The ACA also includes provisions related to freestanding birth centers under Section 2301, requiring all states with licensed or otherwise state-approved birth centers to cover birth center services under Medicaid. Medicaid coverage of maternity services from nonphysician providers such as midwives, and out-of-hospital births such as at freestanding birth centers, varies by state and is dependent on licensure and credentialing laws. Despite these provisions, midwifery-led care and freestanding birth centers have become a luxury limited to mostly White women in the U.S. with commercial insurance coverage or who can afford to pay out-of-pocket. Furthermore, frequent eligibility redeterminations, confusing and inaccessible application

³⁰⁴ Rouse Statement, at 5.

³⁰⁵ See, Shannon Dowler, Chief Medical Officer, North Carolina Medicaid, Written Statement for the Racial Disparities in Maternal Health Briefing before the U.S. Comm'n on Civil Rights, Nov. 13, 2020 at 3 (hereinafter "Dowler Statement"); Jacoby Statement at 10; Strauss Statement at 5.

³⁰⁶ Norma I. Gavin, PhD, E. Kathleen Adams, PhD, Katherine E. Hartmann, MD, PhD, M. Beth Benedict, DrPH, JD, and Monique Chireau, MD, MPH, "Racial and Ethnic Disparities in the Use of Pregnancy-Related Health Care Among Medicaid Pregnant Women," *Maternal and Child Health Journal*, Vol. 8, No. 3 (September 2004): 113-126, https://www.researchgate.net/profile/Katherine_Hartmann/publication/8216960_Racial_and_Ethnic_Disparities_in_the_Use_of_Pregnancy-

Related Health Care Among Medicaid Pregnant Women/links/59400a5f45851554614a511d/Racial-and-Ethnic-Disparities-in-the-Use-of-Pregnancy-Related-Health-Care-Among-Medicaid-Pregnant-Women.pdf.

³⁰⁷ Usha Ranji, Ivette Gomez, and Alina Salganicoff, "Expanding Postpartum Medicaid Coverage," *The Henry J. Kaiser Family Foundation*, (Mar. 9, 2021), , https://www.kff.org/womens-health-policy/issue-brief/expanding-postpartum-medicaid-coverage/.

³⁰⁸ The Patient Protection and Affordable Care Act (PPACA), Pub. L. No. 111-148, 2010, 124 Stat. 119.

processes, and work requirements have been adopted to varying degrees by states to constrain enrollment.³⁰⁹

Typically, pregnancy-related Medicaid coverage for the mother must extend through 60 days postpartum, although states have the option of extending that coverage past that 60 day period.³¹⁰ In states that have expanded Medicaid coverage, women are typically eligible to remain covered past the 60 day period due to the modified qualification criteria.³¹¹ Additionally, individuals 138-400 percent of the federal poverty level purchasing insurance through private market coverage are eligible for subsidies provided under the Affordable Care Act. 312 In contrast, in states that have no expanded Medicaid coverage, many women find that they do not meet the income eligibility requirements due to their income being too high (above that 138 percent threshold) which creates a lapse in coverage during that particularly vulnerable postpartum period. 313 A recent study found that approximately 55 percent of women with health insurance coverage at delivery still experienced a coverage gap lasting six months, due to a variety of factors (e.g., geographic, being unmarried, limited English proficiency, and lower income levels), including having Medicaid or Children's Health Insurance Program (CHIP) coverage (as opposed to private insurance coverage). 314 Additionally, there are racial disparities associated with gaps or disruptions in coverage (both Medicaid and private insurance), as from preconception to postpartum, 75.3 percent of White women had continuous coverage as compared to 55.4 percent of Black women, 49.9 percent of Native American women, and 20.5 percent of Spanish-speaking Latinas. 315 Furthermore, 4 in 10 mothers with Medicaid do not access a postpartum visit—a critical opportunity to receive support or care for postpartum depression or breastfeeding challenges, or get information about nutrition, exercise, and how long to wait until getting pregnant again.³¹⁶ Barriers that may prevent women with Medicaid coverage from accessing

³⁰⁹ Jennifer E. Moore, Ph.D., R.N., F.A.A.N., Founding Executive Director, Institute for Medicaid Innovation, Written Statement for the *Racial Disparities in Maternal Health Briefing* before the U.S. Comm'n on Civil Rights, Nov. 13, 2020, at 2 (hereinafter "Moore Statement") (internal citations omitted).

³¹⁰ Ibid.

³¹² U.S. Dep't of Health and Human Services, Response to USCCR Interrogatories for the *Racial Disparities in Maternal Health* briefing before U.S. Comm'n on Civil Rights (on file).

³¹¹ See supra note 297.

³¹³ Usha Ranji, Ivette Gomez, and Alina Salganicoff, "Expanding Postpartum Medicaid Coverage," *The Henry J. Kaiser Family Foundation*, May 2019, pp. 1-2, http://files.kff.org/attachment/Issue-Brief-Expanding-Postpartum-Medicaid-Coverage.

³¹⁴ Jamie R. Daw, Laura A. Hatfield, Katherine Swartz, and Benjamin D. Sommers, "Women In The United States Experience High Rates Of Coverage 'Churn' In Months Before And After Childbirth," *Health Affairs*, Vol. 36, No. 4 (April 2017): 598, https://www.healthaffairs.org/doi/pdf/10.1377/hlthaff.2016.1241.

³¹⁵ Daw, Jamie R. PhD; Kolenic, Giselle E. MA; Dalton, Vanessa K. MD, MPH; Zivin, Kara PhD, MS; Winkelman, Tyler MD, MSc; Kozhimannil, Katy B. PhD, MPA; Admon, Lindsay K. MD, MSc, "Racial and Ethnic Disparities in Perinatal Insurance Coverage," *Obstetrics and Gynecology*, Vol. 35, No. 4 (April 2020): 917-924, https://journals.lww.com/greenjournal/Fulltext/2020/04000/Racial and Ethnic Disparities in Perinatal.20.aspx.

³¹⁶ Alison Stuebe, Jennifer E. Moore, Pooja Mittal, Lakshmi Reddy, Lisa Kane Low, and Haywood Brown, "Extending Medicaid Coverage For Postpartum Moms," May 6, 2019, https://www.healthaffairs.org/do/10.1377/hblog20190501.254675/full/.

postpartum care include coverage ending at 60 days postpartum, returning back to work, and not having access to sick leave.³¹⁷

Variation of Hospital Quality

There are significant disparities in the quality of care, or the care that is provided to women before, during, and after pregnancy, that women of color receive, 318 compared with White women; and a major part of this quality of care issue is in the variation of hospital quality where women deliver. 319 Research has shown that women of color tend to deliver in lower quality hospitals in the U.S. than White women, one contributing factor to disparities in maternal health outcomes. 320 These studies found that many hospitals that disproportionately serve Black patients tend to have higher overall mortality rates and lower rates of effective evidenced-based medical treatments, 321 and in several states, they perform worse than other hospitals on delivery-related indicators. 322 Approximately 75 percent of Black women deliver in a specific set of hospitals, where health outcomes are worse for both Black and White women, and fewer than 20 percent of White women deliver in those same hospitals. 323

³¹⁷ Ibid. Ibid. Ibid; Emily M. Johnston, Stacey McMorrow, Clara Alvarez Caraveo, and Lisa Dubay, *Post-ACA*, *More Than One-Third of Women With Prenatal Medicaid Remained Uninsured Before Or After Pregnancy*, HEALTH AFFAIRS, 40 no. 4 571-578 (2021) https://www.healthaffairs.org/doi/pdf/10.1377/hlthaff.2020.01678. ³¹⁸ Howell Statement, at 2.

³¹⁹ Ibid; Cox Statement, at 4.

³²⁰ Howell EA, Egorova NN, Balbierz A, Zeitlin J, Hebert PL, "Site of delivery contribution to black-white severe maternal morbidity disparity," *Am J Obstet Gynecol*, Vol. 215, No. 2 (August 2016): 143–152, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4967380/; Howell EA, Egorova N, Balbierz A, Zeitlin J, Hebert PL, "Black-white differences in severe maternal morbidity and site of care," *Am J Obstet Gynecol*, Vol. 214, No. 1 (January 2016): e121–127, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4698019/ (while hospital quality is one factor contributing to disparities in maternal health outcomes, the CDC found that disparities persist when controlling for hospital quality and access to care).

Morales LS, Staiger D, Horbar JD, et al, "Mortality among very low-birthweight infants in hospitals serving minority populations," *Am J Public Health*, Vol. 95, No. 12 (December 2005): 2206–2212, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1449508/; Barnato AE, Lucas FL, Staiger D, Wennberg DE, Chandra A, "Hospital-level racial disparities in acute myocardial infarction treatment and outcomes," *Med Care*, Vol. 43, No. 4 (April 2005): 308–319, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2121607/; Stansbury JP, Jia H, Williams LS, Vogel WB, Duncan PW, "Ethnic disparities in stroke: epidemiology, acute care, and postacute outcomes," *Stroke*, Vol. 36, No. 2 (February 2005): 374–386; Elizabeth A. Howell, MD, MPP, "Reducing Disparities in Severe Maternal Mortality and Morbidity," *Obstet Gynecol*, Vol. 61, No. 2 (June 2018): 4, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5915910/.

³²² Creanga AA, Bateman BT, Mhyre JM, Kuklina E, Shilkrut A, Callaghan WM., "Performance of racial and ethnic minority-serving hospitals on delivery-related indicators," *Am J Obstet Gynecol*, Jun. 5, 2014; Elizabeth A. Howell, MD, MPP, "Reducing Disparities in Severe Maternal Mortality and Morbidity," *Obstet Gynecol*, Vol. 61, No. 2 (June 2018): 4, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5915910/.

³²³ Howell Statement, at 2; Howell EA, Egorova N, Balbierz A, Zeitlin J, Hebert PL, "Black-white differences in severe maternal morbidity and site of care," *Am J Obstet Gynecol*, Vol. 214, No. 1 (January 2016): e121–127, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4698019/.

Racial disparities in care persist across urban and rural parts of the country. For example, in New York City, Black women are more likely to deliver in hospitals with higher severe maternal morbidity rates, and this distribution may contribute to the racial disparity seen in severe maternal morbidity rates for Black women compared to those of White women.³²⁴ Recent examinations that aimed to quantify the impact of delivery location on the disparity of severe maternal morbidity found that the rate of severe maternal morbidity for Black and Latina women could be reduced significantly if women of color delivered at the same hospitals or went to hospitals in the same proportion as White women.³²⁵ Dr. Crear-Perry testified at the Commission's briefing about racial disparities in care, explaining:

As an OB/GYN, many of us are trained in the hospitals and facilities where there were only Black and Brown bodies. We assume, still, the legacy of history of eugenics that the people who we have to train on have to be, are communities of color, right?

So if you go to any place in your cities, in your town, the hospital training institutions are Black and Brown bodies. So what would it look like to be a structural system that said, training doesn't mean Black and Brown, training doesn't mean poor people, training doesn't mean non-centered people.

If we trained, we invest in, ensure that the people who need the most resource, so those communities, if you're talking Charity Hospital, where I train, or Grady Hospital in Atlanta, those patients actually need the most. They are the most complex patients and we are sending them to places where there is training.

We're not investing in those institutions so both Charity and Grady are always struggling to get budget, that's racism, that's structural. They're begging for money to even keep their doors open, and yet we're sending the most complex patients to those centers.³²⁶

Additionally, research has shown that Black and Latina women are more likely to experience severe maternal morbidity within the same hospital, after accounting for factors such as maternal age, obesity, hypertension, and diabetes.³²⁷

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³²⁴ Howell EA, Egorova NN, Balbierz A, Zeitlin J, Hebert PL, "Site of delivery contribution to black-white severe maternal morbidity disparity," *Am J Obstet Gynecol*, Vol. 215, No. 2 (August 2016): 143–152, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4967380/; Howell EA, Egorova N, Balbierz A, Zeitlin J, Hebert PL, "Black-white differences in severe maternal morbidity and site of care," *Am J Obstet Gynecol*, Vol. 214, No. 1 (January 2016): e121–127, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4698019/; Elizabeth A. Howell, MD, MPP, "Reducing Disparities in Severe Maternal Mortality and Morbidity," *Obstet Gynecol*, Vol. 61, No. 2 (June 2018): 4, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5915910/.

³²⁵ Elizabeth A. Howell, MD, MPP, "Reducing Disparities in Severe Maternal Mortality and Morbidity," *Obstet Gynecol*, Vol. 61, No. 2 (June 2018): 4, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5915910/; Howell EA, Egorova NN, Janevic T, Balbierz A, Zeitlin J, Hebert PL, "Severe Maternal Morbidity Among Hispanic Women in New York City: Investigation of Health Disparities," *Obstet Gynecol* Vol. 129 (2017):285-94.

³²⁶ Crear-Perry Testimony, Maternal Health Briefing, pp. 92-93.

In rural America, maternity care is disappearing from hospitals, with less than half of all rural hospitals providing maternity care.³²⁸ A recent study noted that a loss of hospital-based obstetrics services led to increases in out-of-hospital births, preterm births, or births in hospitals without any obstetrics services.³²⁹ The loss of maternity care in these hospitals can be attributed to physician shortages and low reimbursement for Medicaid³³⁰ due to low numbers of births in any given rural hospital.³³¹ As of 2008, only 6.4 percent of obstetrician-gynecologists worked in rural areas.³³² In addition, one study found that the maternal mortality rate is approximately 61 percent higher in rural areas than in more urban areas, which can be possibly attributed to underlying health conditions, poor prenatal care, and a lack of geographic access.³³³ Reductions in available healthcare services perpetuate racial disparities in health care, as many obstetrics services are being cut from hospitals that serve Black women in rural America, who experience some of the worst birth outcomes in the U.S.³³⁴

With regard to Native Americans, the federal Indian Health Service (IHS) also funds the Urban Indian Health Program, which receives federal funds to provide healthcare services to serve urban dwelling Native Americans.³³⁵ However, only one percent of the IHS budget is allocated

³²⁷ Howell Statement, at 2; Howell EA, Egorova NN, Janevic T, et al, "Race and Ethnicity, Medical Insurance, and Within-Hospital Severe Maternal Morbidity Disparities," *Obstet Gynecol*, Vol. 135 (2020): 285-93.

³²⁸ See supra note 288; Gaby Galvin, "Rural Mothers, Babies at Risk When Hospitals Cut Obstetric Services," US News and World Report, Jun. 13, 2019, https://www.usnews.com/news/healthiest-communities/articles/2019-06-13/what-happens-when-rural-communities-lose-their-hospital-maternity-care; Adriana Gallardo and Nina Martin, "Another Thing Disappearing From Rural America: Maternal Care," ProPublica, Sep. 5, 2017, https://www.propublica.org/article/another-thing-disappearing-from-rural-america-maternal-care; Dina Fine Maron, "Maternal Health Care Is Disappearing in Rural America," Scientific American, Feb. 15, 2017, https://www.scientificamerican.com/article/maternal-health-care-is-disappearing-in-rural-america/.

³²⁹ Katy B. Kozhimannil, PhD, MPA; Peiyin Hung, PhD, MSPH; Carrie Henning-Smith, PhD, MPH, MSW; et al, "Association Between Loss of Hospital-Based Obstetric Services and Birth Outcomes in Rural Counties in the United States," *JAMA*, Vol. 319, No. 12 (2018): 1239-1247, https://jamanetwork.com/journals/jama/fullarticle/2674780.

³³⁰ National Center for Health Statistics, Division of Vital Statistics, "Births: Final Data for 2018," *National Vital Statistics Reports*, Vol. 68, No. 13 (Nov. 27, 2019): p. 2, https://www.cdc.gov/nchs/data/nvsr/nvsr68/nvsr68_13-508.pdf. Medicaid paid for 42.3 percent of all births in the U.S. in 2018.

³³¹ Gaby Galvin, "Rural Mothers, Babies at Risk When Hospitals Cut Obstetric Services," *US News and World Report*, Jun. 13, 2019, https://www.usnews.com/news/healthiest-communities/articles/2019-06-13/what-happens-when-rural-communities-lose-their-hospital-maternity-care.

³³² American College of Obstetricians and Gynecologists, "Health Disparities in Rural Women," Committee Opinion No. 586, February 2014, https://www.acog.org/clinical/clinical-guidance/committee-opinion/articles/2014/02/health-disparities-in-rural-women.

³³³ Dina Fine Maron, "Maternal Health Care Is Disappearing in Rural America," *Scientific American*, Feb. 15, 2017, https://www.scientificamerican.com/article/maternal-health-care-is-disappearing-in-rural-america/.

³³⁴ Adriana Gallardo and Nina Martin, "Another Thing Disappearing From Rural America: Maternal Care," *ProPublica*, Sep. 5, 2017, https://www.propublica.org/article/another-thing-disappearing-from-rural-america-maternal-care; Crear-Perry Statement, at 7.

³³⁵ American College of Obstetricians and Gynecologists, "Health Care for Urban American Indian and Alaska Native Women," Committee Opinion No. 515, January 2012, p. 3, https://www.acog.org/clinical/clinical-guidance/committee-opinion/articles/2012/01/health-care-for-urban-american-indian-and-alaska-native-women.

to this healthcare program. The program serves a larger proportion of non-Native Americans due to these programs accepting supplementary funds such as Medicare, Medicaid, or private insurance which restricts these programs from limiting services to just Native Americans. 336 Clinics funded by this program reportedly lack electronic medical records, limiting data collection and reporting of statistics, particularly on Native Americans, for whom there is already a lack of data. 337 They also lack sufficient communication with referral facilities, adequate space, and consistent funding sources. Moreover, care is fragmented due to a lack of on-site resources such as radiology services or pharmacies which patients typically will have to pay for separately, out-of-pocket. 339

Bias and Implicit Bias in Healthcare

As discussed further below provider bias, both explicit and implicit, has been shown to be a significant factor in the creation and prolonging of disparities in maternal health care, as well as healthcare at large – often irrespective of socioeconomic status.

Data, as well as the personal accounts of women of color, point to significant differences in the character and quality of care from providers experienced between white mothers and mothers of color, particularly Black women. This includes administrative and relational disparities, such as longer wait times and decreased communication with the patients of color and their families. This also includes inconsistent differences in treatments and recommendations to patients (i.e. disproportionate overuse of the cesarean section, tendency on the part of maternity care providers to forgo centering patient preference and advocate for a specific treatments). Implicit bias also manifests itself in forms such as a lack of attention to the cultural and linguistic differences between patients and providers; and in approaches to addressing systemic racism in healthcare itself (i.e. attributing health disparities to intrinsic, individual characteristics of patients of color instead of focusing on eliminating bias).

Research suggests structural racism in the U.S. healthcare system must be addressed as a whole in order to effectively address the disparate impacts of bias.

³³⁶ Ibid.

³³⁷ U.S. Comm'n on Civil Rights, *Broken Promises: Continuing Federal Funding Shortfall for Native Americans*, p. 18, note 63, https://www.usccr.gov/pubs/2018/12-20-Broken-Promises.pdf.

³³⁸ Ibid.

³³⁹ American College of Obstetricians and Gynecologists, "Health Care for Urban American Indian and Alaska Native Women," Committee Opinion No. 515, January 2012, p. 3, https://www.acog.org/clinical/clinical-guidance/committee-opinion/articles/2012/01/health-care-for-urban-american-indian-and-alaska-native-women.

A substantial body of research indicates the role that implicit racial bias³⁴⁰ plays in creating and perpetuating racial disparities in healthcare.³⁴¹ U.S. Representative Ayanna Pressley encapsulated this point in testimony at the Commission's briefing, stating:

Access to healthcare is only part of the battle if we are truly going to address racial disparities in maternal health, we need to also confront systemic racism head on. Even Black women with access to healthcare with the highest levels of education, with fame and fortune, experience severe maternal morbidity. When Black women seek care, they are pushed into the cracks of a racist healthcare system that too often ignores our pain, our voices, and discounts our lives.³⁴²

Racial stereotypes can have a negative impact on the relationships between pregnant women of color and their physicians.³⁴³ Studies have shown different treatment among White patients and patients of color—possibly driven by healthcare providers' attitudes towards people of color—

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2219763/pdf/11606_2007_Article_258.pdf; Kelly M. Hoffman, Sophie Trawalter, Jordan R. Axt, M. Norman Oliver, "Racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between blacks and whites," *Proceedings of the National Academy of Sciences*, Vol. 113, No. 16 (Apr. 19, 2016): 1-6,

https://www.pnas.org/content/pnas/early/2016/03/30/1516047113.full.pdf; Erin Dehon PhD Nicole Weiss PhD Jonathan Jones MD Whitney Faulconer MD Elizabeth Hinton MSIS Sarah Sterling MD, "A Systematic Review of the Impact of Physician Implicit Racial Bias on Clinical Decision Making," *Society for Academic Emergency Medicine*, May 4, 2017, 895-904, https://onlinelibrary.wiley.com/doi/epdf/10.1111/acem.13214; William J. Hall, PhD, Mimi V. Chapman, PhD, Kent M. Lee, MS, Yesenia M. Merino, MPH, Tainayah W. Thomas, MPH, B. Keith Payne, PhD, Eugenia Eng, DrPH, Steven H. Day, MCP, and Tamera Coyne-Beasley, MD, "Implicit Racial/Ethnic Bias Among Health Care Professionals and Its Influence on Health Care Outcomes: A Systematic Review," *American Journal of Public Health*, Vol. 105, No. 12 (December 2015): e60-e-76.

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4638275/pdf/AJPH.2015.302903.pdf; Cox Statement, at 5; Howell Statement, at 2; Crear-Perry Statement, at 4; Jamila Taylor, Director of Health Care Reform and Senior Fellow, The Century Foundation, Testimony before the U.S. Senate Committee on Finance on Addressing America's Maternal Health Crisis, Apr. 3, 2020, https://tcf.org/content/commentary/testimony-recommendations-senate-addressing-americas-maternal-health-crisis/?session=1.

³⁴⁰ Implicit Bias can be defined as: "The unconscious attitudes, stereotypes and unintentional actions (positive or negative) towards members of a group merely because of their membership in that group." Anti-Defamation League, "Race, Perception and Implicit Bias" https://www.adl.org/education/resources/tools-and-strategies/table-talk/race-perception-and-implicit-bias (last accessed Apr. 6, 2021.)..).

³⁴¹ Institute of Medicine, "Unequal Treatment: What Healthcare Providers Need to Know About Racial and Ethnic Disparities in Health-Care," March 2002, pp. 10-12, https://www.nap.edu/resource/10260/disparities_providers.pdf; The American College of Obstetricians and Gynecologists, "Racial and Ethnic Disparities in Obstetrics and Gynecology," Committee Opinion No. 649, December 2015 (reaffirmed 2018), p. 2, https://www.acog.org/-/media/project/acog/acogorg/clinical/files/committee-opinion/articles/2015/12/racial-and-ethnic-disparities-in-obstetrics-and-gynecology.pdf; Alexander R. Green, MD, MPH, Dana R. Carney, PhD, Daniel J. Pallin, MD, MPH, Long H. Ngo, PhD, Kristal L. Raymond, MPH, Lisa I. Iezzoni, MD, MSc, and Mahzarin R. Banaji, PhD, "Implicit Bias among Physicians and its Prediction of Thrombolysis Decisions for Black and White Patients," *Journal of General Internal Medicine*, Vol. 22, No. 9 (September 2007): 1231-1238,

³⁴² Pressley Testimony, *Maternal Health Briefing*, p. 15.

³⁴³ Gabrielle T. Wynn, "The Impact of Racism on Maternal Health Outcomes for Black Women," *University of Miami Race & Social Justice Law Review*, Vol. 10, No. 1 (2019): 98, https://repository.law.miami.edu/umrsjlr/vol10/iss1/6/.

including healthcare providers spending less time with patients of color, keeping patients of color waiting longer for assessment or treatment, speaking to patients of color in a more condescending tone, failing to provide interpreters to Limited English Proficiency individuals, doing less diagnostic work for patients of color, recommending different treatment options for patients of color based on assumptions about their capability to adhere to the treatment, limiting visitation to families of patients of color, and others.³⁴⁴ A recent study of 1.8 million hospital births between 1992 and 2015 in Florida found the mortality rate of Black babies is cut roughly in half when the babies are cared for by Black doctors.³⁴⁵ However, researchers did not find a similar decrease in maternal mortality rates when Black women are cared for by Black doctors.³⁴⁶ The authors of the study posited that this difference may be explained by the lifetime effects of institutional racism.³⁴⁷ Similarly, the American medical education system may be propagating the effects of structural racism through the misuse of race in medical school curricula and misrepresentations of race in all aspects of medical school coursework.³⁴⁸ Jonathan Webb, CEO of the Association of Maternal & Child Health Programs, summarized this issue in his written testimony to the Commission:

If we are looking to really advance racial equity, we need to shift our conversation from eliminating racial and ethnic disparities in maternal and infant health specifically—which continues a focus and blame on people—to eliminating the systemic, structural, and institutional inequities that produce the racial disparities. We also need to acknowledge that these systems, structures, and institutions were not created to produce equitable outcomes for Black, Indigenous, Latinx, Pacific Islanders, and other People of Color. They are the products of systems created over time that create an advantaged group and a disadvantaged group, in part because communities of color have not had a seat at the table in the creation of these systems.³⁴⁹

³⁴⁴ William J. Hall, PhD, Mimi V. Chapman, PhD, Kent M. Lee, MS, Yesenia M. Merino, MPH, Tainayah W. Thomas, MPH, B. Keith Payne, PhD, Eugenia Eng, DrPH, Steven H. Day, MCP, and Tamera Coyne-Beasley, MD, *American Journal of Public Health*, Vol. 105, No. 12 (December 2015): e61, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4638275/pdf/AJPH.2015.302903.pdf.

³⁴⁵ Brad N. Greenwood, Rachel R. Hardemanb, Laura Huange, and Aaron Sojournerd, "Physician—patient racial concordance and disparities in birthing mortality for newborns" *Proceedings of the National Academy of Sciences of the United States of America*, Vol. 117, No. 35 (Sept. 1, 2020) https://l410c6d1-d135-4b4a-a0cf-5e7e63a95a5c.filesusr.com/ugd/c11158 150b03cf5fbb484bbdf1a7e0aabc54fb.pdf.

³⁴⁶ Ibid.

³⁴⁷ Ibid.

³⁴⁸ Christina Amutah, B.A., Kaliya Greenidge, Adjoa Mante, A.B., Michelle Munyikwa, Ph.D., Sanjna L. Surya, B.A., Eve Higginbotham, M.D., David S. Jones, M.D., Ph.D., Risa Lavizzo-Mourey, M.D., M.B.A., Dorothy Roberts, J.D., Jennifer Tsai, M.D., M.Ed., and Jaya Aysola, M.D., D.T.M.H., M.P.H., "Misrepresenting Race — The Role of Medical Schools in Propagating Physician Bias" *The New England Journal of Medicine*, (Jan. 6, 2021) https://www.nejm.org/doi/full/10.1056/NEJMms2025768.

³⁴⁹ Webb Statement at 3.

One member of the public who watched the Commission's briefing submitted a public comment after, stating:

Multiple participants in the briefing on Racial Disparities in Maternal Mortality attested to experiencing racial discrimination in healthcare settings or witnessing such discrimination against their clients. We need to trust the information that is being provided to us by the people who have been working to address racial disparities in maternal health for many years. These reports also should not be surprising, given information that has long been available in the Institute of Medicine's Report "Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care". It is clear that implicit bias among healthcare workers is an issue that should be addressed by any effort to reduce racial disparities in maternal health.³⁵⁰

One study found that patients of color are more likely to have their pain underestimated by providers, less likely to have their pain scores documented in their medical records, less likely to receive opioid analysesics, and more likely to have undertreated pain than White patients.³⁵¹

Similarly, the Colorado Advisory Committee to the Commission concluded bias in healthcare settings causes detrimental outcomes for Black patients, stating:

Maternal mortality in Colorado disproportionately impacts Black Women. Black women account for around five percent of all births in Colorado but make up around ten percent of all maternal deaths. This is due to the disparity in medical treatment that Black women – and Black patients in general – receive. According to testimony, Black women in emergency rooms are more likely to have their pain dismissed as non-serious, and Black babies are less likely than their white counterparts to receive a high level of care. 352

Another study surveyed White medical students and residents and found that those who falsely believe in inherent biological differences between Black and White people (half of the sample of 418 participants) were more likely to underestimate Black patients' pain severity. 353

³⁵⁰ Individual Public Comment 3 for the *Racial Disparities in Maternal Health Briefing* before the U.S. Comm'n on Civil Rights, pp. 2-3; *see generally*, Brian D. Smedley, Adrienne Y. Stith, Alan R. Nelson, Eds., *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, Institute of Medicine (US) Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care, (2003), https://pubmed.ncbi.nlm.nih.gov/25032386/.

³⁵¹ Alexie Cintron and Sean Morrison, "Pain and Ethnicity in the United States: A Systematic Review," *Journal of Palliative Medicine*, Vol. 9, No. 6 (2006): 1454-1473, https://pubmed.ncbi.nlm.nih.gov/17187552/.

³⁵² Advisory Memorandum on Maternal Mortality and Fetal/Infant Mortality, Colorado Advisory Committee to the U.S. Commission on Civil Rights, September 22, 2020, https://www.usccr.gov/files/2020-10-05-CO-Advisory-Memorandum-Maternal-Mortality-and-Fetal-Infant-Mortality-pdf, p. 3

³⁵³ Kelly M. Hoffman, Sophie Trawalter, Jordan R. Axt, M. Norman Oliver, "Racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between blacks and whites," *Proceedings of the National Academy of Sciences*, Vol. 113, No. 16 (Apr. 19, 2016): 1-6, https://www.pnas.org/content/pnas/early/2016/03/30/1516047113.full.pdf.

Representative Ayanna Pressley provided testimony to the Commission positing that the best evidence that racial disparities cannot be explained by socioeconomic status or access to healthcare alone comes from listening to the experiences of Black women, writing:

The best evidence is the experiences of Black women, from all walks of life, who consistently share that during their pregnancies or the pregnancies of their mothers, sisters, aunts, and best friends – they were dismissed when they told a healthcare professional about symptoms they were experiencing.

. . .

Income and wealth disparities should not be a death sentence. We cannot be more accepting of maternal mortality and morbidity for individuals with limited economic resources. But when even high wealth and high access is failing Black mothers, our narrative about maternal health must shift.

The common thread is that when Black women—regardless of income—enter healthcare settings, their experiences are ignored, their pain is invalidated, and their voices are unheard. Black women's experiences with chronic racism have serious impacts on their health throughout their life course, and especially during pregnancy. For pregnant individuals, elevated and prolonged stress, anger, and sadness from experiencing racism erodes the health of both mother and child.³⁵⁴

A survey conducted in California to learn about women's childbearing experiences found that 11 percent of Black women reported being treated unfairly by health care providers during their hospital stay based on their race or ethnicity, as compared to eight percent of Asian/Pacific Islander women, five percent of Latinas, and fewer than one percent of White women reporting unfair treatment.³⁵⁵ The survey also reported that compared to White women, more Black and Asian women felt that a nurse or maternity care provider used harsh, rude, or threatening language, or handled them roughly during their hospital stay.³⁵⁶ Nicolle Gonzales of the Changing Women Initiative testified about the discrimination that Native American face in seeking treatment:

During the 2 years I spent working at the Santa Fe Indian Hospital, I myself experienced lateral violence by white higher-ranking nurses overseeing my employment there. I

³⁵⁴ U.S. Representative Ayanna Pressley, Response to Follow-Up Questions from the U.S. Comm'n on Civil Rights, p. 2 (available at https://www.usccr.gov/pubs/briefing-reports/2020-11-13-Racial-Disparities-in-Maternal-Health.php).

³⁵⁵ National Partnership for Women & Families, *Listening to Mothers in California: A Population-Based Survey of Women's Childbearing Experiences*, p. 64, https://www.chcf.org/wp-content/uploads/2018/09/ListeningMothersCAFullSurveyReport2018.pdf?utm_source=National%20Partnership&utm_edium=PDF_Link&utm_campaign=Listening%20to%20Mothers.
356 Ibid., 66.

witnessed unnecessary placement of 16 gauge IVs in Native American women by white nurses who used "fear" as their primary motive for excessive medical use of abnormally large IV needles, that were not backed by current hospital polices. The "harm" done to Native American women was unconsented and not informed care, with the excessive use of a medical devices like the IV needle, resulting in increased pain with placement.

While most of my time was working night shift in the small hospital, the nights would get cold in the winter, to the point where I had to wear long-johns under my scrubs. One of the first pregnant women I took care of on the OB floor was someone from the community. There was a lot of concern by the other nurses regarding this patient, because the story was that her baby had died in childbirth at that hospital last year, and here she was again having another child there again. Because this woman was from my community, I went in and asked her why she came back to have another baby there, knowing what happened the year before. She said "I didn't feel like I could go anywhere else."

On another occasion, I overheard the white nurse-midwives be proud of a recent birth they had attended of a woman who was from my community and was their patient. The conversation from the midwives was related to how the Native patient was so stoic in her birth and didn't need pain medication. When I spoke to this community member about her birth experience, she said to me "I wanted pain medicine and I asked for it, but the midwives just told me to go walk instead." ³⁵⁷

Jennifer Jacoby, Federal Policy Counsel at the Center for Reproductive Rights, testified to the Commission about her own lived experience during childbirth:

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

³⁵⁷ Gonzales Statement at 1-2 (cleaned up).

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 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. 358

While cesarean section births can be life-saving for both the fetus and/or the mother, the American College of Obstetricians and Gynecologists has recommended against the overuse of cesarean section births for all women, indicating that "the rapid increase in cesarean birth rates from 1996 to 2011 without clear evidence of concomitant decreases in maternal or neonatal morbidity or mortality raises significant concern that cesarean delivery is overused."³⁵⁹ Research has shown that cesarean deliveries for low-risk pregnancies pose a greater risk of maternal mortality and morbidity than vaginal births.³⁶⁰ The California survey described above reported that Black women experience higher rates of cesarean section births (42 percent) than White women (29 percent), ³⁶¹ and these results are echoed at the national level, where 36 percent of Black women have cesarean section births as compared to 30.9 percent of White women. 362

The American College of Obstetricians and Gynecologists states that shared decision making in maternity care is patient-centered care that involves a process in which patients and healthcare

³⁵⁸ Jacoby Statement at 3-4.

³⁵⁹ American College of Obstetricians and Gynecologists, "Safe Prevention of the Primary Cesarean Delivery," Obstetric Care Consensus No. 1, March 2014, p. 1, https://www.acog.org/-/media/project/acog/acogorg/clinical/files/obstetric-care-consensus/articles/2014/03/safe-prevention-of-the-primarycesarean-delivery.pdf.

³⁶⁰ Ibid., 1-2; Steven L. Clark, MD; Michael A. Belfort, MD; Gary A. Dildy, MD; Melissa A. Herbst, MD; Janet A. Meyers, RN; Gary D. Hankins, MD, "Maternal death in the 21st century: causes, prevention, and relationship to cesarean delivery," American Journal of Obstetrics & Gynecology, Vol. 199 (July 2008): 36.e1-36.e5, https://www.ajog.org/action/showPdf?pii=S0002-9378%2808%2900268-8.

³⁶¹ National Partnership for Women & Families, Listening to Mothers in California: A Population-Based Survey of Women's Childbearing Experiences, p. 56, https://www.chcf.org/wpcontent/uploads/2018/09/ListeningMothersCAFullSurveyReport2018.pdf?utm source=National%20Partnership&ut m medium=PDF Link&utm campaign=Listening%20to%20Mothers.

³⁶² Jamila Taylor, Cristina Novoa, Katie Hamm, and Shilpa Phadke, Eliminating Racial Disparities in Maternal and Infant Mortality, Center for American Progress, May 2, 2019, https://www.americanprogress.org/issues/women/reports/2019/05/02/469186/eliminating-racial-disparitiesmaternal-infant-mortality/.

providers share information, values, treatment preferences, and collaboratively arrive at a treatment plan, including a birth plan.³⁶³ The College maintains that shared decision making should ideally start during antenatal care and continue throughout birth, with regular visits to build a relationship and navigate complex care decisions.³⁶⁴ While it has been linked with increased patient satisfaction, improved health outcomes, and lower healthcare costs,³⁶⁵ data show that this process is vulnerable to bias and can be met with a number of barriers.³⁶⁶ Since maternity care is complex, patients often have inadequate knowledge to make informed decisions.³⁶⁷

A recent study found that maternity care providers tend to give patients disproportionate information in favor of specific interventions rather than center the discussion around the patient's preferences. For example, 47 percent of women who were told their baby might be large reported a discussion about possible labor induction versus waiting for labor; and 87 percent of women who have had one or more previous cesarean section births and had a discussion about a repeat cesarean section wound up having one compared to women who did not have that discussion with their doctor. Additionally, 27 percent of women who had

³⁶³ American College of Obstetricians and Gynecologists, "Committee Opinion No. 587: Effective Patient-Physician Communication," February 2014, https://www.acog.org/clinical/clinical-guidance/committee-opinion/articles/2014/02/effective-patient-physician-communication.

³⁶⁴ Marianne J Nieuwenhuijze, Irene Korstjens, Ank de Jonge, Raymond de Vries, and Antoine Lagro-Janssen, "On speaking terms: a Delphi study on shared decision-making in maternity care," *BMC Pregnancy and Childbirth*, Vol. 14 (2014): 1, https://bmcpregnancychildbirth.biomedcentral.com/track/pdf/10.1186/1471-2393-14-223; Birthtools.org, "Shared Decision-Making," https://birthtools.org/Shared-Decision-Making.

³⁶⁵ Boston University School of Public Health, "Lack of Shared Decision-Making in Maternity Care," August 2, 2018, https://www.bu.edu/sph/2018/08/02/lack-of-shared-decision-making-in-maternity-care/.

³⁶⁶ American College of Nurse-Midwives, "Shared Decision Making in Midwifery Care," http://www.midwife.org/acnm/files/ACNMLibraryData/UPLOADFILENAME/000000000305/Shared-Decision-Making-in-Midwifery-Care-10-13-17.pdf; Keith Begley PhD, Deirdre Daly PhD, Sunita Panda MSc, Cecily Begley PhD, "Shared decision-making in maternity care: Acknowledging and overcoming epistemic defeaters," *Journal of Evaluation in Clinical Practice*, Vol. 25 (Jul. 5, 2019): 1113-1120, https://onlinelibrary.wiley.com/doi/epdf/10.1111/jep.13243.

³⁶⁷ Birthtools.org, "Shared Decision-Making," https://birthtools.org/Shared-Decision-Making; Gee, Rebekah E., MD, MPH; Corry, Maureen P., MPH, "Patient Engagement and Shared Decision Making in Maternity Care," *Obstetrics and Gynecology*, Vol. 120, No. 5 (November 2012): 995, https://journals.lww.com/greenjournal/pages/articleviewer.aspx?year=2012&issue=11000&article=00003&type=Citation&sessionEnd=true, respectively.

³⁶⁸ Boston University School of Public Health, "Lack of Shared Decision-Making in Maternity Care," August 2, 2018, https://www.bu.edu/sph/2018/08/02/lack-of-shared-decision-making-in-maternity-care/; Eugene R. Declercq PhD, Erika R. Cheng PhD, MPA, Carol Sakala PhD, MSPH, "Does maternity care decision-making conform to shared decision- making standards for repeat cesarean and labor induction after suspected macrosomia?," *Birth Issues in Prenatal Care*, Vol. 45, No. 3 (September 2018): 236-244, https://onlinelibrary.wiley.com/doi/abs/10.1111/birt.12365.

³⁶⁹ Eugene R. Declercq PhD, Erika R. Cheng PhD, MPA, Carol Sakala PhD, MSPH, "Does maternity care decision-making conform to shared decision-making standards for repeat cesarean and labor induction after suspected macrosomia?," *Birth Issues in Prenatal Care*, Vol. 45, No. 3 (September 2018): 236-244, https://onlinelibrary.wiley.com/doi/abs/10.1111/birt.12365.

previous cesarean sections and 18 percent of mothers told that their babies were large indicated that their providers had not fully explained their choices or that they even had choices. This study also noted that women who had repeat cesarean sections without prior discussion were most likely to be lower-income, Latina women without a college degree. Another study reported similar disparities, where Black women without a college degree reported low levels of shared decision making, and shared decision making odds were particularly low for Black women who delivered via cesarean section. Transle Shirazian, Founder and President of Saving Mothers and practicing gynecologic surgeon and Associate Professor at New York University Langone Medical Center, testified to this point at the Commission's briefing:

Systemic racism is one of the challenges affecting Black women and maternal mortality in New York State. Saving Mothers has repeatedly demonstrated that when you advance [training of healthcare workers], the health workers, the doulas, the community health workers, the birth attendants and the mothers understanding of basic medical information and hone their communication and advocacy skills, the result is a self-sustaining resilience in families and communities. We've demonstrated this in Guatemala, Kenya and around the globe.³⁷³

While the effects of explicit bias are often conscious, implicit bias often has unconscious effects, which may not be easily acknowledged or controlled.³⁷⁴ Disparities can also stem from "subtle ambiguities in practitioners' and patients' interpretations of medical information because of cultural and language differences."³⁷⁵ With regard to systemic racism in obstetrics and gynecology, one article pointed out the skewed focus on the shortcomings of pregnant women of color as opposed to addressing bias on the part of practitioners, and noted the experience of Black women:

³⁷⁰ Boston University School of Public Health, "Lack of Shared Decision-Making in Maternity Care," August 2, 2018, https://www.bu.edu/sph/2018/08/02/lack-of-shared-decision-making-in-maternity-care/.

³⁷² Laura B. Attanasio, Ph.D., Katy B. Kozhimannil, Ph.D., M.P.A., and Kristen H. Kjerulff, Ph.D., M.A., "Factors influencing women's perceptions of shared decision making during labor and delivery: Results from a large-scale cohort study of first childbirth," *Patient Education Counseling*, Vol. 101, No. 6 (January 2018): 1130-1136, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5977392/.

³⁷³ Shirazian Testimony, *Maternal Health Briefing* at 74-75.

³⁷⁴ Kelly M. Hoffman, Sophie Trawalter, Jordan R. Axt, M. Norman Oliver, "Racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between blacks and whites," *Proceedings of the National Academy of Sciences*, Vol. 113, No. 16 (Apr. 19, 2016): 1-6, https://www.pnas.org/content/pnas/early/2016/03/30/1516047113.full.pdf.

³⁷⁵ The American College of Obstetricians and Gynecologists, "Racial and Ethnic Disparities in Obstetrics and Gynecology," Committee Opinion No. 649, December 2015 (reaffirmed 2018), p. 3, https://www.acog.org/-/media/project/acog/acogorg/clinical/files/committee-opinion/articles/2015/12/racial-and-ethnic-disparities-in-obstetrics-and-gynecology.pdf.

It seems that, rather than addressing systemic racism in obstetrics and gynecology, medical practitioners have instead to some extent emphasized all of the ways Black women allegedly make themselves prone to being ill during their pregnancies. Black pregnant women and non–gender binary folks are told their fatness, advanced age, dietary choices, and lack of prenatal care have increased their chances of dying during childbirth. Yet, whereas Black pregnant people and mothers are made into culprits and the initiators of their deaths, doctors, nurses, and the hospitals they run are not looked at as critically as they should be.³⁷⁶

Some experts suggest that disparities in maternal healthcare could be reduced by adopting more "culturally congruent" maternity care in the U.S., and by increasing workforce diversity.³⁷⁷ Healthcare providers of color can help "mitigate cultural barriers" in the healthcare system in the U.S., but the lack of workforce diversity can impede that effort.³⁷⁸ For example, a recent report indicated that "Black physicians are more likely than White physicians to serve medically underserved areas and populations and have been shown to increase access to health care for Black patients, earn higher levels of patient trust and satisfaction, and in some cases, spend more time with Black patients than White physicians do."³⁷⁹ Black and Latino individuals make up almost a third of the U.S. population,³⁸⁰ yet Black and Latino healthcare professionals each make up only 3 to 6 percent of the total,³⁸¹ and only about nine percent of physicians identify as Black, Latino, or Native American.³⁸²

³⁷⁶ Deirdre Cooper Owens PhD, and Sharla M. Fett PhD, "Black Maternal and Infant Health: Historical Legacies of Slavery," *American Journal of Public Health*, Vol. 109, No. 10 (October 2019): 1342-1345, https://ajph.aphapublications.org/doi/10.2105/AJPH.2019.305243.

³⁷⁷ Crear-Perry Statement, at 4; U.S. Rep. Pressley, testimony *Maternal Health Briefing*, p. 16; Moore testimony, *Maternal Health Briefing*, pp. 30, 48 (Moore defines culturally congruent care as "...taking in account the values, beliefs, and preferences of the individual, being aware of it. Not imposing your own beliefs, values, and preferences as clinicians within the healthcare system. Hearing where they're at, what they need, what they want, and being responsive to that."); Shirazian testimony, *Maternal Health Briefing*, p. 88; Porchia-Albert, testimony, *Maternal Health Briefing*, p. 118.

³⁷⁸ Center for Reproductive Rights, "Research Overview of Maternal Mortality and Morbidity in the United States," p. 6,

https://www.reproductiverights.org/sites/crr.civicactions.net/files/documents/USPA_MH_TO_ResearchBrief_Final_5.16.pdf.

³⁷⁹ Ibid.

³⁸⁰ William H. Frey, "Six maps that reveal America's expanding racial diversity," *Brookings*, Sep. 5, 2019, https://www.brookings.edu/research/americas-racial-diversity-in-six-maps/?gclid=CjwKCAjw1v_0BRAkEiwALFkj5qRsLTszjhfWrQVI1KGWecfl0FQgVzyAN0MDD6-VJXHBbKk0_NmfkxoCWsoQAvD_BwE.

³⁸¹ Kevin Grumbach and Rosalia Mendoza, "Disparities In Human Resources: Addressing The Lack Of Diversity In The Health Professions," *Health Professions*, Vol. 27, No. 2 (March/April 2008): 413-422, https://www.wiche.edu/info/rmCollaborative/Grumbach.pdf.

³⁸² Health eCareers, "Minorities in Medicine: A Look at Physician Diversity," Apr. 25, 2018, https://www.healthcareers.com/article/healthcare-news/minorities-in-medicine-a-look-at-physician-diversity.

Over the past few years, ProPublica and National Public Radio have collected hundreds of stories of mothers who have died in childbirth or of pregnancy-related complications. Their series of articles surrounding this topic, called *Lost Mothers*, seeks to address the issue of maternal mortality in the U.S., and has specifically highlighted the racial disparities that affect women of color, particularly Black women. One of their studies focusing on Black mothers who experienced fatal complications to pregnancy identified a common theme: these women expressed feelings of being "devalued and disrespected by medical providers." This bias also transcends social status, income, or education; all women of color are at risk, with Black women often experiencing the brunt of the impact, including:

The young Florida mother-to-be whose breathing problems were blamed on obesity when in fact her lungs were filling with fluid and her heart was failing. The Arizona mother whose anesthesiologist assumed she smoked marijuana because of the way she did her hair. The Chicago-area businesswoman with a high-risk pregnancy who was so upset at her doctor's attitude that she changed OB-GYNs in her seventh month, only to suffer a fatal postpartum stroke. . .. Over and over, black women told of medical providers who equated being African American with being poor, uneducated, noncompliant and unworthy. 386

In testimony to the Commission, Nan Strauss of Every Mother Counts wrote:

Evidence has repeatedly and consistently shown that racial disparities in maternal health outcomes cannot be explained by any variable other than race. Data demonstrates significant disparities at all socio-economic levels as indicated by educational attainment, income level, and access to healthcare.³⁸⁷

Similarly, Jennifer Jacoby of the Center for Reproductive Rights wrote:

Data suggests that maternal health disparities have complex causes and that, while socioeconomic inequality and unequal access to health care may contribute, racial disparities in maternal mortality and morbidity cannot be explained by socioeconomic

³⁸³ Nina Martin, Emma Cillekens and Alessandra Freitas, "Lost Mothers," *ProPublica*, Jul. 17, 2017, https://www.propublica.org/article/lost-mothers-maternal-health-died-childbirth-pregnancy.

³⁸⁴ "Lost Mothers: Maternal Care and Preventable Deaths," *ProPublica*, https://www.propublica.org/series/lost-mothers.

³⁸⁵ Nina Martin, ProPublica and Renee Montagne, NPR News, "Nothing Protects Black Women From Dying in Pregnancy and Childbirth," *ProPublica*, Dec. 7, 2017, https://www.propublica.org/article/nothing-protects-black-women-from-dying-in-pregnancy-and-childbirth.

³⁸⁶ Nina Martin, ProPublica and Renee Montagne, NPR News, "Nothing Protects Black Women From Dying in Pregnancy and Childbirth," *ProPublica*, Dec. 7, 2017, https://www.propublica.org/article/nothing-protects-black-women-from-dying-in-pregnancy-and-childbirth.

³⁸⁷ Nan Strauss, J.D., Managing Director of Policy, Advocacy, and Grantmaking, Every Mother Counts, Response to Follow-Up Questions from the U.S. Comm'n on Civil Rights, Jan. 8, 2021, p. 1.1.1 (available at https://www.usccr.gov/pubs/briefing-reports/2020-11-13-Racial-Disparities-in-Maternal-Health.php).

status and access to health care alone. Moreover, the majority of pregnancy-related deaths are preventable, and a national study of five specific pregnancy complications found that Black women were two to three times more likely to die from pregnancy complications than white women, even though Black and white women in the study had a similar prevalence of complications. Based on this evidence, the CDC has concluded that quality of care likely has a role in pregnancy-related deaths and associated racial disparities."

Other research studies have reached similar conclusions, finding that Black women disproportionately deliver in lower quality hospitals with higher risk-adjusted severe maternal morbidity rates, compared to white women, and report higher rates of mistreatment and discrimination during maternity care. Implicit bias and discrimination in maternity care can lead to the dismissal of serious health care concerns and overuse of procedures with increased complications and negative health outcomes, such as cesarean sections, for Black women. The most recent evidence base, including CDC research, indicates that racial disparities in maternal health is a more complicated national problem than health care access alone and that structural racism in the U.S. health care system is a significant contributing factor. 388

While science has long debunked theories about biological differences among the races to explain higher rates of maternal mortality, ³⁸⁹ research shows evidence of the chronic effect of the stress of racism. ³⁹⁰ This concept is referred to as "weathering," and it can impact the health of women of color during all stages of life, including pregnancy, childbirth, and postpartum. ³⁹¹ Research has shown that Black women suffer the burden of this stress, compared to White women. ³⁹² Dr. Arlene Geronimus, who has pioneered this research and coined the term "weathering," described the term as a metaphor for what she believed was happening to Black women's bodies. Geronimus stated that she "meant for *weathering* to evoke a sense of erosion by constant stress. But also, importantly, the ways that marginalized people and their communities coped with the drumbeat of big and small stressors that marked their lives." ³⁹³ As Shanna Cox noted in testimony to the Commission, data show that while maternal mortality and morbidity

³⁸⁸ Jennifer Jacoby, J.D., Federal Policy Counsel, Center for Reproductive Rights, Response to Follow-Up Questions from the U.S. Comm'n on Civil Rights, Jan. 8, 2021, pp. 1-2.1-2.1-2 (available at https://www.usccr.gov/pubs/briefing-reports/2020-11-13-Racial-Disparities-in-Maternal-Health.php).

³⁸⁹ Patti Neighmond, "Why Racial Gaps In Maternal Mortality Persist," *NPR*, May 10, 2019, https://www.npr.org/sections/health-shots/2019/05/10/722143121/why-racial-gaps-in-maternal-mortality-persist.

³⁹⁰ Arline T. Geronimus, ScD, Margaret Hicken, MPH, Danya Keene, MAT, and John Bound, PhD, "'Weathering' and Age Patterns of Allostatic Load Scores Among Blacks and Whites in the United States," *American Journal of Public Health*, Vol. 96, No. 5 (May 2006): 826-833, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1470581/. ³⁹¹ Ibid.

³⁹² Ibid.

³⁹³ Gene Demby, "Making The Case That Discrimination Is Bad For Your Health," *The Code Switch Podcast, NPR*, Jan. 14, 2018, https://www.npr.org/sections/codeswitch/2018/01/14/577664626/making-the-case-that-discrimination-is-bad-for-your-health (emphasis in original).

increase with age, there are sharper increases in maternal morbidity and mortality among Black and American Indian/Alaskan Native women.³⁹⁴

Her research also found that weathering can occur across socioeconomic status, finding that financial security does not necessarily counteract the psychological stressors of racism that can have negative impacts on health over time. Similarly, Jonathan Webb of the Association of Maternal & Child Health Programs provided testimony to the Commission about the effect of social determinants of health, writing:

[F]or decades, we have looked at race as a factor in determining or predicting potential health outcomes. ... Several decades ago, we began with looking at the social determinants of health (SDOH)—the conditions in the places where people live, learn, work, and play that have an effect on a wide range of health, quality-of life-risks and outcomes... more recent research has recognized that the environments in which people live and develop (SDOH) and the lifetime experiences that impact their health and [maternal and child health] outcomes (LCT) are influenced by racism. Structural racism exists in every major system (healthcare, education, housing, workplace, child welfare and criminal justice), and causes intergenerational stress for the people it impacts and likewise determines the investments/policies that support or hinder community well-being. 396

Impacts on Children, Families, and Communities

Maternal mortality and morbidity have wide-ranging impacts on not only children and families, but also their communities. U.S. Representative Ayanna Pressley testified to the Commission about how her grandmother's death in childbirth had long lasting impacts on her family, stating:

You know, I should say my paternal grandmother I never had the blessing to know because she died in the 1950s giving birth to my father's youngest brother, sending their – my father and his five siblings into a downward spiral of great trauma and hardship.

And the fact that my grandmother died in childbirth in the 1950s and Black women are four times more likely to still die really is just, you know, condemnation and confirmation of the embedded biases and systemic racism throughout our healthcare system.³⁹⁷

³⁹⁴ Cox Testimony, Maternal Health Briefing at 2.

³⁹⁵ Patia Braithwaite, "Biological Weathering and Its Deadly Effect on Black Mothers," *Self*, Sep. 30, 2019, https://www.self.com/story/weathering-and-its-deadly-effect-on-black-mothers.

³⁹⁶ Webb Statement at 2.

³⁹⁷ Pressley Statement, *Maternal Health Briefing*, p. 18.

Research from around the world has shown that the loss of a mother can have a multigenerational ripple effect, with negative physical, economic, social, and emotional consequences for her family.³⁹⁸ In some cases, pregnancy complications may have an impact on the health of the infant.³⁹⁹ Spouses, partners, or other family members are left to shoulder the burden of childcare responsibilities as well as provide financially for a child, and may experience lost income due to the death of the mother, as well as potential debt due to hospital bills and funeral costs.⁴⁰⁰ The U.S. does not require parental leave, and there are few states and localities that have implemented parental leave policies, which can be hard to manage for spouses or partners left to shoulder the burden alone.⁴⁰¹ At the same time, families are dealing with the grief for the loss of a loved one, which in and of itself is a huge burden.⁴⁰² Charles Johnson, Founder of 4Kira4Moms, experienced the loss of his wife, Kira Johnson, due to complications from a cesarean section birth of their second son.⁴⁰³ He said of his life after Kira's death:

Kira and I were partners in every sense of the word . . . but I found myself being thrust into this new reality of being a single dad of two VERY small children and trying to figure it out. I knew that I couldn't replace her; I had to step into that gap as best I could, and I was going to change every single diaper, fill every bottle, and I was not going to let Langston [their baby] out of my sight. 404

While the partner's role can change dramatically following the loss of their child's parent, roles for other family members can change as well in the aftermath, including grandparents, aunts, uncles, and siblings. 405 In some cases, extended family members may be able to provide childcare and other support. 406 However, especially if the mother was the primary breadwinner

³⁹⁸ Suellen Miller and José M Belizán, "The true cost of maternal death: individual tragedy impacts family, community and nations," *Reproductive Health*, Vol. 12, No. 56 (2015): 1-4, https://link.springer.com/content/pdf/10.1186/s12978-015-0046-3.pdf.

³⁹⁹ Ibid.

⁴⁰⁰ Ibid., 2; Ben Schwartz, "A new normal: How families and fathers are affected by maternal mortality," *Contemporary OB/GYN*, Sep. 12, 2018, https://www.contemporaryobgyn.net/article/new-normal-how-families-and-fathers-are-affected-maternal-mortality; U.S. Department of Labor, Women's Bureau, Labor Force Participation Rate by Sex, Race and Hispanic Ethnicity, 2016 Annual Averages, https://www.dol.gov/agencies/wb/data/latest-annual-data/labor-force-participation-rates.

⁴⁰¹ Ben Schwartz, "A new normal: How families and fathers are affected by maternal mortality," *Contemporary OB/GYN*, Sep. 12, 2018, https://www.contemporaryobgyn.net/article/new-normal-how-families-and-fathers-are-affected-maternal-mortality; Adam Bulger, "What Are the Laws Around Paternity Leave and Family Leave in the U.S.?," *Fatherly*, Feb. 19, 2020, https://www.fatherly.com/love-money/paternity-leave-laws-state-us/.

⁴⁰² Jacqueline Howard, "When women die in childbirth, these are the fathers left behind," *CNN*, Feb. 22, 2020, https://www.cnn.com/2020/02/21/health/maternal-mortality-fathers-grief/index.html.

⁴⁰³ See "Who We Are," 4Kira4Moms, https://4kira4moms.com/home/#mission.

⁴⁰⁴ Ben Schwartz, "A new normal: How families and fathers are affected by maternal mortality," *Contemporary OB/GYN*, Sep. 12, 2018, https://www.contemporaryobgyn.net/article/new-normal-how-families-and-fathers-are-affected-maternal-mortality.

⁴⁰⁵ Ibid.

⁴⁰⁶ Ibid.

in the household, the child may be sent to live with other relatives if the partner was not a presence in the mother's life. 407

Since data show that women of color are most likely to die from pregnancy-related complications, children and families of color, particularly Black children and families, are more severely impacted by these deaths. Fifty-four percent of Black children in the U.S. live with only one parent—typically the mother who gave birth to the child—as compared to 13 percent of Asian children, 19 percent of White children, 29 percent of Latinx children, and 38 percent of Native American children. In addition, Black mothers are more likely to be in the workforce than mothers of any other race, with over 70 percent of Black mothers in the workforce with a child under the age of 3. Furthermore, 74 percent of Black mothers are the primary breadwinners of their family, so "[n]ot only are these mothers more at risk, but if tragedy does strike, their surviving immediate family members lose their primary breadwinner and often lack the support system within the family structure to adapt."

While no specific study has been conducted to calculate the total cost of maternal mortality, some maternal mortality experts suggest that based on available data, working to prevent pregnancy-related deaths and severe maternal morbidity would also save billions of dollars each year. Costs associated with the treatment of pregnancy-associated complications and conditions can run into the billions, at the expense of women, their families, and the healthcare system. For example, a group of researchers including obstetricians and gynecologists and

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⁴⁰⁷ Ibid.

⁴⁰⁸ See supra notes 166-167.

⁴⁰⁹ Pew Research Center, *The American Family Today*, Dec. 17, 2015, https://www.pewsocialtrends.org/2015/12/17/1-the-american-family-today/; Ben Schwartz, "A new normal: How families and fathers are affected by maternal mortality," *Contemporary OB/GYN*, Sep. 12, 2018, https://www.contemporaryobgyn.net/article/new-normal-how-families-and-fathers-are-affected-maternal-mortality.

⁴¹⁰ National Center for Education Statistics, "Indicator 3: Children's Living Arrangements," Figure 3.1.,

⁴¹⁰ National Center for Education Statistics, "Indicator 3: Children's Living Arrangements," Figure 3.1., https://nces.ed.gov/programs/raceindicators/indicator_RAC.asp.

⁴¹¹ Daniella Zessoules, Annie McGrew, and Michael Madowitz, "The State of the U.S. Labor Market for Mothers: Pre-May 2018 Jobs Release," *Center for American Progress*, May 30, 2018, https://www.americanprogress.org/issues/economy/news/2018/05/30/451414/state-u-s-labor-market-mothers-pre-may-2018-jobs-release/.

⁴¹² U.S. Department of Labor, Women's Bureau, Labor Force Participation Rate by Sex, Race and Hispanic Ethnicity, 2016 Annual Averages, https://www.dol.gov/agencies/wb/data/latest-annual-data/labor-force-participation-rates; Ben Schwartz, "A new normal: How families and fathers are affected by maternal mortality," *Contemporary OB/GYN*, Sep. 12, 2018, https://www.contemporaryobgyn.net/article/new-normal-how-families-and-fathers-are-affected-maternal-mortality.

⁴¹³ Ben Schwartz, "A new normal: How families and fathers are affected by maternal mortality," *Contemporary OB/GYN*, Sep. 12, 2018, https://www.contemporaryobgyn.net/article/new-normal-how-families-and-fathers-are-affected-maternal-mortality.

⁴¹⁴ Katherine Ellison and Nina Martin, "Nearly Dying In Childbirth: Why Preventable Complications Are Growing In U.S.," *NPR*, Dec. 22, 2017, https://www.npr.org/2017/12/22/572298802/nearly-dying-in-childbirth-why-preventable-complications-are-growing-in-u-s.

⁴¹⁵ Ibid.

policy experts estimated in a journal publication that the cost of treating preeclampsia in the United States each year is over \$1 billion. However, the cost is so much more than just financial; there is also the human toll that is taken when a mother suffers pregnancy-related complications. Dr. Moore of the Institute for Medicaid Innovation estimates that \$114 to \$214 of saving to Medicaid would be realized if the racial disparities in maternal outcomes were reduced. 417

Action to Address Racial Disparities in Maternal Health

In recent years, the issue of maternal mortality, morbidity, and racial disparities in maternal health care—particularly as it affects Black women—has become national attention, due to the high rates of maternal death among women of color, particularly Black and Native women. 418 Celebrities such as Beyoncé and Serena Williams have spoken out about surviving potentially fatal pregnancy complications. 419 Beyoncé suffered from preeclampsia and delivered twins via emergency cesarean section after being bedridden for a month. 420 Serena Williams developed a pulmonary embolism after having a cesarean section, and after intense coughing ripped open her wound and prompted surgery, doctors also found a large hematoma in her abdomen. 421 Six-time Olympic gold medalist Allyson Felix developed a severe case of preeclampsia and had to have an emergency cesarean section at 32 weeks. 422 In May of 2019, U.S. Olympic track and field gold-medalist Allyson Felix testified before the Ways and Means Committee of the U.S. House of Representatives on the topic of racial disparities in maternal mortality, stating that:

⁴¹⁶ Ibid.; Warren Stevens, PhD, Tiffany Shih, PhD, Devin Incerti, PhD, George A. Macones, MD, Baha M. Sibai, MD, Anupam B. Jena, MD, PhD, "Short-term costs of preeclampsia to the United States health care system," *American Journal of Obstetrics and Gynecology*, Vol. 217, No. 3 (Jul. 11, 2017): 237-248, https://www.ajog.org/article/S0002-9378(17)30561-6/fulltext.

⁴¹⁷ Testimony of Dr. Moore, et al, Zhang, S hang, S., Cardarelli, K., Shim, R., Ye, J., Booker, K. L., & Rust, G. (2013). Racial disparities in economic and clinical outcomes of pregnancy among Medicaid recipients. Maternal and Child Health Journal, 17(8), 1518–1525.

⁴¹⁸ Centers for Disease Control and Prevention, "Racial and Ethnic Disparities Continue in Pregnancy-Related Deaths," Sept. 5, 2019, https://www.cdc.gov/media/releases/2019/p0905-racial-ethnic-disparities-pregnancy-deaths.html; Roni Caryn Rabin, "Huge Racial Disparities Found in Deaths Linked to Pregnancy," *The New York Times*, May 7, 2019, https://www.nytimes.com/2019/05/07/health/pregnancy-deaths-.html.

⁴¹⁹ Allyson Chiu, "Beyoncé, Serena Williams open up about potentially fatal childbirths, a problem especially for black mothers," *The Washington Post*, August 7 2018, https://www.washingtonpost.com/news/morning-mix/wp/2018/08/07/beyonce-serena-williams-open-up-about-potentially-fatal-childbirths-a-problem-especially-for-black-mothers/.

⁴²⁰ Ibid.

⁴²¹ Ibid.

⁴²² Rick Maese, "Olympian Allyson Felix tells Congress of racial disparities in maternal mortality," THE WASHINGTON POST, May 16, 2019, https://www.washingtonpost.com/sports/2019/05/16/olympian-allyson-felix-tells-congress-racial-disparities-maternal-mortality/.

Mothers don't die from childbirth, right? Not in 2019, not professional athletes, not at one of the best hospitals in the country, and certainly not to women who have a birthing plan and a birthing suite lined up. I thought maternal health was solely about fitness, resources and care. If that was true, then why was this happening to me? I was doing everything right.

. . .

The next month was spent in the NICU and I learned that my story was not so uncommon, there were others like me—just like me. Black like me, healthy like me, doing their best – just like me. 423

These are just a few glaring examples of how life-threatening pregnancy complications can affect Black women of all socioeconomic backgrounds and education levels—including decorated star athletes and millionaire celebrities. 424

As discussed in Chapter 1, Black women are more likely to experience pregnancy complications such as hemorrhage, preeclampsia, pregnancy-induced and chronic hypertension, asthma, placental disorders, gestational diabetes, preexisting diabetes, and blood disorders. Advocates have been fighting for decades to empower women of color to maintain autonomy to make decisions to enable a healthy and safe, childbirth experience. Some advocates consider this "birth justice" movement to be a part of the larger movement, aiming to "dismantle inequities based on race, class, gender, and sexuality. This movement is focused on establishing "systems of care that are equitable and culturally relevant," acknowledging that some women

⁴²⁶ See e.g., Sister Strong, "Reproductive Justice," https://www.sistersong.net/reproductive-justice; Black Women Birthing Justice, "What is Birth Justice?" <a href="https://www.blackwomenbirthingjustice.org/what-is-birth-justice#:~:text=We%20believe%20that%20Birth%20Justice,wider%20movement%20against%20reproductive%20oppression.&text=Join%20BWBJ%20in%20the%20movement%20for%20birth%20justice.; Ideo.org, "A Campaign and Movement to Raise Awareness of Birth Justice," https://www.ideo.org/project/voices-for-birth-justice; Groundswell Fund, "Birth Justice Fund," https://groundswellfund.org/birth-justice-fund/.

⁴²³ Allyson Felix, U.S. Track and Field Olympian, Testimony before the Ways and Means Committee on Overcoming Racial Disparities and Social Determinants in the Maternal Mortality Crisis, May 16, 2019, https://waysandmeans.house.gov/legislation/hearings/overcoming-racial-disparities-and-social-determinants-maternal-mortality-0.

⁴²⁴ Allyson Chiu, "Beyoncé, Serena Williams open up about potentially fatal childbirths, a problem especially for black mothers," *The Washington Post*, August 7 2018, https://www.washingtonpost.com/news/morning-mix/wp/2018/08/07/beyonce-serena-williams-open-up-about-potentially-fatal-childbirths-a-problem-especially-for-black-mothers/; Rick Maese, "Olympian Allyson Felix tells Congress of racial disparities in maternal mortality," *The Washington Post*, May 16, 2019, https://www.washingtonpost.com/sports/2019/05/16/olympian-allyson-felix-tells-congress-racial-disparities-maternal-mortality/.

⁴²⁵ See infra note 192.

⁴²⁷ Black Mamas Matter Alliance, *Advancing Holistic Maternal Care for Black Women through Policy*, December 2018, p. 1, https://blackmamasmatter.org/wp-content/uploads/2018/12/BMMA-PolicyAgenda-Digital.pdf.

⁴²⁸ Ibid.

have struggled to navigate the western healthcare systems that "did not focus on them." These efforts aim to establish these systems of care by "addressing racism, discrimination, and bias and, thus, dismantling existing systems of care that have created and perpetuated inequities in health care service delivery and ultimately resulted in grave disparities in health outcomes." Melanie Rouse of the Virginia Department of Health's Office of the Chief Medical Examiner provided testimony to the Commission about how Virginia is working to reduce racial disparities in maternal health outcomes by:

1) Health Insurance Coverage:

- a. We expect Medicaid expansion to have a positive impact on maternal and infant health outcomes.
- b. Over 290,000 newly eligible adult Virginians have now been enrolled into Medicaid coverage, approximately sixty percent of which are women.
- c. Prior to January 1 of this year, pregnant women enrolled in Medicaid only received coverage during pregnancy and for 60 days postpartum. Now, with Medicaid expansion, women in the expansion population receive continuous coverage. This postpartum coverage is especially important considering the MMRT's data showing the majority of pregnancy-related deaths occurred more than 43 days post-delivery.
- d. The Medicaid program includes care coordination/navigation and transportation benefits. These are crucial to improving maternal health.

2) Improving the quality of care received:

- a. VDH and the Virginia Hospital and Healthcare Association have worked closely to develop a plan for a collaborative partnership with ten Virginia hospitals and their ambulatory providers to implement evidence-based, culturally sensitive training, education, and best practices.
- b. Leadership at VDH and the Department of Health Professions are collaborating on strategies to increase cultural competency training, including implicit bias training, among our healthcare workforce.
- c. The Virginia Neonatal Perinatal Collaborative is working to facilitate the implementation of AIM (Alliance for Innovation on Maternal Health) bundles. They are specifically focusing on Maternal Hemorrhage patient safety bundles and maternal opioid use disorder patient safety bundle.
- 3) Community-based programs and services:

⁴²⁹ Changing Women Initiative, "Our Creation Story," http://www.changingwomaninitiative.com/.

⁴³⁰ Black Mamas Matter Alliance, *Advancing Holistic Maternal Care for Black Women through Policy*, December 2018, p. 5, https://blackmamasmatter.org/wp-content/uploads/2018/12/BMMA-PolicyAgenda-Digital.pdf.

- a. The Children's Cabinet has endorsed a statewide framework for scaling home visiting programs in Virginia. We know that home visiting has been shown to improve both maternal and infant health outcomes.
- b. There is also a push to invest in community-based programs such as "Urban Baby Beginnings" in Richmond, Virginia. Organizations such as this one hire women from their community to provide doula support, home visiting, care navigation, breastfeeding and postpartum classes and childcare assistance. 431

Some advocates have been working to raise awareness to the racial disparity in maternal mortality and morbidity. In addition to the efforts of medical professionals, researchers, academics, journalists, government officials, and lawmakers, there is a strong advocacy movement that seeks to educate, cultivate research, offer recommendations, foster solutions, and create legislation and policy to address and eradicate racial disparities in maternal health. ⁴³² Dr. Taraneh Shirazian of Saving Mothers testified at the Commission's briefing about the lack of evidence-based approaches to reducing maternal mortality, stating:

- Maternal mortality has not significantly changed for over 20 years, despite substantial investment in maternal health programs in New York City.
- Our own comprehensive review of maternal health programs in our city, which is where we started before we started this program, found a lack of programs using evidence-based approaches and a lack of reported outcomes. Despite the investment, the results were not evident. 433

Advocacy efforts to reduce disparities in maternal health include research, policy work, community engagement, and maternal mortality review. For example, the National Birth Equity Collective is working to develop a community-informed theoretical model for understanding

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⁴³¹ Rouse Statement, at 5-6.

⁴³² See e.g. Black Mamas Matter Alliance, https://blackmamasmatter.org/ and its members https://blackmamasmatter.org/our-members/; National Birth Equity Collective, https://birthequity.org/; March for Moms, https://marchformoms.org/; Moms Rising, https://www.momsrising.org/; 4Kira4Moms, https://4kira4moms.com/; Sista Midwife Productions, https://www.sistamidwife.com/; Shades of Blue Project, http://shadesofblueproject.org/index.html; Mama Glow, https://mamaglow.com/; Icahn School of Medicine at Mount Siani, "The Blavatnik Family Women's Health Research Institute," https://icahn.mssm.edu/research/womens-health; Black Women's Health Imperative, http://www.bwhi.org; Ancient Song Doula Services, https://www.ancientsongdoulaservices.com/; Sésé Doula Services, https://www.sesedoulaservices.com/; Changing Women Initiative, http://www.changingwomaninitiative.com/; American College of Obstetricians and Gynecologists, "Policy Priorities: Maternal Mortality Prevention," https://www.acog.org/advocacy/policy-priorities/maternal-mortality-prevention; Association of Maternal & Child Health Programs, "Maternal Health," http://www.amchp.org/programsandtopics/womens- health/Focus%20Areas/MaternalHealth/Pages/default.aspx; Review to Action, https://reviewtoaction.org/; Every Mother Counts, https://everymothercounts.org/our-story/; Maternal Health Task Force, https://www.mhtf.org/; "Lost Mothers," ProPublica, https://www.propublica.org/series/lost-mothers/p2; United States Congresswoman Alma Adams for the Twelfth District of North Carolina, "Congresswomen Adams and Underwood Launch Black Maternal Health Caucus," Apr. 9, 2019, https://adams.house.gov/media-center/press-releases/congresswomen-adams-andunderwood-launch-black-maternal-health-caucus.

⁴³³ Shirazian Testimony, Maternal Health Briefing, pp. 73-74

mistreatment and discrimination in childbirth by the creation and testing of a participatory patient-reported metric.434 The Collective is also active in maternal mortality review, and provides racial equity training that aims to "dismantle the root causes of health inequities."435 Another group, the National Perinatal Task Force, seeks to engage and organize its virtual community by working to address maternal health disparities on the grassroots level, providing tools, technical assistance, community and capacity building support in order to advance racial justice and maternal health equity.436 Angela D. Aina, Co-Founding Executive Director of the Black Mamas Matter Alliance explained the Alliance's approach in testimony to the Commission, writing:

The alliance is a national network of black women-led organizations and multidisciplinary professionals, whose work is deeply rooted in reproductive justice, birth justice, and the human rights framework, in order to ensure that all Black Mamas have the rights, respect, and resources to thrive before, during, and after pregnancy. 437

Entities like the Groundswell Fund and Merck for Mothers have been providing financial resources for entities that seek to advance birth equity and justice, aiming to ultimately help to reduce disparities in maternal health and improve maternal health outcomes. The Birth Justice Fund, administered by the Groundswell Fund, aims to eliminate disparities in pregnancy outcomes experienced by women of color by increasing access to culturally congruent care, supporting midwives, doulas, and community-based birth centers and clinics. This fund also helps to support birthworkers of color (i.e., doulas, midwives, postpartum service workers, etc.) and advocacy work to help improve maternal health outcomes and reduce disparities.

Merck for Mothers has made a 10-year, \$500 million investment in the U.S. to efforts that prevent maternal mortality at the policy, hospital, and community levels. ⁴⁴¹ This includes its collaboration with the Centers for Disease Control Foundation and the Association of Maternal and Child Health Programs to improve data collection and analysis of maternal mortality data to help in the maternal mortality review process. ⁴⁴² Also, Merck for Mothers launched its Safer

⁴³⁴ National Birth Equity Collective, "Mothers Voices Driving Birth Equity," https://birthequity.org/what-we-do/mothers-voices-driving-birth-equity/.

⁴³⁵ National Birth Equity Collective, "Solutions," https://birthequity.org/about/birth-equity-solutions/; National Birth Equity Collective, "Racial Equity Training," https://birthequity.org/what-we-do/racial-equity-training/.

