BLACK MAMAS MATTER

ADVANCING THE HUMAN RIGHT TO SAFE AND RESPECTFUL MATERNAL HEALTH CARE

CENTER FOR REPRODUCTIVE RIGHTS

The Black Mamas Matter Alliance (BMMA) is a Black women-led cross-sectoral alliance. We center Black mamas to advocate, drive research, build power, and shift culture for Black maternal health, rights, and justice. We envision a world where Black mamas have the rights, respect, and resources to thrive before, during, and after pregnancy.

BlackMamasMatter.org

The Center for Reproductive Rights uses the law to advance reproductive freedom as a fundamental human right that all governments are legally obligated to protect, respect, and fulfill. The Center's U.S. Maternal Health and Human Rights Initiative promotes and seeks accountability for the right to equal and nondiscriminatory access to safe and respectful maternal health care.

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BMMA steering committee members and CRR staff gather after the June 2017 "Black Maternal Health Matters" Congressional briefing in Washington, D.C.

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PREFACE TO THE 2018 REPRINT OF THE BMM TOOLKIT

Since this toolkit was first published in 2016, Black Mamas Matter has grown from a group of people meeting to ask tough questions about the state of Black maternal health to a national movement of stakeholders committed to changing the world so Black mamas have the rights, respect, and resources they need to have safe and healthy pregnancy outcomes. In November 2016, the Steering Committee of the Black Mamas Matter Alliance met to sketch out our vision for Black mamas, mission for the Alliance, values that underpin all our work, and goals for issues that needed priority attention.

The Black Mamas Matter Alliance (BMMA) is a Black women-led cross-sectoral alliance. We center Black mamas to advocate, drive research, build power, and shift culture for Black maternal health, rights, and justice. Through our work, we serve as a national voice on Black maternal health and a convener for stakeholders across the country who are fired up to help achieve a vision for a world where Black mamas thrive.

Our work is grounded in values that center and uplift the experiences, knowledge, and leadership of Black women, trans women, and femmes. We trust Black women and believe our community holds the key to overcoming the multiple and systemic oppressions that impede stellar maternal health. Black mamas are worthy of our attention and deserving of our efforts to change policy, cultivate meaningful research, advance holistic care, and shift culture to improve Black maternal health outcomes.

BMMA has contributed to advancing the conversation on maternal health in the United States overall and for Black mamas specifically through our work to raise the nation's awareness and galvanize state and local actors. In spring 2017, the BMMA steering committee was featured in Fusion's international documentary, The Naked Truth: Death by Delivery. In summer 2017, we held the first ever Congressional briefing focused solely on Black maternal health, titled "Black Maternal Health Matters - Policies to Improve Black Maternal Health in the United States," on Capitol Hill. In fall 2017, we engaged over 30 collaborators in the Alliance to drive work that achieves our goals and honed our strategic direction. And in January 2018, we announced the first ever national Black Maternal Health Week campaign.

Now, more people than ever before recognize the growing problem of maternal mortality and morbidity in the United States and how Black mamas are disproportionately negatively affected. There is more pending legislation at both the national and state levels seeking to improve maternal health and address racial disparities in maternal health. Grassroots organizations are increasingly recognized for their efforts to provide holistic and comprehensive care to Black mamas, bring attention to the issues affecting Black mamas in their communities, and spur policy and programmatic action that will have a positive impact.

This toolkit has helped lay the groundwork for policy change while highlighting Black mamas' human right to safe and respectful care. It provides a comprehensive overview of information and resources on Black maternal health and identifies action policymakers can take to address maternal health within the human rights and reproductive justice frameworks. Over one thousand print copies of the toolkit have been distributed across the U.S. and shared with international human rights experts and advocates. Thousands more have accessed it online. The toolkit has been used to train doulas and maternity care providers, sensitize state and federal policymakers to the issue, inform local legislation, and equip stakeholders to effect change.

We hope that the toolkit will continue to serve as a foundational resource for the movement for Black maternal health, rights, and justice, and inspire the action that is so needed.

We have come a long way since we first gathered at the SisterSong Mother House in 2015, but we know there is still a long road ahead to achieving our mission and realizing our vision. We will do whatever it takes for as long as it takes. We will work until all Black mamas have the health they deserve.

Sincerely,

Elizabeth Dawes Gay
Steering Committee Chair
Black Mamas Matter Alliance

Black Mamas Matter Alliance - Steering Committee 2018
Angela Doyinsola Aina
Breana Lipscomb
Elizabeth Dawes Gay
Joia Crear-Perry
Kwajelyn Jackson
Monica Simpson

Learn more about the Black Mamas Matter Alliance and our work at **blackmamasmatter.org**.

INTRODUCTION & ACKNOWLEDGMENTS

In June 2015, the Center for Reproductive Rights (the Center) partnered with SisterSong Women of Color Reproductive Justice Collective to host Black Mamas Matter, a cross-sectoral convening of leaders on Black maternal health. Researchers, service providers, policy experts, and community organizers gathered at the SisterSong Mother House in Atlanta, Georgia, to identify innovative strategies for improving Black maternal health outcomes. Among the many ideas generated on that day, participants identified a need for advocacy tools that would move the conversation one step closer to a rights-based maternal health policy agenda.

This toolkit is a direct response to that call. The Center has worked closely with convening participants and other experts to develop materials that will support the work of state maternal health advocates as they mobilize their communities and communicate with state policy leaders. The resources contained here take a human rights based approach to maternal health, emphasizing the *rights of pregnant and birthing women* and calling out *government responsibilities to ensure safe and respectful maternal health care* for all. Because Black women in Southern states face some of the highest risks for poor maternal health outcomes and care, their experiences are centered throughout this publication. At the same time, the Center recognizes that poor maternal health outcomes affect many other groups of women, and that maternal health rights go well beyond the issues of maternal death and illness. Moving forward, the Center will continue to develop advocacy materials from a human rights based frame that expand the scope of this conversation.

The materials included here attempt to distill outcomes from the Black Mamas Matter conversations (on race, reproduction, parenting, and rights) into concrete steps to improve the maternal health of Black women in the South. Through a series of separate but related briefs, this toolkit presents a collection of resources that advocates can use and adapt to their own needs. It begins by explaining the human rights framework as it applies to maternal health, and then examines the data and research on maternal health in the United States, with a special focus on racial disparities. To help bring that data to life, the toolkit includes personal stories about sexual, reproductive, and maternal health from Black women living in the South.

Moving from an assessment of maternal health challenges to an exploration of potential solutions, the toolkit contains an overview of policy recommendations proposed by various stakeholders. This snapshot of the policy landscape is not intended as a one-size-fits-all prescription for action, but rather a menu

of options for advocates to explore and adapt to their local priorities. The policy brief is followed by a list of resources that advocates can consult for more information, a set of talking points on maternal health, and a set of suggestions for building connections and dialogue with other stakeholders engaged in Black maternal health across the country.

The Center wishes to thank the participants of the Black Mamas Matter convening in June 2015 for their vision, leadership, and dedication to improving maternal health in the United States. This toolkit would not have been realized without the participants' generosity in sharing their extensive knowledge and expertise.

Special thanks are due to Monica Simpson and SisterSong Women of Color Reproductive Justice Collective for co-hosting the convening and building a network of Southern Black women leaders to sustain this work. Elizabeth Dawes Gay, co-organizer of the convening, also provided valuable direction for this toolkit. The Center also gratefully acknowledges the many individuals who reviewed drafts of this resource, provided research and information, and offered inspiring new visions for Black women's maternal health and care, in particular **Kwajelyn Jackson** (Feminist Women's Health Center), **Dr. Joia Crear-Perry** (National Birth Equity Collaborative), **Cherisse Scott** (SisterReach), **Sang Hee Won** (NYC Department of Health), **Amani Nuru-Jeter** (UC Berkeley School of Public Health), **Charity Woods** (Religious Coalition for Reproductive Choice), **Selena Adetunji** (Access Reproductive Care—Southeast), **Linda Goler Blount** (Black Women's Health Imperative), **Andrea Flynn** (Roosevelt Institute), **Andria Cornell** (Association of Maternal and Child Health Programs), **Sarah Verbiest** (Every Woman Southeast), **Nan Strauss** (Choices in Childbirth), **Renee Bracey Sherman**, and **Alicia Walters** (both of Echoing Ida). Special thanks to The Irving Harris Foundation for supporting the production of this resource.

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ADVANCING MATERNAL HEALTH AS A HUMAN RIGHTS ISSUE

Mamas hold their babies high at a Black breastfeeding celebration in Brooklyn, NY organized by Ancient Song Doula Services.

I. BLACK WOMEN'S MATERNAL HEALTH AND RIGHTS AT RISK

Every woman has the right to safe and respectful maternal health care. Human rights standards surrounding safe pregnancy, childbirth, and respectful maternal care are rooted in the human rights to life, health, equality, and non-discrimination. Governments must ensure these rights by creating enabling conditions that support healthy women, healthy pregnancies, and healthy births. Fundamental human rights are violated when pregnant and birthing women endure preventable suffering, including death, illness, injury, mistreatment, abuse, discrimination, and denials of information and bodily autonomy.

Despite government obligations to ensure maternal health and rights, poor maternal health outcomes are an underreported human rights crisis in the United States. Maternal mortality is perhaps the most striking and troubling indicator of the state of women's pregnancy health. At a time when most other countries are making dramatic progress on maternal health, pregnant and birthing women in the United States are suffering death and injury at ever-increasing rates.[1] According to a recent report by the World Health Organization (WHO) and others, the United States is one of only 13 countries worldwide with a rising maternal mortality ratio (MMR), and is the only country with an advanced economy where the MMR is getting worse.[2]

Maternal Health as a Global Development Priority

In 2000, the international community made a historic agreement to work together to improve maternal health. As one of eight Millennium Development Goals (MDGs) that all countries agreed to pursue, improving maternal health and survival became a shared, global priority. For the last 15 years, the MDGs have guided the international development agenda, contributing to a nearly 50% reduction in the global maternal mortality ratio (MMR) between 1990 and 2015.[3] The sustainable development agenda that will now follow the MDGs includes a renewed commitment to further reduce the MMR.[4] However, while the United States consistently shows support for global improvements in maternal health, it has also failed to reduce its own MMR during the MDG period.[5] In order to meet both the new Sustainable Development Goals (SDGs) and its core human rights obligations, the United States will need to achieve higher standards of maternal health at home.

While the overall proportion of women who do not survive pregnancy and childbearing is on the rise in this country, marginalized women tend to be at greater risk than others. In particular, Black women are dying at a rate three to four times higher than White women, a pattern that has persisted across the United States for generations.[6] In some American cities, the MMR for Black women is now higher than the MMR in many developing countries.

II. A RIGHT TO SAFE AND RESPECTFUL MATERNAL HEALTH CARE

Preventing maternal mortality and morbidity and ensuring safe, respectful care has become a collective global priority. This emerging consensus about the importance of maternal health stems from the recognition that many poor maternal health outcomes are not inevitable, but are instead the result of laws, policies, and institutional practices that can be changed.[7] Government demands for women to take greater "personal responsibility" for their own health are not effective solutions to the problems of preventable maternal death and illness. Moreover, maternal health rights are grounded in a set of fundamental human rights contained in international treaties and consensus documents. Like all other governments that have made human rights commitments, the United States has a three-part obligation to respect, protect, and fulfill this set of rights (see text box, "Government Duties to Ensure Safe and Respectful Maternal Health Care").

The international human rights framework identifies fundamental rights that belong to all people, and holds governments accountable for ensuring that those rights can be realized. Human rights include sexual and reproductive rights, which are essential to an individual's self-determination and autonomy. Moreover, human rights bodies have recognized that enabling safe pregnancy and childbirth is essential to women's dignity and exercise of their human rights.[9] As a result, ensuring adequate reproductive and maternal health care is considered a core government obligation.[10] "Core obligations" are the minimum essential levels of care that governments should ensure in order to enable people to achieve the highest attainable standard of health.[11]

Government Duties to Ensure Safe and Respectful Maternal Health Care

Respect: Governments must refrain from interfering, either directly or indirectly, with women's access to the health care services they need, or to the underlying determinants of health (safe communities, affordable housing, employment, social support, etc.).

Protect: Governments must prevent third parties from interfering with the right to safe and respectful maternal health care and must investigate and sanction those who violate this right.

Fulfill: Governments must take positive steps (passing legislation, ensuring adequate funding for programs, training health care providers, etc.) towards the full realization of the right to safe and respectful maternal care.[8]

The right to life

Reproductive rights include first and foremost the fundamental human right to life.[12] The right to life is not meant to be narrowly interpreted.[13] Because government has a duty to protect individuals from arbitrary and preventable loss of life,[14] including preventable deaths related to pregnancy,[15] it must take proactive measures to address both the causes and prevalence of maternal mortality.[16]

The right to health

The human right to health has four essential elements: governments must ensure that health facilities, goods, and services are **available** in sufficient quantity throughout the state, **accessible** to all, ethically and culturally **acceptable**, and of good **quality** (see text box, "Essential Elements of the Right to Health").[17] Recognizing that governments are positioned differently in terms of health system capacity, human rights law defines the right to health not as the right to be healthy, but rather as the right to the highest attainable standard of health.

Privatized health systems do not exempt the government from its obligations regarding the right to health. Even when governments outsource health services to the private sector, they retain a duty to regulate and monitor the delivery of health goods, information, and services to ensure the right to health is met.[18]

Furthermore, the right to health rests on the principle of equity. This means governments must ensure equitable distribution of reproductive health goods and services, such as prioritizing health resource allocation to the most socially disadvantaged groups.[19]

"No one human being should have power to impact another human being's right to self-determination… It is the prerogative of a woman to be self-determining when it comes to her health, when and when not to become a parent, and the health decisions of her family."

—**DR. WILLIE PARKER,** OB/GYN AND ABORTION PROVIDER

Rights to equality and non-discrimination

Cutting across all human rights is the right to equality and the corresponding right to freedom from discrimination of any kind. Black women in the United States experience intersecting forms of discrimination, including on the basis of gender, race, and socio-economic class. Discrimination can occur in law or in practice. Policies that do not intend to discriminate against a particular group, but nonetheless have a discriminatory effect, violate human rights law. Consequently, in order to effectively address maternal health violations, government must address discrimination in *all* its forms, and repeal both types of discriminatory laws and policies.[20]

Maternal health can be undermined by discrimination within and beyond the health system. The racial disparities that surround maternal health in the United States are intertwined with deeply rooted inequalities in social, economic, and political life. Pervasive racial disparities in each of these areas shape the underlying determinants of health, systematically undermining Black women's chances to achieve their best health. In this way, structural inequalities can have negative impacts on the health of Black women, even before they encounter the health care system. Inside the U.S. health care system, contemporary discrimination against Black women manifests as barriers to timely and affordable health care, lower quality maternal health care services, disrespectful treatment, and ultimately, negative medical outcomes.

A human rights based approach to maternal health is especially powerful for ensuring equality and non-discrimination because its purpose is not limited to avoiding isolated clinical pathologies like morbidity and

mortality. Instead, this approach empowers all women to claim their full set of human rights in order to live the healthiest lives possible.[21] It recognizes that discrimination plays a role in undermining women's and girls' access access to reproductive health care, and it requires attention to groups that are experiencing disparities. A human rights based approach to maternal health in the United States therefore requires the government to directly confront racial discrimination in the context of maternal health, and to specifically address the harms and inequalities faced by Black women during pregnancy and childbirth.

Essential Elements of the Right to Health

Availability: Health care facilities, goods, services, and programs must be available in sufficient quantity in all areas, urban and rural. This includes, for example, a sufficient number of health clinics, trained medical personnel receiving domestically competitive salaries, and adequate stocking of medicines in health facilities.

Accessibility: Health facilities, goods, and services have to be accessible to everyone without discrimination. Accessibility has four overlapping dimensions:

1. **Non-discrimination** – health facilities, goods, and services must be accessible—both in law and in fact—to everyone regardless of race, sex, gender, sexual orientation, nationality, disability or other status.

2. **Physical accessibility** – health facilities, goods, and services must be within safe physical reach for all sections of the population, and especially for vulnerable or marginalized groups such as women and ethnic minorities, residents of rural areas, and people with disabilities.

3. **Economic accessibility** – whether publicly or privately provided, health facilities, goods, and services must be affordable for all, and payment for health care services should be based on the principle of equity.

4. **Information accessibility** – information and ideas concerning health issues should be made accessible to everyone, without discrimination, and provided in an accessible format.

Acceptability: Health facilities, goods, and services must respect medical ethics, respect the culture of individuals and their communities, and be sensitive to gender and life-cycle requirements.

Quality: Health facilities, goods, and services must be scientifically and medically appropriate and of good quality.[22]

Foundational human rights principles

In addition to the enumerated rights detailed above, human rights theory rests on a set of foundational principles that apply to all rights and obligations. These principles often have important procedural implications, affecting the way that laws and policies are formulated and implemented. Equality and non-discrimination are two examples of these foundational, underlying values. Other foundational human rights principles include participation and inclusion, interdependence, universality, indivisibility, transparency, and accountability (see text box, "A Human Rights Based Approach to Improving Maternal Health").

III. HOLDING THE U.S. ACCOUNTABLE

As maternal health has become a global human rights priority, poor maternal health conditions in the United States have come under greater international scrutiny. During recent reviews of the U.S. human rights record, independent human rights bodies have highlighted the persistent racial disparities in maternal health as a form of racial and gender discrimination and called on the U.S. to improve access to quality maternal health care.