⁴³⁶ National Perinatal Task Force, *Building a Movement to Birth a More Just and Loving World*, March 2018, p. 18, https://drive.google.com/file/d/08_vxE9qdE1jDZ2Q2TGpLaTB6ME1qSGgyeDFkYnd5b0dRSWxV/view.

⁴³⁷ Aina Statement, at 1.

⁴³⁸ See Groundswell Fund, https://groundswellfund.org/; Merck for Mothers, "https://www.merckformothers.com/.

⁴³⁹ Groundswell Fund, "Birth Justice Fund," https://groundswellfund.org/birth-justice-fund/.

⁴⁴⁰ Ibid.

⁴⁴¹ Merck for Mothers, *Making Pregnancy and Childbirth Safer in the U.S.*, p. 1, https://www.merckformothers.com/docs/Making Pregnancy Safer.pdf.

⁴⁴² CDC Foundation, "CDC Foundation Partnership To Help Reduce Maternal Mortality In The United States," Apr. 19, 2016, https://www.cdcfoundation.org/pr/2016/cdc-foundation-partnership-help-reduce-maternal-mortality-united-states; see also infra note 606.

Childbirth Cities Initiative in 2019, funding local community-based organizations in 10 cities across the U.S. with high levels of maternal mortality and morbidity to implement innovative evidence-based approaches to reducing maternal health disparities and making safer, more equitable cities to give birth.⁴⁴³

The federal government can also play an influential role in reducing racial disparities in maternal health outcomes. For instance, Representative Pressley explained how the federal government can implement policies to reduce maternal mortality in her testimony to the Commission, stating:

We need policies that expand access to care and ensure that that care is comprehensive, community-based, and culturally humble. Like the Healthy MOMMIES Act legislation, I worked to introduce with Senator Booker from New Jersey, which would create strategies to improve access to pre- and postpartum community-based doula care. Because the data tells us that all mothers have better health outcomes when they have doulas or midwives on their care teams. 444

⁴⁴³ Merck for Mothers, "Safer Childbirth Cities Initiative," pp. 1-2, https://www.merckformothers.com/docs/report-safer-childbirth-cities-initiative.pdf.

⁴⁴⁴ Pressley Testimony, Maternal Health Briefing, p. 16.

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CHAPTER 3: THE FEDERAL ROLE IN ADDRESSING RACIAL DISPARITIES IN MATERNAL HEALTH

The federal government has several programs in the Department of Health and Human Services that are charged with serving the public as related to maternal health disparities. As discussed in Chapter 1, the 1964 Civil Rights Act includes a general requirement that recipients of the federal funds that agencies such as the Department of Health and Human Services (HHS) distribute must not discriminate on the basis of race, color, or national origin. Some departments also have specific duties based on their statutory and regulatory mandates that include assisting vulnerable individuals or combatting health disparities. Along with the Health Resources and Services Administration, several other departments including the Centers for Medicare and Medicaid Services, the Centers for Disease Control and Prevention (CDC), the Office of Minority Health, the Office of Population Affairs, and several Institutes within the National Institutes of Health (NIH), including the Eunice Kennedy Shriver National Institute of Child Health and Human Development, administer programs that seek to improve maternal health and reduce racial disparities. This chapter will examine these departments' current federal initiatives to prevent maternal mortality and morbidity, and to eliminate racial disparities in maternal healthcare and maternal health outcomes.

An Examination of Federal Programs

The Government Accountability Office explained the scope of federal programs in its March 2020 report on the federal role in maternal health as follows:

As of September 2019, the Department of Health and Human Services was providing funding for 13 efforts with a stated outcome, goal, or focus on reducing pregnancy-related deaths... Two of these efforts are not discrete funding opportunities, but rather a

⁴⁴⁵ 42 U.S.C. § 2000d *et seq.* (1964); The Commission examined HHS' obligations under the 1964 Civil Rights Act in 2019, *see*, U.S. Comm'n on Civil Rights, *Are Rights A Reality? Examining Federal Civil Rights Enforcement*, pp. 195-224 (Nov. 21, 2019) https://www.usccr.gov/pubs/2019/11-21-Are-Rights-a-Reality.pdf; and see, *Are Rights A Reality?*, p. 1 (describing other major federal civil rights laws enforced by federal agencies) (federal law prohibits recipients of federal funding from discriminating on the basis of race, color, national origin, disability, and sex. This report focuses on racial disparities in maternal morbidity and mortality, thus the report text focuses on Title VI of the Civil Rights Act of 1964).

⁴⁴⁶ See, U.S. Comm'n on Civil Rights, *Are Rights a Reality? Evaluating Federal Civil Rights Enforcement*, pp. 195-198 (Nov. 21, 2019) (discussing the statutory and regulatory authority of the Dep't of Health and Human Services' Office of Civil Rights) https://www.usccr.gov/pubs/2019/11-21-Are-Rights-a-Reality.pdf.

variety of research funding opportunities offered by the Health Resources and Services Administration and the National Institutes of Health. 447

In December of 2020, the Department of Health and Human Services released its report, *Healthy Women, Healthy Pregnancies, Healthy Futures: Action Plan to Improve Maternal Health in America*. The report states that HHS seeks, in part, to "reduce the maternal mortality rate by 50 percent in 5 years." The report identifies five challenges in reducing maternal mortality and morbidity: racial disparities, rural disparities and access to care, health insurance coverage, practice patterns and payment misalignment, and data quality and timeliness. Representative Pressley testified about the need for federal cross-agency work to the Commission, stating that:

We must enact innovative and bold policy solutions that center scientific evidence and the lived experiences of all pregnant people. Combating the maternal mortality crisis requires work at every level of government and in every institution, and the work is worth it, because Black and Brown lives are worth it.⁴⁵¹

Legislation to Improve Maternal Healthcare

Congress passed and former President Trump signed the Preventing Maternal Deaths Act of 2018 into law as a direct result of increased awareness about the maternal mortality crisis in the U.S. 452 This bipartisan legislation aims:

[T]o support States in their work to save and sustain the health of mothers during pregnancy, childbirth, and in the postpartum period, to eliminate disparities in maternal health outcomes for pregnancy-related and pregnancy-associated deaths, to identify solutions to improve health care quality and health outcomes for mothers, and for other purposes. 453

College educated black women are more likely to experience a pregnancy-related death than white, Asian/Pacific Islander, and Hispanic women without a high school diploma. Some of these disparities are related to differences in quality of care and clinical practice, with black patients tending to receive care in hospitals with poorer outcomes. Social determinants of health also have an impact on racial and ethnic maternal health disparities.

⁴⁴⁷ Government Accountability Office, *Maternal Mortality: Trends in Pregnancy-Related Deaths and Federal Efforts to Reduce Them*, p. 38 (March 2020) https://www.gao.gov/assets/710/705331.pdf.

⁴⁴⁸ U.S. Dep't of Health and Human Services, *Healthy Women, Healthy Pregnancies, Healthy Futures: Action Plan to Improve Maternal Health in America*, (Dec. 2020) https://aspe.hhs.gov/system/files/aspe-files/264076/healthy-women-healthy-pregnancies-healthy-future-action-plan 0.pdf.

⁴⁴⁹ Ibid., 9.

⁴⁵⁰ Ibid., 10-11 the report notes:

⁴⁵¹ Pressley Testimony, *Maternal Health Briefing*, p. 16.

⁴⁵² 42 U.S.C. § 247b-12, as amended, The Maternal Deaths Act, Pub. L. 115-344, 132 Stat. 5047 (2018).

⁴⁵³ Id.

This legislation encourages the establishment of Maternal Mortality Review Committees at the state level, who are responsible for reviewing every pregnancy-related death and make recommendations to prevent future deaths. Shanna Cox of the CDC explained the Act, "authorized activities at CDC to support states in their work to conduct maternal mortality reviews to inform strategies to reduce pregnancy-related deaths, eliminate disparities and improve the health of women during pregnancy, childbirth, and in the postpartum period." In 2019, the CDC announced awards of over \$45 million over a five year period to support these committees through cooperative agreements signed with state entities. According to the CDC, "[f]unding recipients will identify and review deaths within 1 year of death and enter clinical and non-clinical data and committee decisions in the Maternal Mortality Review Information Application—a standardized data system managed by CDC—within 2 years of death."

The legislation does not itself, however, directly address racial disparities in maternal health. While the legislation does broaden the scope of capabilities afforded to the Secretary of Health and Human Services by empowering the Secretary to further investigate the underlying reasons for maternal health disparities and expand research into "activities to reduce disparities in maternity services and outcomes," the legislation simply *permits* rather than requires the Secretary to conduct such research. Furthermore, the Maternal Mortality Review Committees supported by the legislation would be required to report a variety of data and findings to the Center for Disease Control and Prevention, as well as required to ensure a focus on populations most at risk for maternal health issues. 459

Nan Strauss of Every Mother Counts emphasizes in her testimony to the Commission that while the Preventing Maternal Deaths Act represents progress, "further action must be taken to target the elimination of disparities, deaths, and complications." Strauss argues that the government must focus on implementing equitable solutions to reduce maternal mortality, such as measuring quality of care and experience and separating the data by race and ethnicity to obtain granular, specific information on disparities, and developing avenues of redress within healthcare systems for families that have been wronged by unequal treatment or lack of informed consent. Strauss also proposes developing "collaborative care teams that are interdisciplinary, integrating

⁴⁵⁴ Mary Caffrey, "Preventing Maternal Deaths Act Headed to Trump's Desk," *AJMC*, Dec. 18, 2018, https://www.ajmc.com/newsroom/preventing-maternal-deaths-act-headed-to-trumps-desk.

⁴⁵⁵ Cox Statement at 3.

⁴⁵⁶ Ibid.; Government Accountability Office, *Maternal Mortality: Trends in Pregnancy-Related Deaths and Federal Efforts to Reduce Them*, p. 24 (March 2020) https://www.gao.gov/assets/710/705331.pdf (The CDC has signed cooperative agreements with 24 recipients in 25 states as of August 2019).

⁴⁵⁷ Ibid.

⁴⁵⁸ 42 U.S.C. § 247b-12 (as amended by the Maternal Deaths Act, Pub. L. 115-344, 132 Stat. 5047 (2018)).

⁴⁵⁹ *Id.* at 132 Stat. 5049.

⁴⁶⁰ Strauss Statement, at 11.

⁴⁶¹ Ibid., 12.

physicians, midwives, nurses, doulas, and the childbearing people and their support people to ensure a team-based approach to care." Similarly, Jennifer Jacoby of the Center for Reproductive Rights notes in testimony to the Commission that the Preventing Maternal Deaths Act focuses on data collection, but does not "comprehensively address the root causes of the [maternal mortality] crisis," i.e., ensuing access to high quality, culturally informed care for all. 463

Over the past few years, Congress has considered several bills that seek to improve maternal healthcare, although none have been enacted into law as of February 2021. 464 On February 8, 2021, U.S. Representatives Lauren Underwood and Alma Adams and Senator Cory Booker, along with other members of the Congressional Black Caucus, announced they would be introducing the Black Maternal Health Momnibus Act of 2021 (the "Momnibus"). 465 The Momnibus was originally introduced in March of 2020 as a package of nine separate bills. 466 In comparison to the original legislation, however, the 2021 Momnibus will include three additional bills, 467 for a combined total of twelve. 468 While the Momnibus contains many provisions that would apply generally toward birthing peoples, the primary goal of the Momnibus is to address the disparate impact of maternal mortality rates among Black women as well as other women and birthing people of color in comparison to White women. 469

To achieve that overarching goal, the twelve individual bills within the Momnibus each emphasize different elements of the maternal health crisis as informed by the communities it seeks to aid. ⁴⁷⁰ The Social Determinants for Moms Act, for example, would aim to provide

⁴⁶² Ibid., 13.

⁴⁶³ Jacoby Statement at 6.

⁴⁶⁴ Katy Backes Kozhimannil, Elaine Hernandez, Dara D. Mendez, Theresa Chapple-McGruder, "Beyond The Preventing Maternal Deaths Act: Implementation And Further Policy Change," Feb. 4 2019, https://www.healthaffairs.org/do/10.1377/hblog20190130.914004/full/; National Partnership for Women and Families, "Federal Legislation to Improve Maternal Health," https://www.nationalpartnership.org/our-work/health/federal-legislation-to-improve-maternal-health.html.

⁴⁶⁵ H.R. 959, 117th Cong. (2021); Marty Johnson and Jessie Hellmann, *Black Maternal Health Omnibus Package Introduced by Democratic Lawmakers*, THE HILL (Feb. 08, 2021) https://thehill.com/homenews/house/537810-black-maternal-health-omnibus-package-introduced-by-democratic-lawmakers.

⁴⁶⁶ *Id.*

⁴⁶⁷ BLACK MATERNAL HEALTH CAUCUS, *Combined Momnibus 1-Pagers* in BLACK MATERNAL HEALTH MOMNIBUS ACT OF 2021, at 1 (2021), https://blackmaternalhealthcaucus-underwood.house.gov/Momnibus.

⁴⁶⁸ H.R. 959, 117th Cong. (2021). The bills included within the Momnibus are: 1) the Social Determinants for Moms Act; 2) the Kira Johnson Act; 3) the Protecting Moms Who Served Act; 4) the Perinatal Workforce Act; 5) the Data to Save Moms Act; 6) the Moms Matter Act; 7) the Justice for Incarcerated Moms Act; 8) the Tech to Save Moms Act; 9) the IMPACT to Save Moms Act; 10) the Maternal Health Pandemic Response Act; 11) the Protecting Moms and Babies Against Climate Change Act; and 12) the Maternal Vaccination Act.

⁴⁶⁹ Black Maternal Health Caucus at 1.

⁴⁷⁰ H.R. 959, 117th Cong. (2021); Jacoby Testimony, *Maternal Health Briefing*, pp. 136-37.

funding to study social determinants of health⁴⁷¹ that produce disparate maternal health outcomes at local levels, as well as arming local health organizations with the funds to tackle them.⁴⁷² Other aspects of the Momnibus seeking to tackle racial disparities include proposals to: fund educational programs focused on anti-racism and anti-discrimination efforts;⁴⁷³ study techniques to increase the number of healthcare workers who can provide culturally-sensitive support;⁴⁷⁴ advancing the availability and use of maternal health technology;⁴⁷⁵ promote equity within Medicaid;⁴⁷⁶ and study the effects of the COVID-19 pandemic and other public health crises on maternal health outcomes.⁴⁷⁷ Furthermore, the Momnibus also incorporates several provisions that would focus on specialized groups among Black birthing women and birthing people of color, such as veterans,⁴⁷⁸ indigenous persons,⁴⁷⁹ persons with maternal mental health conditions and substance use disorders,⁴⁸⁰ incarcerated persons,⁴⁸¹ and persons exposed to climate change-related risks.⁴⁸²

Testimonies provided at the Commission's briefing further illustrate the overarching aims of the Momnibus. Angela Doyinsola-Aina, the co-founding executive director of the advocacy group Black Mammas Matter Alliance, stated that if passed, the Act:

has the potential to be transformative [for] maternal health because it goes beyond address[ing] maternal death. ... It helps to advance maternal health equity through investments in holistic and community-based models of care, expanding research and improving technological initiatives to expand access to maternal services.⁴⁸³

Jennifer Jacoby, a federal policy counsel for a global legal human rights organization, the Center for Reproductive Rights, said she found the Act to be "an important step toward addressing many

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⁴⁷¹ Social determinants of health are defined in the Act as "the conditions where people live, learn, work, and play—conditions that affect a wide range of health risks and outcomes." BLACK MATERNAL HEALTH CAUCUS at 3.

⁴⁷² Jacoby Testimony, *Maternal Health Briefing*, p. 136.

⁴⁷³ As specified within the Kira Johnson Act. See BLACK MATERNAL HEALTH CAUCUS at 5.

⁴⁷⁴ As specified within the Perinatal Workforce Act. See Id. at 9.

⁴⁷⁵ As specified within the Tech to Save Moms Act, the efforts would include, for example, establishing a grant program "to promote digital tools designed to address racial and ethnic disparities in maternal health outcomes, particularly in underserved communities," and studying new technologies in maternal health care "to prevent racial and ethnic biases" from arising among innovations. *See Id.* at 17.

⁴⁷⁶ As specified within the IMPACT to Save Moms Act. See Id. at 19.

⁴⁷⁷ As specified within the Maternal Health Pandemic Response Act. See Id. at 21.

⁴⁷⁸ As specified within the Protecting Moms Who Served Act. *See Id.* at 5.

⁴⁷⁹ As specified within the Data to Save Moms Act. *See Id.* at 11 (seeking to establish Tribal Maternal Mortality Review Committees and fund studies that would seek "to understand the scope of the Native American maternal health crisis").

⁴⁸⁰ As specified within the Moms Matter Act. See Id. at 13.

⁴⁸¹ As specified within the Justice for Incarcerated Moms Act. See Id. at 15.

⁴⁸² As specified within the Protecting Moms and Babies Against Climate Change Act. See Id. at 23.

⁴⁸³ Aina Testimony, *Maternal Health Briefing*, p. 67.

of the existing barriers to accessible, nondiscriminatory, high quality care."⁴⁸⁴ While the Momnibus assuredly addresses several unique issues not yet addressed by the federal government, the Act is chiefly concerned with building upon the existing legislation and infrastructure that are already in place. 486

Medicaid

Medicaid is a national program designed to provide healthcare coverage for low-income people in the U.S. 487 The Center for Medicaid and CHIP Services, a subdivision of the Centers for Medicare & Medicaid Services housed within HHS, 488 is the focal point for national program policies and operations related to Medicaid. 489 All 50 states, the District of Columbia, and all U.S. territories administer their own Medicaid programs within the parameters of federal regulations and guidance, so there is variance in Medicaid coverage across the U.S. 490 The Affordable Care Act gave states the authority, beginning in 2014, to expand Medicaid coverage to certain individuals 19 years old and older and under 65 years old in households that fall at or below 133 percent of the federal poverty level, and standardized rules of determining eligibility. 491 Currently, 36 states and the District of Columbia have so expanded Medicaid coverage. 492 In 2017, total Medicaid spending was approximately \$600 billion, for which the federal government financed approximately \$370 billion (62 percent) and states and localities

⁴⁸⁴ Jacoby Testimony, *Maternal Health Briefing*, p. 129.

⁴⁸⁵ The inclusion of the Maternal Health Pandemic Response Act, for example, was not one of the nine bills contained within the original Momnibus, but was instead added in response to the novel COVID-19 pandemic. *See* Johnson and Hellmann, *supra* note 1.

⁴⁸⁶ Jacoby Testimony, *Maternal Health Briefing*, pp. 136-37.

⁴⁸⁷ Medicaid.gov, "Program History," https://www.medicaid.gov/about-us/program-history/index.html.

⁴⁸⁸ U.S. Department of Health and Human Services, Centers for Medicare and Medicaid, "Organizational Chart," https://www.cms.gov/About-CMS/Agency-

Information/CMSLeadership/Downloads/CMS Organizational Chart.pdf.

⁴⁸⁹ Medicaid.gov, "Program History," https://www.medicaid.gov/about-us/program-history/index.html.

⁴⁹⁰ Ibid.

⁴⁹¹ The Patient Protection and Affordable Care Act (PPACA), Pub. L. No. 111-148, 2010, 124 Stat. 119; Medicaid.gov, "Eligibility," https://www.medicaid.gov/medicaid/eligibility/index.html.

⁴⁹² The Henry J. Kaiser Family Foundation, "Status of State Medicaid Expansion Decisions: Interactive Map," https://www.kff.org/medicaid/issue-brief/status-of-state-medicaid-expansion-decisions-interactive-map/. Alabama, Florida, Georgia, Kansas, Mississippi, North Carolina, South Carolina, South Dakota, Tennessee, Texas, Wisconsin, and Wyoming have not adopted Medicaid expansion; and Medicaid expansion has been adopted but not yet implemented in Missouri and Oklahoma. *See also supra* note 297.

financed approximately \$230 billion (38 percent). 493 Medicaid expenditures represent approximately one-sixth of all dollars spent in the health care system. 494

Medicaid plays a significant role in providing health insurance for women of color. 495 Medicaid was the source of payment for 42.3 percent of all births in 2018. 496 Of those Medicaid-covered births, 65.3 percent were to Black women as compared to 30 percent to White women, and 58.9 percent of Medicaid-covered births were to Latina women (of all races). 497 As Jennifer Moore, Founding Executive Director of the Institute for Medicaid Innovation testified to the Commission:

Medicaid plays a critical role in the health of low-income, reproductive aged (15-49) women. More than 25 million women are covered through Medicaid, approximately 70 percent of whom are of reproductive age. Nearly half of all births in the U.S. are covered by Medicaid, with the share in each state ranging between 20 and 71 percent. 498

A recent study has linked Medicaid expansion with lower maternal mortality rates, showing that mortality rates were lower in Medicaid expansion states than non-expansion states, in part due to increased access to postpartum and preconception care. This study also found that Medicaid expansion effects were concentrated among Black mothers, indicating that expansion could help reduce racial disparities. 500

Although maternal mortality overall continues to increase in the United States, the maternal mortality ratio among Medicaid expansion states has increased at a slower rate compared to non-expansion states.⁵⁰¹ The decrease in the maternal mortality ratio is greater when maternal mortality estimates include late maternal deaths, suggesting that sustained insurance coverage

⁴⁹³ U.S. Department of Health and Human Services, *2018 Actuarial Report on the Financial Outlook for Medicaid*, 2018, p. iv, https://www.cms.gov/files/document/2018-report.pdf.

⁴⁹⁴ Robin Rudowitz, Elizabeth Hinton, Maria Diaz, Madeline Guth, and Marina Tian, "Medicaid Enrollment & Spending Growth: FY 2019-2020," *Henry J. Kaiser Family Foundation*, Oct. 18, 2019, https://www.kff.org/medicaid/issue-brief/medicaid-enrollment-spending-growth-fy-2019-2020/.

⁴⁹⁵ See supra notes 295-296.

⁴⁹⁶ National Center for Health Statistics, Division of Vital Statistics, "Births: Final Data for 2018," *National Vital Statistics Reports*, Vol. 68, No. 13 (Nov. 27, 2019): p. 2, https://www.cdc.gov/nchs/data/nvsr/nvsr68/nvsr68_13-508.pdf; see also supra note 330.

⁴⁹⁷ National Center for Health Statistics, Division of Vital Statistics, "Births: Final Data for 2018," *National Vital Statistics Reports*, Vol. 68, No. 13 (Nov. 27, 2019): p. 7, https://www.cdc.gov/nchs/data/nvsr/nvsr68/nvsr68_13-508.pdf.

⁴⁹⁸ Moore Statement at 1 (internal citations omitted).

⁴⁹⁹ Erica L. Eliason, MPH, "Adoption of Medicaid Expansion Is Associated with Lower Maternal Mortality," *Women's Health Issues*, Feb. 25, 2020, https://www.whijournal.com/article/S1049-3867(20)30005-0/fulltext; see also supra note 298.

⁵⁰⁰ Ibid.

⁵⁰¹ Erica L. Eliason. Adoption of Medicaid Expansion Is Associated with Lower Maternal Mortality. Columbia University School of Social Work, Women's Health Issues 30-3 (2020) 147–152. New York, New York https://www.whijournal.com/action/showPdf?pii=\$1049-3867%2820%2930005-0

after childbirth as well as improved preconception coverage could be contributing to decreasing maternal mortality. Medicaid expansion was significantly associated with lower maternal mortality by 7.01 maternal deaths per 100,000 live births relative to non-expansion states. When maternal mortality definitions excluded late maternal deaths, Medicaid expansion was significantly associated with a decrease in maternal mortality per 100,000 live births by 6.65 relative to non-expansion states. Medicaid expansion effects were concentrated among non-Hispanic Black mothers, suggesting that expansion could be contributing to decreasing racial disparities in maternal mortality. Improving access to care was one of the most common themes identified as a feasible action to avert maternal deaths. Maternal Mortality Review Committees found that 18 percent of pregnancy-related deaths are late maternal deaths, occurring between 43 days and 1 year after the end of pregnancy, and that 58.3 percent of these deaths are considered to be preventable.

Under Medicaid, pregnant women who qualify⁵⁰⁷ are covered for:

- c. (1) Pregnancy-related services and services for other conditions that might complicate the pregnancy.
- (i) Pregnancy-related services are those services that are necessary for the health of the pregnant woman and fetus, or that have become necessary as a result of the woman having been pregnant. These include, but are not limited to, prenatal care, delivery, postpartum care, and family planning services.
- (ii) Services for other conditions that might complicate the pregnancy include those for diagnoses, illnesses, or medical conditions which might threaten the carrying of the fetus to full term or the safe delivery of the fetus; and
- (2) For women who, while pregnant, applied for, were eligible for, and received Medicaid services under the plan, all services under the plan that are pregnancy-related for an extended postpartum period. The postpartum period begins on the last day of pregnancy and extends through the end of the month in which the 60-day period following termination of pregnancy ends. ⁵⁰⁸

Medicaid nondiscrimination regulations stipulate that "[s]tate agencies and any other beneficiaries or subbeneficiaries of Federal financial assistance provided under this subpart are

⁵⁰³ Ibid., 147.

⁵⁰² Ibid., 147.

⁵⁰⁴ Ibid., 147.

⁵⁰⁵ Ibid., 148.

⁵⁰⁶ Ibid., 148.

⁵⁰⁷ See Henry J. Kaiser Family Foundation, "Medicaid and CHIP Income Eligibility Limits for Pregnant Women as a Percent of the Federal Poverty Level," Jan. 1, 2020, <a href="https://www.kff.org/health-reform/state-indicator/medicaid-and-chip-income-eligibility-limits-for-pregnant-women-as-a-percent-of-the-federal-poverty-level/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D.

⁵⁰⁸ 42 C.F.R. §§ 440.210(a)(2)-(3) (1995).

subject to the nondiscrimination requirements in 45 CFR parts 80, 84, and 91," which implement Title VI nondiscrimination provisions and "prohibit individuals from being excluded from participation in, being denied the benefits of, or being otherwise subjected to discrimination under any program or activity which received Federal financial assistance." Section 1557 of the Affordable Care Act prohibits discrimination on the basis of race, color, national origin, sex, age, or disability in health programs or activities receiving federal financial assistance.

Some providers and other stakeholders advocate for an extension of Medicaid to provide 12 months of continuous coverage for women postpartum.⁵¹¹ Research has shown that there is a risk of severe maternal morbidity events or death up to a year postpartum, and that postpartum visits with a health care provider are linked with reducing the rate of maternal deaths. 512 Currently under Medicaid, women are covered for 60 days postpartum, ⁵¹³ although states may individually extend that coverage beyond the federal 60 day minimum required coverage. 514 However, even in states that extend coverage beyond 60 days postpartum, many women lose their Medicaid coverage after the initial 60-day period due to strict eligibility requirements that cause a lapse in coverage during the critical postpartum period.⁵¹⁵ Nearly 40 percent of mothers with Medicaid do not access postpartum visits.⁵¹⁶ At its 2019 Annual Meeting, the American Medical Association adopted a new recommendation to extend Medicaid coverage to 12 months postpartum, pointing out the link between extending coverage and improved maternal health outcomes, and noted "[a]s physicians, we know new mothers' medical needs extend beyond Medicaid's current coverage period, and a longer coverage period would offer a healthier start for America's families."517 The American College of Obstetricians and Gynecologists also issued a statement following the American Medical Association's announcement on this issue, which noted that infants are covered by Medicaid through the first year of life, saying that the

⁵⁰⁹ 42 C.F.R. § 495.356.

⁵¹⁰ 42 U.S.C. § 18116 (2010); Patient Protection and Affordable Care Act, Pub. L. 111–148, Title I, § 1557, Mar. 23, 2010, 124 Stat. 260; 45 C.F.R. § 92.2.

⁵¹¹ American Medical Association, "AMA adopts new policies at 2019 Annual Meeting," Jun. 12, 2019, https://www.ama-assn.org/press-center/press-releases/ama-adopts-new-policies-2019-annual-meeting; American College of Obstetricians and Gynecologists, "ACOG Statement on AMA Support for 12 Months of Postpartum Coverage Under Medicaid," Jun. 12, 2019, https://www.acog.org/news/news-releases/2019/06/acog-statement-on-ama-support-for-12-months-of-postpartum-coverage-under-medicaid.

⁵¹² See supra notes 100,, 107-109, and 181-184.

⁵¹³ See supra note 508.

⁵¹⁴ Ibid.

⁵¹⁵ See supra notes 307-314.

⁵¹⁶ Alison Stuebe, Jennifer E. Moore, Pooja Mittal, Lakshmi Reddy, Lisa Kane Low, Haywood Brown, "Extending Medicaid Coverage For Postpartum Moms," May 6, 2019, https://www.healthaffairs.org/do/10.1377/hblog20190501.254675/full/.

⁵¹⁷ American Medical Association, "AMA adopts new policies at 2019 Annual Meeting," Jun. 12, 2019, https://www.ama-assn.org/press-center/press-releases/ama-adopts-new-policies-2019-annual-meeting.

"baby's mother needs the same level of access to care," and "closing the critical gap in coverage during this vulnerable time can mean the difference between life and death for some women." ⁵¹⁸

The American Rescue Plan Act, signed into law on March 11, 2021, provides states with an option to provide continuous Medicaid eligibility for pregnant individuals through 12 months postpartum. The option provides for a full Medicaid benefit package. States that elect the postpartum extension for Medicaid must also provide the extension in their separate CHIP, for targeted low-income children who are pregnant and targeted low-income pregnant women, as applicable. This state plan option is effective beginning on April 1, 2022, and is currently authorized for a 5-year period.

Maternal, Infant, and Early Child Home Visiting Program

Established in 2010,⁵²⁰ the Maternal, Infant, and Early Child Home Visiting Program seeks to empower pregnant women and families—especially those considered at-risk—with tools, resources, and skills to raise healthy children.⁵²¹ This home visiting program is aimed at protecting infant, child, and maternal health.⁵²² Research has shown a positive link between home visits and maternal and infant health.⁵²³ The Maternal, Infant, and Early Child Home Visiting Program is administered by the Health Resources and Services Administration in collaboration with the Administration for Children & Families, ⁵²⁴ and funds states, territories, and tribal entities to develop and implement evidence-based, voluntary home visiting programs with health, social services, and child development professionals.⁵²⁵ Home visits provide information on a variety of topics, including preventative health, prenatal practices, nutrition,

⁵¹⁸ American College of Obstetricians and Gynecologists, "ACOG Statement on AMA Support for 12 Months of Postpartum Coverage Under Medicaid," Jun. 12, 2019, https://www.acog.org/news/news-releases/2019/06/acog-statement-on-ama-support-for-12-months-of-postpartum-coverage-under-medicaid.

⁵¹⁹ American Rescue Plan Act, Pub. L. No. 117-2 (2021), sections 9812 and 9822. Text available at: https://www.congress.gov/bill/117th-congress/house-bill/1319/text.

⁵²⁰ 42 U.S.C. 711 § 511 (2018); Pub. L. 111-148 § 2951 (2010).

⁵²¹ Health Resources & Services Administration, Maternal and Child Health, "Home Visiting," https://mchb.hrsa.gov/maternal-child-health-initiatives/home-visiting-overview.

⁵²² Ibid.

⁵²³ Health Resources & Services Administration, "The Maternal, Infant, and Early Childhood Home Visiting Program: Program Overview," p. 1,

https://mchb.hrsa.gov/sites/default/files/mchb/MaternalChildHealthInitiatives/HomeVisiting/pdf/2018-MIECHV-program-overview.pdf; Michalopoulos, C, et. al., Evidence on the Long-Term Effects of Home Visiting Programs: Laying the Groundwork for Long-Term Follow-Up in the Mother and Infant Home Visiting Program Evaluation (MIHOPE), OPRE Report 2017-73, 2017, Washington, DC: Office of Planning, Research and Evaluation, Administration for Children and Families, U.S. Department of Health and Human Services, https://files.eric.ed.gov/fulltext/ED579153.pdf.

⁵²⁴ Administration for Children & Families, Office of Child Care, "Home Visiting," https://www.acf.hhs.gov/occ/home-visiting.

⁵²⁵ Health Resources & Services Administration, Maternal and Child Health, "Home Visiting," https://mchb.hrsa.gov/maternal-child-health-initiatives/home-visiting-overview.

breastfeeding, and childcare solutions.⁵²⁶ In addition, they provide support for mothers by screening for postpartum depression, substance abuse, family violence, and other maternal health risks.⁵²⁷

In 2019, the Maternal, Infant, and Early Child Home Visiting Program provided over 1 million home visits, serving approximately 154,000 parents and children in all 50 states, the District of Columbia, and 5 territories. ⁵²⁸ In addition, the Tribal Maternal, Infant, and Early Child Home Visiting Program awarded 17,972 home visits to over 3,800 adults and children in 2018, and currently funds 23 tribes, consortia of tribes, tribal organizations, and urban Indian organizations. ⁵²⁹ In 2018, the Maternal, Infant, and Early Child Home Visiting Program was allocated \$400 million per year through fiscal year 2022, and in September 2020, the Health Resources and Services Administration awarded approximately \$341 million ⁵³⁰ in funds to 55 states, territories, and nonprofit organizations through the Maternal, Infant, and Early Child Home Visiting Program. ⁵³¹ In response to Commission interrogatories, HSRA reported that "[t]he FY21 allocated budget reflects a \$76.383 million investment in the [MIECHV] Program." ⁵³²

There are 19 different approved service delivery models that grantees can select that have been deemed evidence-based.⁵³³ These models have been identified and reviewed through the Administration for Children and Families' Home Visiting Evidence of Effectiveness systematic review, which provides "an assessment of the evidence of effectiveness for home visiting models that target families with pregnant women and children from birth to kindergarten entry."⁵³⁴ The Maternal, Infant, and Early Child Home Visiting Program has six benchmarks in order to measure a grantee's success, including:

⁵²⁶ Health Resources & Services Administration, "The Maternal, Infant, and Early Childhood Home Visiting Program: Program Overview," p. 1,

 $[\]frac{https://mchb.hrsa.gov/sites/default/files/mchb/MaternalChildHealthInitiatives/HomeVisiting/pdf/2018-MIECHV-program-overview.pdf.}{}$

⁵²⁷ Ibid.

⁵²⁸ Health Resources & Services Administration, "The Maternal, Infant, and Early Childhood Home Visiting Program: Partnering with Parents to Help Children Succeed," April 2020,

 $[\]underline{https://mchb.hrsa.gov/sites/default/files/mchb/MaternalChildHealthInitiatives/HomeVisiting/pdf/programbrief.pdf.}$

⁵²⁹ Health Resources & Services Administration, "The Maternal, Infant, and Early Childhood Home Visiting Program: Program Overview," p. 2,

 $[\]underline{https://mchb.hrsa.gov/sites/default/files/mchb/MaternalChildHealthInitiatives/HomeVisiting/pdf/2018-MIECHV-program-overview.pdf.}$

^{530 \$341} million reflects the FY 2020 post-sequestration funding amount.

⁵³¹ Health Resources & Services Administration, Maternal and Child Health, "Home Visiting," https://mchb.hrsa.gov/maternal-child-health-initiatives/home-visiting-overview.

⁵³² U.S. Dep't of Health and Human Services, Health Resources & Services Admin., Response to USCCR Interrogatories at p. 1.

⁵³³ Ibid.

⁵³⁴ Administration of Children and Families, "What is Home Visiting Evidence of Effectiveness?" https://homvee.acf.hhs.gov/.

- Improvement in maternal and newborn health;
- Reduction in child injuries, abuse, and neglect;
- Improved school readiness and achievement;
- Reduction in crime or domestic violence;
- Improved family economic self-sufficiency; and
- Improved coordination and referral for other community resources and supports. 535

Grantees need to demonstrate measurable improvement in at least 4 of these benchmarks. ⁵³⁶ The Health Resources and Services Administration provides technical assistance to grantees by "connecting awardees to technical expertise, sharing best practices, engaging experts and stakeholders, utilizing Continuous Quality Improvement methodologies, and disseminating and translating research findings." ⁵³⁷

The Mother and Infant Home Visiting Program Evaluation – Strong Start was launched in 2012, which evaluated the effectiveness of evidence-based home visiting programs for families enrolled in Medicaid or CHIP—part of Centers for Medicare and Medicaid Services' Strong Start for Mothers and Infants initiative. ⁵³⁸ Data collection for this study ended in 2017, and the study included a random assignment impact analysis and a multi-level implementation research analysis, with 2,900 families from 66 local home visiting programs across 17 states. ⁵³⁹ Mother and Infant Home Visiting Program Evaluation only included programs receiving Maternal, Infant, and Early Child Home Visiting Program funding, but MIHOPE-Strong Start included programs with both MIECHV and non-Maternal, Infant, and Early Child Home Visiting Program funding. ⁵⁴⁰ Mother and Infant Home Visiting Program Evaluation included pregnant women or had children under 6 months old, but MIHOPE-Strong Start was limited to pregnant women in the first 32 weeks of pregnancy. ⁵⁴¹ The enrollees in these programs were primarily young, lowincome, with over a third having not graduated from high school. ⁵⁴² Additionally, the enrollees were racially and ethnically diverse, with approximately 70 percent women of color (including

⁵³⁵ Health Resources & Services Administration, Maternal and Child Health, "Home Visiting," https://mchb.hrsa.gov/maternal-child-health-initiatives/home-visiting-overview.

⁵³⁶ Ibid.

⁵³⁷ Health Resources & Services Administration, "MIECHV Program Technical Assistance," https://mchb.hrsa.gov/maternal-child-health-initiatives/home-visiting/miechv-program-ta.

⁵³⁸ Administration for Children & Families, "Mother and Infant Home Visiting Program Evaluation – Strong Start (MIHOPE-Strong Start), 2012-2018," https://www.acf.hhs.gov/opre/research/project/mother-and-infant-home-visiting-program-evaluation-strong-start-mihope-ss.

⁵³⁹ Administration for Children & Families, "Mother and Infant Home Visiting Program Evaluation – Strong Start (MIHOPE-Strong Start), 2012-2018," https://www.acf.hhs.gov/opre/research/project/mother-and-infant-home-visiting-program-evaluation-strong-start-mihope-ss.

⁵⁴⁰ Ibid.

⁵⁴¹ Charles Michalopoulos, Sarah Shea Crowne, Ximena A. Portilla, Helen Lee, Jill H. Filene, Anne Duggan, and Virginia Knox, *A Summary of Results from the MIHOPE and MIHOPE-Strong Start Studies of Evidence-Based Home Visiting*, Administration for Children and Families, Office of Planning, Research, and Evaluation, January 2019, p. 3, https://www.acf.hhs.gov/sites/default/files/opre/mihope_summary_brief_01_16_19_508.pdf. ⁵⁴² Ibid., 6.

Black, Latinx, or identifying as Other/Mixed Race) in both Mother and Infant Home Visiting Program Evaluation and Mother and Infant Home Visiting Program Evaluation -Strong Start. ⁵⁴³ By comparison, approximately a third of the Maternal, Infant, and Early Child Home Visiting Program participants were Latinx, 28 percent were Black, and 58 percent were White. ⁵⁴⁴

The Administration for Children and Families issued a summary report (summarizing all Mother and Infant Home Visiting Program Evaluation and Mother and Infant Home Visiting Program Evaluation -Strong Start evaluations thus far) in January 2019, finding that:

- Home visiting programs in the studies were generally well implemented, with appropriate support in place to help home visitors administer the intended services; and
- The Mother and Infant Home Visiting Program Evaluation found positive effects on some family outcomes but Mother and Infant Home Visiting Program Evaluation -Strong Start found little effect on birth outcomes and prenatal behaviors. 545

Most families in Mother and Infant Home Visiting Program Evaluation -Strong Start had adequate prenatal care even without home visits, and the women typically did not engage in risky behaviors (e.g. smoking), which may explain the lack of effects in Mother and Infant Home Visiting Program Evaluation -Strong Start. The summary evaluation report indicated that further research would need to be done in order to answer whether Mother and Infant Home Visiting Program Evaluation -Strong Start would improve birth outcomes, prenatal birth behaviors, or neonatal care amongst families if the program served a higher-risk group of families. Mother and Infant Home Visiting Program Evaluation exploratory findings also suggest that home visiting may improve maternal health by improvements in women's general

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⁵⁴³ Charles Michalopoulos, Kristen Faucetta, Carolyn J. Hill, Ximena A. Portilla, Lori Burrell, Helen Lee, Anne Duggan, and Virginia Knox, *Impacts on Family Outcomes of Evidence-Based Early Childhood Home Visiting: Results from the Mother and Infant Home Visiting Program Evaluation*, Administration for Children and Families, Office of Planning, Research, and Evaluation, January 2019, pp. 34-35,

https://www.acf.hhs.gov/sites/default/files/opre/mihope_impact_report_final20_508.pdf; Helen Lee, Sarah Crowne, Kristen Faucetta, and Rebecca Hughes, *An Early Look at Families and Local Programs in the Mother and Infant Home Visiting Program Evaluation-Strong Start: Third Annual Report*, p. ES-5, https://www.acf.hhs.gov/sites/default/files/opre/mihope_ssyr3_acf_compliant.pdf.

⁵⁴⁴ Charles Michalopoulos, Kristen Faucetta, Carolyn J. Hill, Ximena A. Portilla, Lori Burrell, Helen Lee, Anne Duggan, and Virginia Knox, *Impacts on Family Outcomes of Evidence-Based Early Childhood Home Visiting:* Results from the Mother and Infant Home Visiting Program Evaluation, Administration for Children and Families, Office of Planning, Research, and Evaluation, January 2019, p. 35, note 14, https://www.acf.hhs.gov/sites/default/files/opre/mihope impact report final20 508.pdf.

⁵⁴⁵ Charles Michalopoulos, Sarah Shea Crowne, Ximena A. Portilla, Helen Lee, Jill H. Filene, Anne Duggan, and Virginia Knox, *A Summary of Results from the MIHOPE and MIHOPE-Strong Start Studies of Evidence-Based Home Visiting*, Administration for Children and Families, Office of Planning, Research, and Evaluation, January 2019, p. 5, https://www.acf.hhs.gov/sites/default/files/opre/mihope_summary_brief_01_16_19_508.pdf.

⁵⁴⁶ Ibid., 13.

⁵⁴⁷ Ibid.

health, increased rates of health insurance coverage, and reductions in symptoms of depression. 548

Alliance for Innovation on Maternal Health

The Alliance for Innovation on Maternal Health is a foundational "national data-driven maternal safety and quality improvement initiative" with the goal of "eliminating preventable maternal mortality and severe maternal morbidity" in the U.S., housed within the federal Health Resources & Services Administration's Maternal & Child Health Bureau. ⁵⁴⁹ The Alliance for Innovation on Maternal Health is a national partnership that engages a variety of stakeholders including provider organizations, state health and public health systems, consumer groups, and other stakeholders in order to improve overall maternal health outcomes. ⁵⁵⁰ It is funded through a cooperative grant between the Health Resources and Services Administration's Maternal and Child Health Bureau and American College of Obstetricians and Gynecologists, ⁵⁵¹ and funding supports facilitating multidisciplinary collaborations focused on reducing maternal mortality and severe maternal morbidity; implementation and adoption of maternal safety bundles, which will include capturing and reviewing outcome data by race/ethnicity; ⁵⁵² and data collection and analytics within a continuous quality improvement framework to improve the implementation of safety bundles by state-based teams. ⁵⁵³

Maternal safety bundles are "a set of small straightforward evidence-based practices, that when used collectively and reliably in the delivery setting, have improved patient outcomes and reduced maternal mortality and severe maternal morbidity." There are several maternal safety bundles that focus on a variety of areas:

- Maternal venous thromboembolism;
- Obstetric care for women with substance use disorder;
- Obstetric hemorrhage;
- ;Prevention of retained vaginal sponges after birth;
- Reduction of peripartum racial/ethnic disparities;

⁵⁴⁹ Council on Patient Safety in Women's Health Care, "Alliance for Innovation on Maternal Health Program," https://safehealthcareforeverywoman.org/aim-program/.

⁵⁴⁸ Ibid., 14.

⁵⁵⁰ Council on Patient Safety in Women's Health Care, "Alliance for Innovation on Maternal Health Program," https://safehealthcareforeverywoman.org/aim-program/; Health Resources & Services Administration, "Alliance for Innovation on Maternal Health (AIM)," https://www.hrsa.gov/grants/find-funding/hrsa-18-085.

⁵⁵¹ Council on Patient Safety in Women's Health Care, "Alliance for Innovation on Maternal Health Program," https://safehealthcareforeverywoman.org/aim-program/.

⁵⁵² See infra, Table 3.1.

⁵⁵³ Health Resources & Services Administration, "Alliance for Innovation on Maternal Health (AIM)," https://www.hrsa.gov/grants/find-funding/hrsa-18-085.

⁵⁵⁴ Ibid.

- Safe reduction of primary cesarean birth; and
- Severe hypertension in pregnancy. 555

Previously, the AIM program developed a maternal safety bundle that aims to reduce peripartum racial and ethnic disparities. The information included in the bundle provides a wealth of resources to partners broken down into four components. See Table 3.1.

Table 3.1 Reduction of Peripartum Racial/Ethnic Disparities

Readiness

Every Health System

Establish systems to accurately document self-identified race, ethnicity, and primary language.

Provide system-wide staff education and training on how to ask demographic intake questions.

Ensure that patients understand why race, ethnicity, and language data are being collected.

Ensure that race, ethnicity, and language data are accessible in the electronic medical record.

Evaluate non-English language proficiency (e.g. Spanish proficiency) for providers who communicate with patients in languages other than English.

Educate all staff (e.g. inpatient, outpatient, community-based) on interpreter services available within the healthcare system.

Provide staff-wide education on:

Peripartum racial and ethnic disparities and their root causes.

Best practices for shared decision making.

Engage diverse patient, family, and community advocates who can represent important community partnerships on quality and safety leadership teams.

Recognition & Prevention

Every patient, family, and staff member

Provide staff-wide education on implicit bias.

Provide convenient access to health records without delay (paper or electronic), at minimal to no fee to the maternal patient, in a clear and simple format that summarizes information most pertinent to perinatal care and wellness.

Establish a mechanism for patients, families, and staff to report inequitable care and episodes of

⁵⁵⁵ Council on Patient Safety in Women's Health Care, "Alliance for Innovation on Maternal Health Program," https://safehealthcareforeverywoman.org/aim-program/.

miscommunication or disrespect.

Response

Every Clinical Encounter

Engage in best practices for shared decision making.

Ensure a timely and tailored response to each report of inequity or disrespect.

Address reproductive life plan and contraceptive options not only during or immediately after pregnancy, but at regular intervals throughout a woman's reproductive life.

Establish discharge navigation and coordination systems post childbirth to ensure that women have appropriate follow-up care and understand when it is necessary to return to their health care provider.

Provide discharge instructions that include information about what danger or warning signs to look out for, whom to call, and where to go if they have a question or concern.

Design discharge materials that meet patients' health literacy, language, and cultural needs.

Reporting/Systems Learning

Every Clinical Unit

Engage in best practices for shared decision making.

Ensure a timely and tailored response to each report of inequity or disrespect.

Address reproductive life plan and contraceptive options not only during or immediately after pregnancy, but at regular intervals throughout a woman's reproductive life.

Establish discharge navigation and coordination systems post childbirth to ensure that women have appropriate follow-up care and understand when it is necessary to return to their health care provider.

Provide discharge instructions that include information about what danger or warning signs to look out for, whom to call, and where to go if they have a question or concern.

Design discharge materials that meet patients' health literacy, language, and cultural needs.

Source: Council on Patient Safety in Women's Healthcare, "Patient Safety Bundle: Reduction of Peripartum Racial/Ethnic Disparities, https://safehealthcareforeverywoman.org/patient-safety-bundles/reduction-of-peripartum-racialethnic-disparities/#link acc-1-2-d.

By the end of fiscal year 2023, the program aims to:

- Facilitate widespread implementation of the current maternal safety bundles by expanding to all U.S. states, the District of Columbia, U.S. territories, and tribal entities.;
- New maternal safety bundles that address new topics in the quality and safety of maternity care practices; and,

 Develop and implement a national campaign focused on the current state of maternal mortality and severe maternal morbidity that highlights the impact of the Alliance for Innovation on Maternal Health, and how the maternal safety bundles improve maternity care practices.

As of April 2021, there are currently 42 states and jurisdictions that have enrolled in the Alliance for Innovation on Maternal Health, many of which have implemented one or more safety bundles.⁵⁵⁶

The American College of Obstetricians and Gynecologists wrote to the Commission about how the American College of Obstetricians and Gynecologists works with the Alliance for Innovation on Maternal Health program to reduce disparities in maternal health outcomes:

Through quality improvement science, [the Alliance for Innovation on Maternal Health] allows the findings from Maternal Mortality Review Committees to be incorporated into best practices throughout birthing facilities across the country. [The Alliance for Innovation on Maternal Health] works through state-based teams to align national, state, and hospital level quality improvement efforts to improve overall maternal health outcomes. Any birthing hospital in a participating [the Alliance for Innovation on Maternal Health] state may join the growing and engaged [the Alliance for Innovation on Maternal Health] community of multidisciplinary health care providers, public health professionals, and cross-sector stakeholders who are committed to improving maternal outcomes in the U.S.

As [the Alliance for Innovation on Maternal Health] program evolved, it became increasingly evident that inequities in care and social determinants of health play a significant role in the outcomes that the program seeks to address. As a result, [the Alliance for Innovation on Maternal Health] program has shifted over the last 12 to 18 months to an approach that seeks to integrate equity concepts into all aspects of its work. Armed with the knowledge that significant disparate outcomes exist for birthing people who are Black, Latinx, Indigenous, or from other communities of color, [the American College of Obstetricians and Gynecologists] has worked through the [Alliance for

states-systems-2/. Also on file.)

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⁵⁵⁶ Council on Patient Safety in Women's Health Care, "AIM States & Systems,"

https://safehealthcareforeverywoman.org/aim-program/ (accessed May 6, 2020). AIM enrolled states include
Alaska, Arizona, California, Colorado, Delaware, Florida, Georgia, Illinois, Indiana, Louisiana, Maryland,
Massachusetts, Michigan, Mississippi, Missouri, Nebraska, New Jersey, New Mexico, New York, North Carolina,
Oklahoma, Oregon, South Carolina, Tennessee, Texas, Utah, Virginia, Washington, and West Virginia (according to
map). (Archived link: http://web.archive.org/web/20200422155000/https://safehealthcareforeverywoman.org/aim-

Innovation on Maternal Health] program to raise awareness and develop programming to address these inequities. 557

In September 2019, the Health Resources and Services Administration announced that it would be awarding \$1.8 million in grants for the Alliance for Innovation on Maternal Health Community Care Initiative, which builds upon the foundational work of the existing Alliance for Innovation on Maternal Health program by focusing on the development and implementation of maternal safety bundles for non-hospital settings including community-based organizations and outpatient clinical facilities and addressing preventable maternal mortality and severe maternal morbidity among pregnant women and postpartum women in these non-hospital settings. This new initiative aims to convene a maternal safety workgroup comprised of community-focused public health and clinical experts to guide program activities; facilitate the national implementation of two existing non-hospital focused safety bundles, and development of new non-hospital focused safety bundles for use in outpatient clinical settings and community-based organizations; and conduct data collection and analytics within a continuous quality improvement framework to improve the implementation of non-hospital focused safety bundles.

In 2019, the National Healthy Start Association was awarded the sole grant of \$1.8 million for five years to support this effort. The project has established a National Maternal Safety Committee to address and improve maternal health care in community-based settings. The Committee has finalized the Postpartum Care maternal safety bundle, and pilot testing of the bundle is underway. Once the pilot testing is complete, the bundle will be made available for public access via a national rollout and dissemination plans. Grantee performance is measured annually through the submission of a Non-Competing Performance Report, budget and work plan review and analysis. 561

⁵⁵⁷ American College of Obstetricians and Gynecologists, Public Comment for the *Racial Disparities in Maternal Health Briefing* before the U.S. Comm'n on Civil Rights, pp. 10-11.

⁵⁵⁸ U.S. Department of Health and Human Services, "HHS Awards \$374 Million to Programs Supporting Maternal and Child Health," Sep. 12, 2019, https://www.hhs.gov/about/news/2019/09/12/hhs-awards-374-million-programs-supporting-maternal-child-health.html.

⁵⁵⁹ Health Resources & Services Administration, "Alliance for Innovation on Maternal Health (AIM) – Community Care Initiative," https://www.hrsa.gov/grants/find-funding/hrsa-19-109.

⁵⁶⁰ Health Resources & Services Administration, "Maternal Health Awardees FY19," https://mchb.hrsa.gov/maternal-child-health-initiatives/fy19-maternal-health-awards; National Healthy Start Association, "What We Do," https://www.nationalhealthystart.org/what we do.

⁵⁶¹ Health Resources and Services Administration Response to USCCR Interrogatories for the Racial Disparities in Maternal Health Briefing before U.S. Comm'n on Civil Rights, June 13, 2021, at p. 6 (hereinafter Health Resources and Services Administration Response to USSCR Interrogatories).

National Child & Maternal Health Education Program

The National Child & Maternal Health Education Program (NCHMEP), administered by the Eunice Kennedy Shriver National Institute of Child Health and Human Development (National Institute of Child Health and Human Development) of the National Institutes of Health (NIH), aims to "identify key challenges in child and maternal health, review relevant research and initiate educational activities that advance the knowledge base of the field, and improve the health of women and children."562 This is achieved through a partnership with over 30 prominent maternal and child health care provider associations, federal agencies, nonprofit maternal and child health organizations, and other entities nationwide. 563 These partners serve on the National Child & Maternal Health Education Program's Coordinating Committee, and use their scientific and medical expertise to address challenges to maternal and child health through education and outreach.⁵⁶⁴ However, HHS informed USCCR that NICHD's evaluation of NCHMEP's initiatives success and overall efficiency indicated that the program was not cost effective overall and is therefore in the process of being phased out. 565 NCMHEP does not have any set-aside funds or a specific budget and instead NICHD's Office of Communications uses a portion of its contract dollars to support NCMHEP and its activities.⁵⁶⁶ According to the information the program provided, NCMHEP is not a research funding or grant program but an education and outreach effort that highlights certain topics in maternal health and child health and shares evidence-based information that may help address those issues with target audiences, including providers.⁵⁶⁷ NCHMEP initiatives do not have a racial or ethnic population focus, instead broadly targeting audiences including pregnant people, those planning pregnancy, those who have given birth, healthcare providers, and sometimes the family of the pregnant/planning/postpartum person.⁵⁶⁸ Currently, the program has four initiatives that seek to educate mothers on reducing elective deliveries before 39 weeks, depression and anxiety around pregnancy, full-term pregnancy definition, and pregnancy for everybody (i.e., seeking healthy pregnancies for all body types), and materials (e.g., brochures, fact sheets, resources) are

⁵⁶² Eunice Kennedy Shriver National Institute of Child Health and Human Development, "National Child & Maternal Health Education Program," https://www.nichd.nih.gov/ncmhep.

⁵⁶³ See Eunice Kennedy Shriver National Institute of Child Health and Human Development, "Coordinating Committee," https://www.nichd.nih.gov/ncmhep/about/coordinating-committee; see also, Eunice Kennedy Shriver National Institute of Child Health and Human Development, "National Child & Maternal Health Education Program," https://www.nichd.nih.gov/ncmhep.

⁵⁶⁴ Eunice Kennedy Shriver National Institute of Child Health and Human Development, "About the National Child & Maternal Health Education Program (NCMHEP)," https://www.nichd.nih.gov/ncmhep/about.

⁵⁶⁵ NICHD, Response to USCCR Interrogatories for the Maternal Health Briefing before U.S. Comm'n on Civil Rights, June 16, 2021, at p.3 (hereinafter NICHD, Response to USCCR interrogatories).

⁵⁶⁶ Ibid., 3.

⁵⁶⁷ Ibid., 1.

⁵⁶⁸ Ibid., 2.

included on the program website.⁵⁶⁹ As stated by HHS, NCMHEP took a collaborative approach to its activities, where a coordinating committee of representatives from the nation's leading maternal and child health organizations made decisions about the program and its initiatives. This collaborative approach improved conceptual investment and in-kind support for initiatives and messages, but it was also time-consuming and resource intensive for NICHD. The initiatives were successful in raising awareness about certain issues and educating patient and provider communities, but NCMHEP had neither the resources nor the support needed to expand these efforts to have a more national impact. Additionally, according to HHS, NICHD priorities moved away from outreach and education to instead focus on supporting and conducting research. Therefore, NCMHEP is being phased out.⁵⁷⁰

Enhancing Reviews and Surveillance to Eliminate Maternal Mortality

Maternal Mortality Review Committees are multidisciplinary state and local committees convened to identify, review, and characterize maternal deaths that occur within one year of pregnancy using a variety of data sources beyond just vital records. Shanna Cox of the CDC testified to the Commission about the importance of Maternal Mortality Review Committees, describing them as a "core state public health function." While reliance on vital statistics is useful for identifying trends and disparities in maternal mortality and severe maternal morbidity, state and local Maternal Mortality Review Committees are most effective to comprehensively assess maternal deaths and identify methods of prevention. More specifically, Maternal Mortality Review Committees utilize the following process:

A [Maternal Mortality Review Committee] gathers extensive information about each individual case of maternal death selected for review, and this information is synthesized into a story for that case. The committee convenes to further fill in the story and, for each case, answer the question, "What happened?" The committee then determines if the death was related to or aggravated by pregnancy. If so, the death is [] counted in the state's pregnancy-related mortality ratio. Committee members also will craft recommendations specific to the case to ensure that a similar story doesn't unfold in the future. ⁵⁷⁴

⁵⁶⁹ Eunice Kennedy Shriver National Institute of Child Health and Human Development, "Initiatives," https://www.nichd.nih.gov/ncmhep/initiatives.

⁵⁷⁰ NICHD, Response to USCCR Interrogatories, at 3.

⁵⁷¹ See infra notes 598-601.

⁵⁷² Cox Statement at 2.

⁵⁷³ CDC Foundation, Building U.S. Capacity to Review and Prevent Maternal Deaths: Report from Nine Maternal *Mortality Review Committees*, 2018, p. 9,

https://www.cdcfoundation.org/sites/default/files/files/ReportfromNineMMRCs.pdf.

⁵⁷⁴ Review to Action, "What Makes Maternal Mortality Review Unique?" https://reviewtoaction.org/learn/what-makes-maternal-mortality-review-unique.

For each death reviewed, there are six key decisions that Maternal Mortality Review Committees make:

- 1. Was the death pregnancy-related?
- 2. What was the underlying cause of death?
- 3. Was the death preventable?
- 4. What were the factors that contributed to the death?
- 5. What are the recommendations and actions that address those contributing factors?
- 6. What is the anticipated impact of those actions if implemented?⁵⁷⁵

While all questions are essential, the last four questions are unique to what maternal mortality review committees can do that other maternal mortality surveillance systems cannot.⁵⁷⁶ The findings based on these questions can contribute to a better understanding of how to put data into meaningful and impactful action. For example, a recent report of nine Maternal Mortality Review Committees identified 193 recommendations for action that were grouped into ten common themes:

- Improve training;
- Enforce policies and procedures;
- Adopt levels of maternal care/ensure appropriate level of care determination;
- Improve access to care;
- Improve patient/provider communication;
- Improve patient management for mental health conditions;
- Improve procedures related to communication and coordination between providers;
- Improve standards regarding assessment, diagnosis, and treatment decisions;
- Improve policies related to patient management, communication and coordination between providers, and language translation; and,
- Improve policies regarding prevention initiatives, including screening procedures and substance use prevention or treatment programs. 577

These themes are also examined by leading cause of death, in order to better understand how to better prevent, for example, cardiovascular and coronary conditions, or hemorrhage.⁵⁷⁸ In addition, the anticipated impacts of recommended actions are assessed, first by assigning a specific level of prevention to each recommendation (primary prevention, secondary prevention, or tertiary prevention), and second, by assigning an expected level of impact.⁵⁷⁹ See Figure 3.1.

⁵⁷⁷ Ibid., 29.

⁵⁷⁵ CDC Foundation, Building U.S. Capacity to Review and Prevent Maternal Deaths: Report from Nine Maternal *Mortality Review Committees*, 2018, p. 10,

https://www.cdcfoundation.org/sites/default/files/files/ReportfromNineMMRCs.pdf.

⁵⁷⁶ Ibid.

⁵⁷⁸ Ibid., 30.

⁵⁷⁹ Ibid., 31.

Determine the Expected Small Education / Levels of Impact: Counseling Medium A comprehensive strategy Helps to prioritize and Clinical intervention to reduce maternal deaths translate recommendations to and Coordination of would incorporate action Care multiple levels Large Long-lasting protective interventions Extra Large Change in context Giant Address Social Determinants of Health

Figure 3.1 Expected Level of Impact if Recommendation is Implemented

Source: CDC Foundation, Building U.S. Capacity to Review and Prevent Maternal Deaths: Report from Nine Maternal Mortality Review Committees, 2018, p. 10, https://www.cdcfoundation.org/sites/default/files/files/ReportfromNineMMRCs.pdf.

As seen in Figure 3.1, recommended actions are adapted from this Health Impact Pyramid, where actions at the top of the pyramid focus more on the individual level, and actions toward the bottom of the pyramid have a greater potential for population-level impact, focusing less on the individual and more on entire populations. 580 Ideally, Maternal Mortality Review Committees will identify recommended actions across the spectrum for a comprehensive strategy for preventing maternal deaths.⁵⁸¹ In the report from nine Maternal Mortality Review Committees, 36.6 percent of recommended actions were categorized as primary prevention, 39.5 percent as secondary prevention, and 23.8 as tertiary prevention.⁵⁸² This report identified the distribution of the levels of impact if the recommended actions were implemented, finding that 19.5 percent of recommended actions would have a small impact, 40.2 percent would have a medium impact, 29.0 percent would have a large impact, 7.7 would have an extra-large impact, and 3.6 would have a giant impact. 583 For example, from the themes identified above, improving training and patient management of mental health conditions would both have more of a small to medium impact if implemented; whereas, adopting maternal levels of care, ensuring appropriate levels of care determination and improving policies regarding prevention initiatives, including screening procedures and substance use prevention or treatment programs would have more of a

⁵⁸⁰ Ibid., 31.

⁵⁸¹ Ibid., 31.

⁵⁸² Ibid., 32.

⁵⁸³ Ibid., 32.

large to giant impact if implemented.⁵⁸⁴ Furthermore, recommendations with large or extra-large potential impacts represented over two-thirds of recommended actions for the two leading causes of death: cardiovascular and coronary conditions and hemorrhage.⁵⁸⁵

Currently 47 states, in addition to two cities, and Washington D.C. have Maternal Mortality Review Committees in the U.S. 586 Maternal Mortality Review Committees have existed in various forms across the U.S. for nearly a century. 587 One of the goals of the Maternal Mortality Review Committees is to reduce maternal mortality and morbidity in part by identifying opportunities for prevention. 588 However, there has been a significant reduction in Maternal Mortality Review Committee activity since the 1980s, as partially evidenced by a reduction in the number of active state committees to 27 from 44 active committees in 1968. 589 This was, in part, attributed to the reduction of maternal deaths. 590 This also spurred the development of the Pregnancy Mortality Surveillance System in 1986, to meet the need for understanding and interpreting maternal deaths beyond just the death certificate. 591 The reduction in the number of active Maternal Mortality Review Committees during this time was also due to Maternal Mortality Review Committees having difficulty interpreting small numbers of deaths, 592 and to a larger extent, due to concern of liability of committee members and proceedings being used in litigation. 593 Since then, it has been found that liability of participating in maternal mortality review is negligible, since most states have statutes that protect information used for these

https://www.americanprogress.org/issues/women/reports/2019/05/02/469186/eliminating-racial-disparities-maternal-infant-mortality/. See also Centers for Disease Control, "Pregnancy-Related Deaths: Data from 14 U.S. Maternal Mortality Review Committees, 2008-2017," https://www.cdc.gov/reproductivehealth/maternal-mortality/erase-mm/mmr-data-brief.html (discussing a key finding that MMRCs determined that 2 out of 3 deaths reviewed within the scope of the analysis were preventable).

⁵⁸⁴ Ibid., 33.

⁵⁸⁵ Ibid., 34.

⁵⁸⁶ Cox Statement at 3.

⁵⁸⁷ Wanda Barfield, "Transforming Tragedy Into Effective Maternal Mortality Prevention Efforts," *Health Affairs*, Jun. 29, 2017, https://www.healthaffairs.org/do/10.1377/hblog20170629.060774/full/.

⁵⁸⁸ Amy St. Pierre, MBA, Julie Zaharatos, MPH, David Goodman, PhD, and William M. Callaghan, MD, MPH, "Challenges and Opportunities in Identifying, Reviewing, and Preventing Maternal Deaths," *Obstetrics and Gynecology*, Vol. 131, No. 1 (January 2018): 138-142, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6511983/; Jamila Taylor, Cristina Novoa, Katie Hamm, and Shilpa Phadke, "Eliminating Racial Disparities in Maternal and Infant Mortality," *Center for American Progress*, May 2, 2019,

⁵⁸⁹ Amy St. Pierre, MBA, Julie Zaharatos, MPH, David Goodman, PhD, and William M. Callaghan, MD, MPH, "Challenges and Opportunities in Identifying, Reviewing, and Preventing Maternal Deaths," *Obstetrics and Gynecology*, Vol. 131, No. 1 (January 2018): 138-142, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6511983/590 Ibid.

⁵⁹¹ Ibid.

⁵⁹² Ibid.

⁵⁹³ Ronald F. Wright, JD and Jack C. Smith, MS, "State Level Expert Review Committees – Are they Protected?" *Public Health Reports*, Vol. 105, No. 1 (1990): 13.

reviews from disclosure or use in subsequent litigation, and statutes that protect individuals from civil liability. 594

Maternal Mortality Review Committees have historically worked independently from one another, which poses challenges for information-sharing due to non-standardized data collection and data analysis. The Enhancing Reviews and Surveillance to Eliminate Maternal Mortality program (ERASE MM) is a grant program administered by the CDC that directly supports 24 entities that coordinate and manage Maternal Mortality Review Committees covering 25 states to "identify, review, and characterize maternal deaths; and identify prevention opportunities." The ERASE MM program has three goals:

- Facilitate an understanding of the drivers of maternal mortality and complications of pregnancy and better understand the associated disparities;
- Determine what interventions at patient, provider, facility, system, and community levels will have the most effect; and
- Inform the implementation of initiatives in the right places for families and communities who need them most. 597

The Maternal Mortality Review Information Application is an essential data system and tool for Maternal Mortality Review Committees to help organize and standardize maternal mortality data to begin the process of comprehensively identifying and assessing maternal mortality cases. ⁵⁹⁸ The CDC recently added the ability of committees to document the role of discrimination to the Maternal Mortality Review Information Application to increase data collection. ⁵⁹⁹ This system is an upgrade from its predecessor, the Maternal Mortality Review Data System. ⁶⁰⁰ It provides:

- A repository for the collection of clinical and non-clinical information surrounding a woman's life and death, which can help facilitate review by a jurisdiction-based maternal mortality review committee;
- Documentation of committee deliberations on 1) whether the death was related to pregnancy; 2) if it could have been prevented; 3) factors that contributed to the death; and 4) recommendations to prevent future deaths; and

⁵⁹⁴ Ibid.

⁵⁹⁵ Wanda Barfield, "Transforming Tragedy Into Effective Maternal Mortality Prevention Efforts," *Health Affairs*, Jun. 29, 2017, https://www.healthaffairs.org/do/10.1377/hblog20170629.060774/full/.

⁵⁹⁶ Centers for Disease Control and Prevention, "Enhancing Reviews and Surveillance to Eliminate Maternal Mortality (ERASE MM)," https://www.cdc.gov/reproductivehealth/maternal-mortality/erase-mm/index.html.

⁵⁹⁷ Ibid.

⁵⁹⁸ Ibid.

⁵⁹⁹ Shanna Cox, Response to USCCR Follow-Up Questions at 3 (available at https://www.usccr.gov/pubs/briefing-reports/2020-11-13-Racial-Disparities-in-Maternal-Health.php).

⁶⁰⁰ Review to Action, "MMRIA," https://reviewtoaction.org/implement/mmria.

• Standardized indicators, common to most pregnancy-related deaths that can be used for surveillance, monitoring, and examining maternal mortality. 601

The Centers for Disease Control and Prevention provides training and technical assistance to Maternal Mortality Review Committees in order to help them move forward, and also partners with the National Indian Health Board to identify approaches and needs of American Indian and Alaskan Native women. For states without established Maternal Mortality Review Committees, there is a website: "Review to Action" that promotes best practices in maternal mortality review, and provides resources, tools, and support for establishing a review committee. Review to Action also helps to connect established Maternal Mortality Review Committees with resources, tools, and best practices. Review to Action was developed in partnership with the Association of Maternal and Child Health Programs, the CDC Foundation, and the CDC Division of Reproductive Health, and is part of a larger 2016-2019 initiative, Building U.S. Capacity to Review and Prevent Maternal Deaths, which was supported in part by funding from Merck, through an award agreement with its Merck for Mothers program. This larger initiative also helped to support the development of the Maternal Mortality Review Information Application.

Currently 25 states receive CDC funding through ERASE MM, ⁶⁰⁸ funded through a \$45 million grant over five years, starting in 2019. ⁶⁰⁹ The FY 2021 President's Budget requested \$17.25 million to provide a total of 50 awards, including 26 new awards to support all 50 states and Washington, D.C., an increase of \$12 million from the previous budget request. ⁶¹⁰ This funding was appropriated by Congress for each of fiscal years 2019 through 2023, by the Preventing Maternal Deaths Act of 2018, ⁶¹¹ which sought to expand state, local, and tribal Maternal Mortality Review Committees and improve data collection and reporting on maternal

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⁶⁰¹ Centers for Disease Control and Prevention, "Enhancing Reviews and Surveillance to Eliminate Maternal Mortality (ERASE MM)," https://www.cdc.gov/reproductivehealth/maternal-mortality/erase-mm/index.html. ⁶⁰² Cox Statement, at 3-4; Shanna Cox, Response to USCCR Follow-Up Questions at 2-3 (available at https://www.usccr.gov/pubs/briefing-reports/2020-11-13-Racial-Disparities-in-Maternal-Health.php).

⁶⁰³ Centers for Disease Control and Prevention, "Enhancing Reviews and Surveillance to Eliminate Maternal Mortality (ERASE MM)," https://www.cdc.gov/reproductivehealth/maternal-mortality/erase-mm/index.html.

⁶⁰⁵ Review to Action, "About Us," https://reviewtoaction.org/about-us.

⁶⁰⁶ Ibid.; see also CDC Foundation, "CDC Foundation Partnership To Help Reduce Maternal Mortality In The United States," Apr. 19, 2016, https://www.cdcfoundation.org/pr/2016/cdc-foundation-partnership-help-reduce-maternal-mortality-united-states.

⁶⁰⁷ CDC Foundation, "Building U.S. Capacity To Review And Prevent Maternal Deaths," https://www.cdcfoundation.org/building-us-capacity-review-and-prevent-maternal-deaths.

⁶⁰⁸ Centers for Disease Control and Prevention, "Enhancing Reviews and Surveillance to Eliminate Maternal Mortality (ERASE MM)," https://www.cdc.gov/reproductivehealth/maternal-mortality/erase-mm/index.html.

⁶⁰⁹ Review to Action, "About Us," https://reviewtoaction.org/about-us.

⁶¹⁰ Centers for Disease Control and Prevention, FY 2021 Justification of Estimates for Appropriation Committees, pp. 157-158, https://www.cdc.gov/budget/documents/fy2021/FY-2021-CDC-congressional-justification.pdf.

⁶¹¹ Preventing Maternal Deaths Act of 2018, Pub. L. 115–344, 132 Stat. 5047 (2018).

mortality.⁶¹² Since the passage of the Preventing Maternal Deaths Act, all 50 states either have an existing Maternal Mortality Review Committee or are in the process of developing one.⁶¹³

Health Resources and Services Administration - Maternal Mortality Summit

Another division of the Department of Health and Human Services, the Health Resources and Services Administration, is, in part, "charged with improving the healthcare of geographically isolated and economically or medically vulnerable individuals."614 The Maternal and Child Health Bureau within the Health Resources and Services Administration is directed to carry out this mission through the distribution of federal grant money to "public or nonprofit institutions of higher learning and public or nonprofit private agencies and organizations engaged in research or in maternal and child health..."615 with the goal of improving the "health of all mothers and children."616 The Maternal and Child Health Bureau has its origins in the 1935 authorization of maternal and child health programs under Title V of the Social Security Act. 617 In addition to existing anti-discrimination provisions on recipients of federal funding, 618 Title V of the Social Security Act specifically prohibits discrimination on the basis of age, disability, sex, race, color, or national origin. 619 Title V also grants authority to the Secretary of Health and Human Services to enforce these anti-discrimination provisions through administrative action or via a referral to the Attorney General of the United States for appropriate civil action in a federal court of law. 620 Within the Health Resources and Services Administration, the Maternal and Child Health Bureau works to "improve the health of America's mothers, children, and families." 621 After its 2018

^{612 &}quot;Maternal Mortality: A National Crisis," *MD Edge*, Mar. 18, 2020, https://www.mdedge.com/obgyn/article/218024/obstetrics/maternal-mortality-national-crisis/page/0/1; American Academy of Family Physicians, "Improve Maternal Mortality," https://www.aafp.org/dam/AAFP/documents/events/fmas/BKG-MaternalMortality.pdf.

⁶¹³ Committee on Energy & Commerce, Memorandum, Hearing on "Improving Maternal Health: Legislation to Advance Prevention Efforts and Access to Care," Sep. 6, 2019, p. 2, https://energycommerce.house.gov/sites/democrats.energycommerce.house.gov/files/documents/Majority%20Memo

^{%20}maternal%20health_2019.09.10_1.pdf.
614 Health Resources and Services Administration, the Health Resources and Services Administration Maternal Mortality Summit: Promising Global Practices to Improve Maternal Health Outcomes, Technical Report, Feb. 15,

Mortality Summit: Promising Global Practices to Improve Maternal Health Outcomes, Technical Report, Feb. 15 2019, p. 2, https://www.hrsa.gov/sites/default/files/hrsa/maternal-mortality/Maternal-Mortality-Technical-Report.pdf.

⁶¹⁵ 42 U.S.C. § 702(a)(2)(B).

⁶¹⁶ 42 U.S.C. § 701(a).

⁶¹⁷ 42 U.S.C. § 701 *et seq*. (authorizing and providing for the administration of maternal and child health services block grants).

⁶¹⁸ See, U.S. Comm'n on Civil Rights, *Are Rights a Reality?*, pp. 8-10 https://www.usccr.gov/pubs/2019/11-21-Are-Rights-a-Reality.pdf (describing federal anti-discrimination provisions and the development of federal civil rights law).

^{619 42} U.S.C. § 708(a).

⁶²⁰ 42 U.S.C. § 708(b)-(c).

⁶²¹ Health Resources and Services Administration, the Health Resources and Services Administration Maternal Mortality Summit: Promising Global Practices to Improve Maternal Health Outcomes, Technical Report, Feb. 15,

Maternal Mortality Summit, the Health Resources and Services Administration issued a technical report that summarized key findings from the summit, identifying challenges that women face in receiving quality maternal health care from preconception, pregnancy, labor, delivery, postpartum, and interconception, and identified opportunities for improvement in these areas. The report offered key findings applicable both to American and global healthcare policymakers and providers, including:

- Access: Improve access to patient-centered, comprehensive care for women before, during, and after pregnancy, especially in rural and underserved areas;
- Safety: Improve quality of maternity services through efforts such as the utilization of safety protocols in all birthing facilities;
- Workforce: Provide continuity of care before, during, and after pregnancies by increasing the types and distribution of health care providers;
- Life Course Model: Provide continuous team-based support and use a life course model of care for women before, during, and after pregnancies;
- Data: Improve the quality and availability of national surveillance and survey data, research, and common terminology and definitions;
- Review Committees: Improve quality and consistency of maternal mortality review committees through collaborations and technical assistance with U.S. states; and
- Partnerships: Engage in opportunities for productive collaborations with multiple summit participants. 623

Challenges to Improve Maternal Health Outcomes

The Health Resources and Services Administration funded two notable challenges that aimed to foster innovative technology-based solutions to improve maternal health outcomes.⁶²⁴ These two challenges focused on:

• Helping providers remotely monitor the health of pregnant women, and empower women to make informed decisions about their own care; 625 and

2019, p. 2, https://www.hrsa.gov/sites/default/files/hrsa/maternal-mortality/Maternal-Mortality-Technical-Report.pdf.; see, 42 U.S.C. § 709 (directing the Secretary of HHS to "designate an identifiable administrative unit with expertise in maternal and child health within the Department of Health and Human Services...).

624 Health Resources Services Administration, "Remote Pregnancy Monitoring,"

https://mchbgrandchallenges.hrsa.gov/challenges/remote-pregnancy-monitoring; Health Resources Services

Administration, "Addressing Opioid Use Disorder in Pregnant Women and New Moms,"

https://mchbgrandchallenges.hrsa.gov/challenges/addressing-opioid-use-disorder-pregnant-women-and-new-moms.

625 Health Resources Services Administration, "Remote Pregnancy Monitoring," https://mchbgrandchallenges.hrsa.gov/challenges/remote-pregnancy-monitoring.

⁶²² Health Resources and Services Administration, the Health Resources and Services Administration Maternal Mortality Summit: Promising Global Practices to Improve Maternal Health Outcomes, Technical Report, Feb. 15, 2019, p. 2, https://www.hrsa.gov/sites/default/files/hrsa/maternal-mortality/Maternal-Mortality-Technical-Report.pdf.

⁶²³ Ibid., 3.

• Helping improve access to quality health care for pregnant women and new mothers struggling with opioid use disorder. 626

According to federal data regarding poverty rates, many low-income women are women of color. 627 In 2019, the Census Bureau set the poverty threshold at an income of \$26,172 or less for a family of four. 628 In 2019, the Census Bureau found that the Black poverty rate was 26.2 percent, compared with a White poverty rate of 8.3 percent, an Asian poverty rate of 6.3 percent, and the Hispanic poverty rate was 20.9 percent. 629 Since low-income pregnant women often face many barriers to accessing adequate prenatal care, the Health Resources and Services Administration implemented the Remote Pregnancy Monitoring Challenge which sought to increase remote and virtual access to quality care for low-income women; eliminate barriers to quality care; improve communication among patients and providers; provide health education to pregnant women in order to monitor their own health and care; and support access to remote services for women in rural areas and typically underserved areas with limited access to prenatal care. 630 Additionally, since low-income pregnant women and new mothers often face barriers to accessing safe and effective opioid use disorder care and treatment, including stigma, prejudice, and discrimination, and may have limited social supports such as housing, transportation, or employment, the Health Resources and Services Administration also implemented the Addressing Opioid Use Disorder in Pregnant Women and New Moms Challenge, which sought to increase access to substance use disorder treatment, recovery support, and other services, particularly for those in rural or underserved areas. 631

There were two phases to each challenge. Phase 1 winners each received a \$100,000 prize, and Phase 2 winners each received a \$125,000 prize. 632 The sole Phase 3 award recipient was Benten Technologies, in collaboration with ChristianaCare and the Delaware Division of Family Services for Mobile-Accessible Plan of Safe Care for their design of a mobile app designed to

⁶²⁸ Retrieved from, U.S. Census Bureau, *Poverty Thresholds*, https://www.census.gov/data/tables/time-series/demo/income-poverty/historical-poverty-thresholds.html (last accessed Sept. 16, 2020).

⁶²⁶ Health Resources Services Administration, "Addressing Opioid Use Disorder in Pregnant Women and New Moms," https://mchbgrandchallenges.hrsa.gov/challenges/addressing-opioid-use-disorder-pregnant-women-and-new-moms.

⁶²⁷ See infra note 629.

⁶²⁹ Retrieved from, U.S. Census Bureau, *Income and Poverty in the United States: 2019*, https://www.census.gov/data/tables/2020/demo/income-poverty/p60-270.html, (last accessed Sept. 16, 2020).

⁶³⁰ Health Resources Services Administration, "Remote Pregnancy Monitoring," https://mchbgrandchallenges.hrsa.gov/challenges/remote-pregnancy-monitoring.

⁶³¹ Health Resources Services Administration, "Addressing Opioid Use Disorder in Pregnant Women and New Moms," https://mchbgrandchallenges.hrsa.gov/challenges/addressing-opioid-use-disorder-pregnant-women-and-new-moms.

⁶³² Health Resources Services Administration, "Winners," https://mchbgrandchallenges.hrsa.gov/challenges/remote-pregnancy-monitoring/winners; Health Resources Services Administration, "Winners," https://mchbgrandchallenges.hrsa.gov/challenges/addressing-opioid-use-disorder-pregnant-women-and-new-moms/winners.

"keep families engaged in the collaborative care model." 633 The Phase 3 winner received $$130,000.^{634}$

There were three phases to each challenge. Phase 1 winners each received a \$10,000 prize, Phase 2 winners each received a \$30,000 prize, and the final Phase 3 winner of each challenge received a \$130,000 prize. The final Phase 3 winner of the Addressing Opioid Use Disorder in Pregnant Women and New Moms Challenge was Benten Technologies, in collaboration with ChristianaCare and the Delaware Division of Family Services for their design of a mobile app - Mobile-Accessible Plan of Safe Care - designed to "keep families engaged in the collaborative care model". The final winner of the Remote Pregnancy Monitoring Challenge was Zohreh Daly with Quilted Health, for the Maternal Monitoring App (MaMA), a downloadable smartphone app that assesses the correct level of care during pregnancy and up to a year after delivery, based on symptoms and/or data from home health devices and tools.

Federal-State Grants, Programs, and Partnerships

Recent federal efforts to address improve maternal health outcomes and eliminate disparities in maternal mortality and severe maternal morbidity have relied on partnerships among state and local entities. Improvements in data and investment in research at the state level is fundamentally important to addressing the maternal mortality crisis in the U.S. and eliminating racial disparities in maternal health care. Angela Doyinsola-Aina of the Black Mommas Matter Alliance testified to the Commission that:

We need to make room for looking at different models of research that uplifts those [] from these communities that are most impacted, whether we are talking about creating more pipelines for native and indigenous people, black folks, Asian folks, whomever, who are really culturally competent and holistically-minded around different research

635 Health Resources Services Administration, "Winners," https://mchbgrandchallenges.hrsa.gov/challenges/remote-pregnancy-monitoring/winners; Health Resources Services Administration, "Winners," https://mchbgrandchallenges.hrsa.gov/challenges/addressing-opioid-use-disorder-pregnant-women-and-new-moms/winners.

⁶³³ Health Resources Services Administration, "Winners," https://mchbgrandchallenges.hrsa.gov/challenges/remote-pregnancy-monitoring/winners; Health Resources Services Administration, "Winners," https://mchbgrandchallenges.hrsa.gov/challenges/addressing-opioid-use-disorder-pregnant-women-and-new-mons/winners.

⁶³⁴ Ibid.

⁶³⁶ Health Resources Services Administration, "Winners," https://mchbgrandchallenges.hrsa.gov/challenges/remote-pregnancy-monitoring/winners; Health Resources Services Administration, "Winners," https://mchbgrandchallenges.hrsa.gov/challenges/addressing-opioid-use-disorder-pregnant-women-and-new-moms/winners.

⁶³⁷ See, Dowler Testimony, Maternal Health Briefing, p. 36; Graham Testimony, pp. 43, 52; Aina Testimony p. 64, 66.

models and understanding how to collect that evidence to build out the evidence base to show positive and maternal and infant health outcomes.⁶³⁸

However, there have been documented struggles with applying what is learned from research into clinical practice and public health behavior, as it often gets "lost in translation." Some estimates indicate that it may take 15 to 17 years for a nationally endorsed guideline to "achieve widespread adoption in the community." Considering that most health care is delivered in local hospitals, clinics, and offices (many of which receive federal funding), this local environment must be taken into consideration when attempting to bridge that gap to improve the quality of healthcare. Thus, these federal partnerships with state, local, and private entities can have a huge impact in trying to implement innovative, evidence-based policies and practices that can help improve maternal health and address racial disparities.

Healthy Start

Congress established the Healthy Start program in 1991, through Section 301 of the Public Health Services Act. 643 In 2020, Healthy Start was reauthorized through FY 2025 by the Coronavirus Aid, Relief, and Economic Security (CARES) Act (P.L. 116-136)644 with minor changes, including suggesting additional factors the agency may consider in making award determinations, such as social determinants of health, community collaboration, inclusion of substance abuse agencies, and data collection capacity.

Healthy Start is administered by the Health Resources and Services Administration, and currently funds 101 projects in 34 states, Washington, D.C., and Puerto Rico.⁶⁴⁵ Healthy Start targets communities with infant mortality rates that are at least 1½ times the U.S. national average and/or with high indicators of poor perinatal outcomes, particularly among non-Hispanic

⁶³⁸ Aina Testimony, Maternal Health Briefing, p. 114.

⁶³⁹ Claude Lenfant, M.D., "Clinical Research to Clinical Practice — Lost in Translation?" *New England Journal of Medicine*, Vol. 349 (2003): 868-874, https://www.nejm.org/doi/full/10.1056/NEJMsa035507.

⁶⁴⁰ Elliott K. Main, MD, "Reducing Maternal Mortality and Severe Maternal Morbidity Through State-based Quality Improvement Initiatives," *Clinical Obstetrics and Gynecology*, Vol. 61, No. 2 (2018): 320, https://dl.uswr.ac.ir/bitstream/Hannan/48265/1/2018%20COG%20Volume%2061%20Issue%202%20June%20%2816%29.pdf.

⁶⁴¹ Claude Lenfant, M.D., "Clinical Research to Clinical Practice — Lost in Translation?" *New England Journal of Medicine*, Vol. 349 (2003): 868-874, https://www.nejm.org/doi/full/10.1056/NEJMsa035507.

⁶⁴² See Elliott K. Main, MD, "Reducing Maternal Mortality and Severe Maternal Morbidity Through State-based Quality Improvement Initiatives," *Clinical Obstetrics and Gynecology*, Vol. 61, No. 2 (2018): 327, https://dl.uswr.ac.ir/bitstream/Hannan/48265/1/2018%20COG%20Volume%2061%20Issue%202%20June%20%2816%29.pdf.

⁶⁴³ 42 U.S.C. § 241.

⁶⁴⁴ CARES Act, Pub. L. 116–136, 134 Stat. 381 (2020)

⁶⁴⁵ Healthy Start EPIC Center, "Program Overview," https://www.healthystartepic.org/healthy-start/program-overview/.

Black and other disproportionately affected populations. The Healthy Start program provides grants to support community-based strategies to reduce disparities in infant mortality and improve perinatal outcomes for women and children in high-risk communities throughout the nation. Major and persistent racial and ethnic disparities exist for infant mortality, maternal mortality, and other adverse outcomes such as preterm birth and low birth weight.

The Healthy Start program aims to address its purpose by:

- Improving access to quality health care and services for women, infants, children, and families through outreach, care coordination, health education, and linkage to health insurance;
- Strengthening the health workforce, specifically those individuals responsible for providing direct services;
- Building healthy communities and ensuring ongoing, coordinated, comprehensive services are provided in the most efficient manner through effective service delivery; and
- Promoting and improving health equity by connecting with appropriate organizations.
- Healthy Start utilizes four strategic approaches to providing support to women, infants, and families:
- Improve Women's Health to improve coverage, access to care, and health promotion and prevention, and health for women before, during, and after pregnancy;
- Improve family health and wellness to improve infant health and development;
- Promote systems change to maximize opportunities for community action to address social determinants of health; and
- Assure impact and effectiveness to conduct ongoing Healthy Start workforce development, data collection, quality improvement, performance monitoring, and evaluation.⁶⁴⁶

Healthy Start implements community-based interventions and helps to ensure a well-prepared quality workforce; establishes an information system for client services coordination; and supports ongoing evaluation and quality improvement at the local and national levels.

The Healthy Start service delivery model engages the entire family, working with women and their families before, during, and after pregnancy, and through the first 18 months after birth. With the recent emphasis on including the partners of Healthy Start women, the program has begun actively recruiting fathers/males in education, activities, services, and events. Service provision begins with direct outreach by Healthy Start community health workers to women who are at an increased risk of adverse maternal health outcomes. Each enrolled Healthy Start family receives a standardized, comprehensive assessment that considers physical and behavioral health, employment, housing, intimate partner violence risks, and more. Case managers link women and families to appropriate services and a medical home.

⁶⁴⁶ Ibid.

Healthy Start delivers services using a range of approaches, including on-site provider/program locations, in-home visits, and community locations/events. Services incorporate:

- Referrals and ongoing health care coordination for well-woman, prenatal, postpartum, and well-child care;
- Case management and linkage to social services;
- Alcohol, tobacco, and other drug use counseling;
- Nutritional counseling and breastfeeding support;
- Perinatal depression screening and linkage to behavioral health services;
- Inter-conception education and reproductive life planning; and
- Child development education and parenting support.
- Healthy Start provides training and technical assistance to its grant recipients through the Healthy Start EPIC Center. The EPIC Center website provides several resources and tools for providers, including information on program implementation, data collection, monitoring, evaluation, trainings, and more. 648
- In CY 2017, the Healthy Start program initiated a rigorous impact evaluation plan to determine the effect of the program on changes in participant-level characteristics, including behaviors, service use, and health outcomes. Findings from the evaluation showed positive outcomes related to program goals. These include earlier and more-frequent prenatal care, greater engagement in infant safe sleep practices, and lower rates of low birth weight. Healthy Start participants also met or exceeded targets with respect to usual source of care and depression screening;
- 45 percent of Healthy Start projects increased integration of prenatal, primary care and mental health services; and
- 41 percent of Healthy Start projects increased the cultural competence of providers in the community. 649

The Healthy Start program received \$12 million in appropriations in 2019 to help support a new initiative to reduce maternal mortality by hiring clinical service providers to provide well-woman services, maternity care, and other clinical maternal health services to clients at program sites.650 Currently, 93 Healthy Start grant recipients have received funding to hire clinicians. The Healthy Start program measures performance by the number of clinicians hired. To date, there were 173 providers hired, equivalent to 85 Full Time Equivalents.⁶⁵¹

⁶⁴⁸ Healthy Start EPIC Center, "Monitoring, Data, & Evaluation," https://www.healthystartepic.org/healthy-start-implementation/monitoring-data-and-evaluation/.

⁶⁴⁷ Ibid.

⁶⁴⁹ Abt Associates (2020). Evaluation of the Implementation and Outcomes of the Maternal & Child Health Bureau's Federal Healthy Start Program.

⁶⁵⁰ Ibid., 208.

⁶⁵¹ Health Resources and Services Administration Response to USSCR Interrogatories, at p. 6.

Health Center Program

The Health Resources and Services Administration administers the Health Center Program, which funds nearly 1,400 health centers throughout the country. These are "community-based and patient-directed organizations that deliver comprehensive, culturally competent, high-quality primary health care services." Health Centers aim to improve access to health care services by integrating a number of services into one location, such as pharmacy, mental health, substance use disorder, and oral health, where there are otherwise barriers to access for low-income and otherwise vulnerable populations. Most Health Centers receive federal funding to reduce disparities among vulnerable populations, and some receive funding to focus efforts on specific populations identified as medically underserved by the Secretary of Health and Human Services. 654

While Health Centers are not primarily focused on maternity care, they do serve more than nearly 7.6 million women aged 15 to 44.⁶⁵⁵ In 2019, over half a million women received prenatal care at Health Centers, with 74 percent of those women receiving prenatal care in their first trimester.⁶⁵⁶ Providers also performed more than 175,000 deliveries in 2019, and the total number of obstetricians, gynecologists, and certified nurse midwives grew by 6 percent in the past three years.⁶⁵⁷

State Maternal Health Innovation Program

Established in 2019, the State Maternal Health Innovation program is administered by the Health Resources and Services Administration and supports states in fostering partnerships with maternal health experts and optimizing their resources to support programs that help prevent maternal mortality and severe maternal morbidity and reduce disparities in maternal health outcomes. HRSA funded nine 5-year awards to states in FY 2019 with total annual funding of approximately \$18,650,000.

⁶⁵² Health Resources and Services Administration, "What is a Health Center?" https://bphc.hrsa.gov/about/what-is-a-health-center/index.html.

⁶⁵³ Ibid,, Federal law directs health centers to serve "medically underserved populations" defined as: "the population of an urban or rural area designated by the Secretary as an area with a shortage of personal health services or a population group designated by the Secretary as having a shortage of such services." 42 U.S.C. § 254b(b)(3)(A)

⁶⁵⁴ Health Resources and Services Administration, "What is a Health Center?" https://bphc.hrsa.gov/about/what-is-a-health-center/index.html; see 42 U.S.C. § 254b(b)(3)(B) (criteria for identifying medically underserved populations).

⁶⁵⁵ Health Resources and Services Administration, "How We Improve Maternal Health," https://www.hrsa.gov/maternal-health.

⁶⁵⁶ Ibid.

⁶⁵⁷ Ibid.

⁶⁵⁸ Health Resources and Services Administration, "State Maternal Health Innovation Program," https://www.hrsa.gov/grants/find-funding/hrsa-19-107.

The State Maternal Health Innovation projects, which will continue through September 29, 2024 pending continued appropriations for the program, support states' efforts to:

- Establish a state-focused Maternal Health Task Force to create and implement a strategic plan that incorporates activities outlined in the state's most recent State Title V Needs Assessment;
- Encourage collaboration between state and local partners, tribes, and tribal organizations;
- Improve the collection, analysis, and application of state-level data on maternal mortality and severe maternal morbidity;
- Promote and execute innovation in maternal health service delivery, such as improving access to maternal care services, identifying and addressing workforce needs, and/or supporting postpartum and interconception care services.⁶⁵⁹

Progress is measured through annual reporting on performance measures and through the submission of an annual maternal health report. Performance measures for the State MHI Program were established under the SPRANS allocation of the Block Grant provision of Title V of the Social Security Act. Starting September 29, 2020, award recipients are expected to document, and report annually on:

- 1) Increases within the state from baseline on September 30, 2019, for the following:
 - The percentage of women covered by health insurance,
 - The percentage of women who receive an annual well-woman visit,
 - The percentage of pregnant women who receive prenatal care,
 - The percentage of pregnant women who receive prenatal care in the first trimester,
 - The percentage of pregnant women who receive a postpartum visit, and
 - The percentage of women screened for perinatal depression.
- 2) Decreases within the state from baseline on September 30, 2019, for the following:
 - The rate of pregnancy-related deaths; and
 - The racial, ethnic, and/or geographic disparities in pregnancy-related mortality rates.

By September 29, 2021, following the establishment of the Maternal Health Task Force, the award recipients will update the maternal health strategic plan by increasing the number of actionable recommendations based on state-level maternal health data. 660 2021 Maternal and Child Health Block Grant

The State MHI Program is well underway, and \$2 million awards were made to nine states in September 2019. The purpose of this program is to assist states in strengthening their capacity to address disparities in maternal health and improve maternal health outcomes, including the prevention and reduction of maternal mortality and severe maternal morbidity. The State MHI

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⁶⁵⁹ Ibid.

⁶⁶⁰ Health Resources and Services Administration, Response to USSCR Interrogatories, at p. 5.

Program seeks to strengthen partnerships and collaboration by establishing a state-focused Maternal Health Task Force, improving state-level data surveillance on maternal mortality and severe maternal morbidity, and promoting and executing innovation in maternal health service delivery. States are actively implementing selected maternal health innovations. In September 2021, to measure program performance, each state will submit their Maternal Health Strategic Plan and Maternal Health Annual Report to HRSA for review.⁶⁶¹

Funded recipients include:

- Arizona Department of Health Services;
- Iowa Department of Public Health;
- University of Illinois;
- Johns Hopkins University;
- Montana Department of Public Health and Human Services;
- North Carolina Department of Health & Human Services;
- New Jersey Department of Health;
- Ohio Department of Health;
- Oklahoma State Health Department. 662

Rural Maternity and Obstetrics Management Strategies Program

The Rural Maternity and Obstetrics Management Strategies (RMOMS) Program, administered by the Health Resources and Services Administration, is a pilot program that aims to improve access to continuity of maternal and obstetrics care in rural areas throughout the U.S.⁶⁶³ The program's goals are to:

- Develop a sustainable network approach to coordinate maternal and obstetrics care within rural regions;
- Increase the delivery and access of preconception, pregnancy, labor and delivery, and postpartum services;
- Develop sustainable financing models for the provision of maternal and obstetrics care; and
- Improve maternal and neonatal outcomes.

The program encourages funding recipients to utilize innovation to reach the program goals through an established or formal regional network structure, and aims to demonstrate the impact of access and continuity of care in rural areas through testing models that address four focus areas:

662 Ibid 7

⁶⁶¹ Ibid., 6.

⁶⁶³ Health Resources and Services Administration, "Rural Maternity and Obstetrics Management Strategies Program," https://www.hrsa.gov/grants/find-funding/hrsa-19-094.

- Rural Hospital Obstetric Service Aggregation and Rural Regional Approaches to Risk Appropriate Care;
- Network Approach to Coordinating a Continuum of Care;
- Leveraging Telehealth and Specialty Care; and
- Financial Sustainability.

Successful funding recipients will have created programs that foster a safe delivery environment and improved access of prenatal and specialty care for women and infants in rural communities; models of maternal and obstetrics care that are reinforced and sustained by a payment/reimbursement structure; and improved clinical outcomes for maternal and neonatal health for the preconception, pregnancy, labor, delivery, and postpartum periods.

Supporting Maternal Health Innovation Program

Also established in 2019, the Supporting Maternal Health Innovation Program, now known as the Maternal Health Learning and Innovation Center, is administered by the Health Resources and Services Administration and aims to support states and other entities or stakeholders that are focused on initiatives to reduce maternal mortality and severe maternal morbidity by:

- Providing capacity building assistance to recipients of State Maternal Health Innovation program and the Rural Maternity and Obstetrics Management Strategies Program funding to implement innovative and evidence-based strategies; and
- Establishing a resource center to provide national guidance to the Health Resources and Services Administration funding recipients, states, and other key stakeholders. 664

In September 2019, HRSA awarded \$2.6 million to the University of North Carolina Chapel-Hill for the Maternal Health Learning and Innovation Center. 665 The Maternal Health Learning and Innovation Center is intended to support the nine State Maternal Health Innovation funding recipients through 2024 in the following:

- Increasing the percentage of women covered by health insurance;
- Increasing the percentage of women who receive an annual well-woman visit;
- Increasing the percentage of pregnant women who receive prenatal care;
- Increasing the percentage of pregnant women who receive prenatal care in the first trimester:
- Increasing the percentage of pregnant women who receive a postpartum visit;
- Increasing the percentage of women screened for perinatal depression;
- Decreasing the rate of pregnancy-related deaths; and

⁶⁶⁴ Health Resources and Services Administration, "Supporting Maternal Health Innovation Program," https://www.hrsa.gov/grants/find-funding/hrsa-19-106.

⁶⁶⁵ U.S. Department of Health and Human Services, "HHS Awards \$374 Million to Programs Supporting Maternal and Child Health," Sep. 12, 2019, https://www.hhs.gov/about/news/2019/09/12/hhs-awards-374-million-programs-supporting-maternal-child-health.html.

• Decreasing the racial, ethnic, and/or geographic disparities in pregnancy-related mortality rates. 666

University of North Carolina Chapel-Hill held an inaugural National Maternal Health Symposium in September 2020 and provides direct capacity building support to HRSA's maternal health award recipients. More information is available at www.maternalhealthlearning.org.

Title V of the Social Security Act Maternal and Child Health Block Grant Program

The Maternal and Child Health (MCH)Block Grant program was established by Title V of the Social Security Act of 1935, 667 and aimed to protect the health and welfare of mothers and children. The program operated as a federal-state partnership that established state health and/or public welfare departments in certain states, and supported and facilitated efforts of existing agencies in others in order to extend health and welfare services to mothers and children. In 1981, the Title V program was converted to a block grant program, which consolidated several key maternal and child health programs. Since then, the program has been amended several times to reflect changing national approaches to maternal and child health and welfare issues.

The Maternal and Child Health Block Grant program is one of the largest federal block grant programs, ⁶⁷³ and is the only federal program that is solely focused on improving maternal and child health outcomes. ⁶⁷⁴ In fiscal year 2020, Congress appropriated \$687.7 million for the Maternal and Child Health Block Grant program. ⁶⁷⁵ And in fiscal year 2021, an estimated 10%

⁶⁶⁶ Health Resources and Services Administration, *Notice of Funding Opportunity: Supporting Maternal Health Innovation Program, Fiscal Year 2019*, pp. 1-2,

 $[\]underline{https://grants.hrsa.gov/2010/Web2External/Interface/Common/EHBDisplayAttachment.aspx?dm_rtc=16\&dm_attid=d2d1f8cc-35be-40a7-95a9-1c07f25c5eb8.$

⁶⁶⁷ 42 U.S.C. § 701 et seq. (2019).

⁶⁶⁸ Health Resources and Services Administration, Maternal and Child Health Bureau, *Understanding Title V of the Social Security Act*, p. 1, http://www.amchp.org/AboutTitleV/Documents/UnderstandingTitleV.pdf.

⁶⁶⁹ Ibid., 9.

⁶⁷⁰ See Omnibus Budget Reconciliation Act of 1981, Pub. L. 97-35, 95 Stat. 827 (1981); 42 U.S.C. § 701 et seq.

⁶⁷¹ Health Resources and Services Administration, Maternal and Child Health Bureau, *Understanding Title V of the Social Security Act*, p. 1, http://www.amchp.org/AboutTitleV/Documents/UnderstandingTitleV.pdf.

⁶⁷² Ibid., 9.

⁶⁷³ Health Resources and Services Administration, "Title V Maternal and Child Health Services Block Grant Program," https://mchb.hrsa.gov/maternal-child-health-initiatives/title-v-maternal-and-child-health-services-block-grant-program.

⁶⁷⁴ Association of Maternal and Child Health Programs, "About Title V," http://www.amchp.org/AboutTitleV/Pages/default.aspx.

⁶⁷⁵ U.S. Department of Health and Human Services, *Fiscal Year 2021 Health Resources and Services Administration Justification of Estimates for Appropriations Committees*, p. 178, https://www.hrsa.gov/sites/default/files/hrsa/about/budget/budget-justification-fy2021.pdf.

of the base allocated funding to prevent negative pregnancy-related outcomes, including efforts to address and/or eliminate racial disparities. ⁶⁷⁶ The program distributes Title V funds to grantees from 59 jurisdictions to provide health care services to an estimated 60 million pregnant women and children, including an estimated 92 percent of all pregnant women in the United States.⁶⁷⁷ These funds are intended to enable states to help provide:

- Access to quality health care for mothers and children, especially for people with low incomes and/or limited availability of care;
- Health promotion efforts that seek to reduce infant mortality and the incidence of preventable diseases, and to increase the number of children appropriately immunized against disease;
- Access to comprehensive prenatal and postnatal care for women, especially low-income and/or at-risk pregnant women;
- An increase in health assessments and follow-up diagnostic and treatment services, especially for low-income children;
- Access to preventive and childcare services as well as rehabilitative services for children in need of specialized medical services;
- Family-centered, community-based systems of coordinated care for children with special healthcare needs; and
- Toll-free hotlines and assistance in applying for services to pregnant women with infants and children who are eligible for Title XIX (Medicaid). 678

The activities authorized under the Maternal and Child Health Block Grant Program that support the improvement of maternal health outcomes include the State Maternal and Child Health Block Grant program and Special Projects of Regional and National Significance, 679 some of which include:

- "Impact of a Newborn Behavioral Intervention on the Mental Health and Parenting of First-Time Mothers with Late-Preterm Infants";
- "Promoting healthy mother-child relationships: A pragmatic clinical trial for women in opioid treatment and their infants";
- "Identification of Prenatal Risk Factors for Brachial Plexus Birth Injury";
- "Examining Pregnancy-associated Drug Overdose Mortality Using Enhanced National Death Certificate Data";

⁶⁷⁶ Health Resources and Services Administration Response to USSCR Interrogatories, at p. 2.

⁶⁷⁷ Health Resources and Services Administration, "Title V Maternal and Child Health Services Block Grant Program," https://mchb.hrsa.gov/maternal-child-health-initiatives/title-v-maternal-and-child-health-services-blockgrant-program (State maternal and child health agencies apply for Title V funding on an annual basis. HHS notes that "States have flexibility in how Title V funds are used to support a wide range of activities that address state and national needs").

⁶⁷⁸ Ibid.

⁶⁷⁹ U.S. Department of Health and Human Services, Fiscal Year 2021 Health Resources and Services Administration Justification of Estimates for Appropriations Committees, p. 178, https://www.hrsa.gov/sites/default/files/hrsa/about/budget/budget-justification-fy2021.pdf.

- "The impact of Medicaid policy on prenatal care utilization and pregnancy outcomes of immigrant women"
- "Prenatal Counseling for Postpartum Health--A Randomized Trial" and
- "Pregnancy Related Care Research Network (PRCRN)."680

The State Maternal and Child Health Block Grant program distributes formula grants to all 59 states and jurisdictions to provide health care services to an estimated 60 million pregnant women and children, including an estimated 92 percent of all pregnant women in the U.S., ⁶⁸¹ and to help provide health care services to mothers and children and remove barriers "to receiving comprehensive, timely, and appropriate health care". ⁶⁸² The program has improved access to prenatal care, for example, data show that the percentage of women receiving prenatal care in the first trimester of pregnancy increased from 71 percent in 2007 to 77.5 percent in 2018. ⁶⁸³ As discussed in Chapter 2, access to prenatal care correlates with less risk of maternal mortality. ⁶⁸⁴

47 states are working to improve utilization and access to preventative and primary care for women of childbearing age. States and jurisdictions are also working to reduce maternal mortality, with 50states/jurisdictions providing funding for Maternal Mortality Review Committees and another 2 states using Title V funds to support the development of Maternal Mortality Review Committees. Additionally, states are utilizing Title V funds to support the implementation and use of safety bundles through the Alliance for Innovation on Maternal Health program, which is administered by the Health Resources and Services Administration. Mauricio Leone, COO of Obria Group, provided testimony to the Commission explaining in part how Obria, as a recipient of Title V funds, uses the funding to provide services such as sexual risk avoidance education and teen pregnancy prevention programs.

The Special Projects of Regional and National Significance grants have two purposes: 1) to address key emerging issues in maternal and child health; and 2) to support collaborative and

⁶⁸⁰ Health Resources and Services Administration Response to USSCR Interrogatories, at p. 2.

⁶⁸¹ Ibid., 3.

⁶⁸² U.S. Department of Health and Human Services, Fiscal Year 2021 Health Resources and Services Administration Justification of Estimates for Appropriations Committees, p. 180,

https://www.hrsa.gov/sites/default/files/hrsa/about/budget/budget-justification-fy2021.pdf.

⁶⁸³ Ibid.

⁶⁸⁴ See supra notes 250-257.

⁶⁸⁵ U.S. Department of Health and Human Services, Fiscal Year 2021 Health Resources and Services Administration Justification of Estimates for Appropriations Committees, 180.

⁶⁸⁶ Ibid.

⁶⁸⁷ Ibid., 181.

⁶⁸⁸ See supra notes 553-555 and Table 3.1.

⁶⁸⁹ Leone Statement at 1.

innovative learning across states to promote the use of evidence-based best practices. ⁶⁹⁰ In fiscal year 2020, just over half of the appropriated \$119.1 million in Special Projects of Regional and National Significance funding supported programs and initiatives that address "critical and emerging issues" including maternal mortality. ⁶⁹¹ Special Projects of Regional and National Significance funding supports the Alliance for Innovation on Maternal Health program, as well as the new Alliance for Innovation on Maternal Health Community Care program that both help develop and implement safety bundles for hospital and non-hospital care to improve the quality of maternal health care, which included the development of a new safety bundle on the prevention and treatment of opioid use disorder during pregnancy. ⁶⁹² In addition, fiscal year 2019 Special Projects of Regional and National Significance funding supported some new state-focused initiatives to improve maternal health outcomes and reduce disparities in maternal mortality and severe maternal morbidity, including the State Maternal Health Innovation Grants program and the Supporting Maternal Health Innovation Program. ⁶⁹³

States are legislatively mandated to conduct a needs assessment of the health status of the maternal and child health population every 5 years. The results of the needs assessment drive the selection of 7 to 10 priority needs that will be the focus of the 5-year state action plan. A needs assessment was last conducted in 2020. Sixteen states/jurisdictions identified a specific priority need around reducing maternal morbidity and/or mortality. Six states/jurisdictions developed a priority need specific to reducing disparities (usually racial disparities) in maternal morbidity, mortality or other maternal health outcomes. A review comparing the 2020 priority needs to those identified in 2015 found an increase in the number of states selecting priorities in these specific areas. ⁶⁹⁴

The program monitors progress of the formula grants using the Title V Performance Measure Framework last revised in 2015. The national performance measure framework is based on a three-tiered performance measure system: National Outcome Measures (NOMs), National Performance Measures (NPMs), and Evidence-based or -informed Strategy Measures (ESMs). In brief, NOMs are the ultimate health outcomes that Title V is attempting to improve. The NPMs are considered to be more directly modifiable by state Title V program efforts and influence NOMs. ESMs are developed by states to capture their evidence-based or -informed programmatic efforts to affect NPMs and in turn NOMs. The framework is intended to highlight the impact of Title V investments and provides states with flexibility in selecting NPMs and

⁶⁹⁰ U.S. Department of Health and Human Services, Fiscal Year 2021 Health Resources and Services Administration Justification of Estimates for Appropriations Committees, p. 181,

https://www.hrsa.gov/sites/default/files/hrsa/about/budget/budget-justification-fy2021.pdf.

⁶⁹¹ Ibid., 182.

⁶⁹² Ibid., 182; see also supra notes 553-555 and Table 3.1.

⁶⁹³ Ibid., 182

⁶⁹⁴ Health Resources and Services Administration Response to USSCR Interrogatories, at 3.

developing state performance measures (SPMs) and ESMs to address the state's priority needs. 695

The NOMs related to monitoring progress on pregnancy-related/associated health outcomes among women include NOM 1: Early prenatal care, NOM 2: Severe maternal morbidity, NOM 3: Maternal mortality, and NOM 24: Postpartum depression. NOMs are reported for all states on an annual basis. The NPMs related to these NOMs include NPM 1: Well-woman visit, NPM 2: Low-risk cesarean delivery, and NPM 14.1: Smoking during pregnancy. State grantees must select at least one of these NPMs for the women's/maternal health domain to align with their priority need(s). If the NPMs do not directly align with a priority need, state grantees must develop a SPM in addition to the minimum one NPM. All data for NOMs and NPMs are provided annually by the Maternal and Child Health Bureau (MCHB) and are collectively known as the Federally Available Data (FAD) to reduce reporting burden for the grantees. The FAD is pre-populated in the Title V Information System (TVIS). SPMs and ESMs are reported annually by the state grantee into TVIS.

With respect to monitoring the disparities in maternal health outcomes, the NOM and NPM data are also provided by various demographic stratifiers including race/ethnicity, as available from federal data sources. Ninety-five percent of the NOMs and NPMs are stratified by race/ethnicity, including all measures related to maternal health. Additionally, some states have chosen to develop SPMs that focus specifically on the disparity within an existing NOM or NPM such as this example from Texas, "Maternal Morbidity Disparities: Ratio of Black to White severe maternal morbidity rate." 697

Public Health Service Act Title X Family Planning

The family planning grant program under Title X of the Public Health Service Act⁶⁹⁸ is administered by HHS' Office of Population Affairs, and is the only federal grant program dedicated to ensuring access to a broad range of family planning and preventative health services for low-income, uninsured individuals, or others.⁶⁹⁹ The relevant services include family planning education and counseling; screening for breast cancer and cervical cancer; sexually transmitted disease and human immunodeficiency virus (HIV) testing; referral; prevention education; and pregnancy diagnosis and counseling.⁷⁰⁰ Competitive grants are awarded to state

⁶⁹⁶ Ibid., 4.

⁶⁹⁵ Ibid., 3-4.

⁶⁹⁷ Ibid.

⁶⁹⁸ 42 U.S.C. § 300 et seq. (1984); 42 C.F.R. Part 59 Subpart A (2000).

⁶⁹⁹ Office of Population Affairs, "About Title X Grants," https://www.hhs.gov/opa/title-x-family-planning/about-title-x-grants/index.html.

⁷⁰⁰ Office of Population Affairs, "Title X Family Planning Annual Report: 2018 National Summary," p. ES-1, https://www.hhs.gov/opa/sites/default/files/title-x-fpar-2018-national-summary.pdf.

and local health departments and community health, family planning, and other private nonprofit agencies. One key service that Title X grants support is preconception healthcare. Preconception healthcare services help to identify and modify biomedical, behavioral, and social risks to a woman's health, or aim to improve pregnancy outcomes through prevention and management. Grants have supported the development of preconception health care resource centers, which provide educational materials and information for both men and women, which aim to increase the chances of having a healthy pregnancy and birth. Also, these grants support services to help women develop a reproductive life plan, which may help identify unmet reproductive healthcare needs.

Title X has received approximately \$286.4 million in funding each year since 2014. ⁷⁰⁶ In 2019, Title X-funded services were implemented through 100 grants to 47 state and local health departments and 53 nonprofit family planning and community health agencies. ⁷⁰⁷ Title X funds supported a network of 3,825 service sites operated by either grantees or 1,060 subrecipients in the 50 United States, the District of Columbia, and eight U.S. territories. ⁷⁰⁸ Title X-funded providers served over 3.1 million family planning users through almost 4.7 million family planning encounters. About 9 of every 10 users (87%) were female, 61% were under 30 years of age, and 64% had family incomes at or below the poverty level. Of the 3.1 million family planning users served in 2019, 32% self-identified with at least one of the nonwhite Office of Management and Budget race categories (black or African American, Asian, Native Hawaiian or Pacific Islander, American Indian or Alaska Native, or more than one race), 33% self-identified as Hispanic or Latino, and 15% were limited English proficient. ⁷⁰⁹

Although the program does not directly conduct research/provide funding for research concerning (negative) pregnancy-related/associated health outcomes and pregnancy-related/associated deaths of women in the US, Title X funding does support collection and

⁷⁰¹ Ibid.

⁷⁰² Office of Population Affairs, "Preconception Health & Reproductive Life Plan," https://www.hhs.gov/opa/title-x-family-planning/preventive-services/preconception-health-and-reproductive-life-plan/index.html.

⁷⁰³ Ibid.

⁷⁰⁴ Ibid. *See also* Centers for Disease Control and Prevention, "Before Pregnancy," https://www.cdc.gov/preconception/index.html.

⁷⁰⁵ Ibid.

⁷⁰⁶ U.S. Department of Health and Human Services, *Budget in Brief, Fiscal Year 2021*, p. 32, https://www.hhs.gov/sites/default/files/fy-2021-budget-in-brief.pdf; U.S. Department of Health and Human Services, *Budget in Brief, Fiscal Year 2020*, p. 33, https://www.hhs.gov/sites/default/files/fy-2020-budget-in-brief.pdf? Population Affairs, "Funding History," https://www.hhs.gov/opa/title-x-family-planning/about-title-x-grants/funding-history/index.html.

⁷⁰⁷ U.S. Dep't of Health and Human Services, Office of the Assistant Secretary for Health, Response to USCCR Interrogatories at 1-2.

⁷⁰⁸ Ibid.

⁷⁰⁹ Ibid.

reporting of key data that enables the program to estimate unintended pregnancies and STIs averted, key outcomes related to maternal morbidity and mortality.⁷¹⁰

Annual submission of the Family Planning Annual Report (FPAR) is required of all Title X service grantees. The 15-table FPAR provides grantee-level data on the demographic and social characteristics of Title X clients, their use of family planning and related preventive health services, staffing, and revenue. FPAR data have multiple uses, which include monitoring performance and compliance with statutory requirements, fulfilling federal accountability and performance reporting requirements, and guiding strategic and financial planning. Furthermore, OPA monitors progress of grants towards stated outcomes through regular monitoring calls with grantees and technical reviews of required annual reporting.

Levels of Care Assessment Tool

The CDC developed the Levels of Care Assessment Tool based on medical guidelines issued in 2012 and 2015,⁷¹⁵ to promote risk-appropriate maternal and neonatal care in order to improve health outcomes for pregnant women and infants.⁷¹⁶ Because definitions and monitoring of levels of care vary widely across the U.S., there was a need to standardize assessments of levels of maternal and neonatal care.⁷¹⁷ The Levels of Care Assessment Tool can help states and jurisdictions create standardized assessments of levels of maternal and neonatal care, which allows for better information sharing to ensure that women and infants can receive care at a health facility that can best attend to their needs.⁷¹⁸ The Levels of Care Assessment Tool based upon the most recent guidelines from a policy statement issued by the American Academy of Pediatrics in 2012, and a joint policy statement from the American College of Obstetricians and Gynecologists and the Society for Maternal-Fetal Medicine issued in 2015 (and revised in 2019).⁷¹⁹

⁷¹¹ Ibid.

⁷¹⁰ Ibid.

⁷¹² Ibid.

⁷¹³ Ibid.

⁷¹⁴ Ibid.

⁷¹⁵ Andrea Catalano, M.P.H., Amanda Bennett, Ph.D., Ashley Busacker, Ph.D., Alethia Carr, M.B.A., David Goodman, Ph.D., Charlan Kroelinger, Ph.D., Ekwutosi Okoroh, M.D., M.P.H., Mary Brantley, M.P.H., and Wanda Barfield, M.D., M.P.H., "Implementing CDC's Level of Care Assessment Tool (LOCATe): A National Collaboration to Improve Maternal and Child Health" *J. Womens Health (Larchmt)* (Dec. 2017) Vol. 26 No. 12, at p. 3, https://stacks.cdc.gov/view/cdc/56565/Print.

⁷¹⁶ Centers for Disease Control and Prevention, "CDC Levels of Care Assessment Tool (CDC LOCATe)," https://www.cdc.gov/reproductivehealth/maternalinfanthealth/cdc-locate/index.html#tool.

⁷¹⁷ Ibid.

⁷¹⁸ Ibid.

⁷¹⁹ Ibid.; *see also* American Academy of Pediatrics, "Policy Statement: Levels of Neonatal Care," *Pediatrics*, Vol. 130, No. 3 (September 2012): 587-597, https://pediatrics.aappublications.org/content/pediatrics/130/3/587.full.pdf;

As of February 2019, there were 15 states (California, Colorado, Delaware, Georgia, Illinois, Iowa, the southeast perinatal region of Michigan, Mississippi, New Hampshire, New Mexico, North Carolina, Oklahoma, Tennessee, Utah, and Wyoming) and Puerto Rico that received technical assistance to use the CDC Levels of Care Assessment Tool.⁷²⁰

Office of Minority Health Partnership Grants

As discussed in Chapter 2, there are racial disparities in maternal health and maternal mortality rates in the United States. In 1990, Congress took into account health disparities among racial and ethnic minorities, and created the Office of Minority Health. Although the 1990 legislative findings did not focus directly on maternal health, they did note that the incidence of infant mortality among minorities is almost double that for the general population. The Office of Minority Health, a division of HHS, administers several grant programs that focus on collaborative partnerships with states or other entities in order to eliminate health disparities and improve health outcomes for minority populations. Dr. Garth Graham, former Deputy Assistant Secretary for Minority Health who led the Office of Minority Health at HHS, testified to the Commission that Office of Minority Health "plays a key role in coordinating issues related to health disparities."

The Office of Minority Health grew out of a recommendation in the 1985 Health and Human Services' *Report of the Secretary's Task Force on Black and Minority Health* also known as the *Heckler Report*.⁷²⁵ The resulting legislation directed the Office of Minority health to improve "the health of racial and ethnic minority groups."⁷²⁶ Former HHS Secretary Heckler's report also called for research to "[c]ontinue to evaluate the effect on perinatal outcomes of major programs such as Maternal Infant Care, Improve Pregnancy Outcome, and Supplemental Food Programs

The American College of Obstetricians and Gynecologists and The Society for Maternal-Fetal Medicine, "Obstetrics Care Consensus No. 9: Levels of Maternal Care," *Obstetrics and Gynecology*, Vol. 134, No. 2 (August 2019): e41-e55, https://www.acog.org/-/media/project/acog/acogorg/clinical/files/obstetric-care-consensus/articles/2019/08/levels-of-maternal-care.pdf.

⁷²⁰ Centers for Disease Control and Prevention, "Participating States & Success Stories," https://www.cdc.gov/reproductivehealth/maternalinfanthealth/cdc-locate/participating-state-success-stories.html.

⁷²¹ Disadvantaged Minority Health Improvement Act of 1990, Pub. L. 101-527, 104 Stat. 2312 (1990); 42 U.S.C. § 300 u-6; Section 2 (a), https://www.govinfo.gov/content/pkg/STATUTE-104/pdf/STATUTE-104-Pg2311.pdf#page=2.

⁷²² Disadvantaged Minority Health Improvement Act of 1990, Pub. L. 101-527, 104 Stat. 2311, Section 1 (b)(4), (1990).

 $^{{}^{723}\} Office\ of\ Minority\ Health,\ ``Partnerships,"\ \underline{https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=2\&lvlid=51}.$

⁷²⁴ Graham Testimony, *Maternal Health Briefing*, p. 43.

⁷²⁵ U.S. Dep't of Health and Human Services, *Report of the Secretary's Task Force on Black and Minority Health Vol. 1*, pp. 9-47 (1985) https://collections.nlm.nih.gov/ext/heckler/8602912X1/PDF/8602912X1.pdf.

⁷²⁶ 42 U.S.C. § 300u-6(b) (2010) (describing the duties of the Office of Minority Health) (while the report does not directly address racial disparities in maternal health outcomes, the report did find some racial disparities in the level and quality of care women experience during and after pregnancy in discussing infant birthweights, *see e.g.*, pp. 16, 177-181).

for Women, Infants, and Children."⁷²⁷ It also found that in Asian and Pacific Islander, Black, Hispanic, and Native American communities, there were models of successful community-based, comprehensive and culturally sensitive maternal and child health programs.⁷²⁸

Between 2010-2013, the Office of Minority Health administered the State Partnership Program to Improve Minority Health and awarded nearly \$6 million in grants to state and territorial departments of health between 2010-2013, and renewed that grant program, awarding \$3.2 million to agencies working towards eliminating disparities in access to healthcare, asthma, cancer, cardiovascular disease/stroke, immunizations, diabetes, HIV/AIDS, infant mortality/low birth weight, mental health and/or obesity.⁷²⁹ Currently, there are two relevant grant programs:

- State Partnership Initiative to Address Health Disparities; and
- Partnerships to Achieve Health Equity 730

The State Partnership Initiative to Address Health Disparities (SPI) is a grant program that partners with state offices of minority health, health equity, tribes/tribal health agencies, or similar private organizations to conduct projects to improve health outcomes in select geographical areas and address health disparities that affect minority and disadvantaged populations. Between 2015 and 2020, the Office of Minority Health awarded \$4.1 million to 21 different agencies under this grant program.

The Partnerships to Achieve Health Equity is a grant program that seeks to foster collaborative initiatives with a nationwide reach that address social determinants of health, and:

- Improve access to and utilization of care by racial and ethnic minority and/or disadvantaged populations;
- Increase the diversity of the health workforce through programs at the high school or undergraduate level that focus on racial and ethnic health disparities and health equity and include mentoring as a core component; and
- Increase data availability and utilization of data that increases the knowledge base regarding health disparities and facilitates the development, implementation, and assessment of health equity activities; 733
- The grant program runs from July 2017 through June 2022; and has awarded \$2.3 million in grants to six different organizations. ⁷³⁴

⁷³¹ Ibid.

⁷³² Ibid.

⁷³³ Ibid.

⁷³⁴ Ibid.

⁷²⁷ U.S. Dep't of Health and Human Services, *Report of the Secretary's Task Force on Black and Minority Health Vol. 1*, pp. 9-47 (1985) https://collections.nlm.nih.gov/ext/heckler/8602912X1/PDF/8602912X1.pdf, at 58 ⁷²⁸ Ibid., 210.

⁷²⁹ Office of Minority Health, "Partnerships," https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=2&lvlid=51.

⁷³⁰ Ibid.

Perinatal Quality Collaboratives

Perinatal Quality Collaboratives (PQC) are state or multistate collaboratives working to improve the quality of maternal and infant health care.⁷³⁵ Perinatal Quality Collaboratives aim to help identify areas of improvement for health care systems and implement changes to improve the systems of care.⁷³⁶ Efforts to improve the quality of maternal health care include:

- Reduce severe pregnancy complications associated with high blood pressure and hemorrhage;
- Reduce racial/ethnic and geographic disparities; and
- Reduce cesarean births among low-risk pregnant women. 737

According to the CDC, Perinatal Quality Collaboratives are typically comprised of multidisciplinary stakeholders including a state health department, a state hospital association, and clinician leadership (representatives from physicians' or nurses' associations or other health systems), although many also liaise with representatives from public and private insurance agencies or systems, patient advocacy groups, foundations, or community health organizations. One key partnership that may occur is among state Perinatal Quality Collaboratives and state or local Maternal Mortality Review Committees, where the Maternal Mortality Review Committee is able to provide data and metrics, and potentially provide "state and local incentive and drive for improvement."

There are currently 13 state Perinatal Quality Collaboratives that are funded through the CDC's Division of Reproductive Health, although state Perinatal Quality Collaboratives exist in other states that do not receive federal support. Shanna Cox of the CDC testified about the work Perinatal Quality Collaboratives perform, writing that:

PQC members use data to identify health care processes that need to be improved and use the best available methods to make changes as quickly as possible. PQCs are working on

⁷³⁵ Centers for Disease Control and Prevention, "Perinatal Quality Collaboratives," https://www.cdc.gov/reproductivehealth/maternalinfanthealth/pqc.htm.

⁷³⁶ Ibid.

⁷³⁷ Ibid.

⁷³⁸ Centers for Disease Control and Prevention, "Perinatal Quality Collaboratives (PQCs)," p. 1 https://www.cdc.gov/reproductivehealth/pdfs/maternal-infant-health/perinatal-quality-collaboratives-PQCs.pdf; Elliott K. Main, M.D., "Reducing Maternal Mortality and Severe Maternal Morbidity Through State-based Quality Improvement Initiatives," *Clinical Obstetrics and Gynecology*, Vol. 61, No. 2 (2018): 320, https://dl.uswr.ac.ir/bitstream/Hannan/48265/1/2018%20COG%20Volume%2061%20Issue%202%20June%20%28 16%29.pdf.

⁷³⁹ Ibid., 321.

⁷⁴⁰ Centers for Disease Control and Prevention, "State Perinatal Quality Collaboratives," https://www.cdc.gov/reproductivehealth/maternalinfanthealth/pqc-states.html.

maternal health initiatives addressing things like maternal opioid use disorder, hypertension, and hemorrhage. 741

Additionally, CDC funds the National Network of Perinatal Quality Collaboratives that supports the state Perinatal Quality Collaboratives in their efforts by helping to strengthen Perinatal Quality Collaboratives' leadership, identify and disseminate best practices, and identify tools, training, and other resources to support the sharing of information and best practices to support a sustainable infrastructure.⁷⁴²

Recommendations for Eliminating Racial Disparities and Improving Maternal Health Outcomes

Despite numerous Federal programs, disparities in access to maternal health care remain. ⁷⁴³ Even more troubling are the high maternal mortality rates in the United States. ⁷⁴⁴ Jennifer Jacoby of the Center for Reproductive Rights testified to the Commission about how the federal government can reduce disparities in maternal mortality absent legislation, such as steps that include requiring Medicaid to cover services provided by alternative birth workers, midwifes, and doulas; extending Medicaid coverage to one year postpartum; allowing a special healthcare enrollment period for pregnancy; and requesting increased funding for existing federal programs such as under Title V. ⁷⁴⁵

Public health researchers and other stakeholders agree that a multi-faceted approach is needed to improve maternal health outcomes and the quality of care for all women, in order to eliminate racial disparities. The following are some recommendations and strategies from researchers, practitioners, advocates, academics, policymakers, and other stakeholders:

• Improve data collection

Chapter 1 discussed the difficulties in identifying pregnancy-related deaths and the challenge of accurately reporting maternal mortality and morbidity data and statistics on a national level.⁷⁴⁶ Efforts have been made to improve the data, ⁷⁴⁷ but having more accurate national data from the

⁷⁴¹ Cox Statement at 5.

⁷⁴² Centers for Disease Control and Prevention, "National Network of Perinatal Quality Collaboratives," https://www.cdc.gov/reproductivehealth/maternalinfanthealth/nnpqc.htm.

⁷⁴³ *See supra* notes 167-193.

⁷⁴⁴ *See supra* notes 73-79.

⁷⁴⁵ Jacoby Statement at 8-10.

⁷⁴⁶ *See supra* notes 125-139.

⁷⁴⁷ See supra notes 130-139.

Pregnancy Mortality Surveillance System is imperative to understand the reasons why women are dying, the drivers of disparities, and how to prevent maternal deaths.⁷⁴⁸

One mechanism for improving the accuracy of data is conducting a detailed review of maternal deaths, as a means of supplementing cause-of-death data from vital records. Maternal Mortality Review Committees are convened at the state and local level and are multidisciplinary, comprised of representatives from "public health, obstetrics and gynecology, maternal-fetal medicine, nursing, midwifery, forensic pathology, mental and behavioral health, patient advocacy groups, and community-based organizations." Maternal Mortality Review Committees are responsible for "identify[ing] and review[ing] maternal deaths that occur within one year of pregnancy," using data from "diverse sources beyond vital records and include clinical and non-clinical information such as prenatal care and hospital records, autopsy reports, informant interview, and social services records" to get a better understanding of the "details and circumstances surrounding each death in order to develop actionable recommendations to prevent future deaths." On the state or local level, these Maternal Mortality Review Committees are currently in various stages of development and not every state currently has a Committee, however there has been increasing momentum to establish and enhance Maternal Mortality Review Committees across the U.S. Test

• Expand research on maternal mortality, maternal morbidity, and racial disparities

Research is critical in gaining a deeper understanding of the maternal mortality crisis and developing an evidence base on "how institutional policies impact the racial and socioeconomic disparities observed in maternal mortality."⁷⁵⁴ Juanita J. Chinn with the NIH explained that research is "an iterative and cumulative process," and the information learned can help document "pervasive disparities," identify "innovative evidence-based solutions [for] informed intervention and prevention."⁷⁵⁵ Similarly, Dr. Emily Petersen of the Centers for Disease Control stated that

⁷⁴⁸ Cox Statement, at 2.

⁷⁴⁹ Ibid.

⁷⁵⁰ See supra note 571.

⁷⁵¹ Cox Statement, at 3.

⁷⁵² Ibid.

⁷⁵³ Centers for Disease Control and Prevention, "Enhancing Reviews and Surveillance to Eliminate Maternal Mortality (ERASE MM)" https://www.cdc.gov/reproductivehealth/maternal-mortality/erase-mm/index.html (last accessed Dec. 18, 2020) (currently 25 states have Maternal Mortality Review Committees: Alaska, Arizona, California, Colorado, Connecticut, Delaware, Illinois, Indiana, Louisiana, Mississippi, Missouri, Nebraska, New Hampshire, New Jersey, New Mexico, New York, North Carolina, Ohio, Pennsylvania, Tennessee, Texas, Utah, Washington, Wisconsin, and Wyoming).

⁷⁵⁴ Chinn Statement, at 2.

⁷⁵⁵ Ibid., 5.

"[t]here is an urgent need to identify and evaluate the complex factors contributing to these disparities and design interventions that will reduce preventable pregnancy-related deaths." ⁷⁵⁶

The Health Resources and Services Administration (HRSA), a division of HHS, has published key findings following a Maternal Mortality Summit. The Health Resources and Services Administration issued a technical report that summarized key findings from the summit, one being the improvement of the quality and availability of national surveillance and survey data, research, and common terminology of definitions. The Center for Reproductive Rights asserts in order to diminish racial disparities in maternal health outcomes requires stronger systems on the local, state, and federal levels for analyzing maternal health information and producing evidence-based recommendations for prevention.

• Improve access and coverage of maternal healthcare

The first key finding of the Health Resources and Services Administration's Maternal Mortality Summit is to improve access to patient centered, comprehensive care for women before, during, and after pregnancy, especially in rural and underserved areas. ⁷⁵⁹ Improving access to quality maternity care for women is critical, including preconception and inter-conception care to manage chronic illness and optimize health; prenatal care; delivery care; and postpartum care for 12 months post-delivery, ⁷⁶⁰ all of which is necessary for improving pregnancy-outcomes. ⁷⁶¹ This includes efforts to expand medical insurance coverage to allow women access to medical care throughout the stages of pregnancy and beyond by protecting the Affordable Care Act, by Medicaid expansion, ⁷⁶² and by the extension of Medicaid coverage for women 12 months postpartum. ⁷⁶³ Additionally, Dr. Joia Crear-Perry, Founder and President of the National Birth Equity Collaborative, emphasized that rural health care systems cannot be left out of policy and funding discussions, as access to maternity care in rural America is becoming scarce. ⁷⁶⁴

• *Improve the quality of maternal healthcare*

⁷⁵⁶ Centers for Disease Control and Prevention, "Racial and Ethnic Disparities Continue in Pregnancy-Related Deaths," Sept. 5, 2020, https://www.cdc.gov/media/releases/2019/p0905-racial-ethnic-disparities-pregnancy-deaths.html.

⁷⁵⁷See supra notes 520-548.

⁷⁵⁸ Center for Reproductive Rights, "Research Overview of Maternal Mortality and Morbidity in the United States," p. 7,

https://www.reproductiverights.org/sites/crr.civicactions.net/files/documents/USPA_MH_TO_ResearchBrief_Final_5.16.pdf.

⁷⁵⁹ *See supra* notes 531-535.

⁷⁶⁰ Howell Statement, at 2.

⁷⁶¹See supra notes 209-237.

⁷⁶² Crear-Perry Statement, at 5; see also supra notes 297-298.

⁷⁶³ Howell Statement, at 2; American College of Obstetricians and Gynecologists, "ACOG Statement on AMA Support for 12 Months of Postpartum Coverage Under Medicaid," Jun. 12, 2019, https://www.acog.org/news/news-releases/2019/06/acog-statement-on-ama-support-for-12-months-of-postpartum-coverage-under-medicaid.

⁷⁶⁴ Crear-Perry Statement, at 7; see also supra notes 288-289 and 328-334.

As discussed previously, efforts need be made to improve hospital quality, particularly for women of color if maternal health disparities are to be eliminated. Improvements in safety culture are linked with improved maternal health outcomes. One recommendation for improving safety in maternal healthcare is to implement standardized care practices across hospitals and health systems. One such mechanism that has seen success is the Alliance for Innovation on Maternal Health Program, a "national data-driven maternal safety and quality improvement initiative based on proven implementation approaches to improving maternal safety and outcomes in the U.S." that strives to "eliminate preventable maternal mortality and severe morbidity" throughout the U.S.

The Alliance for Innovation on Maternal Health strives to standardize health care processes through the use of safety bundles, which "do not introduce new guidance but are built upon established best-practices," designed "to collate a critical set of processes based on the broad universe of existing guidance, tools, and resources that have been developed by trusted organizations" and "to be universally implementable and able to be consistently used across disciplines and settings." Expansion of the HRSA-funded the Alliance for Innovation on Maternal Health program may also help increase utilization of best practices among birthing facilities to show measurable impact and improved maternal health outcomes within a short period. 770

Perinatal quality collaboratives (PQCs) are state or multistate networks of teams working to improve the quality of care for mothers and babies. PQC members identify health care processes that need to be improved and use the best available methods to make changes as quickly as possible. PQCs are the structural mechanism for which quality improvement initiatives can be implemented for innovation and evaluation.

Perinatal regionalization is an important component of quality of care supported by efforts such as CDC LOCATe.

• Address racial bias in maternal healthcare and promote culturally congruent care

⁷⁶⁵ *See supra* notes 318-339.

⁷⁶⁶ E.A. Howell and J. Zeitlin, "Improving Hospital Quality to Reduce Disparities in Severe Maternal Morbidity and Mortality," *Semin Perinatol*, Vol. 41, No. 5 (August 2017): 266-272, https://www.ncbi.nlm.nih.gov/pubmed/28735811.

⁷⁶⁷ Howell Statement, at 2.

⁷⁶⁸ Ibid.; Council on Patient Safety in Women's Health Care, "Alliance for Innovation on Maternal Health Program," https://safehealthcareforeverywoman.org/aim-program/.

⁷⁶⁹ Council on Patient Safety in Women's Health Care, "Patient Safety Bundles: Getting Started," https://safehealthcareforeverywoman.org/patient-safety-bundles/getting-started/.

⁷⁷⁰ Health Resources and Services Administration, the Health Resources and Services Administration Maternal Mortality Summit: Promising Global Practices to Improve Maternal Health Outcomes, Technical Report, Feb. 15, 2019, p. 18, https://www.hrsa.gov/sites/default/files/hrsa/maternal-mortality/Maternal-Mortality-Technical-Report.pdf.

Researchers and healthcare professionals have found that utilizing education, technical assistance, and health equity tools to build workforce capacity can also help address disparities in maternal health care. Stakeholders posit that The U.S. Department of Health and Human Services could expand upon the "Foundational Practices for Health Equity Action and Learning Tool" developed by the Region V Social Determinants of Health Team of the Infant Mortality Collaborative Improvement and Innovation Network and the U.S. Health Resources and Services Administration. These tools include providing training on implicit bias for providers and increasing cultural competency training among healthcare professionals in order to improve the delivery of culturally congruent care. The Commission received testimony from Elizabeth Howell suggesting that utilization of "disparities dashboards," which stratify quality of care metrics by race and ethnicity could also decrease racial disparities.

Improved communication between clinicians and patients and their families has also been identified as critical to quality maternal care, which includes extending available translation services. There are efforts like CDC's Hear Her campaign, that seek to raise awareness of potentially life-threatening warning signs during and after pregnancy and improve communication between patients and their healthcare providers. Additionally, strengthening local community partnerships with hospitals and health systems can be helpful for addressing disparities, as community-based programs can provide needed education and supplementary support for pregnant women to provide, for example, doula support, home visiting, care navigation, and postpartum classes. In Moore of the Institute for Medicaid Innovation was part of an HHS interagency maternal health workgroup that found that:

[H]igh-income countries with low rates of maternal mortality and morbidity valued and emphasized person-centered care. In this environment, individuals weren't simply told

⁷⁷¹ See e.g., Association of Maternal & Child Health Programs, "How We Can Really Advance Health Equity: Tools from the National MCH Workforce Development Center,"

http://www.amchp.org/AboutAMCHP/Newsletters/Pulse/NovDec17/Pages/How-We-Can-Really-Advance-Health-Equity-with-Tools-from-the-National-MCH-Workforce-Development-Center.aspx.

⁷⁷² Ibid; see, Minnesota Dep't of Health, "Foundational practices for health equity: A learning and action tool for state health departments" https://www.health.state.mn.us/communities/practice/resources/equitylibrary/coiin-hrsa-foundational.html (last accessed Feb 26, 2021); Ass'n of State and Territorial Health Officials, "Foundational Practices for Health Equity" https://www.astho.org/Health-Equity/Foundational-Practices-for-Health-Equity/ (last accessed Feb. 26, 2021).

⁷⁷³ Howell Statement, at 2.

⁷⁷⁴ Rouse Statement, at 6; Crear-Perry, at 4; Black Mamas Matter Alliance, *Setting the Standard for Holistic Care of and for Black Women*, April 2018, p. 6, http://blackmamasmatter.org/wp-content/uploads/2018/04/BMMA BlackPaper April-2018.pdf.

⁷⁷⁵ Howell Statement, at 2.

⁷⁷⁶ Howell Statement, at 2.

⁷⁷⁷ Ibid., see also, Center for Disease Control and Prevention, Hear Her, www.cdc.gov/hearher.

⁷⁷⁸ Ibid

⁷⁷⁹ See supra note 405; Rouse Statement, at 6.

what to do and how their birth would be, but rather were informed and supported in making their own decisions based on their own values, beliefs, and preferences. ⁷⁸⁰

Additionally, Representative Ayanna Pressley recommended in her testimony that Congress create a national center for anti-racism within the CDC and declare racism a public health crisis.⁷⁸¹

• Implement an Equity Framework for Research, Planning, and Evaluation

Jonathan Webb of the Association of Maternal & Child Health Programs provided testimony to the Commission about the importance of equity in data, writing:

We must acknowledge that data sources our country has been using weren't created by the people most acutely impacted by negative outcomes—people of color. Given this, we are left wondering if we are capturing critical information, like lived experiences, making appropriate statistical comparisons, etc., that provide us with valuable insight into actionable and targeted solutions. We must ensure we're asking the right questions by engaging the people most impacted in what we collect and when and how we distribute it. We have to thoughtfully partner with tribal communities, ensure their solutions are being supported and think about how government can facilitate justice for them, while not further perpetuating inequities. When it comes to research and data, we must ensure we are answering these questions and then use what we learn to formulate solutions. ⁷⁸²

The Commission also received testimony from Professor Diane Rowley, who formerly worked on health disparities at the CDC, explained that an equity approach must be used when working to eliminate disparities in maternal mortality and morbidity. Dr. Rowley stated that this approach must "acknowledge the historical forces that created inequitable outcomes, works in the present [] to correct the health effects of those exposures, and restructures society to prevent the continuation of those influences." Additionally, Rowley asserts acknowledging that "[e]quity work is a transformative, participatory process that is different from traditional approaches to creating discrete interventions or health behavior messages, requires changing the structural racism that overlays the social determinants of health."

⁷⁸⁰ Moore Testimony, *Maternal Health Briefing*, pp. 27-28.

⁷⁸¹ Pressley Testimony, *Maternal Health Briefing*, p. 16.

⁷⁸² Webb Statement at 2.

⁷⁸³ Diane L. Rowley, Emeritus Professor of the Practice of Public Health, Department of Maternal and Child Health, and Senior Researcher, Sheps Center for Health Services Research, University of North Carolina, Written Statement for the Racial Disparities in Maternal Health Briefing before the U.S. Commission on Civil Rights, Nov. 13, 2020, at 1 (hereinafter Rowley Statement).

⁷⁸⁴ Ibid.

One model, called the R4P model, offers five components in order to "translate complex causality into a public health equity planning, assessment, and research tool." The five components are:

- 1) Remove: "identifying and undoing racism as it exists in institutional structures and individual actions";
- 2) Repair: "identifying and addressing exposures that occurred in the past, but which continue to have impact in the present";
- 3) Remediate: "identifying and addressing exposures that are occurring in present time and is the risk reduction approach now prominent in public health";
- 4) Restructure: "identifying and addressing exposures that will continue to affect populations into the future because risk is embedded in the structural nature of an organization or policy"; and
- 5) Provide: "careful implementation of actions, programs, and policies that address multiple and intersecting axes of disadvantage experienced by disparity population, taking into consideration the environments in which people work, live and play within affected communities and seek help from institutions". 786

⁷⁸⁵ Ibid,, Vijaya Hogan, Diane L. Rowley, Stephanie Baker White, Yanica Faustin, "Dimensionality and R4P: A Health Equity Framework for Research Planning and Evaluation in African American Populations," *Maternal and Child Health Journal*, Vol. 22 (2018): 147-153 (on file).

⁷⁸⁶ Rowley Statement, at 2; Vijaya Hogan, Diane L. Rowley, Stephanie Baker White, Yanica Faustin,

[&]quot;Dimensionality and R4P: A Health Equity Framework for Research Planning and Evaluation in African American Populations," *Maternal and Child Health Journal*, Vol. 22 (2018): 147-153 (on file).

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CHAPTER 4: A REVIEW OF THREE STATES: GEORGIA, NORTH CAROLINA, AND NEW JERSEY

The Commission studied three states in which policies are being developed to gather information about trends and possible best practices to reduce racial disparities in maternal health. These state programs receive federal funding, and although they are led by the states, they illustrate the potential of federal-state programs to reduce maternal mortalities and associated racial disparities at the state level. The three states studied—Georgia, New Jersey, and North Carolina—are also geographically and racially diverse. Table 4.1 below provides the racial composition of each state provided by the U.S. Census Bureau. Another common feature across the three states studied is that each state evaluated the preventability of types of maternal deaths and subsequently enacted measures to reduce the number of maternal deaths in the respective state.

Table 4.1 Racial and Ethnic Composition of Georgia, North Carolina, and New Jersey

	Georgia	North Carolina	New Jersey
Total population	10,403,847	10,264,876	8,878,503
Race			
White	58.6%	68.7%	67.8%
Black or African American	31.6%	21.4%	13.5%
American Indian and Alaska Native	0.4%	1.2%	0.2%
Asian	4.0%	2.9%	9.5%
Native Hawaiian and Other Pacific Islander	0.1%	0.1%	0.0%
Some other race	2.8%	3.1%	6.3%
Ethnicity			
Hispanic or Latino (of any race)	9.5%	20.2%	9.4%
Not Hispanic or Latino	90.5%	79.8%	90.6%

Source: U.S. Census Bureau, 2019 ACS 5-Year Demographic and Housing Estimates, Georgia, North Carolina, New Jersey,

 $\underline{\text{https://data.census.gov/cedsci/table?g=0400000US13,34,37\&tid=ACSDP5Y2019.DP05\&tp=false\&hidePreview=tru}\underbrace{e.}$

Georgia

Prior to the development of the Georgia Maternal Mortality Commission in 2013, official data surrounding pregnancy-related deaths in the state are not available. For the available years, trends in maternal mortality and racial disparities in Georgia tend to be higher than what is seen nationally. The overall maternal death rate in Georgia has increased between 2009 and 2011 from 24.8 deaths per 100,000 live births to 28.7 deaths per 100,000 live births, respectively (see Figure 4.2). Not only were both rates above the national average for those years, but Georgia's rate increased while the national rate decreased, see Figure 4.1 below. More recently, the rate of maternal mortality in Georgia was 66.3 per 100,000 live births in 2019, as compared to 39.3 deaths per 100,000 live births in 2016. As indicated in Figure 4.2 below, the rate of pregnancy-related deaths in Georgia rose from 24.2 in 2009 to 28.7 in 2011, compared to the national rate which decreased from 17.8 in 2009 to 15.9 in 2011.

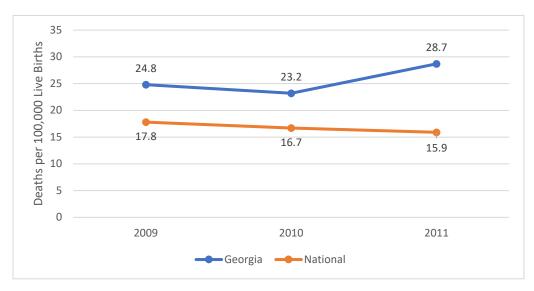


Figure 4.2 Pregnancy-Related Deaths in Georgia and the U.S. (2009-2011)

Source: Georgia Department of Public Health. Georgia Maternal Mortality Report 201, https://dph.georgia.gov/document/publication/maternal-mortality-2012-case-review/download; Centers for Disease Control and Prevention, "Pregnancy Mortality Surveillance System," https://www.cdc.gov/reproductivehealth/maternal-mortality/pregnancy-mortality-surveillance-system.htm.

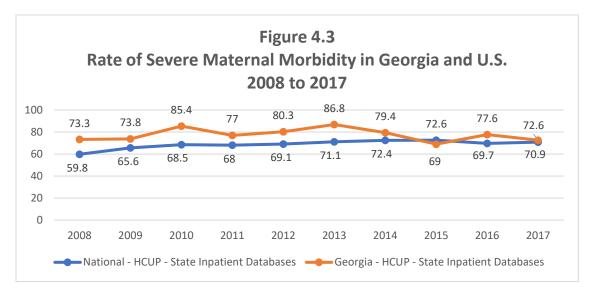
While Georgia's pregnancy-related deaths increased from 2009 to 2011, according to the Health Resources & Services Administration National Outcomes Measures, Georgia's severe maternity

⁷⁸⁷ Georgia Department of Public Health, Georgia Maternal Mortality Report 201, https://dph.georgia.gov/document/publication/maternal-mortality-2012-case-review/download.

⁷⁸⁸ America's Health Rankings, "Health of Women and Children: Maternal Mortality, 2016, <u>Explore Maternal Mortality in Georgia | 2016 Health of Women and Children Report | AHR (americashealthrankings.org)</u>

⁷⁸⁹ See supra, Figure 4.1.

morbidity rate saw some variability from 2008 to 2017. For instance, data showed an overall decrease from 2008 to 2015, an increase in 2016, and then a measurable decrease from 2016 to 2017.⁷⁹⁰ Rates have remained slightly higher than the national average, with an exception in 2015, as shown in Figure 4.3.



Source: U.S Department of Health and Human Services, Maternal and Child Health Bureau, "National Outcome Measures", Health Resources & Services

Administration, https://mchb.tvisdata.hrsa.gov/PrioritiesAndMeasures/NationalOutcomeMeasures

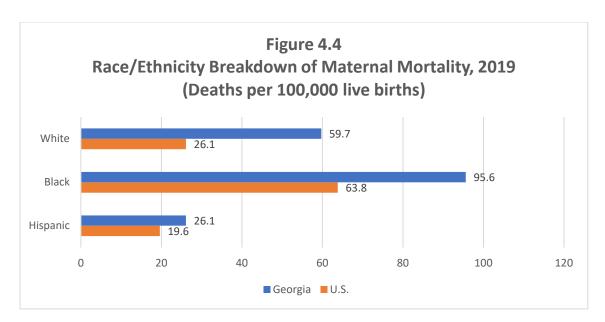
In terms of maternal mortality, the 2019 rate in Georgia was higher than the national average for Black, Latina, and White women; however, disparities between these groups were pronounced (see Figure 4.4).⁷⁹¹ In 2019, the maternal mortality rate for Black women in Georgia was 95.6 deaths per 100,000 live births compared to 26.1 per 100,000 live births for White women, a rate approximately 3.7 times higher for Black women than for White women.⁷⁹²

⁷⁹⁰ U.S Dep't of Health and Human Services, Maternal and Child Health Bureau, "National Outcome Measures", Health Resources & Services Administration,

https://mchb.tvisdata.hrsa.gov/PrioritiesAndMeasures/NationalOutcomeMeasures

⁷⁹¹ America's Health Rankings, "Health of Women and Children: Maternal Mortality, 2019, https://www.americashealthrankings.org/explore/health-of-women-and-children/measure/overall_mch/state/GA?edition-year=2019.