- In August 2014, the **UN Committee on the Elimination of Racial Discrimination** (CERD) called on the United States to eliminate racial disparities in health in order to fulfill its international human rights promises to end racial discrimination in all its forms.[23] This group of independent experts expressed concern over persistently high rates of maternal mortality among Black women, and called on the U.S. government to ensure access to adequate and affordable health care services for all. It also recommended improved monitoring and accountability mechanisms for preventable maternal mortality, such as standardized data collection and state-level maternal mortality review boards.[24]
- Poor maternal health was also raised as a key human rights concern during the May 2015 **Universal Periodic Review** of the United States by the Human Rights Council. In this high-level global review of the overall U.S. human rights record, the government of Finland called on the United States to ensure equal access to quality maternal health services.[25] The United States accepted this recommendation without reservation, recognizing that the high rate of preventable maternal mortality—including racial disparities in maternal health outcomes—warrants government action and accountability.
- Two independent UN expert groups have also raised alarms about maternal health disparities. In December 2015, the **UN Working Group on the issue of discrimination against women in law and practice** made an official visit to the United States. Their 2016 report to the Human Rights Council calls on the U.S. government to address the root causes of increasing maternal mortality, particularly among Black women.[26] In 2016, members of the **UN Working Group of Experts on People of African Descent** also conducted an official visit to the United States. Their report describes how multiple forms of structural and institutional discrimination impede access to healthcare and negatively impact the social determinants of health for Black women. It further recommends that the U.S. expand access to quality, affordable health care, with targeted goals for reducing the maternal mortality among Black women.[27]

Notably, the United States has been an engaged participant in this emerging global consensus regarding the importance and urgency of improving maternal health. The U.S. government directs substantial resources towards combatting preventable maternal mortality around the world, and its efforts include aid for development projects, technical assistance, and partnerships with the global health community. In recent years, the United States has exercised considerable leadership on global maternal health through special initiatives, the work of USAID and other government agencies, and a sizeable global health budget.[28] However, a comparable commitment to improving maternal health within the U.S. is currently lacking.

A Human Rights Based Approach to Improving Maternal Health[30]

Accountability: Governments must create mechanisms of accountability to enforce the right to safe and respectful maternal health care, including monitoring and evaluation of policies and programs, corrective action when violations are found, and remedies for women and families.

Transparency: People should have access to information that enables them to make decisions about their health care choices, or understand how decisions affecting their health are made. This includes transparency in budgeting and funding allocations.

Participation: All people have a right to participate in decision-making processes that affect their right to safe and respectful maternal care, including decisions about government policies and distribution of health resources.

Empowerment: Women and girls must be valued and engaged as agents and rights-holders when it comes to decisions or actions that affect their sexual and reproductive lives.

Non-Discrimination: The right to safe and respectful care should be ensured without discrimination of any kind, regardless of whether the discrimination is committed purposefully or results from seemingly neutral policies and practices that have a discriminatory effect on Black women.

Equity: Health care resources, goods, and services must be distributed and accessed based on a model of equity, which is based on need and remedying historical injustice, rather than a model of equality.

Universality: Health care goods and services must be available to everyone, without exception or distinction based on any discriminatory ground.

Researchers converse during the June 2015 Black Mamas Matter convening.

IV. ALIGNING STATE POLICY CHOICES WITH HUMAN RIGHTS STANDARDS

A human rights approach to safe and respectful maternal health care involves developing supportive policies, creating and sustaining institutions, and allocating resources that allow people to exercise their rights in relation to maternal health.[29] While all levels of government have duties to ensure human rights, the decentralized, mixed public/private health system in the United States creates unique challenges for implementing sweeping human rights standards across the country. As a result, some of the best opportunities for change may be found at the state level. State governments are uniquely situated to understand the particular barriers to care and other constraints that lead to poor health outcomes for women in their state. For that reason, they are also strategically poised to develop appropriate policy solutions.

Adopting human rights based frameworks and methodologies

The human rights framework provides a structural blueprint for U.S. states to use as they develop policy measures tailored to the needs of local populations. A human rights based approach to maternal health incorporates human rights principles and methodologies into government policy and practice. By integrating mechanisms that promote accountability, transparency, participation, empowerment,[31] non-discrimination, universality,[32] and equity,[33] governments can ensure that the health policies they create are meeting people's core needs and respecting their human dignity.

Incorporating best practices into local policy agendas

Advocates can encourage their states to internalize human rights principles by identifying policies in need of reform, proposing policy solutions rooted in human rights law, and holding their governments politically accountable to human rights standards. Although each state's unique needs may necessitate a distinct maternal health policy agenda, state advocates can adapt best practices developed in the global sphere to their own local context.

The Office of the UN High Commissioner for Human Rights has developed technical guidance to help governments implement a human rights based approach to reducing preventable maternal mortality and morbidity, based on the rights and principles outlined above.[34]

Reproductive Justice and Human Rights

Reproductive justice and human rights are complementary frameworks. The term "reproductive justice" was coined in 1994 by U.S. women of color who attended the International Conference on Population and Development in Cairo. It has since become a critical framework for understanding the intersections of reproductive oppression that women experience, both individually and as members of distinct communities.[35] Fundamentally, reproductive justice aims to transform inequalities so that "all people have the social, political, and economic power and resources to make healthy decisions" about their "gender, bodies, sexuality, and families."[36] This includes the right to have children, to not have children, to parent one's children, and to control one's birthing options.[37]

As the reproductive justice framework has developed, women of color leaders have applied the human rights framework to the specific reproductive oppressions faced by women of color and others who experience multiple oppressions. By integrating concepts from human rights, reproductive rights, and social justice, reproductive justice advocates have formed a powerful new vision of reproductive freedom.[38] SisterSong Women of Color Reproductive Justice Collective has played a leading role in theorizing reproductive justice and building a movement based on this approach. SisterSong and other reproductive justice organizations have consistently invoked a human rights framework to support a more holistic vision for the U.S. reproductive health, rights, and justice movement, and their engagement in global human rights spaces has allowed them to work in solidarity with other global social justice movements.[39]

Key takeaways from the technical guidance for the U.S. context include the following:

- All women need the resources, opportunities, and support that enable them to protect their human rights to health and life and to make the best decisions for themselves and their families;
- These needs become especially urgent during pregnancy and childbirth but remain important throughout a woman's entire life cycle;
- At a minimum, ensuring these rights requires access to comprehensive reproductive health services and information, freedom from discrimination and bias, and living conditions that set women up for health, rather than risk;
- While sound public health practices are certainly crucial to improving maternal health, they must also be accompanied by measures that empower women.[40]

Governments may implement these human rights standards through administrative measures, legislation, allocation of resources, and comprehensive policies and programs that support women and their maternal health. Although priorities may vary according to context, all states should give effect to the right to health through the following measures:

Improve Health Care Access & Quality

- Remove existing barriers to care during and after pregnancy and throughout the lifespan
- Develop a more diverse health care workforce that is trained in human rights standards and engaged in generating solutions to maternal health problems
- Ensure that every woman receives quality care, regardless of the site or setting of care
- Facilitate greater availability of obstetric care and family planning services

Address Underlying Determinants of Health

- Prioritize social supports for Black women and Black communities
- Address nutrition and food security for pregnant women
- Ensure adequate, safe housing and safe communities
- Facilitate healthy occupational and environmental conditions

Eliminate Discrimination in Law and Practice

- Reform discriminatory laws and policies that impact Black women's health and well-being
- Take proactive measures to address discrimination in practice, particularly for groups that have faced historical discrimination or injustice
- Address racial bias, stereotypes, stigma, discrimination, and disrespect in health care encounters specifically
- Eliminate disparities in the maternal health safety and survival outcomes for Black women

Ensure Accountability

- Collect and disseminate adequate, disaggregated data on maternal mortality and morbidity
- Set targeted goals and benchmarks for improved maternal health outcomes
- Design state plans to improve maternal health that consider the specific needs of vulnerable populations, especially Black women and girls
- Develop policy solutions aimed at the conditions that make it likely for maternal health violations to re-occur
- Provide remedies for violations of the right to access safe and respectful maternal health care

Include and Empower

- Encourage human rights education and outreach to Black women on their sexual and reproductive health and rights
- Involve Black women, especially at the community level, in maternal health policy design, budgeting, monitoring, and review processes
- Build partnerships between government, civil society, and other key stakeholders to assess maternal health needs and devise solutions

RESEARCH OVERVIEW OF MATERNAL MORTALITY AND MORBIDITY IN THE UNITED STATES

Midwife, doula trainer, and cultural competency expert Shafia Monroe works with a client.

Maternal health is a complex issue that is influenced by many interrelated factors. This section provides background information about maternal health outcomes in the United States generally, as well as those specific to Black women. It analyzes the known and suspected drivers of Black maternal mortality and morbidity while also identifying research gaps and areas in need of further investigation. The information presented here draws from research in the fields of medicine and public health, but advocates should note that it is not a comprehensive review of the scientific literature. Rather, this brief provides maternal health advocates with a sampling of relevant research that can be used to inform a rights-based policy agenda that is guided by evidence and beneficial to Black women.

I. DEFINING MATERNAL MORTALITY AND MORBIDITY

In the United States, a growing number of women die or face serious injury as a result of pregnancy and childbirth. To measure the extent of these risks, researchers commonly discuss maternal deaths in terms of ratios, with the maternal mortality ratio (MMR) representing the number of women who die from pregnancy-related causes for every 100,000 live births. As defined by the Centers for Disease Control and Prevention (CDC), pregnancy-related deaths are those that occur during pregnancy or within the following year due to pregnancy complications, because of a chain of events initiated by pregnancy, or because of an unrelated condition that was aggravated by pregnancy.[1]

A directly related event called severe maternal morbidity (SMM) refers to instances where women almost die from a life-threatening complication during pregnancy or childbirth.[2] Maternal morbidity can be understood as a continuum, with a healthy pregnancy at one end of the spectrum, and maternal death at the other.[3] Some researchers refer to severe maternal morbidity as a "near miss,"[4] and to maternal mortality as "the tip of the iceberg."[5]

Maternal mortality and morbidity are on the rise in the United States

At the global level, a greater proportion of women are surviving pregnancy and childbirth every year.[6] Since 1990, 169 different countries have successfully managed to reduce their MMR.[7] But after achieving decades of stunning progress on maternal health during the early twentieth century, the U.S. MMR is rising again.[8] With an MMR of 14 deaths for every 100,000 live births, the United States currently ranks 46th in the world in measures of maternal mortality.[9] This not only puts the United States behind wealthy countries like the United Kingdom, Japan, and Sweden, but also behind less wealthy countries such as Libya and Kazakhstan.[10]

Midwife Jennie Joseph teaches and practices an approach to maternal health care that emphasizes respect for the families she works with.

Significantly, the United States is one of only 13 countries in the world where the MMR is now worse than it was 15 years ago.[11] Although some of this recorded increase in the U.S. MMR may be due to improvements in detecting maternal deaths, experts believe that data collection changes cannot fully explain it.[12] The simultaneous rise in maternal morbidity further suggests that the rising U.S. MMR represents a very real decline in maternal health outcomes.

Like maternal mortality, cases of SMM are becoming more common. For every woman who dies as a result of her pregnancy, approximately 100 women receive a life-threatening diagnosis or undergo a life-saving procedure during their delivery hospitalization.[13] Such severe maternal morbidity now affects around 60,000 women in the United States every year, and that number has been increasing steadily.[14] For instance, the rate of hospitalizations due to severe delivery complications more than doubled between 1998 and 2011.[15] These increases in SMM are likely driven by a combination of factors, including (but not limited to) higher maternal age, obesity, rising cesarean delivery rates, and a growing number of pregnant women with pre-existing chronic medical conditions.[16] The increase in SMM combined with the increase in maternal mortality in the United States sharply contrast with global trends towards safer pregnancy and childbirth, and is especially significant considering that the United States spends more on health care than any other country.[17]

"Black women's maternal death rate has been shockingly high for decades, with few voices outside public health communities calling for action. What will it take to get people to recognize not just the racial disparity in death rates but the disparity in concern over U.S. Black women's health and lives?"

—**CYNTHIA GREENLEE,** HISTORIAN AND WRITER

Black women are most at risk for poor maternal health outcomes

Not all women face the same risks during pregnancy and childbirth. Black women in the United States are between three and four times more likely to die from pregnancy-related causes than White women,[18] and are twice as likely to suffer from SMM.[19] The Black/White disparity in maternal mortality applies to Black women across all education levels[20] and persists even after controlling for differences in socio-economic status.[21] It is this disproportionate risk that Black women face during and after childbirth that drives the maternal mortality and morbidity crisis in the United States. Thus, understanding and addressing factors impacting maternal mortality and morbidity among Black women will not only reduce disparities, it will improve MMR and SMM rates overall.

Where a Black woman resides may also affect her maternal health outcomes. Cities and states with large Black communities have some of the worst maternal health outcomes. This pattern can be seen in urban coastal cities like New York and Washington D.C., but is particularly apparent across the American South.[22] For example, Georgia has one of the highest maternal death rates in the country. This is in large part due to the fact that Black women in Georgia have an MMR of 39 deaths per 100,000 live births, a ratio that is four times greater than the ratio for White women there.[23] Similarly, Mississippi has an MMR of 29 for White women, but the MMR for Black women is even higher at 54.[24] At that rate, a Black woman in Mississippi is more likely to suffer a maternal death than a woman in Palestine, Mexico, or Egypt.[25]

II. RACIAL AND GENDER INEQUALITIES SURROUND BLACK WOMEN'S HEALTH

According to the medical community, the leading direct causes of maternal death in the United States include heart conditions, infections, severe bleeding (hemorrhage), blood clots (embolism), pregnancy-induced high blood pressure (preeclampsia), and stroke (cerebrovascular accident).[26] A large proportion of these deaths are preventable.[27] Health experts agree that it is possible for the United States to reduce maternal mortality and morbidity,[28] and the avoidable inequalities in health between Black and White women provide evidence of that. The clinical solutions to preventing and managing pregnancy complications already exist, and are well known within the health field.[29] Health experts have also established that good maternal health outcomes require sufficient access to prenatal care, skilled attendants during birth, and postnatal care.[30] Since research shows that some women in the United States don't receive the optimal or recommended levels of maternal care, these shortcomings represent opportunities to prevent future deaths.

More and more, public health research is focusing on the ways that social and economic conditions influence people's risk of poor health, as well as the systems that are put in place to prevent or treat those health problems. The social determinants of health—the social and economic circumstances in which people are born, grow up, live, work and age—are shaped by social hierarchies, economics, and policy decisions.[31] These conditions explain in part why some people are healthier than others, or at a minimum, not as healthy as they could be.[32] In the United States, racial disparities in health are closely linked to economic disadvantage, reflecting systemic obstacles to health that disproportionately affect women of color.[33] Factors such as poverty, lack of access to health care, social inequality, and exposure to racism all undermine health,[34] and may contribute to the elevated number of Black maternal deaths.[35]

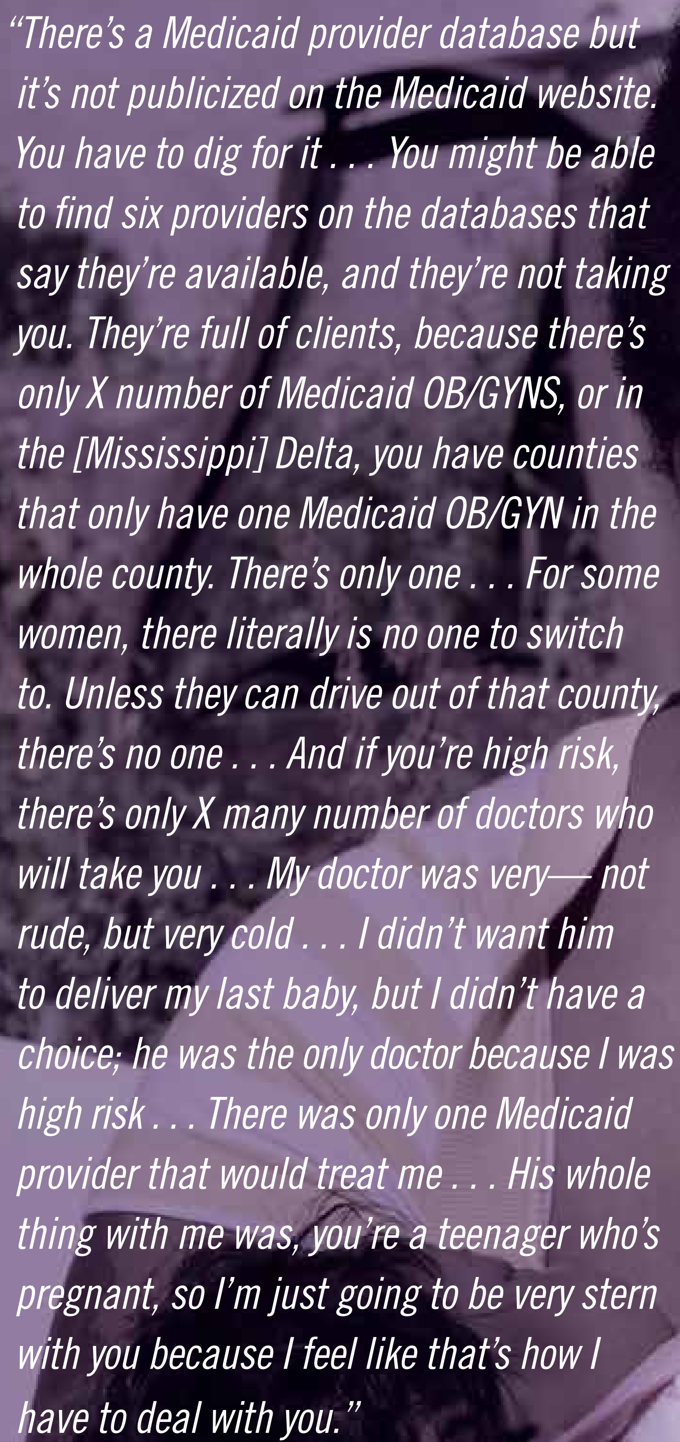
Poverty

Although the root causes of maternal mortality and morbidity are multiple and complex,[36] the maternal health crisis in the United States must be understood in the context of rising poverty levels and significant economic inequalities. Higher poverty rates are associated with higher rates of maternal mortality for all women,[37] but Black women are more than twice as likely to live in poverty as White women are.[38] Nationally, a quarter of all adult Black women live below the federal poverty threshold.[39] Across the South, the proportion of Black women living in poverty is even higher.[40] A 2011 report on maternal mortality by Amnesty International showed that U.S. states with high poverty rates had MMRs that were 77% higher than states where more people live above the poverty line.[41] With 19.5 million people living in poverty, the South is the poorest region of the country.[42]

For nearly four decades, both income inequality and wealth inequality have risen in the United States as the richest segment of society has captured a greater share of the country's wealth.[43] The Great Recession (2007-2009) has further stressed low and middle income families, and despite the recent economic recovery, the median household income is still 6.5% lower than it was before the recession began.[44] Unemployment is twice as high for Black women compared to White women,[45] and fully employed Black women earn an average of 63 cents for every dollar paid to White men[46] (White women earn 78 cents for every dollar that White men earn[47]). Education can help increase Black women's total earnings, but it doesn't close the pay gap.[48] Thus, the same communities that are experiencing some of the highest rates of maternal mortality and morbidity are also those struggling with low, unequal, or stagnant wages, unemployment and underemployment, home foreclosures, a lack of health insurance, and reductions to safety net programs that many low-income families rely on for their health and economic security.