⁷⁹² Ibid.



Source: America's Health Rankings, "Health of Women and Children: Maternal Mortality, 2019", United Health Foundation, https://www.americashealthrankings.org/explore/health-of-women-and-children/measure/maternal mortality a/state/GA?edition-year=2019.

Additionally, there is a significant variation in pregnancy-related mortality ratios when classifying the deaths by race. While the ratio for White, non-Hispanic women was 14.3 deaths per 100,000 live births, the ratio for Black, non-Hispanic women was 47 deaths per 100,000 live births, which is three to four times higher. Between 2012-2014, over half (60 percent) of the pregnancy-related deaths in Georgia occurred among Black, non-Hispanic women, while nearly one-quarter (24 percent) of pregnancy-related deaths occurred among White, non-Hispanic women. The third highest racial-ethnic group, Hispanic, accounted for 10 percent pregnancy-related deaths. Finally, Other, non-Hispanic women represented the remaining 6 percent of pregnancy-related deaths.

Between 2012 and 2014, the leading causes of pregnancy-related death varied by racial-ethnic group. Cardiomyopathy was the leading cause of death among White, non-Hispanic women (21 percent) and Black, non-Hispanic women (17 percent). The leading causes of the 24 pregnancy-related deaths among White, non-Hispanic women, were hemorrhage (17 percent), cardiovascular and coronary conditions (13 percent), mental health conditions (13 percent),

⁷⁹⁶ Ibid., 17

⁷⁹³ House of Representatives Study Committee on Maternal Mortality. House Budget & Research Office: Final Report.

https://www.house.ga.gov/Documents/CommitteeDocuments/2019/MaternalMortality/HR_589_Final_Report.pdf
794 Georgia Department of Public Health, Georgia Maternal Mortality Report 2014, p.11,
https://dph.georgia.gov/sites/dph.georgia.gov/files/related_files/site_page/Georgia%20Maternal%20Mortality%20R
eport%202014.pdf.

⁷⁹⁵ Ibid.

homicide (8 percent), and amniotic fluid embolism (8 percent).⁷⁹⁷ The leading causes of the 60 pregnancy-related deaths among Black, non-Hispanic women, were cardiovascular and coronary conditions (13 percent), preeclampsia and eclampsia (13 percent), embolism (12 percent), and hemorrhage (10 percent).⁷⁹⁸ These numbers equate to Georgia having a pregnancy-related maternal mortality ratio of 25.9 pregnancy-related deaths per 100,000 live births, which is higher than the national ratio of 17 pregnancy-related deaths per 100,000 live births for this same three-year time period.⁷⁹⁹ Further variations in the ratios of pregnancy-relate maternal deaths are also seen when examining age groups, with women over the age of 35 experiencing the highest number of deaths (a ratio of 52.2 deaths per 100,000 live births), compared to 17.5 deaths per 100,000 live births for women under the age of 25.⁸⁰⁰

Data also show disparities between rural and urban populations in Georgia. According to publicly available data from the CDC analyzed by *Scientific American*, rural areas nationwide had a pregnancy-related mortality ratio of 29.4 per 100,000 live births versus 18.2 in urban areas in 2015. In Georgia, rural Black women have a 30 percent higher maternal mortality rate than urban Black women, and rural White women have a 50 percent higher risk than urban White women. 803

As discussed previously, attending prenatal visits is linked to better maternal health outcomes. 804 In Georgia, the rate of women attending fewer than five prenatal visits in 2017 was highest among Native Hawaiian and Pacific Islanders at 14.9 percent, followed by American Indian or Alaskan Native women at 13.5 percent, Black/African American women at 11.2 percent, and Hispanic or Latina women at 9.7 percent. 805 In 2017, the highest frequency of late or no prenatal care was seen among Native Hawaiian and Pacific Islanders at 9.6 percent followed by

⁷⁹⁷ Ibid.

⁷⁹⁸ Ibid.

⁷⁹⁹ Georgia House of Representatives Study Committee on Maternal Mortality. House Budget & Research Office: Final Report.

https://www.house.ga.gov/Documents/CommitteeDocuments/2019/MaternalMortality/HR_589_Final_Report.pdf 800 Ibid.

⁸⁰¹ National Advisory Committee on Rural Health and Human Services. Maternal and Obstetric Care Challenges in Rural America: Policy Brief and Recommendations to the Secretary.

 $[\]underline{https://www.hrsa.gov/sites/default/files/hrsa/advisory-committees/rural/publications/2020-maternal-obstetric-care-challenges.pdf.}$

⁸⁰² Dina Fine Maron, "Maternal Health Care is Disappearing in Rural American," *Scientific American*, Feb. 15, 2017, https://www.scientificamerican.com/article/maternal-health-care-is-disappearing-in-rural-america/.

⁸⁰³ Ibid., 1

⁸⁰⁴ *See supra* notes 250-257.

⁸⁰⁵ Healthy Mothers, Healthy Babies Coalition of Georgia. 2019 State of the State: Maternal and Infant Health in Georgia Report. http://hmhbga.org/wp-content/uploads/2019-HMHBGA-State-of-the-State-Report-FINAL.pdf.

multiracial women at 8.6 percent, Black/African American women at 8 percent, and American Indian or Alaskan Native women at 5.1 percent. 806

Georgia's Maternal Mortality Review Committee was re-established in the 2013-2014 Legislative Session. During the Legislative Session, Georgia's General Assembly passed Senate Bill 273 to establish the Georgia Maternal Mortality Review Committee and strengthen the Department of Public Health (DPH)'s authority to obtain the records needed for case review. 807 S.B. 273 mandated nearly all aspects of the Maternal Mortality Review Committee's functioning is left to the discretion of the DPH. 808 Specifically, the bill instructs the Maternal Mortality Review Committee to "identify maternal death cases," "review medical records and other relevant data," "contact family members and other affected or involved persons," "consult with relevant experts," "make determinations regarding the preventability of maternal deaths," "develop recommendations," and "disseminate findings." 809

In addition to the Maternal Mortality Review Committee reviewing cases of maternal death in Georgia, the Department of Public Health's Office of Health Indicators for Planning manages Georgia's Online Analytical Statistical Information System. This system compiles and displays statistical information on maternal death in Georgia that can be broken down across age, race, geography, and other demographic indicators. However, the Online Analytical Statistical Information System records only those maternal deaths that occur during or within 42 days after a pregnancy as identified by ICD-10 codes, and thus likely underreports the number of maternal deaths that occur in the state. 811

The Georgia Department of Public Health defines a pregnancy-associated, but not related, death as "the death of a woman while pregnant or within one year of the end of pregnancy, due to a cause unrelated to pregnancy (e.g., motor vehicle crash, homicide or cancer, as determined by

⁸⁰⁶ Healthy Mothers, Healthy Babies Coalition of Georgia. 2019 State of the State: Maternal and Infant Health in Georgia Report. http://hmhbga.org/wp-content/uploads/2019-HMHBGA-State-of-the-State-Report-FINAL.pdf.

⁸⁰⁷ Georgia House of Representatives Study Committee on Maternal Mortality, House Budget & Research Office: Final Report, p. 4,

https://www.house.ga.gov/Documents/CommitteeDocuments/2019/MaternalMortality/HR 589 Final Report.pdf 808 S.B. 273 (NS), 152nd General Assembly, Reg. Sess. (Ga 2013); Eric Baudry, Nicole Gusman, Victoria Strang, Krysten Thomas, Elizabeth Villarreal. When the States Fail: Maternal Mortality & Racial Disparity in Georgia; Yale Law School and Yale School of Public Health;

https://law.yale.edu/sites/default/files/area/center/ghjp/documents/ghjp_2018_when_the_state_fails_maternal_mortality_racial_disparity_in_georgiarev.pdf.

⁸⁰⁹ Eric Baudry, Nicole Gusman, Victoria Strang, Krysten Thomas, Elizabeth Villarreal. When the States Fail: Maternal Mortality & Racial Disparity in Georgia; Yale Law School and Yale School of Public Health, p. 62; https://law.yale.edu/sites/default/files/area/center/ghjp/documents/ghjp_2018_when_the_state_fails-maternal_mortality_racial_disparity_in_georgiarev.pdf

⁸¹⁰ Ibid.

⁸¹¹ Ibid.

the Georgia Maternal Mortality Review Committee)."812 The Georgia Maternal Mortality Review Committee uses this broader definition to understand the nuanced determinants that contribute to maternal deaths. Given that there are three distinct points in time to measure maternal deaths (up to 42 days after termination of pregnancy, more than 42 days but less than one year after termination of pregnancy, and up to one year postpartum), using calculations across databases that are comparable can be difficult to evaluate.⁸¹³

There are various data sources that track maternal deaths, such as the National Center for Health Statistics and the Pregnancy Mortality Surveillance System on the national level and the Online Analytical Statistical Information System and the Maternal Mortality Review Information App on the state level for Georgia. 814 Georgia is one of 12 states that participated in the Every Mother Counts Initiative from May 2013 to April 2016, which helped the state strengthen its maternal mortality surveillance and review processes. 815

Georgia's first Maternal Mortality Review Committee report analyzed 85 maternal death cases from 2012 and was published in June 2015, and identified and analyzed 25 pregnancy-related deaths and 60 pregnancy-associated deaths. ⁸¹⁶ The report outlined disparities and inequities in Georgia by race, age, ethnicity, education, region, and insurance status. ⁸¹⁷ Black and African American women in Georgia experience worse maternal and infant outcomes than all other races and ethnicities. ⁸¹⁸ Since then, the Georgia Maternal Mortality Review Committee has released reports for the cases that occurred in 2013 and 2014. ⁸¹⁹ In November 2017, the Maternal

Realthy Mothers, Healthy Babies Coalition of Georgia. 2019 State of the State: Maternal and Infant Health in Georgia Report. http://hmhbga.org/wp-content/uploads/2019-HMHBGA-State-of-the-State-Report-FINAL.pdf.
 Ibid., 29

⁸¹⁴ Georgia House of Representatives Study Committee on Maternal Mortality. House Budget & Research Office: Final Report.

https://www.house.ga.gov/Documents/CommitteeDocuments/2019/MaternalMortality/HR 589 Final Report.pdf.

⁸¹⁵ Eric Baudry, Nicole Gusman, Victoria Strang, Krysten Thomas, Elizabeth Villarreal. When the States Fail: Maternal Mortality & Racial Disparity in Georgia; Yale Law School and Yale School of Public Health; https://law.yale.edu/sites/default/files/area/center/ghjp/documents/ghjp_2018_when_the_state_fails-maternal_mortality_racial_disparity_in_georgiarev.pdf.

 ⁸¹⁶ Georgia Dept. of Public Health, Georgia Maternal Mortality 2012 Case Review,
 https://dph.georgia.gov/document/publication/maternal-mortality-2012-case-review/download.
 817 Ibid.

 ⁸¹⁸ Healthy Mothers, Healthy Babies Coalition of Georgia. 2019 State of the State: Maternal and Infant Health in Georgia Report. http://hmhbga.org/wp-content/uploads/2019-HMHBGA-State-of-the-State-Report-FINAL.pdf.
 819 House of Representatives Study Committee on Maternal Mortality. House Budget & Research Office: Final Report.

https://www.house.ga.gov/Documents/CommitteeDocuments/2019/MaternalMortality/HR 589 Final Report.pdf

Mortality Review Committee released its second report, an analysis of pregnancy-related deaths in Georgia from 2013. 820

The 2013 case review identified 79 pregnancy-associated deaths overall (deaths during pregnancy or within one year of pregnancy from any cause), which are referred to as total maternal deaths. ⁸²¹ Forty-seven deaths (59 percent) occurred while pregnant or within one year of the end of pregnancy, due to a cause unrelated to pregnancy (pregnancy-associated, not related). ⁸²² Thirty-two deaths (41 percent) were found to be related to or aggravated by the cause of pregnancy or its management (pregnancy-related). ⁸²³

In March 2019, the Maternal Mortality Review Committee released its third report, a revised analysis of pregnancy related deaths in Georgia from 2014. 824 A total of 186 potential maternal deaths were identified. 825 Among 85 confirmed maternal deaths, 43 (51 percent) were determined by the Georgia Maternal Mortality Review Committee to be related to or aggravated by pregnancy or its management (pregnancy-related death) and 42 (49 percent) were determined to be due to a cause unrelated to pregnancy and having only a temporal relationship to pregnancy (pregnancy-associated). 826

In 2014, of the 43 pregnancy-related deaths, a majority, 21 (49 percent) were Black women. 827 The second highest racial-ethnic group, White women accounted for 12 (28 percent) pregnancy-related deaths. 828 The third highest racial-ethnic group, Hispanic women, accounted for 12 percent pregnancy-related deaths. Finally, Other, non-Hispanic women represented the remaining 12 percent of pregnancy-related deaths. 829

The three Maternal Mortality Review Committee 2012-2014 aggregate reports identified and analyzed a total of 250 maternal deaths. Of these, 101 were determined to be pregnancy-related.⁸³⁰ Moreover, 60 percent of the pregnancy-related deaths were found to be preventable.⁸³¹

⁸²⁰ Georgia Department of Public Health. Reducing Maternal Mortality in Georgia 2013. Case Review Update. https://dph.georgia.gov/sites/dph.georgia.gov/files/MCH/Perinatal/Maternal_Mortality_Report_Nov2017_FINAL.Screen.pdf.

⁸²¹ Ibid., 5

⁸²² Ibid.

⁸²³ Ibid., 5

⁸²⁴ Georgia Department of Public Health, Georgia Maternal Mortality Report 2014, https://dph.georgia.gov/sites/dph.georgia.gov/files/related_files/site_page/Georgia%20Maternal%20Mortality%20Report%202014.pdf.

⁸²⁵ Ibid., 6.

⁸²⁶ Ibid., 8.

⁸²⁷ Ibid.

⁸²⁸ Ibid.

⁸²⁹ Ibid.

⁸³⁰ Ibid., 12.

⁸³¹ Ibid., 3.

There were 64 maternal deaths for every 100,000 live births. 832 There were 26 pregnancy-related deaths for every 100,000 live births.833 Between 2012-2014, the six leading causes of pregnancy-related death in Georgia were cardiomyopathy, hemorrhage, cardiovascular and coronary conditions, embolism, preeclampsia and eclampsia, and amniotic fluid embolism. 834 The six leading causes comprise 68 percent of all (101) pregnancy-related deaths. 835 The leading cause of death was cardiomyopathy which accounted for 16 deaths (16 percent). 836 The other leading causes of death were cardiovascular and coronary conditions and hemorrhage, each accounting for 13 deaths (13 percent), embolism 10 deaths (10 percent), preeclampsia and eclampsia 9 deaths (9 percent), and amniotic fluid embolism 8 deaths (8 percent). 837 The remaining causes of pregnancy-related deaths included: anesthesia complications, autoimmune disease, blood disorders, cerebrovascular accidents, conditions unique to pregnancy, homicide, liver/gastrointestinal conditions, malignancies, mental health metabolic/endocrine conditions, pulmonary conditions, seizure disorder, and unintentional iniury.838

Georgia is one of the poorest states in the country, with 14.3 percent of its population in 2018 living in poverty. The rate of uninsured Georgians rose to over 13 percent in 2018, placing the state as the third-highest uninsured state following Texas and Oklahoma. Poor women of reproductive age in Georgia have four main insurance options: coverage through employer plans; through non-group (private purchase) plans, military or Veterans Administration, or by the government-sponsored plans such as Medicare, Medicaid and Children's Health Insurance Program (CHIP). Within this latter group, the largest covered proportion are covered by Medicaid (32 percent). However, a sizable and larger proportion of this population remains uninsured (42 percent).

832 Ibid., 3.

https://www.census.gov/library/visualizations/interactive/2018-poverty-rate.html (accessed Feb. 23, 2021).

⁸³³ Ibid.

⁸³⁴ Ibid., 15.

⁸³⁵ Ibid., 3.

⁸³⁶ Ibid., 15.

⁸³⁷ Ibid.

⁸³⁸ Ibid.

⁸³⁹ U.S. Census Bureau, "2018 Poverty Rate in the United States,"

⁸⁴⁰ U.S. Census Bureau, "Selected Characteristics of Health Insurance Coverage in the United States, Georgia, American Community Survey 2018",

https://data.census.gov/cedsci/table?t=Health%20Insurance&g=0400000US13&tid=ACSST1Y2018.S2701&hidePreview=false; Jade Abdul-Malik, "Rate of Uninsured Americans Rises, Georgia Now Ranks 3rd," *GPB News*, Aug. 13, 2020, https://www.gpb.org/news/2019/09/15/rate-of-uninsured-americans-rises-georgia-now-ranks-3rd. 841 Ibid., 42.

⁸⁴² Eric Baudry, Nicole Gusman, Victoria Strang, Krysten Thomas, Elizabeth Villarreal. When the States Fail: Maternal Mortality & Racial Disparity in Georgia; Yale Law School and Yale School of Public Health;

The Georgia Medicaid program is administered by the Georgia Department of Community Health. In Georgia, pregnant women and their infants are covered at or below 220 percent of the federal poverty level. However, pregnant women are only eligible for two months of care, the federal minimum, after giving birth or miscarriage. Has a concerning because Georgia's Medicaid program generally only covers parents at or below 133 percent of the federal poverty level, meaning that many mothers stand to lose Medicaid coverage 60 days post-delivery, and those in the coverage gap who are not eligible for premium tax credits may then be completely uninsured. This loss of coverage and resulting disruption of care at 60 days post-delivery is concerning in the context of maternal mortality in Georgia in particular. The CDC and American College of Obstetricians and Gynecologists guidance recommends monitoring for maternal death for up to a year, as this extended post-birth period can be critical for accessing lifesaving care, as many pregnancy-related deaths happen after the 42nd day post-delivery. Here is minimal continuity surrounding pregnancy and post-birth care under Georgia's Medicaid Program.

Continued poor outcomes for low-income women may be, at least in part, attributed low rates of Medicaid coverage, ⁸⁴⁸ as Georgia has not expanded Medicaid under the Affordable Care Act. ⁸⁴⁹

Thus, uninsured adults in the state who would have been newly eligible for Medicaid have remained without a coverage option. The ten states ranked highest in overall health outcomes

https://law.yale.edu/sites/default/files/area/center/ghjp/documents/ghjp_2018_when_the_state_fails_maternal_mortality_racial_disparity_in_georgiarev.pdf

On October 15, 2020, Centers for Medicare and Medicaid Services approved a 1115 waiver called Georgia Pathways to Coverage which extends Medicaid coverage to 100% of the federal poverty level for parents and childless adults with initial and continued enrollment conditioned on compliance with work and premium requirements and other eligibility and benefit restrictions at the regular state match rate. Although coverage under this eligibility extension is set to begin on July 1st, 2021, the Biden Administration has recently begun to withdraw waivers that contain work requirement provisions.

⁸⁴³ Georgia Medicaid, "Medicaid FAQs," https://medicaid.georgia.gov/organization/about-georgia-medicaid/medicaid-faqs (accessed Feb. 24, 2021).

⁸⁴⁴ Eric Baudry, Nicole Gusman, Victoria Strang, Krysten Thomas, Elizabeth Villarreal. When the States Fail: Maternal Mortality & Racial Disparity in Georgia; Yale Law School and Yale School of Public Health; https://law.yale.edu/sites/default/files/area/center/ghjp/documents/ghjp_2018 when the state failsmaternal mortality racial disparity in georgiarev.pdf

⁸⁴⁵ Ibid., 42.

⁸⁴⁶ Ibid.

⁸⁴⁷ Ibid., 43.

⁸⁴⁸ Ibid., 45.

⁸⁴⁹ Kaiser Family Foundation, "Status of State Action on the Medicaid Expansion Decision," <a href="https://www.kff.org/health-reform/state-indicator/state-activity-around-expanding-medicaid-under-the-affordable-care-act/?activeTab=map¤tTimeframe=0&selectedDistributions=status-of-medicaid-expansion-decision&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D#note-12 (accessed Feb. 24, 2021).

have expanded Medicaid programs, while Georgia and more than half of the states ranked below Georgia in health outcomes have not.⁸⁵⁰

Because poverty in Georgia is concentrated among Black communities and communities of color, the expansion of Medicaid in Georgia would be especially beneficial to these populations. 851 Black residents have the highest poverty rate in Georgia with 31 percent living below the poverty line. Latinx residents have a 27 percent poverty rate and White residents have the lowest poverty rate at 9 percent. Within those communities of color, Medicaid expansion would significantly impact women of reproductive age who are considering pregnancy.⁸⁵² Notably, this includes poor women, and women who are considered "not poor enough" to qualify for Medicaid under the present eligibility criteria. Currently, Georgia residents who live between 44 percent and 100 percent of the federal poverty level find themselves in the Medicaid coverage gap, as they earn too much to qualify for Medicaid and too little to qualify for subsidies to purchase individual insurance plans on the health insurance exchanges created by the ACA. 853 While Georgia's Medicaid program covers pregnancy care for women living on incomes up to 220 percent of the poverty line, those non-pregnant women in the "gap" category, who may become pregnant, are left behind. 854 Moreover, mothers who qualified for Medicaid during pregnancy, but lose that coverage 60 days post-delivery, may find themselves completely uninsured if they fall in the coverage gap and are not eligible for health insurance premium tax credits.855

Preconception visits allow women to prepare for pregnancy by minimizing risky behaviors and maximizing positive behaviors to reduce overall risk of maternal mortality and morbidity. ⁸⁵⁶ If the state expanded Medicaid coverage, it would allow women, including those in the Medicaid coverage gap, to take advantage of preconception care options. ⁸⁵⁷

As discussed previously, women and other birthing individuals cited that transportation and maternity care deserts are a significant impediment in seeking and accessing quality care. ⁸⁵⁸ In Georgia, which lacks a reliable or expansive public transit system, distance to hospitals becomes a barrier to accessing prenatal care. Transportation and travel time has been found to be a

852 Ibid., 47.

⁸⁵⁰ Ibid., 46.

⁸⁵¹ Ibid.

⁸⁵³ Ibid.

⁸⁵⁴ Ibid.

⁸⁵⁵ Ibid.

⁸⁵⁶ Ibid.

⁸⁵⁷ Ibid.

⁸⁵⁸ See supra notes 210-211, 281-287.

significant barrier to the use of health services among minorities, ⁸⁵⁹ and Black and Latina women were significantly more likely to report delaying or not seeking medical care due to transportation than White women. ⁸⁶⁰ Ninety-three rural Georgia counties have no hospital with a labor and delivery unit, and no rural Georgia counties have a maternal-fetal medicine specialist doctor. ⁸⁶¹ Two-thirds of rural births in Georgia occur outside of the mother's home county. ⁸⁶² Over 70 counties in Georgia currently have no OB physician and over 40 counties have no obstetrical care of any kind (no OB/GYN, family physician doing OB, or midwife). Over the last 21 years, at least 31 Labor and Delivery Units have closed, 19 in rural counties, ⁸⁶³ leaving over 70 percent of Georgia's 159 counties without Labor and Delivery units. ⁸⁶⁴ Eighty-three percent of Georgia women must travel outside their home county to deliver. ⁸⁶⁵

A 2016 Obstetrics & Gynecology article, *Pregnancy-Associated Deaths in Rural, Nonrural, and Metropolitan Areas of Georgia* characterized pregnancy-associated deaths and examined the relationship between area of residence and pregnancy-associated deaths and pregnancy-related mortality ratios in Georgia from 2010 to 2012. Reference Of the 262 pregnancy-associated deaths examined, 40.1 percent were pregnancy-related. The 2010–2012 pregnancy-related mortality ratio was 26.5 per 100,000 live births and the pregnancy-related mortality ratio did not differ statistically among rural (27.1), nonrural (24.4), and metropolitan Atlanta (27.7) areas. Reference Most pregnancy-related deaths were the result of hemorrhage and cardiovascular factors. In the aggregate, pregnancy-related mortality ratios for Black women were 49.5 compared with 14.3 for White women. The gap in pregnancy-related mortality ratio between Black and White women was highest for metropolitan Atlanta (51.6 compared with 12.4), less in nonrural areas

⁸⁵⁹ Emmanuel Scheppers, Els van Dongen, Jos Dekker, Jan Geertzen, and Joost Dekker, "Potential Barriers to the Use of Health Service Among Ethnic Minorities: A Review," *Family Practice*, 2006, https://pubmed.ncbi.nlm.nih.gov/16476700/.

⁸⁶⁰ Healthy Mothers, Healthy Babies Coalition of Georgia. 2019 State of the State: Maternal and Infant Health in Georgia Report, p. 47, http://hmhbga.org/wp-content/uploads/2019-HMHBGA-State-of-the-State-Report-FINAL.pdf.

⁸⁶¹ Georgia House of Representatives Study Committee on Maternal Mortality. House Budget & Research Office: Final Report,

https://www.house.ga.gov/Documents/CommitteeDocuments/2019/MaternalMortality/HR_589_Final_Report.pdf. 862 Ibid.

⁸⁶³ Eric Baudry, Nicole Gusman, Victoria Strang, Krysten Thomas, Elizabeth Villarreal. When the States Fail: Maternal Mortality & Racial Disparity in Georgia; Yale Law School and Yale School of Public Health; https://law.yale.edu/sites/default/files/area/center/ghjp/documents/ghjp_2018 when the state failsmaternal mortality racial disparity in georgiarev.pdf.

⁸⁶⁴ Advancing the Human Right to Safe and Respectful Maternal Health Care. The Center for Reproductive Rights https://www.reproductiverights.org/sites/crr.civicactions.net/files/documents/Maternal-Health-and-Georgia-Fact-Sheet.pdf.

⁸⁶⁵ Ibid.

 ⁸⁶⁶ Platner, M., Loucks, T. L., Lindsay, M. K., & Ellis, J. E., Pregnancy-Associated Deaths in Rural, Nonrural, and Metropolitan Areas of Georgia. Obstetrics & Gynecology, July 2016. 128(1): p. 113-120. Accessed Pregnancy-Associated Deaths in Rural, Nonrural, and Metropol...: Obstetrics & Gynecology (lww.com)
 ⁸⁶⁷ Ibid., 1.

(50.3 compared with 12.0), and comparable in rural areas (39.4 compared with 22.4).⁸⁶⁸ The report found that although the pregnancy-related mortality ratio was similar for rural, nonrural, and metropolitan Atlanta areas, it was significantly higher for Black women compared with White women living outside of rural areas.⁸⁶⁹

The National Advisory Committee on Rural Health and Human Services consistently heard about the challenges rural women in Georgia face navigating pregnancy and the years following. Rollowing. Many women are single mothers and lack support from their family and/or partner. Therefore, there is great need to support social service programs such as Healthy Start, Early Head Start, and the Maternal, Infant, and Child Home Visiting Program as these human services programs provide holistic care for mothers and help them navigate the challenges that arise before, during, and after childbirth. These programs address multiple social determinants of health for mothers as they provide a wide array of health and human services. The report noted that these programs address the physical, emotional, and social wellbeing of the mother and child by assisting mothers on how best to breastfeed and care for their babies to promoting positive parenting to working with mothers to set goals for the future, continue their education, and find employment and childcare solutions. These programs, especially in rural areas, however continue to be underfunded and lack adequate resources and support.

The Maternal, Infant, and Child Home Visiting Program is a federal initiative dedicated to expansion of access to evidence-based home visiting in the U.S. and tribal communities and territories. The state Department of Public Health oversees administration of Georgia's Maternal, Infant, and Child Home Visiting Program, partnering with community-based organizations that provide screening and direct home visiting services. ⁸⁷⁶ The Maternal, Infant, and Child Home Visiting Program in Georgia, known as the Georgia Home Visiting Program, is administered by the Health Resources and Services Administration at HHS in close partnership with the Administration for Children and Families. The Health Resources and Services Administration is the primary federal agency for improving access to health care services for people who are

869 Ibid.

 $\underline{https://www.hrsa.gov/sites/default/files/hrsa/advisory-committees/rural/publications/2020-maternal-obstetric-care-challenges.pdf.}$

⁸⁶⁸ Ibid.

National Advisory Committee on Rural Health and Human Services, "Maternal and Obstetric Care Challenges in Rural America: Policy Brief and Recommendations to the Secretary,"

⁸⁷¹ Ibid., 7.

⁸⁷² Ibid.

⁸⁷³ Ibid.

⁸⁷⁴ Ibid.

⁸⁷⁵ Ibid.

⁸⁷⁶ Maternal, Infant and Early Childhood Home Visiting Program. Georgia Department of Public Health. <u>FY18</u> <u>MIECHV Annual Report (1).pdf.</u>

uninsured, isolated, or medically vulnerable at-risk communities – currently the Georgia Home Visitation Program provides services to eligible families in 11 of Georgia's 159 counties.⁸⁷⁷ The Administration for Children and Families is a division of the Department of Health & Human Services that promotes the economic and social well-being of families, children, individuals and communities with partnerships, funding, guidance, training and technical assistance.⁸⁷⁸

The Georgia Department of Public Health contracts with 15 Local Implementing Agencies and uses evidence-based home visiting models that are proven to improve child health and to be cost effective.⁸⁷⁹ Georgia leverages federal funds to implement one of the following four models to serve children and families across the state: (1) Early Head Start-Home Visiting; (2) Healthy Families Georgia; (3) Parents as Teachers; and (4) Nurse-Family Partnership.⁸⁸⁰

Georgia joined the National Alliance for Innovation on Maternal Health initiative in 2017. 881 The Alliance for Innovation on Maternal Health safety bundles were implemented in birthing facilities as a result of the committee's findings in birthing facilities to prevent leading causes of maternal morbidity and mortality. In fiscal year 2018, \$1,946,799 funds were awarded for perinatal and maternal health in Georgia's State Appropriation Bill 882 and continuing commitment to address racial/ethnic or other health disparities with block grant funding, through their Maternal Mortality Review Committees, or other efforts. 883 Georgia uses infant health programs to address maternal morbidity and mortality of Black mothers in the late maternal period. 884

Georgia officials use Maternal Mortality Review Committee findings, Maternal Child and Maternal and Child Health block grant funding and other efforts collectively to address pregnancy-related deaths. For example, according to Georgia officials, Georgia's PQC (GaPQC) received funding from the CDC and implemented the Alliance for Innovation on Maternal Health obstetric hemorrhage maternal safety bundle in 2018 based on the state's Maternal Mortality Review Committee finding that hemorrhage was a leading cause of pregnancy-related deaths in Georgia. According to officials, Georgia's Maternal Mortality

⁸⁷⁷ Ibid.

⁸⁷⁸ Ibid.

⁸⁷⁹ Ibid.

⁸⁸⁰ Ibid.

⁸⁸¹ Maternal and Child Health Services. Georgia Department of Public Health. Maternal and Child Health Services Title V Block Grant.

 $[\]frac{https://dph.georgia.gov/sites/dph.georgia.gov/files/MCH/TitleV/2020/Georgia\%20Title\%20V\%20Block\%20Grant\%20Submission\%207-15-2019.pdf.$

⁸⁸² Ibid., 68

⁸⁸³ United States Government Accountability Office. MATERNAL MORTALITY: Trends in Pregnancy-Related Deaths and Federal Efforts to Reduce Them. https://www.gao.gov/assets/710/705331.pdf.

⁸⁸⁴ Ibid., 26.

⁸⁸⁵ Ibid.

Review Committee was funded primarily through the Maternal and Child Health Services Block Grant. 886

Georgia has also received funding for several national programs through various offices of the federal Department of Health and Human Services' Health Resources and Services Administration Maternal, Infant, and Child Home Visiting Program, which supports Georgia's Home Visiting Program, and served 2,849 participants in 1,362 households in 2018, providing a total of 19,385 home visits that year. The Governor's Office of Children and Families (GOCF) was designated as the lead agency to administer the Maternal, Infant, and Child Home Visiting Program Grant program for Georgia. The overall goal of Georgia's Maternal, Infant, and Child Home Visiting Program is to improve child and family outcomes in Georgia by implementing evidence-based home visiting as a major service strategy within Great Start Georgia. This program is designed to: (1) strengthen and improve the programs and activities carried out under Title V funding; (2) expand and improve the coordination of services within atrisk communities; and (3) provide evidence-based home visiting services.

Georgia utilizes two evidence-based models for home visiting: Healthy Families Georgia, and Nurse-Family Partnership.⁸⁹¹ In FY 2019, Georgia received \$7 million in federal funds for its Home Visiting Program,⁸⁹² as well as six awards through the Health Resources and Services Administration's Healthy Start Program for a total of \$6.96 million in FY 2020 funding.⁸⁹³ In 2019, the Health Resources and Services Administration funded 35 Health Centers in Georgia, that served over 589,000 patients, a majority of whom were low-income, women, and people of color.⁸⁹⁴

The Georgia General Assembly created the Georgia House Study *Committee on Maternal Mortality* in 2019. ⁸⁹⁵ The committee heard from numerous organizations and entities that are working around the state to lower Georgia's maternal mortality rate. Many of these programs

⁸⁸⁷ Georgia Department of Public Health. Health Resources and Services Administration, "Georgia's MIECHV Program FY 2018," https://nationalhomevisitingcoalition.org/wp-content/uploads/ga.pdf.

⁸⁹¹ Georgia Department of Public Health. Health Resources and Services Administration, "Georgia's MIECHV Program FY 2018" https://nationalhomevisitingcoalition.org/wp-content/uploads/ga.pdf.

⁸⁸⁶ Ibid.

⁸⁸⁹ Governor's Office of Children and Families. MIECHV Program. https://greatstartgeorgia.org/miechv-program-2/.

⁸⁹⁰ Ibio

⁸⁹² Health Resources and Services Administration, "Maternal, Infant, and Early Childhood Home Visiting Awards FY19," https://mchb.hrsa.gov/maternal-child-health-initiatives/home-visiting/fy19-awards.

⁸⁹³ Health Resources and Services Administration, "2020 Healthy Start Grant Awards," https://mchb.hrsa.gov/maternal-child-health-initiatives/healthy-start/awards.

⁸⁹⁴ Health Resources and Services Administration, "2019 Georgia Program Awardee Data," <u>Health Center Program</u> Data (hrsa.gov).

⁸⁹⁵ H.R. 589 (NS), 159th General Assembly, 2019-2020 Reg. Sess. (Ga 2019).

work in conjunction with one another to implement broad-reaching projects. ⁸⁹⁶ An example of this is the Georgia Perinatal Quality Collaborative and its partnership with the Department of Public Health. The Georgia Perinatal Quality Collaborative engages its stakeholders in implementing equitable, evidenced-based perinatal care through a data-driven quality improvement collaborative, and the organization works with DPH to implement the Alliance for Innovation on Maternal Health bundles in Georgia. ⁸⁹⁷ The Alliance for Innovation on Maternal Health bundles are sets of best practices for maternal care that include recommendations for hospital-based protocols, policies, practice charges, drills, and systems of data tracking. Georgia became the thirteenth state to implement the Alliance for Innovation on Maternal Health bundles when it was awarded funding from the Centers for Disease Control and Prevention in 2017. ⁸⁹⁸

The Georgia Perinatal Quality Collaborative also launched the Obstetric Hemorrhage bundle in April 2018 and the Severe Hypertension in Pregnancy bundle in June 2019. As of September 2019, 62 Georgia hospitals are participating in the bundles, representing 80 percent of the birthing hospitals in Georgia and impacting 87 percent of all Georgia births. ⁸⁹⁹ Of these 62 hospitals, 44 hospitals are implementing the Obstetrical Hemorrhage bundle and 36 hospitals are implementing the Severe Hypertension in Pregnancy bundle (see Table 4.5). Additionally, 47 hospitals are implementing a Neonatal Abstinence Syndrome program. ⁹⁰⁰ The participating hospitals are spread throughout the state's six perinatal regions, with the distribution shown in the following table.

Table 4.5 Hospitals Participating in Alliance for Innovation on Maternal Health Bundles Per Perinatal Region

Perinatal Region	Number of GaPQC Hospitals	Percent of Region
Albany	5	71%
Atlanta	26	84%
Augusta	4	67%
Columbus	9	100%

⁸⁹⁶ Georgia House of Representatives Study Committee on Maternal Mortality. House Budget & Research Office: Final Report,

⁸⁹⁹ Georgia House of Representatives Study Committee on Maternal Mortality. House Budget & Research Office: Final Report.

 $\frac{https://www.house.ga.gov/Documents/CommitteeDocuments/2019/MaternalMortality/HR_589_Final_Report.pdf.}{900}\ Ibid.$

https://www.house.ga.gov/Documents/CommitteeDocuments/2019/MaternalMortality/HR_589_Final_Report.pdf. 897 Ibid.

⁸⁹⁸ Ibid.

Macon	11	100%
Savannah	7	64%

Source: House Budget & Research Office, House of Representatives Study Committee on Maternal Mortality, https://www.house.ga.gov/Documents/CommitteeDocuments/2019/MaternalMortality/HR 589 Final Report.pdf

Because of low patient volumes and lack of obstetric providers in rural areas, many rural hospitals (especially those without obstetrical services) are not prepared to handle complications that arise both during and after childbirth. The National Advisory Committee on Rural Health and Human Services believes treatment protocols should be developed and implemented in critical access hospitals in order to prevent both maternal mortality and morbidity. The Maternal and Child Health Bureau, the Alliance for Innovation on Maternal Health is a national data-driven maternal safety and quality improvement initiatives based on proven implementation approaches to improve maternal safety and outcomes in the U.S. Currently, the Alliance for Innovation on Maternal Health works through state teams and health systems to align national, state and hospital-level quality improvement efforts to improve maternal health outcomes. The Alliance for Innovation on Maternal Health is funded through a cooperative agreement with the Maternal and Child Health Bureau and although they offer numerous safety bundles on a range of issues, there is no bundle specifically addressing hospitals and clinics that do not have obstetrical services. The services of th

With supportive funding of \$2 million from the Georgia General Assembly, the Georgia Perinatal Quality Collaborative also implemented a Rural Hospital Initiative to support smaller rural hospitals in implementing the Alliance for Innovation on Maternal Health bundles. 904 Currently, 16 rural hospitals are implementing the Obstetrical Hemorrhage bundle, 10 hospitals are implementing the Severe Hypertension in Pregnancy bundle, and 14 are implementing the Neonatal Abstinence Syndrome program. 905

In April 2019, Mercer University School of Medicine (MUSM) faculty members received a \$5.5 million grant over 5 years from the federal Health Resources and Services Administration to

⁹⁰¹ National Advisory Committee on Rural Health and Human Services. Maternal and Obstetric Care Challenges in Rural America: Policy Brief and Recommendations to the Secretary.

 $[\]frac{https://www.hrsa.gov/sites/default/files/hrsa/advisory-committees/rural/publications/2020-maternal-obstetric-care-challenges.pdf. \\https://www.hrsa.gov/sites/default/files/hrsa/advisory-committees/rural/publications/2020-maternal-obstetric-care-challenges.pdf. \\https://www.hrsa.gov/sites/default/files/hrsa/advisory-challenges.pdf. \\https://www.hrsa.gov/sites/default/files/hrsa/advisory-challenges.pdf. \\https://www.hrsa.gov/sites/default/files/hrsa/advisory-challenges.pdf. \\https://www.hrsa.gov/sites/default/files/hrsa/advisory-challenges.pdf. \\https://www.hrsa.gov/sites/default/files/hrsa/advisory-challenges.pdf. \\https://www.hrsa.gov/sites/default/files/hrsa/advisory-challenges.pdf. \\https://www.hrsa.gov/sites/default/files/hrsa/advisory-challenges.pdf. \\https://www.hrsa.gov/sites/default/files/hrsa/advisory-challenges.pdf. \\https://www.hrsa.gov/site$

committees/rural/publications/2020-maternal-obstetric-care-challenges.pdf

⁹⁰² Ibid., 8.

⁹⁰³ Ibid.

⁹⁰⁴ Georgia Department of Public Health. Health Resources and Services Administration, "Georgia's MIECHV Program FY 2018," County MIECHV Program FY 2018,, <u>nationalhomevisitingcoalition.org</u>.

⁹⁰⁵ Georgia House of Representatives Study Committee on Maternal Mortality. House Budget & Research Office: Final Report,

https://www.house.ga.gov/Documents/CommitteeDocuments/2019/MaternalMortality/HR 589 Final Report.pdf.

combat maternal and infant mortality in a seven-county region of rural Georgia. 906 The grant will establish a program called South Georgia Healthy Start to implement and determine the impact of a multi-level initiative that establishes new systems of physical and mental health care for pregnant women in rural areas, provides comprehensive case management and health promotion to at-risk mothers and families, engages in workforce development, and promotes systems change to improve maternal and infant health. 907

New Jersey

State trends in maternal mortality and racial disparities in New Jersey mirror national statistics. 908 The overall maternal death rate in New Jersey has decreased between 2009 and 2012 from 51.0 deaths per 100,000 live births to 32.8 deaths per 100,000 live births respectively. 909 New Jersey's definition of maternal death aligns with the definition of the World Health Organization. 910 Examining pregnancy-related deaths in New Jersey (which follow the CDC's definition), 911 the overall rate has decreased slightly since 2009 (see Figure 4.6). 912

⁹⁰⁶ Kyle Sears. "MUSM Faculty Members Receive \$5.5 Million Federal Grant to Combat Maternal and Infant Mortality in Rural Georgia," April 02, 2019, https://news.mercer.edu/musm-faculty-members-receive-5-5-million-federal-grant-to-combat-maternal-and-infant-mortality-in-rural-georgia/.

⁹⁰⁷ Ibid.

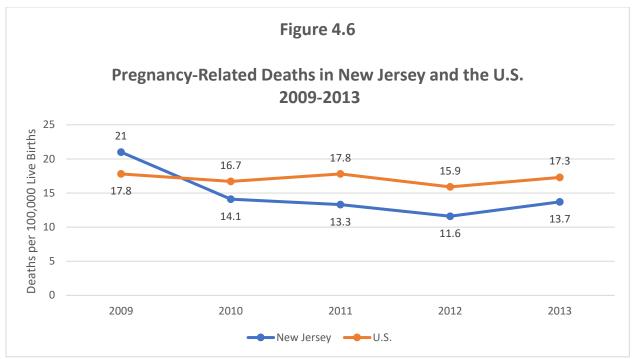
⁹⁰⁸ State of New Jersey Department of Health, *Trends in Statewide Maternal Mortality: New Jersey 2009-2013*, p. 1, https://nj.gov/health/fhs/maternalchild/documents/nj_maternal_mortality_trends_2009_2013.pdf.

⁹⁰⁹ Ibid., 17.

⁹¹⁰ State of New Jersey Department of Health, "Maternal Mortality and Morbidity: Terms for New Jersey to Know," https://nj.gov/health/maternal/documents/MM definitions infographic.pdf.

⁹¹¹ Ibid, see also supra note 76.

⁹¹² State of New Jersey Department of Health, *Trends in Statewide Maternal Mortality: New Jersey 2009-2013*, p. 1, https://nj.gov/health/fhs/maternalchild/documents/nj maternal mortality trends 2009 2013.pdf.



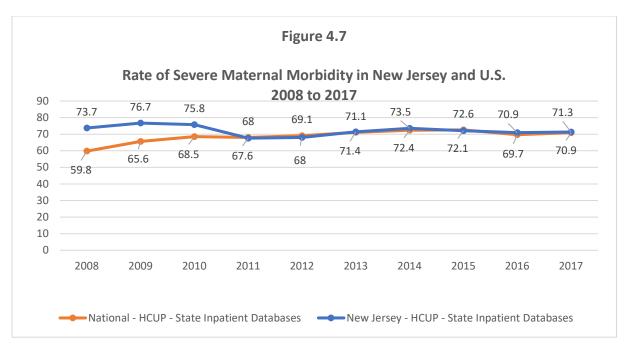
Source: State of New Jersey Department of Health, *Trends in Statewide Maternal Mortality: New Jersey 2009-2013*, p. 17, https://nj.gov/health/fhs/maternalchild/documents/nj_maternal_mortality_trends_2009_2013.pdf; Centers for Disease Control and Prevention, "Pregnancy Mortality Surveillance System," https://www.cdc.gov/reproductivehealth/maternal-mortality/pregnancy-mortality-surveillance-system.htm.

Since 2009, the pregnancy-related death rate in New Jersey decreased from 21 deaths per 100,000 live births in 2009 to 13.7 in 2013. Pregnancy-related death rates in New Jersey trended below national averages from 2010 to 2013.

Similar to pregnancy-related deaths, New Jersey's severe maternal morbidity rate closely reflects national statistics from 2008 to 2017, according to the Health Resources and Services Administration National Outcomes Measures data. Rates of severe maternal mortality in New Jersey have been consistently trending above the national average from 2008 to 2015 (see Figure 4.7). 913

^{*}New Jersey defines a pregnancy-related death as the death of a woman during pregnancy or within one year of the end of a pregnancy from a pregnancy complication, a chain of events initiated by pregnancy, or the aggravation of an unrelated condition by the physiologic effects of pregnancy.

⁹¹³ Health Resources and Services Administration, "National Outcome Measures," https://mchb.tvisdata.hrsa.gov/PrioritiesAndMeasures/NationalOutcomeMeasures.



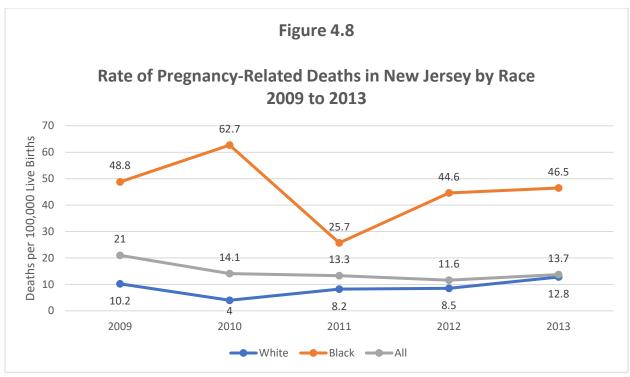
Source: Health Resources and Services Administration, "National Outcome Measures," https://mchb.tvisdata.hrsa.gov/PrioritiesAndMeasures/NationalOutcomeMeasures. Chart adapted by the Commission.

In 2016, New Jersey reported the percentage of severe maternal morbidity events with transfusions was 32.8 percent for women who experienced surgical/cesarean births, as opposed to 9.9 percent for women who had vaginal births and 18.1 percent for all hospitalizations. 914

While the state's rates have decreased from 2009 to 2017, there are significant racial disparities in pregnancy-related deaths in New Jersey.⁹¹⁵ In particular, the maternal mortality rate in New Jersey is more than 5 times higher for Black women than White women (see Figure 4.8).

⁹¹⁴ State of New Jersey Department of Health, "Overview of Statewide Rates of Complications Associated with Delivery Hospitalizations, 2016," https://nj.gov/health/maternal/morbidity/mhh_reportcard/statewide_rates.shtml.

⁹¹⁵ State of New Jersey Department of Health, *Trends in Statewide Maternal Mortality: New Jersey 2009-2013*, p. 1, https://nj.gov/health/fhs/maternalchild/documents/nj maternal mortality trends 2009 2013.pdf.



Source: State of New Jersey Department of Health, *Trends in Statewide Maternal Mortality: New Jersey 2009-2013*, pp. 17-18, https://nj.gov/health/fhs/maternalchild/documents/nj_maternal_mortality_trends_2009_2013.pdf

The pregnancy-related death rate for Black women in New Jersey has decreased slightly over time, on par with national trends, from 48.8 deaths per 100,000 live births in 2009 to 46.5 deaths per 100,000 live births in 2013. However, the racial disparity in pregnancy-related deaths among Black and White women in New Jersey has persisted during this period. Women of color accounted for a disproportionate number of all pregnancy-related deaths in New Jersey from 2009 through 2013 (almost 60 percent). Black women had the highest percentage of pregnancy-related deaths (46.2 percent), followed by Latinas at 15.4 percent, and 7.7 percent being Asian women. Compared to White women, who accounted for 26.9 percent of pregnancy-related deaths over the same time period. 916

Data from 2016 on severe maternal morbidity in New Jersey shows significant racial disparities. ⁹¹⁷ In 2016, the rate of severe maternal morbidity events with transfusions in New Jersey was highest for Black women, with 31.2 per 1,000 delivery hospitalizations, as compared to 20.3 per 1,000 delivery hospitalizations for Latina women, 19.3 per 1,000 delivery

⁹¹⁶ State of New Jersey Department of Health, *Trends in Statewide Maternal Mortality: New Jersey 2009-2013*, pp. ii and 6, https://nj.gov/health/fhs/maternalchild/documents/nj maternal mortality trends 2009 2013.pdf. This report did not report maternal mortality statistics for any other racial/ethnic groups aside from those already mentioned.

⁹¹⁷ State of New Jersey Department of Health, "Overview of Statewide Rates of Complications Associated with Delivery Hospitalizations, 2016," https://nj.gov/health/maternal/morbidity/mhh reportcard/statewide rates.shtml.

hospitalizations for "Other/Multi-race" women, 5.8 per 1,000 delivery hospitalizations for Asian women, and 13.4 per 1,000 delivery hospitalizations for White women. The rate for women who experienced postpartum hemorrhages with transfusions in 2016 was also highest for Black women, with 54.4 hemorrhages per 1,000 delivery hospitalizations, as compared to 50.6 for Latina women, 50.0 for White women, 46.1 for Asian women, and 40.5 percent for "Other/Multi-race" women (per 1,000 delivery hospitalizations).

New Jersey has a long history of reviewing maternal deaths, having been the second state in the U.S. to establish a Maternal Mortality Review Committee in 1932. Since 1999, the maternal mortality review process has evolved to become interdisciplinary, using a steering committee to oversee the process. Since 1999, the state Maternal Mortality Review Committee has reviewed approximately 700 cases of maternal death, and reported that it has aided the process of several quality improvement initiatives to improve the safety of pregnant women in New Jersey.

In 2019, New Jersey Governor Phil Murphy signed legislation that formalized the establishment of a Maternal Mortality Review Commission at the state agency level to annually review and report maternal deaths in the state. The Commission would be comprised of 31 interdisciplinary members who would be mandated to perform reviews and prepare reports to inform about maternal mortality on a regular basis. This legislation formally established New Jersey's Maternal Mortality Review Committee within the New Jersey Department of Health and increased the legal authority of the committee by directing the Maternal Mortality Review Commission to review statistical data on maternal deaths to identify:

Statewide and regional maternal death rates; trends, patterns, and disparities in adverse maternal outcomes; and medical, non-medical, and system-related factors that may have contributed to maternal deaths and treatment disparities. 925

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 $^{^{918}}$ Ibid. Rates of severe maternal morbidity were not reported for any other specific racial/ethnic groups aside from those already mentioned.

⁹¹⁹ Ibid. Rates of hemorrhage were not reported for any other specific racial/ethnic groups aside from those already mentioned.

 ⁹²⁰ Centers for Disease Control and Prevention, State Maternal Mortality Review: Accomplishments of Nine States,
 p. 46, http://www.amchp.org/Calendar/Webinars/Womens-Health-Info-Series/Documents/StrII.pdf.
 921 Ibid.

⁹²² State of New Jersey Department of Health, *Trends in Statewide Maternal Mortality: New Jersey 2009-2013*, p. 1, https://nj.gov/health/fhs/maternalchild/documents/nj maternal mortality trends 2009 2013.pdf.

⁹²³ P.L.2019, c.75; N.J. A1862 (2018), https://www.njleg.state.nj.us/2018/Bills/A2000/1862 I1.HTM.

⁹²⁴ *Id.*; *see also* State of New Jersey, Governor Phil Murphy, "Governor Murphy Signs Legislation to Establish Maternal Mortality Review Committee," May 1, 2019,

https://nj.gov/governor/news/news/562019/approved/20190501a.shtml.

⁹²⁵ P.L.2019, c.75; N.J. A1862 (2018).

The legislation also directs the Maternal Mortality Review Commission to deliver an annual report to the New Jersey Department of Health, the Governor of New Jersey, and the New Jersey State Legislature detailing the Maternal Mortality Review Commission's findings and recommendations on maternal mortality during the previous year. 926

In 2019, New Jersey's Maternal Mortality Review Committee was awarded a total of \$2.25 million in funding through the CDC's ERASE MM program to support the enhancement of its state Maternal Mortality Review Committee. 927 New Jersey is promised to receive \$450,000 annually through September 29, 2024. 928 New Jersey also received and allocated \$11.5 million in federal Title V funds in its FY 2020 budget to maternal and child health programs, ⁹²⁹ and spent \$10.3 million on these programs in FY 2018. 930 New Jersey's Maternal Mortality Review Committee is supported by these Title V funds. 931

One notable initiative to emerge from recommendations from New Jersey's Maternal Mortality Review Committee⁹³² was the Perinatal Mood Disorders Initiative, also known as the Speak Up When You're Down campaign. 933 In 2006, New Jersey became the first state in the U.S. to pass legislation to mandate universal screening, education, and referral for perinatal mood disorders in hospitals that offer inpatient obstetric services. 934 The program collaborates with member hospitals, health centers, mental health clinicians, and community-based organizations in order to further the following goals:

927 Association for Maternal & Child Health Programs, "AMCHP Congratulates States that Win New Federal Grants to Support Maternal Mortality Reviews," Aug. 16, 2019,

http://www.amchp.org/AboutAMCHP/NewsRoom/Documents/MM%20Review%20Federal%20Grants.pdf: Lilo H. Stainton, "New Federal Funding to Boost NJ Maternal Health Improvements," NJ Spotlight, Sep. 25, 2019, https://www.njspotlight.com/2019/09/new-federal-funding-to-boost-nj-maternal-health-improvements/.

⁹²⁶ *Id*.

⁹²⁸ State of New Jersey Department of Health, "New Jersey Department of Health Receives \$450,000 Federal Grant to Support Maternal Mortality Efforts," Aug. 22, 2019, https://www.nj.gov/health/news/2019/approved/20190822a.shtml.

⁹²⁹ Association of Maternal & Child Health Programs, "New Jersey Maternal and Child Health Block Grant 2020," http://www.amchp.org/Policy-Advocacy/MCHAdvocacy/2020%20State%20Profiles/New%20Jersey%202020%20FINAL.pdf.

⁹³⁰ Health Resources and Services Administration, "Title V MCH Block Grant Funding: State Information," https://mchb.tvisdata.hrsa.gov/State/Detail/NC.

⁹³¹ Maternal and Child Health Services Title V Block Grant, New Jersey FY 2020 Application/FY2018 Annual Report, 2019, p. 10,

https://mchb.tvisdata.hrsa.gov/uploadedfiles/StateSubmittedFiles/2020/NJ/NJ TitleV PrintVersion FY20.pdf.

⁹³² State of New Jersey Department of Health, Trends in Statewide Maternal Mortality: New Jersey 2009-2013, p. 20, https://nj.gov/health/fhs/maternalchild/documents/nj maternal mortality trends 2009 2013.pdf.

⁹³³ Partnership for Maternal & Child Health of Northern New Jersey, "Perinatal Mood Disorders," https://partnershipmch.org/programs/ppd/; State of New Jersey Department of Health, "Mental Health Concerns for New Parents," https://nj.gov/health/fhs/maternalchild/mentalhealth/.

⁹³⁴ Partnership for Maternal & Child Health of Northern New Jersey, "Perinatal Mood Disorders," https://partnershipmch.org/programs/ppd/.

- Provide education to healthcare providers on perinatal mood disorders signs and symptoms and screening methods, and information on local perinatal mental health resources;
- Raise awareness about perinatal mood disorders and provide information about hospital and community referrals to assist women and their families;
- Support member hospitals and community-based organizations by establishing new mothers' groups;
- Provide a continuum of care during the perinatal period by conducting follow-up phone
 calls to at-risk mothers to ensure they are connected to mental health services and/or
 support groups;
- Monitor, collect and analyze member hospital perinatal mood disorders screening data; and,
- Maintain an updated listing of regional support groups and a directory of perinatal mental health providers.935

Since the Speak Up When You're Down initiative started, over \$9 million has been invested into education, screening, and treatment of perinatal mood disorders in the state. 936

New Jersey also has an Improving Pregnancy Outcomes program, aimed at improving maternal and infant health outcomes for high-need women and reducing racial, ethnic, and economic disparities through a collaborative and community-driven approach. This initiative utilizes two different models, which are 1) the Community Health Worker model that conducts outreach and client recruitment within a targeted community; and 2) the Central Intake, which is a single point of entry for screening and referral, using standardized screening tools and working to eliminate duplication of services and efforts. Both the Speak Up When You're Down and Improving Pregnancy Outcomes programs are funded through the Maternal and Child Health Title V Block Grant program.

The State of New Jersey has been focused on understanding the needs and experiences of Black women in the state, and supporting community models of care that acknowledge the impacts of structural racism. ⁹⁴⁰ In 2018, New Jersey awarded \$4.3 million in funds through its Healthy Women, Healthy Families initiative in an effort to improve maternal and infant health outcomes for Black families across New Jersey. ⁹⁴¹ This effort would work to improve access and quality of

936 State of New Jersey Department of Health, *Trends in Statewide Maternal Mortality: New Jersey 2009-2013*, p. 1, https://nj.gov/health/fhs/maternalchild/documents/nj_maternal_mortality_trends_2009_2013.pdf.

⁹⁴⁰ Kim Krisberg, "Programs work from within to prevent black maternal deaths: Workers targeting root cause — Racism," *The Nation's Health*, August 2019, http://thenationshealth.aphapublications.org/content/49/6/1.3-0.

⁹⁴¹ New Jersey Department of Health, "NJ Agencies Awarded \$4.7 Million to Improve Black Infant, Maternal Mortality," Jul. 11, 2018, https://www.state.nj.us/health/news/2018/20180711a.shtml.

⁹³⁵ Ibid.

⁹³⁷ Association of Maternal & Child Health Programs, "New Jersey Maternal and Child Health Block Grant 2019," http://www.amchp.org/Policy-Advocacy/MCHAdvocacy/2019%20State%20Profiles/New%20Jersey%202019.pdf. 938 Ibid.

⁹³⁹ Ibid.

perinatal care in order to reduce disparities. In addition, \$450,000 was allocated for a doula pilot program, partnering with Uzazi Village in Kansas City, MO for community doula training, in municipalities with high rates of Black infant mortality to improve birth outcomes for Black families. Shereef Elnahal, MD, MBA, Commissioner at the New Jersey Department of Health, reported that approximately 17,000 women had been screened through Healthy Women, Healthy Families, and more than 9,000 had been referred to health and community health services. Additionally, more than 60 healthy babies were born with the help of doulas, as part of the pilot program, and New Jersey's state Medicaid program started reimbursing the cost of doula care in July 2019 as a direct result of the program's success. Shades and shades and success of the program of the program

New Jersey received federal funding for participation in several national HHS programs. The Health Resources and Services Administration's Maternal, Infant, and Early Childhood Home Visiting Program supports New Jersey's Home Visiting Program, 945 and served 10,595 participants, 5,805 households in 2019, providing a total of 60,869 home visits that year. 946 New Jersey utilizes three evidence-based models for home visiting: Healthy Families America, Nurse-Family Partnership, and Parents as Teachers. 947 In FY 2019, New Jersey received \$10.8 million in funds for its Home Visiting Program. 948 In 2019, the state received three awards through the Health Resources and Services Administration's Healthy Start Program for a total of \$3.2 million in funding. 949 In 2019, the Health Resources and Services Administration funded 24 Health Centers in New Jersey that served nearly 585,000 patients, the majority of which were low-income, women, and people of color. 950 In addition, through the Office of Minority Health's State Partnership Program to Improve Minority Health, the New Jersey Minority and Multicultural Health Office received a grant for \$140,000 for 2010-2013. 951 This award funded a

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⁹⁴² Ibid...: Kim Krisberg, "Programs work from within to prevent black maternal deaths: Workers targeting root cause — Racism," *The Nation's Health*, August 2019, http://thenationshealth.aphapublications.org/content/49/6/1.3-0.

⁹⁴³ Kim Krisberg, "Programs work from within to prevent black maternal deaths: Workers targeting root cause — Racism," *The Nation's Health*, August 2019, http://thenationshealth.aphapublications.org/content/49/6/1.3-0.
944 Ibid.

⁹⁴⁵ State of New Jersey, Department of Children and Families, "Home Visitation Programs," https://www.nj.gov/dcf/families/early/visitation/.

⁹⁴⁶ Health Resources and Services Administration, "North Carolina's MIECHV Program FY 2019," https://mchb.hrsa.gov/sites/default/files/mchb/MaternalChildHealthInitiatives/HomeVisiting/pdf/nc.pdf.
⁹⁴⁷ Ibid.

⁹⁴⁸ Health Resources and Services Administration, "Maternal, Infant, and Early Childhood Home Visiting Awards FY19," https://mchb.hrsa.gov/maternal-child-health-initiatives/home-visiting/fy19-awards.

⁹⁴⁹ Health Resources and Services Administration, "2019 Healthy Start Grant Awards," https://mchb.hrsa.gov/maternal-child-health-initiatives/healthy-start/awards.

⁹⁵⁰ Health Resources and Services Administration, "2018 New Jersey Health Center Data," https://bphc.hrsa.gov/uds/datacenter.aspx?year=2018&state=NJ.

⁹⁵¹ Office of Minority Health, "State Partnership Grants," https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=2&lvlid=51#:~:text=The%20purpose%20of%20the%20State, %2C%20asthma%2C%20cancer%2C%20cardiovascular%20disease; Office of Minority Health, "New Jersey

project that sought to strengthen, evaluate, and develop new collaborations among programs in the department to develop policies for a comprehensive infrastructure, targeting racial and ethnic populations. 952

New Jersey also has a Perinatal Quality Collaborative, which is a statewide partnership of stakeholders that work to improve the quality and safety of maternal and infant healthcare in New Jersey, and receives federal funding. New Jersey is one of 13 states funded through the CDC's Division of Reproductive Health, so receiving \$1 million in funding over the course of five years. New Jersey is enrolled in the Alliance for Innovation on Maternal Health, and its Perinatal Quality Collaborative has implemented both the obstetrical hemorrhage and severe hypertension patient safety bundles, so and has developed a toolkit for implementation of these patient safety bundles. It is also partnering with the New Jersey Department of Health to reduce the incidence of cesarean section births for low-risk, first-time mothers.

New Jersey adopted and implemented Medicaid expansion in 2014. New Jersey's Medicaid program serves pregnant women and covers eligible women with household incomes at or below 200 percent of the federal poverty level. New Jersey Medicaid covers pregnant women during the pregnancy and for 60 days after delivery or after the date of the end of the pregnancy. The state Medicaid program covers clinical physician services, inpatient and outpatient hospital services, including pediatric and prenatal care, nurse midwife services, and mental health services. As discussed in Chapter 2, Medicaid plays a significant role in insuring people of

Minority and Multicultural Health Office - State Partnership Program," https://minorityhealth.hhs.gov/omh/content.aspx?ID=9166&lvl=2&lvlID=51.

https://www.state.nj.us/humanservices/dmahs/clients/medicaid/pregnant/pregnancy fact sheet.pdf.

⁹⁵² Office of Minority Health, "New Jersey Minority and Multicultural Health Office - State Partnership Program," https://minorityhealth.hhs.gov/omh/content.aspx?ID=9166&lvl=2&lvlID=51.

⁹⁵³ "New Jersey Perinatal Quality Collaborative," p. 1, https://www.essexadapt.org/wp-content/uploads/2018/10/NJ-Perinatal-Quality-Collaborative Informational-Flyer-10-02-18.pdf.

⁹⁵⁴ Centers for Disease Control and Prevention, "State Perinatal Quality Collaboratives," https://www.cdc.gov/reproductivehealth/maternalinfanthealth/pqc-states.html.

^{955 &}quot;New Jersey Perinatal Quality Collaborative," p. 1, https://www.essexadapt.org/wp-content/uploads/2018/10/NJ-Perinatal-Quality-Collaborative_Informational-Flyer-10-02-18.pdf.

956 Ibid.

⁹⁵⁷ New Jersey Hospital Association Perinatal Quality Collaborative, *Reducing Maternal Morbidity and Mortality Toolkit*, http://www.njha.com/media/516755/NJ-AIM-Toolkit-NJHAFinal.pdf.

⁹⁵⁸ "New Jersey Perinatal Quality Collaborative," p. 1, https://www.essexadapt.org/wp-content/uploads/2018/10/NJ-Perinatal-Quality-Collaborative Informational-Flyer-10-02-18.pdf.

⁹⁵⁹ The Kaiser Family Foundation, "Status of State Medicaid Expansion Decisions: Interactive Map," https://www.kff.org/medicaid/issue-brief/status-of-state-medicaid-expansion-decisions-interactive-map/.

⁹⁶⁰ State of New Jersey, Department of Human Services, Division of Medical Assistance & Health Services, "NJ Medicaid, Pregnant Women," https://www.state.nj.us/humanservices/dmahs/clients/medicaid/pregnant/index.html. ⁹⁶¹ Ibid.

⁹⁶² State of New Jersey, Department of Human Services, Division of Medical Assistance & Health Services, "NJ Familycare Maternal Health Coverage," p. 2,

color, and expansion of Medicaid is significantly associated with lower maternal mortality rates. ⁹⁶³ In New Jersey, expansion of Medicaid through the Affordable Care Act lowered the uninsured rate of Black adults from 22.4 percent in 2013 to 10.7 percent in 2018. ⁹⁶⁴

In 2020, New Jersey's First Lady Tammy Murphy spearheaded a new initiative to reduce maternal mortality in New Jersey and eliminate racial disparities in maternal healthcare called Nurture NJ. 965 This initiative acknowledges that New Jersey's maternal mortality rate is one of the worst in the U.S., and seeks to boost a statewide awareness campaign with a "multi-pronged, multi-agency approach to improve maternal and infant health among New Jersey women and children." The stated goal of this initiative is to make New Jersey the safest place in the country to give birth and raise a baby. 967 Specific initiatives include:

- An annual Black Maternal and Infant Health Leadership Summit
- First Lady's Family Festival event series
- Quarterly interdepartmental maternal and infant health meetings
- A comprehensive, statewide strategic plan to reduce maternal mortality by 50% over five years and eliminate racial disparities in birth outcomes ⁹⁶⁸

The Nurture NJ initiative will be funded by philanthropic and community partners, such as the Nicholson Foundation and the Community Health Acceleration Partnership that have committed \$282,000 to the initiative through June 2020. ⁹⁶⁹ This initiative is a short-term strategy to "triage" maternal health problems, seeking to connect low-income women with diverse health services, but a long-term solution is reportedly being developed that will build upon existing findings and programs that will seek additional investment and will solicit input from clinicians, academics, mothers, and other nongovernmental experts to help low-income women access quality maternal care. ⁹⁷⁰

In recent years, the New Jersey legislature has also been more focused on addressing maternal mortality and reducing racial disparities in maternal health care. New Jersey recently passed legislation to form the New Jersey Maternity Care Quality Collaborative, ⁹⁷¹ a multidisciplinary

⁹⁶⁹ Lilo H. Stainton, "First Lady Spearheading Plan to Reduce NJ's High Maternal Mortality Rate," Jan. 24, 2020, https://www.njspotlight.com/2020/01/first-lady-spearheading-plan-to-reduce-njs-high-maternal-mortality-rate/.

⁹⁷⁰ Ibid.

⁹⁶³ See supra notes 295-298.

⁹⁶⁴ Sarah Gantz, "In Pa., N.J., and across the country, the ACA has narrowed racial gaps in health-care access," *The Philadelphia Inquirer*, Jan. 16, 2020, https://www.inquirer.com/health/consumer/aca-medicaid-insurance-racial-disparities-20200116.html.

⁹⁶⁵ Lilo H. Stainton, "First Lady Spearheading Plan to Reduce NJ's High Maternal Mortality Rate," Jan. 24, 2020, https://www.njspotlight.com/2020/01/first-lady-spearheading-plan-to-reduce-njs-high-maternal-mortality-rate/.

⁹⁶⁶ State of New Jersey, Governor Phil Murphy, "Nurture NJ," https://nj.gov/governor/admin/fl/nurturenj.shtml. 967 Ibid.

⁹⁶⁸ Ibid.

⁹⁷¹ N.J. P.L. 2019, Chapter 133 (June 24, 2019), https://www.njleg.state.nj.us/2018/Bills/AL19/133 .HTM.

stakeholder team to identify quality improvements for birthing centers in order to improve maternal health outcomes. ⁹⁷² The Collaborative aligns its focus on overarching statewide goals of decreasing maternal mortality, maternal morbidity, and racial disparities in maternal health in New Jersey, working under the umbrella of Nurture NJ. ⁹⁷³

In 2019, the New Jersey Department of Health was awarded over \$10 million in federal funding over 5 years for the State Maternal Health Innovation program, one of 9 awardees working to improve maternal health outcomes. ⁹⁷⁴ The funding is to support the efforts of the newly-formed New Jersey Maternity Care Quality Collaborative, ⁹⁷⁵ to develop blueprints for change and identify proven strategies to help birthing centers improve maternal health outcomes. ⁹⁷⁶ This funding also aims to enhance New Jersey's capacity to collect and analyze maternal health data. ⁹⁷⁷

In May 2019, the New Jersey Department of Health announced the launch of its Maternal Data Center. This launch also included the release of surgical/cesarean section birth rates by hospital among women at low-risk for complications, indicating a rate of 30.3 surgical procedures per 100 live births, which is higher than the national target of 23.9 surgical procedures per 100 live births. The Maternal Data Center's website includes these data on unnecessary surgical births, as well as other data on maternal health including a Maternal Health Report Card of hospitals across the state. New Jersey Health Commissioner Shereef Elnahal indicated that this launch "represents the first data to action release through the New Jersey Maternal Data Center and the New Jersey Maternal Care Quality Collaborative," and that

⁹⁷² Lilo H. Stainton, "New Federal Funding to Boost NJ Maternal Health Improvements," *NJ Spotlight*, Sep. 25, 2019, https://www.njspotlight.com/2019/09/new-federal-funding-to-boost-nj-maternal-health-improvements/.

⁹⁷³ State of New Jersey Department of Health, "New Jersey Department of Health Launches Maternal Data Center with Release of Cesarean Birth Rates," May 28, 2019,

 $[\]frac{\text{https://www.nj.gov/health/news/2019/approved/20190528a.shtml\#:\sim:text=The\%20New\%20Jersey\%20Maternal\%20}{\text{Care\%20Quality\%20Collaborative\%20is\%20a\%20multidisciplinary,of\%20maternal\%20healthcare\%20in\%20NJ.\&text=The\%20data\%20released\%20today\%20is,System\%20and\%20birth\%20record\%20data.}$

⁹⁷⁴ Lilo H. Stainton, "New Federal Funding to Boost NJ Maternal Health Improvements," *NJ Spotlight*, Sep. 25, 2019, https://www.njspotlight.com/2019/09/new-federal-funding-to-boost-nj-maternal-health-improvements/; Health Resources and Services Administration, "Maternal Health Awardees FY19," https://mchb.hrsa.gov/maternal-health-awards.

⁹⁷⁵ *See supra* notes 971-972.

⁹⁷⁶ Lilo H. Stainton, "New Federal Funding to Boost NJ Maternal Health Improvements," *NJ Spotlight*, Sep. 25, 2019, https://www.njspotlight.com/2019/09/new-federal-funding-to-boost-nj-maternal-health-improvements/.

⁹⁷⁷ Ibid.

⁹⁷⁸ Ibid.

⁹⁷⁹ State of New Jersey Department of Health, "New Jersey Maternal Health Data Center," https://nj.gov/health/maternal/.

⁹⁸⁰ State of New Jersey Department of Health, "New Jersey Department of Health Launches Maternal Data Center with Release of Cesarean Birth Rates," May 28, 2019,

 $[\]frac{\text{https://www.nj.gov/health/news/2019/approved/20190528a.shtml\#:\sim:text=The\%20New\%20Jersey\%20Maternal\%20}{\text{Care\%20Quality\%20Collaborative\%20is\%20a\%20multidisciplinary.of\%20maternal\%20healthcare\%20in\%20NJ.\&text=The\%20data\%20released\%20today\%20is,System\%20and\%20birth\%20record\%20data.}$

"Nurture NJ and the Department are focused on sharing high quality data in order to drive improvements." 981

Also in 2019, New Jersey passed legislation that provides for the expansion of Medicaid for group prenatal care, which allows health centers to bill for these services. Specifically, group prenatal care that follows the CenteringPregnancy® model is covered by Medicaid, which provides for 10 prenatal visits of 90 to 120 minutes each. In passing the legislation, the New Jersey Legislature found that "CenteringPregnancy appears to provide even greater benefits to certain high-risk populations and can be effective at reducing health disparities related to race, ethnicity, and socio-economic status." Other bills have also been signed into law that provide Medicaid coverage for doula care; establish a perinatal episode of care pilot program in Medicaid; prohibit health benefits coverage for certain non-medically necessary early elective deliveries under Medicaid; and codify current practice regarding the completion of a Perinatal Risk Assessment form by certain Medicaid providers. Set

Additionally, bills have been introduced in New Jersey that would establish a maternal healthcare pilot program to evaluate a shared decision making tool; establish a maternity care public awareness campaign; require that hospital emergency departments ask women of childbearing age about recent pregnancy history; develop a set of standards for respectful care at birth and a public outreach initiative; and urge the CDC to develop a uniform data collection system on maternal mortality. 986 In addition, New Jersey was the first state to recognize January 23rd as Maternal Health Awareness Day in 2018. 987

982 2019 NJ A.R., No. 5021, https://www.njleg.state.nj.us/2018/Bills/A9999/5021_R2.PDF; "New Jersey Expands Medicaid Program to Include Coverage for CenteringPregnancy® to Improve Maternal Health and Birth Outcomes," *Globe Newswire*, Aug. 13, 2019, https://www.globenewswire.com/news-release/2019/08/13/1901222/0/en/New-Jersey-Expands-Medicaid-Program-to-Include-Coverage-for-CenteringPregnancy-to-Improve-Maternal-Health-and-Birth-Outcomes.html.

⁹⁸¹ Ibid.

^{983 &}quot;New Jersey Expands Medicaid Program to Include Coverage for CenteringPregnancy® to Improve Maternal Health and Birth Outcomes," *Globe Newswire*, Aug. 13, 2019, https://www.globenewswire.com/news-release/2019/08/13/1901222/0/en/New-Jersey-Expands-Medicaid-Program-to-Include-Coverage-for-CenteringPregnancy-to-Improve-Maternal-Health-and-Birth-Outcomes.html

⁹⁸⁴ N.J. P.L.1968, c.413.

⁹⁸⁵ State of New Jersey, Governor Phil Murphy, "Governor Murphy Signs Legislative Package to Combat New Jersey's Maternal and Infant Health Crisis," May 8, 2019, https://www.nj.gov/governor/news/news/562019/20190508a.shtml.

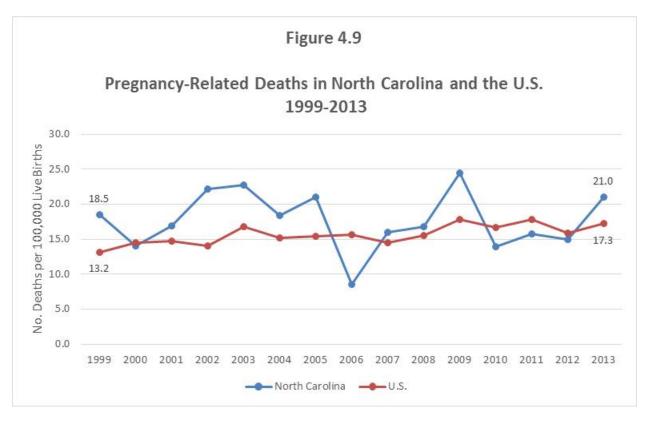
⁹⁸⁶ "Assembly Approves Maternal Health Bills that Address Disparities in Maternal Mortality Rates between African-American and White Women," *Insider NJ*, Mar. 25, 2019, https://www.insidernj.com/press-release/assembly-approves-maternal-health-bills-address-disparities-maternal-mortality-rates-african-american-white-women/.

⁹⁸⁷ State of New Jersey Department of Health, "January 23rd is Maternal Health Awareness Day in New Jersey," https://www.nj.gov/health/news/2018/approved/20180123a.shtml.

North Carolina

North Carolina has implemented a number of federally funded programs to address the racial disparities in maternal health. While some of the programs, outlined below, have seen some level of success, overall, North Carolina still struggles to ensure the safety and wellness of Black birthing people. In Raleigh-Durham, a city known internationally for exceptional medical care and resources, 40% of Black women do not receive prenatal care in their first trimester, and Black infants are 3.5x more likely to die than white babies in their first year of life ⁹⁸⁸.

Since 1999, the rate of pregnancy-related deaths in North Carolina has fluctuated, but ultimately has slightly increased. The rate of pregnancy-related deaths in North Carolina was 18.5 per 100,000 live births in 1999, as compared to 21.0 deaths per 100,000 live births in 2013. When examining state data from 1999-2013, the rate of pregnancy-related deaths in North Carolina was higher than the national rate in 1999 and 2013, however North Carolina's rate fell below the national average in 2006 but spiked to its highest rate in 2009, before decreasing below the national average again between 2010 and 2012 (see Figure 4.9).



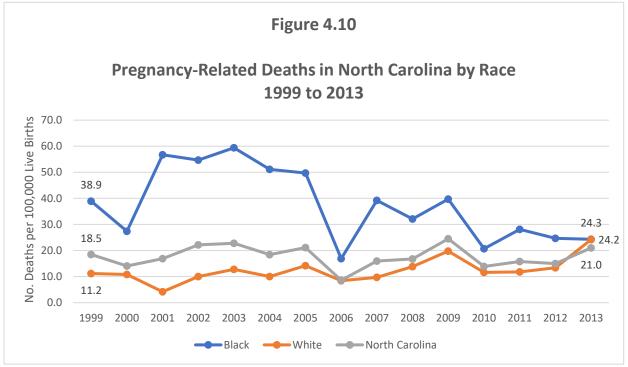
⁹⁸⁸ Triangle Black Maternal Wellness Collaborative, Public Comment.

⁹⁸⁹ North Carolina State Center for Health Statistics, "Figure 3: Trends in Pregnancy-related Death Rates, North Carolina Residents 1999-2013," https://schs.dph.ncdhhs.gov/data/maternal/Figure3_MaternalMortality2013.pdf; Centers for Disease Control and Prevention, "Pregnancy Mortality Surveillance System," https://www.cdc.gov/reproductivehealth/maternal-mortality/pregnancy-mortality-surveillance-system.htm.

Source: North Carolina State Center for Health Statistics, "Figure 3: Trends in Pregnancy-related Death Rates, North Carolina Residents 1999-2013," https://schs.dph.ncdhhs.gov/data/maternal/Figure3_MaternalMortality2013.pdf; Centers for Disease Control and Prevention, "Pregnancy Mortality Surveillance System," https://www.cdc.gov/reproductivehealth/maternal-mortality/pregnancy-mortality-surveillance-system.htm.

*North Carolina data include pregnancy-related deaths of women aged 10-50 within a year of childbirth, in line with the CDC definition of pregnancy-related death. Pregnancy Mortality Surveillance System national data was used as a comparator, as it utilizes the same definition.

From 1999 through 2013, North Carolina saw numbers of pregnancy-related deaths among Black women decline, however the rate of pregnancy-related deaths among Black women remained higher than the state's overall rate between 1999 and 2013 (see Figure 4.10).



Source: North Carolina State Center for Health Statistics, "Figure 4. Non-Hispanic White and Non-Hispanic African-American Pregnancy-related Mortality Rates by Year North Carolina Residents 1999-2013," https://schs.dph.ncdhhs.gov/data/maternal/Figure4_MaternalMortality2013.pdf; North Carolina State Center for Health Statistics, "Figure 3: Trends in Pregnancy-related Death Rates, North Carolina Residents 1999-2013," https://schs.dph.ncdhhs.gov/data/maternal/Figure3_MaternalMortality2013.pdf.

In 1999, the rate of pregnancy-related deaths in North Carolina for Black women was 38.9 deaths per 100,000 live births as compared to 11.2 deaths per 100,000 live births for White women, which was about 3.5 times higher for Black women than for White women. Over time, the rate of pregnancy-related deaths for Black women declined significantly, measuring at 24.3 deaths per 100,000 live births in 2013, which was slightly higher than the state average of 21.0 deaths per 100,000 live births (see Figure 4.10). However, the rate of pregnancy-related deaths for White women increased from 1999-2013, similar to state trends, which contributed to the

closing of the disparities gap by 2013, where the rate of pregnancy-related deaths for White women was 24.2 deaths per 100,000 live births, as compared to 24.3 deaths per 100,000 live births for Black women. 990 But overall, the rate of maternal mortalities is higher for all races in North Carolina compared to the national average, and there are still racial disparities with slightly better outcomes for White women in North Carolina. As discussed herein, researchers continue to caution the interpretation of these data on disparities for Black women in the state, stating that the dataset for studies has been too small and that North Carolina is far from achieving racial equity in maternal mortalities. 991 Shannon Dowler, Chief Medical Officer for North Carolina Medicaid, testified that the narrowing gap is not an indicator of improved care for Black women, it is rather an illustration of worsening outcomes for White women. 992 The uptick of pregnancy-related deaths among White women in North Carolina mirrors an uptick nationwide of White mortality since the late 1990s. 993 This rise is due to both rises in the number of deaths due to illicit drugs, alcohol, and suicide, as well as a slowdown in progress against mortality from heart disease and cancer. 994 However, the reasons for the increase in pregnancyrelated death rate of White women in North Carolina remain unknown, as Kathryn Menard, Upjohn Distinguished Professor of Maternal-Fetal Medicine at the University of North Carolina's School of Medicine states, "[w]e do not have a good explanation, but there is...a modest increase for white women."995

The vast majority of pregnancy-related deaths in North Carolina from 1999-2013 reportedly occurred among Black women and White women (49.9 percent and 40.2 percent, respectively). 996 North Carolina data only showed 19 pregnancy-related deaths (5.9 percent) occurred among Latinas; 8 pregnancy-related deaths (2.5 percent) occurred among Asian

⁹⁹⁰ North Carolina State Center for Health Statistics, "Figure 4. Non-Hispanic White and Non-Hispanic African-American Pregnancy-related Mortality Rates by Year North Carolina Residents 1999-2013," https://schs.dph.ncdhhs.gov/data/maternal/Figure4_MaternalMortality2013.pdf; North Carolina State Center for Health Statistics, "Figure 3: Trends in Pregnancy-related Death Rates, North Carolina Residents 1999-2013," https://schs.dph.ncdhhs.gov/data/maternal/Figure3_MaternalMortality2013.pdf.

⁹⁹¹ See infra notes 1035-1039.

⁹⁹² Shannon Dowler, Chief Medical Officer, North Carolina Medicaid, Written Statement for the *Racial Disparities* in *Maternal Health* briefing before the U.S. Commission on Civil Rights, Nov. 13, 2020, p. 2.

⁹⁹³ Anne Case and Angus Deaton, "Rising morbidity and mortality in midlife among white non-Hispanic Americans in the 21st century," *PNAS*, Vol. 112, No. 49 (Nov. 2015), https://www.pnas.org/content/112/49/15078; Anne Case and Angus Deaton, "Mortality and Morbidity in the 21st Century," *Brookings Papers on Economic Activity*, Spring 2017, https://www.brookings.edu/wp-content/uploads/2017/08/casetextsp17bpea.pdf.

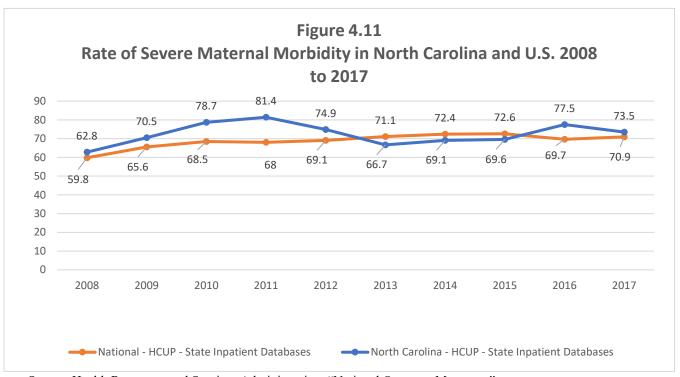
⁹⁹⁴ Anne Case and Angus Deaton, "Mortality and Morbidity in the 21st Century," *Brookings Papers on Economic Activity*, Spring 2017, https://www.brookings.edu/wp-content/uploads/2017/08/casetextsp17bpea.pdf (this paper does not differentiate between deaths due to illicit drugs versus prescription drugs).

⁹⁹⁵ Allison Winter, "More Black mothers are dying. This N.C. congresswoman wants it to stop." *NC Policy Watch*, May 28, 2019, http://www.ncpolicywatch.com/2019/05/28/more-black-mothers-are-dying-this-n-c-congresswoman-wants-it-to-stop/.

⁹⁹⁶ North Carolina State Center for Health Statistics, "Table 3. Pregnancy-related Mortality by Race and Ethnicity, North Carolina Residents 1999-2013," https://schs.dph.ncdhhs.gov/data/maternal/Table3 MMReport2013.pdf.

women; and 5 pregnancy-related deaths (1.5 percent) occurred among Native American women. 997

According to the Health Resources and Services Administration National Outcomes Measures data, North Carolina's severe maternal morbidity rates hovered above national rates from 2008 to 2017, with an exception for years 2013 through 2015 (see Figure 4.11). 998



Source: Health Resources and Services Administration, "National Outcome Measures," https://mchb.tvisdata.hrsa.gov/PrioritiesAndMeasures/NationalOutcomeMeasures. Chart adapted by the Commission.

North Carolina has been reviewing maternal deaths since the 1940s, starting with a public-private partnership between the North Carolina Division of Public Health and the Wake Forest School of Medicine.⁹⁹⁹ In 1988, the North Carolina State Center for Health Statistics, a division of North Carolina Department of Health and Human Services, was one of the pioneers in establishing an enhanced population-based surveillance system that links death files with live

⁹⁹⁷ Ibid. Pregnancy-related maternal mortality rates for Native American women, Asian women, Latina women, and women of other races were not individually reported for 1999-2013, thus were not included in the chart above.

⁹⁹⁸ Health Resources and Services Administration, "National Outcome Measures," https://mchb.tvisdata.hrsa.gov/PrioritiesAndMeasures/NationalOutcomeMeasures. Chart adapted by the Commission.

⁹⁹⁹ Association of State and Territorial Health Offices, "North Carolina Leverages a Long History of Maternal Mortality Review," p. 1, https://www.astho.org/Maternal-and-Child-Health/Documents/North-Carolina-Leverages-a-Long-History-of-Maternal-Mortality-Review/10-30-18/.

births and fetal deaths. 1000 This linkage model resulted in a 30 percent increase in successfully identifying the drivers of pregnancy-related deaths in North Carolina. 1001 The State Center for Health Statistics identifies pregnancy-related deaths among women aged 10-50 who died during pregnancy or within one year after childbirth or delivery annually, 1002 and the North Carolina Maternal Mortality Review Committee reviews these identified deaths tri-annually. 1003

In 2019, the North Carolina Maternal Mortality Review Committee was awarded funds through the federal ERASE-MM program. North Carolina allocated \$17.4 million in federal Title V Maternal and Child Health Services funds in its FY 2020 budget to maternal and child health programs, and spent \$14.6 million on these programs in FY 2018. North Carolina's Maternal Mortality Review Committee is mainly supported by Title V funds.

In 2005, North Carolina issued a study that found 40 percent of pregnancy-related deaths reviewed by the state Maternal Mortality Review Committee were preventable. The study found that almost all pregnancy-related deaths due to hemorrhage or chronic disease were preventable, and cited improved quality of medical care as the most important factor in preventing these deaths. Forty-six percent of maternal deaths among Black women in North Carolina were reported to be preventable, as compared to 33 percent of deaths among White women in the state. 1010

¹⁰⁰⁰ Ibid.

¹⁰⁰¹ Ibid.

¹⁰⁰² North Carolina State Center for Health Statistics, "Trends in Maternal Mortality Statistics," https://schs.dph.ncdhhs.gov/data/maternal/.

¹⁰⁰³ Review to Action, "Brief Overview of State MMR or PAMR: North Carolina," https://reviewtoaction.org/content/north-carolina.

¹⁰⁰⁴ Association of Maternal & Child Health Programs, "AMCHP Congratulates States that Win New Federal Grants to Support Maternal Mortality Reviews," Aug. 16, 2019,

http://www.amchp.org/AboutAMCHP/NewsRoom/Documents/MM%20Review%20Federal%20Grants.pdf.

¹⁰⁰⁵ Association of Maternal & Child Health Programs, "North Carolina Maternal and Child Health Block Grant 2020," http://www.amchp.org/Policy-

Advocacy/MCHAdvocacy/2020%20State%20Profiles/North%20Carolina%202020%20FINAL.pdf.

¹⁰⁰⁶ Health Resources and Services Administration, "Title V MCH Block Grant Funding: State Information," https://mchb.tvisdata.hrsa.gov/State/Detail/NC.

¹⁰⁰⁷ Maternal and Child Health Services Title V Block Grant, North Carolina FY 2020 Application/FY2018 Annual Report, 2019, p. 84, https://publichealth.nc.gov/wch/doc/NC-TitleV-PrintVersion-FY20-092619.pdf.

¹⁰⁰⁸ Berg, Cynthia J. MD, MPH, Harper, Margaret A. MD, MS, Atkinson, Samuel M. MD3, Bell, Elizabeth A. MD, Brown, Haywood L. MD, Hage, Marvin L. MD, Mitra, Avick G. MD, Moise, Kenneth J. Jr MD, Callaghan, William M. MD, MPH, "Preventability of Pregnancy-Related Deaths: Results of a State-Wide Review," *Obstetrics and Gynecology*, Vol. 106, No. 6 (December 2005): 1228-1234,

https://journals.lww.com/greenjournal/pages/articleviewer.aspx?year=2005&issue=12000&article=00004&type=Fulltext.

¹⁰⁰⁹ Ibid.

¹⁰¹⁰ Ibid.

Based on this study, the North Carolina Maternal Mortality Review Committee developed a definition of preventability as when "the death may have been averted by one or more changes in the health care system related to clinical care, facility infrastructure, public health infrastructure and/or patient factors." The Maternal Mortality Review Committee also categorized these preventable deaths into 4 different categories that encompass underlying factors or actions that could potentially have prevented a pregnancy-related death: 1) preconception care and counseling, 2) patient actions, 3) systemic factors, and 4) quality of care. ¹⁰¹²

In 2008, North Carolina developed its Preconception Health Strategic Plan, which was updated in 2014 and expected to be in place until 2019. The original 2008 plan highlighted 6 strategic areas of focus:

- Pregnancy intendedness
- Obesity and related conditions
- Substance abuse
- Mental health
- Collaborative research on preconception-focused topics
- Policy development and access to care 1014

The more recent supplement noted that many of these priority areas have been implemented in North Carolina, but it indicated the need to broaden these priorities moving forward. Thus, two theoretical models were included to address 1) the social determinants of health and 2) life course perspective. Life course perspective theory aims to "positively affect factors which influence the 'programming' of an individual's future health and development," such as exposure in utero; a mother's health before conception; the impact of multiple stressors; risk behaviors such as smoking, food insecurity, or domestic violence; economic security; or family nurturing. 1017

North Carolina has also issued a Perinatal Health Strategic Plan 2016-2020, which aims to:

¹⁰¹³ North Carolina Department of Health and Human Services, *North Carolina Preconception Health Strategic Plan: Supplement 2014-2019*, p. 1,

 $\frac{http://www.everywomansoutheast.org/sites/default/files/North\%20Carolina\%20Preconception\%20Health\%20Strategic\%20Plan\%20Supplement\%202014-2019.pdf.$

¹⁰¹⁵ Ibid.

¹⁰¹⁶ Ibid.

¹⁰¹⁷ Ibid.

¹⁰¹¹ Association of State and Territorial Health Offices, "North Carolina Leverages a Long History of Maternal Mortality Review," p. 1, https://www.astho.org/Maternal-and-Child-Health/Documents/North-Carolina-Leverages-a-Long-History-of-Maternal-Mortality-Review/10-30-18/.

¹⁰¹² Ibid.

¹⁰¹⁴ Ibid.

- Improve healthcare, including providing inter-conception care to women with prior adverse pregnancy outcomes, increased access to preconception care, improved quality of prenatal care, and expanded access to healthcare;
- Strengthen families and communities, including the coordination and integration of family support services, supporting the coordination and cooperation to promote reproductive health within communities, and investing in community building and urban renewal; and,
- Addressing social and economic inequalities, including closing the education gap, reducing poverty among families, supporting working mothers and families, and undoing racism. 1018

In September 2019, North Carolina Department of Health and Human Services and the University of North Carolina at Chapel Hill received a total of \$10 million from the federal Health Resources and Services Administration in Maternal and Child Health grant funds to be distributed over five years to support its efforts to address maternal mortality and severe maternal morbidity. North Carolina is one of nine recipients of this funding, and the federal funds will support its Perinatal Health Strategic Plan and other efforts. The University of North Carolina at Chapel Hill was also awarded \$2.6 million a year in funding for five years through the Supporting Maternal Health Innovation program to support the North Carolina Department of Health and Human Services' efforts. 1022

In 2011, North Carolina launched a program called Pregnancy Medical Home, developed by Community Care of North Carolina, which aims to improve the quality of perinatal care among Medicaid customers. ¹⁰²³ The program provides increased access to comprehensive care for

¹⁰¹⁸ North Carolina Department of Health and Human Services, *North Carolina's Perinatal Health Strategic Plan:* 2016-2020, p. 2, https://whb.ncpublichealth.com/docs/PerinatalHealthStrategicPlan-WEB.pdf.

¹⁰¹⁹ North Carolina Department of Health and Human Services, "North Carolina Receives Maternal Health Innovation Grant to Strengthen Perinatal Care," Sep. 20, 2019, https://www.ncdhhs.gov/news/press-releases/north-carolina-receives-maternal-health-innovation-grant-strengthen-perinatal; Health Resources and Services Administration, "Maternal Health Awardees FY19," https://mchb.hrsa.gov/maternal-child-health-initiatives/fy19-maternal-health-awards.

¹⁰²⁰ The other jurisdictions are in Phoenix, AZ; Des Moines, IA; Chicago, IL; Baltimore, MD; Helena, VT; Trenton, NJ; Columbus, OH; and Oklahoma City, OK. Health Resources and Services Administration, "Maternal Health Awardees FY19," https://mchb.hrsa.gov/maternal-child-health-initiatives/fy19-maternal-health-awards.

¹⁰²¹ North Carolina Department of Health and Human Services, "North Carolina Receives Maternal Health Innovation Grant to Strengthen Perinatal Care," Sep. 20, 2019, https://www.ncdhhs.gov/news/press-releases/north-carolina-receives-maternal-health-innovation-grant-strengthen-perinatal; Health Resources and Services Administration, "Maternal Health Awardees FY19," https://mchb.hrsa.gov/maternal-child-health-initiatives/fy19-maternal-health-awards.

¹⁰²² North Carolina Department of Health and Human Services, "North Carolina Receives Maternal Health Innovation Grant to Strengthen Perinatal Care," Sep. 20, 2019, https://www.ncdhhs.gov/news/press-releases/north-carolina-receives-maternal-health-innovation-grant-strengthen-perinatal; Health Resources and Services Administration, "Maternal Health Awardees FY19," https://mchb.hrsa.gov/maternal-child-health-initiatives/fy19-maternal-health-awards.

¹⁰²³ North Carolina Department of Health and Human Services, "Pregnancy Medical Home," https://medicaid.ncdhhs.gov/providers/programs-services/family-planning-and-maternity/pregnancy-medical-home.

women receiving Medicaid, promoting evidence-based, quality maternity care across the state for 95 percent of prenatal care providers that serve the Medicaid population. 1024 Pregnancy Medical Home has six core components:

- Statewide provider network. PMH has over 450 practices and 1,000 individual providers in 95 percent of counties in North Carolina, which represents 95 percent of practices that serve pregnant women who receive Medicaid.
- Standardized risk screening. Nearly 80 percent of PMH patients receive a standardized risk screening, typically administered at the first prenatal visit, which captures medical, obstetric, and psychosocial risk factors associated with preterm birth.
- Community-based care management. Care Management for High-Risk Pregnancies (CMHRP) is a care coordination model used for Medicaid patients at risk for preterm birth identified during the screening process. CMRHP services are administered by county health department nurses and social workers, who partner with prenatal care providers.
- Local clinical leadership. Statewide PMH clinical leadership teams ("OB Teams") work to provide clinical leadership, provider education, technical assistance, and practice-level analytics by disseminating state care pathways that establish evidence-based best practices.
- Care pathways. This program promotes evidence-based clinical best practices to standardize care and set performance expectations across all PMH settings. Care pathways are available online for download on a variety of topics, including hypertension, obesity, tobacco use, substance use, and multiple gestation, and specific components of care, such as induction of labor, progesterone treatment, and postpartum
- Informatics. The program reports quarterly metrics using Medicaid claims, birth certificates, and risk screening data. 1025

According to the Institute of Health Improvement, North Carolina has been a leader in the development of this maternal home model. 1026 Early data has shown that the Pregnancy Medical Home program, which primarily focuses on the prevention of preterm birth, has seen some success. 1027 Pregnancy Medical Home providers have been generally receptive to the care pathways and have been on board with the clearly-defined guidance provided in them. 1028 According to Dr. Elizabeth Howell's article published by the National Institutes of Health, some

1026 Jeffrey Rakover, "The Maternity Medical Home: The Chassis for a More Holistic Model of Pregnancy Care?" Institute for Healthcare Improvement, March 22, 2016,

http://www.ihi.org/communities/blogs/ layouts/15/ihi/community/blog/itemview.aspx?List=7d1126ec-8f63-4a3b-9926-c44ea3036813&ID=222.

¹⁰²⁷ Ibid.

1028 Kate Berrien, Arthur Ollendorff, M. Kathryn Menard, "Pregnancy Medical Home Care Pathways Improve Quality of Perinatal Care and Birth Outcomes," North Carolina Medical Journal, Vol. 76, No. 4 (Sep. 11, 2015): 265, https://www.ncmedicaljournal.com/content/ncm/76/4/263.full.pdf.

¹⁰²⁴ Community Care of North Carolina, "Pregnancy Medical Home," https://www.communitycarenc.org/what-wedo/clinical-programs/pregnancy-medical-home.

¹⁰²⁵ Ibid.

researchers believe this program is a promising way to reduce racial disparities in maternal mortalities 1029 and Pew published an article stating that it may become a model for other states. 1030 Currently Missouri, Oregon, and Wisconsin have implemented similar programs. 1031 Some believe this model has the potential of shifting maternal healthcare towards "a holistic, patient-centered approach to pregnancy care." 1032

The Pregnancy Medical Home program received media attention in 2017 discussing that the declining maternal mortality rate for Black women was in part attributed to the implementation of this program, as Black women are disproportionately represented in North Carolina's Medicaid population, thus better able to benefit from Pregnancy Medical Home. ¹⁰³³ In FY2019, the Pregnancy Medical Home program screened almost 80 percent of pregnant women in the North Carolina Medicaid population, and since 2015, women receiving care from a Pregnancy Medical Home had a 3 percent increase in the timeliness to prenatal care and there has been a 10 percent increase in the postpartum visit rate. ¹⁰³⁴ However, other research has shown that North Carolina is far from achieving racial equity in maternal mortality. ¹⁰³⁵

A recent journal article noted that recent news on this topic "highlights the pitfalls and interpretative error associated with small numbers," and noted that "[w]hen aggregate data are examined, the disparity in maternal deaths for Black women compared to White women persists." The journal article also noted that "[in] North Carolina, many maternal deaths underscore the importance of programs like care management services and "fourth trimester" efforts to continue the trajectory of maternal death reduction and the elimination of the Black-White disparity in maternal mortality." When looking at pregnancy-related deaths from 2000 to 2015 using 4-year aggregate pregnancy-related death ratios, it appears that the racial gap

¹⁰²⁹ Elizabeth A. Howell, "Reducing Disparities in Severe Maternal Morbidity and Mortality," *Clin Obstet Gynecol*, Vol. 61, No. 2 (June 2018): 387-399, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5915910/.

¹⁰³⁰ Michael Ollove, "New Maternal Mortality Strategy Relies on 'Medical Homes," *Pew*, Dec. 5, 2017, https://www.pewtrusts.org/en/research-and-analysis/blogs/stateline/2017/12/05/new-maternal-mortality-strategy-relies-on-medical-homes.

¹⁰³¹ Amber Bellazaire and Erik Skinner, *Preventing Infant and Maternal Mortality: State Policy Options*, National Conference of State Legislatures, April 2019, p. 12, https://www.ncsl.org/Portals/1/Documents/Health/Infant-Maternal-Mortality_v05_web.pdf.

¹⁰³² Ibid.

¹⁰³³ Julia Belluz, "Black moms die in childbirth 3 times as often as white moms. Except in North Carolina." *Vox*, Jul. 3, 2017, https://www.vox.com/health-care/2017/7/3/15886892/black-white-moms-die-childbirth-north-carolina-less.

¹⁰³⁴ Zero to Three, "North Carolina Pregnancy Medical Homes," Sept. 20, 2016 (Updated Mar. 2020), https://www.zerotothree.org/resources/866-north-carolina-pregnancy-medical-

 $[\]underline{homes\#:} \sim : text = In\%20FY2019\%2C\%20 the\%20PMH\%20 program, in\%20 the\%20 postpartum\%20 visit\%20 rate...$

¹⁰³⁵ Maria J. Small, Belinda Pettiford, Tara Owens Shuler, Kathleen Jones-Vessey, "Addressing Maternal Deaths in North Carolina: Striving to Reach Zero," *North Carolina Medical Journal*, Vol. 81, No. 1 (Jan. 6, 2020): 55, https://www.ncmedicaljournal.com/content/ncm/81/1/55.full.pdf.

¹⁰³⁶ Ibid.

¹⁰³⁷ Ibid.

between Black and White women has narrowed, but disparities still exist. ¹⁰³⁸ These data show that White women have significantly lower pregnancy-related mortality rates than Black women throughout that time, and while the rates for Black women have declined steadily, Black women are still 1.6 times more likely to experience a pregnancy-related death than White women in North Carolina. ¹⁰³⁹

North Carolina is involved with other federally funded initiatives to address maternal mortality and reduce racial disparities in the state. The Health Resources and Services Administration's Maternal, Infant, and Early Childhood.

Home Visiting Program¹⁰⁴⁰ supports North Carolina's Home Visiting Program,¹⁰⁴¹ and served 821 participants, 402 households in 2019, providing a total of 6,174 home visits that year.¹⁰⁴² North Carolina utilizes two evidence-based models for home visiting: Healthy Families America and Nurse-Family Partnership.¹⁰⁴³ In FY 2019, North Carolina received \$3.5 million in funds for its Home Visiting Program.¹⁰⁴⁴ In 2019, North Carolina received three awards through the Health Resources and Services Administration's Healthy Start Program for a total of \$3 million in funding.¹⁰⁴⁵ In 2019, the Health Resources and Services Administration funded 39 Health Centers in North Carolina that served over 610,000 patients, a majority of whom were low-income, women, and people of color.¹⁰⁴⁶ In addition, through the Office of Minority Health's State Partnership Program to Improve Minority Health, the North Carolina Department of Health and Human Services received a grant for \$140,000 for 2010-2013.¹⁰⁴⁷ This award funded a project that sought to address disparities in chronic disease burden among people of color, working with community based organizations and Native American tribes to engage in effective

¹⁰⁴⁰ See supra notes 520-548, for a description of the federally funded program.

https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=2&lvlid=51#:~:text=The%20purpose%20of%20the%20State, %2C%20asthma%2C%20carcer%2C%20cardiovascular%20disease; Office of Minority Health, "North Carolina Department of Health and Human Services - State Partnership Program," https://minorityhealth.hhs.gov/omh/content.aspx?ID=9159&lvl=2&lvlID=51.

¹⁰³⁸ Ibid., 60.

¹⁰³⁹ Ibid.

¹⁰⁴¹ North Carolina Department of Health and Human Services, "WCH: Maternal, Infant, and Early Childhood Home Visiting Program," https://publichealth.nc.gov/wch/aboutus/ebhv.htm.

¹⁰⁴² Health Resources and Services Administration, "North Carolina's MIECHV Program FY 2019,"
https://mchb.hrsa.gov/sites/default/files/mchb/MaternalChildHealthInitiatives/HomeVisiting/pdf/nc.pdf.

¹⁰⁴³ Ibid; North Carolina Department of Health and Human Services, "WCH: Maternal, Infant, and Early Childhood Home Visiting Program," https://publichealth.nc.gov/wch/aboutus/ebhv.htm.

¹⁰⁴⁴ Health Resources and Services Administration, "Maternal, Infant, and Early Childhood Home Visiting Awards FY19," https://mchb.hrsa.gov/maternal-child-health-initiatives/home-visiting/fy19-awards.

¹⁰⁴⁵ Health Resources and Services Administration, "2019 Healthy Start Grant Awards," https://mchb.hrsa.gov/maternal-child-health-initiatives/healthy-start/awards.

¹⁰⁴⁶ Health Resources and Services Administration, "2018 North Carolina Health Center Data," https://bphc.hrsa.gov/uds/datacenter.aspx?year=2018&state=NC.

¹⁰⁴⁷ Office of Minority Health, "State Partnership Grants,"

interventions. ¹⁰⁴⁸ In addition, the Office of Minority Health awarded the North Carolina Department of Health and Human Services \$150,000 for 2013 to 2015 to help community-based organizations and local health departments build their capacity to provide culturally and linguistically competent services and support evidence-based health and disease promotion interventions to eliminate health disparities. ¹⁰⁴⁹

North Carolina also has a Perinatal Quality Collaborative that leads the federally funded the Alliance for Innovation on Maternal Health program in the state. North Carolina has adopted two the Alliance for Innovation on Maternal Health safety bundles on the Safe Reduction of Primary Care Cesarean Birth and Obstetric Hemorrhage. NCCARE360, a statewide coordinated care network that connects individuals with identified needs to community resources, is a result of a public-private partnership between the North Carolina Department of Health and Human Services and the Foundation for Health Leadership and Innovation. The network launched in 2019, and by June 2020, the platform was available in all 100 counties in the state. The Commission received testimony that this tool's ability to link resources in every county of the state is working to "close care gaps."

North Carolina has not adopted Medicaid expansion. ¹⁰⁵⁶ However, for pregnant women who are eligible under North Carolina's Medicaid program (NC Medicaid), the state has offered access to maternal support services through the Baby Love Program. ¹⁰⁵⁷ This program is offered to pregnant women during pregnancy and postpartum up to 60 days after the pregnancy ends. ¹⁰⁵⁸

 $^{^{1048}}$ Office of Minority Health, "North Carolina Department of Health and Human Services - State Partnership Program," $\frac{\text{https://minorityhealth.hhs.gov/omh/content.aspx?ID=9159\&lvl=2\&lvlID=51.}$

¹⁰⁴⁹ Office of Minority Health, "State Partnership Grants,"

https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=2&lvlid=51#:~:text=The%20purpose%20of%20the%20State, %2C%20asthma%2C%20carcer%2C%20cardiovascular%20disease; Office of Minority Health, "North Carolina Department of Health and Human Services, Division of Public Health, https://minorityhealth.hhs.gov/omh/content.aspx?ID=10159&lvl=2&lvlid=51.

¹⁰⁵⁰ North Carolina Perinatal Quality Collaborative, "Initiatives," https://www.pgcnc.org/initiatives.

¹⁰⁵¹ North Carolina Perinatal Quality Collaborative, "AIM - Safe Reduction of Primary Cesarean Birth," https://www.pqcnc.org/node/13902.

¹⁰⁵² North Carolina Perinatal Quality Collaborative, "AIM - Obstetric Hemorrhage," https://www.ncdhhs.gov/about/department-initiatives/healthy-opportunities/nccare360.

¹⁰⁵³ North Carolina Department of Health and Human Services, "About NCCARE360," https://nccare360.org/about/ (last accessed Apr. 6, 2021).

¹⁰⁵⁴ NCCARE360, "North Carolina Creates Nation's First Statewide Infrastructure Connecting Healthcare and Human Services," Jun. 22, 2020, https://nccare360.org/nccare360-statewide-announcement/.

¹⁰⁵⁵ Dowler Statement, p. 4.

¹⁰⁵⁶ Kaiser Family Foundation, "Status of State Medicaid Expansion Decisions: Interactive Map," Apr. 27, 2020, https://www.kff.org/medicaid/issue-brief/status-of-state-medicaid-expansion-decisions-interactive-map/.

¹⁰⁵⁷ North Carolina Department of Health and Human Services, "Maternal Support Services (Baby Love Program)," https://medicaid.ncdhhs.gov/beneficiaries/get-started/find-programs-and-services/maternal-support-services-baby-love-program.

¹⁰⁵⁸ Ibid.

This program offers childbirth education to help women understand the changes during pregnancy, prepare for labor and delivery, and understand the postpartum period; health and behavior intervention with counseling and emotional support; and medical home visits conducted by qualified staff and include referrals to other programs for nutrition/dietary education, dental care, and counseling. Medicaid recipients also have access to the Pregnancy Medical Home program, even though Pregnancy Medical Home is not exclusively for customers of Medicaid. Medicaid. Medicaid.

North Carolina was one of 12 states to participate in the Every Mother Initiative between 2013 and 2016. ¹⁰⁶¹ This initiative, supported by Merck for Mothers and launched by the Association of Maternal & Child Health Programs, was designed to strengthen the capacity of these states—which represent one-third of the nation's population—to better understand why women are dying from pregnancy complications in order to implement more effective solutions. ¹⁰⁶² The Maternal Mortality Review Committees in each of these states identified underlying causes of death (i.e., hypertension, hemorrhage) and examined emerging causes of death (i.e., mental health issues, substance use), and used their findings to craft solutions for health providers, women, and community stakeholders who aim to save lives. ¹⁰⁶³

North Carolina's Maternal Mortality Review Committee found that a disproportionate number of maternal deaths were caused by complications from cardiovascular disease and hypertension, and women were generally unaware of how their heart health may affect pregnancy. ¹⁰⁶⁴ From this, North Carolina developed the Show Your Heart Some Love marketing campaign, through a partnership with other state-wide programs in order to prevent chronic disease and improve preconception health, which reached 8,400 women in the state. ¹⁰⁶⁵ In addition, the Maternal Mortality Review Committee collaborated with Community Care of North Carolina to implement a pilot project that identifies women of reproductive age with risk factors for maternal mortality or severe maternal morbidity by analyzing Medicaid claims data, and works to develop targeted strategies to improve primary care and preconception health for these women. ¹⁰⁶⁶

¹⁰⁵⁹ Ibid.

¹⁰⁶⁰ North Carolina Department of Health and Human Services, "Pregnancy Medical Home," https://medicaid.ncdhhs.gov/providers/programs-services/family-planning-and-maternity/pregnancy-medical-home.

¹⁰⁶¹ The 12 states include: Colorado, Delaware, Florida, Georgia, Illinois, Louisiana, Missouri, New York, North Carolina, Ohio, Oklahoma and Utah. Merck for Mothers, *Making Pregnancy and Childbirth Safer in the U.S.: Insights from 12 States*, p. 2, https://www.merckformothers.com/docs/States-Insights.pdf.

¹⁰⁶² Ibid.

¹⁰⁶³ Ibid.

¹⁰⁶⁴ Ibid., 5.

¹⁰⁶⁵ Ibid.

¹⁰⁶⁶ Ibid.

In May 2020, North Carolina legislators introduced House Bill 1141. 1067 This bill would require the North Carolina Department of Health and Human Services, the Division of Public Health, and the Office of Minority Health and Health Disparities to study whether implementation of an evidence-based implicit bias program for health care providers would improve maternal health and reduce infant mortality for Black women in North Carolina and would appropriate funds for this study. 1068

Summary

In sum, these three states have received millions of dollars in federal funding to reduce maternal mortalities and for programs designed to reduce racial disparities in maternal mortalities. All three states have continuing racial disparities but have also decreased the severity of disparities between Black and White mothers.

In Georgia, pregnancy-related deaths from 2009 through 2011 remained higher than national averages, ¹⁰⁶⁹ and severe maternal morbidity trended higher in the state than the national average from 2008 through 2017, with the exception of 2015. ¹⁰⁷⁰ From 2010 through 2012, the pregnancy-related mortality ratio was 49.5 per 100,000 for Black women compared with 14.3 per 100,000 for White women. Black women accounted for 131 (50%) of the 262 pregnancy-associated deaths. ¹⁰⁷¹ White women accounted for 111 (42.4%) deaths and 20 (7.6%) deaths were in women of Other races. ¹⁰⁷² Of the 262 pregnancy-associated deaths, 105 were pregnancy-related. Black women accounted for almost 61.9 percent of pregnancy-related deaths during that period. ¹⁰⁷³ 49 percent of pregnancy-related deaths in 2014 occurred among Black women, 28 percent among White women, and 12 percent among Latinas. Georgia's MMR for pregnancy-related deaths from 2012-2014 was 26 per 100,000 births. Racial disparity in pregnancy-related deaths among Black and White women in Georgia has persisted. ¹⁰⁷⁴

In New Jersey, the pregnancy-related death rate decreased from 2009 through 2013 and trended below national averages from 2010 through 2013, 1075 although severe maternal morbidity

¹⁰⁶⁷ Study Implicit Bias Program/Maternal Health, NC H.B. 1141, (May 14, 2020), https://www.ncleg.gov/Sessions/2019/Bills/House/PDF/H1141v1.pdf.

¹⁰⁶⁸ Id.

¹⁰⁶⁹ See supra, Figure 4.1

¹⁰⁷⁰ See supra, Figure 4.2

¹⁰⁷¹ Platner, M., Loucks, T. L., Lindsay, M. K., & Ellis, J. E., Pregnancy-Associated Deaths in Rural, Nonrural, and Metropolitan Areas of Georgia. Obstetrics & Gynecology, July 2016. 128(1): p. 113-120. Accessed Pregnancy-Associated Deaths in Rural, Nonrural, and Metropol...: Obstetrics & Gynecology (lww.com)

¹⁰⁷² Ibid.

¹⁰⁷³ Ibid.

^{1074 2019-}HMHBGA-State-of-the-State-Report-FINAL.pdf

¹⁰⁷⁵ See supra, Figure 4.3.

increased from 2011 through 2017, along with the national averages. ¹⁰⁷⁶ The pregnancy-related death rate for Black women in New Jersey has decreased slightly over time, from 48.8 deaths per 100,000 live births in 2009 to 46.5 deaths per 100,000 live births in 2013. ¹⁰⁷⁷ However, the racial disparity in pregnancy-related deaths among Black and White women in New Jersey has persisted, and women of color accounted for almost 60 percent of pregnancy-related deaths during that period. ¹⁰⁷⁸

Finally, the rate of pregnancy-related deaths in North Carolina has fluctuated over time, but ultimately has slightly increased: from 18.5 per 100,000 live births in 1999 to 21.0 deaths per 100,000 live births in 2013. 1079 From 2013 through 2017, the state saw numbers of pregnancy-related deaths among Black women decline, virtually closing the disparities gap among Black and White women; however, questions remain regarding the undercounting of these data. 1080

¹⁰⁷⁶ See supra, Figure 4.4.

¹⁰⁷⁷ See supra, Figure 4.5.

¹⁰⁷⁸ *See supra* note 916.

¹⁰⁷⁹ See supra, Figure 4.6.

¹⁰⁸⁰ See supra, Figure 4.7. Researchers continue to critique the disparities for Black women, stating that the dataset for studies has been too small and that North Carolina is far from achieving racial equity in maternal mortalities, see infra notes 1035-1039.

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STATEMENT OF COMMISSIONER DEBO P. ADEGBILE IN WHICH CHAIR NORMA V. CANTÚ AND COMMISSIONER DAVID KLADNEY CONCUR

Maternal mortality is recognized as a key indicator of the overall health metrics of a nation. The data and analysis reflected in the Commission's report Racial Disparities in Maternal Health reflects intolerable racial disparities and trendlines that require immediate and focused attention to redress. The U.S. has the highest maternal mortality rate among developed countries. As the USCCR Report notes: Within these unconscionably high rates, Black women experience the highest rates of nearly all of Centers for Disease Control and Prevention's (CDC) severe lifethreatening and long-term maternal complications. Black women in the U.S. are 3 to 4 times more likely to die from pregnancy-related complications than white women in the U.S., and Native American women are more than 2 times more likely to die from pregnancy-related complications than white women in the U.S. These disparities have become more severe over the last thirty years.

These dramatic discrepancies in the rates of survivorship point to the stark reality that in our nation, access to care, quality of care, and the experience of pregnant individuals is not equal. Research is now connecting the effects of racism to maternal health disparities, including maternal deaths. The research on these racial disparities in maternal health show that they cannot be adequately explained by socio-economic factors or pre-existing conditions. Provider bias, both explicit and implicit, has been shown to be a significant factor in the creation and prolonging of disparities in maternal health care, as well as healthcare at large – often without regard to socioeconomic status.

In response to the question of whether these maternal health disparities can be explained by socioeconomic status and access to healthcare, Jennifer Jacoby from the Center for Reproductive Rights explained that a national study of five specific pregnancy complications found that Black women were two to three times more likely to die from pregnancy complications than white women, even though Black and white women in the study had a similar prevalence of complications. ¹⁰⁸² She stated, in part:

Data suggests that maternal health disparities have complex causes and that, while socioeconomic inequality and unequal access to health care may contribute, racial

¹⁰⁸¹ Rikkanen, Gunja, FitzGerald, Zephyrin, "Maternal Mortality and Maternity Care in the United States Compared to 10 Other Developed Countries", *The Commonwealth Fund, Improving Health Care Quality*, November 2020 ¹⁰⁸² Myra J. Tucker, et al., The Black-White Disparity in Pregnancy-Related Mortality From 5 Conditions: Differences in Prevalence and Case-Fatality Rates, 97(2) AM. J. PUB. HEALTH 247, 248 (2007), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1781382/.

disparities in maternal mortality and morbidity cannot be explained by socioeconomic status and access to health care alone... Implicit bias and discrimination in maternity care can lead to the dismissal of serious health care concerns and overuse of procedures with increased complications and negative health outcomes, such as cesarean sections, for Black women ¹⁰⁸³. The most recent evidence base, including CDC research, indicates that racial disparities in maternal health is more complicated than access to health care access alone, and that structural racism in the US is a significant contributing factor. ¹⁰⁸⁴

Data, as well as the personal accounts of women of color, point to significant differences in the character and quality of care from providers experienced between white mothers and mothers of color, particularly Black women. ¹⁰⁸⁵ This includes administrative and other disparities, such as

How We Fail Black Patients in Pain, AM. ASS'N MED. COLLS. (Jan. 6, 2020), https://www.aamc.org/news-insights/how-we-fail-black-patients-pain; see also, Kelly M. Hoffman et al., Racial Bias in Pain Assessment and Treatment Recommendations, and False Beliefs About Biological Differences Between Blacks and Whites, PROC. 113(16) NAT'L ACAD. SCI. USA 4296 (2016).

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2219763/pdf/11606_2007_Article_258.pdf; Kelly M. Hoffman, Sophie Trawalter, Jordan R. Axt, M. Norman Oliver, "Racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between blacks and whites," *Proceedings of the National Academy of Sciences*, Vol. 113, No. 16 (Apr. 19, 2016): 1-6,

https://www.pnas.org/content/pnas/early/2016/03/30/1516047113.full.pdf; Erin Dehon PhD Nicole Weiss PhD Jonathan Jones MD Whitney Faulconer MD Elizabeth Hinton MSIS Sarah Sterling MD, "A Systematic Review of the Impact of Physician Implicit Racial Bias on Clinical Decision Making," Society for Academic Emergency Medicine, May 4, 2017, 895-904, https://onlinelibrary.wiley.com/doi/epdf/10.1111/acem.13214; William J. Hall, PhD, Mimi V. Chapman, PhD, Kent M. Lee, MS, Yesenia M. Merino, MPH, Tainayah W. Thomas, MPH, B. Keith Payne, PhD, Eugenia Eng, DrPH, Steven H. Day, MCP, and Tamera Coyne-Beasley, MD, "Implicit Racial/Ethnic Bias Among Health Care Professionals and Its Influence on Health Care Outcomes: A Systematic Review," American Journal of Public Health, Vol. 105, No. 12 (December 2015): e60-e-76,

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4638275/pdf/AJPH.2015.302903.pdf; Cox Statement, at 5; Howell Statement, at 2; Crear-Perry Statement, at 4; Jamila Taylor, Director of Health Care Reform and Senior Fellow, The Century Foundation, Testimony before the U.S. Senate Committee on Finance on Addressing America's Maternal Health Crisis, Apr. 3, 2020, https://tcf.org/content/commentary/testimony-recommendations-senate-addressing-americas-maternal-health-crisis/?session=1.

¹⁰⁸³ Samia Noursi et al., Using the Ecological Systems Theory to Understand Black/White Disparities in Maternal Morbidity and Mortality in the United States, J. RACIAL ETHN. HEALTH DISPARITIES (2020), online ahead of print at: https://pubmed.ncbi.nlm.nih.gov/32720294/.

lueprint, CTR. FOR AM. PROGRESS (May 2, 2019), https://www.americanprogress.org/issues/women/reports/2019/05/02/469186/eliminating-racial-disparities-maternal-infant-mortality/. Indeed, research shows that implicit bias in clinical settings influences patient pain management treatment and can often lead to a failure to appropriately treat Black patients' pain. Janice A. Sabin, How Wa Fail Black Patients in Pain AM. ASS'N MED. COLLS. (Jan. 6, 2020), https://www.appro.org/pays/

¹⁰⁸⁵ Institute of Medicine, "Unequal Treatment: What Healthcare Providers Need to Know About Racial and Ethnic Disparities in Health-Care," March 2002, pp. 10-12, https://www.nap.edu/resource/10260/disparities-providers.pdf; The American College of Obstetricians and Gynecologists, "Racial and Ethnic Disparities in Obstetrics and Gynecology," Committee Opinion No. 649, December 2015 (reaffirmed 2018), p. 2, https://www.acog.org/-/media/project/acog/acogorg/clinical/files/committee-opinion/articles/2015/12/racial-and-ethnic-disparities-in-obstetrics-and-gynecology.pdf; Alexander R. Green, MD, MPH, Dana R. Carney, PhD, Daniel J. Pallin, MD, MPH, Long H. Ngo, PhD, Kristal L. Raymond, MPH, Lisa I. Iezzoni, MD, MSc, and Mahzarin R. Banaji, PhD, "Implicit Bias among Physicians and its Prediction of Thrombolysis Decisions for Black and White Patients," *Journal of General Internal Medicine*, Vol. 22, No. 9 (September 2007): 1231-1238,

longer wait times and decreased communication with the patients of color and their families. This also includes inconsistencies in treatments and recommendations to patients 1086 (i.e. disproportionate overuse of the cesarean section, tendency on the part of maternity care providers to forgo centering patient preference and advocate for a specific treatments). Implicit bias also manifests itself in forms such as a lack of attention to the cultural and linguistic differences between patients and providers; and in approaches to addressing systemic racism in healthcare itself (i.e. attributing health disparities to intrinsic, individual characteristics of patients of color instead of focusing on eliminating bias). 1087

With data indicating that over 60% of pregnancy related deaths can be defined as *preventable*, ¹⁰⁸⁸ there is an urgent need for immediate implementation of effective, multifaceted solutions. Social determinants of health, access and quality of healthcare, explicit and implicit bias, gender oppression, lack of cultural training for medical staff, the inadequacy of data collection all play roles in maternal mortality outcomes.

Multiple participants in our briefing on *Racial Disparities in Maternal Mortality* described experiences with racial discrimination in healthcare settings or witnessing discrimination against their clients.

The data is troubling and requires varied responses, including some of those outlined in pending bills with Congress.

Among other points, the data shows that:

- The pregnancy-related mortality ratio (PMMR) for Black women is 221% higher than that of White women.
- In one sample, Black infants were more than 3.5x more likely than white infants to die in their first year of life.
- Even when taking into account specific pregnancy complications Black women were 2 to three times more likely to die from pregnancy complications than white women, even though Black and white women had similar prevalence of complications.
- During 2007-2016, the pregnancy-related mortality ratio for all U.S. women was 16.7 deaths per 100,000 live births. The pregnancy-related mortality ratio for white women

William J. Hall, PhD, Mimi V. Chapman, PhD, Kent M. Lee, MS, Yesenia M. Merino, MPH, Tainayah W. Thomas, MPH, B. Keith Payne, PhD, Eugenia Eng, DrPH, Steven H. Day, MCP, and Tamera Coyne-Beasley, MD, American Journal of Public Health, Vol. 105, No. 12 (December 2015): e61, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4638275/pdf/AJPH.2015.302903.pdf.

¹⁰⁸⁸ Emily E. Petersen, MD; Nicole L. Davis, PhD; David Goodman, PhD; Shanna Cox, MSPH; Nikki Mayes; Emily Johnston, MPH; Carla Syverson, MSN; Kristi Seed; Carrie K. Shapiro-Mendoza, PhD; William M. Callaghan, MD; Wanda Barfield, MD, "Vital Signs: Pregnancy-Related Deaths, United States, 2011–2015, and Strategies for Prevention, 13 States, 2013–2017," *Morbidity and Mortality Weekly Report*, Centers for Disease Control and Protection, Vol. 68, No. 18 (May 10, 2019): 423, https://www.cdc.gov/mmwr/volumes/68/wr/pdfs/mm6818e1-H.pdf.

during those years was 12.7 deaths per 100,000 live births. In contrast, the pregnancy-related mortality ratio for Black women over that time period was 40.8 deaths per 100,000 live births. 3.2 times that of white women. The pregnancy-related mortality ratio for Native American women during that time was 29.7 deaths per 100,000 live births, which is 2.3x that of white women. The pregnancy-related mortality ratios for Asian/Pacific Islander women and Latinas during that time were 13.5 and 11.5 deaths per 100,000 live births respectively, which was 1.1x and 0.9x that of white women, respectively. Additionally, some studies have found greater disparities compared to white women among Latinas in certain geographic areas.

- For each maternal death, nearly 100 women have experienced severe, life threatening, complications with lasting impacts on their overall health, and those rates are even higher for women of color. Studies report severe, life-threatening maternal complications are more than 2 times higher for Black women, and at nearly 2 times higher for Native American women compared to white women.
- A multitude of race-corresponding variables impact the likelihood of a pregnancy-related death. These include education level, access to quality healthcare, insurance status, and the presence of pre-existing conditions. However, even when controlling for these factors, Black and Native women have consistently, dramatically, higher rates of pregnancy-related death, demonstrating that race is the determining factor when assessing the likelihood of maternal mortality. In fact, Black and Native women with college degrees are still more likely to die from pregnancy-related causes a than a white woman without a high school diploma.
- Analysis of county-level data collected by the CDC shows residential racial segregation of Black Americans has historically been one of the leading causes of U.S. racial socioeconomic inequality and played a significant role in perpetuating racial disparities in health.

The overall rate of severe, life threatening complications with lasting impacts on maternal health, has not improved over the last decades. In 1993, 49.5 per 10,000 birthing people experienced severe maternal morbidity, in 2014 that rate has increased to 144 per 10,000, a 200% increase. Maternal morbidity is defined as the "physical and psychologic conditions that result from or are aggravated by pregnancy and have an adverse effect on a woman's health. 1089"

Although there are clearly discernible and troubling patterns in the data, there are also critical deficits in maternal mortality data collection that should be addressed in order facilitate effective responses. Among other issues:

• Data collection and consensus in definitions and measures are lacking, making it difficult to track the progress and efficiencies (or absence thereof) of the policies enacted to prevent maternal mortality and close the racial gap between outcomes.

¹⁰⁸⁹ Source: Centers for Disease Control and Prevention, "Rates in Severe Morbidity Indicators per 10,000 Delivery Hospitalizations, 1993–2014," https://www.cdc.gov/reproductivehealth/maternalinfanthealth/smm/rates-severe-morbidity-indicator.htm.

- Identifying cases of severe, life-threatening complications is challenging. To date, there is no consensus among states and localities on which conditions represent severe complication risks—making it nearly impossible to effectively track trends.
- The Pregnancy Risk Assessment Monitoring System (PRAMS), a project of the CDC and state health departments, collects "state-specific, population-based data on maternal attitudes and experiences before, during, and shortly after pregnancy," but only covers about 83 percent of births.
- Access to quality care is a structural and important remedial challenge in addressing maternal healthcare disparities.
- Access to preconception care has been found to be particularly critical to reducing racial disparities in maternal healthcare between Black and White women.
- Women receiving no prenatal care are 3 times to 4 times more likely to have a pregnancy-related death than women who receive prenatal care.
- Federal Medicaid health insurance program was the source of payment for 42.3% of all births in 2018.
- Access to maternal fetal medicine subspecialists has been linked to improved health outcomes among pregnant women with chronic illness and pregnancy-related complications.
- The postpartum period following the end of a pregnancy or "fourth trimester" has also been identified as critically important for the long-term health and wellbeing of a woman who has given birth.
- In rural America, there is a lack of access to quality maternal healthcare because of several factors such as: hospital and obstetric department closures, workforce shortages, and challenges to accessing care arising from social determinants of health that affect people in those regions.
- Native American women and other women of color are disproportionately impacted by these disparities in access to care ¹⁰⁹⁰. Forty percent of all Native people live in rural areas and often must travel for hours to access a birthing center or hospital.
 - O A recent study found that from 2004 2014, 179 rural counties in the U.S. lost hospital-based obstetrics services. In 2004, 45% of rural counties in the U.S. did not offer any hospital-based obstetrics services, and this increased to 54% by 2014, with the most severe impacts in largely Black counties.
- Medicaid is a significant source of healthcare coverage for people of color, particularly Black, Native American, and Latinx individuals. 32% of both Black and Native Americans, and 30% of Latinx people are insured by Medicaid.
 - O In states that have not expanded Medicaid, many women, particularly women of color, are left in the so called 'coverage gap,' where they earn too much to qualify for Medicaid, but not enough to purchase private health insurance, even with tax subsidies. 1091

¹⁰⁹⁰ National Indian Health Board, Public Comment for the *Racial Disparities in Maternal Mortality Briefing* before the U.S. Comm'n on Civil Rights, Dec. 13, 2020, p. 3.

¹⁰⁹¹ Nan Strauss, Managing Director of Policy, Advocacy, and Grantmaking, Every Mother Counts, Written Statement for the *Racial Disparities in Maternal Health Briefing* before the U.S. Comm'n on Civil Rights, Nov. 13, 2020 at 5 (hereinafter "Strauss Statement").

• Many hospitals that disproportionately serve Black patients tend to have higher overall mortality rates and lower rates of effective evidenced-based medical treatments.

Eliminating maternal health disparities should be a national healthcare priority with an investment of resources to ensure impact. Public health researchers and other stakeholders agree that a multi-faceted approach is needed to improve maternal health outcomes and the quality of care for all women, and to eliminate racial disparities. While this public health crisis is both very troubling and complicated, it is not unsolvable. Targeted and comprehensive practices could help us to start closing the racial maternal health gap.

Among other responses, the federal government could undertake efforts to address structural and systemic inequities in the country's healthcare, economic, social, and criminal legal systems.

We should enhance and improve data collection. Among other efforts we should:

- Provide consistent definitions for terms, and mandate robust reporting across all 50 states, the District of Columbia, and U.S. territories.
- Acknowledge the CDC's data that notes that approximately 66% of maternal mortalities are "preventable." Improved accuracy in reporting, and data collection is necessary to address these preventable causes.
- Ensure that PRAMS is resourced to reach and cover 100% of all births, and collects data for a full year following the birth (Currently, their reporting covers just over 80% of births).
- Data reporting should also measure quality of care and experience. Data should be collected by race and ethnicity to obtain granular, specific information on disparities, and develop avenues to redress them within health systems for families that have been wronged by unequal treatment.

We must tackle racial bias in maternal healthcare and promote culturally congruent care. An awareness and response to address the social determinants of health, including structural and systemic inequities in the country's healthcare, economic, social, and criminal legal systems may include:

- A new focus on addressing resource gaps by eliminating glaring inequities for hospitals servicing primarily Black and Native expectant mothers.
- Ensuring access to Medicaid coverage.
- Adopting more culturally congruent maternal care, and increasing workforce diversity and training, including beginning in medical and nursing school programs.
- Increasing availability of federal funds for training of doulas and birthing support specialists and allow Medicaid funds to cover doulas for birthing mothers.
- Ensuring that incarcerated pregnant and birthing persons have access to health care and social services outside of the prison system, before, during, and after childbirth, for an appropriate length of time.

We should improve the accessibility and quality of maternal healthcare. Among other initiatives, we should:

- Endorse the best practice of having a maternal 'check-up' during the period after birth and continuing 'maternal-focused' checkups for at least a year postpartum.
- Enhance coverage and support for birthing people during the postpartum period and ensure that robust maternal care is provided for at least a full year postpartum.
- Encourage healthcare providers to screen for post-partum depression in the first post-natal visit.
- Provide physicians with 'checklists' that include objectively defined symptoms to screen for common postpartum complications such as cardiomyopathy, embolism, and infection.
- Ensure that rural and Native-servicing healthcare centers have adequate resources to provide every item of robust care outlined here.
- Effective interventions should be replicated and expanded. For example:
- North Carolina's program Pregnancy Medical Home which improves the quality of perinatal care among Medicaid customers and provides increased access to comprehensive care for women receiving Medicaid, promoting evidence-based quality maternity care should be scaled and replicated nationwide.
- Medicaid should be expanded to anyone under 133% of the federal poverty level in all 50 states. Data shows that Medicaid expansion is associated with fewer maternal deaths for all women, with a particularly beneficial impact on maternal mortality rates for Black women.
- Extend healthcare coverage from 60 days postpartum to a full year postpartum.
- Remove income and immigration status limitations for coverage.
- Ensure coverage applies to the full health needs of the pregnant person (not restricted to pregnancy-related health care services).
- Mandate that pregnancy automatically a qualifies a person for a Special Enrollment Period.
- Develop and disseminate national standards for patient-centered maternity care. Establish a national maternal health training center that develops and disseminates curricula and other guidance, and funds delivery of onsite training on racism, implicit bias, gender oppression, and trauma informed care, as well as technical assistance to implement institutional changes to assure respectful, high quality and safe perinatal care for all people receiving perinatal health care, and reportable, publicly available accountability measures to monitor implementation and impact of these efforts.
- Establish a Maternal Health Advisory Group that includes senior level representatives from federal agencies including the CDC, HHS, HRSA, the Surgeon General's Office as well as national maternal, perinatal and/or reproductive health organizations led by women of color, national midwifery organizations, American College of Obstetricians and Gynecologists, state and city health departments, and community members leading efforts to improve maternal health. This advisory group would develop and/or review statements, curricula, draft documents and other materials prior to dissemination, and would be able to present recommendations to members Congress and to the leadership of relevant federal agencies.

Congressional legislation can play an essential role in realizing the diminishment of these racial disparities. Some provisions making their way in current proposed legislation are:

- Provide funding to study social determinants of health that produce disparate maternal health outcomes and equip local health organizations to address them.
- Fund educational programs focused on anti-racism and anti-discrimination efforts.
- Study techniques to increase the number of healthcare workers who can provide culturally-sensitive support.
- Advancing the availability and use of maternal health technology.
- Promote equity within Medicaid.
- Study the effects of the COVID-19 pandemic and other public health crises on maternal health outcomes.
- Direct actions to address maternal healthcare deficits for specialized groups including:
 - o Veterans
 - o Indigenous persons
 - o Persons with maternal mental health conditions and substance use disorders
 - Incarcerated persons
 - o Persons exposed to climate change-related risks

The racial disparities in maternal care and maternal mortality in the United States are severe, urgent, and addressable. There are tangible steps we can take to begin to close these gaps. Data and research demonstrate that Medicaid program expansion, systemic pre and postpartum care enhancements, and targeted funding of rural and minority-servicing hospitals would improve maternal care, particularly for women of color. Multifaceted responses are necessary and long overdue. We must reverse this trend of racial disparity in maternal health outcomes.

STATEMENT OF COMMISSIONER STEPHEN GILCHRIST IN WHICH CHAIR NORMA V. CANTÚ CONCURS

I want to thank the staff, special assistants, expert panelists, and my fellow Commissioners for the hard work they put into this report. It is often difficult to get eight people to agree on anything, particularly a group as diverse and talented as those that contributed to this report. It is with sincere hope that my comments regarding this report are helpful and useful in ascertaining my thoughts regarding this issue.

When I was appointed to the Commission last year, I was excited to learn that the Commission was examining Maternal Mortality. Several years ago, I served on my state's Child and Infant Mortality Committee (CIMC). While serving on that committee I learned a lot, particularly just how vulnerable women and children are during the birthing process. It is often taken for granted that safe deliveries in the United States are routine. And for most pregnancies that is the case. ¹⁰⁹² But there have been too many mothers that have experienced the pain of losing a child at birth. In the United States, as of 2018, the infant mortality rate was 5.7 deaths per 1,000 live births. ¹⁰⁹³ For black babies their mortality rates during the 2016-2018 years were 10.5 per 1,000 live births. ¹⁰⁹⁴ While on face value these statistics might not seem bad, but in the aggregate, they amount to too many precious lives lost too soon. In fact, some of the leading causes of infant mortality were birth defects, low birthweight and preterm birth, maternal pregnancy complications, sudden infant death syndrome and unintentional injuries. ¹⁰⁹⁵ As a father of three, I could not imagine my wife and I losing a child during one of the most precious moments in our lives, and I certainly could not imagine losing my wife. Many of the issues and vulnerabilities that affect Black babies were also consistent with the vulnerabilities of Black women.

Maternal Mortality is truly a bipartisan issue. In the House of Representatives Republican Jaime Herrera Beutler and Democrat Diane DeGette lead the charge for passage of the Preventing

¹⁰⁹² https://www.cdc.gov/nchs/fastats/delivery.htm

 $[\]frac{1093}{https://www.cdc.gov/reproductive health/maternal in fan the alth/infant mortality.htm \#: \sim : text = In\%202018\%2C\%20t he\%20 in fant\%20 mortality, deaths\%20 per\%201\%2C000\%20 live\%20 births.$

 $[\]underline{https://www.marchofdimes.org/peristats/ViewSubtopic.aspx?reg=99\&top=6\&stop=94\&lev=1\&slev=1\&obj=1\&dv=ms$

¹⁰⁹⁵ Infant Mortality| Maternal and Infant Health|Reproductive. https://www.cdc.gov/reproductivehealth/maternalinfanthealth/infantmortality.htm

Maternal Deaths Act 2018.¹⁰⁹⁶ And in the Senate Senators Heidi Heitkamp and Shelley Moore Capito were strong proponents of the bill.¹⁰⁹⁷

The bill was also important enough to garner the support and signage of the Maternal Death Act into law by President Donald J. Trump. 1098

A couple of things this report revealed to me; that too many women lack access to care, there isn't enough quality care for women, and too many women, particularly Black women feel as though their issues are not adequately addressed by healthcare practicioners. 1099 Some of this is rooted in the history of the medical field utilizing Black women bodies as experimental tools and some of it is rooted in the present. 1100 According to this report, even when you control for income, obesity, environment and education, Black women consistently have worse outcomes. 1101 And in my beloved state of South Carolina there are no Obstetricians-Gynecologists in 14 of the 46 counties and least 50% of those counties are majority minority counties. 1102 I will not automatically attribute that to race, that is to easy and too convenient. But the birthing picture seems more complicated than just what mothers need to do to ensure a healthy birthing experience; exercise, eat better, diligently attend doctor appointments, etc. None of that means that much if mothers cannot access quality care. 1103

 $^{^{1096}}$ Bipartisan Bill to Prevent Maternal Deaths Passes U.S. House. $\underline{\text{https://degette.house.gov/media-center/press-releases/bipartisan-bill-to-prevent-maternal-deaths-passes-us-house}$

¹⁰⁹⁷ Heidi Murkoff, "Senators Heidi Heitkamp and Shelley Moore Capito on Why They'll Never Stop Fighting For Maternal Health Care." What to expect, July 25, 2018, https://www.whattoexpect.com/news/family/heidi-heitkamp-shelley-moore-capito-maternal-health-accountability-act-interview/

^{1098 &}quot;President Signs Critical Maternal Mortality Legislation," Preeclampsia Foundation, December 13, 2018, President Signs Critical Maternal Mortality Legislation (preeclampsia.org)

¹⁰⁹⁹ This report cited; Deirdre Cooper Owens PhD, and Sharla M Fett PhD, "Black Maternal and Infant Health: Historical Legacies of Slavery," American Journal of Public Health, Vol. 109, No. 10 (October 2019): 1342-1345, https://ajph.aphapublications.org/doi/10.2105/AJPH.2019.305243.

¹¹⁰⁰ This reported cited; Amy Metcalfe, James Wick and Paul Ronksley, "Racial Disparities in Comorbidity and Severe Maternal Morbidity/Mortality in the Unites States: an Analysis of Temporal Trends," Acta Obstetricia et Gynecologica Scandinavica, No 97 (2018), 94, https://obgyn.onlinelibrary.wiley.com/doi/pdf/10.1111/aogs.13245.

¹¹⁰¹ This report cited: Figure 1.6 Emily E. Peterson, MD, Nicole L. Davis, PhD, David Goodman, PhD, Shanna Cox, MSPH, Carla Syverson, Racial/Ethnic Disparities in Pregnancy-Related Deaths-United States, 2007-2016," Morbidity and Mortality Weekly Report, Centers for Disease Control and Prevention, Vol. 68, No35 (Sep. 6, 2019): 762-765, https://www.cdc.gov/mmwr/volumes/68/wr/pdfs/mm6835a3-H.pdf.

¹¹⁰² Lauren Sausser, "In South Carolina women are increasingly giving birth without prenatal care." Charleston Post and Courier, Oct. 14, 2017, updated Sept 14, 2020, https://www.postandcourier.com/health/in-south-carolina-pregnant-women-are-increasingly-giving-birth-without-prenatal-care/article_cedc219e-af7e-11e7-b452-4fecca0e3504.html

¹¹⁰³ This report cited: U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality, National Healthcare Quality and Disparities Report 2018, September 2019,

https://www.ahrq.gov/sites/default/files/wysiwyg/research/findings/nhqrdr/2018qdr-final.pdf; E. Richard Brown, PhD, Victoria D. Ojeda, MPH, Roberta Wyn, PhD, Rebecka Levan, MPH, Racial and Ethnic Disparities in Access to Health Insurance and Health Care, UCLA Center for Health Policy Research and the Henry J. Kaiser Family Foundation, April 2000, p. xi, https://www.kff.org/wp-content/uploads/2013/01/racial-and-ethinic-disparities-in-access-to-health-insurance-and-health-care-report.pdf; American College of Physicians, Position Paper: Racial and

As a husband and father, it is important that we look at this issue from a balanced perspective. Just blaming it all on race will not get us to a solution, neither will totally disregarding it. There are too many communities within our Country that lack access to quality health care.

Now do I believe health care providers are intentionally trying to kill women and signaling out Black women in particular?" Absolutely not! But I cannot ignore the lived experiences of too many Black women that feel as if their voices and medical needs are not adequately addressed. I believe that life is a precious gift, and the gift of motherhood is one of the most precious gifts of all, it is quite disturbing that it is estimated that a little over half of these deaths were preventable. 1104 And the United States rates are some of the worst in the industrialized world, especially when you consider the cost. 1105

I do believe support of this report will sound the alarm that more needs to be done to save the lives of women, all women. We are the United States of America, and we can do better, all our women deserve better from their medical institutions, particularly those that have historically been denied access to quality care. While there is no perfect document, this document provided enough expert testimony, studies and lived experiences of many women to garner my support for its approval.

Ethnic Disparities in Health Care, April 2010, pp 1-2, https://www.acponline.org/acp-policy/policies/racial-ethnic disparities-2010.pdf; Samantha Artiga, Kendal Orgera, and Olivia Pham, "Disparities in Health and Health Care: Five Key Questions and Answers," Mar. 4, 2020, https://www.https://www.https://www.https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2594273/pdf/jnma00325-0024.pdf. 8 (August 2020): 666-668, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2594273/pdf/jnma00325-0024.pdf.

¹¹⁰⁴ This report cited: Emily E. Peterson, MD; Nicole L. Davis, PhD; David Goodman, PhD; Shanna Cox, MSPH; Nikki Mayes; Emily Johnston, MPH; Carla Syverson, MSN; Kristi Seed; Carrie K. Shapiro-Mendoza, PhD; William M. Callaghan, MD; Wanda Barfield, MD, "Vital Signs; Pregnancy-Related Deaths, United States, 2011-2015, and Strategies for Prevention, 13 States, 2013-2017," *Morbidity and Mortality Weekly Report*, Centers for Disease Control and Protection, Vol. 68, No. 18 (May 10, 2019): 423, https://www.cdc.gov/mmwr/volumes/68/wr/pdfs/mm6818e1-H.pdf.

¹¹⁰⁵ Centers for Disease Control and Prevention, National Center for Health Statistics, *Maternal Mortality and Related Concepts*, Series 3, No. 33, February 2007, pp. 8-9 https://www.cdc.gov/nchs/data/series/sr 03/sr03033.pdf.

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DISSENTING STATEMENT OF COMMISSIONER J. CHRISTIAN ADAMS

I would agree with Commissioner Kirsanow that this report is pushing a narrative that black minority women are dying in high numbers during and after maternity due to racial animus. The Commission's report implies that racial animus in the health care system and on the part of its workers is to blame for higher maternal death rates for blacks than whites. Yet the report -- and the testimony of the Commission witnesses (even after being specifically asked by Commissioner Kirsanow) -- do not provide any specific examples or statistics demonstrating this to be the case.

The report notes repeatedly, unsurprisingly, that maternal health outcomes in more affluent higher quality hospitals are better than outcomes in less affluent lower quality hospitals, which generally have high numbers of low-income patients. As Commissioner Kirsanow points out in his statement, the data cited by the Commission's witnesses and the report itself for the argument that black women are dying of pregnancy related causes at higher rates basically boils down to "black women are poor."

Higher poverty rates for black and other minority women mean that as a percentage of the population, they are more likely to be covered by Medicaid (with its lower provider reimbursement rates) and thus they disproportionately receive maternal care at less affluent, lower quality hospitals than do non-Hispanic white women.

Here, the report lacks curiosity and any pretense at economic literacy. It is no surprise, to me at least, that the hospitals most dependent on government funding, are the places where women are most likely to suffer poor maternal healthcare. This should surprise nobody who has ever become familiar with services provided by the government – whether at the department of motor vehicles or the social security office. When the government intrudes in the private economy, it is rare occurrence where the product improves in quality.

Why doesn't the report explore in greater detail the more likely disparity in maternal health outcomes: lousy government supported healthcare? Where the report does venture into economic explanations for maternal health disparities, it trips over itself with errors and upside-down statistical reasoning.

For instance, on page 105, the report notes that: "In 2019, the Census Bureau found that the Black poverty rate was 26.2 percent, compared with a White poverty rate of 8.3 percent, an Asian poverty rate of 6.3 percent, and the Hispanic poverty rate was 20.9 percent." On page 86, quoting CDC, the report notes that: "Medicaid was the source of payment for 42.3 percent of all births in 2018. Of those Medicaid-covered births, 65.3 percent were to Black women as compared to 30 percent to White women, and 58.9 percent of Medicaid-covered births were to Latina women (of all races)."

Despite the higher Hispanic poverty rate as compared to those for whites, the maternal mortality rate for Hispanic women is actually lower than it is for white women. As Commissioner Kirsanow points out, citing the CDC's most recent data, the maternal mortality rate for Hispanic women is 11.8 deaths per 100,000 live births, while the rate is 14.7 for white women and 37.1 for black women.

So much for the report's conclusion that maternal health disparities are tied to race.

The report, on page 34, similarly says that from 2006-2017 the mortality rate (per 100,00) for Hispanic women was 11.5 vs. 12.7 for White women, and 40.8 for Black women. The Commission's report never explains or even begins to explore the reasons behind the lower mortality rates for Hispanic women vs. White women. The lower Hispanic vs. white maternal mortality rate, despite higher Hispanic poverty, undercuts the report's narrative that minority maternal health disparities are predominantly due to issues related to racism.

On page 13 citing the Center for Reproductive Rights, the report states that: "Black women have the highest uninsured rates among all women, are more likely to have chronic health conditions that are risk factors for maternal death, and are less likely to get care for disease prevention and management." If so, the report is substituting one actual explanation for maternal health disparities – preexisting conditions – with an explanation more in line with prevailing winds, namely racism. Are chronic health conditions and poorly run hospitals dependent on government funding of one form or another the more likely cause of maternal health disparities, or is it racism?

These days, there can only be one answer, regardless of the science or common sense, and the report adopts that answer.

There's more of this in the report. On page 42, the report quotes testimony to the Commission by Dr. Elizabeth Howell, Chair of the Department of Obstetrics and Gynecology at the Perelman School of Medicine at the University of Pennsylvania who said: "Black women tend [to] deliver in specific hospitals and those hospitals have worse outcomes for both Black and White pregnant women regardless of patient risk factors." [emphasis added] Later, on page 59, the report quotes Dr. Howell again: "Approximately 75 percent of Black women deliver in a specific set of hospitals, where health outcomes are worse for both Black and White women, and fewer than 20 percent of White women deliver in those same hospitals."

This again undercuts the narrative that specific racial animus is at play in the medical system as a whole, since both black and white women have worse outcomes in the same lower quality hospitals frequented by most black women. Based on Dr. Howell's testimony, I would have expected the report to look further into the issue of whether disparities in maternal outcomes are more strongly related to which hospitals rich vs. poor women (regardless of race) receive their maternity care. But that would be asking too much when the conclusions in the report about causes of maternal health disparities seem more important than how we got to those conclusions.

It didn't have to be this way, and a genuine good faith bipartisan effort to answer these answerable quantitative questions did not occur. For instance, questions about whether there are indeed racial disparities in maternal outcomes between Black and White women within the same specific hospitals referenced by Dr. Howell that are frequented by 75% of black women might have been asked. They weren't.