Access to care

Disparities in access to care for racial minorities in the United States persist despite the enactment of the Affordable Care Act (ACA), which included the elimination of racial disparities as a primary goal. Women of color are still more likely than White women to lack health insurance,[49] and the barriers to care that they face place them at higher risk for poor maternal health. Moreover, the states with some of the widest health disparities in the country have rejected Medicaid expansion, one of the ACA's main tools to cover the uninsured. As a result, poor adults in these states fall into a coverage gap when they earn too much to qualify for Medicaid, but not enough to purchase private health insurance, even with tax subsidies.[50]



"There's a Medicaid provider database but it's not publicized on the Medicaid website. You have to dig for it . . . You might be able to find six providers on the databases that say they're available, and they're not taking you. They're full of clients, because there's only X number of Medicaid OB/GYNS, or in the [Mississippi] Delta, you have counties that only have one Medicaid OB/GYN in the whole county. There's only one . . . For some women, there literally is no one to switch to. Unless they can drive out of that county, there's no one . . . And if you're high risk, there's only X many number of doctors who will take you . . . My doctor was very— not rude, but very cold . . . I didn't want him to deliver my last baby, but I didn't have a choice; he was the only doctor because I was high risk . . . There was only one Medicaid provider that would treat me . . . His whole thing with me was, you're a teenager who's pregnant, so I'm just going to be very stern with you because I feel like that's how I have to deal with you."

—**KAYLA,** SISTERSONG STORY CIRCLE PARTICIPANT, MS

A mama holds her baby while visiting with the (Ancient Song) doulas who supported her during pregnancy.

Nine out of ten people who fall into the coverage gap live in the South, and Black adults are more likely than any other racial group to be affected by it.[51] The states that have refused to expand Medicaid are primarily located in the Deep South, and they remain among the lowest ranked states when it comes to Black women's health insurance coverage.[52] However, if all the states in the United States were to expand Medicaid, nearly six in ten currently uninsured Black adults would be eligible.[53]

For many women, problems with access to health care start before pregnancy due to lack of access to family planning services and regular primary care. Low-income people and people of color are less likely than higher income people and White people to have a usual primary care provider,[54] and many of the rural and inner-city areas where Black women live suffer from provider shortages and a lack of health care infrastructure.[55] Inadequate transportation options, caregiving responsibilities, and the inability to take time off work can push routine health care visits even further out of reach.[56]

The poorest women in the United States are also five times more likely than their wealthy counterparts to experience an unintended pregnancy, a circumstance that raises the risk of complications, and can contribute to poorer health outcomes for both mothers and their babies.[57] Since 1981, low-income women have seen a substantial increase in unintended pregnancies, while the rates for higher-income women consistently declined.[58] And compared to women of other racial and ethnic groups, Black women have the highest unintended pregnancy rate of all.[59] Without the support necessary to effectively time their pregnancies, Black women are more likely to enter pregnancy having missed out on the benefits of preconception care.

Additionally, since Black women are less likely than other women to be insured, they are also less likely to get recommended care for disease prevention and management.[60] As a result, Black women living in Southern states are not only more likely to lack access to health care and insurance,[61] they are also more likely to have chronic health conditions that are risk factors for maternal death, such as diabetes and chronic hypertension.[62] While early identification of these types of co-morbidities and pregnancy complications through preconception and prenatal care can help ensure appropriate treatment and better outcomes, Black women receive alarmingly low rates of prenatal care during the first trimester of pregnancy compared to women from most other racial and ethnic groups.[63] Postnatal care is also limited because most U.S. health plans restrict such care to a single appointment six weeks after childbirth, unless a complication has been recognized.[64] Combined, these disparities in access expose a pattern in which Black women have more limited access to adequate health care at every point along the reproductive life course, raising the likelihood of a higher risk pregnancy, maternal morbidity, and maternal mortality.

Quality of care

When serious complications like hemorrhage or stroke are identified, monitored, and treated efficiently and appropriately, women are more likely to survive them. However, even when health care is accessible to them, women of color may not receive appropriate, timely, quality care on an equitable basis. According to the 2013 National Healthcare Disparities Report, Blacks and Latinos received worse care than Whites on 40% of measures, while poor people received worse care on 60% of measures compared to higher income people.[65] Problems with quality of care extend to sexual and reproductive health care, and they ultimately contribute to higher rates of maternal mortality and morbidity.

Village Birth International and Co-Mothering Syracuse partner to serve families and improve maternal and child health outcomes in upstate New York.

"Medical education has to teach racial health disparities as a disease caused by racism and lack of cultural competency in America. The two are interconnected."

—**SHAFIA MONROE,**
SHAFIA MONROE CONSULTING

A safe experience with childbirth may depend heavily on the health care setting where a pregnant woman delivers. Standards of care and best practices for handling obstetric emergencies do exist, but variability in clinical performance still contributes to disparities and poor outcomes.[66] Without standard approaches to handling such emergencies, some women receive appropriate, high quality care while others do not.[67] Site of care is especially important for Black women. Black people receive health care in a concentrated number of U.S. hospitals, and these sites have been shown to provide lower quality of care in a range of areas, including obstetrics.[68] For instance, three-quarters of Black women in the United States deliver their babies in only one-quarter of U.S. hospitals.[69] A recent, nationwide study of hospital deliveries found that hospitals serving higher proportions of Black patients also have the highest rates of SMM. Even after adjusting for sociodemographic characteristics, clinical factors, and hospital characteristics, Black women delivering at hospitals that serve many Black patients had the highest risk, while White women delivering at hospitals that serve few Black patients had the lowest risk. Notably, in the high Black-serving hospitals, the adjusted risk of SMM increased for women of all backgrounds.[70] This evidence adds to a growing body of literature suggesting the need to target improvements in quality of care at hospitals serving Black and minority communities.[71]

> *"We have to address race—and racial discrimination in particular—if we are going to see any improvement in maternal and infant health in the United States."*
>
> —**ELIZABETH DAWES GAY,** PUBLIC HEALTH AND REPRODUCTIVE JUSTICE CONSULTANT

Racial Discrimination

Past and present experiences with racial discrimination shape Black patients' interactions with their medical providers, and stereotypes, implicit bias, and mistrust continue to interfere with care. Studies show that Black patients are treated differently than White patients with the same symptoms, receiving fewer diagnostic and therapeutic interventions, and even less pain medication.[72] While providers of color can help to mitigate cultural barriers in the U.S. health system, the lack of diversity in medicine limits their impact. Black physicians are more likely than White physicians to serve medically underserved areas and populations[73] and have been shown to increase access to health care for Black patients,[74] earn higher levels of patient trust and satisfaction,[75] and in some cases, spend more time with Black patients than White physicians do.[76] However, while Black people make-up 13% of the U.S. population, only 4% of U.S. physicians are Black.[77]

Racism may also contribute to poor maternal health by acting as a stressor that compromises Black women's overall health and well-being.[78] Research into racism as a psychosocial stressor suggests that, over time, such stress can lead to physiological changes that make the body more susceptible to disease.[79] In the absence of sufficient resources to cope with the stress of racism, physiological responses may weather the Black body, leading to poor maternal health outcomes.[80] Existing research involving infant health supports this theory. High levels of racial discrimination have been associated with negative birth outcomes.[81] Unlike White mothers, Black mothers and their babies have an increasing risk of poor birth outcomes between their late teens and their twenties.[82] As Black women age, their health profiles worsen, especially among those who are also low-income. Researchers suggest that these adverse health characteristics are related to the hardships associated with persistent social inequality, and that these effects compound with age.[83]

III. AN URGENT NEED FOR MORE RESEARCH AND ACTION ON BLACK MATERNAL HEALTH

The U.S. health system is the most technologically reliant and expensive health system in the world.[84] Fatal and near-fatal pregnancy complications escalate the costs of this health care, as do the increasing numbers of chronic health conditions and unintended pregnancies. Beyond the financial costs, maternal mortality and morbidity have profound repercussions for women and their families. For the 60,000 women who survive SMM,[85] many will experience short or long term disability.[86] For over 600 women in the United States each year, pregnancy will lead to death.[87] Some of these women will leave children behind, and their families will lose needed income, support, and stability. The implications of such a loss are difficult to quantify. But Black communities, particularly those in the South, know that these losses are not rare enough. For the last six decades, Black women have suffered a maternal mortality risk that is at least three times higher than White women, and yet this disparity has persisted, unaddressed.[88]

As U.S. maternal mortality and morbidity rates rise to a level that cannot be ignored, stark racial disparities in the experience and provision of health care are coming to light. The problems associated with poor maternal health are finally gaining visibility, but more research into the causes and solutions is greatly needed. Insightful research will first require more comprehensive data collection. The Centers for Disease Control and Prevention (CDC) currently requests records of pregnancy-related deaths from all states, but there is no nationwide standard or system to compel, collect, and analyze high-quality, comprehensive data on maternal deaths and complications. Moreover, state and local practices vary substantially in terms of the depth of data they collect, their commitment to analyzing it, and the steps they take to prevent future maternal health problems.

Beyond data collection, we need stronger systems for analyzing maternal health information and generating evidence-based recommendations that prevent future harms. Some states have taken proactive measures to understand and correct the systemic failures that lead to maternal deaths by implementing maternal mortality review processes. However, there is an ongoing need to strengthen these processes through the development of best practices and to expand them in states where there is currently no mechanism in place to identify and review maternal deaths.[89] And, since these review mechanisms focus solely on maternal mortality, it is essential that similar efforts are made to better understand cases of maternal morbidity, as well as the underlying determinants of health that most impact Black women. Finally, a comprehensive maternal health research agenda must ensure that the insights gained from this research are shared with stakeholders and translated into sustainable, evidence-based solutions.

A STATE POLICY FRAMEWORK FOR THE RIGHT TO SAFE AND RESPECTFUL MATERNAL HEALTH CARE

A child helps care for his mama at midwife Jennie Joseph's Easy Access clinic in Florida.

This section presents an array of potential policy options aimed at improving maternal health and ensuring the right to safe and respectful maternal health care. The measures included here have been proposed by stakeholders from various fields, including human rights, public health, policy, and reproductive justice. The result is a synthesized snapshot of current ideas, themes, and strategies that maternal health advocates can consider as they build a policy agenda that is rooted in human rights and tailored to the needs of their own state. In some instances, examples are included to highlight the work that advocates are already doing in support of these various measures.

Scope

Because evidence shows that Black women in the South are disproportionately affected by preventable maternal deaths and illnesses, the measures included here are intentionally tailored to address that disparity. However, other groups of women are also impacted by poor maternal health outcomes and low quality care, including Native American women and Black women living in other regions of the U.S. (such as urban cities in the North like New York and Washington D.C.). In many cases, more research is needed to fully understand the specific maternal health challenges faced by different subpopulations of women. For the purposes of this project, we have focused on policy solutions that aim to improve maternal health outcomes and experiences among Black Southern women, though many of the policies identified have the potential to improve outcomes for other groups of women as well.

Purpose

State governments play an important role in shaping the environment in which we live. The policies that they pursue influence our health status, our access to care, and the resources that exist in our communities. To improve maternal health, advocates will need to hold state and local decision-makers accountable for these policy choices, while also pushing forward new ideas that respect, protect, and fulfill our human right to safe and respectful maternal health care. In the face of relentless racial disparities and rising maternal mortality and morbidity, it is crucial that we hold state governments accountable for their duty to act against this human rights crisis.

When it comes to maternal health, states are strategically positioned to leverage regional knowledge about community needs and obstacles, build stakeholder networks, and implement targeted solutions. State leaders and lawmakers can take proactive measures to ensure that their states have effective health care systems to treat sickness and prevent disease and injury. They also have the power to design and implement other kinds of systems that create and promote health. The capacity of states to influence factors beyond the biomedical model represents a powerful opportunity to improve health, which the World Health Organization defines as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity."[1]

The human right to the highest attainable standard of health requires that governments ensure that health facilities, goods, and services are available in sufficient quantity throughout the state, accessible to all, ethically and culturally acceptable, and of good quality.[2] Accessibility has four overlapping dimensions: non-discrimination, physical accessibility, economic accessibility, and information accessibility.[3] Following this framework, the policy recommendations listed below are arranged according to the human rights standards that they fulfill: ***access***, ***quality***, ***acceptability***, ***availability***, ***non-discrimination***, and ***accountability***.

The range of topics represented here acknowledges both the complexity of the issues involved and the intersectional nature of existing barriers to maternal health and to safe, respectful care. A growing body of research into the underlying social determinants of health supports such an expansive view of health policy, and a human rights based approach to maternal health actually requires it. A human rights based approach to maternal health recognizes that all human rights are interdependent, and governments have a duty to address social inequalities that contribute to poor maternal health outcomes.

This guide is meant to be a springboard for visualizing a broad policy landscape and for generating new ideas and deeper analysis. It includes a variety of policy options and guiding principles that have been proposed by experts and stakeholders concerned about maternal health. This resource is not meant to be exhaustive or prescriptive. Instead, it is intended to serve as a generative tool that will encourage continued conversations about maternal health, aid state advocates in their interactions with policymakers, open the door to technical assistance, and contribute to the creative process whereby new and innovative solutions emerge.

Steps for applying a human rights based approach to maternal health policy

1. **Analyze and address** both the immediate and underlying causes of maternal mortality, morbidity, or mistreatment during pregnancy and childbirth.

2. **Identify responsibility** for each of these factors, some of which may transcend the health sector.

3. **Suggest and prioritize actions** that different actors can take to change the conditions that are causing the problem.[4]

I. IMPROVE *ACCESS* TO REPRODUCTIVE HEALTH CARE

If we want to improve pregnancy outcomes, we need to invest in the health and wellness of women and girls throughout their lives, not only when they are pregnant. This section identifies policies to improve access to health services and information that will allow women to determine whether and when to become pregnant according to their individual and family needs.

A. Increase affordability of reproductive health services

Ensure health insurance coverage for all low-income women

The Patient Protection and Affordable Care Act (ACA) of 2010 enacted comprehensive health insurance reforms that have expanded coverage and access for many people. However, health insurance remains out of reach for a significant number of Black women. Many low-income uninsured people whom the ACA was intended to cover have fallen through the cracks because state legislatures with ideological objections to the federal law have opted out of Medicaid expansion. The states that have failed to expand Medicaid are some of the poorest states in the country and are home to disproportionately high numbers of Black people living in poverty. As a result, Black women living in these states are at a disadvantage when it comes to accessing health insurance.

The Medicaid expansion outlined in the ACA would expand the program to all adult citizens with incomes that fall below 138% of the federal poverty line. However, in states that have rejected this change, millions of people remain stuck in a coverage gap because they don't qualify for Medicaid under the original criteria, they can't afford to purchase insurance coverage through the health care exchanges, and they aren't eligible to receive the subsidies that were set up to make the exchanges more affordable.

Recommendations for policymakers:

- **Expand Medicaid or provide an alternative, state-based solution to close the coverage gap.** Medicaid expansion is an important mechanism for improving maternal health because it would provide millions of currently uninsured women in the United States with access to basic health care. Primary care can help prevent health problems that lead to pregnancy complications. It can also help with the diagnosis and management of chronic conditions that may be exacerbated during pregnancy, and it can help women achieve higher levels of preconception health.

Promote continuity of care and insurance coverage

The U.S. health care system is complex and fragmented. It involves a mix of both public and private entities, a vast array of specialized providers and services, and a parallel system of health insurance coverage that typically determines which services a patient can afford to access. For some pregnant women, navigating this system can be difficult and may lead to interruptions in care. Mechanisms that help to coordinate various pieces of this system may improve continuity of care.

States can also take steps to protect low-income Black women from interruptions in health care due to temporary changes in their eligibility for public health insurance. There are several different government sponsored insurance programs that exist to serve specific populations, and for some women, eligibility for these programs may fluctuate or even overlap. During transitions between these programs, women and girls may lose coverage.

Mama Shafia, of Shafia Monroe Consulting, mentors student birth workers.

Recommendations for state health departments:

- **Promote a coordinated care experience that facilitates women's access to safe, quality care.** Facilitate integrated service delivery between public and private systems, coordination of care between different providers (including social service providers), and connections between rural doctors and specialists in nearby cities (i.e. telemedicine, consultations, referrals, etc.). State health agencies and private insurance providers can further help pregnant women connect to the services they need by providing patient navigation services. Patient navigators can help women understand their health insurance benefits, find appropriate providers, and make appointments for care. Given the complexity of the health care system, simplified information about how to access care is helpful for some people. However, patient navigators also require training and monitoring to ensure that the information they provide is accurate, up to date, and communicated respectfully.

Recommendations for health systems and providers:

- **Invest in electronic health record systems.** Electronic records can facilitate continuity of care by enabling different providers to view and share information, providing more complete medical histories (especially during emergencies), enabling better monitoring of care, and giving patients better access to their own records. Advocates can explore opportunities to promote the use of interoperable record systems and to ensure that developments in health IT reach and benefit low-income women and safety-net providers.[5]

Recommendations for policymakers:

- **Enable continuity of care and coverage during transitions in insurance program eligibility.** States can take measures to ensure that women retain access to health care when they move from one health insurance plan to another. Potential mechanisms include: presumptive eligibility for pregnant women while their Medicaid application is being processed; extending time limits on emergency Medicaid coverage (in states that have not expanded) so that women can seek pregnancy-related follow-up care; offering automatic family planning coverage to girls as they age out of insurance programs for children; providing for continuity of care transition periods when a pregnant woman switches insurance policies; suspending (rather than terminating) Medicaid coverage when people become incarcerated; and incentivizing providers to participate in both the Medicaid and exchange markets to avoid care disruptions.

"I'm kind of surprised to hear you use the phrase 'family planning.' I've never had anyone talk to me in terms of, 'this health care is about you, any type of family planning you'd like to do?' [Health care providers] just assumed you were sexual and that you probably were unmarried, and judgment was passed. No one ever said, 'Do you want babies?' It was more like, 'Don't have any [babies]' and basically, 'stop having sex.'"

—**KIMBERLY,** SISTERSONG STORY CIRCLE PARTICIPANT, GA

Strengthen the family planning safety net

Expanding access to contraception services improves the likelihood that women will enter planned pregnancies in optimal health. Nevertheless, Black women are much more likely than White women to lack access to contraceptive services[6] and have the highest rates of unintended pregnancy among all racial and ethnic groups.[7]

Publicly funded "safety-net" health centers are important sites of contraception access for many women, but they are especially important for poor women and adolescents.[8] These clinics are operated by a variety of different providers (such as public health departments, Planned Parenthood affiliates, hospitals, community health centers and other organizations), and they use some public funds to provide contraception services to the general public at free or reduced cost.[9] These family planning-focused safety-net centers are the only source of health care for many low-income women who lack health insurance.[10]

Public funding for family planning is currently available through a patchwork of different government programs, but research indicates that the need for publicly subsidized services exceeds the level of support that is provided.[11] Three-quarters of the public money that goes toward family planning flows through the Medicaid program,[12] allowing women enrolled in the program to access contraceptive services, while state governments pays only 10% of the cost.[13] Title X of the Public Health Service Act also provides some federal funding to subsidize family planning services for people who do not meet

Medicaid's narrow eligibility requirements. States appropriate about 12% of public family planning funding, and other sources of public funding such as the maternal and child health block grant, the social services block grant, and Temporary Assistance for Needy Families contribute as well.[14]

Recommendations for policymakers:

- **Increase the amount of state funding appropriated for family planning services**. State appropriations for family planning must keep up with state demand for these goods and services. As the need for publicly funded contraception care has increased over the years, government funding has failed to keep pace.[15]
- **Expand eligibility criteria for publicly funded family planning coverage to those ineligible for regular Medicaid.** A State Plan Amendment to the state's Medicaid program can help women maintain access to affordable contraception even if they lose Medicaid coverage, cover women who lose Medicaid postpartum, or allow individuals to qualify for family planning expansion coverage based on their individual (rather than household) income.
- **Ensure that all qualified family planning providers are able to participate in state-funded family planning programs.** Some states have attempted to shut down or defund certain providers, including Planned Parenthood. In areas with already limited health care infrastructure, Black women may depend on these entities for essential family planning services.
- **Dedicate funds toward training primary care providers in family planning counseling and service provision, especially in medically underserved areas.** Primary care providers can help women plan and achieve their reproductive goals by incorporating family planning services into routine, well-woman care.[16]
- **Ensure that family planning funding is sufficient to enable clinics to stock all FDA-approved contraceptive methods.** Most safety-net centers are able to offer oral contraceptives, injectables (such as Depo Provera), condoms, and emergency contraceptive pills, but fewer of them offer long-acting reversible contraceptive (LARC) methods.[17] Centers with a reproductive health focus tend to have more contraceptive options available on site than clinics that focus on primary care.[18]

Remove economic barriers to contraception

Contraception provides women with more control over the timing and spacing of pregnancies, reducing maternal health risks associated with unintended pregnancies, and enabling women to optimize their pre-conception health. However, many women encounter significant economic barriers when trying to access contraception, even when they have health insurance. Some of these obstacles are related to rules imposed by governments and insurance companies regarding what contraception products are deemed acceptable, who can provide them, and how they will be dispensed. Although the ACA requires most private insurance plans to cover all FDA-approved contraceptive methods without additional cost-sharing, many women continue to cope with economic barriers in the process of obtaining contraception. By making contraception convenient and affordable, policymakers can help ensure that every woman is able to make informed decisions about her health, and is able to access the method that is right for her and her particular pregnancy goals.

Recommendations for policymakers:

- **Require all health insurers in the state to cover the full range of FDA-approved contraceptive methods, devices, and products, and associated counseling, without cost-sharing or delays**.[19] Federal regulations prohibit insurers from including coverage for some contraceptive methods while excluding others, but they do allow Medicaid and other insurers to use "reasonable medical management techniques" like prior authorization, or step therapy (which prioritizes coverage for generics rather than name brands) to limit the range of no-cost options within each method.[20] Insurers that use medical management techniques for contraception are supposed to have an efficient, accessible process in place to ensure that a woman can get no-cost coverage of specific items when her provider deems them medically necessary.[21] But in practice, these processes are lacking and women continue to experience delays or denials of coverage. States can improve access to the full range of FDA-approved birth control methods (as well as condoms and sterilization procedures for men and women) by ensuring that all of these are covered by insurers without extra costs or delays.
- **Monitor the accuracy of information that insurance companies provide to women about their rights to contraception.**[22] In some cases, insurance companies may be communicating inaccurate information about contraception coverage to their beneficiaries. Misinforming women about their rights and insurance benefits can prevent women from accessing the copay-free contraception to which they are entitled. In addition, women searching for information about the maternity services that their insurance plan will cover may also run into similar problems. More transparency is needed around reproductive health insurance benefits so that women are able to plan their futures and make informed decisions about their care.

"I asked for my tubes to be tied [after] my first time [having a baby], and they told me no. 'You're not old enough, you're not married.' . . . I don't think that any doctor should have the right to tell you if and when you can have your tubes tied . . . [Not having a baby] is an option. I thought that was an option, and it wasn't. I don't feel like it was for the doctor to make a decision for you . . . I didn't ever want to have a second child, [but] it happened."

—**KENDRA,** SISTERSONG STORY CIRCLE PARTICIPANT, MS

- **Require insurers to provide coverage for a year's supply of contraception at one time.** Many insurers will only cover a limited supply of contraception, requiring women to refill their birth control prescriptions frequently, typically every month or every three months. There is no medical reason for this. For many women, extra trips to the pharmacy are made even more difficult by lack of transportation, caregiving responsibilities, work schedules, and other barriers. Research has shown that low-income women relying on public coverage are better able to avoid unintended pregnancies when they can get a year's supply of contraception at one time.[23] When women choose methods that need to be refilled (such as oral birth control pills, patches, or rings), states can make it easier for women to use their preferred contraceptive method consistently by promoting insurance coverage policies that permit a 365-day supply.[24]

Kwajelyn Jackson brainstorms during the June 2015 Black Mamas Matter convening in Atlanta, GA.

- **Allow a broader range of health professionals to provide contraception.**[25] Some states have introduced bills that expand the capacity of registered nurses, nurse practitioners, nurse-midwives, physician assistants, naturopathic physicians, and pharmacists to provide contraception. These bills still limit the methods that a particular professional is authorized to provide (i.e. naturopathic physicians can provide barrier methods but not IUDs), but they also increase the variety of providers that a woman can go to for care. For many women, this may also lower the economic barriers associated with accessing contraception. For example, when pharmacists are permitted to prescribe hormonal contraceptives, women who want to use these methods do not have to go to (and pay for) a separate doctor appointment first. Instead, they can make a single trip to the pharmacy and obtain both the prescription and the birth control at once.[26]

B. Improve access to sexual health information and education

Black women in the United States are more likely than White women to lack access to comprehensive sexuality education.[27] Both adults and young people need this information in order to make informed decisions about their sexual and reproductive health. Comprehensive sexual and reproductive health information helps women and girls understand their bodies and sexuality, plan their families, protect themselves from sexually transmitted diseases, and recognize signs of ill health. In addition, this knowledge promotes maternal health by reducing unplanned pregnancies and sexually transmitted infections, both of which increase the likelihood of pregnancy complications and poor maternal health outcomes.

Access to sexual and reproductive health information is important throughout people's sexual and reproductive lives, but it is especially critical for young people. According to the Centers for Disease Control and Prevention (CDC), nearly half of high school students are sexually active, and young people are at especially high risk for unintended pregnancies and STDs.[28] Youth of color have the highest risks of all,[29] and one in every 32 Black women in the United States will be diagnosed with HIV during her lifetime.[30]

Although all states are involved in some way with sex education for public school children, the content of that education varies substantially from state to state, and even within states.[31] This is because sexual health education is largely controlled at the local, district, or school level. However, state and federal funding, as well as statewide policies outlining basic standards, can also have an influence. For instance, state guidelines can help identify important topics and skill sets that all classes should cover, or ensure that the material that is taught is scientifically sound.

Recommendations for policymakers:

- **Require that all public schools provide comprehensive sexuality education to their students and mandate that sexuality education curricula be evidence-based and grounded in public health guidance.**[32] Currently, some states require public schools to teach sex education, but others do not. Where sexuality education is provided in public schools, many states do not require it to be medically accurate.[33]
- **Ensure that sexual and reproductive health information is available to all people in a community**. While access to developmentally and culturally appropriate information about sexual and reproductive health must be improved for young people, the need for such information is ongoing throughout most people's lives. As such, school-based education models must be complemented by other resources in the community that adults (and youth not reached at school) can turn to for trusted information. This again points to the central role that access to basic health care and family planning services must play in efforts to improve maternal health.

Recommendations for advocates:

Beyond ensuring that curricula teaches young people about contraception and disease prevention, reproductive justice advocates are envisioning new models of education that take a more holistic, strengths-based view of sexual health and rights. For instance, the Sexuality Education Justice (SEJ) Framework developed by the *SexEd! Strategic Cohort* takes a supportive, inclusive approach to sexuality and sexual health education, with the understanding that sexuality is a natural part of human development.[34]

- **The SEJ Framework** calls for "*attention, commitment and resources* that focus on promoting [the] overall sexual health of all people, including marginalized communities – people of color, LGBTQ folks, people with disabilities, immigrants." It also recognizes sexual health education as an equity issue because students in some schools receive high quality instruction about health while others either receive no information at all, or endure education that ignores their identities, realities, and histories. Advocates may find the SEJ Framework useful as they explore potential legislative models. It can also be used by parents, educators, community organizations and youth as they participate in the implementation of sexual health education policies through program design and service delivery.

- In Tennessee, reproductive justice **advocates at SisterReach are proactively developing sexual and reproductive health programs that are both medically accurate and culturally relevant**. By collecting qualitative data about the educational needs of the communities they serve, building intentional relationships with faith communities, and engaging the arts as a communication tool, SisterReach is creating sexual health curricula that simultaneously recognizes existing cultural strengths as well as opportunities for culture shift. Advocates may find this work to be a useful example of community-based education and awareness-raising.

C. Ensure access to legal, safe abortion services

Without sufficient access to preventive care necessary to effectively control the timing or spacing of their pregnancies, Black women have a heightened need for abortion services, and thus use these services at higher rates than women of other races/ethnicities.[35]

In recent years, there has been a dramatic increase in the number of anti-abortion measures passed by state legislatures. These restrictions have closed high-quality reproductive health clinics throughout the South (and other areas of the country), and have imposed countless barriers on patients seeking care. The impacts of these measures disproportionately harm low-income women, women of color, and rural women. Moreover, these measures are passed in the face of abundant evidence showing that the removal of restrictions on abortion care reduces maternal deaths, while the imposition of restrictions increases reproductive health inequalities.[36]

Maternal health advocates can help prevent unnecessary death and disability among pregnant women in their state by opposing measures that restrict access to safe, legal abortion services. In addition to opposing laws that restrict the practice of abortion (such as facility regulations and medical license requirements) or interfere with women's decision-making (such as mandatory waiting periods and ultrasound requirements), policymakers and advocates can support a number of federal and state measures that promote both safe abortion care and maternal health.

Recommendations for policymakers:

- **Expand the provider base for early abortion care.** Permit non-physician clinicians to perform first-trimester aspiration abortions and/or medication abortions. A shortage of abortion providers in the United States contributes to delays in care. First trimester abortions have lower risks of complications than

"By the time I was sexually active [in my 20s], I had already been involved in Reproductive Justice work and had known about how to do your own well-woman exam . . . so when I was going back again for well-woman visits, I was like, 'Okay, I have a billion questions—can you tell me what you're doing before you do it?' . . . At that point I had a really good black woman doctor . . . I was very particular about who I was going to choose as a care provider . . . and so [my questions were] received really warmly—I asked a billion questions, and she answered every one very patiently. It was a completely different experience than my initial experience being 18 . . ."

—**JAMILA,** SISTERSONG STORY CIRCLE PARTICIPANT, GA

Village Birth International and CoMothering Syracuse staff use the the BMM toolkit to "address the human rights violations many women of African descent are facing in upstate New York."

later ones,[37] and studies show that trained non-physician providers can perform them safely.[38] Thus, increasing the types of qualified clinicians allowed to provide early abortion care may ensure earlier access for women, especially in medically underserved areas. Nevertheless, most states currently require abortions to be provided only by licensed physicians.[39] Advocates interested in exploring these measures can look to California, Washington, and Connecticut for examples.[40]

- **Ensure every woman has coverage for abortion care** (including public employees[41] and those who get their health coverage from public insurance programs such as Medicaid), and support policies that prohibit discriminatory insurance policies. Since 1977, the Hyde Amendment has discriminated against low-income women by withholding coverage for basic care.[42] It prohibits federal funding for abortion under the Medicaid program, except in cases of rape, incest, or life endangerment. To remedy this gap in care, some states have chosen to use their own money to cover abortion care in their Medicaid programs, and four states have accomplished this by enacting statutes.[43] At the federal level, the EACH Woman Act would ensure abortion coverage for every woman, however much she earns or however she is insured.
- **Expand private insurance coverage for abortion care.** The ACA permits states to ban abortion coverage in private health plans that are purchased on the insurance marketplaces, and half of U.S. states have done so.[44] In addition, several states force all private insurance companies to withhold coverage for abortion.[45] Other states, including Washington, have tried to proactively enact legislation that prohibits these discriminatory policies.[46] The EACH Woman Act would prohibit political interference with the decisions of private insurance companies to offer abortion coverage.

- **Require Crisis Pregnancy Centers (CPCs) to provide clients with notice of the services that they do not provide, and ensure that public health funding supports legitimate health care providers**. CPCs often appear to be legitimate medical providers, but instead function to deter women from obtaining abortions. These institutions have been found to provide misleading information about pregnancy, abortion, and contraception, and they are not a substitute for legitimate prenatal care. In some states, CPCs are receiving state health care dollars, despite the fact these facilities often lack licensed medical providers and do not fill the unmet need that many communities still have for comprehensive, non-directive sexual and reproductive health care information and services—including contraception, abortion, preconception care, and maternal health care. Moreover, CPC's provision of deceptive, medically inaccurate information about abortion has been well documented[47] and can delay women's medical care, potentially pushing them past the legal limits for abortion in their state.[48]
- **Support the Women's Health Protection Act**. This federal bill (S. 217/H.R. 448) would prohibit states from imposing restrictions on abortion that apply to no similar medical care, interfere with patient's personal decision making, and block access to safe, legal abortion care.[49]

II. IMPROVE *QUALITY* OF MATERNAL HEALTH CARE

The U.S. spends more money on health care than any other country, and yet the quality and cost of maternal care varies significantly from one pregnancy or birth to another. Inconsistency in maternal health care results in some women experiencing better outcomes than others. Such disparities in quality of care—and ultimately in maternal health outcomes—are linked to race.

A. Strengthen the capacity of state health departments to address maternal health

Although quality care depends in large part on the actions of individual clinical providers, there are opportunities to influence the rules, resources, and information that shape provider actions. Government health agencies are critical partners in this effort. State health agencies are often well positioned to understand local health needs, bring together different stakeholders, and access both federal and state resources.

Since 1935, Maternal and Child Health (MCH) Services Block Grants have helped to establish or strengthen the capacity of state health departments to address maternal health. This funding has been used for training and research programs that address the social, economic, behavioral, and structural barriers to care for women, children, and families. It has facilitated the development of health guidelines and recommended standards, and the projects that it funds are often incorporated into state health systems.[50] The Association of Maternal and Child Health Programs further strengthens these state health agencies by partnering with their leaders and serving as a national resource for advocates working to improve maternal and child health.[51]

Recommendations for policymakers:

- **Ensure sustained and sufficient funding for state health departments and related maternal and child health agencies or programs.** Federal funding alone is not sufficient to meet a state's public health funding needs. State health departments also require adequate state funding every year. In recent years, many state and local public health budgets have been substantially reduced, hampering health departments' ability to address maternal health and many other health issues.[52]

Recommendations for advocates:

- **Collaborate with state health departments and MCH agencies.** Through engagement with government health leaders, advocates can push for programs that align with community needs and encourage practices that facilitate quality care.

Recommendations for state health departments:

- **Establish formal maternal health care collaboratives**. Perinatal Quality Collaboratives are networks of public health experts and perinatal care providers that work to improve maternal health outcomes by advancing evidence-based clinical practices.[53] These groups help influence clinical practices and improve quality through better cross-sector communication and knowledge sharing. Engaging clinical partners may also encourage the "buy-in" needed to implement quality improvement measures and change clinical behaviors.