Or how about the other end of the spectrum? The report could have examined whether racial disparities in outcomes occur within other higher quality hospitals that treat both black and white women. But again, the report failed to do so. Therefore, the question remains whether the maternal racial disparities alleged are the result of "racism" within the health care community or more the result of differences in outcomes between rich vs. poor women (of any race) by virtue of being treated in higher quality vs. lower quality hospitals.

In short, the report's narrative regarding the existence of underlying racism in the healthcare system would be more persuasive had the report examined whether pregnant low-income white women had better outcomes than pregnant low-income minority women — or the inverse, whether white affluent women had better outcomes than black affluent women.

These are not advanced social science inquiries. They are common sense questions in any credible examination.

The unasked questions in the report were missed opportunities to explore possible disparities in maternal health outcomes that do not divide Americans along racial lines. Instead, we are left with the familiar script that racial animus explains just about anything bad in American life. Such a preordained approach to examining social science questions exhausts the good faith of Americans who care about their fellow Americans who suffer tragic outcomes during medical care. The better approach is to examine the relevant questions the report skipped over on the way to accusing health workers and doctors of racial animus.

There's more. The report should have also compared racial outcomes within individual low and high-quality hospitals, instead of comparing outcomes across the country as a whole. Failing to do so mixes the results from both the higher quality and lower quality hospitals.

While every unnecessary or preventable death should concern everyone, the Commission's report never puts the scale of the problem in context since it never mentions the annual number of births in the U.S. The CDC's National Center for Health Statistics states that there were 3,747,540 births registered in the United States in 2019. The Commission's report on page 9, also citing the National Center for Health Statistics, states that the number of maternal mortality deaths in the U.S in 2018 was 658 and in 2019 it was 754 deaths. In other words, 754 maternal deaths in 2019 when there were almost 3.75 million births.

This is an astounding advancement over the course of human history. At one time in our not so distant past, the maternal mortality rate was 607 deaths per 100,000 live births (1915) compared

to what it is today. Something is moving these numbers in the right direction, and I very much suspect it has nothing to do with the elimination of racism in health care. A thorough report would have more closely examined the "something" behind the incredible achievements of the last century in maternal health care — achievements likely supercharged by the American free market system, technological innovation, and scientific knowledge — and found ways to encourage *more of the same*. Instead, we are left with an inadequate examination of the causes. Instead we have an explanation that falls neatly into the orthodoxy of the day that ascribes racial bias or animus to nearly every facet of American life. That's a shame, and sloppy.

Consider for additional perspective that the CDC's National Center for Health Statistics earlier this month reported that over 92,000 Americans died of drug overdoses in 2020. [https://www.cdc.gov/nchs/nvss/vsrr/drug-overdose-data.htm.] 92,000? That is the population of Santa Monica, California, or Boca Raton, Florida, every year dying of drug overdoses. The trendlines regarding drug overdoses are also moving in the wrong direction, in contrast.

It appears the report fails to put blame on any maternal health disparity where it is due. The disproportionate economic circumstances of Black patients push them into health care corroded by the cumbersome limits of the government funded health care system, usually Medicaid. Of the over 43% of births covered by Medicaid, more than 65% of the Medicaid coverage was for Black women while 30% was for white women. Most importantly, 75% of all Black women (rich or poor) deliver in a specific set of hospitals, where health outcomes are worse for both Black and White pregnant women, and 80 percent of White pregnant women avoid these lower performing hospitals in part because they can afford to.

Based on those factors and others, the racial disparities in maternal health outcomes highlighted in the report as currently written would seem more attributable to economic factors than the result of any underlying racial animus rooted in the actual care provided patients by health care workers or by medical institutions themselves. The Commission report repeatedly insinuates that racism and racial animus are behind these disparities, but the reader is left without specific examples, evidence or any genuine finding of racism or racial animus.

DISSENTING STATEMENT AND REBUTTAL OF COMMISSIONER GAIL L. HERIOT

This report of the U.S. Commission on Civil Rights—entitled "Racial Disparities in Maternal Health"—deals with an important topic: Too many mothers, especially African American and American Indian/Alaska Native mothers, are needlessly dying.

Alas, like many of our Commission reports, this one is a disappointment. We're unlikely to save lives if we don't make a greater effort to sort out fact from fiction. I don't see nearly enough of that effort in this report.

I will discuss in this Statement a few of what I believe are the report's more significant problems. 1106 But perhaps the most serious is its repeated allegation—usually in the form of unexamined quotes from supposed experts—that "racism" is what's causing racial disparities in maternal mortality. This allegation (which lately I have also been seeing on publicly funded posters and billboards here in San Diego) will not help us reduce maternal deaths. Instead, it will encourage racial minority mothers to view medical professionals as hostile or even malicious. That is much more likely to make things worse than better.

A. IT IS UNLIKELY THAT AMERICAN WOMEN ARE DYING IN CHILDBIRTH TODAY AT RATES 50% HIGHER THAN THEY DID A GENERATION AGO.

¹¹⁰⁶ In this Statement, for the sake of accuracy, I use the same terminology used by the underlying study to which I am referring at the time. For example, some studies say, "non-Hispanic black," some say, "non-Hispanic African American," some say, "African American," etc. I do not use the novel descriptor "Latinx," although this report frequently does so even when citing to underlying studies that use the term "Hispanic." *See, e.g.*, Rep. at 37, n. 234 (asserting that "Black and Latinx individuals report higher levels of stress than White respondents," whereas the underlying study refers only to "Black and U.S.-born Hispanic individuals"). I note that Hispanic respondents consistently prefer the terms "Hispanic" or "Latino" over "Latinx." *No Preferred Racial Term Among Most Black, Hispanic Adults*, GALLUP (Aug. 4, 2021), https://news.gallup.com/poll/353000/no-preferred-racial-term-among-black-hispanic-adults.aspx (showing only 5% of Hispanic respondents prefer the term "Latinx").

I do not deal with severe maternal morbidity in this Statement and concentrate instead on maternal mortality. The reason for that is that, if one's goal is to determine whether rates of morbidity are increasing or decreasing, the statistics on morbidity discussed in the report are hopelessly flawed. It is extremely difficult for physicians to agree on what should count as severe maternal morbidity. As time goes on, what gets viewed as "severe" naturally changes. The CDC has chosen to get at the issue indirectly by assuming all cases in which the mother receives a transfusion are cases of "severe maternal morbidity." But that's counting the treatment, not the condition. Rather than showing that severe morbidity is getting worse and worse, these statistics may simply mean that treatment is getter better and better as doctors increasingly use transfusions just to be on the safe side.

I sympathize with the CDC's difficulty and realize that for certain purposes counting the number of transfusions numbers can be useful. Keeping track of "severe treatments" can help hospitals that are seeking to go over each such case in detail to ensure that no error has occurred. But they aren't much good for agencies like the Commission that are engaged in making broad policy recommendations.

The report quotes—with seeming approval—Dr. Neel Shah who stated that a woman today is "50 [percent] more likely to die in childbirth than her own mother was." Rep. at xii. The report echoes that claim in its own voice when it states that "overall maternal mortality rates in the United States have worsened during the past 30 years." Rep. at 29. 1108

1107 To support this assertion, the report cites an advocacy organization, Global Citizen, which in turn cites the Associated Press, which in turn quotes Dr. Neel Shah, co-founder of another advocacy organization. Rep. at xii (citing Jackie Marchildon, *Racial Bias in Health Care Is Killing Mothers Around the World*, GLOBAL CITIZEN (May 10, 2019), https://www.globalcitizen.org/en/content/racial-inequalities-maternal-mortality-rates/ (citing Ashley Welch, *More Than Half of Pregnancy-Related Deaths Are Preventable, Associated Press* (May 7, 2019), https://www.cbsnews.com/news/more-than-half-of-pregnancy-related-deaths-are-preventable-cdc-says/ (quoting Dr. Neel Shah))). Primary sources are much to be preferred, especially when making a claim as surprising as this one. Surprising claims have an unsurprising tendency to be untrue.

In his proposed findings for the Commission, Commissioner Adegbile asked the full Commission to adopt Shah's figures as one of its "Findings." His proposal was voted upon at our public business meeting and did not pass. Transcript of U.S. Commission on Civil Rights Telephonic Business Meeting at 68 (July 23, 2021).

Additionally, Commissioner Adegbile asked the Commission to adopt other dubious "Findings." For example, one proposed finding stated, "In one sample, Black infants were over 3.5 times more likely than white infants to die in their first year of life." That Finding cited to page 154 of the report, which says, "In Raleigh-Durham, a city [sic: Raleigh and Durham are two cities, one mainly in Wake County and the other wholly within Durham County] known internationally for exceptional medical care and resources . . . Black infants are 3.5x more likely to die than white babies in their first year of life." The footnote cites to "Triangle Black Maternal Wellness Collaborative, Public Comment." That comment states, "In Durham in 2018, only 60% of Black pregnant people received prenatal care in their first trimester and Black infants are 3.5X more likely than White infants to die in their first year of life." No citation is provided for this assertion. The Commission should not be assuming the accuracy of a public comment that does not provide a citation. The 2018 infant mortality statistics for North Carolina recorded 23 total infant deaths in Durham County in 2018; 3 were non-Hispanic white and 10 were non-Hispanic African American. 2018 North Carolina Infant Mortality Report, N.C. ST. CTR. FOR HEALTH STAT. (Sept. 26, 2019), https://schs.dph.ncdhhs.gov/data/vital/ims/2018/2018rpt.html.

Perhaps this is what the Triangle Black Maternal Wellness Collaborative meant. But this is much too small a sample size to tell us about Durham County in general, much less to suggest that Durham County's experience might reflect national or even state trends.

For those trends, the following would be more accurate and telling: In North Carolina in 2018, there were 300 non-Hispanic white infant deaths (or 4.7 per 1,000 live births) and 363 non-Hispanic African American infant deaths (or 12.5 per 1,000 live births). *Id.* Thus, one could say that non-Hispanic African American infants were about 2.7 times more likely than non-Hispanic white infants to die in North Carolina in 2018. Nationwide infant mortality rates in 2018 were 4.63 per 1,000 live births for non-Hispanic white infants and 10.75 per 1,000 live births for non-Hispanic black infants. Danielle M. Ely & Anne K. Driscoll, *Infant Mortality in the United States, 2018: Data From the Period Linked Birth/Infant Death File*, 69 NAT'L VITAL STAT. REP. 1, 4, (July 16, 2020). Thus, one could say that non-Hispanic black infants were about 2.3 times more likely than non-Hispanic white infants to die across the country in 2018.

1108 Similarly, it states: "The pregnancy-related mortality ratio (reported from PMSS data) in 1987 was 7.2 pregnancy-related deaths per 100,000 live births as compared to 17.3 deaths per 100,000 live births in 2017. As previously mentioned, National Center for Health Statistics data differs slightly, showing that the maternal mortality rate in 1987 was 6.6 deaths per 100,000 live births as compared to 17.4 in 2018, showing a higher estimated increase of 163 percent. Both data sets show a high increase in maternal mortality." Literally, the foregoing statements may well be true in the sense that these are indeed the reported numbers. But they omit to state that the reason for the increase is much more the difference in how statistics are kept than in the actual numbers of maternal deaths.

If the rate of maternal mortality were indeed up 50%, that would be alarming. But this is unlikely. All or nearly all of this alleged increase appears to be an artifact of changes in how the United States keeps track of maternal mortality. 1109

Here's the story as I understand it: In 2003, a pregnancy question was added to the revision of the U.S. Standard Certificate of Death. This question includes a series of checkboxes designed to elicit whether the decedent was pregnant at the time of her death or whether she had been pregnant in the last year. 1111

These checkboxes were added for a reason: Researchers feared that pregnancy-related deaths were being under-reported and hoped the checkboxes would improve the likelihood that a pregnancy-related death would be reported as such.¹¹¹²

The checkboxes made it more likely that a physician preparing a death certificate would inquire into the decedent's pregnancy status. If it turned out she was or had recently been pregnant, the physician could be more attentive to the possibility that pregnancy increased the likelihood of the

Physicians tend to collect data on death in the hope that they can learn from that data and reduce deaths in the future. Physicians therefore are interested in cases in which, for example, hypertension increases by 20% the likelihood of a death in a general scenario, even if they can't tell whether the death would have occurred anyway in a particular case. Lawyers and judges, on the other hand, are often in the business of assigning legal liability and hence tend to be concerned with whether pregnancy is more likely than not a "but for" cause of the death. If the death probably would have occurred anyway, lawyers and judges would ordinarily prefer not to classify it as a "pregnancy-related death."

Causation has been a slippery concept since the days of Aristotle. See ARISTOTLE, THE METAPHYSICS (John H. McMahon, trans., 1991); see also Bertrand Russell, On the Notion of Cause, in 6 THE COLLECTED PAPERS OF BERTRAND RUSSELL: LOGICAL AND PHILOSOPHICAL PAPERS 1909–1913 (J. Slater, ed., 1992).

For a discussion of the checkboxes, see Lauren M. Rossen et al., The Impact of the Pregnancy Checkbox and Misclassification on Maternal Mortality Trends in the United States, 1999–2017, 3 NAT'L CTR. FOR HEALTH STAT. VITAL HEALTH STAT. 1 (2020).

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¹¹⁰⁹ See Detailed Evaluation of Changes in Data Collection Methods, NAT'L CTR. FOR HEALTH STAT. (Nov. 21, 2019), https://www.cdc.gov/nchs/maternal-mortality/evaluation.htm.

¹¹¹⁰ See U.S. Standard Certificate of Death, https://www.cdc.gov/nchs/data/dvs/death11-03final-acc.pdf.

¹¹¹¹ Two alternative time frames are given for recent pregnancies—those within 42 days and those that occurred between 43 days and one year before the death.

¹¹¹² Researchers may well have been right that pregnancy-related deaths were being under-reported. But that issue is a complicated one. What should count as a pregnancy-related death? That depends in part on why one wants to know the number of pregnancy-related deaths that have occurred. If the only point of keeping data on pregnancy-related deaths is to make international comparisons, then what's important is that each country define pregnancy-related death in the same way so that apples are being compared to apples. But rarely will that be the whole point. Further methodological issues have to be resolved before the count can begin: Pregnancy may be a "contributing factor" to a particular death in the sense that it increased the likelihood that the death would occur without it necessarily being so that without the pregnancy the death would not have occurred. For example, suppose being more than eight months into a pregnancy increases the chance that a woman of childbearing age will die of a heart attack by 30%. But if ten women who are more than eight months pregnant all die of a heart attack, that does not mean all ten would have survived if they had not been pregnant. And it may be impossible to tell which ones would have survived and which ones would have died even if they had not been pregnant.

death. Such cases could, for example, be referred to medical professionals with expertise in making a judgment about pregnancy relatedness.

The federal government, however, does not directly control the form of death certificates. Individual states do. Not all states were quick to adopt the checkbox recommendation (and some had made efforts even before 2003 to improve the likelihood that a pregnancy-related death would be reported as such). As each state eventually fell into line, the reported rate of maternal mortality ticked up in that state—not because more pregnancy-related deaths were occurring, but rather because more deaths were being classified as pregnancy-related. This is exactly what those who recommended the checkboxes had hoped for. We shouldn't be surprised that what they intended is what actually happened.

The National Center for Health Statistics recognizes this: "Estimated trends suggest that the observed increases in [maternal mortality rates] from 1999 through 2017 reported in the literature were largely due to the staggered implementation of the checkbox. Potential misclassification of pregnancy status using the pregnancy checkbox likely also contributed, which disproportionately inflated [maternal mortality rates] among women aged 40 and over." 1113

Collecting accurate statistics about complex medical issues is a lot harder than one might imagine. Unfortunately, changes (including improvements) in the methods for collecting and analyzing data can end up making comparisons between the pre- and post-change time periods unreliable. The so-called increase in maternal mortality rates appears to be largely, if not totally, an instance of exactly that. 1115

¹¹¹³ *Id.* at 1 ("Accounting for the checkbox, predicted [maternal mortality rates] did not change significantly from 1999 through 2017, although trends varied by subgroup (age, race and Hispanic origin, cause of death)."). *See also* Daniel B. Nelson et al., *Population-Level Factors Associated with Maternal Mortality in the United States, 1997–2012*, 18 BMC PUBLIC HEALTH 1007 (2018).

¹¹¹⁴ The horrifying death rates for COVID-19 that were being reported out of Italy, Spain, and a number of other countries early in the pandemic are a good example of this. Those rates decreased dramatically as the pandemic wore on. At first blush, one may want to attribute the decrease to dramatically improved methods of treatment. But that would be a mistake; the death rates are not actually comparable. Most of the difference probably came from a dramatic rise in the number of COVID-19 tests available for use. Early in the pandemic, there was a shortage of such tests. Consequently, only those with serious symptoms were being tested. Many milder COVID-19 cases were not being caught. As tests became plentiful, COVID-19 cases with mild symptoms or no symptoms at all were being identified. In computing the death rates, these cases were being added to the denominator. That made the death rate appear to be dramatically declining when in fact it was probably a case of better identifying the many COVID-19 cases that were not resulting in death. See Jon Hamilton, Antibody Tests Point To Lower Death Rate For The Coronavirus Than First Thought, NPR (May 28, 2020), https://www.npr.org/sections/healthshots/2020/05/28/863944333/antibody-tests-point-to-lower-death-rate-for-the-coronavirus-than-first-thought; see also David Baud et al., Real Estimates of Mortality Following COVID-19 Infection, 20 LANCET INFECTIOUS DISEASES 773 (2020) ("Notably, the full denominator remains unknown because asymptomatic cases or patients with very mild symptoms might not be tested and will not be identified. Such cases therefore cannot be included in the estimation of actual mortality rates, since actual estimates pertain to clinically apparent COVID-19 cases."). For the same reason, international comparisons must be taken with a grain of salt. Mexico, for example, is still reporting

Interestingly, at other points in the report, it asserts (somewhat inconsistently) that pregnancy-related deaths have *not decreased* over the last few decades. ¹¹¹⁶ This is a more modest assertion. From the medical literature I have been able to look at, it may well be true (or at least closer to true than anyone would like).

Even this assertion, however, must be viewed cautiously. What, for example, is a pregnancy-related death? Is it necessary that the death would not have occurred without the pregnancy? That's a very high standard, especially if the proof of that connection must be drawn by clear and convincing evidence. At the other extreme, is it sufficient that pregnancy increased the likelihood that the death would occur? That's a very low standard, especially if the pregnancy need only

a death rate that is similar to those reported by Italy and Spain early in the pandemic. But Mexico continues to have a shortage of COVID-19 tests. These tests are likely going to those experiencing serious symptoms, who are also those most likely to die. The real COVID-19 death rate in Mexico is likely lower than what is being reported. *See RCP Corona Virus Tracker: Coronavirus (COVID-19) Global Deaths*, REALCLEARPOLITICS, https://www.realclearpolitics.com/coronavirus/ (last visited Aug. 13, 2021).

¹¹¹⁵ The report also states that maternal mortality rates are higher in the United States than they are in many other developed nations. The question one must always ask is whether data collection and analysis in those other countries are similar or different to what is done here. Efforts are almost certainly being made to ensure that they are, but efforts do not always produce results.

One reason for pessimism on this front is that within this country it is doubtful that the even states employ uniform methods for collection and analysis. According to one report, reported maternal death rates have increased dramatically between 1997 and 2012 in Georgia, but not at all in Alabama. Indiana's rates have shot up; North Carolina's have barely changed. Daniel B. Nelson et al., *Population-Level Factors Associated with Maternal Mortality in the United States*, 1997–2012, 18 BMC PUBLIC HEALTH 1007 (2018). Such changes seem implausible to me.

It is worth noting that the United States also tends to lag behind many other developed nations in infant mortality. Yet a closer look suggests that this is largely the result of the different ways that countries keep statistics on the issue:

It has been widely reported that the United States has a relatively high infant mortality rate compared with other developed countries: More than 23,000 American infants died in 2014, or about 6 for every 1,000 live births, putting us on par with countries like Serbia and Malaysia. Most other developed countries -- as geographically diverse as Japan, Finland, Australia and Israel -- have lower rates, closer to 2 or 3 deaths out of every 1,000. However, carefully parsing out the data shows that the story is more complicated than those simple statistics.

The first nuance is one of definition. Infant mortality is defined as the death of babies under the age of one year, but some of the differences between countries can be explained by a difference in how we count. Is a baby born weighing less than a pound and after only 21 weeks' gestation actually "born?" In some countries, the answer is no, and those births would be counted as stillbirths. In the United States, on the other hand, despite these premature babies' relatively low odds of survival, they would be considered born -- thus counting toward the country's infant mortality rates.

These premature births are the biggest factor in explaining the United States' high infant mortality rate. Tex. A&M Univ., *Why* American *Infant Mortality Rates Are So High* (Oct. 13, 2016), https://www.sciencedaily.com/releases/2016/10/161013103132.htm.

¹¹¹⁶ I found it surprising that the report would make both assertions—that pregnancy-related maternal deaths have gotten much worse and that they have not gotten better—without clarifying the situation more. Perhaps the report was drafted by more than one hand.

slightly increase the likelihood of death given the rest of the decedent's medical profile. Whatever standards apply, the odds that they will be evenhandedly implemented over long decades are not very great, particularly given that deaths that occur as much as one year after the birth may still be counted as pregnancy related. The tendency is going to be to inflate the numbers over time.

Of course, to fully appreciate where we are, it is worth knowing that the reduction in maternal mortality over the past century has been astonishing. According to the CDC, "[a]t the beginning of the 20th century, for every 1000 births, six to nine women in the United States died of pregnancy-related complications." By 1997, that rate "declined almost 99% to less than 0.1 reported death per 1000 live births." 1117

Just in case your eyes got tired and you didn't quite read that last sentence, let me restate it: *Maternal death declined almost 99% over the course of the 20th century*. That's not just improvement. It's a medical triumph.

But when strides are that impressive, they may be difficult to sustain over time. Major breakthroughs were important to achieving that result—like the discovery of penicillin by Scottish scientist Alexander Fleming, the synthesis of the labor-inducing hormone oxytocin by American biochemist Vincent du Vigneaud, and the discovery of a drug—methyldopa—that manages hypertension for pregnant women, among others, by researchers at American pharmaceutical corporation Merck & Co. 1118 Discoveries like those don't happen every day. 1119

Nonetheless, it is fair to ask: Why haven't maternal mortality rates gone down in more recent years? Why have they stalled (assuming the data are correct that they have stalled)? Most Americans have been lucky enough to live through an era of fairly sustained improvement in many aspects of their lives. Why not here?

A significant part of the answer might be that in recent decades more Americans have become obese, ¹¹²⁰ and more obesity means more hypertension and more diabetes, both of which lead to higher maternal mortality rates. ¹¹²¹ Another part of the answer might be that a higher percentage of births are to women over 40, ¹¹²² and maternal mortality rates for women over 40 have always

¹¹¹⁹ Smaller improvements—the kind that are made through better nutrition, better maternal education, or better professional education—matter too. Unlike the major breakthroughs, these often proceed one mother, one nurse midwife or one obstetrician at a time.

¹¹¹⁷ Nat'l Ctr. for Chronic Disease Prevention and Health Promotion, *Achievements in Public Health*, 1900–1999: *Healthier Mothers and Babies*, 48 MORBIDITY AND MORTALITY WKLY. REP. 843, 849, (Oct. 1, 1999).

¹¹¹⁸ Walter Sneader, Drug Discovery: A History 168, 219, 290 (2005).

¹¹²⁰ Cheryl D. Fryar et al., Nat'l Ctr. for Health Stat., Prevalence of Overweight, Obesity, and Severe Obesity Among Adults Aged 20 and Over: United States, 1960–1962 Through 2015–2016, 3 (Sept. 2018).

¹¹²¹ Wilbert S. Aronow, Association of Obesity with Hypertension, 5 Annals OF TRANSLATIONAL MED. 350 (2017).

¹¹²² T. J. Mathews & Brady E. Hamilton, *Mean Age of Mothers is on the Rise: United States, 2000–2014*, 232 NAT'L CTR. FOR HEALTH STAT. DATA BRIEF 1 (Jan. 2016).

been much higher than those for younger mothers. I will comment more on causes in a later section of this Statement.

For now, allow me to put the problem in perspective. The number of pregnancy-related maternal deaths per year now is approximately 700. That's 700 too many—especially given that the CDC estimates that 60% of these deaths are in one way or another "preventable." We can and must do better. But it's also true that according to the CDC in 2019 there were 47,511 deaths by "intentional self-harm" in the United States. Additionally, 39,107 individuals died from motor vehicle accidents, 19,141 died from homicide, 11,252 died from malnutrition, 3,692 died from accidental drowning and submersion, and 2,692 died from accidental exposure to smoke, fire, and flames. All of these areas—very much including pregnancy-related deaths—need improvement. The question is how to go about getting that improvement.

B. WHILE IT IS TRUE THAT AFRICAN AMERICAN AND AMERICAN INDIAN/ALASKA NATIVE MOTHERS HAVE HIGHER PREGNANCY-RELATED MORTALITY RATES THAN WHITE MOTHERS, IT IS *NOT TRUE* THAT ALL CATEGORIES OF MINORITY MOTHERS HAVE HIGHER MORTALITY RATES THAN WHITE MOTHERS. THE RATES FOR HISPANIC AND LIKELY FOR ASIAN MOTHERS ARE ACTUALLY *LOWER*. THIS DETRACTS SOMEWHAT FROM THE NOTION THAT HAS BECOME POPULAR IN RECENT YEARS—THAT RACIAL DISPARITIES IN MATERNAL MORTALITY ARE LARGELY DUE TO RACISM.

¹¹²³ Underlying Cause of Death 1999–2019, https://wonder.cdc.gov/ucd-icd10.html. ¹¹²⁴ Ld

Racial disparities can be found for theses modes of death too, but the disparities often cut in quite different directions. For example, for suicides, the highest rates for per 100,000 (age-adjusted) were for non-Hispanic American Indian or Alaska Native at 11.0 (Female) and 33.8 (Male). Notably, the next highest group was non-Hispanic white at 7.9 (Female) and 28.2 (Male). Suicide rates for non-Hispanic blacks (2.8 Female/11.4 Male), Hispanics (2.6 Female/11.2 Male) and non-Hispanic Asian or Pacific Islanders (3.9 Female/ 9.9 Male) are much lower. Sally C. Curtin & Holly Hedegaard, *Suicide Rates for Females and Males by Race and Ethnicity: United States, 1999 and 2017*, NAT'L CTR. FOR HEALTH STAT. 1, 3–4 (June 2019).

This holds true for women of prime childbearing years in particular. For example, for women ages 25-44, the suicide rates for non-Hispanic American Indian or Alaska Natives and for non-Hispanic whites were 20.7 and 10.4 respectively. By contrast, the rates for non-Hispanic blacks, non-Hispanic Asian or Pacific Islanders and Hispanics were 4.3, 4.2 and 3.5.

For automobile accident deaths, American Indians or Alaska Natives are represented at more than twice the overall rate per 100,000 in population. The fatality rate for non-Hispanic whites, on the other hand, exceed those for both non-Hispanic African Americans and Hispanics, but only by a small amount. The rate for Asians is less a third that of the other groups. NAT'L HIGHWAY TRAFFIC SAFETY ADMIN., *TRAFFIC SAFETY FACTS: 2006 DATA, RACE AND ETHNICITY* 2 (2009).

Among homicide victims, black Americans are vastly over-represented relative to their numbers in the population with ~53.7% of the total. *Number of Murder Victims in the United States in 2019, by Race/Ethnicity and Gender*, (Feb. 2, 2021), https://www.statista.com/statistics/251877/murder-victims-in-the-us-by-race-ethnicity-and-gender/.

1125 Curtin & Hedegaard, *supra* note 1124, at 3.

One of the underlying themes of the report is that racism accounts for the differing maternal mortality rates in the United States. For example, the report quotes with seeming approval the written testimony of Joia Crear-Perry, the founder of the National Birth Equity Collaborative. Dr. Crear-Perry, a physician whose own medical career has not been without considerable controversy, 1126 stated: "We know the root causes of poor maternal health—racism and gender oppression inside of healthcare systems and every other facet of society." Rep. at xii. 1127 In her oral testimony, she also stated, "Not valuing the lives of Black and indigenous people is driving the maternal health crisis in the United States." Similarly, the report quotes the written testimony of Jonathan Webb, CEO of the Association of Maternal & Child Health Programs: "[F]or decades, we have looked at race as a factor in determining or predicting potential health outcomes. More recently, research demonstrates that racism and not race is the actual risk factor." Rep. at 29. 1129

If so, one might expect racism to take its toll on all minority races, not just African Americans and American Indian/Alaska Natives. But the facts are otherwise. The pregnancy-related

was initially suspended in 2008 after her hospital privileges were suspended by Baptist Memorial Medical Center [now called Ochsner Baptist Medical Center]. Based on her representation that she would take remedial training, she was permitted to treat the privileges suspension by Baptist Memorial as a leave of absence. Rather than undergo that training, she sought and obtained hospital privileges at East Jefferson General Hospital without informing that hospital that her privileges at Baptist Memorial had been suspended. This was, of course, against East Jefferson's rules, so she was suspended there too. Her initial license suspension was stayed on several conditions, including the following: (1) that she refrain from practicing obstetrics until such time as she completes an additional year of residency in that specialty as approved by the board; (2) that a board-approved physician supervise and monitor her practice; and (3) that she get a comprehensive medical and mental health examination. The board found that she had failed to comply with any of those conditions. Her license was thus fully suspended in 2009. In re Joia Crear-Perry, M.D., Certificate No. 023616, Opinion and Ruling, Louisiana State Board of Medical Examiners, No. 09-A-017 (Dec. 14, 2009). See also Martha Carr, Mitch Landrieu's Acting Health Director Joia Crear-Perry Steps Down Amid Controversy Over Suspended Medical License, NOLA.COM (May 8, 2010),

https://www.nola.com/news/politics/article_0e8ad81a-c6f7-543d-9853-fc526d91a44c.html; New Orleans' Acting Health Director Faces Medical Malpractice Suits, Station Reports, NOLA.COM (May 7, 2010), https://www.nola.com/news/politics/article_eb389fbf-7d6c-51e4-9870-f0a2fcf48a3a.html.

In 2014, her license was reinstated. The reinstatement order recited that she had told the board that she had "no intention of engaging in the practice of medicine in a clinical or institutional setting but instead wish[ed] to pursue a career in health care administration." In re Joia Crear-Perry, M.D., Certificate No. 023616, Order for Reinstatement of Unrestricted License, Louisiana State Board of Medical Examiners, No. 09-A-017 (Aug. 11, 2014).

The experience of having one's medical license suspended is likely to have influenced Crear-Perry's attitude toward the healthcare system generally and needs to be considered in evaluating her accusations.

¹¹²⁷ Citing Joia Adele Crear-Perry, M.D., F.A.C.O.G., Founder and President, National Birth Equity Collaborative, Written Statement for the Maternal Health Briefing Before the U.S. Commission on Civil Rights, November 13, 2020 at 1.

¹¹²⁸ USCCR, *Racial Disparities in Maternal Health*, YouTube (Nov. 13, 2020), https://www.youtube.com/watch?v=FUnERDDFDTM (beginning at 1:24:45).

¹¹²⁹ Citing Jonathan Webb, Chief Executive Officer, Association of Maternal & Child Health Programs, Written Statement for the Racial Disparities in Maternal Health Briefing before the U.S. Comm'n on Civil Rights, Nov. 13, 2020, at 2.

mortality rates for Hispanic and very likely for Asian American mothers are *lower* than the rates for whites. ¹¹³⁰

The CDC report cited by the Commission clearly shows that from 2007 to 2016, the pregnancy-related mortality rate for Hispanic mothers was 11.5 per 100,000 live births while the rate for non-Hispanic white mothers was 12.7. Put differently, Hispanic mothers were 10% less likely than non-Hispanic white mothers to suffer such a death (per 100,000 births). 1131

The Asian American rate is more difficult to come by. That's because the CDC report combines Asians with Pacific Islanders. But, it is usually helpful to disaggregate Asians and Pacific Islanders where possible, because the numbers are often quite different—sometimes strikingly different. Combining them can obscure more than it illuminates. 1133

In this case, it is likely that disaggregation would show that the rate for Asian mothers is somewhat lower than the rate for white and Hispanic mothers, while the rate for Pacific Islanders is much higher. Such is the evidence from Hawaii, where the numbers of Asian and the number of Pacific Islanders (including Native Hawaiians) is the largest in the nation in terms of a percentage of the population. According to an article entitled *Our Mothers Are Dying: The Current State of Maternal Mortality in Hawai'i and the United States*, Pacific Islanders were 44% of maternal deaths while only 22% of the population. Asians were 32% of maternal deaths while 37% of the population. 1134

Another way that one can get at the differences between Asian maternal mortality and Pacific Islander maternal mortality is to look at the differences in the rates of characteristics that are associated with maternal mortality. A study on pre-pregnancy obesity with subgroups

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¹¹³⁰ Commissioner Kirsanow, in his Statement, contends that the Report deliberately obscures the lower Hispanic rate specifically "[b]ecause the Commission is committed to the narrative that the comparatively poor maternal outcomes of black women are due to 'systemic racism.'" I touch on the counterproductive narrative of "systemic racism" in Section D below.

¹¹³¹ This does not appear to be simply a result of the average age of Hispanic mothers; maternal mortality rates for Hispanics tend to be lower than white rates even within particular age ranges (e.g. 20-24 and above 40 years of age). See Emily E. Petersen, et al., *Racial/Ethnic Disparities in Pregnancy-Related Deaths* — *United States*, 2007–2016, 68 MORBIDITY AND MORTALITY WKLY. REP 762, 763. (Sept. 6, 2019).

¹¹³² See, e.g., Andrew E. Williams, et al., Work, Weight, and Wellness: the 3W Program: A Worksite Obesity Prevention and Intervention Trial, 15 OBESITY 16S, (Sept. 6, 2007), (showing that Pacific Islanders have the highest rates of obesity (46%) and shortest life expectancy (68 years) of any U.S. race/ethnic group and that the body mass index (BMI, kg/m2) of Pacific Islanders and Filipinos is greater than that of Whites, while BMI of other Asians is lower than that of Whites).

¹¹³³ See Janice Hata & Adam Burke, A Systematic Review of Racial and Ethnic Disparities in Maternal Health Outcomes among Asians/Pacific Islanders, 3 ASIAN/PACIFIC ISLAND NURSING J. 139 (2019) (noting that "[s]tudies that disaggregate APIs are limited" and "highlighting the need to understand the unique differences in maternal health and obstetric outcomes").

¹¹³⁴ Melanie Maykin & Stacy Pai-Jong Tsai, *Our Mothers Are Dying: The Current State of Maternal Mortality in Hawai'i and the United States*, 79 HAWAII J. HEALTH & SOC. WELFARE 302 (2020). The authors state that these figures above are "stratified by a single-race identifier."

disaggregated shows 22.3% of non-Hispanic whites; 32.4% of Hawaiians; 60.23% of Samoans; 2.58% of Chinese; 4.25% of Japanese; 3.26% of Vietnamese; 18.98% of Cubans; 27.95% of Mexicans; and 19.92% of Central/South Americans with pre-pregnancy obesity. 1135

Yet another way to get at the issue is to look at *infant* mortality, which tends to track maternal mortality rates reasonably well (though not perfectly). Here the CDC disaggregates. It reports that the Asian infant mortality rate per 1,000 live births is 3.6, which is somewhat better than the non-Hispanic white rate of 4.6. The Native Hawaiian or Other Pacific Islander rate, on the other hand, is much higher at 9.4, which places it in between the American Indian/Alaska Native rate of 8.2 and the non-Hispanic black rate of 10.8. 1136

The report appears at certain points to be deliberately obscuring these facts. Rather than make it clear that the pregnancy-related mortality rate for Hispanic mothers is lower than that for white mothers, the report focuses only on the notion that it is higher "in some geographic areas." Rep. at x. But this is always the case. If one carves up the territory carefully enough, one can always find a place where the disparities are reversed. In general, for example, African Americans and women earn less than whites and men. But on the street where Oprah Winfrey lives, that may well not be true. 1137

For Asians the report states: "Pregnancy-related mortality is also slightly elevated for Asian women (a 1.1 disparity ratio) Rep. at x. This is simply error. The source it cites is for "Asian/Pacific Islander," not Asian Americans alone. Given how little the two populations have in common for so many measures of medical well-being, that is a serious error. 1138

What does all this tell us? For one thing it tends to discredit the hypothesis that racism is the root of the disparity issue. Anyone familiar with American history, especially that of the American West, knows that discrimination against Hispanics and Asians was a serious problem and it has not altogether disappeared. Yet the rate of pregnancy-related mortality for Hispanics and likely for Asians is lower, not higher, than that for whites. Something more is going on here.

C. THE PROXIMATE CAUSES OF RACIAL DISPARITIES IN PREGNANCY-RELATED MORTALITY ARE DIVERSE AND COMPLICATED.

If not racism, then what? Why are mortality rates so high for African American, American Indian/Alaska Native and almost certainly Pacific Islander mothers? I doubt anyone can explain

¹¹³⁵ Gopal K. Singh & Jessica N. DiBari, Marked Disparities in Pre-Pregnancy Obesity and Overweight Prevalence among US Women by Race/Ethnicity, Nativity/ Immigrant Status, and Sociodemographic Characteristics, 2012–2014, J. of Obesity (2019).

¹¹³⁶ Ely & Driscoll, *supra* note 1107, at 4.

¹¹³⁷ The only example the report gives—New York City—is for "maternal morbidity," not maternal mortality. Rep. at 26.

¹¹³⁸ See Petersen et al., supra note 1131, at 763.

that fully. Nevertheless, there are a number of things that are clear, some of which may be intuitive and others which may not be. Here are just a few:

(1) TWINS: Women who are bearing twins, triplets or more are more likely to suffer complications or death than women bearing a single child at a time. One multi-country study found the maternal mortality rate for twin birth was almost four times that for single births. Comparing the birthrates tabulated in the study shows that, for reasons I can't explain, non-Hispanic black mothers have a 22.5% higher twin birth rate than non-Hispanic white mothers. The non-Hispanic black birth rate for triplets or higher was 10.5% higher than the non-Hispanic white rate. On the other hand, the twin birth rate for Hispanic mothers was 26.34% lower than the rate for non-Hispanic white mothers, and the rate for triplets or more was 31.6% lower.

These data are consistent over the years and are in line with what I believe to be the maternal mortality rates by race and ethnicity for the four largest racial/ethnic groups in the country. It is worth pointing out that, given the lower Hispanic rate, the differing rates are unlikely to be caused by lower socio-economic status, the availability of insurance, or racism.

(2) HYPERTENSION: Hypertension is a huge risk factor for pregnancy-related mortality. Complications from hypertension for the mother can include preeclampsia, eclampsia, and stroke; for the infant: preterm delivery and low birth weight. 1143 I was not able to find statistics specific to pregnancy on this issue. I did find, however, that for women generally, rates of hypertension were as follows: non-Hispanic black (41.5%), non-Hispanic white (26.5%), Hispanic (26.2%), and non-Hispanic Asian (23.5%). These numbers may well overstate the rate of hypertension among women of childbearing age. But I have no evidence to suggest the racial disparities would be less striking. 1144

Note again that these figures are in line with maternal mortality rates by race and ethnicity with African Americans faring the worst, followed by whites, then by Hispanics, and finally by Asian Americans (assuming my belief that disaggregating Asians Americans from Pacific Islanders would put them in a somewhat better position than Hispanics is correct).

¹¹⁴² See id.

¹¹³⁹ See Danielly S. Santana et al., Twin Pregnancy and Severe Maternal Outcomes: The World Health Organization Multicountry Survey on Maternal and Newborn Health, 127 OBSTETRICS & GYNECOLOGY 631, 637 (2016).

¹¹⁴⁰ See Joyce A. Martin et al., *Births: Final Data for 2019*, NAT'L VITAL STAT. REP., Mar. 23, 2021, at 47 (tabulating twin and triplet and higher-order multiple births in the United States from 2010 to 2019 by race and Hispanic origin of mother).

¹¹⁴¹ See id.

¹¹⁴³ See High Blood Pressure During Pregnancy, CDC (May 6, 2021), https://www.cdc.gov/bloodpressure/pregnancy.htm.

¹¹⁴⁴ Sung Sug (Sarah) Yoon et al., *Hypertension Prevalence and Control Among Adults: United States, 2011–2014*, NAT'L CTR. FOR HEALTH STAT. DATA BRIEF, NOV. 2015, at 2–3.

Some have argued that African American hypertension rates are high because African Americans must put up with racism and racist micro-aggressions. But for a variety of reasons this seems unlikely to be the explanation for differences in rates. To begin with, hypertension (chronic high blood pressure) is not usually associated with anxiety. Anxiety causes temporary spikes in blood pressure, not hypertension. Moreover, the racial group most likely to be diagnosed with anxiety disorders appears to be whites, not African Americans. Similarly, it appears to be Hispanics, not African Americans who are most likely to be depressed. That makes it unlikely that racism is the explanation for African Americans being the outlier in hypertension rates.

It is also worth pointing out that suicide rates tend to detract from the argument that African Americans' hypertension rates are a reflection of uniquely difficult lives due to racism. Here we have reasonably reliable comparisons: Suicide rates are much higher for non-Hispanic whites (7.9 female / 28.2 male) than for non-Hispanic blacks (2.8 female / 11.4 male). Non-Hispanic Asian or Pacific Islander females commit suicide at a higher rate (3.9) than their non-Hispanic black counterparts, while non-Hispanic Asian or Pacific Islander males commit suicide at a lower rate (9.9). Hispanic rates of suicide (2.6 female / 11.2 male) are slightly lower than non-Hispanic black rates for both sexes. 1150

Note that suicide due to post-partum depression is not considered a pregnancy-related death under current recordkeeping practices and that, if it were considered, it would probably help shrink the black-white racial disparities we see today. Rep. at 6.

(3) DIABETES: Women with diabetes prior to their pregnancy are more likely to suffer complications or death than other women. According to National Vital Statistics Reports, non-Hispanic black mothers were 62.5% more likely to have been diagnosed pre-pregnancy with diabetes than non-Hispanic white mothers. American Indian or Alaska Native mothers were 212.5% more likely to have been so diagnosed. The figures

¹¹⁴⁵ See Sheldon G. Sheps, Anxiety: A Cause of High Blood Pressure?, MAYO CLINIC, https://www.mayoclinic.org/diseases-conditions/high-blood-pressure/expert-answers/anxiety/faq-20058549 ("Anxiety doesn't cause long-term high blood pressure (hypertension). But episodes of anxiety can cause dramatic,

temporary spikes in your blood pressure.").

1146 See Anu Asnaani et al., A Cross-Ethnic Comparison of Lifetime Prevalence Rates of Anxiety Disorders, 198 J.

Nervous & Mental Disease 551 (2010).

¹¹⁴⁷ See Dorothy D. Dunlop et al., Racial/Ethnic Differences in Rates of Depression Among Preretirement Adults, 93 Am. J. Pub. HEALTH 1945 (2003).

¹¹⁴⁸ Curtin & Hedegaard, supra note 1124, at 3-4.

¹¹⁴⁹ *Id*

¹¹⁵⁰ Id

¹¹⁵¹ See Diabetes and Pregnancy, CDC (July 14, 2020), https://www.cdc.gov/pregnancy/diabetes.html.

¹¹⁵² Joyce A. Martin et al., Births: Final Data for 2019, NAT'L VITAL STAT. REP., Mar. 23, 2021, at 31.

for Native Hawaiian or Other Pacific Islander, Hispanic and Asian mothers were 125%, 37.5%, and 25% higher respectively. 1153

These numbers, too, are in line with maternal mortality rates with the exception of the rate for whites, who fare better on diabetes relative to Asians and Hispanics than they did on hypertension. 1154

(4) OBESITY: Body weight is a risk factor that is related to diabetes and hypertension, but may also be independent of those factors. According to the National Vital Statistics Reports, 75.0% of Native Hawaiian or Other Pacific Islander mothers, 68.4% of American Indian or Alaska Native mothers, and 65.9% of non-Hispanic black mothers were obese or overweight (defined as a BMI of 25.0 or over). The corresponding figures for Hispanic, non-Hispanic white, and non-Hispanic Asian mothers were 63.2%, 52.2%, and 33.9% respectively. 1155

Note that these numbers are in line with the maternal mortality rates by race I have discussed so far with the exception of the rate for Hispanics, who were more likely to be "obese or overweight" than whites, but less likely to experience a pregnancy-related death.

Hardly anyone is foolish enough to call someone with a BMI of 25 "obese." I therefore wondered what the figures would look like if they were focused on what is much more likely to be called obesity (defined as a BMI of 30 or greater) or extreme obesity (defined as a BMI of 40 or greater). Would they be even more in line with the racial disparities in maternal mortality or would they be less in line?

I was not able to find mother-specific figures for obesity or extreme obesity (keeping the above definitions in mind). But I did find that 40.4% of American women are either obese or extremely obese, while 9.9% are extremely obese. 1156 The racial disparities

¹¹⁵³ Id.

¹¹⁵⁴ The report refers repeatedly to the fact that the maternal mortality rate is high even for college-educated African American mothers. E.g., Rep. at 23. To some, this is thought to be evidence for the notion that racism must be to blame. A more likely explanation is that some adverse medical conditions are higher among African Americans than among other Americans even after level of education is accounted for, possibly for genetic or other reasons not understood at this time. Diabetes is an example; it is usually less common the higher one goes on the educational ladder. The one exception I have found is for African Americans. According to one study, the incidence of diabetes among African Americans with a bachelor's degree or higher was 6.3, which was higher than the rate for African Americans with some college but no bachelor's degree (5.9). It is also higher than the incidence of diabetes in Non-Hispanic whites with only a high school diploma (6.0), some college but no bachelor's degree (4.3), or a bachelor's degree or higher (3.2) and for Hispanics with only a high school diploma (5.6), some college but no bachelor's degree (4.5), or a bachelor's degree or higher (3.5). Luisa N. Borrell et al., Education and Diabetes in a Racially & Ethnically Diverse Population, 96 AM. J. PUBLIC HEALTH 1637 (2006) ("Educational attainment was inversely associated with diabetes prevalence among Whites, Hispanics, and women but not among Blacks."). ¹¹⁵⁵ *Id*.

¹¹⁵⁶ See Overweight & Obesity Statistics, NAT'L Inst. of DIABETES AND DIGESTIVE AND KIDNEY DISEASES, https://www.niddk.nih.gov/health-information/health-statistics/overweight-obesity (last updated Aug. 2017).

were also mostly consistent with the racial disparities in maternal mortality: For example, African American adults are 33% more likely to be obese than Non-Hispanic whites and 63% more likely to suffer from extreme obesity. At the other extreme, non-Hispanic Asians are only about a third as likely as non-Hispanic whites to suffer from obesity and extreme obesity was too rare to be accurately measured in the study. But here's the interesting part: Hispanic adults are 17% *more* likely than non-Hispanic white adults to be obese, but they are 6.6% *less* likely to suffer from extreme obesity. For extreme obesity, therefore, the racial disparities are precisely in line with those of maternal mortality I have discussed with African Americans faring worst, then whites, then Hispanics and finally Asian Americans. While these statistics are hardly the last word on this topic, they are interesting. 1160

What does all this tell us? How can it help us reduce maternal mortality? As a lawyer rather than a medical professional, I am not in the best position to make concrete recommendations. The same is true of our Commission staff. Yet concrete recommendations are what's needed—most likely focused on factors like hypertension, diabetes, and obesity—not vague resolutions to spend more money or to do more research. Hospitals could paper the walls with government reports that generally recommend more research and spending. Reports like that are not much help in solving the problem.

One of the disappointing aspects of the report is its lack of curiosity about what the CDC meant when it estimated that 60% of pregnancy-related deaths are "preventable." Rep. at xiii. Preventable how? And by whom? Should pregnant women be encouraged to purchase home

¹¹⁵⁷ *Id*.

¹¹⁵⁸ See id.

¹¹⁵⁹ See id.

¹¹⁶⁰ A study dealing only with California yielded only slightly different results. It showed 14.9% of white California women delivering in 2007 were obese (BMI 30-40); 22% of black California women; and 20.3% of Hispanic California women. See Jonathan M. Snowden et al., The Impact of Maternal Obesity and Race/Ethnicity on Perinatal Outcomes: Independent and Joint Effects, 24 OBESITY (SILVER SPRING) 1590 (2016). On the other hand, 2.6% of white California women delivering in 2007 were a BMI of above 40; 5.7% of black California women; and 2.8% of Hispanic California women. Id. Obesity in Asian California women was comparatively negligible. See id. In both cases, the Hispanic rate of obesity (BMI 30-40) was well above the white rate, but the Hispanic rate of extreme obesity (BMI above 40) was very close to the white rate. Id.

¹¹⁶¹ When the CDC says a death was preventable, it does not mean that medical professionals are responsible. For example, the CDC calls smoking the number 1 cause of preventable death. See The Health Consequences of Smoking—50 Years of Progress. A Report of the Surgeon General, U.S. DEP'T OF HEALTH & HUMAN SERV. (2014) ("Most smokers visiting health care settings are now routinely asked and advised about tobacco use. On the other hand, cigarette smoking remains the chief preventable killer in America, with more than 40 million Americans caught in a web of tobacco dependence."). That's not something a doctor or nurse can do for a patient. They can recommend, cajole, and even prescribe ways to make quitting easier, but in the end, it's up to the individual patient to quit.

blood pressure monitors and report their readings each day to their doctors? Should doctors be more aggressive in prescribing anti-hypertensive drugs? Should they counsel extremely obese women to lose weight before they get pregnant? Should they counsel ultrahigh-risk women not to have children?

D. IT IS COUNTERPRODUCTIVE TO DIVERT ATTENTION AWAY FROM THE FACTORS THAT LEAD TO MATERNAL MORTALITY WITH VAGUE CLAIMS OF RACISM. WE SHOULD NOT BE TRYING TO CAUSE AFRICAN AMERICAN AND OTHER MINORITY MOTHERS TO VIEW THE MEDICAL PROFESSION WITH UNWARRANTED SUSPICION.

It is fashionable these days to attribute nearly everything to racism. Much—from Italian fashion to Trader Joe's 1163—has been alleged to be racist.

¹¹⁶² Blood pressure monitors are available on Amazon for less than \$20. Should doctors provide them at no additional charge?

2017), https://www.vice.com/en/article/evb4zw/why-so-many-white-supremacists-are-into-veganism; Cecilia D'Anastasio, D&D Must Grapple With the Racism in Fantasy, WIRED (Jan. 24, 2021, 7:00 AM), https://www.wired.com/story/dandd-must-grapple-with-the-racism-in-fantasy; Lisa Selin Davis, The Racist History of Celebrating the American Tomboy, LIT. HUB (Aug. 11, 2020), https://lithub.com/the-racist-history-of-celebratingthe-american-tomboy; Devin Dwyer & Stephanie Ebbs, America's national parks face existential crisis over rates, ABC News (July 1, 2020), https://abcnews.go.com/Politics/americas-national-parks-face-existential-crisisrace/story?id=71528972; Margaret Eby, The Difference Between Yams and Sweet Potatoes Is Structural Racism, FOOD & WINE, https://www.foodandwine.com/vegetables/the-difference-between-yams-and-sweet-potatoes-isstructural-racism (last updated Feb. 6, 2020); Jenny Gross, A Jane Austen Museum Wants to Discuss Slavery, Will Her Fans Listen?, N.Y. TIMES (Apr. 27, 2021), https://www.nytimes.com/2021/04/27/world/europe/jane-austenslavery-museum.html; Jenn M. Jackson, Women Have Always Been a Part of White Supremacy, TEEN VOGUE (July 1, 2020), https://www.teenvogue.com/story/women-white-supremacy-history-america; Tamari Kitossa, How Hollywood's 'Alien' and 'Predator' Movies Reinforce Anti-Black Racism, CONVERSATION (Aug. 16, 2020, 8:12 AM), https://theconversation.com/how-hollywoods-alien-and-predator-movies-reinforce-anti-black-racism-127088; Harmon Leon, Why Are So Many Robots White? Study Shows There's a Racial Bias, OBSERVER (Aug. 9, 2019), https://observer.com/2019/08/robot-racial-bias-study; Julia Lurie, This is How Racist Your Air Is, MOTHER JONES (Apr. 28, 2014), https://www.motherjones.com/environment/2014/04/air-pollution-racial-disparities; Jack Malvern, Why Mozart is a Singular 'Symbol of the White Patriarchy', THE TIMES (Oct. 28, 2020), https://www.thetimes.co.uk/article/why-mozart-is-symbol-of-the-white-patriarchy-580vpwl73; Mark Pratt, 6 Dr.

¹¹⁶³ In recent years, charges of racism have been leveled at the filibuster in the U.S. Senate, the Texas Rangers, weight loss, the "yoga-industrial-complex," Italian fashion, veganism, Dungeons & Dragons, the celebration of American tomboys, the National Park System, the interchangeability of yams and sweet potatoes, Jane Austen, women, the films "Alien" and "Predator," robots, the air we breathe, Wolfgang Mozart, several Dr. Seuss books, fried chicken, Western Philosophy, and Trader Joe's. See Mike Allen, AXIOS: AXIOS AM (Mar. 18, 2021), https://www.axios.com/newsletters/axios-am-c514b18c-70bf-4fa3-8f67-6553d4757246.html ("Sen. Elizabeth Warren told Alayna Treene the Senate's legislative filibuster, which requires 60 votes for most legislation, wasn't a creation of the founding fathers . . . 'The filibuster has deep roots in racism, and it should not be permitted to serve that function, or to create or to create a veto for the minority. In a democracy, it's majority rules.""); Karen Attiah, The Texas Rangers' Team Name Must Go, WASH. POST (July 13, 2020, 12:06 PM), https://www.washingtonpost.com/opinions/2020/07/13/texas-rangers-team-name-must-go; Lindo Bacon & Sabrina Strings, The Racist Roots of Fighting Obesity, SCI. AM. (July 2020), https://www.scientificamerican.com/article/theracist-roots-of-fighting-obesity2; Susanna Barataki, How to Decolonize Your Yoga Practice, DECOLONIZING YOGA (Feb. 7, 2015), https://decolonizingyoga.com/decolonize-yoga-practice; Soffia Bettiza, Is Italian fashion racist?, BBC NEWS (Sept. 8, 2020), https://www.bbc.com/news/av/world-europe-54061928; Alexis de Coning, Why So Many White Supremacists Are into Veganism, VICE (Oct. 23,

The report is replete with such allegations. 1164 Most, if not all, are in the form of quotes from individuals who purport to be experts on the topic. In addition to the quotes from Dr. Joia Crear-Perry and Jonathan Webb cited above, there are many others in the report alleging racism: Ndidiamaka Amutah-Onukagha, Assistant Dean for Diversity, Equity & Inclusion and Associate Professor of Public Health and Community Medicine at Tufts Medical School is quoted about how "racism is embedded in the healthcare system." Rep. at 29. Congresswoman Ayanna Pressley is quoted expressing similar sentiments: "[T]he fact that my grandmother died in childbirth in the 1950s and Black women are four times more likely to still die really is just, you know, condemnation and confirmation of the embedded biases and systemic racism throughout our healthcare system." Rep. at 64. Dr. Taraneh Shirazian is quoted noting that "[s]ystemic racism is one of the challenges affecting Black women and maternal mortality in New York State." Rep. at 60. Even during the Commission's public business meeting one commissioner attributed racial disparities to "structural racism in our healthcare system" and stated that "black women are treated differently in the maternity ward than others in terms of being listened to, and recognized as custodians of their own care, and advocates of their own care." 1165

The following quote from an article by Deirdre Cooper Owens and Sharla M. Fett particularly caught my eye, since it attempts to focus attention away from factors that directly increase the likelihood of maternal death:

It seems that, rather than addressing systemic racism in obstetrics and gynecology, medical practitioners have instead to some extent emphasized all the ways Black women allegedly make themselves prone to being ill during their pregnancies. Black pregnant women and non-gender binary folks are told their fatness, advanced age, dietary choice,

Seuss Books Won't Be Published for Racist Images, A.P. (Mar. 2, 2021), https://apnews.com/article/dr-seuss-books-racist-images-d8ed18335c03319d72f443594c174513; Melissa Thompson, I've always loved fried chicken. But the racism surrounding it shamed me, GUARDIAN (Oct. 13, 2020), https://www.theguardian.com/food/2020/oct/13/ive-always-loved-fried-chicken-but-the-racism-surrounding-it-shamed-me; Bryan W. Van Norden, Western Philosophy is Racist, AEON (Oct. 31, 2017) https://www.the-western-philosophical-canon-is-xenophobic-and-racist; Jenny G. Zhang, Trader Joe's to Remove Product Names Like Trader José and Trader Ming's Following Accusations of Racism, EATER (Jul. 21, 2020, 11:33 AM), https://www.eater.com/2020/7/21/21332645/trader-joes-changes-racist-product-names-branding-online-petition.

1164 One of the most puzzling suggestions of racism in the report is Dr. Crear-Perry's remark that "black and brown bodies" are at a disadvantage because they are more likely to be treated at a teaching hospital. She objects that we are taking the patients that "actually need the most" and "sending them to places where there is training," and she mentioned Grady Memorial Hospital in Atlanta as an example. Rep. at 50. All my life I've been told that teaching hospitals—hospitals that are associated with a medical school—tend to be the best hospitals. (And indeed my family actively tried to get my father transferred to a teaching hospital when he was gravely ill.) A 2002 study reviewed the empirical literature comparing teaching hospitals to ordinary hospitals. The strong weight of the evidence was that teaching hospitals—particularly major teaching hospitals like Grady—are at least as good as ordinary hospitals and frequently better on most measures of quality. Of course, nearly everyone understands that teaching hospitals excel at rare and cutting edge medical treatments and research. It was useful to know that they also frequently excel at routine treatments as well. John Z. Ayanian & Joel S. Weissman, *Teaching Hospitals and Quality of Care: A Review of the Literature*, 80 MILBANK Q. 569 (2002).

¹¹⁶⁵ Transcript, *supra* note 1107, at 24 (quoting Commissioner Yaki).

and lack of prenatal care have increased their chances of dying during childbirth. Yet, whereas Black pregnant people and mothers are made into culprits and the initiators of their deaths, doctors, nurses and the hospitals they run are not looked at as critically as they should be. 1166

Rep. at 61. If the goal is to reduce deaths, it is not clear that focusing attention away from the factors Owens and Fett identify is a good idea. ¹¹⁶⁷ I have similar concerns over Congresswoman Ayanna Pressley's recommendation in her testimony before the Commission. Rep. at 125. She stated there that Congress should declare racism a "public health crisis" and create a national center for anti-racism within the CDC. ¹¹⁶⁸ This approach, too, seems ill-suited to saving lives. It works well, however, if the goal is to attract the applause of Americans for whom ideology has become more important than saving lives.

Unfortunately, this report is not the only place one finds vague allegations of "racism" cited as the cause for racial disparities in maternal death. Here in San Diego County, where I reside, billboards and posters have been popping up with photographs of African American mothers with the following message:

Our black mothers are 3x more likely to die during pregnancy because of racial bias.

¹¹⁶⁶ Deirdre Cooper Owens & Sharla M. Fett, *Black Maternal and Infant Health: Historical Legacies of Slavery*, 109 Am. J. Pub. Health 1342 (2019).

A similar sentiment is taken from a written statement submitted to the Commission by Nicolle L. Gonzales, Medical Director & Founder of the Changing Woman Initiative:

Not only do Native American women experience disproportionately higher maternal mortality rates then [sic] white or Hispanic women, they are portrayed in the data like it is there [sic] fault for not accessing prenatal care in the first trimester, or that they have higher rates of obesity and diabetes—when needed services, education, access to clean water, healthy foods, and adequately funded services are lacking, across the nations.

Rep. at 1. Jonathan Webb appears to agree. He is quoted in the report this way:

If we are looking to really advance racial equity, we need to shift our conversation from eliminating racial and ethnic disparities in maternal and infant health specifically—which continues a focus and blame on people—to eliminating the systemic, structural, and institutional inequities that produce the racial disparities. We also need to acknowledge that these systems, structures, and institutions were not created to produce equitable outcomes for Black, Indigenous, Latinx, Pacific Islanders, and other People of Color. They are products of systems created over time that create an advantaged group and a disadvantaged group, in part because communities of color have not had a seat at the table in the creation of these systems.

Rep. at 54.

¹¹⁶⁷ With obesity, hypertension and diabetes, it isn't a matter of being made into "culprits." Some bodies have all the luck and can keep off weight and avoid hypertension and diabetes seemingly without effort. Most of us are not so lucky. We all have to play the cards we're dealt. One role physicians, nurses and other health professionals have traditionally played is to advise their patients on how to best play those cards. They shouldn't be discouraged from fulfilling that role.

¹¹⁶⁸ Since giving her testimony, she has sponsored such a bill. Anti-Racism in Public Health Act of 2021, H.R. 666, 117th Cong. (2021) (establishing "within the [CDC] a National Center on Antiracism and Health and a law enforcement violence prevention program. . . . [which] must declare racism a public health crisis, collect and analyze data, and administer research and grant programs to address racism and its impact on health and well-being.").

Others contain similar messages: "Our black infants are 3x more likely to die **because of racial bias**;" "Our babies are 60% more likely to be premature **due to discrimination**;" and "**Racism hurts your baby** long before they are born."

The boldface type is in the original; I have not added it.

These posters and billboards are part of a campaign—titled Black Legacy Now—funded by the County of San Diego. ¹¹⁶⁹ They were rolled out with great fanfare this past January.

What is the point of the accusations of racism, racial bias, and discrimination? I find it hard to imagine why someone would make such claims if he or she is motivated by a desire to reduce maternal and infant deaths among African Americans. If anything these messages will make things worse. They will tend to frighten African American (and possibly other minority) mothers into being unduly suspicious of medical care providers. That's not a step in the right direction. 1170

It is well established that African American mothers are less likely than other mothers to see a doctor early in their pregnancies. As far as I know, no one has studied exactly why. But this lack of early medical attention probably accounts for some portion of the high rate of maternal mortality among that group. Suggesting to these mothers that the medical profession is racist is unlikely to make them seek that help more readily. More likely it will do the opposite.

The problem is not just with pregnancy-related medical attention. African Americans are also less likely to seek to be vaccinated against COVID-19 than other Americans. As of May, CDC data showed that only 22% of blacks had received a shot. On the other hand, by then, 45% of American Indians, 41% of Asians, 33% of whites, and 29% of Hispanics had received at least one shot. This is not because African Americans are less likely to be insured or to have the financial resources to pay for the shots. The shots are free. Part of the reason is almost certainly a lack of trust in the medical establishment.

¹¹⁶⁹ See generally The Issue, BLACK Legacy NOW, https://blacklegacynowsd.com/ (last visited Aug. 13, 2021).

¹¹⁷⁰ In his Statement, Commissioner Gilchrist writes, "Now do I believe health care providers are intentionally trying to kill women and singling out Black women in particular? Absolutely not!" I fear, however, that this report does not make that sentiment clear and will continue to contribute to the fear campaign.

¹¹⁷¹ The difference does not appear to be simply a result of fewer resources to devote to medical care (though that may be a factor). Planned pregnancies are more likely to result in prompt medical attention than unplanned pregnancies. In 2011, the rate of unplanned pregnancies among non-Hispanic blacks was 79 per 1,000 women ages 15–44. Lawrence B. Finer & Mia R. Zolna, *Declines in Unintended Pregnancy in the United States, 2008–2011*, 374 NEW ENG. J. OF MED. 843 (2016). For non-Hispanic whites, the rate was less than half that—33 per 1,000. *Id.*

¹¹⁷² See Amelia M. Jamison et al., "You Don't Trust a Government Vaccine": Narratives of Institutional Trust and Influenza Vaccination among African American and White Adults, 221 Soc. Sci. & Med. 87 (2019).

¹¹⁷³ Hannah Recht et al., *Stark Racial Disparities Persist in Vaccinations, State-Level CDC Data Shows*, WEBMD (May 20, 2021), https://www.webmd.com/vaccines/covid-19-vaccine/news/20210520/racial-disparities-persist-in-vaccinations-cdc-data-shows.

This lack of trust in the medical profession in general is likely hurting African Americans in other ways too. In one study of privately insured patients, African Americans (and other minorities too) failed to follow through with instructions to take medicine more often than whites did. ¹¹⁷⁴ In that study, African Americans were 38.9% more likely to fail to take a prescribed anti-hypertensive as directed. ¹¹⁷⁵ Similarly, they were 32.5% more likely to fail to take an oral anti-diabetic as directed. ¹¹⁷⁶ The reason for this unlikely to be lack of financial resources, since all the patients in the study were privately insured. Instead, lack of trust in a doctor's recommendation may be playing a significant role. Hypertension and diabetes are unseen killers. It's easy for a patient who distrusts the doctor's advice to decide treatment is unnecessary or undesirable. That kind of distrust can be deadly.

At press conference launching The Black Legacy Now project held on January 29, 2021, one woman working on the project spoke as follows: "When I was pregnant it was complicated finding care. I especially wanted a black OB/GYN to deliver my baby. And [it's] very hard to find one in San Diego. I finally found care with a team of midwives and doulas." 1177

Everyone should be able to agree that delays in seeking medical attention in the early stages of pregnancy are undesirable. But when the delay is motivated by the patient's desire to find a doctor who is of a particular race, it is also ill-advised. San Diego County is only about 5% African American, which is less than half the proportion of the country as a whole. It is thus not a surprise that there are not a lot of black OB/GYNs here. Like the rest of the country, we have a shortage of OB/GYNs generally. Why tell African American mothers things that may cause them to want to limit themselves to OB/GYNs of their own race? Why make finding an OB/GYN that much more difficult?

¹¹⁷⁴ See Zhiwen Xie et al., Racial and Ethnic Disparities in Medication Adherence Among Privately Insured Patients in the United States, 14 PLOS ONE (2019) (numbers derived from Table 2, which give adherence rates rather than non-adherence rates).

¹¹⁷⁵ *Id*.

¹¹⁷⁶ *Id*.

¹¹⁷⁷ Countysandiego, *Black Legacy Now Campaign Launches In San Diego County*, YOUTUBE (Jan. 29, 2021), https://www.youtube.com/watch?v=OzZq2NXMrLY.

¹¹⁷⁸ It is worth noting, however, that, nationwide, African Americans are only slightly under-represented among OB/GYNs relative to their numbers in the population at large. They are 11.1% of OB/GYNs, while 13.4% of the population at large. William F. Rayburn et al., *Racial and Ethnic Differences Between Obstetrician-Gynecologists and Other Adult Medical Specialists*, 127 OBSTETRICS & GYNECOLOGY 148 (2016). Compared to the other specialties studied in that article (family medicine, general internal medicine, emergency medicine, and general surgery), obstetrics & gynecology had more African Americans.

¹¹⁷⁹ The American Colleges of Obstetricians and Gynecologists predicted in 2017 this would result in 8,000 fewer practitioners than needed by 2020. I have seen no data suggesting that this prediction was not fulfilled. *See* DOXIMITY, 2019 OB-GYN WORKFORCE STUDY 3 (Sept. 2019).

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DISSENTING STATEMENT OF COMMISSIONER PETER KIRSANOW

All untimely deaths are tragic. The tragedy is especially poignant when the decedent is a new or expectant mother. The death is tragic regardless of the mother's race. Unfortunately, nothing in the testimony received by the Commission or the research compiled by our staff has persuaded me that there is a civil rights issue here, much less that there is anything the Commission can recommend to reduce maternal mortality or racial disparities in maternal mortality.

This report is pushing a narrative. The narrative is that black women (and to a lesser extent other minority women) are dying of pregnancy-related causes in staggering numbers due to racism, whereas white women rarely die of pregnancy-related causes. The report pushes a story of "white women doing well, black women doing poorly due to nefarious forces." In reality, for the most recent year in which data is available, non-Hispanic black women experienced 37.1 maternal deaths per 100,000 live births, non-Hispanic white women experienced 14.7 maternal deaths per 100,000 live births, and Hispanic women experienced 11.8 maternal deaths per 100,000 live births. In other words, Hispanic women have the *lowest* rates of maternal mortality of the three largest racial/ethnic groups. This is an inconvenient fact, one the report does its best to obscure by stating "[p]regnancy-related mortality is slightly elevated . . . for Hispanic women in some geographic areas" and otherwise drawing no attention to the disparity between white and Hispanic outcomes.

Why would the report deliberately obfuscate the data in this way? Because the Commission is committed to the narrative that the comparatively poor maternal outcomes of black women are due to "systemic racism." The fact that Hispanic women have better maternal mortality outcomes than white women undercuts this claim.

The emotional, sweeping language used by the report and by witnesses at the Commission briefing would lead one to believe that thousands of black women are dying of pregnancy-related causes every year. In fact, according to the CDC, there are approximately 700 maternal deaths per year.1182 Every one of those deaths is a great loss. Nonetheless, it is 700 deaths in a nation of 330 million. Approximately 60% of those deaths are theoretically preventable (I say "theoretically" because if there is a world in which symptoms are never misdiagnosed, patients never tell themselves, "It'll be fine, no need to go to the emergency room," and doctors do not choose a treatment that turns out to be sub-optimal, we are not living in it.) This leads to the inescapable conclusion that 40% of those deaths are *not* preventable. The best-case scenario is

¹¹⁸⁰ Amy Branum, Ph.D, *Mortality Data Release: Maternal Mortality Data Highlight*, NAT'L CTR. FOR HEALTH STAT., at 18 (Jan. 30, 2020), https://www.cdc.gov/nchs/maternal-mortality/2018-mortality-data-webinar-508.pdf. ¹¹⁸¹ Report at n. 16.

¹¹⁸² Emily E. Petersen, MD, et al., *Racial/Ethnic Disparities in Pregnancy-Related Deaths* — *United States*, 2007–2016, 68 MORBIDITY AND MORTALITY WKLY. REP 762, 763. (Sept. 6, 2019), https://www.cdc.gov/mmwr/volumes/68/wr/mm6835a3.htm?s_cid=mm6835a3_w.

that the U.S. will experience 280 maternal deaths per year. This is an improvement over 700 deaths per year, but readers should not imagine that we will ever reach zero. 1183

It should first be acknowledged that the most the combined forces of the health care system, scientific community, and the federal government can achieve is 420 fewer maternal deaths per year. It is unclear how the U.S. Commission on Civil Rights can contribute to this effort, beyond "raising awareness" of an issue that is already attracting a great deal of attention from the medical community.

The Commission, however, is uninterested in maternal mortality as a stand-alone issue. It is interested in it because black women, in particular, have much higher rates of maternal mortality than white women. If white women had higher rates of maternal mortality than black women, the Commission likely would have little interest at all in this topic. As noted, white women *do* have higher rates of maternal mortality than Hispanic women, a fact that the report is at pains to minimize.

According to data shared with the CDC by 14 state maternal mortality review committees (MMRCs), *white* women accounted for the largest share of preventable deaths. According to the MMRCs, 61.8% of Hispanic pregnancy-related deaths (21 women) were preventable, 63.0% of non-Hispanic black pregnancy-related deaths were preventable (87 women), and 68.2% of non-Hispanic white pregnancy-related deaths were preventable (103 women). 1184

In other words, if we could somehow prevent all pregnancy-related deaths that were deemed "preventable," the white/black racial disparity in maternal mortality rates would increase, not decrease. More women of all races would be alive, which would be a wonderful thing, but the racial disparity would persist. The Commission report, however, states "preventability does not differ by race." Preventability does not differ significantly, but it does differ, which matters when the concern centers around a racial disparity.

It is also worth noting that racial disparities in maternal mortality are what you might expect if you simply examined overall death rates in the United States. According to CDC data, from 2000-2017 (the most recent year for which data has been released), every year the age-specific death rate for adults age 25 and older has been lowest for Hispanics, with whites in the middle, and blacks the highest. For example, in 2017, the age specific death rate for Hispanics age 25 and

¹¹⁸³ Emily E. Petersen, MD, et al., *Vital Signs: Pregnancy-Related Deaths, United States, 2011–2015, and Strategies for Prevention, 13 States, 2013–2017*, 68 MORBIDITY AND MORTALITY WKLY. Rep 423 (May 10, 2019), https://www.cdc.gov/mmwr/volumes/68/wr/pdfs/mm6818e1-H.pdf.

¹¹⁸⁴ N.L. Davis, et al., *Pregnancy-Related Deaths: Data from 14 U.S. Maternal Mortality Review Committees, 2008-2017*, NAT'L CTR. FOR CHRONIC DISEASE PREVENTION 3 tbl.4 (2019), https://www.cdc.gov/reproductivehealth/maternal-mortality/erase-mm/MMR-Data-Brief 2019-h.pdf.

¹¹⁸⁵ Report at n. 26.

older was 108.1 per 100,000. For whites, it was 175.1 per 100,000, and for blacks, it was 234.7 per 100,000.

Neither the Commission report nor the witness testimony provided any evidence that doctors and hospitals are specifically discriminating against black women on the basis of race. The report includes conclusory statements from witnesses such as Dr. Joia Crear-Perry, who stated, "We know the root causes of poor maternal health—racism and gender oppression inside of healthcare systems and every other facet of society. Women of color are more likely to experience a comorbid illness and report being unfairly treated within healthcare settings based on their race or ethnicity." 1186

"Racism and gender oppression inside of healthcare systems and every other facet of society." Well. That does sound bad. Yet the panelists were unable to provide any specific examples of widespread *racism* in the provision of healthcare, even when asked directly. During the briefing, I asked the members of the first panel:

COMMISSIONER KIRSANOW: Several panelists have testified that structural and systemic racism is one of the principal causes of maternal health care disparity. Can, and this is to anybody, can anyone give me specific examples of what you mean by systemic and structural, invidious racism or racial discrimination in systemic structures and medical systems that cause maternal health care disparities on the basis of race?

DR. CREAR-PERRY: This is my life all day. I feel like I can't help but start.

So, and the specific example is, how we structure even the policies around who gets access to care. As an OB/GYN, many of us trained in the hospitals and facilities where there were only black and brown bodies. We assume, still, the legacy of history of eugenics that the people who we have to train on have to be, are communities of color, right?

So if you go to any place in your cities, in your town, the hospital training institutions are black and brown bodies. So what would it look like to be a structural system that said, training doesn't mean black and brown, training doesn't mean poor people, training doesn't mean non-centered people.

If we trained, we invest in, ensure that the people who need the most resources, so those communities, if you're talking Charity Hospital, where I train, or Grady Hospital in Atlanta, those patients actually need the most. They are the most complex patients and we are sending them to places where there is training.

¹¹⁸⁶ Report at n. 27.

We're not investing in those institutions so both Charity and Grady are always struggling to get budget, that's racism, that's structural. They're begging for money to even keep their doors open, and yet we're sending the most complex patients to those centers. So, over and over again.

Then we get poor outcomes. And we're trying to figure out, well, where do poor outcomes come from.

We're never invested in the people who actually need continuity, who need a birth center in their community led by a midwife, have a doula supporting them from their community who's invested in them. That's what they want, that's what we should be investing in.

That's a structural decision that we are making as policy makers to not allow for the growth of birth centers, the growth of midwives, the growth of doulas. That's how structuralism works.

It devalues groups of people, and also institutions, and invest in things that are harmful to support the legacy and hierarchy of White supremacy.

DR. SHIRAZIAN: Yes. I mean, I completely agree with Dr. Crear-Perry in terms of like how our health care infrastructure is setup, I'm also an OB/GYN, in how systems are setup.