B. Improve the quality and consistency of primary and preconception care

Healthy pregnancies and births begin prior to conception. Access to primary care and preventive services is critical to reducing the risk of maternal mortality and morbidity. When delivered according to standardized, evidence-informed guidelines, regular preventive care lowers women's risk of developing conditions that complicate pregnancy, and helps them manage conditions they may already have.[54] State maternal and child health programs can improve the quality and consistency of women's preconception care in several ways.

Recommendations for state health departments:

- **Ensure that evidence-informed standards of preventive care for reproductive-aged women are updated, disseminated, and adopted throughout the state**.[55] Preconception health services can be integrated into routine well-woman visits, and state MCH programs are well positioned to coordinate dissemination of the most current standards for well-woman care.[56]
- **Strengthen coordination by convening leaders** from Medicaid, Title X, Federally Qualified Health Centers, and provider groups to identify opportunities to improve clinician's capacity to provide quality preventative and preconception care.

Recommendations for policymakers:

- **Increase funding for preconception health services** that can be integrated into the care provided by the state's publicly funded family planning clinics.[57]

C. Improve prenatal care for women at risk

All pregnant women and girls should have access to high quality maternal care regardless of their individual health needs. Quality prenatal care should include effective management of complex or overlapping conditions. Routine prenatal care can be improved through adherence to quality care standards and support for practices that are known to improve maternal health outcomes for women at risk.

Recommendations for health systems and providers:

- **Identify women's risks early**. Incorporating maternal risk screenings into early prenatal care visits can help identify women in need of special services or referrals. Genetic risk factors, behaviors, and conditions that are identified early can often be treated and/or managed more effectively. These risk screenings could include chronic and infectious illnesses, HIV, intimate partner violence,

mental health issues, and substance use. Obese women also face a heightened risk of negative maternal health outcomes. Providers can develop practice guidelines and protocols for how to manage pregnancy weight gain and appropriately and respectfully provide care to pregnant women who are obese, ensuring that these women receive quality care that meets their specific needs.

- **Increase providers' and patients' capacity to detect changes in the patient's condition, and establish plans for what should happen next.** Maternal health outcomes may be improved if providers and patients are able to recognize the warning signs of complications early. Providers must be able to quickly identify complications and potential emergencies, and effectively educate their patients about how to recognize these symptoms of critical illness on their own. Continuity of care during pregnancy may help providers recognize changes in their patient's condition and communicate more effectively with them.

Recommendations for policymakers:

- **Consider legislation on universal maternal risk screenings in collaboration with providers and advocates.** Universal screenings must be designed with the participation of community members to ensure that supportive treatment options are available to women once they are identified as "at risk." Currently, many states criminalize pregnant women who use substances. Moreover, many poor women and women of color already feel highly exposed to state surveillance as a result of racial discrimination and/or participation in public assistance programs. As a result, the privacy burdens and collateral consequences of imposing additional risk screenings must be weighed in each state, and implemented thoughtfully if pursued.
- **Protect the human and civil rights of pregnant women and ensure that criminal laws do not infringe on women's access to health care.** Regular prenatal care visits provide pregnant women and their providers with an opportunity to address substance abuse and reduce the health risks associated with it. However, an increasing number of states are choosing to pursue laws that punish and stigmatize pregnant women who use substances or suffer from addiction. States have enacted legislation that defines drug use during pregnancy as child abuse, permits the civil commitment of pregnant women for treatment, and provides for the termination of their parental rights. Tennessee has gone even farther, enacting a criminal law that allows pregnant women who use substances to be prosecuted for assault or homicide. Because these measures punish pregnant women who are suspected of using drugs, they function to deter pregnant women from seeking both drug treatment and prenatal care. Every major medical association in the United States has taken a stand against the criminalization of mothers for substance use.
- **Address the underlying issues leading to substance abuse and provide treatment**. States may need to expand access to substance abuse treatment, create a statewide referral resource, and ensure that there are treatment options that accommodate mothers (family friendly or child care included). Treatment facilities that accept government funds should also accept and prioritize pregnant women. Policymakers can enable women to communicate openly with their providers regarding their health needs by ensuring confidentiality protections for substance use disclosures, while also ensuring that regulatory restrictions don't inhibit coordination between prenatal care and substance abuse treatment.
- **Address intimate partner violence (IPV) and provide the resources and support that women experiencing IPV need.** IPV is one of the leading causes of maternal mortality in the United States[58] and it raises the risk of unintended pregnancy, sexually transmitted infections, and

Alicia Walters of Echoing Ida facilitates a session at the June 2015 Black Mamas Matter convening.

poorer birth outcomes for both mothers and babies.[59] More than a third of women in the United States experience rape, physical violence, or stalking by an intimate partner during their lifetime.[60] For some women, IPV escalates during pregnancy.[61] Prenatal care presents an opportunity for women and their providers to talk about IPV and devise strategies to reduce the pregnant woman's risks. States can explore opportunities to support IPV survivors through screening, training, and protocol measures. For example, some states have chosen to enact laws that mandate clinical screening for IPV.[62] Others have passed laws that require health care professionals to complete training in domestic violence and IPV.[63] A few states require protocols for the standard of care and information that IPV survivors are provided.[64]

- **Build the capacity of providers and state agencies to provide comprehensive services that address intersections** between different risk factors, such as IPV, substance abuse, mental health, and homelessness.

"When a Black woman walks into a doctor's office, hospital, or clinic, just like everyone else, she wants help. She also wants to be seen as fully human and autonomous, capable of making good decisions for herself."

—**ALICIA WALTERS,**
FOUNDER OF ECHOING IDA

D. Improve responses to obstetric emergencies

The leading direct causes of maternal death in the United States can be attributed to a relatively small number of conditions—heart failure, infection, bleeding, blood clots, high blood pressure, and embolism.[65] These conditions are also associated with high rates of morbidity.[66] When these events occur, an appropriate clinical response can often prevent the situation from becoming a case of severe maternal morbidity or death. However, not all providers and facilities are prepared to recognize and respond to these complications.

Evidence-based practices for managing these emergencies do exist, but the strategies need to be implemented. Moreover, it may not be feasible to implement certain practices in places where the health care infrastructure is already limited. As a result, quality care improvements aimed at managing obstetric emergencies must be adapted to the realities of each state's health system.

Recommendations for state health departments:

- **Assess the geographic distribution of facilities within the state and the level of obstetric care that they are able to provide.** The National Partnership for Maternal Safety proposes categorizing birthing facilities according to the level of maternal risk they are capable of managing. The designation criteria would consider the equipment, space, and personnel required to provide standard care levels. States could assess the geographic distribution of facilities that are able to provide high levels of care for high-risk patients, and systems could then be established to transfer patients between various facilities during obstetric emergencies.[67]
- **Promote implementation of patient safety bundles at birthing sites throughout the state.** Patient safety bundles combine several evidence-based interventions that have been shown to improve outcomes in certain situations when they are used together.[68] The Alliance for Innovation on Maternal Health (AIM) is developing a set of safety bundles and supporting quality improvement materials that will be made freely available to interested U.S. birth centers. Technical assistance will also be available. Through a data exchange process, AIM will be able to help hospitals benchmark their progress.[69]

"[I had] six months [of post-natal Medicaid coverage for myself], exactly six months. Then after that you're like . . . well at least [the baby's] okay [because coverage for the baby lasts longer] but I wish that I could have had longer because you feel like in your mind like, okay, I'll just get myself together within six months but with a baby and everything, then you go to the doctor and they're like, 'you don't have no health care,' and you're like, 'Oh yeah, I forgot.' I wish there was more time or maybe it was more accessible."

—**BRITTANY,** SISTERSONG STORY CIRCLE PARTICIPANT, GA

E. Prioritize quality improvements at sites of care serving Black women

Quality improvement initiatives must be implemented in areas with high rates of maternal mortality and at hospitals serving a high proportion of Black patients. Studies indicate that Black women receive care in a concentrated number of hospitals, and that these facilities tend to provide lower quality care.[70] Aiming quality improvement measures at these sites may have the most impact in terms of reducing maternal mortality and severe maternal morbidity.

Recommendations for state health departments:

- **Build the capacity of health facilities serving high numbers of Black women to provide quality care.** Engage these facilities through quality collaboratives (where they can learn from other facilities), conduct statewide assessments of birthing facilities' capacity to implement safety bundles, disseminate checklists, clinical posters, and other quick provider reference tools to these facilities; and provide technical assistance.

Recommendations for policymakers:

- **Mandate provider training measures.** Some states may want to consider mandatory training requirements. For example, Illinois passed a statute requiring all hospitals providing maternity services to complete a set of educational activities related to obstetric hemorrhage. The law was initiated in response to findings from the Illinois Maternal Mortality Review Committee, and the requirements were developed in consultation with maternal health experts.[71]

F. Improve continuity of postpartum care

To ensure the health of women during the postpartum period, advocates may wish to explore opportunities to educate patients about health risks, ensure that they have adequate support systems, and maintain their connections with health care providers.

Recommendations for state health departments:

- **Ensure that women have access to health information and services immediately after birth**. Opportunities to improve maternal health during this critical time period may include implementation of model standards for effective postpartum discharge planning; ensuring that warning signs for complications are understood by women before they leave the hospital or birthing site; ensuring that women and their newborns have safe conditions to go home to; and ensuring that women and their families know where to return for emergencies and regular follow-up care.
- **Ensure that quality care is available to women after pregnancy ends.** Women must continue to receive safe, respectful, comprehensive care after pregnancy has ended. This may include access to breastfeeding support and family planning, and facilitated access to routine postpartum care, such as a home-visiting option for women with substantial transportation barriers.

G. Ensure that health care payment and delivery systems incentivize safe and respectful maternal health care

Most women pay for their maternal health care with some type of health insurance. However, providers may charge substantially different prices for the same procedure depending on who the payer is, and the cost of any given procedure can vary widely from one location to another. Moreover, most insurance payments reimburse providers for each intervention that they provide, rather than for a holistic course

of treatment. Thus, providers are given an economic incentive to perform procedures that may be unnecessary or even harmful to women's health. At the same time, services that would improve women's maternal health are often not used because they are not covered by insurance.

Unnecessary interventions in the labor and delivery process can increase health risks. Induction of labor before 39 weeks may increase a woman's risk of obstetric hemorrhage, while cesarean delivery increases the risk of postpartum complications and poor outcomes in future pregnancies, and increases medical costs. Although optimal thresholds for certain procedures remain controversial,[72] cesarean deliveries have increased sharply in recent years and are now used in one-third of all U.S. births.[73] There is a growing consensus that this and other surgical interventions are overused.

Recommendations for policymakers:

- **Deter unnecessary early deliveries and other procedures that can be harmful when not medically indicated.** Minnesota implemented a policy to deter early elective deliveries through its Medicaid statute, requiring hospitals to implement measures that reduce the number of planned delivery inductions before 39 weeks, as well as the number of cesarean deliveries among low-risk, first-time mothers. Under this law, hospitals are incentivized to avoid these procedures unless they are medically indicated.[74]
- **Expand the types of beneficial services that are covered by Medicaid, and possibly other large insurers.** This might include reimbursements for services such as lactation consults and breastfeeding support (not just the pump), language translation, care coordination, community engagement, nurse home visitation, midwives, and doula support.[75]
- **Reimburse Medicaid providers at higher rates and ensure that they are consistently paid for the services they provide.** To ensure that low-income women have access to quality maternal health care providers, the rate at which different obstetric providers are reimbursed may need to be altered. In some cases, providers may be reluctant to take on Medicaid patients or provide high quality care because the Medicaid reimbursements are considered too low or are not paid in a timely, efficient manner. This can be especially harmful in states with health provider shortages.
- **Align health insurance payment systems with incentives for providing high quality care**. State Medicaid agencies and other large insurers in a state may be able to change the way they pay for services in order to better align incentives. For instance, bundling payments related to a particular episode of care (such as birth) and eliminating the extra fee paid for cesarean deliveries could remove economic incentives to surgically intervene in a woman's delivery process. Similarly, underutilized services that are known to improve maternal health outcomes could be separated out to encourage their use (i.e. separate payments for first trimester prenatal care visits, or postpartum follow-up).[76]
- **Demonstrate best practices in state health programs.** The state government may be the largest purchaser of health care in the state, and thus has an opportunity to demonstrate best practices by establishing payment mechanisms that reward the delivery of quality health care and improve maternal health outcomes.

Recommendations for health systems and providers:

- **Educate providers** and promote cultural shifts within the profession that will help change harmful patterns and practices.

BMMA steering committee members and collaborators share ideas during the October 2017 Black Mamas Matter Alliance convening in New Orleans, Louisiana.

III. ENSURE *ACCEPTABILITY* OF MATERNAL HEALTH CARE FOR WOMEN MOST AT RISK

A. Incentivize community models supporting Black women's maternal care

Some pregnant and birthing women have options in terms of the providers they see, the support people they depend on, and the places where they go for safe and respectful maternal health care. But for many Black women, these choices about care are constrained by level of income, geographic location, an under-resourced health care infrastructure, transportation barriers, and a deficit of providers who understand their needs.

Advocates can explore opportunities to expand the options available to Black women as they seek out maternal health care. For example, some women want access to holistic care. Women who feel marginalized in mainstream medical systems may find the presence of an advocate, or a community-based health care setting, especially beneficial. Nevertheless, low-income women of color are often unable to use these types of care because they cannot get to them, cannot afford them, or they are not aware of them.[77]

Recommendations for policymakers:

- **Ensure access to doula support and midwifery care**. Studies have shown that doula care improves maternal health outcomes by reducing the likelihood of surgical interventions (such as cesarean delivery), and providing woman-centered care. Studies also show that Medicaid reimbursement of doula care is likely to result in cost savings.[78] Similarly, states that allow certified nurse-midwives (CNMs) to practice autonomously have lower rates of cesarean sections, preterm births, and low birthweight infants.[79] Expanding access to these providers may require changes to regulations, provider licensure rules, hospital policies, and insurance reimbursement systems. These efforts may also be resisted by other members of the health professions.

Black Mamas Matter Alliance steering committee members bring collaborators together for the third annual meeting of Black maternal health stakeholders.

- **Direct state Medicaid agencies to amend their state plans and cover doula support** under the recently revised CMS Preventive Services Rule.[80] Doula support could also be incorporated into new and existing Delivery System Reform Incentive Payment (DSRIP) waiver programs. States may also consider mandating coverage for doula care in private insurance plans.[81]
- **Support and scale up innovative and emerging practices that serve Black women and their communities.** Models of care like "The JJ Way" and "Centering Pregnancy" may provide promising insights into effective, culturally acceptable care. For example, "The JJ Way," is a midwifery-based model of care that uses a team approach to maternal care emphasizing respect for the client, peer educators and group learning processes. Women are provided with a maternity medical home during pregnancy (regardless of their ability to pay) and can choose to give birth wherever they are most comfortable.[82] This model has been shown to improve birth outcomes among the low-income women and women of color it serves[83] and is designed to be easily duplicated.[84] Centering Pregnancy is another model that has been shown to improve birth outcomes and lower racial disparities through group prenatal care.[85] This model emphasizes self-care and confidence while building community among women who are experiencing pregnancy at the same time.[86]

B. Build the cultural competency of providers to meet the needs of Black women

Advocates can encourage a health care culture that organizes relationships, institutions, and systems of care in ways that ensure all women's human rights.

Recommendations for health systems and providers:

- **Ensure that health providers receive training on implicit bias, class and gender bias, anti-racism, and human rights in the practice of health care.** These trainings can be incorporated into providers' educational development, and can be included in continuing education courses.

Recommendations for policymakers:

- **Build the cultural competency of providers in the state.** Mechanisms to achieve this include (but are not limited to) supporting implementation of the National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health[87] and mandated cultural competency training for health care providers.
- **Cultivate a more diverse health care workforce.** While all providers have a duty to provide respectful, culturally competent care to their patients, a more diverse health care workforce is needed. States can explore opportunities to support people from under-represented backgrounds in pursuing careers in primary care and the maternity professions. This could include recruitment, scholarships and grants, housing or childcare assistance during training, mentoring programs, and state loan forgiveness programs.

C. Build a culture of respect for women's decision making power and bodily autonomy during care

The right to safe and respectful maternal health care encompasses a woman's right to actively participate and make informed decisions about her care. To make an informed decision, a woman must be provided with information about her condition, her health care options, and the risks and benefits associated with each one. Maternal health care providers can empower their patients to become engaged decision-makers by centering them, educating them, and listening to them.

In the context of pregnancy and childbirth, women are presented with multiple opportunities to participate in their care and make decisions that substantially affect their health. Decisions may relate to the management of chronic conditions, the timing and circumstances of labor and delivery, and choices about breastfeeding or contraception postpartum.

Advocates can help improve participation, respect, and quality during health care encounters by exploring opportunities to ensure that women know their rights regarding the care they receive, that decision-making is a shared process between patient and provider, and that all women have the information and support they need to make these important decisions.

Recommendations for health systems and providers:

- **Promote respectful communication and information accessibility during encounters between women and their providers.** Tools like patient decision aids, patient-centered birthing plans, clinical conversation guides, and the participation of doulas or patient advocates may help. Providers may

also need additional training in order to meaningfully obtain consent, especially where power differences between a woman and her provider are substantial.

- **Enable pregnant and birthing women to incorporate their chosen support people into their maternal health care experience.** Some pregnant women may want to include their partners, children, family members, and loved ones in their care, and this can sometimes be at odds with hospital policies, a provider's wishes, or confidentiality requirements. Solutions must balance these needs while ensuring that safe and respectful maternal health care is provided without discrimination.

Recommendations for advocates:

- **Empower women to engage with their providers and make active decisions about care**. A woman's experience with maternal health care is an important aspect of quality.[88] Advocacy groups are drawing attention to consumer experiences with maternal health, helping individual women claim their rights, while also raising awareness about areas of care that need system-wide change. Through patient education, advocacy groups can empower women to enter maternal health care settings with more information about their options.

Recommendations for policymakers:

- **Ensure access to mental health services for women who need them.** Although maternal morbidity is typically discussed in terms of physical health conditions, women who have traumatic experiences with birth can suffer negative mental health outcomes. Disrespectful care or denial of informed consent can cause or exacerbate these negative experiences. Advocates may wish to explore opportunities to encourage more research into the mental health implications of different birth experiences, and expand the options available for women who need to heal from them.

IV. ENSURE WIDESPREAD *AVAILABILITY* OF MATERNAL HEALTH SERVICES

In addition to measures designed to improve availability of services that are specified in the section, "Improve Quality of Maternal Health Care," community-based health programs can help bring relevant, culturally competent, effective care to women who are vulnerable or isolated.

"I ended up with emergency C-section . . . but when they gave me the epidural it never really worked. They gave me four, five doses, like more than they're supposed to give somebody but I could still feel. Nobody listened to me . . . I just didn't have an advocate there for me . . . It was a very traumatic experience . . . There was no counseling covered by that expensive health care that I paid for. I think [it was] only up until last year I really psychologically recovered from that experience."

—**LAKEISHA,** SISTERSONG STORY CIRCLE PARTICIPANT, GA

Recommendations for policymakers:

- **Support the role of community health workers (CHWs) in improving maternal health**. CHWs provide health education and counseling, helping women to manage chronic diseases and reduce the risk of complications in childbirth. They are often members of the communities they serve, and may be physically and culturally accessible in ways that other providers are not. States can support CHWs by funding training and certification opportunities, and ensuring the stability of health programs that employ them.
- **Support mobile health services and providers that bring specialized care to women near their homes.** Mobile health clinics can help mediate gaps in health infrastructures by bringing critical services into underserved neighborhoods. Similarly, home visiting programs (which are often used to promote infant health) can be designed to assess and address the needs of new mothers and can be an important tool for overcoming barriers to postpartum care.
- **Support access to care providers during evenings and weekends**. Some women may be unable to visit a provider for the care they need during regular business hours. Making maternal health services available outside this time frame may improve access for women who have to work, attend school, or care for others during the week day.

V. ENSURE *NON-DISCRIMINATION* IN ACCESS TO MATERNAL HEALTH CARE AND SOCIAL DETERMINANTS OF HEALTH

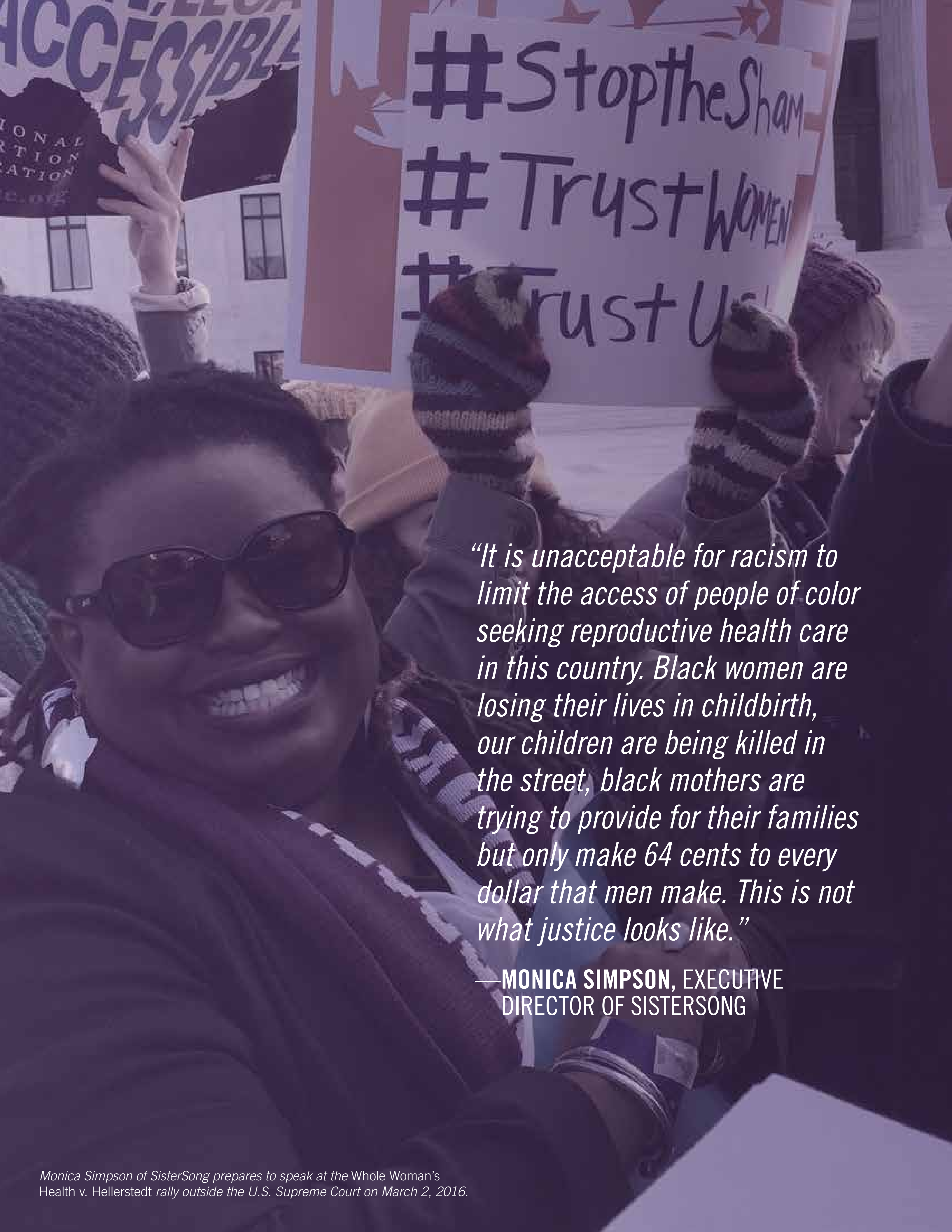
Health care must be accessible to all people, free from discrimination based on gender, race, income, or any other protected category.[89] Ensuring this freedom is especially crucial for those who face discrimination on many intersecting grounds. For instance, while all Black women in the United States are made more vulnerable by anti-Black racism and gender oppression, incarcerated Black women are particularly vulnerable to discrimination in the exercise of their human rights.

In addition, some laws and policies that harm Black women's health were not enacted with the intent to discriminate, but nonetheless discriminate in effect. To ensure that all people can exercise their right to health free from discrimination, state governments must take proactive measures to eliminate discrimination in law and practice, paying special attention to structural barriers to health for groups affected by historical injustice.

State governments have a duty to directly confront racial inequities in maternal health, and they cannot remedy this decades-old disparity by focusing solely on medical interventions or individual behavior modification. Instead, governments must acknowledge the root causes of maternal health problems, proactively remove barriers that put Black women at risk, and prioritize policies that advance health equity.

A. Ensure the maternal health and rights of incarcerated women

U.S. policies that support mass incarceration are having a negative impact on Black women's maternal health. There are currently around 1,251,600 women in the country living under correctional supervision,[90] and many of them are Black. The majority of women in prison are mothers, and one in twenty-five women in state prisons arrives pregnant.[91] A large proportion of incarcerated women are survivors of physical and sexual abuse and suffer from mental and physical health problems while in prison, including HIV.[92] Incarcerated pregnant women report mistreatment by correctional guards and



"It is unacceptable for racism to limit the access of people of color seeking reproductive health care in this country. Black women are losing their lives in childbirth, our children are being killed in the street, black mothers are trying to provide for their families but only make 64 cents to every dollar that men make. This is not what justice looks like."

—**MONICA SIMPSON,** EXECUTIVE DIRECTOR OF SISTERSONG

Monica Simpson of SisterSong prepares to speak at the Whole Woman's Health v. Hellerstedt *rally outside the U.S. Supreme Court on March 2, 2016.*

staff during their pregnancies, lack of access to adequate nutrition and health care providers, and inhumane conditions during birth.[93] In many states, women are shackled while they labor and give birth, and in most cases, infants born to incarcerated mothers are immediately taken away.[94]

Reproductive-aged Black women in the United States have a significant risk of experiencing incarceration.[95] Some advocates are responding to this crisis by working to reduce state reliance on the criminal justice system and are supporting alternative methods of accountability and rehabilitation. Others are attempting to reduce the harm caused by incarceration systems and are working to reform the policies that are most damaging to women's health and well-being.

Recommendations for policymakers:

- **Ensure that state prisons respect women's maternal health and rights.** This may include efforts to: improve the quality of maternal health care provided in state prisons; improve data collection, reporting, transparency, and oversight of maternal care conditions in correctional settings; ensure that pregnant women have access to appropriate nutrition; ensure that women who experience warning signs for pregnancy complications are given prompt access to a health care provider; ensure access to doula care; pass and implement anti-shackling laws; train guards and providers to enable safe, respectful maternal health care within high security settings; and ensure access to counseling and treatment for substance use, domestic violence, HIV, chronic conditions, and mental health needs.
- **Ensure that incarcerated women have access to health promoting resources at the time they are released**. Policies may include measures to: prevent termination of Medicaid eligibility when women become incarcerated (which leaves them without health insurance when they are released);[96] provide HIV testing, counseling, and referral upon release;[97] offer contraceptive counseling and LARC methods in a non-coercive manner prior to release;[98] support prison nurseries that enable women to parent and breastfeed their newborns; eliminate incarceration as grounds for terminating parental rights; remove questions about criminal history from job applications; and remove restrictions on food assistance, housing and other resources that prevent women with criminal convictions from accessing essential services.

B. Address the social determinants of health and other influential indicators

Health is determined in part by our access to social and economic opportunities, the resources and supports that are available in the places where we live, and the safety of our workplaces, our food and water, and our environment.[99] However, disparities in these conditions of daily life give some people better opportunities to be healthy than others.[100] As a result, a human rights based policy agenda for improving Black women's maternal health cannot be confined to the health sector. Instead, it will require immediate health system improvements, along with longer-term efforts at "social transformation" in a range of other sectors.[101]

Moreover, for many women, good health is not limited to surviving pregnancy and childbirth or even managing life-threatening complications. Instead, it is seen as a more comprehensive experience of physical, mental, spiritual, political, economic, and social well-being[102] that enables one to live a satisfying life. Each person or community may define health differently, but most people value safety, physical functioning,

financial security, emotional security, nourishing relationships, a sense of control over one's life, and a sense of meaning and purpose.[103] Thus, supportive social determinants are not just necessary for producing better health outcomes, they are also elements of a satisfying life that depend on good health.

For decades, reproductive justice advocates have been making this connection between reproductive health and social justice, arguing that women and girls cannot realize their right to health and well-being when society systemically denies them the economic, social and political power and resources that facilitate health and self-determination. Maternal and child health professionals are also making these connections and are voicing their own support for social justice movements.[104] Though it may not be possible to work on every issue, maternal health advocates can explore opportunities to enhance collaboration between public agencies, organizations, and communities that are working to achieve the following goals:

Adequate housing

Black women and girls need access to housing that is safe, stable, affordable, and family friendly. Adequate housing must also encompass sanitary conditions and basic utilities like electricity and water. This is true at every moment across the life course, but is especially important for pregnant women and women who have just given birth.

Recommendations for policymakers:

- **Align housing laws with women's health**. For example, states can enact health-promoting housing codes, fund enforcement and proactive rental inspection programs, train code enforcement officers, partner with community organizations to ensure housing laws are understood and violations are discovered, and promote coordination across government agencies involved in health and safety.[105]
- **Ensure that women and families have access to affordable housing**, and that the availability of these units matches the need for them.

Transportation equity

Access to transit improves health by increasing physical activity, lowering diseases related to environmental factors, and improving pedestrian and vehicular safety.[106] When low-income people have access to public transportation, they are better able to access health care facilities, grocery stores, and recreation centers.[107] However, many Black women in the South experience transportation barriers that isolate them from resources and interfere with health care. This lack of access often reflects longstanding inequities in public infrastructure, particularly in poor, Black communities.

Recommendations for policymakers:

- **Improve public transit** and ensure that transit investments benefit (rather than displace) low-income communities and communities of color. Advocates may need to determine whether proposed transportation plans connect Black women to health care facilities, affordable housing, good jobs, education, healthy environments and other resources.[108]
- **Ensure that women have transportation to and from health care visits**, as well as options that bring providers to the places where pregnant women live.

Nutritious food

Black women, girls, and their families need information and education about nutritious food, access to nutritious food, and food security.

Recommendations for policymakers:

- **Support government programs that supplement women's food budgets and enable access to healthy food.** Support policies that promote nutrition education, physical activity, and healthy weight, as well as community development projects that incorporate access to fresh food in their design (i.e. locating affordable housing in areas with grocery stores, supporting community gardens, farmer's markets, etc.).

Clean water

Access to clean, safe water is critical to health, but as the recent water crises in Michigan and other places have demonstrated, low-income communities of color are at heightened risk of exposure to environmental toxins and failing infrastructure. State and local governments have a duty to ensure that the water systems in their jurisdiction are safe and that clean water is fairly distributed.

Recommendations for policymakers:

- **Implement measures to ensure equitable access to safe water**, such as regular testing of water quality, affordability protections, infrastructure investments in underserved areas, funding for lead poisoning prevention efforts, remedies for contamination, and appropriate health services for people who are exposed to unsafe water.

Environmental justice

Advocates can analyze the specific environmental threats that exist in their state and explore opportunities to prevent and address reproductive health risks caused by environmental toxins.

Recommendations for policymakers:

- **Implement measures to protect Black women and girls from health threats** in the workplace and address environmental racism by incorporating racial equity considerations into regulations, environmental impact evaluations, permitting decisions, and other government processes.

Safety and freedom from violence

Safety is an essential ingredient for health, yet many Black women, girls, and their families are exposed to high levels of violence—in their homes, their neighborhoods, and in their interactions with the state.

Recommendations for policymakers:

- **Address police brutality and the criminalization of people of color**, promote training and protocols that build the capacity of social and health services providers to respond to gender-based violence, provide resources for survivors of violence, and support the reproductive health care needs and rights of incarcerated women.

Economic justice

Advocates in many states are proposing legislative changes that challenge poverty and economic inequality.

Recommendations for policymakers:

- **Support pregnant and parenting women in the workforce**. Proposed policy measures include: paid parental and family leave; work related pregnancy discrimination protections; educational protections and school-based supports for pregnant and parenting young people; promoting the right to breastfeed; paid sick leave; and access to safe, affordable childcare.
- **Raise the minimum wage**. Although these measures don't address the deeper issues that cause so many Black women to be concentrated in low-wage employment, raising the minimum wage could still have a significant impact on the health and well-being of many Black women.

Access to Justice

Some women may need civil legal support in order to address barriers to health or health care.

Recommendations for policymakers:

- **Support Medical-Legal Partnerships.** These partnerships between health care providers and lawyers may be an effective tool for addressing certain obstacles to health, such as the denial of health, food, or disability benefits, protection from domestic violence, or the resolution of various housing issues.[109] Pregnancy is a time of frequent contact between women and the health system. Sometimes the illnesses that health care providers treat are caused or exacerbated by health-harming social conditions. Having a lawyer on the health care team may help to address some of these social conditions in a more comprehensive way.

Intersectional policy analysis

Advocates can explore opportunities to ensure that policymakers consider the health and equity impacts of *all* of their public policy decisions.

Recommendations for policymakers:

- **Implement Health Impact Assessments**, which help to identify the potential health and equity impacts of proposed policies, as well as generate recommendations for mitigating them.[110]
- **Review existing policies and legal codes** and analyze their relationship to health outcomes and health promoting conditions.

VI. ENSURE *ACCOUNTABILITY* TO HUMAN RIGHTS STANDARDS ON MATERNAL HEALTH

A. Build state systems to collect, monitor, analyze, and share data

Many experts believe that maternal deaths, injuries, and illnesses are significantly underreported.[111] In order to understand the nature and true magnitude of maternal health problems occurring in their state, states need to develop the ability to collect accurate, complete data on a range of relevant variables. Maternal health surveillance activities should be a core, routine component of the public health work that state health departments engage in.[112] A standardized maternal mortality review process can integrate these data collection and case identification activities into its operations. However, in states where formal review processes have not been implemented, state health departments can still work to strengthen data collection strategies in order to identify the scope and nature of pregnancy-related deaths.

"With my twins, I worked so much right after the six weeks [of maternity leave], I didn't even see them; I wouldn't even see them awake. I would turn them over to my mother or grandmother in the morning when they were still asleep, and I would come home at night and they'd be still asleep. When they cut their first teeth, I didn't even know for three days because I didn't see them. I worked two jobs so I would work 16 hour days… If I hadn't had my mother and my grandmother to babysit for me, I don't know what I would have done. Breastfeeding was horrible because when I was trying to explicitly breastfeed and I worked in low-wage, hourly work, like fast food work, they don't give you breaks. It's not like, 'Hey, my boobs are full. I need to go pump. Can somebody go waitress for me?' That doesn't happen."

—**KAYLA**, SISTERSONG STORY CIRCLE PARTICIPANT, MS

The proposals discussed below aim to strengthen states' capacity in four areas: (1) accurately recording and quantifying the number of women who suffer maternal mortality and morbidity; (2) identifying cases of maternal mortality and morbidity that will be treated to a more detailed analysis; (3) providing those review processes with the information they need to conduct a thorough analysis and make evidence-based recommendations; and (4) understanding the needs and experiences of women of reproductive age living in the state. Advocates can help build state capacity in these four areas by exploring the strategies outlined below.