I can just give you a few examples from a very like personal perspective. Not my lived experience, but certainly the community health workers that I work with and what they tell me. And what I actually see as well.

So, if you're a patient. So I'm just going to give you like an individual patient kind of perspective. But if you're a Black pregnant woman and you come into a clinic, let's say, in New York City, and you have to wait eight hours in the waiting room for care, that is structural and implicit racism right there.

Because that, you know, that waiting room, it just devalues that patient, right? She has to wait nine hours to see a doctor. The clinic is busy.

When she sees the doctor, the doctor gives her five minutes to talk to her, to answer any questions. Maybe she's not a sophisticated speaker, presenter. She can't even get out her issues or complaints. Maybe she doesn't know how to articulate them.

You know, brings in issues of health literacy and how she's heard. Whether the doctor hears her, whether he or she understands what she's saying, whether they bother to listen.

So, I mean, those are just some very simple examples. But I think from an individual patient perspective, if you go into those clinics and hospitals or you go to see your doctor and you don't feel valued, you don't feel respected, you don't feel listened to, why would you ever go back. Like, why would you go back if you have a true problem, you're going to stay home.

And that's where we see, sometimes maternal deaths happening because people don't come back in that quickly. I mentioned before, most maternal deaths, at least looking nationally at the data, they happen before delivery or in that first week postpartum.

So if you go home and you had a horrible birth experience and now you have pain in your leg that could be a blood clot, you're not going to raise your hand to go in and see the doctor, you're going to call your friend, someone in your community. Maybe that front-line health care provider.

That's why I say, a lot of the solution lies in the communities because people, women trust their community leaders, they trust their community health providers.

And until there is a day where they can also trust their clinics and their hospitals to listen to them and be respectful and not make them wait for hours, you know, that system is going to take a long time to change. So that's why I always say, community first, educate the community, empower the community, the results lie there. 1187

So the responses to my question regarding examples of systemic racism essentially boiled down to "black women are poor". Some of their statements also seem to be in tension with each other. Dr. Crear-Perry said it is racism that many pregnant black women wind up going to teaching hospitals, even though they are the most complex cases. First, if they are presenting as the most complex cases, it is unsurprising that they might have the worst pregnancy outcomes, regardless of what hospital they go to. Second, if the problem is that these women with high-risk pregnancies are being sent to supposedly lesser hospitals, it does not follow that the solution is to establish more birthing centers run by *midwives*. Surely you would want these complex cases to be at hospitals where there is equipment for emergency Caesarean sections, NICUs, etc.

It is fairly easy to predict what will happen if federal or state governments fund birthing centers to cater to black women and the black maternal mortality rate does not improve. In ten years, our successors on this Commission will be back here listening to witnesses explain that the disparity is due to black women being funneled to birthing centers run by midwives, whereas white women go to hospitals where they are treated by MDs. "The fact that white women are treated by MDs, whereas women of color are shunted to birthing centers where they are treated by midwives who have less formal training, is an example of this country's pervasive racism and white supremacy," the witness will intone.

I asked a similar question later in the briefing.

COMMISSIONER KIRSANOW: I'm trying to further isolate and identify those factors that could yield optimal outcomes for pregnant women and those about to give birth.

¹¹⁸⁷ Briefing transcript at 92-96.

Can you or does anyone have any idea of the why – What are the factors that result in Asian-American women having better outcomes than white women? Anybody?

MS. PORCHIA-ALBERT: I mean if we want to speak from a — We could speak to colorism and speak to the way in which people sometimes, you know, how Asian-Americans are often times treated as our white counterparts if we want to talk about that, right, because what we are talking about here on the panel is racial discrimination and bias and the ways in which [it] shows up and particular around melanated people and those melanated discriminations are something that are far and vast and wide so we can't pinpoint it to one.

One could say, oh, it was just chronic health conditions, but chronic health conditions are a bypart of what has happened systemically centered around structural and institutional racism, right.

We could say, oh, well, you know, it's because they are low income or they have a particular literacy level, but we have also seen that regardless of literacy level, regardless of income, it's that we still are seeing the same poor outcomes.

So one must say that then the diagnosis has to be then that it goes far deeper than that, right. It goes into the ways in which people's humanity is centered at bedside. 1188

Once again, no one was able to provide an example of actual explicit or implicit racial bias. This particular witness claimed that "chronic health conditions" are also due to structural and institutional racism. That's interesting. Pulmonary embolisms are one of the most common causes of death among black women (10.9%). Studies suggest that susceptibility to venous thromboembolism (VTE), which includes both deep vein thrombosis and pulmonary embolism, is highly heritable, "with approximately 50-60% of the variance in VTE prevalence attributed to genetic effects." Although confounding factors make it difficult to reach a firm conclusion, "The risk of incident VTE is also thought to differ by race, with the highest risk thought to be among Black individuals, then White individuals, and the lowest risk among Asian or Hispanic individuals." Individuals.

Likewise, African-Americans are more likely to develop Type 2 diabetes than are whites. ¹¹⁹² The reason for this is unclear, although obesity is also a risk factor for developing diabetes and nearly

¹¹⁸⁸ Briefing transcript at 148-49.

¹¹⁸⁹ Report at Table 1.9.

¹¹⁹⁰ Marta Crous-Bou, et al., *Environmental and genetic risk factors associated with venous thromboembolism*, 42 SEMINARS IN THROMBOSIS AND HEMOSTASIS 808 (Nov. 2016), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5146955/.

¹¹⁹¹ *Id*.

¹¹⁹² Elias K. Spanakis and Sherita Hill Golden, *Race/Ethnic Difference in Diabetes and Diabetic Complications*, 13 CURRENT DIABETES REPORTS 814 (Sept. 15, 2013), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3830901/.

half of African-Americans are obese.¹¹⁹³ Obesity and diabetes can both contribute to cardiovascular problems and complex pregnancies. Our witnesses, of course, might claim that this too is evidence of systemic racism. These days, "racism" appears to be the explanation for everything, from genetics to why the sun rises in the east.

And yet even the prevalence of obesity and diabetes do not tell the full story. Both conditions are more prevalent among Hispanics than among whites, yet Hispanic women still have lower maternal mortality than white women.

In short, maternal mortality is a complex issue with multiple genetic, biological, and environmental factors in play. The Commission has added nothing to the sum total of knowledge on these topics. What it has done is proved a negative: Even our panelists offered no specific evidence that black women are being subjected to discriminatory treatment when they seek prenatal and delivery care.

¹¹⁹³ Craig M. Hales, et al., *Prevalence of Obesity and Severe Obesity Among Adults: United States, 2017-2018*, 360 NAT'L CTR. FOR HEALTH STAT. DATA BRIEF 1 (Feb. 2020), https://www.cdc.gov/nchs/data/databriefs/db360-h.pdf.

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APPENDIX A: LINKS TO WRITTEN TESTIMONY

<u>Jennifer E. Moore, Ph.D., R.N., F.A.A.N. – Founding Executive Director, Institute for Medicaid Innovation</u>

Shanna Cox, M.S.P.H. – Associate Director for Science, Division of Reproductive Health, Center for Disease Control and Prevention

Shannon Dowler, M.D. – Chief Medical Officer, North Carolina Medicaid

<u>Angela Doyinsola Aina, M.P.H. – Co-Founding Executive Director, Black Mamas Matter</u> Alliance

<u>Joia Adele Crear-Perry, M.D., F.A.C.O.G. – Founder and President, National Birth Equity</u> Collaborative

<u>Taraneh Shirazian, M.D., F.A.C.O.G. – President and Medical Director, Saving Mothers;</u> Associate Professor of OBGYN, Director of Global Women's Health, NYU Langone Health

Mauricio Leone, M.P.A. - Chief Operating Officer and Senior Director, Obria Group

Nan Strauss - Managing Director, Policy, Advocacy & Grantmaking, Every Mother Counts

<u>Jennifer Jacoby – Federal Policy Counsel, U.S. Policy and Advocacy Program, Center for Reproductive Rights</u>

Nicolle L. Gonzales, B.S.N., R.N., M.S.N., C.N.M. – Executive Director and Founder, Changing Women Initiative

<u>Juanita Chinn - Program Director, Population Dynamics Branch, Division of Extramural</u>
Research, Eunice Kennedy Shriver National Institute of Child Health and Human Development

Jonathan Webb - CEO, Association of Maternal and Child Health Programs

Ndidiamaka Amutah-Onukagha - Associate Professor of Public Health and Community Medicine, Tufts University School of Medicine

Elizabeth A. Howell - Director, The Blavatnik Family Women's Health Research Institute

Dr. Melanie Rouse, M.D. - Maternal Mortality Projects Manager, Virginia Department of Health, Office of the Chief Medical Examiner

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APPENDIX B: LINKS TO PUBLIC COMMENTS RECEIVED BY THE COMMISSION

American College of Obstetricians and Gynecologists

<u>U.S. House of Representatives Black Maternal Health Caucus – U.S. Representatives Adams and Underwood</u>

Individual Public Comment 1

Individual Public Comment 2

<u>Individual Public Comment 3</u>

Individual Public Comment 4

National Indian Health Board

National Women's Law Center

Triangle Black Maternal Wellness Collaborative

Upstream USA

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APPENDIX C: BRIEFING TRANSCRIPT

U.S. COMMISSION ON CIVIL RIGHTS

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PUBLIC BRIEFING

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RACIAL DISPARITIES IN MATERNAL HEALTH

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FRIDAY, NOVEMBER 13, 2020

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The Commission convened via videoconference at 10:00 a.m. EST, Catherine Lhamon, Chair, presiding.

PRESENT:

CATHERINE E. LHAMON, Chair

DEBO P. ADEGBILE, Commissioner

STEPHEN GILCHRIST, Commissioner

GAIL HERIOT, Commissioner

PETER N. KIRSANOW, Commissioner

DAVID KLADNEY, Commissioner

MICHAEL YAKI, Commissioner

MAURO MORALES, Staff Director

MAUREEN RUDOLPH, General Counsel

PANELISTS PRESENT:

ANGELA DOYINSOLA AINA, M.P.H.

SHANNA COX

JOIA ADELE CREAR-PERRY, M.D., F.A.C.O.G.

SHANNON DOWLER, M.D.

NICOLLE L. GONZALES, B.S.N., R.N., M.S.N.,

C.N.M.

GARTH GRAHAM, M.D., M.P.H.

JENNIFER JACOBY

MAURICIO LEONE, M.P.A.

JENNIFER E. MOORE, Ph.D., R.N., F.A.A.N.

CHANEL PORCHIA-ALBERT

AYANNA PRESSLEY, U.S. REPRESENTATIVE

TARANEH SHIRAZIAN, M.D., F.A.C.O.G

NAN STRAUSS

STAFF PRESENT:

NICK BAIR, Civil Rights Analyst

PAMELA DUNSTON, Chief ASCD

COMMISSIONER ASSISTANTS PRESENT:

RUKKU SINGLA

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PROCEEDINGS

2 | 10:00 a.m.

CHAIR LHAMON: This briefing of the US Commission on Civil Rights comes to order at 10:00 a.m. Eastern Time on Friday, November 13, 2020 and takes place online.

I'm Chair Catherine Lhamon. Commissioners virtually present at this briefing in addition to me are Commissioner Adegbile, Commissioner Gilchrist, Commissioner Heriot, Commissioner Kirsanow, Commissioner Kladney, and Commissioner Yaki. A quorum of the Commissioners is present. I note for the record that the Staff Director and the Court Reporter are present.

And I welcome everyone to our briefing titled Racial Disparities in Maternal Health. My Commission colleagues and I voted to take up this topic last year and had originally planned to hear from experts in March 2020 in person. Our plans shifted with the rise of the coronavirus pandemic, but we remain committed to examining the issues we take up today.

Since we voted to investigate this topic, two among our Commissioners cycled off the Commission when their terms ended, and we have welcomed two

additional Commission members. We've built into our planning for this investigation an opportunity for new Commissioners Gilchrist and Adams to offer suggestions for panelists and for information for Commissioners' review in advance of today's briefing.

With this investigation, we examine the federal role in addressing racial disparities in maternal health outcomes, including negative pregnancy-related health outcomes and pregnancy-related deaths of women in the United States.

We will analyze current data regarding pregnancy-related and pregnancy-associated deaths, including data from institutions we will hear from such as the Centers for Disease Control and Prevention, the National Institute of Minority Health and Health Disparities, and the Department of Health and Human Services State Partnership Initiative to address health disparities.

Today, we will hear testimony from experts, including government officials, academics, healthcare providers, advocates, and impacted persons.

We will hear a range of perspectives today, and I note here that we had also invited several more members of the Administration to participate in today's briefing, including representatives from the

National Institutes of Health and the Department of Health and Human Services, though they declined to participate.

We are also grateful to the witnesses who provided testimony in writing. They include Juanita Chinn, who is Program Director, Demography of Health, Mortality and Population Composition, Population Dynamics Branch, Eunice Kennedy Shriver National Institute of Child Health and Human Development; Elizabeth A. Howell, who is the Director the Blavatnik Family Women's Health Research Institute; Jonathan Chief Executive Officer, who is the Association of Maternal Child Health Programs; Melanie J. Rouse, Maternal Mortality Projects Manager at Virginia Department of Health, Office of the Chief Medical Examiner; and Ndidiamaka Amutah-Onukagha, Associate Professor of Public Health and Community Medicine at Tufts University School of Medicine.

I thank all who join us now to focus on this critical topic. Your views help us to fulfill our mission to be the nation's eyes and ears on civil rights. I'm now turning to Commissioner Adegbile, who proposed this project for the commission.

Commissioner Adequile.

COMMISSIONER ADEGBILE: Thank you, Madam,

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and thanks to all who are joining us today for this very important briefing on maternal healthcare outcomes and the causes of maternal health disparities.

I want to begin by saying that we're gathered today in the midst of a national and local health crisis to discuss the nature, causes, and possible solutions to address another health crisis that afflicts the United States and many of our people in the country.

The United States has what is considered to be the worst set of outcomes of developed countries in the area of maternal healthcare along some measures. And we understand from the CDC that Black women face maternal healthcare outcomes and the risk of maternal death at as high a rate as three times White pregnant mothers.

This is a very serious concern. It's the first time that the Commission has turned its attention to this issue, as far as I am aware. But because it's the first doesn't mean that it's not terribly important. We have turned to it because it needs to be lifted up, as the Chair said.

I'm grateful to the staff for helping us put on this briefing today. I'm grateful to my

Special Assistant, Irena Vidulovic, and the fellow Commissioners, including, as the Chair mentioned, our new Commissioners, who helped us work to make today possible. And of course to the witnesses, who we will ask today to do a couple of things.

We will ask them today to help us figure out what are the facts so we can learn more about these (telephonic interference). We will ask our witnesses to help us understand what are the causes and drivers of the disparities that we see so we can understand them better.

And most importantly, we will ask our witnesses to help us think about what more can be done. What are the remedies and solutions so that we can improve maternal healthcare outcomes and reduce disparity? And in particular, use the levers of the federal government to the extent that the federal government plays a role in these things, to improve these outcomes.

Finally, I will say that just last week there was a story about a Black pediatrician in Indianapolis in the national media, who, delivering by C-section, lost her life as a result of complications associated with the pregnancy. timely, These issues are they are

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important, they are life-and-death issues, and I'm grateful that the Commission, with the support of all of the Commissioners, is taking up these issues.

Thank you Madam Chair and I look forward.

Thank you, Madam Chair, and I look forward to the testimony of our witnesses.

CHAIR LHAMON: Thank you, Commissioner Adeabile. I'll now turn to us to begin our briefing with some housekeeping items. I share deep thanks to Commission staff who researched and brought today's briefing into being, including the expert team who worked logistics, for which this virtual on presents a whole host of additional And I thank Staff Director Morales for challenges. his leadership.

I caution all speakers, including our Commissioners, to refrain from speaking over each other for ease of transcription. And additionally, because this briefing is virtual, I will need to cue our staff behind the scenes for the appropriate video and audio support, so please wait to speak until I have called on you.

For any member of the public who would like to submit materials for our review, our public record will remain open until December 14, 2020.

Materials, including if individuals would like to

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submit anonymously, can be submitted by email to maternalhealth@USCCR.gov, or by mail to the US Commission on Civil Rights, Office of Civil Rights Evaluation, Public Comments, Attention Maternal Health, 1331 Pennsylvania Avenue, NW, Suite 1150, Washington, DC 20425. We encourage the use of email to provide public comments, due to the current COVID-19 pandemic.

During the briefing, each panelist will have five minutes to speak. After the panel presentation, Commissioners will have the opportunity to ask questions within the allotted period of time, and I will recognize Commissioners who wish to speak, and then I will recognize panelists who wish to respond.

Please raise your hand so it is visible in the Zoom window or text my Special Assistant with the information in your materials if you wish to speak so I can recognize you. I will strictly enforce the time allotments given to each panelist to present his or her statement. And unless we did not receive your testimony before today, you may assume we have read your statements, so you do not need to use time to read them to us as your opening remarks.

Please focus your remarks on the topic of

our briefing. I ask my fellow Commissioners to be cognizant of the interest of each Commissioner to ask questions, so please be brief in asking your questions so we can move quickly and efficiently through today's schedule. I will step in to move things along if necessary.

Panelists, please note that to ensure we have sufficient time for our discussion this morning, I will, again, enforce the five-minute time limit. Please monitor your time so you do not risk my cutting you off mid-sentence.

Given some of the topics that come up with regard to maternal mortality, I want to inform the panelists and the public and remind my fellow Commissioners that since 1983, Congress has prohibited the Commission from, quote, studying and collecting, or quote, serving as a clearinghouse for any information with respect to abortion. Please tailor your remarks accordingly, consistent with this statutory restriction.

We will now proceed to our first panel of speakers, who will speak about policy and legislation in this area. We are honored to begin with Congresswoman Ayanna Pressley, who represents Massachusetts' Seventh District. Due to her schedule,

we will hear her opening remarks for five minutes and open up for Commissioner questions for ten minutes, and then we will continue with the remainder of the panel, whom I will introduce then.

Congresswoman Pressley, please begin.

PANEL 1 -- POLICY AND LEGISLATION

MS. PRESSLEY: Good morning, and thank you for the opportunity to address the Commission and to discuss the stark racial disparities in maternal health across our nation.

It is critical we understand that the maternal mortality crisis is part of the fight for healthcare justice. A safe pregnancy should be a right, not a privilege. Every person should be able to experience their pregnancy without worrying if they will survive delivery or make it to their child's first birthday.

Unfortunately, at alarmingly disproportioned rates, that is not the reality for pregnant people of color, especially those who are Black. Black women in particular face significantly more pregnancy-related health risks than any other ethnic group. As Black women, we are four times more likely to experience life-threatening complications or death during labor, delivery, and the postpartum

period.

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while And the Commonwealth $\circ f$ Massachusetts has one of the lowest maternal mortality rates in the nation, in my district, the Massachusetts of the starkest Seventh, we have some health inequities and disparities. Predominantly Black neighborhoods in my district like Dorchester and Mattapan lead in low birth rate, preterm birth, and infant mortality.

In Boston, a city in my district, pre-term birth is 50% higher among Black women compared to our White counterparts. This has been the status quo for the Black families I serve, and these challenges have only been exacerbated the by COVID-19 pandemic. The truth is our current public health emergency has taken a significant toll on the mental health of pregnant people.

Many pregnant or new mothers are isolating at home for safety and due to COVID-19 protocols. Many must attend hospital visits and even go through labor without their support team, critical support systems linked to positive birth, and postpartum mental health outcomes. The CDC reported that half of COVID-positive infants were born pre-term, while Black, Brown, and indigenous communities are at least

twice as likely to contract COVID, be hospitalized, and die from the disease.

The numbers are clear: we are trapped. We are trapped in an unconscionable cycle of harm that is needlessly robbing Black and Brown communities of life, and we must act. As we work towards a COVID-19 recovery, we must reject the notion of simply returning to normal. We know that normal was unjust and unequal in the first place.

Instead, we must work to expand access to quality healthcare and ensure every pregnant person is covered for 365 days after they give birth. This is commonsense policy that will ensure our lowest income mothers are able to access comprehensive maternal care and save lives.

But make no mistake. Access to healthcare is only part of the battle if we are truly going to address racial disparities in maternal health, we need to also confront systemic racism head on. Even Black women with access to healthcare with the highest levels of education, with fame and fortune, experience severe maternal morbidity. When Black women seek care, they are pushed into the cracks of a racist healthcare system that too often ignores our pain, our voices, and discounts our lives.

This is why I introduced the Anti-Racism and Public Health Act with Congresswoman Barbara Lee and Senator Elizabeth Warren. Our bill will create a national center for anti-racism at the CDC, declare racism is a public health crisis, and further develop a base of practical knowledge to root our racism from our healthcare system.

We need policies that expand access to care and ensure that that care is comprehensive, community-based, and culturally humble. Like the Healthy MOMMIES Act legislation I worked to introduce with Senator Booker from New Jersey, which would create strategies to improve access to pre- and postpartum community-based doula care. Because the data tells us that all mothers have better health outcomes when they have doulas or midwives on their care teams.

We must enact innovative and bold policy solutions that center scientific evidence and the lived experiences of all pregnant people. Combating the maternal mortality crisis requires work at every level of government and in every institution, and the work is worth it, because Black and Brown lives are worth it.

Although it seems the nation is just now

catching up to this irrefutable fact, Black women have always been critical to the functioning of our country's democracy. We are saving and creating lives. We are raising and sustaining our families and communities. Black women continue to show up for this country, and we must fight for their lives with as much energy and urgency as they fight for the soul of this nation.

Again, I appreciate the opportunity to speak on this urgent crisis, and I look forward to answering any questions you may have. Thank you.

CHAIR LHAMON: Thank you so much,

Congresswoman. I'll open for questions from my fellow

Commissioners. Commissioner Adequile.

COMMISSIONER ADEGBILE: Thank you. Thank you, Congressperson, that was very important testimony, and thanks for your leadership on these issues.

I was wondering if you could help us understand a little bit about the federal architecture here. You mentioned some bills that you have been behind and sponsored and co-sponsored, and I'm wondering if you could help us understand what limitations you may have perceived in the existing Preventing Maternal Death Act that caused you to think

more broadly about additional federal interventions in these areas.

MS. PRESSLEY: Sure. Well, I mean, the data, the numbers are just sobering, they're damning. You know, I should say my paternal grandmother I never had the blessing to know because she died in the 1950s giving birth to my father's youngest brother, sending their -- my father and his five siblings into a downward spiral of great trauma and hardship.

And the fact that my grandmother died in childbirth in the 1950s and Black women are four times more likely to still die really is just, you know, condemnation and confirmation of the embedded biases and systemic racism throughout our healthcare system.

For too long, the pain of Black women has been delegitimized. And so the US has the highest rate of maternal mortality in the developed world, despite spending more money on healthcare than any other country on Earth. And the rates of maternal mortality in the United States has more than doubled since the 1980s. So again, Black women are nearly four times as likely to die.

And within my district which I represent, while the Commonwealth of Massachusetts has one of the lowest maternal mortality rates in the nation, we

continue to see stark disparities in maternal outcomes and infant mortality across the state. The rate of infant mortality for Black mothers is nearly double that of White mothers. Predominantly Black neighborhoods like Dorchester and Mattapan lead the district in low birth, pre-term, in low birth weight, preterm birth, and infant mortality.

So, you know, all of the confluence of all of these things, and then against the backdrop of both this national reckoning on racial injustice, and also the pandemic, which has really laid bare these inequities and disparities as we see with marginalized communities living under the co-morbidities of structural racism, unequal access to healthcare, underlying conditions. And so the maternal mortality crisis has the potential to only be exacerbated by this pandemic.

And so while we're in the midst of this national reckoning on racial injustice, I think it's critical that the first thing we do is acknowledge that there is racism in public health. And that is exactly why Senator Warren, Representative Barbara Lee, and I have introduced the Anti-Racism in Public Health Act of 2020.

So what this would do, and I think is a

first step, and then I have, you know, other bills that support the work of that, but it's to create a center for anti-racism at the CDC to declare racism as the public health crisis that it is, to further develop the research base and knowledge of the science and practice of anti-racism. Because this is systemic. We must be intentional and active in the dismantling of it.

The center would be responsible for conducting research, collecting data, awarding grants, and for providing leadership and coordination on the science and the practice of anti-racism in the provision of healthcare, the public health impacts of systemic racism, and the effectiveness of intervention to address these impacts.

Now, two things I'll lift up very quickly that are interventions that have been proven to work, is investing in our community health centers. We know that they are already proven in combating disparities, they do have those wraparound services, and they also operate with that cultural humility. The other is doula care. You know, these are non-medical persons professionally trained in childbirth to support pregnant persons in childbirth, you know, in delivery.

Can I ask one

And there's really growing evidence that the integration of professional doulas into the US maternity care system would result both in cost savings and increased cost effectiveness. Professional doula care leads to fewer caesarian births, fewer adverse maternal outcomes.

And that's exactly why I've introduced the Healthy MOMMIES Act with Senator Booker, which would expand access to doula care.

COMMISSIONER ADEGBILE:

quick follow-up question. Under the MOMMIES Act, is one of the issues that Medicaid coverage is limited -is it limited to pregnancy services and doesn't reach the postpartum pieces? Or what is your understanding of the gap that the MOMMIES Act is trying to get to? Right. MS. PRESSLEY: So what we're trying to is that providing that full, get to comprehensive care throughout the entire postpartum period, rather than services that are only related to pregnancy. So it, what is does, the Health MOMMIES Act that I've introduced with Senator Booker, is that it requires the expansion of Medicaid's pregnancy pathway coverage from 60 days to 365 days postpartum.

So this is really commonsense policy that will save lives. This bill would also encourage state

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Medicaid programs to improve access to pre- and postpartum doula care programs. Because, again, the data tells us that all mothers have better health outcomes when they have doulas or midwives as a part of their care teams.

And then, you know, again, against the backdrop of the pandemic, I want to also talk about the importance of access to telemedicine, which is also a tenet of our Healthy MOMMIES Act. Our bill explores ways that the telemedicine can increase access to quality socially distanced maternity care and services.

COMMISSIONER ADEGBILE: Thank you. That point about postpartum seems very important. I mentioned in my opening remarks, I alluded to Chaniece Wallace, who died two days after her pregnancy on October 22, in Indianapolis. So I think that the risks clearly exist beyond the delivery time. And we know and you have alluded to the impact of that, so I thank you for it and for your leadership.

Thank you, Madam Chair, and thank you, Congresswoman.

MS. PRESSLEY: Thank you, Commissioner, and thank you for bringing her into the room. It's so important that, you know, in the retelling of these

very sobering statistics that we not lose sight of the fact that behind each of those statistics is a person, you know, who was loved and was the member of a family and a community. And so thank you for bringing her into the room.

If you don't mind, I would also just like to speak to a vulnerable population in the midst of the pandemic that I do not believe it getting enough oxygen, focus, or attention, and that is those that are pregnant and are incarcerated.

We know that our county jails and our prisons are really petri dishes for the virus to thrive. Because of mass incarceration, we have overcrowding. And so it's virtually impossible to socially distance. And we have seen surges throughout the country, and it's why I have been pushing for the de-carceration of pregnant women, because they are more vulnerable to contracting this. And I don't believe that this should be -- being incarcerated should be a death sentence.

And so while I continue to advocate for those that are medically vulnerable to be released, I'm prioritizing in that those incarcerated women who are pregnant. I did also introduce legislation as a part of a broader omnibus package with Representative

Lauren Underwood, a Justice for Incarcerated Moms Act, which I'm happy to further unpack if there's an interest in that as well.

CHAIR LHAMON: I'm certain there's interest and I'm also worried about time, so I just to make that fellow Commissioners have opportunity for questions. Commissioner Kirsanow, I couldn't tell if you were raising your hand. No? Okay. Watching people's screens. I'm going to ask my question, but I hope people will raise their hands if they have them as well.

Representative Pressley, you compellingly described the bills that you've introduced, and I note that you have a sort of one-two punch, your focus on this, increasing access to healthcare for all people who will give birth and then also a focus on antiracism in particular as a way of addressing this issue.

And I wonder if you could unpack a bit for us how you know that we need to be focused specifically on systemic racism in healthcare delivery for Black women in particular in this area. We have received testimony on a variety of fronts about the causes of the disparities, and some of that testimony posits that racism is not the cause.

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And so I am interested in your view about why it is that we need to take both approaches in the legislative response.

MS. PRESSLEY: Well, the point is that racism is systemic, it is structural. And because it is structural, it shows up in all of our institutions, it shows up -- it's pervasive even in our policies, which, you know, what I consider to be policy violence, which has often been short-sighted or discriminatory, resulting in those co-morbidities of structural racism and unequal access to healthcare.

And so again, as we find ourselves in the midst of a pandemic which has laid bare these inequities, disparities, racial injustices across all outcomes, including and especially health, you know, the way to reverse course is to get to the root. And so the way to get to the root and to bring about systemic change is to first confront and acknowledge how embedded these biases are within our systems.

Again, this is not about individuals, this is about systems. And the data, you know, bears out that, I know there have been some narratives which lean very heavily on assumption. But again, this has no ties to socioeconomic status, education level.

And so the fact that whether you are low

1 income or affluent, educated, non-educated, that if you are a Black woman, that you are still four times 2 3 more likely to have your pain de-legitimized when you 4 express it. And to have those biases potentially result in not only complications, but fatality. 5 6 CHAIR LHAMON: Thank you very much and I 7 now see that we are just past your time limit. 8 so appreciate your giving us your time this morning. 9 We're grateful --10 MS. PRESSLEY: Thank you. 11 For your testimony and CHAIR LHAMON: 12 we'll move on with the rest of the panel. 13 MS. PRESSLEY: Thank you very much. Thank 14 you all for your service. Take care. 15 So we'll now move to the CHAIR LHAMON: 16 other experts on our first panel, who will speak in 17 order as follows: Jennifer Moore, who is the Founding 18 Executive Director, Institute for Medicaid Innovation. 19 Then Shanna Cox, who is Associate Director for 20 Science, Division of Reproductive Health, Centers for 21 Disease Control and Prevention. Then Shannon Dowler, 22 who's the Chief Medical Officer at North Carolina 23 And finally Garth Graham, who is the former Medicaid. 24 Deputy Assistant Secretary for Minority Health at the

US Department of Health and Human Services.

1 We'll begin with Dr. Moore. Please 2 proceed. 3 DR. MOORE: Chairperson Lhamon and 4 distinguished Commissioners, thank you for the 5 invitation to speak with you today on the critical 6 topic of racial disparities in maternal health. 7 noted in my written statement, the US has the worst 8 rates of maternal mortality and morbidity amongst all 9 developed countries. We also spend the most on 10 healthcare. 11 As we did deeper into the data, we see 12 glaring disparities for people of color and those 13 enrolled in Medicaid, the public insurance option for 14 low-income individuals and families. With almost 50% 15 all pregnancies covered by Medicaid, 16 important for us to consider the root causes of these 17 inequities within the context of this population. 18 It has been noted that structural racism 19 has greatly influenced the maternal health system. 20 has also defined the development of the Medicaid 21 program for decades, contributing to the outcomes that 22 we are currently faced with. 23 While I was working in the US Department 24 of Health and Human Services as a Senior Advisor, I

co-chaired an interagency maternal health workgroup

that culminated in a multi-day event in DC. The event provided an opportunity to learn from global experts and to identify opportunities for the US to be responsive. A report was developed with the recommendations to address maternal health disparities and poor birth outcomes and is waiting to be cleared for its release.

As a co-author, I will share the five key takeaways from the report that the Commission has the opportunity to elevate. First, it was observed that the high-income countries with low rates of maternal mortality and morbidity valued and emphasized personcentered care. In this environment, individuals weren't simply told what to do and how their birth would be, but rather were informed and supported in making their own decisions based on their own values, beliefs, and preferences.

Second, these countries acknowledge that pregnancy and birth is a normal physiologic event. It is not a disease; it is not a medical emergency or crisis that automatically requires a suite of interventions that are led by a trained surgeon. More does not mean better in maternal health. In fact, research is showing us that the US's high intensity, high intervention approach to maternity care results

in poor outcomes.

Third, and most notable during the multiday discussion, other high-income countries maximized utilization of midwives who provide expert, high value, evidence-based care, with a obstetrician as trained surgeon serving only as specialists who are called in if needed.

Midwives are considered the standard of care for all pregnant and birthing people. Maternity care begins and ends with a midwife. As such, other high-income countries consistently have higher rates of midwifery-supported births, and it should come as no surprise that their birth outcomes are significantly better than in the US.

Fourth, these countries offer continuous access and coverage for women's healthcare needs. Other countries recognize that there's a need for continuous healthcare coverage for women if you want positive birth outcomes and healthy children now and in the future.

In contrast, for many low-income women in the US, they are kicked off their healthcare coverage through Medicaid within 60 days postpartum. However, some states have become to explore extending Medicaid program up to one year postpartum.

Fifth and finally, the high-income countries will low maternal mortality and morbidity rates emphasize the importance of offering culturally congruent care that is respectful of individuals. The multi-day event named structural racism as a social determinant of health and one of the primary root causes of the staggering rates of maternal mortality and morbidity in the US.

It is astounding the extent to which racism has been embedded into all facets of the US healthcare system, and how social, gender, and economic oppression has fed into this system. The low number of midwives of color, the opposition to Medicaid expansion, and the reliance on surgeons to care for healthy pregnant people is linked to racism and social, gender, and economic oppression.

Commission has an opportunity to take this information from the report and lead the nation. What if in the US, as we consider how to tackle the alarming disparities in maternal health, we choose solutions that we already known are innovative and cost effective?

Specific opportunities for the federal government to consider include supporting Medicaid covering during the first full year of the postpartum

1 Developing evidence-based federal clinical period. 2 and programmatic guidelines to set expected standards of care. Establishing a national framework on access 3 4 in coverage in Medicaid to midwifery-led models of Providing federal guidance to state Medicaid 5 care. 6 agencies on how to support birth equity in Medicaid. 7 Developing performance measures based on 8 guidelines to drive improvement, inform consumers, and 9 improve payment. Developing support of funding 10 strategies aimed at reducing or eliminating financial 11 barriers. Midwifery-led care models and freestanding 12 birth centers, as acknowledge in the provisions of the 13 ACA. And finally, enabling implementation 14 quideline and performance measures. 15 evidence We do not need more 16 demonstrate what we need to do and we can't wait for 17 others to prioritize women and people of color. 18 just need to take the lead and do it. 19 Thank you for your time and I look forward 20 to the questions. 21 Thank you very much. CHAIR LHAMON: 22 now hear from Ms. Cox. Please proceed. 23 Good morning, members of the MS. COX: 24 Commission. My name is Shanna Cox and I serve as the

Associate Director for Science in the Division of

Reproductive Health at the Centers for Disease Control and Prevention. Thank you for the opportunity to speak with you today.

related death and eliminating related disparities.

Sadly, each year about 700 women die in the United

States as a result of pregnancy-related complications.

CDC's Division of Reproductive Health conducts

national surveillance of pregnancy-related deaths

through the Pregnancy Mortality Surveillance System,

or PMSS.

PMSS data show that the pregnancy-related mortality ratio in the US is not decreasing, and given these deaths are largely preventable, these numbers are absolutely unacceptable. Considerable racial disparities exist, with Black and Native women two to three times more likely to die from pregnancy-related complications than White women.

There is a sharp increase in racial disparities with age. Black and Native women older than 30 are four to five times more likely to die from pregnancy-related complications than White women of the same age. Black women with a college degree are five times more likely to die from complications of pregnancy than White women with a similar education.

Detailed data is key to understanding the causes of maternal deaths, the drivers of disparity, and what we can do to prevent these deaths. Acknowledging this, CDC has emphasized the importance of maternal mortality review as a core public health function. Maternal mortality review is a process by which multi-disciplinary committees at the state or city level thoroughly identify and review maternal deaths.

Clinical and non-clinical information are used to provide a deeper understanding of the circumstances surrounding each maternal death in order identify contributing factors and develop actionable recommendations. CDC provides funding for 24 awardees representing 25 states to support the review committees through the enhancing reviews and surveillance to eliminate maternal mortality for ERASE MM Program.

We are already receiving powerful information. Review committees have determined that pregnancy-related deaths are associated with a multitude of contributing factors, including access to appropriate and high quality care, missed or delayed diagnoses, a lack of knowledge around urgent warning signs. These data suggest that a majority of deaths,

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about two in three, could have been prevented.

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Of note, the proportion of maternal deaths that are preventable does not differ by race/ethnicity.

So factors driving what these are There is evidence of variation in the disparities? quality received in hospitals of care by race/ethnicity. Some chronic conditions are more prevalent in Black women and increase the risks of maternal death. Native women are more likely to live in rural and frontier areas where there may be challenges in accessing risk-appropriate care.

Structure racism and implicit bias also play a role in generating these differences. For example, racial segregation impacts healthcare facility access. And personal experiences of racism are associated with delayed prenatal care initiation. The weathering hypothesis posits that Black and Native women experience earlier deterioration of health due to cumulative exposure to psycho-social, economic, and environmental stressors.

This hypothesis may be supported by the data I noted earlier. Where increases of pregnancy-related death by age is much sharper for Black and Native women than White women. So in addition to

strengthening the data, CDC funds 13 state perinatal quality collaboratives and the national network of PQCs to implement and disseminate strategies related to improving quality of care for mothers and babies.

assessment tool, or LOCATe, to strengthen states' ability to understand the resources in their healthcare system and to support risk-appropriate care. CDC's Pregnancy Risk Assessment and Monitoring System, or PRAMS, can provide contextual data on the experiences of women with a recent live birth, such as the content of healthcare received and barriers to postpartum care attendance.

In August 2020, CDC released a national communication campaign that brings attention to this issue. Hear Her seeks to raise awareness of potentially life-threatening maternal warning signs and encourages the people supporting pregnant and postpartum women to truly listen and take action when she expresses concerns.

So over time ensuring we have robust data to inform action will give us the tools to eliminate preventable maternal deaths in the US. Eradicating racial disparities are a critical piece of this work to ensure that reductions are achieved among those

that bear the largest burden. 1 Thank you for your time and your interest 2 in this important issue, and I'm happy to answer any 3 4 questions you may have. Thank you so much, Ms. Cox. 5 CHAIR LHAMON: We'll now hear from Dr. Dowler. 6 7 DR. DOWLER: Good morning, it's 8 privilege to speak with you today from North Carolina 9 Medicaid, where we care for almost 2.4 million 10 beneficiaries and cover over 60,000 deliveries a year. 11 Any death in a woman related to pregnancy 12 is tragic. I can tell you from personal experience 13 that looking in the eye of a new father cradling a 14 tiny newborn and explaining he'll now suddenly be 15 caring alone is unspeakably difficult. 16 But the majority of pregnancy-related 17 deaths actually occur outside the day of delivery, or 18 even after the first postpartum week. Two out of 19 three maternal deaths are preventable. 20 We dance around the statistics, 21 inconsistent data collection, billing nuances, varied 22 documentation and data, and incompatible data systems 23 ability to comprehensively study impede our 24 understand maternal morbidity and mortality. 25 Substantive federal funding for states to build

infrastructure and capacity that will teach us how to reverse these tragic trends.

Racial and ethnic disparities in maternal mortality exist even when you control for socioeconomic status in medical co-morbidities. Consistent race and ethnicity data tracking must become normative in this country if we hope to discern the path forward.

Another alarming trend we see is increasing numbers of pregnant women with chronic health conditions at the time they become pregnant. Cardiovascular conditions alone are responsible for more than one-third of pregnancy-related deaths.

For many, pregnancy is the first time a young woman has access to healthcare outside of family planning services. In states like North Carolina where Medicaid expansion's been blocked, women often only learn of pre-existing conditions once they become pregnant.

A funding and policy focus on comprehensive, pre-conception care will improve the outcomes of future pregnancies. Currently, as you heard before, we're limited in Medicaid to only cover 60 days of postpartum care. Many women develop chronic disease during pregnancy, experience an

exacerbation of prior diseases, or develop a complication at delivery. All of which require ongoing care.

High blood pressure, diabetes, anemia, dental caries, depression -- these conditions too often go untreated because women lose coverage before they can pause from the demands of a new infant to care for themselves.

One of the single most impactful things we can do in this country today is to allow, actually to insist on, one year of postpartum coverage for women who were pregnant on Medicaid. One of the real positives from COVID is the way that we've seen telehealth move forward rapidly. In North Carolina we've seen improved visit completion rates and we've seen consistent utilization across race, age, and gender.

But at the same time, we've telehealth use decrease as rurality increases and as access to broadband decreases. Access to ante-partum and postpartum telehealthcare could be a tremendous in our toolbox, but it must be provided tool We have to bridge the digital divide. equitably.

In my Appalachian county and many around me, there's no public transportation, no OB/GYNs, no

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nurse-midwives. While family doctors lead the care teams locally, women must travel almost an hour to see a maternal fetal specialist, get advanced imaging studies, get a hospital or freestanding birth center. Six delivery units alone in western North Carolina have closed since 2012.

Strengthening local communities is a far more efficient driver of equity than sending women off to far-off horizons for care. Increasing training slots for teaching health centers could improve access to high quality care closer to home. Understanding complex social needs is really critical. In North Carolina, we implemented a pregnancy risk screen to identify high risk pregnant women to identify a linkage to care management early.

A statewide collaborative called NC Care 360 contains resources for every county of the state to help meet the social driver of health needs for women. Reimbursing care teams in the medical home for time-intensive screening and referral allows us to engage pregnant women early and often and provide for their unique needs.

Too many women in this country continue to be adversely affected by deeply rooted systemic racism. Historical fear of healthcare due to tragic

experimentation and abuse of the physician-patient relationship helped create this dynamic. building is a crucial step. Recognizing training and reimbursing a broader ensemble of team members, such as community healthworkers and doulas, will allow us to diversify our workforce rapidly and help women feel safe in their care. Simultaneously, we must embrace firstgeneration minority college students and STEM majors and to help build a diverse pipeline of future doctors and advanced practitioners. To overcome health inequities entrenched in a system that created rather than eliminated barriers to equitable care means we must be prepared to share a disproportionate amount of resources to raise up historically marginalized populations. And I'11 close with this: continue listening to the field. Let us not forget the enduring mantra, not about them without them. you very much for your time. CHAIR LHAMON: Thank you, Dr. Dowler. We'll now hear from Dr. Graham. Dr. Graham, please proceed. DR. GRAHAM: Thank you. And I want to

thank the Commission and my fellow panelists for

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enlightening and discussing a very important issue that has been affecting communities, and certainly I think an increasing challenge.

I want to repeat some of the statistics that were already mentioned for emphasis. The US maternal mortality rate continues to increase, especially compared to some of our peer nations. We are at around 26.4 deaths per 100,000 live births, compared to many other OECD nations like United Kingdom that has 9.2 deaths per live births, or Germany that has 9 deaths per live births.

Earlier this year, the National Center for Health Statistics released three new reports on maternal mortality that continue to emphasize the challenges and the issues faced around maternal mortality and in particular disparities related to maternal mortality.

As said earlier, disproportionate impact of maternal mortality borne by African American, Native American, Hispanic, and other minority women were emphasized as well in those reports. Those reports updated the 2018 maternal mortality statistics and continue to emphasize the grim nature of the challenge faced ahead of us.

What's also important in terms of

understanding leading causes of mortality is realizing that up to 50-60% of those causes are preventable. Understanding the impact during pregnancy, impact of infection during pregnancy, day of delivery related to hemorrhage and other complications. Hemorrhage and other infections one to six days postpartum.

But also understanding the cardiovascular impact 43 to 365 days postpartum and the impact that those have, particularly on the lives of women.

I want to briefly touch on both clinical and non-clinical policy factors that could play a specific role. Preeclampsia prevention and the clinical interventions played there. Multiple medical professional societies recommend a low-dose aspirin for women at risk of developing preeclampsia.

Recommendation for these include starting low-dose aspirin 12 to 28 weeks and continuing through delivery. Those are associated with a 34% decrease in risk of preeclampsia, and up to a 14% decrease in preterm birth in terms of impact of low-dose aspirin.

I want to briefly touch on non-clinical factors and the impact of health disparities overall, and much in terms of what's been articulated structural racism. The Institute of Medicine in 2003 released an unequal treatment report document and the

impact of health disparities on our nation. It also identified a number of solutions that I think are relevant in maternal mortality space and relevant for tapping health disparities overall.

Those include issues related to cultural competency, and also improving the diversity of the workforce. Recognizing the importance of patient concordance, and also the impact of treating and eliminating health disparities overall.

Another factor that was brought into play with the Institute of Medicine report was the issue of data collection. It was mentioned earlier and I wanted to emphasize, collecting data on race/ethnicity and being able to track these factors throughout not just issue the rates of maternal mortality, but through a number of health disparity issues are particularly important.

Lastly, I want to emphasize the importance of the federal agencies that play a discreet and specific role. Certainly there's the Office of Minority Health within the Department of Health and Human Services. I had the privilege of leading that office in prior lives. That office plays a key role in coordinating issues related to health disparities.

Overall, I'm paying attention to issues

related to not just maternal health, but some of the issues related to social determinants of health overall. Within the National Institutes of Health as well, the Office of Women's Health and Research there also plays a key role and has been implementing a number of programs that are particularly impactful related to health disparities and related to maternal health.

Strengthening the role of these organizations is going to be a key component in terms of making sure that we have a robust federal response.

I'll close by saying I thank the Commission for taking up this very important issue. It is timely, it is relevant, most importantly I said earlier, it's about the lives of mothers, babies, and the health of our communities.

CHAIR LHAMON: Thank you, Doctor -- thank you Dr. Graham. At this point we'll accept questions from Commissioners. As a reminder, please do not speak until I recognize you, Commissioners, to ask a questions and panelists to respond to the question. Please raise your hand or notify my assistant if you have a question or would like to respond the question.

I understand Commissioner Yaki, you are ready? Go ahead.

COMMISSIONER YAKI: Thank you very much. I want to thank the panel for their testimony and for being here today under somewhat different circumstances than normally in our hearing room in Washington, DC.

This is a, you know, pretty -- this is a very important issue. It's an issue that I brought up when I was on the Board of Supervisors in San Francisco, you know, nearly 20 years ago, and it's still a problem today.

I wanted to ask the entire panel, I think some of you would have more of this than others, to what extent have there been any measurements or statistics regarding the impact or the disparity for Black and Brown populations with regard to where there — where Medicaid expansion exists and has it been adopted by a state and where it has not.

I actually in, just in noting that I would say that doing a little research and looking at the census scope and the state of Medicaid expansion that there is a almost unfortunately one-to-one correlation between the largest concentrations of African Americans -- Black Americans in this country and the lack of Medicaid expansion adopted by the states.

But to the extent that, you know, we have

1 the information available, I would of any appreciative to hear what you have to say about that. 2 3 CHAIR LHAMON: So panelists, I'm looking 4 at you for you to raise your hand so I'll know. ahead, Ms. Moore. 5 6 DR. MOORE: That's really 7 question, and my colleagues and myself have been 8 leading work at the Institute for Medicaid Innovation 9 and using the exceptional federal data sets to compare 10 a variety of birth outcomes, stratifying by Medicaid 11 expansion versus non-expansion states. And further 12 drilling down by rural, urban, and race/ethnicity. 13 And we have certainly found increased 14 disparities among states that have not expanded. 15 have a JAMA article that was published looking at the 16 impact of expansion versus non-expansion in preterm 17 birth. 18 We also have another publication that will 19 be out soon on the same topic, specifically to 20 maternal mortality and morbidity showing increased 21 disparities in non-expansion states compared to 22 expansion states, and then further drilling down to 23 race/ethnicity, urban versus rural. 24 CHAIR LHAMON: Thank you. I saw Dr. 25 Dowler nodding her head. Do you have an answer as

47 1 well? 2 DR. DOWLER: I was just commiserating. 3 someone in one of the southern non-expansion states 4 seeing that it significantly impacts and 5 disparities. 6 CHAIR LHAMON: Thank you. Pausing to see 7 if Ms. Cox or Dr. Graham also wants to answer, otherwise I know that Commissioner Gilchrist has a 8 9 question. 10 Go ahead, Ms. Cox. 11 MS. COX: One thing that our maternal 12 mortality review committees are able to do is take the 13 data and understand what strategies they 14 And so states like Illinois have been able implement. 15 to take maternal mortality review committee and focus 16 their legislation in order to do expansion of Medicaid 17 in their state. So the data really does inform these 18 initiatives. 19 Commissioner Thank you. CHAIR LHAMON: 20 Gilchrist. 21 Thank you, Madam COMMISSIONER GILCHRIST: 22 Chair. Let me just thank the panel as well today for

mentioned the concept of culturally congruent care.

My first question is to Dr. Moore.

your testimony.

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1 Can you help me understand a little bit more about that and give me an example of what that actually is? 2 3 DR. MOORE: Yeah, so it's taking 4 account the values, beliefs, and preferences of the individual, being aware of it. Not imposing your own 5 6 beliefs, values, and preferences as clinicians within 7 the healthcare system. Hearing where they're at, what 8 they need, what they want, and being responsive to 9 that. 10 Another term that's frequently used is 11 culturally competent. So as a clinician, we have to 12 go through cultural competencies to maintain our 13 license. 14 The term culturally congruent is really 15 intended to imply an active process, not necessarily 16 competency, but the active process of ensuring that 17 you're being responsive to that individual. Whether 18 it's their race/ethnicity, their religious beliefs, 19 whatever they're bringing to the table, making sure 20 that you understand that from their perspective and 21 how to ensure that your care is respectful and 22 responsive to those needs. 23 COMMISSIONER GILCHRIST: Thank you. 24 DR. GRAHAM: If I could add to some of the 25 expanding on that well-articulated comment, and again pointing the Commission back to the studies and into the medicine report. You know, cross-cultural education, including issue on cultural competency, addressing bias, attitudes, knowledge, and skills has been shown to demonstrate improvement and effective impact in a variety of clinical illnesses, including what we're discussing here.

And so it is -- referring back to the Institute of Medicine or the National Academy's report really does provide a good basis of the evidence base that supports much in which was discussed earlier around this topic.

CHAIR LHAMON: Thank you. I saw Dr. Dowler had a response as well.

DR. DOWLER: Yeah, I think the issue of implicit bias amongst healthcare providers is significant. And I know it was not part of my medical school training, although that was a long time ago now.

But the American Academy of Family Physicians has been very intentional with our work with the help of the public to really encourage our members to do implicit bias training. And there's some question about whether that should be mandated. Should all healthcare providers go through an implicit

1 bias training and to understand their own unintentional biases. 2 3 COMMISSIONER GILCHRIST: Okay. Madam 4 Chair, I have one other question, if I may. CHAIR LHAMON: Go ahead, thank you. 5 6 COMMISSIONER GILCHRIST: In 2018, 7 Preventing Maternal Death Act was actually signed into 8 know it's early, but would any of law. Ι 9 panelists have any comments about how that act is --10 you know, what we're seeing with regard to that act 11 being signed and if it's beginning to address some of 12 these concerns? 13 CHAIR LHAMON: Ms. Cox, I see you have an 14 answer. And I'll go to you, Dr. Dowler, next. 15 MS. COX: Yes. So through that act, CDC 16 was able to receive appropriations to fund 25 states 17 through 24 awardees to support maternal mortality 18 review committees, where they're able to identify data 19 and strategies to prevent future maternal death. 20 since that time, we've seen an improvement 21 timeliness of maternal mortality review data, more 22 comprehensive recommendations in regards to strategies 23 to prevent future deaths. 24 as we continue to build the 25 robustness of maternal mortality review the

committees, they will partner with others within their state, such as perinatal quality collaboratives, patient-centered organizations, and really identify what are those strategies to be able to reduce maternal deaths.

So there definitely has been improvement in the data that's collected and the standardization of data over time. And as more and more recommendations are developed and more standardization of data, we'll really be able to have robust national recommendations to reduce, preventable maternal deaths.

CHAIR LHAMON: Thank you. Dr. Dowler.

DR. DOWLER: Yeah, as a state that's gotten a grant recently for some technical assistance to help us to investigate and understand our own data, I can tell you that the complexities of our disparate data systems and how we collect data between the Office of Vital Statistics and through the Medicaid program and through our HIE makes it incredibly complex. And some of our systems are very, very old. And none of my systems talk to other state systems.

So in order for us to aggregate the data at a national level, we've got to somehow invest in that infrastructure to build compatible systems that

are measuring in the same way and using at least similar data tools.

MS. COX: And if I would add another technical assistance tool that CDC does provide for

technical assistance tool that CDC does provide for maternal mortality review committees is what we call MMRIA, the maternal mortality review information application. And it does speak to what Dr. Dowler is speaking of in regards to standardizing that data so that states are tracking similar data, the case narratives are built in similar ways, and the recommendations are -- are developed in similar ways.

And so as we continue to hear from states and understand their needs in regards to importing vital statistics information, linking to Medicaid data, and really continuing to learn from states in regard to best practices, we can continue to develop this information application, such that more and more states can be collecting standardized data to inform these recommendations.

CHAIR LHAMON: Dr. Graham, it looked like you had unmuted. Do you have a response?

DR. GRAHAM: Thank you. Yeah, so this issue of standardization of data I think is an important issue I think for the Commission to grasp and elevate it is how we track and understand what's

1 happening in these communities. And just in terms of the evolution, improvement, or lack of improvement 2 3 thereof in terms of health disparities. The federal charter for the task force on 4 research specific to pregnant women and lactating 5 6 women was renewed recently, and it really emphasized 7 designing health records to link and monitor and track 8 this issue around a data collection. So I just wanted 9 to emphasize the importance of that as a core building 10 block to really tackle issues around maternal 11 morbidity and mortality. 12 COMMISSIONER GILCHRIST: Thank you, Madam 13 Chair. 14 CHAIR LHAMON: Great. Waiting for other 15 Commissioners. Commissioner Kladney. 16 Thank you, Madam COMMISSIONER KLADNEY: 17 Chair, and I'd like to thank all the panelists, along 18 with everybody else, for appearing today. I don't 19 know how many of you may be on the West Coast, but 20 thanks for getting up so early. 21 My question really is I'm in an expanded 22 Medicaid state, and my question is we have a shortage 23 of doctors here and we are a low paying Medicaid 24 state. How difficult is it for women to find care, 25 even if it may available, without it necessarily, in

1 those kinds of conditions? Nobody? 2 CHAIR LHAMON: Dr. Dowler. 3 DR. DOWLER: I think a lot of that depends 4 on your state's infrastructure for community health North Carolina has a rich community health 5 6 center presence across our state and to all rural 7 counties. We have family doctors practicing in every 8 county in North Carolina. So we have been lucky I 9 guess in making sure that care is there. 10 But it definitely is built on a strong 11 Medicaid program. We have over 90% of our physicians 12 participate in Medicaid in North Carolina, and we've 13 built a very, I think, supportive environment for 14 medical homes and to make Medicaid be something that 15 they trust and they want to participate in. 16 And definitely in states that have had bad 17 experiences with managed Medicaid and where rates and 18 reimbursement tanked and went very low, they struggle 19 with a very different problem. 20 CHAIR LHAMON: Dr. Moore. 21 DR. MOORE: Yeah, I'd just like to add to 22 that that this is a wonderful opportunity to have a 23 conversation about the role of midwives and how 24 midwives can help to support that infrastructure.

what we're talking about is network adequacy within

the Medicaid population.

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Considering that the majority of pregnancies are low risk, it really sets up a really nice opportunity to invest in the training of midwives ensuring that they are able to reach this population and this population is aware of evidence-based services that they do provide. think that that's a really key opportunity for us that is glaringly absent compared to our contemporary countries across the world.

CHAIR LHAMON: Dr. Graham.

DR. GRAHAM: I think Commissioner Kladney brought up a very good point about access in general that I think it's important to understand that pregnancy starts way before preconception and the health of the mother overall. And it was mentioned too before on the importance of access points like community health centers.

And I think that, again, needs to be thought of in terms of the overall strategy when we're addressing issues related to maternal morbidity and mortality is the health of the mother, even prior to even prior to preconception care, and the importance of longitudinal care overall.

CHAIR LHAMON: Thank you.

1 COMMISSIONER ADEGBILE: Madam Chair. 2 CHAIR LHAMON: Commissioner Adegbile. 3 COMMISSIONER ADEGBILE: Thanks to this 4 terrific panel. We've learned a lot already, and thank you for your work and your commitment and your 5 6 thoughtful answers. 7 Dr. Moore, I would like it if you could 8 unpack your important testimony that explains that 9 more does not mean better. I'd like to understand in 10 a moment that idea and the things that could be better 11 and maybe not more so that we can figure those out, 12 particularly the federal government is positioned to 13 do something about these things and to just spread 14 that notion. 15 And let me just put on the table a couple 16 of questions for the entire panel so that, because I 17 see we're getting short on time. So maybe we can have 18 short answers to these. Do maternal healthcare 19 outcomes correlate with certain hospitals? 20 We've heard a little bit about geography 21 along an urban and rural dimension. Are there some of 22 these dimensions that are about the hospitals, and is 23 it the hospitals or the geography, so that we can 24 understand what's going on there.

And more broadly for the panel, what are

the best sources of the dimension of the scope of the problem for Native Americans and in Native American communities, and are the interventions that we're talking about generally the same one helpful in those communities or different? Help us understand the dimension for Latinx communities as well, and whether or not there's a disparity with respect to Asian Americans would be helpful to know.

And then finally, we've heard a lot about how many of these deaths are preventable. And a real focus on the types of interventions, we heard a little bit about low-dose aspirin, for example. What are the things that help us hone in on prevention? I understand that one of the things you're saying is that data matters a lot and uniformity of collection would help us know more. But it seems to me that you already know some things about these.

There's more, but not more time, so I'll stop there.

CHAIR LHAMON: I will say we have two minutes left. So we're going to do a lightening round of answers, and we also will welcome you submitting written testimony in response as well.

Who's going to go first in our lightening round? Dr. Moore, go ahead.

DR. MOORE: So in response to your last question about how we prevent deaths, first and foremost we need to listen to women. And if you look at the postpartum deaths, especially for Black women, families will share that, you know, they were not being listened to and they weren't being heard about their symptoms and weren't being taken seriously. So first and foremost, we need to listen to women.

In terms of the hospital as an issue, there's an example in a state that will be not be named in which they have one of the highest rates of caesarian sections in their hospital. We looked at evidence-based approaches to reduce that rate. They saw the midwifery model as an opportunity. They brought in midwives. Their C-section rates dropped dramatically.

Also what dropped is their NICU admissions. The NICU admissions is a critical part of their business model that helps them to remain financially sustainable. So there's this conflict between evidence-based care and the business model that we have to work through as a nation.

And then more does not mean better, because we don't have a lot of time, I'll just say check out the work of Gene Declercq, Birth by Numbers

1 and the Cascade Events. 2 Thank you. Dr. Graham. CHAIR LHAMON: 3 DR. GRAHAM: Really quickly, there's a 4 Journal of the American Medical Association paper published recently on the indigenous maternal health, 5 and I'll point to the inventions, I'll say them really 6 7 quickly that they are recommending. 8 They're collecting better data and 9 reporting data among indigenous people in tribal 10 nations, ensuring decision making includes indigenous 11 and tribal representation, especially in maternal 12 Improving workforce diversity and paying 13 attention to violence as a maternal health issue 14 especially for indigenous peoples. 15 Thank you. Dr. Dowler. CHAIR LHAMON: 16 DR. DOWLER: So, having levels of care for 17 hospitals is really important. We have that for 18 babies, for NICUs, but we don't necessarily have it 19 for maternity care. Also, developing regional hubs 20 for a hub-and-spoke model where we take centers of 21 excellence and use their expertise to help feed the 22 communities around them. 23 And from a prevention standpoint, I'd say 24 the one thing we should do is make prenatal vitamins

free and available to every woman.

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We can prevent

1 birth defects that'll happen years down the road by 2 having prenatal vitamins now, and it should be 3 available to everyone. 4 CHAIR LHAMON: Thank you. Ms. Cox, will you bring us home? 5 6 MS. COX: Sure. From clinical 7 perspective, implementing bundles of care using 8 perinatal quality collaboratives to improve healthcare 9 outcomes from a clinical side. But we also have to 10 acknowledge the social determinants of health 11 things such as transportation and housing and how that 12 impacts prevention for maternal deaths as well. 13 Understanding Latin and Asian Americans 14 often have lower rates of maternal deaths. What we've 15 seen with other data over time is generational impacts 16 that there are also differences in multi-generational 17 health for Latin and Asian Americans. 18 Also understanding and working with the 19 National Indian Health Board and other Native-serving 20 organizations, as was mentioned, to really and truly 21 hear from Native women and what their concerns are 22 what their issues in regards to access of care and 23 around maternal mortality will be really important for 24 addressing the issues for Native women.

So overall, I think we've all kind of

1 summarized that there are clinical interventions, but there are also non-clinical interventions. 2 3 really, it's addressing all of these factors at the 4 patient, provider, health system and community level that will really give us the information and the 5 6 strategies to prevent maternal deaths in this country. 7 Thank you. 8 Thank you so much for that CHAIR LHAMON: 9 close, and I thank all of our panelists. 10 terrific first panel, we very much appreciate your 11 participation. I will remind you that we would 12 welcome follow-up written testimony if there's more 13 information that we should know that we didn't have 14 time to address today. 15 Thank you very much for now. We'll take a 16 brief break, and we'll reconvene for our next panel at 17 11:15 a.m. Eastern Time. 18 Panelists, you can go ahead and leave the 19 And you can -- we invite to resume watching the 20 briefing on our YouTube stream. We'll see you at 21 11:15, thank you. 22 (Whereupon, the above-entitled matter went 23 off the record at 11:08 a.m. and resumed at 11:16 24 a.m.) 25 CHAIR LHAMON: Welcome back everyone.

1 We'll now move to our second panel, during which we 2 will hear from service providers and private 3 organizations. 4 PANEL 2: SERVICE PROVIDERS/PRIVATE ORGANIZATIONS CHAIR LHAMON: The panel will proceed as 5 6 Angela Doyinsola Aina, Interim Executive 7 Director and research lead at Black Mamas Matter 8 Alliance. 9 And Joia Adele Crear-Perry, who is the 10 and President of National Birth Equity 11 Collaborative. 12 Taraneh Then Shirazian, who is the 13 president and Medical Director, Saving Mothers and 14 assistant professor at New York University Langone 15 Medical Center. 16 And then finally, Mauricio Leone, who is 17 the Chief Operating Officer and Senior Director at 18 Obria Group. 19 Given some of the topics that come up with 20 regard to maternal mortality, I want to remind our 21 panelists and the public again, and my fellow 22 Commissioners, that since 1983, Congress has 23 prohibited the Commission from, quote, studying and 24 collecting or, quote, serving as a clearinghouse for

any information with respect to abortion.

1 tailor your remarks accordingly, consistent with this 2 statutory restriction. 3 And with that, we will begin with Ms. 4 Aina. Please proceed. MS. Good morning 5 AINA: to the Commissioners, the Staff of the U.S. Commission on 6 7 Civil Rights, and my fellow panelists. 8 My name is Angela Doyinsola-Aina and I am 9 the co-founding executive director of the Black Mammas 10 Matter Alliance. 11 The alliance is a national network of 12 Black women led organization and multi-disciplinary work 13 professionals whose is deeply rooted 14 reproductive justice, birth justice and the human 15 rights framework in order to ensure that all Black 16 mammas have the rights, respect and resources to 17 thrive before, during, and after pregnancy. 18 We use the phrase "Black Mammas" 19 represent the full diversity of our lived experience 20 that includes birthing persons and all people of 21 African descent across the diaspora. 22 We are all aware that the U.S. is facing a 23 maternal health crisis. Global data trends have shown 24 that the maternal mortality rate declined in many 25 countries around the world in the last 30 years.

during the same time period, the United States

maternal mortality rate rolled significant.

Even more disturbing, the maternal

mortality rate for Black women is three to five times greater than that of White women. And ironically in the U.S., we spend about \$111 billion annually on maternal and newborn care.

A recently published March of Dimes report indicated that 54 percent of U.S. counties have limited or no access to maternity care. And 35 percent of those counties are considered maternity care deserts. Meaning, within several areas across the U.S. there is limited or absent skilled maternity care providers within that county.

But presenting raw data alone does not explain the full story of why these maternal health disparities exist in the U.S. We must take a deeper dive into the root cause of these issues.

Black women and girls in the U.S. have been dehumanized and subjected to violence. Including enslavement, segregated health care and medical experimentation that entails sexual and reproductive abuses.

Lack of accountability for preventable pregnancy relates deaths in hospital settings,

mistreatment for pregnant and birthing people, limitations to quality health care and telehealth services, pervasive acts of reproductive coercion and neglect during labor in hospital settings are all contributors of maternal health inequities experienced by Black women and birthing people.

All of these issues are still an underacknowledged problem in the U.S. And yes, more research is needed to better understand the nature and prevalence of this discrimination. And under this pressure of a pandemic, these inequities have been further exasperated.

Over the past few years, there have been various legal and legislative actions spearheaded by grassroots organizations, elected officials and advocacy matrix of remedies to address pregnancy related deaths.

In 2018, the Prevent Maternal Deaths Act was signed into federal law expanding the safe motherhood initiative. Including authorizing support for state and tribal maternal mortality review committees allowing states to collect demographic and health condition specific data on pregnancy related deaths.

Though other acts exist to protect women,

mechanisms for filing complaints on the basis of discrimination are not timely to the pregnancy process. And claims based on racial discrimination require a higher threshold of proof.

And then further, federal and state laws little to provide adequate reimbursement midwives, doulas and other birth workers who are not physicians that fit a standard insurance system. This further gaps within the maternity workforce, legislation, to discontinue to the piecemeal approach to eliminating inequities and maternal health outcomes.

To see significant positive change we believe a holistic approach is needed to increase maternity care, workers of color through equitable pay structures, provide holistic quality care to pregnant and birthing people, protections for the disenfranchised, incarcerated and detained, birthing people by upholding their human rights.

Data collection must also be a priority in new legislation for real-time maternal outcomes that offer detailed data useful for clinicians, healthcare and public health system, organizations and legislatures and in academia.

A recommendation for federal government

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1 officials is that help in the fight to end preventable 2 maternal deaths in the U.S. by supporting the Momnibus 3 Act of 2020. If passed, the act has the potential to 4 be transformative from maternal health because it goes beyond address maternal death. 5 6 It helps to advance maternal health equity 7 through investments in holistic and community-based 8 models of care, expanding research and improving 9 technological initiatives to expand access to maternal 10 services. 11 Thank you, again, to the entire U.S. 12 Commission on Civil Rights for allowing us, the Black 13 Mammas Alliance, the opportunity to provide 14 statement for today's briefing on racial disparities 15 and maternal health. 16 CHAIR LHAMON: Thank you, Ms. Aina. 17 now hear from Dr. Crear-Perry. Please proceed. 18 DR. CREAR-PERRY: Good morning. My name 19 is Dr. Joia Crear-Perry. I'm an OB/GYN by training 20 and serve as the founder and president of the National 21 Birth Equity Collaborative where we create solutions 22 that optimize Black maternal and infant health through 23 training, policy advocacy, research and community 24 centered collaboration.

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professionals from the deep south, my dad is an ophthalmic surgeon, and my mother is a pharmacist. From very early on I understood the value of caring for the health in lots of America's most minoritized group the descendants of Africans enslaved in the Americas.

While I grew up with those values, my medical education tried to teach me the opposite. Not valuing the lives of Black and indigenous people is driving the maternal health crisis in the United States, where they are two to three times more likely to experience maternal death than White women.

We are the only industrialized national where maternal health is on the decline. My daughter Jade is more likely to die in childbirth, than when I had her over 27 years ago.

And in wealthy cities like New York, the disparity is even greater. Black women are 8 to 12 times more likely to die of pregnancy related causes than White women.

We know that the root cause of poor maternal health, racism and gender oppression, inside of health care systems and every other facet of societies, women of color are more likely to experience co-morbid illnesses and report being

unfairly treated within healthcare settings based upon on their race and ethnicity.

Inequities that Black women face have become more urgent as the pandemic and civil unrest show the many ways racism can kill. Whether from COVID, police brutality or hemorrhage during childbirth.

But if we know how we got here, we know what we must do, and undo, to get ourselves out. And wealthy countries, like the United States, there is a grassroots of political call for action for a radical shift in practice to reduce inequities in birth outcomes using respectful maternity care as a model for change.

Respectful maternity care is defined as, care provided to all women in a matter that maintains their dignity, privacy and confidentiality. Ensures freedom from harm and mistreatment and enables and informs choice and continuous support during labor and childbirth by the Worlds Health Care Organization.

The National Birth Equity Collaborative is optimized as Black maternal infant health through training, positive advocacy, research and community center collaboration. Including respectful maternity care.

In partnership with the Institute for Women and Ethnic Studies, Tulane, OVIA, and Johns Hopkins University and many others, we've have been asking women across the United States, particularly Black women, about their needs. What we have learned has the potential to radically transform what it's like to be pregnant in America.

Black birthing people and babies are consistently the most impacted by adverse health outcomes in the United States. Therefore, health care systems and quality improvement should be designed with them at the helm. Patients don't need to be more trusting, health care systems need to be more trustworthy.

That means treating everyone as experts in their own bodies. That means shared decision making that takes places at most marginalized, at the center.

And as I always say, there is no quality, quality improvement, without equity.

Transforming the maternity care to value Black lives in service of sexual and reproductive well-being could not only improve outcomes in America but have an impact worldwide. Anti-Blackness and gender oppression are worldwide phenomena.

The opportunities and risks that Black

1 people experience, whether in Brazil, Botswana 2 Birmingham, have a common thread because of the social 3 construction of race. 4 Whiteness too has a global definition. And so when the west transports its medical systems 5 6 through international development and philanthropy we 7 replicate the American exceptionalism and 8 supremacy that is killing so many people right here. 9 am committed to dismantling 10 supremacy and I hope you are too. But I'm also just 11 as committed to Black justice, liberation and joy. 12 And yes, liberation and joy can even be a 13 part of birth. And they are a core tenant of sexual 14 and reproductive well-being that values more than mere 15 survival or the absence of disease. That's what birth 16 equity is all about. 17 So, thank you, to the Commission, 18 allowing us to present. 19 Thank you, Dr. Crear-Perry. CHAIR LHAMON: 20 We'll hear from Dr. Shirazian. 21 DR. SHIRAZIAN: Hello. Thank you for 22 asking me to present today. 23 I am Tara Shirazian. I'm an OB/GYN and 24 the President and Founder of Saving Mothers. We are a 25 501c3 medical non-profit. We develop maternal health

1 programs to decrease maternal mortality globally and 2 locally. 3 We have worked around the world to create 4 low cost, high impact programs that unify community and hospital-based efforts to improve maternal health 5 6 and reduce death. Our programs target the front-line 7 women's health workers. 8 We target the community health workers and 9 birth attendants, to enhance their medical knowledge 10 of maternal risks and complications. We empower them 11 to communicate and be heard within the health care 12 infrastructure in their own communities 13 are front-line maternal health 14 In 2019, our efforts turned from global to trainers. 15 local. Unlike the global setting where health 16 resources are scarce, here, where I live in New York 17 City, with an abundance of resources, yet we have 18 staggering rates of maternal death. 19 Who are most affected? Well, 20 already heard from all our panelists, data from the 21 CDC indicates that nationally, Black women are more 22 than three times more likely than White women to die 23 from pregnancy-related complications. 24 Tragically, the disparity for Black women

in New York City, where I live, is even greater.

1 Where they are twelve times more likely than Black women to die from pregnancy-related complications. 2 3 In 2018, the severe maternal morbidity 4 rate for Black women was at least twice as high as for White women in half of the State's regions. Over 60 5 6 percent of pregnancy related deaths in New York City 7 occurred antepartum, prior to delivery, or within one 8 week postpartum. So that's the period of time. 9 Maternal outcomes are persistently worse 10 for Black and Latina women relative to White women, 11 even after controlling for health status, 12 sociodemographic factors, and neighborhood income. 13 Maternal mortality has not significantly 14 changed for over 20 years, despite substantial 15 investment in maternal health programs in New York 16 City. 17 Our own comprehensive review of maternal 18 health programs in our city, which is where we started 19 before we starting this program, found a lack of 20 programs using evidence-based approaches and a lack of 21 reported outcomes. Despite the investment, the 22 results were not evident. 23 Among the programs reviewed, there was 24 only a single community-based model addressed adverse

birth outcomes. But it did not address the maternal

outcomes in any way.

Hospital-based approaches to decrease maternal death have also failed to demonstrate any change in maternal death.

Ten years of global health work with Saving Mothers has produced a clear truth. Reduction in the high rates of maternal morbidity and mortality for any disproportionately affected community requires a participatory, collaborative process. Our more recent local projects have also shown this to be true in New York.

To affect real change, there must a parallel process to train front-line maternal health workers, mothers and health providers so they can challenge and overcome the disparate outcomes of pregnancy.

Systemic racism is one of the challenges affecting Black women and maternal mortality in New York State. Saving Mothers has repeatedly demonstrated that when you advance those, the health workers, the doulas, the community health workers, the birth attendance and the mothers understanding of basic medical information and hone their communication and advocacy skills, the result is a self-sustaining resilience in families and communities. We've

demonstrated this in Guatemala, Kenya and around the globe.

Our mPOWHER Curriculum focuses on providing front-line maternal health workers with needed, high quality health information and advocacy-building skills. The Mom's mPOWHER Kit provides a pregnant woman with easy to use tools to be health more literate about pregnancy her and communication coaching that will better prepare her to identify and challenge systemic racism and sexism in the healthcare system, skills she can use throughout her life.

Phase 1 of our mPOWHER program consisted of using participatory and qualitative methods to develop and evaluate the key components of our proposed community health worker training. We learned that current community health worker maternal health training is non-standardized in New York.

Community health worker training was varied, and despite their dedication to clients, respondents noted a lack of confidence in recognizing health risks and communicating health information to low health literacy clients.

Our mPOWHER curriculum and training focuses on identifying pregnancy risks, health

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1 literacy, and self-advocacy. We really believe that 2 empowering the front-line health workers, empowering 3 the mothers empowers their community. And we also 4 believe in teaching and training, again, the health care providers themselves. 5 We would further love to collaborate in 6 7 broader ways and bring our mPOWHER program to more 8 cities, with larger community and hospital 9 Saving Mothers develops the evidence stakeholders. 10 based, collaborative public health programs 11 tackles the staggering disparity in maternal health. 12 CHAIR LHAMON: Thank you, Dr. Shirazian. 13 DR. SHIRAZIAN: Thank you for having me. 14 CHAIR LHAMON: Next we'll hear from Mr. 15 Mr. Leone, your camera is off. Well, we may 16 need to come back to Mr. Leone when he can return. 17 At this point we'll accept questions from 18 the Commissioners. Commissioner Adequile. 19 COMMISSIONER ADEGBILE: Sure. Thank you, 20 Madam Chair. And thank you to all the witnesses for 21 your work and for your important testimony. 22 One question I have for you because you 23 sort of focused today on the issue broadly, but also 24 on what the federal government is doing and could 25 conceivably do better to move the dial on these

issues.

And so, one of my questions to you is, what is your assessment of where the federal government is in terms of its contribution to trying to eliminate these disparities, and what specific interventions, whether they be policy or legislation based, are you thinking would make sense that the federal government should be taking up?

CHAIR LHAMON: I see Mr. Leone has returned, so we'll go ahead and take answers to this question and then after that we'll turn it back to Mr. Leone for his statement.

Go ahead, Dr. Shirazian.

DR. SHIRAZIAN: I think investing in the communities is extremely important. I think investing in community health workers and front-line workers that serve women in our most marginalized areas is key to overcoming a lot of the barriers.

If we want to build trust, if we want to have collaborative programs, if we want our patients to trust us and we want the most underserved to actually come to the hospitals when there is a need, we have to gain that trust. And through community participatory work. And also research and showing the evidence for our programs.

1 CHAIR LHAMON: Dr. Perry. Crear-Perry. DR. CREAR-PERRY: Thank you. So, where we 2 3 are right now, is we finally started to recognize it's 4 an issue. I was honored to be able to present and 5 6 testify in front of Congress for the one bill that was 7 passed to actually start sending money through the CDC 8 to pay for counting maternal deaths. We went decades 9 without even funding that work. 10 And we have not created a requirement so 11 the federal government could do, is actually require 12 states to count maternal deaths. Right now it's a 13 nice to have. 14 But we know that we don't value what you 15 don't count. And so, you can start tomorrow with the 16 requirement that all maternal deaths are counted. 17 That's a big start. 18 Another thing that we could, as a federal 19 government, is actually invest in women's health. And 20 that doesn't just mean health care services, 21 transactional services, but that also means paid 22 leave, it also means childcare. 23 I know right now my 4th Grade virtual 24 schooling that I'm trying to do, and also testify in 25 front of you all, is really complicated. And so, it's

1 important for us to really think about how we can invest, and as a federal government, women, birthing 2 3 career folk, people who are 4 families to ensure that they can survive and thrive after having a baby. 5 6 CHAIR LHAMON: Thank you. Okay, 7 Leone, why don't we return to you for your statement. 8 You have five minutes. And then I'll go back to the 9 rest of the question and answer period. 10 MR. LEONE: Okay. Can you hear me? 11 CHAIR LHAMON: Yes. 12 MR. LEONE: Great. Good morning. Thank you so much for 13 morning, everyone. 14 invitation to testify and share my experience. 15 My name is Mauricio Leone. I am the Chief 16 Operations Officer for The Obria Group and I am here 17 today to present a "boots-on-the ground" perspective 18 from the field. 19 We are a nonprofit organization with a 20 national network of more than 20 life affirming health 21 clinics in several states across the nation. 22 target population experiences significant disparities 23 accessing health care studies and health education. 24 We provide life affirming health care

services to anyone in need, regardless of race,

ethnicity, age, gender, creed, national origin or ability to pay.

We offer prenatal care services, well woman care, STD testing and treatment, sexual risk avoidance education, parenting education, and pregnancy resources to over 10,000 patients a year. Mostly women and minorities.

Although we live in one of the most developed nations in the planet, there remains significant barriers to life-affirming health care services. We at Obria have observed the following.

There are still challenges navigating health insurance for pregnant women, which is a significant barrier to access of prenatal care.

Although pregnancy Medicaid coverage is widely available in California, and I believe in the nation for all low-income pregnant women, it is still extremely difficult to navigate or use.

There is a lack of providers who accept Medicaid for pregnant women. Health care providers don't necessarily have a contract with every single Medicaid HMO out there, or don't want to serve Medicaid patients due to the low payments. Others accept Medicaid insurance but provide lower quality care.

1 There is lack of access to evidence-based primary prevention strategies, such as sexual risk 2 3 avoidance education. Especially for the 4 population in public schools, which results in a higher rate of teen pregnancy and STDs. 5 6 This is very important because 7 pregnancy is linked to low birth weight and infant 8 mortality. 9 In spite of the documented benefits of 10 sexual risk avoidance education, in 2016 the State of 11 California enacted the Healthy Youth Act, which 12 intended to prevent pregnancies and STDs in young 13 people. 14 But cases of STDs have reached a 30 year 15 high in California. Over 400 percent increases in Sadly, women are more impacted with 16 some counties. 17 STDs than men. 18 Unintended teen pregnancies are also very 19 prevalent in some communities, which have higher rates 20 of pregnancies than the national average. 21 Although there is a positive downward 22 late or trend no prenatal care, in we 23 significant proportion of expectant mothers who still 24 come in late to our clinics for prenatal care services

due to lack of knowledge about their options in the

community.

Our medical providers have reported that there is very little information available for pregnant women about their health care options in the community. Including information about their health insurance coverage options, for bringing pregnancies to term.

There is a prevalence of substance abuse among pregnant women coming to our clinics. This can produce preterm births and have a negative impact in women and babies who are at risk for poor outcomes.

We see the need for risk avoidance primary prevention strategies because they can lead to health outcomes that are improved when risky behaviors are avoided.

There is no consistency or follow through with preventive screening and treatment, which leads to disparities in pregnancy care. We see a trend in our patient population that, due to low educational attainment and health literacy, patients don't follow preventive health screening recommendations. They usually come to our clinics when they are already overweight, already infected with an STD, or are late in their pregnancy.

Lastly, we observe a lack of medical

compliance by our pregnant women. This is small, but consistent percentage of patients that don't comply with their care recommendations.

This includes complying with follow-up appointments and routine laboratory tests. This is due to transportation, childcare, health insurance, communication or other psychosocial issues.

In sum, there are significant disparities still affecting low-income pregnant women in this country. These disparities have a negative impact on accessing quality life affirming the early pregnancy. Which might partially explain the differences in pregnancy outcomes among different populations.

We also think that it is critical to address another social determinant of health that is equally important to achieve positive outcomes for mother and child, evidence-based risk avoidance education because it has an emphasis on personal responsibility, healthy relationships, and self-regulation skills.

As public health representatives, we advocate for strategies that help low-income women, and individuals, develop the skills necessary to make healthy choices and avoid risky behaviors. Our goal for every patient is optimal health outcomes. When we

1 have the active involvement of the patient in avoiding risky behaviors, we're more likely to achieve this 2 3 goal. 4 Thank you so much the invitation. Thank you very much. 5 CHAIR LHAMON: We're 6 continue with our questions from 7 Commissioners. Commissioner Kirsanow. no, 8 Commissioner Kladney. 9 COMMISSIONER KLADNEY: So, we've had your 10 testimony, and the last panel's testimony, and they've 11 given us a lot of food for thought. But is there a 12 model program in the country, in the community, that 13 you could cite that handles this problem better than 14 anyone else? 15 And where would that be, and if there 16 isn't one, is there somebody who has proposed a 17 program to move this problem forward? 18 Panelists, if you could CHAIR LHAMON: 19 raise your hand or unmute, I'll know you're ready to 20 talk. Dr. Shirazian. And then Aina next. 21 DR. SHIRAZIAN: We actually did a review 22 of all the maternal health programs that exist in the 23 And then we focused in on New York State, U.S. 24 because as I said, we live in New York State so we 25 wanted to start very local.

There are a number of programs that have enjoyed some variation of success and have had elements that have been successful. But there is not like one dominating one that I would say has sort of really, really been able to do everything.

So, that's why when I mentioned the mPOWHER program and us starting sort of these, this program here in New York and starting with the participatory collaborative process of interviewing all of our community health workers and speaking with them about training and how, what training they've had to date and what training they would like, and even through this pandemic we've been doing Zoom trainings with them, focus groups and trying to understand exactly what their needs are in order to develop a more comprehensive program.

So, as I said at the beginning, at Saving Mothers we are at the beginning stages of trying to develop that type of collaborative, participatory, community engaged program that would start with the community but then would extend out into the hospitals.

And we have models of this that we've done in other communities globally. We're a global women's health organization. So we're in Kenya on the ground

doing very similar programs.

Out in the community with the birth attendants developing training for them that then allows them to be cultural brokers and advocate for women at the level of the hospital and the clinic.

So, what I'm suggesting is we use some of our global approaches to maternal health and death, apply them locally, use a collaborative community, and also hospital based model. Bring those two together, bridge our front-line workers, bring them along with us.

We have so many community health workers across this country. Most people don't even know what they do. It's kind of amazing to me.

In New York, we have so many community health workers, and whenever I mention them people are like, oh, those people exist, I'm like, yes. They go into the homes, they go into shelters. They talk to pregnant women there in the most marginalized regions of the city.

So, I think we need a collaborative training for our front-line workers that intersects with our hospitals and our clinics. We get participation from each and we build a broad collaborative program that way.

1 So we're prepared to work with whatever groups are interested in this, but we really firmly 2 3 believe that we have a very good training model and we 4 can start training front-line workers. CHAIR LHAMON: Thank you. Ms. Aina. 5 What I wanted to add to 6 MS. AINA: Yes. 7 the question that was just asked is to, I'm going to 8 take us back, to understand that the challenges of the 9 maternal health crisis in the United States is very, 10 very complex. 11 So, therefore it requires complexity and 12 diversity in how we address these issues. 13 needs to be addressed at multiple levels, across 14 multiple sectors. 15 So, for example, we need more support of 16 federal policy to be passed. Such as the Momnibus 17 That definitely needs to be passed. 18 That will help with a lot of the system 19 challenges that we see at the state and local levels 20 to get a lot of our public health programs further 21 equipped to actually do these partnerships. 22 multi-disciplinary partnerships. 23 Whether we're talking about community, 24 with community-based organizations, with academia, 25 with hospital systems. All of these things need

further investment.

In addition to that, we know that we need to start creating more pipelines around providing an opportunity for maternity care providers and not just investing only in producing more and more physicians.

We need to produce more midwives, more doulas, yes, more perinatal health support workers. And this can look like a multitude of things.

And then finally, what I will add to this conversation is that there is several organizations within the alliance, including the national birth equity collaborative. And several organizations across the countries that are doing this work from a holistic, maternity and reproductive health care perspective.

There is not one solution to this very complex problem. But, we definitely know that there is a significant gap in providing those necessary investments, in culturally congruent community-based approaches to addressing this, these multitude of issues.

And we know that the solution really to make these necessary changes is based at the local level. So that's why we really do emphasize really uplifting and supporting the work of community-based

1 organizations that had been doing first equity work, 2 providing midwifery services for decades to their 3 communities. And last but not least, I also think it's 4 important to understand that while we do talk about 5 expansion of Medicaid, ensuring that we have programs 6 7 and educational services around building health 8 literacy, sometimes that can have an assumption that 9 this issue is only impacting low-income people. 10 This issue is impacting people of all 11 educational backgrounds and social economic status. 12 So we have to have a very multi-prong and multitude 13 approach to this. 14 And we do believe, here at the Black 15 Mammas Matter Alliance, along with all of our partner 16 organizations, that we have a solution to that. 17 Thank you. I'm looking to CHAIR LHAMON: 18 see if the other panelists, Mr. Leone. 19 MR. LEONE: Yes. So I believe there are 20 several universities showing positive pregnancy 21 outcomes with some of the programs. 22 And most of the programs that I know, I 23 don't remember exactly the names of them, but those 24 programs that are showing positive pregnancy outcomes 25 are the ones that are using health education, are

1 investing our time in educating the patients. And I agree with the other panelists that 2 3 say that we need to embrace these or confront these in 4 a holistic way. So, it's not just physical issues 5 patients are dealing with, also that are our 6 psychosocial issues and spiritual issues and social 7 issues. 8 So, if we have these programs that are 9 holistic in nature and address physical issues, but 10 also psychological, emotional and spiritual issues, I 11 think that patients can have better pregnancy issues. 12 CHAIR LHAMON: Thank you. 13 Perry. 14 DR. CREAR-PERRY: I just want to add and 15 build on, especially with, so we know despite income 16 or education, Black women are still more likely to die 17 in childbirth than their White counterparts. 18 Black woman, the CDC released a report that a Black 19 women who is college educated and above, is five times 20 more likely to die than a White female in a similar 21 situation. 22 So this idea that if we can place, got a 23 good job, got some health insurance and exercise and 24 move to a nice neighborhood that everything would be

okay, if we were just more compliant and showed up to

1 our appointments, it's not based on the actual data. The fact is, when we do all those things we're still 2 more likely to die. 3 4 So whatever programs, to Angela's point, to Taraneh's point and Mr. Leone's point, whatever we 5 do has to be comprehensive, but it can't be based upon 6 7 bias and lack of truth. 8 So the truth is, even when we do all the 9 things that's, prevalence responsibilities that we 10 should do, we are still more likely to die. And we're 11 not investing in the things that allow for us to have 12 psychosocial and spiritual wellness and joy. 13 So, those things require us to actually 14 invest in women's health, regardless if they're 15 pregnant or not, community's investment, regardless or 16 not. And not contain this fallacy that it's because 17 we don't show up for the doctor or because we are not 18 getting access to Medicaid. 19 Like, those are the reasons we die. 20 Because even when those things happen, we're still 21 more likely to die. 22 CHAIR LHAMON: Thank you. Commissioner 23 Kirsanow. 24 COMMISSIONER KIRSANOW: Well, thank you, 25 Madam Chair. And thanks to the panel, this has been a

very informative testimony.

Several panelists have testified that structural and systemic racism is one of the principle causes of maternal health care disparity. Can, and this is to anybody, can anyone give me specific examples of what you mean by systemic and structural, invidious racism or racial discrimination in systemic structures and medical systems that cause maternal health care disparities on the basis of race?

CHAIR LHAMON: Dr. Crear-Perry.

DR. CREAR-PERRY: This is my life all day.

I feel like I can't help but start.

So, and the specific example is, how we structure even the policies around who gets access to care. As an OB/GYN, many of us trained in the hospitals and facilities where there were only Black and Brown bodies. We assume, still, the legacy of history of eugenics that the people who we have to train on have to be, are communities of color, right?

So if you go to any place in your cities, in your town, the hospital training institutions are Black and Brown bodies. So what would it look like to be a structural system that said, training doesn't mean Black and Brown, training doesn't mean poor people, training doesn't mean non-centered people.

If we trained, we invest in, ensure that the people who need the most resource, so those communities, if you're talking Charity Hospital, where I train, or Grady Hospital in Atlanta, those patients actually need the most. They are the most complex patients and we are sending them to places where there is training.

We're not investing in those institutions so both Charity and Grady are always struggling to get budget, that's racism, that's structural. They're begging for money to even keep their doors open, and yet we're sending the most complex patients to those centers. So, over and over again.

Then we get poor outcome. And we're trying to figure out, well, where do poor outcomes come from.

We've never invested in the people who actually need continuity, who need a birth center in their community led by a midwife, have a doula supporting them from their community whose invested with them. That's what they want, that's what we should be investing in.

That's a structural decision that we are making as policy makers to not allow for the growth of birth centers, the growth of midwives, the growth of

1 That's how structuralism works. 2 It devalues groups of people, and also 3 institutions, and invest in things that are harmful to 4 support the legacy and hierarchy of White supremacy. 5 I thank you, Dr. Shirazian, CHAIR LHAMON: 6 oh, sorry, Dr. Shirazian, I saw you had an answer as 7 well? 8 I mean, I completely DR. SHIRAZIAN: Yes. 9 agree with Dr. Crear-Perry in terms of like how our 10 health care infrastructure is setup, I'm also 11 OB/GYN, in how systems are setup. 12 I can just give you a few examples from a 13 verv like personal perspective. Not mу lived 14 experience, but certainly the community health workers 15 that I work with and what they tell me. And what I 16 actually see as well. 17 So, if you're a patient. So I'm just 18 going to give you like an individual patient kind of 19 perspective. But if you're a Black pregnant woman and 20 you come into a clinic, let's say, in New York City, 21 and you have to wait eight hours in the waiting room 22 for care, that is structural and implicit racism right 23 there. 24 Because that, you know, that waiting room, 25 it just devalues that patient, right? She has to wait

nine hours to see a doctor. The clinic is busy.

When she sees the doctor, the doctor gives her five minutes to talk to her, to answer any questions. Maybe she's not a sophisticated speaker, presenter. She can't even get out her issues or complaints. Maybe she doesn't know how to articulate them even.

You know, brings in issues of health literacy and how she's heard. Whether the doctor hears her, whether he or she understands what she's saying, whether they bother to listen.

So, I mean, those are just some very simple examples. But I think from an individual patient perspective, if you go into those clinics and hospitals or you go to see your doctor and you don't feel valued, you don't feel respected, you don't feel listened to, why would you ever go back. Like, why would you go back if you have a true problem, you're going to stay home.

And that's where we see, sometimes maternal deaths happening because people don't come back in that quickly. I mentioned before, most maternal deaths, at least looking nationally at the data, they happen before delivery or in that first week postpartum.

1 So if you go home and you had a horrible 2 birth experience and now you have pain in your leg that could be a blood clot, you're not going to raise 3 4 your hand to go in and see the doctor, you're going to call your friend, someone in your community. 5 6 that front-line health care provider. 7 That's why I say, a lot of the solution 8 lies in the communities because people, women trust 9 their community leaders, they trust their community 10 health providers. 11 And until there is a day where they can 12 also trust their clinics and their hospitals to listen 13 to them and be respectful and not make them wait for 14 hours, you know, that system is going to take a longer 15 time to change. So that's why I always say, community 16 first, educate the community, empower the community, 17 the results lie there. 18 CHAIR LHAMON: Mr. Leone, it looked like 19 you had an answer. 20 MR. LEONE: Yes. So, I just wanted to say 21 that I agree with Dr. Perry that health care services 22 is not just what is needed here. 23 What we need is a primary prevention 24 strategy. Something that can educate patients when 25 they are done. When they're, early in life so they

1 don't engage in risky behaviors. And then they don't show up with these comorbidities to their care. 2 3 So, again, I agree with her that health 4 care is not, the only pin that we need to address here 5 is also primary prevention. Because primary 6 prevention studies are more cost effective 7 efficient than later remediation. 8 So, I believe that we need to make an 9 effort in educating the patient early in life. And I 10 believe that sexual reasonable education is 11 alternative, or one good alternative for you guys to 12 consider. 13 CHAIR LHAMON: Thank you. Ms. Aina. 14 I believe that the MS. ATNA: Yes. 15 question was originally talking about racial and other 16 systemic discrimination in our hospital settings and 17 just around the entire system. 18 We have spoken to several women of varying 19 ages and socioeconomic statuses via focus groups, for 20 the past three years. 21 And what's pretty consistent is that when 22 they do come into a hospital facility, the types of 23 treatment that they receive tends to be based on the 24 type of health insurance that they have. 25 they're on Medicaid or they don't have insurance at

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And many of them have reported actually being discriminated against by health professionals. Whether it be the front desk administrators who are not taking some of their complaints very seriously, or they have gone, they're in the laboring process and they're trying to explain to their clinical provider of any pain or challenges that they're having. Or may not understand why all of a sudden some kind of surgical intervention has been deciding upon them without their consent.

These are examples of systemic discrimination, based upon the fact that, one, basic patient consent to understanding what services are being provided to them is not happening in these facilities.

Further, during this COVID-19 pandemic, earlier on in the pandemic, a lot of hospital systems, unfortunately, were passing policies that restricted the ability for different birthing persons to bring support for, their support persons with them. Whether that's a doula or somebody else that they wanted to bring with them during that process.

And so, you know, these policies get passed at the local health care system's level at any

1 kind of realm, depending on what's going on. And so, these are, I'm just providing that as specific 2 3 examples because they do lead to negative health 4 outcomes. And we see that more nationally on, fort, 5 6 I mean, this is very unfortunate. We see that in the 7 story of Amber Rose Isaac in terms of, you know, she 8 did everything that she possibly could to navigate the 9 health care system in New York. 10 She requested for midwife services and 11 still wasn't provided that. And unfortunately died 12 after being serviced at the hospital's system. 13 We saw that with Sha-Asia Washington, who 14 was ignored. Her blood pressure, I believe, was 15 rising and no one attended to her and she still died. 16 So these are actual examples 17 discrimination in the health care system. This is not 18 because these young ladies came into the hospital and 19 they had all these preexisting conditions, these were 20 preventable deaths that health care providers are 21 trained to actually intercede in and it didn't happen. 22 So these are examples of discriminatory 23 acts in these health care systems. 24 CHAIR LHAMON: Thank you. Mr. Kirsanow. 25 COMMISSIONER KIRSANOW: Yes. Thank you

1	very much for that.
2	Dr. Shirazian, I think you indicated that
3	female Black mortality rates are higher than that of
4	Whites. I'm supposing that that's controlling for
5	socioeconomic conditions?
6	DR. SHIRAZIAN: Yes.
7	COMMISSIONER KIRSANOW: How do they
8	compare with Asians?
9	DR. SHIRAZIAN: Black women have the
10	highest rates, then Hispanic, then Asians and then
11	Whites. So, it was a cross, I listed here health
12	state, health status, sociodemographic factors and
13	neighborhood income. It was taking into account all
14	three of those things.
15	I definitely is true that even a long
16	socioeconomic lines, Black women die at significantly
17	higher rates than White women.
18	COMMISSIONER KIRSANOW: Thank you.
19	CHAIR LHAMON: Dr. Crear-Perry, it looked
20	like you had an answer as well?
21	DR. CREAR-PERRY: I just wanted to,
22	because we talk a lot, we use White as like the
23	default race. And in so many experiences, actually,
24	Asian Americans have better outcomes than White folks.
25	So we got to really reframe how we talk

1 about race and the implications of race. Race is not 2 biological. 3 I don't have a Black gene, I'm just as 4 likely to have the same genetics as Dr. Shirazian has. We are all one human race. We completed the entire 5 6 human genome project. 7 So when you think about the differences of 8 how Black women are treated in the hospital and the 9 outcomes we have in birthed, it's not because our 10 kidneys are different shaped or our lungs are a 11 different size and White women have different kidneys 12 and lungs and Asian people have different, it's how we It's how the 13 are treated and seen in the system. 14 structures show up when we are addressed. 15 So, even as Angela mentioned, 16 studies and data that shows, despite payer, Dr. Liz 17 Howell did a study that show that Black women who have 18 insurance payers who have good insurance still get 19 treated worse than their White counterparts who have 20 no insurance, who show up with no prenatal care. 21 So, until can have an honest we 22 conversation about the devaluation of people based 23 upon skin color, based upon gender, based upon income, 24 we're never going to fix maternal health crisis. 25 Thank you. Commissioner

CHAIR LHAMON:

Yaki.

COMMISSIONER YAKI: Thank you very much. And thank all of you for taking time today on this important topic.

I come at this from sort of two different angles here. One, I used to be in local government, so I understand and really appreciate and quite championing the idea of locally based, community-based organizations in delivering really critical services to communities.

The other part of me is when I was at the federal level working for the speaker and talking about how do we get the resources necessary to make that happen.

And that tension between funding us studies, who controls the studies, this kind of stuff, if we want that information. And then sort of the control. Where is it going to be distributed is really sort of the crux of how do we address this.

Are there any good models out there that the federal government can look at to say, okay, this is the kind of mechanism that we can direct dollars to that will achieve these kinds of results that we want to see on the aggregate, but at the local level, reduce the kinds of individual changes that we want to

1 see. 2 I guess, is, are there things out there 3 that the feds can latch on to and say, this is how we 4 want to be able to figure out a way to distribute the dollars necessary to meet this critical health need? 5 6 I see people smiling, that's interesting. 7 (Laughter.) 8 CHAIR LHAMON: Dr. Crear-Perry. 9 DR. CREAR-PERRY: Well, because 10 excited about the opportunity. I'm in a place of 11 justice and joy today and I'm like, listen, what are 12 we going to do different, how are we going to do 13 something different. 14 So one of my favorite programs in the 15 world is the Healthy Start Association. A healthy 16 start program. 17 My first job in maternal child health was 18 the medical director for the Healthy Start in New 19 And this idea that you can actually give Orleans. 20 money to communities and they can fix their own 21 problem. 22 It was actually a Republican idea. This 23

was amazing. We had never scaled it up, we never invested in it and we've never, and it keeps showing that healthy start communities have better birth

24

1 outcomes. We know that through the data and yet we've 2 never actually invested in it. 3 So we keep doing trickle down. 4 give, the federal government gives money to the state 5 and the state tries to figure out. 6 And you know the city, how as a city 7 person, states, city fights can cause that to be a lot 8 of drama, that can be very complicated. Mayors don't 9 get along with the governors, all that stuff happens 10 quite a bit. 11 So what does it look like for the federal 12 government to be billed out by health start model, to 13 trust communities with the dollars to do the work. 14 They were doing social determinism of health before 15 the WHO made it up. 16 They've been doing, having housing and 17 having legal aid and having everybody to work on 18 infant mortality for 25 years. So, that's the kind of 19 innovation you get when you actually invest in local 20 communities. 21 COMMISSIONER YAKI: Great. 22 CHAIR LHAMON: I see Dr. Shirazian has an 23 answer as well. 24 DR. SHIRAZIAN: Yes. And this kind of 25 talk gets me excited me.

So, I think that, I think as Dr. Crear-Perry just said, that it really does, as I've been saying, lay in the community. But I do think that we need to understand all the communities that are out there doing this kind of work, I think we need a broad, collaborative force that brings them all together.

I think we need standardized approach and training. Like, every body gets the same roadmap.

I think we need standardized approach and training. Like, every body gets the same roadmap, not, individuals are sort of kind of creating their own.

Because I do think that consistency is important because then we have a model that works, we have a plan that works, we have an evidence-based approach.

We need better data. I mean, we talked about death rates, we need to track death rates. It's not only in this country but it's everywhere by the way around the globe. I mean, tracking death rates in terms of mothers is horrendous everywhere.

But we need consistency in terms of the approach and we need to have training to be consistent, we need to the approach to be consistent and we need to collect data because. Because, when I did a review of the data I was shocked. I mean, there

1 is so many groups out there doing good work. I know 2 their good work. 3 But if I go on a PubMed search and look 4 for like their articles or their published data, I mean, I don't find anything, I find very little. 5 Ι 6 mean, that's a problem. I need to be able to look 7 there and see the evidence for myself and read it. 8 And people, we need to be accountable for 9 the dollars, right? We can't just give states money 10 and then who knows what happened to the money, right? 11 It didn't go back to the communities. 12 know if there was any change in maternal 13 outcomes of death. That's a problem. 14 The other problem, while I have one more 15 second, is that people track birth data, right? 16 look at the babies, a lot. 17 They look at, this drives me crazy, okay, 18 they look at preterm delivery rates, they look at low 19 birth weight. How many years have we been looking at 20 low birth weight and preterm birth weight, okay. 21 What about the mothers? That's why we're 22 about the mothers. Like, we want to know, did the 23 mothers die, did the mothers have to come back for 24 other interventions, did they have surgery, what 25 happened to the mothers, it's not all about the

1	infant.
2	So, I think there is this issue of
3	maternal infant health. And the maternal gets diluted
4	under the infant sometimes.
5	And we really, in order to have good
6	programs that actually address maternal mortality, we
7	need to focus on the maternal. We need to focus on
8	the mothers.
9	CHAIR LHAMON: Thank you. Mr. Leone.
10	MR. LEONE: Yes. So, I think that a good
11	idea for the Federal Government to consider is to fund
12	organizations that are life affirming. Organizations
13	that are providing life affirming health care
14	services.
15	Why? Because we provide health care in a
16	holistic way. Emotionally, psychologically,
17	spiritually and physically. And we tend to expand
18	more time with our patients then other organizations
19	do.
20	So, if you can direct funding to life
21	affirming organizations, that would be ideal. And we
22	can show that we have a higher patient satisfaction
23	rate too.
24	And also, I would like to share with you

that the University of California, two months ago,

1 they came to us because they have a program to serve pregnant women in the local jail in Orange County 2 3 California. And they came to us because they couldn't 4 find any other organization in the community that would accept those women. 5 And that is very interesting because the 6 7 programs are already funding several fairly funded 8 health care clinics that are supposed to serve these 9 And they are putting barriers to them. 10 So, we serve anyone regardless of their 11 ability. And we don't discriminate based on race or 12 national origin. We are life affirming organization 13 so I believe that if you guys take a look at what life 14 affirming organizations are doing, it will give you 15 another perspective or alternative to what is needed 16 in the country. 17 CHAIR LHAMON: Thank you. Ms. Aina. 18 MS. AINA: Yes. What I wanted to add is 19 really does need to take a both-and this 20 approach, and not an either or approach. 21 And I say that because I know it was 22 mentioned earlier about really investing in a lot of 23 evidence-based models and honing in on a standardized 24 training and things of that nature.

I do want to lift up that those also

1 actually serve as structural barriers to a lot of our, 2 for a multitude of communities. Most especially Black 3 and indigenous communities. 4 And specifically, Black and more indigenous midwives. Black indigenous midwives who 5 6 practice at the public level. 7 We know that across several states there's 8 different rates of regulations of how midwives can 9 Same thing for doulas as well. practice. 10 And so, we really do tout that we need 11 multiple options. Because, just having multiple 12 options around choices is really important for a lot 13 of birthing people across the nation. No matter their 14 socioeconomic status in income. 15 And so, definitely more investments 16 minority serving institutions that can do this type of 17 research to build the evidence of the positive birth 18 and maternal health outcomes that we know that a lot 19 of our communities of color are doing. 20 More investment in non-profit 21 organizations that can do a better job of not only 22 providing a space for workforce development but to 23 also provide comprehensive training around whether 24 you're talking about a holistic approach to perinatal

health care or holistic approach to midwifery care,

1 doula care. 2 There is not always these, again, this 3 one-sided, one-narrow way approach to these things. 4 Because, multiple communities look like multiple different things. And have multiple different 5 6 challenges. 7 And especially, and I have to lift this 8 up, especially for a lot of us in the south region 9 area of the United States. Our rural communities need 10 a lot of programs and services. 11 And we have people in those communities, 12 organizations, academics. People of 13 disciplinary background who are ready right now to 14 engage in a team-based approach to addressing a lot of 15 these issues. 16 And need equity-focused investments. 17 not just investments in the traditional players in the 18 maternal and child health sector. 19 Thank you. I see that we CHAIR LHAMON: 20 have two minutes left for this panel, so I'm looking 21 to see if there is one last Commissioner question. 22 looks like Commissioner Adegbile. And then we'll do a 23 lightning round to take us home. 24 COMMISSIONER ADEGBILE: Great. Thanks

This has been a very enlightening panel.

very much.

1	I'm trying to understand if one of the
2	takeaways that we should have from the collective
3	testimony, or the aggregation of all this great
4	testimony, is that because of the concept of maternal
5	health care deserts and the absence, in some
6	communities, of access, that part of what we need is
7	more of the, the sort of birth centers, community
8	localized approach to be reaching folks with
9	interventions.
10	I'm just trying to understand. I get that
11	we have big hospitals and there are issues there.
12	Regardless of what your socioeconomic status is in
13	your education. But I'm also trying to get at this
14	gap point.
15	And then the other thing I was a little
16	bit confused about is, what is life affirming?
17	I'm assuming that in the plain English I
18	would guess that all of your organizations are life
19	affirming. You're working on issues that are trying
20	to prevent death and disparity. And so, I'm trying to
21	understand what is life affirming and what the object
22	we're trying to move away from. Thanks very much.
23	MR. LEONE: Yes. So I can answer that
24	question about life affirming, the concept.
25	I would say that life affirming, life

1 affirming organization is an organization that values life. And not only the life of the mother, but also 2 3 the life of the baby. 4 So when you have that perspective, when you approach health care with that view, with that 5 6 concept decision, you really take care of, you really 7 pay attention, you really address the needs of the 8 woman and the baby. 9 So, if you have that holistic approach to 10 women, at the local level, then I believe we can have 11 better pregnancy outcomes, as we see in our clinics. 12 With higher patient satisfaction and a higher birth 13 rate. 14 CHAIR LHAMON: Thank you. Dr. Crear-15 Perry. 16 DR. CREAR-PERRY: Yes. So, yes, you're 17 right, Commissioner, that it is a mixture, we believe 18 it's a mixture of local solution that the federal 19 government can really invest in more birth centers, 20 more midwives, more doulas, education for culturally 21 congruent. 22 We left out, we didn't talk a lot about 23 our indigenous sisters. And I think there is a lot in 24 the tribal community that we were missing, investing 25 in the tribal community and their maternal care.

1 But the goal, why I brought up that I'm the child of an ophthalmologist, is because surgery 2 3 happens in hospitals, birthing a baby is not an ICU 4 event. So all of the things we've been doing to fix maternal mortality have been as if we were 5 all 6 ophthalmologists and we need more technology and 7 higher more bigger hospitals. And what people want, 8 want patients want is care in their communities. Life affirming, our mission is maternal 9 10 and infants, so I guess I can start calling myself 11 that too, right? 12 Life affirming care in their communities, 13 ensuring that we are addressing the needs of the 14 people, with people who actually look like them. 15 Thank you. Dr. Shirazian. CHAIR LHAMON: 16 DR. SHIRAZIAN: Yes. I mean I think to 17 fill these deserts that exist, we definitely need 18 community-based organizations. We need community 19 players, doulas, community health workers, all of the 20 community players that help us serve the needs of 21 women everywhere in this country. 22 I wanted to just say one thing about 23 I don't think that standardized has to standardized. 24 be negative here, I really don't. I think that 25 standardized just means that we have a common playbook

It doesn't mean that it has to be the 2 3 hospital or the doctors that design the playbook, 4 right? It doesn't mean that they have to be the ones creating the playbook. In fact, I think that the 5 6 community investors, the doulas, the community health 7 workers should be the ones laying the groundwork for 8 those playbooks. But I do think that we need to rethink how 9 10 we talk about standardized and we do need to have this 11 sort of common whatever you want to call it, but 12 common model, common playbook, whatever it is, because 13 we need to know what is actually working and we need 14 to have the data. We just do. Like, we cannot not 15 It's just -have evidence. 16 I'm going to move to Ms. CHAIR LHAMON: 17 Aina for the last point. 18 MS. AINA: Yes, and I would agree. Definitely we are about wellness. We are about what 19 20 our people want. And especially to uplift the fact 21 that we should always trust black women in this 22 instance and that includes over their entire life 23 So it is very much life-affirming whatever 24 choice that they seek to make about their lives.

that we can take up program and we can apply it.

And definitely to agree, I do agree with

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you that we do need standards. And I think that also what I was trying to say earlier is that we need to make room for community-based models of care and practice to help add to those standards.

We need to make room for looking at different models of research that uplifts those (telephonic interference) from these communities that are most impacted, whether we are talking about creating more pipelines for native and indigenous people, black folks, Asian folks, whomever, who are really culturally competent and holistically-minded around different research models and understanding how to collect that evidence to build out the evidence base to show positive and maternal and infant health outcomes.

And, lastly, by doing that we also believe that that will help to debunk, right, misinformation that get pushed in our communities and anything that seeks to dehumanize our communities through services or any kind of programs that seeks to mystify or shame black women and birthing people about their choices around their maternal and reproductive health care.

So all of those things are very important. Thank you.

CHAIR LHAMON: Thank you all. This was an

1 extraordinary panel and we're very grateful to you for 2 your time and your expertise. 3 We will take a brief break now that we 4 have come to the end of our second panel. As we'll be very brief, we'll be back in six minutes at 12:25 p.m. 5 6 Panelists, you can go ahead and leave the 7 Zoom and we invite you to resume watching on the 8 YouTube stream for the rest of next panel. So thank 9 See you all back in, now, you very much. 10 minutes. 11 (Whereupon, the above-entitled matter went 12 off the record at 12:20 p.m. and resumed at 12:26 13 p.m.) 14 CHAIR LHAMON: Welcome back, everyone. 15 will now move to our third and last panel during which 16 we will hear from individuals about their lived 17 experience. 18 Panel 3: Lived Experience 19 The panel will proceed as CHAIR LHAMON: 20 follows: 21 Chanel Porchia-Albert, who is a board 22 member, March for Moms, and founder of Ancient Song 23 Doula Services; then Nan Strauss, who is Managing 24 Director, Policy, Advocacy & Grantmaking, Every Mother 25 Counts; and Jennifer Jacoby who is Federal Policy

Counsel, U.S. policy and Advocacy Program, Center for Reproductive Rights; and Nicolle L. Gonzales, who is Executive Director and Founder, Changing Women Initiative.

Given some of the topics that come up with regard to maternal mortality, I want to remind our panelists and the public again, and my fellow Commissioners, that since 1983, Congress has prohibited the Commission from, quote, studying and collecting or, quote, serving as a clearinghouse for any information with respect to abortion. Please tailor your remarks accordingly, consistent with this statutory restriction.

And with that, we will begin with Ms. Porchia-Albert. Please proceed.

MS. PORCHIA-ALBERT: To the members of the United States Commission on Civil Rights, good afternoon, Chair Lhamon and distinguished members of the United States Commission, I would like to thank you, thank the Commission for convening this briefing and the opportunity to provide testimony on the state of maternal health disparities in the United States and the role of the federal government in addressing them.

My name is Chanel Porchia-Albert and I'm

the mother of six children and the founder of Ancient Song Doula Services located in Brooklyn, New York. Ancient Song is a community-based organization working to reduce racial disparities and inequities within reproductive health care.

We've provided approximately over 1,400-York City parents with personalized, plus comprehensive, culturally relevant care, trained and certified thousands of nationally doulas internationally, and demanded justice for black women and families and spearheaded the fight against racial disparities and maternal mortality and morbidity since its founding in 2008. And we're a vital community entity, a leading voice for underserved black women, pregnant people and women of color in marginalized communities in New York City.

I was ushered into this work because of my own birthing experience with a midwife and a doula. The care that was given to me was unlike anything I had experienced. I was listened to. I was centered. I was shown genuine care and warmth.

This experience led me to become a doula to support others in their birthing experiences. I started this work naive to the realities of how black, brown and indigenous women and birthing people were

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discriminated against at almost every turn.

Attending prenatal visits with someone who was on Medicaid to sit with them for over four hours to only be seen for ten minutes, and then once in the room with an air of condescension. Supporting someone in labor and witnessing them be drug tested without their consent and not because they showed signs of substance usage, but because they are poor and black.

I've witnessed police officers called to escort partners out of a birthing room when trying to center their family's rights and that of their newborn child.

Delayed care or no care, it all becomes the deciding factor of whether you will seek out care because of the dehumanization that one faces when entering these healthcare institutions steeped in structural racism and bias on an institutional and interpersonal level.

Over the past few years, doulas have become key players in the fight to end racial disparities and maternal mortality and morbidity. And while legislation is critical to widening the lens of access to proper pregnancy and birth support, few outside the birthing community fully understand the long-term effects on black women, birthing people and

families in the communities when we experience maternal death or suffer a near miss due to racial constructs developed during the enslavement of African peoples that still plays out in our medical system today.

Our healthcare system is infected with a crippling disease that has seeped into every aspect of care delivery and that disease is racism. It needs to be eliminated in order to truly center a healthcare framework that is just and equitable for all.

These racialized perceptions infiltrate every single system in our country, especially health care. And the voices of our ancestors demonstrate that when we work together to centralize health care for those most disenfranchised, we center all peoples.

We owe this to the countless children who are being raised by fathers, partners and grandparents. We owe it to Shalon Irving, to Amber Rose Isaac, to Sha-Asia Washington, the names of a few individuals who have died of postpartum complications or suffered a near miss because of the ways in which they have been treated within the healthcare system.

We are at this juncture today because the United States has failed as a nation to center those most disenfranchised because of the vast inequities

that continues to plague this nation, such as redlining, inequitable housing, food apartheid and environmental injustice, poor educational systems, high incarcerable rates and police brutality.

We are here because the United States' lack of accountability in centering those who are at the greatest risk. We have an opportunity at this time to center full comprehensive collaborative care, meeting people where they are, not where we expect them to be. We have an opportunity to save lives and center hope.

Some of those key strategies are centered around fund black women-led birth worker organizations, increase access to midwives and midwifery care, community-based doula models must be paid at a living wage and a reasonable amount for the services provided, and to successfully reduce racial in maternal health outcomes federal disparities Medicaid coverage for up to one-year postpartum.

Legislation must include input from birth community stakeholders and measures must be taken to address the root causes of structural and institutional racism within the healthcare system beyond expanding access to doula care. Measures must be taken to address accountability mechanisms for

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1 consumers self-reporting and provider reporting that can inform institutional policy and reform. 2 3 In close, we have a duty to center hope, 4 as we are the hope of our ancestors standing in the present building a foundation for hope for future 5 6 generations to rest upon. Thank you. 7 CHAIR LHAMON: Thank you very much, Ms. 8 Portia-Albert. Ms. Strauss, you may proceed. 9 10 MS. STRAUSS: Good afternoon, Chair Lhamon 11 and distinguished Commissioners. Thank you for 12 conducting this briefing and for the opportunity to 13 address the state of maternal health disparities. 14 My name is Nan Strauss. I'm the Managing Director of 15 Policy, Advocacy & Grantmaking at Every Mother Counts. 16 In 2010, Amnesty International reported 17 that high rates of U.S. maternal deaths and extreme 18 racial disparities constituted a maternal health 19 crisis and a violation of human rights. Ten years 20 later, little has improved. 21 The U.S. ranks 55th in the world in 22 maternal deaths. We spend over a \$111 billion a year 23 on maternal and newborn care, and severe complications 24 and deaths are increasing even though both are mostly 25 preventable.

But none of that is why we're here. We're here because of the fundamental injustice that when a Black or Indigenous woman brings a new life into this world, she faces a greater risk of death than a white woman. To be clear, maternal health disparities cannot be explained away as an inevitable consequence of socioeconomic other factors.

Disparities are reported between Black and white women in all regions of the country at all ages at all levels of income and education, among women with particular health conditions, among women at the same hospital. Even when you control for other factors, no matter how you analyze the data, you see the same results. So there is no way to avoid the conclusion that the devastating inequities are rooted in structural and interpersonal racism in our healthcare system.

Recent high-profile stories have shown the life and death consequences when Black women's concerns are ignored, care delayed and voices silenced. Stories like those of Dr. Shalon Irving, a CDC epidemiologist, who died after repeatedly bringing dangerous warning signs to her doctor's attention.

And Kira Johnson who was told she was not a priority and who died after her husband spent ten

excruciating hours begging and pleading for doctors to help her. Disrespect, belittling and coercion occur with unacceptable frequency and tangibly influence our outcomes and survival.

Healthcare provider factors, particularly a delayed response to clinical warning signs and ineffective care, are the greatest contributors to preventable maternal deaths. A large nationwide study found that one in three people of color reported experiencing mistreatment or disrespectful care during childbirth in U.S. hospitals -- one in three people. That makes them twice as likely to be mistreated as white women.

The most common forms of mistreatment included being shouted at or scolded by a care provider, being ignored or having their requests for help refused, violations of physical privacy, and providers withholding treatment or forcing unwanted treatment. And, currently, there's no reliable pathway for hospitals to get feedback from or provide redress to patients whose rights are violated or who experience discrimination or mistreatment, which means that no one puts a stop to these harms and they go on and on and on without being addressed.

Today, we have the opportunity to

collectively decide that Black women's lives are worth saving. To do that we have to build a maternity care system that's rooted in equity, transparency and accountability so that all women can access the high-quality, respectful maternity care that they need and that they deserve.

And do this by we can creating accountability, requiring hospitals to collect and publish data not just on deaths but on complications, on procedure rates and on the experience of care that is disaggregated by race and ethnicity to identify disparities at a targeted level, by developing respectful person-centered measures for care, establishing а system to address reports of and mistreatment discrimination, integrating underused, high-value, evidence-based solutions like the midwifery model of care and like community-based doula support and by extending Medicaid to cover people for a full year following childbirth and, above all, by listening to women.

Our country's deep, persistent maternal healthcare disparities are not inevitable. They're the results of decisions that we make as a society, decisions about whose lives matter, whose lives we value and whose lives we choose to save.

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1 Our action's overdue. It's time that we 2 need to do everything in our power to ensure not one 3 more Black woman, Native American woman or woman of 4 color suffers a preventable death while giving birth. 5 Thank you. 6 CHAIR LHAMON: Thank you, Ms. Strauss. 7 We'll next hear from Ms. Jacoby. MS. JACOBY: Good afternoon. 8 My name is 9 Jennifer Jacoby and I am a federal policy counsel at 10 the Center for Reproductive Rights, a global legal 11 human rights organization, and it is my honor to brief 12 this Commission. 13 As you have heard many, many times today, 14 research shows that black women experience worse 15 maternal health outcomes than white women do, even 16 when factors such as other health conditions or 17 socioeconomic status are the exact same. The CDC has 18 indicated that issues with the quality of care black 19 women receive plays a role. So the story I am about 20 to tell you will bring this data to life because, 21 unfortunately, my own close call while giving birth to 22 my own daughter is not a unique experience, not even 23 with within my own family. 24 I am the daughter of a black mother and

white Jewish father born and raised in New York City.

And 32 years ago, while pregnant with me, my mother nearly lost her life. Toward the end of her pregnancy, she presented with symptoms of preeclampsia, but her complaints were ignored and racist assumptions about her weight were made.

Now 20 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 and I had a Cesarean 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 in two different states 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.

And experiences like ours have occurred over and over again for decades and the data reflects it. But, meanwhile, the United States government has yet to mount an adequate response to the maternal health crisis disproportionately impacting black, brown and indigenous people.

Eliminating disproportionate risks that

marginalized people face while forming families is an essential component of a broader struggle for racial justice and civil rights and that's why we are talking about this today.

So far, our civil rights laws have not protected these communities from inequalities in maternal health care. And, still, as a matter of human rights, we know pregnant and birthing people have the right to safe and respectful maternal health care, free from discrimination, coercion and yes, violence.

But the United States has failed to meet its obligations to protect, respect and fulfill those rights. Indeed, international treaty monitoring bodies and other U.N. experts have assessed the U.S. human rights record on maternal health and have made clear recommendations. The U.S. has not implemented these.

Just this week, a comprehensive U.N. review of the United States called on this country to address the crisis yet again and ensure universal access to maternal health care. It is clear that the federal government has an important role to play in ending racial disparities in maternal health.

The issue is overwhelmingly bipartisan.

No one wants to see mothers die and there is no question on either side of the aisle that certain moms are at greater risk. And while recent federal law has mainly focused on advancing data collection, more must be done on that process specifically to ensure timely, systematic collection of data and to ensure stronger legal guarantees to safe, respectful care.

We need the federal government's commitment to addressing this civil and human rights issue. This includes federal legislation, regulations and guidance that strengthens community conditions and safety net supports for pregnant, birthing and postpartum people.

See, the Black Maternal Health Momnibus Act is an important step toward addressing many of the existing barriers to accessible, nondiscriminatory, high quality care that improves maternal health outcomes led by members of the bipartisan Black Maternal Health Caucus, the Momnibus aims to address each dimension of the crisis from expanding the perinatal workforce to protecting our veterans.

An interagency task force on respectful care and the issuance of regulations that encourage patient-centered care and accountability in healthcare systems is one of many agency actions that would

1 support the advancement of such legal guarantees. 2 Thank you and I look forward to your 3 questions. 4 CHAIR LHAMON: Thank you, Ms. Jacoby. Now we'll hear from Ms. Gonzales. 5 afternoon, 6 MS. GONZALES: Good 7 distinguished members of the United States Commission 8 on Civil Rights. Thank you for this opportunity to 9 provide testimony on the state of maternal health 10 disparities in the United States as it pertains to the 11 Native American women. 12 My name is Nicolle Gonzales. I'm (native 13 language spoken) from the Navajo Nation in New Mexico. 14 I'm a certified nurse midwife, founder and medical 15 director at Changing Women Initiative. 16 CWI is a nonprofit made up of indigenous 17 leaders and community leaders who are centering our 18 families and communities by transforming the cultural 19 narrative and setting in motion policy changes. CWI's 20 mission is to support our diverse indigenous 21 cultural birth communities to renew and the 22 fundamental indigenous human right to reproductive 23 health, dignity and justice. 24 I've been a registered nurse for over 19 25 I've been practicing full-scope nurse vears and

midwifery for the last nine years. I'm one of only 20 Native American nurse midwives practicing in the United States today.

I chose to become a nurse midwife following my own birthing experiences as a Native American mother birthing in a hospital and also from witnessing the mistreatment of Native American women while working as a nurse at the Santa Fe Indian Hospital in Santa Fe, New Mexico.

During my two years I spent working at the Santa Fe Indian Hospital, I, myself, experienced lateral violence by white, higher-ranking nurses overseeing my employment there. Ι witnessed unnecessary placement of 16-gauge IVs in Native American women by white nurses who used fear as their primary motive for excessive medical use of abnormally large IV needles that were not backed by current hospital policies. The harm done to Native American women was unconsented and not informed care with the excessive use of medical devices like the IV needle resulting in increased pain with placement.

Most of the time was working, I was working night shift in a small hospital. The nights would get cold in the winter to the point where I had to wear longjohns under my scrubs.

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One of the first pregnant women I took care of on the OB floor was someone from my community. There was a lot of concern by the other nurses regarding this patient because the story was that her baby had died in childbirth at that hospital last year, and here she was again having another child there again.

Because this woman was from my community,

I went in and asked her why she came back to have

another baby there knowing what happened that year

before. She said, I don't feel like I could go

anywhere else.

On another occasion, I overheard the white nurse midwives be proud of a recent birth they attended of a woman who was from my community and was a patient. The conversation from the midwives was related to how the Native patient was so stoic in her birth and didn't need pain medication. When I spoke to this community member about her birth experience, she said to me, I wanted pain medicine and I asked for it, but the midwives just told me to go walk instead.

The combination of these experiences and feeling helpless to really advocate for my community while working primarily as a nurse is what pushed me to return to school to get my master's degree in nurse

midwifery.

While getting my degree at the University of New Mexico and attending conferences specific to Native American women's health, I continued to hear two conversations happening around the care of Native American women.

I sat next to doctors and midwives who loved working with Native American women because they appeared stoic and never asked questions. When I would return to my community to talk to women who had their babies at the Indian Hospital, they spoke of their requests not being honored.

They spoke of medical procedures being done to them they didn't really understand or even like they had enough information about it. Some questioned the care they received, but felt helpless in pursuing anything legal or didn't feel confident it would go anywhere.

Historically, we know that Native American women in the United States were sterilized against their consent in the 1970s at the Indian Hospital across the Nations. But today, in 2020, Native American women still receive high rates of unconsented care where they are not adequately educated at all on their options, and due to government restrictions and

1 funding are denied the choice to have all of their 2 options available to them. 3 Presently, I spend much of my 4 educating legislators and policymakers on the working of Native communities, while there is little to no 5 6 Native representation in policy-forming bodies like 7 this Commission. 8 If that is not a clear example of how 9 little control or advocacy Native women have around 10 their own bodies, then let me be clear. 11 American women are directly impacted by any and all 12 decisions made around our funding, or under funding 13 needed healthcare services. 14 With regard to maternal health care, IHS 15 does not consistently provide reproductive health care 16 for Native American women. For example, in 2009, 17 Santa Fe IHS facility closed and Native women are 18 required to divert to other facilities to have their 19 babies. 20 More recently, the medical center 21 Phoenix, Arizona, also is closing and is requiring 22 women to go to other facilities to have their babies 23 without any prior given notice. 24 CHAIR LHAMON: Thank you, Ms. Gonzales. 25 I'm going to have to stop us there, just so we have a

chance to answer questions. Thank you very much. 1 I'll open for questions from my fellow 2 3 Commissioners. Raise your hand or unmute so I can 4 know that you want to ask. Go ahead, Commissioner Adegbile. 5 6 COMMISSIONER ADEGBILE: Thank you for all 7 of this important testimony. It was very enlightening 8 and it's been a day of enlightening testimony. 9 I wanted to drill down on some of the 10 points we've touched upon which is the role of the 11 federal government, the adequacy of existing efforts, 12 specific thoughts you may 13 interventions that the federal government could do one 14 way or another whether it be pending bills, whether 15 they're adequate, or something else that the agencies can be doing to better serve our women in our nation 16 17 in this respect. 18 The panelists, go ahead. CHAIR LHAMON: 19 Ms. Jacoby? 20 MS. JACOBY: Thank you, Commissioner. 21 Yes, so right now there is significant 22 interest in this issue specifically in Congress. Ιn 23 the last -- in the 115th Congress, we saw about 25 24 bills alone on maternal health. Two became law and 25 is perhaps the most notable, which is the

Preventing Maternal Deaths Act.

However, that only focuses on improving data collection. It was an important first step, a tremendous bipartisan effort, however, we have not really seen bills that address the root cause of the issue which we've talked about today is structural racism in care.

And so legislation that's pending right now is the Momnibus Act. It is meant to be additive of other legislation that's out there, so that speaks to Representative Ayanna Pressley's points earlier this morning where she has several other bills including postpartum Medicaid extension and doula coverage bills as well.

So the Momnibus is really, really an important part of this process because it was created alongside the community, so it was a very, very indepth process where community members helped inform what was needed and it's a nine-bill package.

And like I said before, it covers studying veterans and coordination of VA maternity care, to perinatal workforce and diversifications, different grant programs. It touches on indigenous women's maternal health care as well as incarcerated women. So it's very, very comprehensive and meant to really

support other efforts out there.

The other thing is that we're seeing in the agencies is that there are a number of campaigns right now from various agencies in NIH. CDC has, you know, the bulk of the data collection efforts, but a lot of what we're saying is purely public health and educational campaigns as opposed to really focusing on racial disparities.

So there's a lot that can be done and I think there's tremendous opportunity in, you know, in future administrations to really focus on creating interagency taskforce or certain offices that really focus on a full federal government commitment to this issue.

It's not going to be just legislation. We need administrative buy-in here and we're not seeing it at this time.

CHAIR LHAMON: Thank you. Ms. Strauss?

MS. STRAUSS: Thank you. Thank you for those comments and that insightful question.

I want to add a couple of points to those just made which are that if you look at the history of the Preventing Maternal Deaths Act that was passed when it was originally introduced in prior form in 2011 that bill had a section intended to specifically

focus on eliminating maternal health disparities and that section was removed from the legislation, I think troubling so.

But we know that we need more work to be done because we know that in areas where there have been reductions in maternal mortality, such as California, which is the only state presently to have consistently reduced maternal deaths, and New York City, we know that not only does an overall reduction in maternal deaths not reduce disparities, because in California those disparities have remained consistent even as numbers have come down.

But what we saw in New York City was there was a significant reduction in maternal death rates for white women. At the same time rates came down a tiny bit for Black women, and what you saw was that the disparities then grew.

So now in New York City a Black woman is not three or four times more likely to die from causes of pregnancy and childbirth; Black women are 12 times more likely to experience a maternal death in New York City compared with white women in New York City.

So we can't limit our approach to one that wholesale addresses maternal mortality, we have to be targeted.

Also, the ways that we need to be targeted need to go beyond what we have seen in that legislation which looks at maternal deaths as opposed to looking more broadly at complications and targeting disparities and we really need to shift from looking at emergencies/problems after they occur.

We need to shift our perspective upstream to a prevention model so that we are utilizing the high-value evidence-based practices that are really person-centered that emphasize relationship-based care, building trust in the community and having community-based models like community-based doula support, perinatal support in the prenatal period and in the postpartum period.

Those issues are addressed by bills like the MOMMIES Act as well as the Momnibus and bills like Midwives for Moms, which integrates a midwifery model that is comprehensive, much more holistic, wellness-oriented, and has been found to have better outcomes overall, better experiences of care, but also really address those issues that are specifically underlying disparities related to trust, communication, et cetera, bills like the BABIES Act that would put birth centers in more communities.

I think there is also an opportunity for

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non-legislative action such as enforcement of civil rights laws.

I think there is an underappreciated opportunity for looking into how can the requirement of the federal government either in the Department of Justice, in the Civil Rights Division, or in the HHS, Office of Civil Rights, looking at how there can be greater impactful, robust, enforcement of civil rights protections.

COMMISSIONER ADEGBILE: Thank you. Thank you for those good answers. I wanted to drill down for a second on this New York City problem which seems extraordinary and really severe and requiring important attention.

I wanted ask Ms. Porchia-Albert, who also does this work in New York, if we have any understanding of why it is that New York City has this level of disparity and what the interventions may be to change it, and then more broadly to the panel, we are interested in all of the disparities, so we are very interested in what's happening to black women nationally, but we want to hear about the Native American population, the Latinx population, so that we understand the full dimension.

It would helpful if you could just send us

sources that have the worst, the places that are the worst so we can shine a light on all of this and do better.

MS. PORCHIA-ALBERT: Greetings. Thank you for the opportunity to speak today, again. So, yes, I mean being in New York City I think some of the biggest challenges that folks have witnessed is, you know, they want to be seen, they want to be heard, and they want to know that someone genuinely cares, and that is what is not happening. They are not being listened to.

I recently supported a client who had a labor who, you know, postpartum -- Had to have a caesarean, it was medically necessary, came home the very next, or not the very next day, but two days postpartum, was, you know, I went to go do a postpartum visit with her and noticed signs of preeclampsia.

She was not given information around being able to diagnosis this. I told her about, you know, some of the signs and symptoms of preeclampsia. Later that day she ended up going to the hospital calling me saying, you know, she had increased edema.

The fight that we had to have just for her to get care in the postpartum period was something

that was atrocious. She was placed outside in a gurney in a hallway, and this is someone who had served in the military, who also is a police officer, and a black woman who, you know, found herself with individuals who were in the ER who were handcuffed to chairs.

I had to call the hospital administration just for her to get the care that was necessary for her to get. At the end it was told to us that the reason why that, you know, she was sent from ER back up into labor and delivery, back down to ER, gone back to L&D, and she was told by the hospital we apologize but we don't have a policy around individuals who come back during the postpartum period.

So once you give birth you are found in this situation where you are left out in the cold. You are left with no type of resources and no information.

She was not provided education around preeclampsia and what are the signs and symptoms to expect. So I think a lot of it has to do with education and having providing proper education to patients during the prenatal period but also understanding the warning signs for postpartum care.

It also has to center around medical and

provider education around interpersonal biases and racism, because also this individual experiences biases.

She had a Russian provider who when expressing and trying to give a timeline of what had happened to her was met with condescending tones, was then left to her own devices in a room by herself that had no windows and was not seen again until hours later when the shift would change and the doctor came back in and said, oh, I'm leaving now.

Then when the new doctor came in it was told to her that no orders had been given to her. Now between that time that she was admitted at 9:00 to 7:00 in the morning she could have experienced eclampsia where she could have had a severe case of hypertension and then she could have had postpartum seizures.

But this is something that people experience all the time and if it wasn't for her sitting there and advocating for herself and saying repeatedly like, no, I need to be seen, having me there helped her to advocate for herself and saying this during this time then she would have been sent home.

She would have been sent home and she

could have also become, you know, one of the statistics that we are talking about today.

And so а lot of it is centered respectful care at birth around education, around listening to patients, around, you know, collaborative care framework where you have, you know, OBs, midwives, nurses, and doulas working together, but also accountability measures and transparency, which is something that is truly lacking within our healthcare infrastructure, which is that accountability.

We have offices and task forces for almost everything, but when it comes to maternal health services we don't take the same level of consideration for the women and pregnant people in our country and to me that is sad.

When we are supposed to be one of the most industrialized nations and have the most advanced technologies to be able to center individuals we find ourselves in predicaments where individuals can't get the proper care that is necessary based on fear-based coercion, based on the overuse of medical devices, right, and not allowing for someone to be seen and to be heard.

We really need to center our human rights

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framework within our birthing and our care system that sees the bodily autonomy within the individual because what is happening is that black, brown, and indigenous walking into these hospital-based people are institutions and are being treated like they are in the carceral system where their rights are no longer their own, where their rights are taken away from them, where they are told what something is going to happen to them as opposed to speaking to someone and asking how can we best assist you through process, what does that look like, which tells me that we have lost the humanity and seeing in one another.

We have lost our moral compass and what it means to really center people where they are and really give them the care that is necessary. So I think that what we need is, you know, what we definitely need is institutions and offices that are separate that really are looking at maternal deaths and near misses.

We need to have a commission or an office that looks at gender equity and centers accountability measures and transparency that holds institutions accountable because we spend so much money in our healthcare infrastructure to have to have poor outcomes is a really poor reflection of spending, I

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1 mean like really and truly. And so we really need to think about how 2 3 are we really keeping our house in order. Are we 4 keeping our finances in order? Are we really like taking care of the individuals who hold our house 5 And that is the women and the folks who 6 together? 7 guide us through our nation, and we're not doing that 8 right now. 9 COMMISSIONER ADEGBILE: Thank you. 10 CHAIR LHAMON: Commissioner Kirsanow? 11 Commissioner Kirsanow, you're on -- Oh, good. 12 Thank you, Madam COMMISSIONER KIRSANOW: 13 Thanks very much for your testimony. It has 14 been informative. 15 I'm trying to further isolate and identify 16 those factors that could yield optimal outcomes for 17 pregnant women and those about to give birth. 18 Can you or does anyone have any idea of the why -- What are the factors that result in 19 20 Asian-American women having better outcomes than white 21 women? Anybody? 22 CHAIR LHAMON: I see no hands raised. 23 am also not sure if that data is accurate. I think on 24 a prior panel we heard a different data, but I am 25 waiting for hands raised if there any.

1 COMMISSIONER KIRSANOW: One of the prior 2 panelists said that Asian-Americans do have better outcomes than white women. 3 4 CHAIR LHAMON: We check can our 5 transcript. 6 COMMISSIONER KIRSANOW: Thank you. 7 MS. PORCHIA-ALBERT: I mean if we want to 8 speak from a -- We could speak to colorism and we can 9 speak to the ways in which people sometimes, you know, 10 how Asian-Americans are often times treated as our 11 white counterparts if we want to talk about that, 12 right, because what we are talking about here on the 13 panel is racial discrimination and bias and the ways 14 in which shows up and particular around melanated 15 melanated discriminations people and those 16 something that are far and vast and wide so we can't 17 pinpoint it to one. 18 One could say, oh, it was just chronic 19 health conditions, but chronic health conditions are a 20 by-part of what has happened systemically centered 21 around structural and institutional racism, right. 22 We could say, oh, well, you know, it's 23 because they are low income or they have a particular 24 literacy level, but we have also seen that regardless

of literacy level, regardless of income, it's that we

1 still are seeing the same poor outcomes. 2 So one must say that then the diagnosis 3 has to be then that it goes far deeper than that, 4 It goes into the ways in which people's right. humanity is centered at bedside. 5 6 It goes into the ways in which people are 7 When a birthing person -- Me, as a black treated. 8 woman, who sits before you right now as a mother, when 9 I go into a space the things that I think about are is 10 someone listening to me as a black woman. 11 When I take my child to an emergency room 12 I am not thinking about, oh, are they necessarily 13 about the care aspects of it as much as are they going 14 to see them as a human being, right. 15 I have two black sons and four daughters 16 and the ways in which they grow up in this world is 17 reflective of how they are seen in this world, right, 18 and how they are seen and perceived in this world is 19 the basis for how they are treated in this world. 20 When you don't see young black men treated 21 as such as men or as the individuals and the human 22 beings that they are then they are dismissed and 23 thrown aside. 24 But the same goes for our black women and 25 our young girls, they are also dismissed. They are

not listened to. A lot of that injustice happens at bedside. It happens when we are expressing pain and that pain is not listened to.

It happens when we can identify what is going on in our bodies and people are dismissing that, it is identified when people use fear-based coercion to get people to comply with medical procedures, or when other systems, such as child protective services, are used as a tool to get someone to agree to something, because automatically if someone tells you, oh, I'm going to take your child away from you then you are automatically going to comply with them.

So when we start to talk about this issue, again, it's not one thing, it's a multitude of things that culminate into someone's birthing experience. A provider will look at something as a good outcome based on, oh, we have a healthy mother, we have a healthy child.

But when it comes to the patient, the patient and the one who is experiencing is how was I treated, did someone listen to me, right, did they take the time to explain things to me and to my family.

Did they take the time to really center us and to say you know what I may not understand, please

tell me, what has been your experience since you came,
since you were birthed into this world, that has
shaped your identity and how you are able to function
in this world, because all of those different things
are factors into how someone can and will access
healthcare services and what they will look like.
But it's also based on the perceptions
that have been told about black, brown, and indigenous
people throughout the United States.
CHAIR LHAMON: Thank you. Any other
questions? Ms
(Simultaneous speaking.)
COMMISSIONER ADEGBILE: I have one.
Sorry, Madam Chair, did you want to get in?
CHAIR LHAMON: Go ahead. I can go after
you.
COMMISSIONER ADEGBILE: Okay. Just very
quickly, one of the things we have heard about are
making sure that people's voices are heard and in a
sense taking apart the way people are trained and the
social construct which lowers and debases some
people's stories and pain and ability to provide
inputs that are necessary for medical care.
Is there training going on on any broad
scale for medical professionals to understand these
scare for medical professionars to understand these

things that are now manifest and that we are having a 1 better understanding about? 2 3 It's very important to understand how to 4 use needles, how to give a drug, in what dose, all of those things are important, but you are sharing with 5 6 us and the other panelists are sharing with us things 7 that are leading to people dying because they are 8 unable to relate to other people and diminishing 9 inputs that are vital in healthcare, and so I 10 wondering both in medical schools and in other venues 11 are we doing training in this regard? 12 would Ι add there was recent 13 Administration Executive Order that makes it harder to 14 have diversity and inclusion type trainings and raises 15 questions about it that's having an effect in the 16 federal government. 17 How does that impetus affect what you are 18 telling us needs to be more understanding not less? 19 MS. PORCHIA-ALBERT: Yes, so I know -- Oh, 20 go ahead, Nicolle. 21 MS. GONZALES: So I work primarily in New 22 Mexico which is 90 percent rural. We have a high rate 23 of traditional indigenous birth attendants in our 24 state because Department of Health actually supported 25 the Native indigenous traditional midwives and birth

attendants historically.

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And so I believe when we start to privatize and professionalize a service, midwifery or birthing attendants, to colonize standards in regards to license and regulation, we actually curved a lot of these areas that are without healthcare providers and basically what our communities really need is skills and knowledge and so how are we making skills and knowledge accessible to everyone regardless of education or background.

tell Ι can you in other countries traditional indigenous birth attendants are widely and are accepted and are actually addressing this maternal health crisis in their own communities and it's from a community center while including preservation knowledge and cultural of their traditional indigenous ways.

And so for me when I see, and I get this question regarding, you know, privatization, professionalization of midwifery and skills and service, really it's our own thinking and way of navigating and limiting how skills and services are delineated to our communities.

We can actually address these issues by training those in communities who live in rural

settings like Gallup Indian Center, Window Rock, you know, all of these areas that my community members are from where there is not only one healthcare provider for 50 miles, but you are limiting what people can have access to.

We have trained doulas, we have trained birthing assistants, we have trained lactation people. So how are we training community people without the labels and the education and all the credentials to actually provide skills and services to their community.

They are actually very hungry for this information. It's just do we have funding focused on those areas and are we thinking about innovative ways to use the funding and not just focusing on people who are medically trained. It costs a lot of money to train a nurse midwife.

My student loans are \$100,000 right now. Imagine if we could use that \$100,000 to train several indigenous midwives, birth assistants, lactation specialists, doulas, many communities who are already the experts in how their communities function and take away this whole credentials on who is appropriate to provide the services in their community.

We are actually creating those barriers

1 and those holes in services in our communities by 2 thinking this way. 3 CHAIR LHAMON: Ms. Porchia-Albert, 4 looked like you had an answer, too? MS. PORCHIA-ALBERT: Yes. I wanted to say 5 6 that there are many organizations like Black Mamas 7 Matter Alliance, individuals within the organization 8 who are kindred partners who have been providing that education to medical providers who have been working, 9 10 like Dr. Joia Crear-Perry who gave testimony earlier, 11 have been providing training to medical providers. 12 I, myself, have taught grand rounds at 13 many hospital-based institutions. I also mentor 14 medical students around what does it mean to provide 15 anti-racist medical model frameworks. 16 It has been, you know, a challenge to be 17 able to continue to still provide that care, you know, 18 that education, but I think that, you know, folks are 19 finding creative ways to be able to still educate and 20 to give the information that is necessary because 21 providers are also very hungry for it, right. 22 They want to do a better job. I think 23 that when they take their oath, you know, they are 24 saying, you know, to do no harm, and they mean that, 25 but we also have to remember that they, too, are

experiencing the same racism and bias.

When you have providers of color who are presenting themselves who get into this work because they want to serve their communities in equitable ways but then come against these institutional barriers that don't allow them to provide care in the ways and means that it really centers them in the communities that they want to serve.

And so it's not just from a patient perspective as well, it's also from the provider's perspective of being able to really meet people where they are and give them the care that is necessary in a way that centers them.

Having being able to have, you know, institutions having adequate funding, you know, giving providers the freedom in the room to be able to think creatively and have solution-based and evidence-based answers to, you know, institutional problems that are affecting various communities, and those will look different based on the community, right, and so understanding that it is not just one single approach to care.

As, you know, Nicolle mentioned, you know, within the indigenous community it's creating and sustaining and decolonizing the frameworks that have

already, that have been placed on them, right, in the structures and institutions.

But it's also within black and brown communities, you know, teaching and providing the education that is necessary so that people can take care of themselves.

People don't want handouts. People want to know that they have full bodily autonomy and the basic human rights to live in a way that they, you know, that's freedom of expression, right, but that's not what is happening.

And so, you know, folks like Deirdre Cooper Owens who wrote the book "Medical Bondage" is a prime example, who is a professor who goes around and teaches medical students about the history of medicine in the United States and its very complicated relationship as it pertains to black, brown, and indigenous people as well as immigrant individuals who have immigrated here, right.

And so it's really important for us and for these healthcare institutions, these educational systems, to have a framework that talks about the history of other people, not just white males and white women, but also of black, brown, and indigenous people who live within this country who have not had

the same experiences, whose experiences have been steeped in for sterilizations, fear-based coercion, Tuskegee experiments, which all play a role, too, on that inter-generational trauma of being relayed down to the present time and folks feeling like how can I trust this space that has never really truly centered me and centered my identity and who I am as a human being and as an individual.

And so, again, it's a trust-based factor of the institutions and hospitals really working to build trust within communities, listening to them, but then also having those accountability measures to really center the voices of the patient and the provider who is doing that work within those communities.

Ms. Strauss? Thank you. CHAIR LHAMON: MS. STRAUSS: Thank you. In addition I do want flag that the American College Gynecologists Obstetricians and acknowledges themselves that racial bias is contributing to the disparities in maternal health outcomes.

This is not just an issue for advocates, it's an issue that the main professional association themselves notes is a problem and that implicit bias training is needed.

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It's needed at all levels. It's needed in initial training, medical training, nursing training, but also in professional development. There needs to be continuing education around implicit bias, around trauma-informed care, consent, patient-centered approaches.

There are a number of bills that have been introduced that do address these issues, including the

There are a number of bills that have been introduced that do address these issues, including the Maternal Health Quality Improvement Act, the Maternal Care Act, and the MOMMA's Act.

It is a big part of the Black Maternal Health Momnibus that you have heard about today many times.

I think also one of the other ways of approaching this issue of getting at implicit bias and getting at really truly person-centered models, models that center the needs, the perspective, and the respect and dignity for the pregnant and childbearing person is to advance models that have that at their core.

That means making community-based doula support and perinatal support workers available, making sure that they are covered through Medicaid, covered by insurance, so that those models that already are doing this work well are available and

accessible to people, making sure that people have access to midwives, making sure that there is enough of a pipeline of midwives who are being trained, making sure that it is a diverse workforce and a strong workforce so that we are coming at this issue from all different directions from increasing the training, improving the training and perspective of physicians and nurses, all sorts of providers, everyone in the healthcare system, and then lifting up those models that we know are already doing well in these areas. CHAIR LHAMON: Ms. Jacoby, I think you had your hand raised. Thank you. And my colleagues MS. JACOBY: have addressed many of the points that I wanted to raise, but I will add just a few things. Again, yes, the federal government has an obligation here and, exactly right, there are a number of federal bills that would support implicit bias 20 training. At the same time I think we need to take a step back and realize the two tensions here. everyone wants to birth in a hospital, right, and we have the right to, you know, labor and deliver where

you want to, so there is a tension between dismantling

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white supremacy and racism in our hospital and healthcare systems but also supporting, you know, home births and community-based healthcare workers, folks like Nicolle, folks like Chanel, not just even in hospital settings but in other, you know, birth centers and home births.

It is really important that we focus both on, you know, dismantling the racial bias in traditional systems but also supporting and funding those workers who we know have really, really successful models and outcomes.

MS. PORCHIA-ALBERT: Yes. And just to, you know, also I have six children and I have birthed my children at home with home birth midwife and doulas, but I also, you know, went to the hospital.

I have identical twin daughters who, you know, I had in the hospital via caesarean because of preeclampsia. You know, understanding, too, that when that framework is necessary then it is necessary, you know, but if someone can have the option to have a home birth and they want that they should be able to afford that.

They should be able to have the care providers that look like them, that can center their culture identities, be able to support them through

1 that process, and the providers should be respected 2 and should have the necessary means to be able to 3 practice in a way that is, you know, self-sustaining, 4 not for just themselves but also for the communities in which they serve. 5 6 MS. JACOBY: And I will add quickly just 7 in the COVID-19 pandemic we have seen an influx of 8 folks wanting to birth at home, right, because there 9 is fear about the disease of the virus in hospitals, 10 and so we are at a point where the COVID-19 pandemic 11 is exacerbating the maternal health crisis. 12 Our system was not built for, you know, to 13 sustain this anyway and then you have people trying to 14 birth at home and there are issues like what Nicolle 15 deals with regularly in terms of midwifery regulations 16 and prohibitions on where she can provide care. 17 So it's a very interesting intersection of 18 that we are seeing right now during the 19 pandemic. 20 CHAIR LHAMON: Commissioner Yaki, I saw 21 off mute, is that because you have a 22 question? 23 COMMISSIONER YAKI: Not yet. 24 CHAIR LHAMON: Okay. 25 COMMISSIONER YAKI: But soon.

1	(Simultaneous speaking.)
2	CHAIR LHAMON: Well, soon is now because
3	we are at the end of
4	COMMISSIONER YAKI: I have been enjoying
5	the testimony.
6	CHAIR LHAMON: We are at the end of this
7	panel so if there is one last question we can go
8	forward, otherwise we will thank your panelists.
9	Seeing none I will thank our panelists.
10	This has been just an extraordinary day of testimony
11	and an extraordinary final panel, very, very grateful
12	to all of our participants, including our public
13	participants and also those who sent in comments.
14	Today has been just tremendously
15	informative and on behalf of the entire Commission I
16	thank all who presented for sharing your time,
17	expertise, and experience with us.
18	As I said earlier our public record will
19	remain open until December 14, 2020. Materials,
20	including if individuals would like to submit
21	anonymously, can be submitted by email to
22	<pre>maternalhealth@usccr.gov or by mail to the U.S.</pre>
23	Commission on Civil Rights, Office of Civil Rights
24	Evaluation, Public Comments, Attention: Maternal

Health, at 1331 Pennsylvania Avenue, NW, Suite 1150,

1	Washington D.C. 20425. We encourage the use of email
2	to provide public comments due to the current COVID-19
3	pandemic.
4	Before we adjourn our meeting today I do
5	want to recognize that today's briefing will be the
6	last business meeting for our General Counsel, Maureen
7	Rudolph.
8	Maureen, thank you for your service to the
9	Commission and thank you for your ongoing service in
10	the federal government in your next position.
11	If there is nothing further I hereby
12	adjourn our meeting at 1:22 p.m. Eastern Time. Thank
13	you.
14	(Whereupon, the above-entitled matter went
15	off the record at 1:22 p.m.)
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