Improve the quality of data recorded on vital records

When a vital event such as a live birth or death occurs, it is registered in the state where it took place, and a certificate or record of the event is then created. All states have laws that require registration for births and deaths, and some states also include registration for fetal deaths or pregnancy terminations.[113] Because vital records collect data

Dr. Joia Crear-Perry, Dr. Willie Parker, and Shafia Monroe offer the service providers' perspective at the June 2015 Black Mamas Matter convening.

about certain events from everyone in a state (rather than a smaller sample of selected individuals), they are an important source of population-based data.[114] In states that do not have a maternal death review committee in place, vital statistic data can be an especially important source of information for policymakers.[115]

The CDC National Center for Health Statistics (NCHS) and the National Association for Public Health Statistics and Information Systems (NAPHSIS) encourage states to maintain some level of conformity with one another, providing standard forms, model regulations, and other guidance to states.[116] The U.S. standard death certificate, which is recommended for national use,[117] requests information about whether or not the person who died was pregnant within a year of her death.

Even though most states now have forms that align with the standard death certificate, vital records may still lack complete and accurate information about pregnancy. For example, the medical certifier who fills out the death certificate may not be aware of a woman's recent pregnancy, and may make errors in filling out the checkbox or describing the cause of death and contributing factors. Implementing standard mechanisms to catch and correct these reporting errors can improve the reliability of vital record data on maternal health.[118]

Recommendations for policymakers:

- **Link death certificates with birth and fetal death certificates.** Using names or other identifying information, the death certificates of reproductive-aged women can be compared against certificates of live births and fetal deaths in order to identify any recent pregnancies. Studies have found that pregnancy-related deaths are substantially underestimated when cases are

identified through death certificates alone, and that linking records lowers the number of missed cases.[119] If states can build their capacity to match and compare vital statistic files, they will be better equipped to identify victims of pregnancy-related death, and will have access to more comprehensive data about each case.

- **Establish a timely process for amending death certificates** when new information from other sources (such as autopsy reports) becomes available.

Recommendations for state health departments:

- **Establish a process to assess the quality of data that is obtained from the pregnancy checkbox question** on the death certificate. Once the nature and degree of misclassifications are known, a state can then take steps to appropriately address those errors. This will help ensure that states are correctly identifying all pregnancy-related deaths.

Integrate data sources via electronic record systems

In addition to vital records, states can look to other sources of data that will help them paint a more complete picture of maternal health and its challenges. Integrating multiple sources of maternal health surveillance data can help states accurately identify the number of women who suffer from maternal mortality and morbidity every year. Multiple data sources can also be used to inform deeper review processes that investigate the factors underlying individual cases of maternal mortality and morbidity.

Integrating multiple sources of information may require changes to the way that states gather and share health-related information among various stakeholders. Technological advances can create new opportunities for better data collection, while also making it easier to share information across systems. Moreover, when standardized protocols and definitions are used, the data that is shared can be integrated and interpreted in a meaningful way.

Recommendations for health systems and providers:

- **Implement electronic health record (EHR) systems.** Electronic record systems can facilitate effective collection, analyses, and sharing of data about maternal health by reducing the number of redundant, manual data entries and documenting a more complete health history. By capturing birth and death data in electronic health record systems and making that data exchangeable with vital records systems, the timeliness, accuracy and completeness of vital records could be improved. The federal government, and some states and payers provide incentives to hospitals and clinicians that adopt EHR.[120]

Recommendations for policymakers:

- **Standardize data collection methods.** A nationally standardized approach to data collection that is compatible with electronic record systems would allow for better identification of pregnancy-related deaths, greater options for integrating and linking data, and new opportunities to monitor the health system. The CDC, state representatives, and other stakeholders are working to develop vital records standards that would enable this kind of interoperable electronic data exchange.[121] These standards also ensure that data can be compared across jurisdictions and internationally. NCHS supports states in adopting e-Vital Standards-based interoperability through pilot testing and trial implementation.[122] In addition, states can use the Maternal Mortality Review Data System (MMRDS) developed by the CDC to help them collect and abstract data, develop case summaries, conduct analysis, and document committee findings and recommendations.

Recommendations for state health departments:

- **Utilize administrative data sets in addition to vital records** to gather information about the health of reproductive-aged women in the state. For example, state hospital discharge files provide information about specific health conditions, outcomes, and health system performance. Population-based surveys also contain valuable data. The Pregnancy Risk Assessment Monitoring System (PRAMS), a survey that collects state-specific data about women's experiences before, during and after pregnancy[123] is a collaboration between the CDC and state health departments. Its online data system (PRAMStat) provides the public with access to maternal health indicators.

Expand the sources and scope of data that a state collects

In order to ensure that each state keeps an updated and accurate record of maternal deaths, advocates may consider pursuing mandatory reporting requirements, maximally inclusive reporting criteria, and innovative methods of data collection.

Recommendations for policymakers:

- **Implement a mandatory reporting process for pregnancy-related deaths.** Require certain professionals and providers to report these cases to state public health authorities through a standardized protocol. State medical examiners and health and social service providers can be among those required to notify the maternal health reporting system whenever they encounter deaths that might be pregnancy related. According to AMCHP, such systems should be confidential and non-punitive, and should include deaths of women up to 42 days postpartum.[124]
- **Support the collection of qualitative data** to provide richer insights into the impact of racial discrimination on Black women's health and information about how Black women view the maternal health care that they receive. For instance, qualitative data that includes subjective measures of women's satisfaction may provide unique insights into perceptions of quality or specific access barriers.
- **Support research that addresses the complexities of Black women's identities.** For example, data collection strategies often use broad categories or imperfect definitions that can obscure the specific experiences of Black Latinas, African immigrants, and other sub-populations of Black women. More research is needed to understand the unique maternal health challenges and opportunities that are associated with these intersectional identities, including intersections of race, ethnicity, immigration status, gender identity, sexual orientation, class, ability, and age.

Recommendations for state health departments:

- **Identify and track all pregnancy-associated deaths, not just pregnancy-related ones.** Pregnancy-associated deaths are defined by the American Congress of Obstetricians and Gynecologists (ACOG) and the CDC as deaths that occur when a woman is pregnant, or within one year of the pregnancy ending, regardless of the cause.[125] These include deaths from violent injuries, drug overdoses, or motor vehicle accidents, and they may or may not be pregnancy-related.[126] Pregnancy-related deaths are defined more narrowly as deaths that occur when a woman is pregnant, or was pregnant within the last year, and the cause of death was related to or aggravated by her pregnancy or its management. (To determine whether a death is pregnancy-related, it helps

to ask the following question: *"If the woman had not been pregnant, would she have died?*)[127] Using the broader definition maximizes the number of deaths identified and provides additional information about risks to perinatal women.

- **Participate in the National Violent Death Reporting System (NVDRS).** This database is maintained by the CDC and contains information on violent deaths. Some of the victims included in this system are pregnant women or women who were recently pregnant. Violence is a significant health risk for many Black women, and in some states, homicide is one of the leading causes of death among pregnant women.[128] Thirty-two states currently participate in NVDRS, allowing them to identify maternal deaths that might be missed through other case identification methods and to gain access to more detailed information about individual cases.
- **Build capacity to capture information about maternal morbidity**. As states build their capacity to collect and integrate information about pregnancy-associated deaths, they can simultaneously explore options to replicate or adapt these surveillance systems in order to capture similar information about maternal morbidity.
- **Use robust indicators to monitor and evaluate maternal health**. Recognizing that positive maternal health outcomes require supportive social, economic, and physical environments throughout the life course, AMCHP launched a project establishing a standardized set of life course indicators that can be used to measure progress on maternal and child health.[129] The 59 indicators include reproductive experiences, such as stressors during pregnancy; community well-being factors, such as concentrated disadvantage; and indicators that directly engage with race, including experiences of race-based discrimination or racism among women.[130] AMCHP offers online access to the indicators and has provided intensive technical assistance to several states, including Louisiana, Mississippi, and Georgia.[131] Similarly, the Core State Preconception Health and Health Care Indicators provide a comprehensive, standardized tool that states can use to monitor, evaluate and improve pre-conception health.[132]

Recommendations for advocates:

- **Develop participatory research models** that acknowledge community-based perspectives on care and can be used to set research agendas.[133] Reproductive justice organizations and other community-based groups can be engaged to conduct this type of research, simultaneously strengthening maternal health data and community involvement.

B. Implement and improve maternal health review processes

Once data has been collected, it must be processed, analyzed, and acted upon. A formal review process helps states uncover the specific factors that are contributing to maternal mortality and morbidity among local women. They provide a mechanism for various stakeholders to come together and discuss individual cases, which may then reveal opportunities for systems change. The maternal health review committees that are currently in place in approximately half of U.S. states have a mandate to analyze cases of maternal death. However, in performing this analysis, they may also discover valuable information about maternal morbidity and respectful care as well. The trends uncovered during these reviews can inform best practices and recommendations that will help policymakers and providers improve maternal health.

Maternal mortality review (MMR) and pregnancy-associated mortality review (PAMR) committees require state commitments in terms of time, resources, and political support. For example, they may require supporting legislation, additional data processing, the participation of government employees and other health experts, civil society engagement, and other resources. Nearly half of all U.S. states have no such mechanism to review maternal mortality.[134]

Recommendations for policymakers:

- **Enact legislation formalizing a MMR or PAMR process.** Prior to establishing the review process, states will need to decide on the mandate, including definitions and methodology for case review.[135] The membership and staffing of the MMR committee is also a critical consideration. Generally, members should be diverse, multi-disciplinary, and include medical experts in maternity care, pathology, and specialty disciplines.[136] Additionally, non-medical members such as representatives from community-based organizations can bring an analysis of social determinants and help illuminate circumstances that drive poor maternal health outcomes.
- **Provide legal protections that enable the review process to function.** States can provide committee members and others involved in maternal death inquiries with certain legal protections that help the review mechanism to function effectively. These include: (1) legislation to ensure visibility and stability, clearly defined duties, and – optimally – a dedicated budget;[137] (2) confidentiality of case investigations to protect the privacy of the women who die and their families; (3) immunity from disciplinary action; and (4) access to medical records, in conformity with Health Insurance Portability and Accountability Act (HIPAA) privacy regulations.[138]
- **Ensure adequate funding and support for the review process**. In order to plan and organize review activities, the committee will need coordination and administrative support, ideally from state health agencies.[139] Dedicated funding can help ensure that important preliminary steps are completed, and that MMR committees are properly prepared to conduct a structured, efficient discussion of the available facts. For example, states can hire or fund a case abstractor to synthesize information from whatever data sets are available, flag cases for review, and deliver data to the committee in the form of detailed case summaries.[140]

C. Implement maternal health solutions based on the results of maternal health data and maternal mortality review processes

Data and insights that emerge from the maternal mortality review process must be used to inform state policies and practices. Maternal health advocates can explore opportunities in their state to create spaces and mechanisms for sharing results and best practices, and for translating findings into successful interventions.

Recommendations for state health departments:

- **Aggregate and share findings from the review process** with policymakers and other stakeholders that can take action to improve maternal health. To better understand opportunities for intervention, results can be categorized according to the type of contributing factor, demographic information (race, ethnicity, age, insurance status), location within the state, and comorbidities.[141] Depending on how many pregnancy-related deaths occur each year, states must determine ways to aggregate and disaggregate this data while still ensuring the privacy of the women who died.

Tanay Harris, of MommyUp, shares ideas during the October 2017 Black Mamas Matter Alliance convening.

- **Share best practices** learned during the review process and via subsequent intervention programs with other state health departments. Southern states may find it especially helpful to hear about the successes and challenges of other states in their region. AMCHP's *MMR Web Portal* provides a mechanism for states to share ideas for improving review mechanisms and establishing innovative interventions.

Recommendations for policymakers:

- **Translate maternal health review findings into evidence-informed laws and policies.** So far, state responses include new legislation, universal health screenings, health system standards, health education materials, research, and new programs or services.[142] Advocates can help ensure that the results of maternal mortality review processes are used to implement solutions around both systemic issues and issues related to individual patients.
- **Monitor and evaluate interventions** to determine which ones are most successful at improving maternal health. Advocates can support the replication or "scaling up" of policies found to be successful.

"Gathering the information is only step one. We must also demand that this nation make the needless loss of women, especially black women, a priority that the community invests in together to eliminate."

—**DR. JOIA CREAR-PERRY,** FOUNDER OF NATIONAL BIRTH EQUITY COLLABORATIVE

- **Ensure funding for translation efforts.** Given the current lack of dedicated funding for the maternal mortality review process itself, there may be a need to develop additional sources of funding to implement committee recommendations.

Recommendations for advocates:

- **Engage affected communities.** Once funding is found, advocates can also look for opportunities to fund maternal health solutions that engage the participation and knowledge of affected communities and emphasize asset-based, resilience cultural models.

D. Ensure community participation in planning and budgeting

In order to create effective, sustainable, and democratically legitimate solutions to the problems that underlie maternal mortality and morbidity, solutions need to be devised through a transparent process and with the meaningful participation of those who are most affected.[143] States can develop maternal health action plans that implement best practices and draw from public health and human rights strategies.

Recommendations for policymakers:

- **Ensure community participation in maternal health assessments and improvements.** Create opportunities for inclusion and input from a wide net of potential stakeholders. Potential mechanisms include commissions to study and advise on maternal health, participatory research projects, town hall events, community education, and awareness-raising initiatives.
- **Facilitate coordination among government stakeholders** to implement state action plans on maternal health. Maternal health programs located in state health departments are important sources of expertise, leadership, and coordination.[144]
- **Ensure transparency and public participation in budget decisions.** Budgets reflect priorities**.** They say a lot about what and who is valued in a particular community. Public participation in policymaking must therefore include decisions about how collective resources will be allocated.
- **Allocate existing resources in new ways.** In addition to dedicated funding for maternal health projects, governments and institutions can allocate existing resources in new ways (by holding trainings, distributing information, directing funding to community-based organizations, etc.) and to new entities, such as organizations led by women of color, that can best articulate the needs of Black women and families.

Recommendations for advocates:

- **Ensure that community concerns are represented in the policymaking process by supporting voter protections and voter engagement efforts.** For example, advocates at Women Engaged in Georgia are empowering the leadership and civic participation of women and young people interested in health equity by providing training in grassroots organizing, fundraising, and civic engagement campaigns.
- **Formalize human rights based budgeting practices.** For example, advocates in Vermont supported statutory amendments that define the purpose of the state's budget in terms of human rights principles. The law now specifies that "the state budget should be designed to address the needs of the people of Vermont in a way that advances human dignity and equity" and that the "administration will develop a process for public participation in the development of budget goals, as well as general prioritization and evaluation of spending and revenue initiatives."[145]

E. Support accountability measures

In a decentralized health care system with many different actors, it can sometimes be difficult to determine who is responsible for maternal health problems, and where the entry points for change are located. However, even when health care is delegated to private actors, the government retains a responsibility to ensure that women's human rights are respected, protected, and fulfilled.

Ultimately, a national plan for improving maternal health is needed. A human rights based approach to maternal health requires that the federal government take responsibility for preventable maternal mortality and morbidity, and that it take steps to improve maternal health across all states in the country. Federal legislation would represent a positive step in that direction. Even so, state governments will always have a profound influence over the health of their residents, and maternal health is no exception.

Recommendations for policymakers:

- **Support federal legislation**. Federal measures, such as the Maternal Health Accountability Act of 2014 (H.R. 4216), could help states to address several key systemic challenges, including identification of maternal deaths, implementation of state review processes, research gaps, standardized protocols and data sharing on maternal mortality and morbidity, expanded access to evidence-based services, and the dissemination of best practices for maternal health.
- **Provide civil society members with information about state government efforts** to prevent maternal mortality and morbidity, and ensure safe and respectful maternal health care.
- **Ensure accountability for different maternal health actors at different levels**. This may include support for professional accountability (such as sanctions by professional associations or licensing bodies for incidents of negligence, abuse, and malpractice), institutional accountability (such as facility-level complaint processes and ethics committees), and accountability for health system failures or violations by private actors.

Recommendations for advocates:

- **Advocates may need to consider how proposed accountability mechanisms will impact care,** including any unintended consequences. (For example, some providers believe that fear of medical malpractice lawsuits contributes to overuse of cesarean deliveries and undermines quality care.)

TALKING POINTS FOR ADVOCATES

Marsha Jones, of the Afiya Center, shares her insights with other advocates at the 2017 Black Mamas Matter Alliance convening.

I. KEY TALKING POINTS

This section provides advocates with key talking points regarding U.S. challenges with maternal mortality and morbidity and the human right to safe and respectful maternal health care. These points are offered as suggestions, and more research is needed to determine the most effective communication strategies and framing for improving maternal health. Advocates are further encouraged to develop and use messages that reflect their own goals, strategies, and advocacy environments.

Our Values:

Black Mamas Matter. All women have the right to safe and respectful maternal health care that supports healthy pregnancies and births. Before, during, and after pregnancy, every woman needs access to quality health services and information, and the social and economic resources that will help her be as healthy as she can.

The Problem:

In the U.S., too many women are suffering from pregnancy complications that lead to serious injury and death. The U.S. currently ranks lower than all other developed countries when it comes to maternal death ratios. Some women are more at risk than others. Black women are 3 - 4 times more likely to die from pregnancy-related causes than White women, and women in Southern states have a higher risk of pregnancy-related death than women in most other parts of the country.

The Solution:

Many of these deaths and illnesses are preventable. The U.S. could avoid about 40% of maternal deaths if all women—regardless of age, race, and zip code—had access to quality health care. In addition to improving health care access and quality, government actors need to address the root causes of Black maternal mortality and morbidity—including socioeconomic inequalities and racial discrimination in the health care system and beyond.

Every level of government has a duty to advance policies that promote safe and respectful maternal health care. Ensuring safe pregnancies and births for all women in the U.S. will require sustained political will and long-term investments in the health and well-being of Black women and girls especially. There are a number of steps that states can take immediately to improve maternal health outcomes.

Articulate a vision:

- Safe and respectful maternal health care is a recognized human right throughout the U.S., and state governments adopt a human-rights based approach to ensuring safe pregnancy and childbirth.
- Black women lead a movement to improve maternal health, and are valued decision-makers in health care spaces.
- Black women's health and survival are prioritized by all levels and branches of government.
- Women and girls receive safe, respectful, affordable, quality health care where they live, throughout the course of their lives.
- Black women have full access to culturally competent, community-based models of care.
- Black women in the South survive and thrive before, during, and after pregnancies.

Articulate the problem:

- **Black women's lives and families are at stake.** Black women in the U.S. suffer from life-threatening pregnancy complications twice as often as White women, and they die from pregnancy-related complications four times as often as White women. When mothers die, it breaks apart families and can lead to negative health consequences for their children.
- **Preventable maternal mortality is a human rights crisis in the United States.** The U.S. is one of only 13 countries in the world where pregnancy-related deaths are on the rise. Women in the U.S. are more likely to die from pregnancy complications than women in 45 other countries, including the United Kingdom, Libya, and Kazakhstan.
- **Poor maternal health outcomes are getting worse.** Both the likelihood of experiencing a severe pregnancy complication and dying from it are on the rise in the United States. Although the U.S. spends more on health care per capita than any other country, maternal health outcomes are deteriorating overall and racial disparities are as wide as they were in the 1930's.
- **The risk of dying from a pregnancy complication should not depend on one's race or zip code.** But the reality is that women in the South are at much higher risk than women in other areas of the country. A Black woman in Mississippi is almost twice as likely to die as a White woman in Mississippi or a Black woman in California.
- **Maternal mortality affects Black women of all socio-economic backgrounds.** Racial disparities in pregnancy-related deaths show that across all income and education levels, Black women in the U.S. are at higher risk for poor outcomes than White women.

"The toolkit allows us to take our power back as birthing women. What happens in birth becomes apart of our life forever. We use this toolkit to demand humane treatment but also to inform ourselves. Having a baby is sometimes seen as something we don't have control over. We actually have power and choice in birth. The Black Mama Matter Toolkit gives us the language we need to speak up for ourselves."

—**KETURAH ALBRIGHT,** BI DOULA PROGRAM MANAGER HEALTHY START @ SYRACUSE COMMUNITY CONNECTIONS

- **To tackle the problem of maternal mortality, we need to address racial discrimination and structural racism.** Poor maternal health outcomes expose inequalities in U.S. society that go beyond the health system. Improving those outcomes will require more equitable access to health care and the social determinants of health.

Articulate solutions:

To improve U.S. maternal health outcomes we must prioritize Black women's health and lives and commit to taking meaningful action. **Every state must take steps to ensure safe and respectful maternal care for all women**.

At a minimum, these steps include policy measures that address the following areas:

- **Respect:** States must trust Black women with the decisions and resources that empower them and their families. Health care providers and systems must approach every woman with respect and compassion, build her capacity to engage in informed health care decision-making, and honor her autonomy to make decisions about her body and care.
- **Education:** States must ensure that women are equipped with the knowledge, tools, and power to determine if and when they want to become pregnant and have a child. At a minimum, this requires: comprehensive, evidence-based information about sexual, reproductive, and maternal health.
- **Access:** Every woman must have access to health care before, during, and after childbirth. States must ensure health coverage for low-income women before they get pregnant, promote continuity of care and insurance coverage as women's life circumstances change, address barriers to prenatal and postpartum care, and reach women in the communities where they live.
- **Prevention:** Every state must take action to address and prevent risk factors for poor maternal health outcomes such as obesity, chronic conditions like heart disease and diabetes, and underlying determinants of health. Policymakers influence the structural conditions in which women live, work, and grow, and in turn, these conditions influence maternal health.
- **Quality:** States must ensure that every pregnant woman has access to facilities, health care providers, and support persons that are capable of safely and respectfully managing chronic conditions, identifying, monitoring, and appropriately addressing obstetric emergencies, and providing unbiased care.
- **Equity:** To prevent pregnancy-related deaths and sustainably improve maternal health, states must make transformative investments in the health and well-being of Black women and girls throughout the life course, including in the areas of housing, nutrition, transportation, violence, environmental health, and economic justice.
- **Data:** Every state must have a process in place to collect and disaggregate data about maternal health in a timely manner. Data collection should include both quantitative and qualitative methods, including community-based participatory data, in order to understand the impact of race and socio-economic inequality on Black women's health.
- **Accountability:** States must create systems to design and implement recommendations, and hold institutions accountable when they fail women. These include independent and fully funded maternal mortality review boards, supportive maternal health programs that implement review findings, and attention to social determinants of health.

RESOURCES ON MATERNAL HEALTH IN THE UNITED STATES

Kay Matthews, of Shades of Blue Project, plans for a year of collaboration with members of the Black Mamas Matter Alliance.

I. PUBLIC HEALTH RESEARCH AND INITIATIVES

Alliance for Innovation on Maternal Health (AIM): works to reduce maternal morbidity and mortality through a national partnership of organizations; aligns national, state, and hospital level efforts to improve maternal safety; develops safety bundles to promote consistency in maternal care.

Association of Maternal & Child Health Programs (AMCHP): provides resources aimed at improving the health of women, children, youth, and families, including technical assistance, best practices, and convening opportunities; serves as a partner and advocate for state public health leaders and other maternal and child health stakeholders who make up its membership. AMCHP has taken the lead on developing and sharing resources about state-level maternal mortality review processes, providing: a maternal health resource guide (*Health for Every Mother*); assistance to select states in building capacity around data collection, case review, and translation of findings (the Every Mother Initiative); and a web-based *MMR Resource Portal* for sharing tools and examples with and among states.

Every Woman Southeast: connects a coalition of partners across nine southern states focused on improving women's health and health equity over the life course; provides resources and training; conducts research; builds leadership across the Southeast; and emphasizes women's participation in health policy decisions.

Health and Medicine Division (HMD) of the National Academies of Sciences: (formerly the Institute of Medicine, or IOM) provides independent, objective analysis and evidence to help government and private actors make informed policy decisions related to health; operates under congressional charter and serves in an advisory role by providing studies at the request of federal agencies, independent agencies, and Congress; produces reports on racial and ethnic disparities in health and health care, and women's health.

The Kaiser Family Foundation: provides information on key health policy issues, including Medicaid, disparities, and women's health; maintains interactive state profiles with facts on women's health.

Maternal Health Taskforce (MHTF) of the Harvard School of Public Health: provides a database of resources covering all aspects of maternal health in order to help eliminate preventable maternal mortality and morbidity; compiles research and information from news, journals, and global health and development sources to facilitate a well-informed, integrated maternal health community with equitable access to high-quality technical evidence.

Merck for Mothers: provides $500 million over 10 years to reduce preventable maternal mortality worldwide; applies Merck's scientific and business expertise, as well as financial resources, to solutions focused on improving the quality of maternal care that women receive at facilities; includes support for programs that work to address maternal mortality in the United States.

World Health Organization (WHO): serves as the public health arm of the UN, directing and coordinating international health within the UN system; provides leadership on matters critical to health; shapes the global health research agenda; sets norms and standards and monitors their implementation; articulates ethical, evidence-based policy options; provides technical support; offers authoritative guidance on maternal health in the course of standard activities such as promoting health, monitoring disease outbreaks, and assessing the performance and preparedness of health systems around the world; publishes key reports and roadmaps including *Strategies Toward Ending Preventable Maternal Mortality (EPMM), Trends in Maternal Mortality: 1990-2015*, and the *Global Strategy for Women's, Children's and Adolescent's Health 2016-2030.*

II. PROVIDERS AND PROFESSIONAL ORGANIZATIONS

American College of Nurse Midwives (ACNM): provides advocacy, research analysis, and education related to pregnancy, childbirth, and reproductive health; serves as a professional association representing certified nurse midwives (CNMs) and certified midwives (CMs).

American College of Obstetrics and Gynecologists (ACOG): provides education, advocacy, and research related to women's health care (including state and federal legislative advocacy around reproductive health and access, and improving pregnancy outcomes); serves as a membership organization for obstetricians and gynecologists.

Association of Women's Health, Obstetric and Neonatal Nurses (AWHONN): promotes the health of women and newborns; serves as a resource for nurses and health care professionals; provides advocacy, research, and education.

Association of State and Territorial Health Officials (ASTHO): represents the leaders of state and territorial health agencies; formulates and influences public health policy to improve state-based public health practice; provides policy and position statements on various topics, including maternal mortality and morbidity.

Commonsense Childbirth: provides midwifery services in Florida using an approach to maternal child health care developed by founder and midwife Jennie Joseph (called *The JJ Way)*; provides perinatal training and certification programs to address maternal health provider workforce shortages and increase provider diversity; provides an empowering model of care that has successfully reduced racial disparities and poor outcomes while expanding access to safe and respectful maternal health care.

Feminist Women's Health Center: provides reproductive health services, community education, and policy advocacy in Atlanta, GA; sustains a state legislative agenda focused on public policies that enable a full range of reproductive health rights and options for all; offers an online advocacy toolkit to help advocates in Georgia engage with their lawmakers.

International Center for Traditional Childbearing: provides midwife and doula training to increase the number of Black maternal health providers in order to empower families and eliminate infant and maternal mortality.

National Association of Certified Professional Midwives (NACPM): represents the interests of certified midwives in coalitions and policy advocacy to improve maternal health outcomes; works to eliminate racial disparities in maternal health by supporting anti-racism in midwifery care, the leadership of midwives of color, and broader access to CPMs.

National Healthy Start Association: serves as the membership organization for federal Healthy Start programs; promotes the development of community-based maternal and child health programs and access to a continuum of affordable quality health care and related services to improve birth outcomes and reduce racial health disparities; emphasizes newborn health but also includes support for mothers and families.

Society for Maternal Fetal Medicine: provides a forum for physicians and scientists with additional training in high-risk, complicated pregnancies to share knowledge, resources, and best practices in order to improve pregnancy and perinatal outcomes; advocates for health policies and systems of care that support people with high-risk pregnancies.

III. ADVOCACY

Access Reproductive Care (ARC)—Southeast: provides funding and public advocacy to help individuals and families in the South navigate pathways toward safe, compassionate, and affordable reproductive health care access.

Amnesty International: investigates and exposes human rights abuses as the world's largest grassroots human rights organization; published a 2010 report on U.S. maternal health problems titled *Deadly Delivery: The Maternal Health Care Crisis in the USA.*

Center for Reproductive Rights: uses the law to advance reproductive freedom as a fundamental human right; provides technical assistance to state-based partners on reproductive health law, policy and human rights advocacy strategies, including those related to maternal health in the South.

Childbirth Connection: engages consumers to improve the quality and value of maternal health care; advocates for evidence-based, high quality care, shared decision-making, and improved health outcomes; maintains a directory of maternal and perinatal care quality collaboratives; publishes reports and surveys including the *Transforming Maternity Care* project, which lays out a vision and action plan for improving maternity care in the United States.

Choices in Childbirth: provides expectant parents with information and education so they can experience the birth they want and choose; conducts education and advocacy activities to expand families' choices about where, how, and with whom to birth.

National Birth Equity Collaborative: engages in research, advocacy, and family centered collaboration to reduce African American infant mortality; mobilizes health and civil rights organizations; and targets ten U.S. cities with the highest Black infant mortality rates and provides support to local leaders through the Campaign for Black Babies.

National Healthy Mothers, Healthy Babies Coalition (HMHB): creates partnerships among community groups, nonprofits, professional associations, businesses, and government agencies to improve the health and safety of mothers, babies, and families; provides educational materials and opportunities for collaboration (including state and local HMHB coalitions) and influences maternal health policy.

National Perinatal Taskforce: creates a network of support to improve maternal health outcomes by building a virtual community of people and encouraging the growth of grassroots movement building and the formation of Perinatal Safe Spots—physical or virtual spaces where individual communities can share ideas about what's working and what's not.

National Women's Law Center (NWLC): champions laws and policies that promote equality and opportunity for women and families; provides resources and advocacy on pregnancy and health issues, including resources on women's health care coverage; publishes state-by-state reports that track key state laws and policies affecting women; maintains a national and state-by-state report card on women's health, which includes maternal mortality and prenatal care indicators.

National Health Law Program (NHeLP): advocates, educates, and litigates for the health rights of low-income and underserved people at the federal and state levels; works on policy topics including Medicaid, reproductive health, and health disparities; publishes information and reports.

March of Dimes: in addition to its primary work on preventing infant morbidity and mortality, provides funding for local programs that address racial disparities in birth outcomes; produces resource materials and a data book for policymakers that includes information about maternal health; provides access to maternal and infant health data by state and region through a tool called *PeriStats.*

Robert Wood Johnson Foundation: provides funding for projects that aim to improve U.S. health and health care; provides information and resources about various health topics (such as social determinants and health disparities); offers the County Health Rankings report, which compares counties across the country on a broad range of health related measures, and identifies health gaps in each state.

IV. FEDERAL GOVERNMENT

Centers for Disease Control and Prevention (CDC): conducts scientific research, monitors U.S. health, and provides health information while acting as the national agency responsible for health protection; tracks diseases and analyzes data related to U.S. maternal mortality and morbidity; uses science and technology to prevent disease; provides resources, training, and guidance to the public health workforce. States can use the Maternal Mortality Review Data System (MMRDS) developed by the CDC to help them collect and abstract data, develop case summaries, conduct analysis, and document committee findings and recommendations.

Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB): partners with key stakeholders to improve the physical and mental health, safety, and well-being of the nation's women, children, and families; funds programs, research and other efforts to address the needs of these groups across the lifespan; provides funds to states and jurisdictions through the Title V Maternal and Child Health Block Grant, as well as discretionary grants; focuses on health disparities, health equity, and social causes of health outcomes.

Healthy People 2020: provides science-based, ten-year national objectives for improving U.S. population health (at national, state, and local levels) as part of a national health promotion and disease prevention agenda; includes goals aimed at improving health equity and addressing social determinants of health; includes maternal health indicators and benchmarks related to maternal mortality and morbidity, access to maternal health services, and pregnancy and postpartum care; provides recommendations on maternal health interventions and other tools and resources.

National Institutes of Health (NIH): serves as the nation's medical research agency, and the largest funder of biomedical research in the world; funds projects aimed at enhancing health and life expectancy and reducing illness and disability in the United States, including projects related to maternal health; drives discovery and translation of new health ideas.

Office of Minority Health, U.S. Department of Health and Human Services: works to improve the health of racial and ethnic minority populations through the development of health policies and programs that help eliminate health disparities; maintains the OMH Resource Center, which provides access to literature and information on the health status of racial and ethnic minority populations.

Black Mamas Matter Alliance steering committee members and Dr. Monica McLemore celebrate after presenting to a packed room at the 2018 AMCHP (Association of Maternal and Child Health Programs) conference.

V. STATE GOVERNMENTS

California Maternal Quality Care Collaborative: brings stakeholders from multiple sectors together to with a mission to end preventable maternal morbidity, mortality, and racial disparities in maternity care in California; provides resources and support for improvements in quality care and data collection; may serve as a leading example for quality care collaboratives in other states.

NYC Department of Health and Mental Hygiene: protects and promotes the health of all New Yorkers; as one of the nation's oldest public health agencies and one of the world's largest, is often recognized as a leader in the field of public health; conducted enhanced surveillance of maternal mortality from 2001-2010 before the New York State Department of Health took over review of maternal deaths (reports available at http://www.nyc.gov/html/doh/downloads/pdf/ms/ms-report-online.pdf and http://www1.nyc.gov/assets/doh/downloads/pdf/ms/pregnancy-associated-mortality-report.pdf); conducted the first citywide surveillance of severe maternal morbidity and expects to release its report in Spring 2016.

VI. REPRODUCTIVE JUSTICE

Echoing Ida: develops and promotes the thought leadership of Black women change-makers in media spaces; sustains a growing network of writers, editors, media professionals, organizers, and policy advocates; provides analysis on issues impacting Black women and their diverse communities, including maternal health; features the work of maternal health leaders.

Black Women's Health Imperative: works to improve the health and wellness of Black women and girls—physically, emotionally and financially; identifies the most pressing health issues and invests in the best strategies, partners, and organizations working to ensure that Black women live longer, healthier, more prosperous lives; addresses a range of reproductive health and justice issues.

In Our Own Voice: National Black Women's Reproductive Justice Agenda: amplifies the voices of Black women at national and regional levels to secure reproductive justice; focuses on abortion rights and access, contraceptive equity, and comprehensive sex education; represents a partnership between the following five reproductive justice organizations: Black Women for Wellness, Black Women's Health Imperative, New Voices Pittsburgh, SisterLove, and SPARK Reproductive Justice Now.

Mothering Justice: empowers mothers in Michigan to organize and influence policies that will affect them and their families; focuses primarily on engaging mothers as leaders, advocates, and voters on issues of economic security; advocates for maternal health and rights.

National Advocates for Pregnant Women: challenges punitive reproductive health and drug policies through the courts and provides litigation support in cases across the country; engages in policy advocacy to protect the rights of pregnant and parenting women, particularly low-income women and women of color; engages in organizing and public education.

Religious Coalition for Reproductive Choice (RCRC): brings religious people who believe in reproductive justice together to advocate for public policies that improve access to reproductive health services and eliminate disparities in these areas; provides tools for faith leaders and activists.

SisterReach: empowers, organizes, and mobilizes women and girls in Tennessee around their reproductive and sexual health, encouraging them to become advocates for themselves; supports women and girls to lead healthy lives, have healthy families, and live in healthy communities by offering comprehensive education about their sexual and reproductive health; engages with education, policy, and advocacy on behalf of women and girls.

SisterSong Women of Color Reproductive Justice Collective: serves as a Southern-based, national membership organization for reproductive justice advocates; works to strengthen the collective voices of indigenous women and women of color to achieve reproductive justice by eradicating reproductive oppression and securing human rights; mobilizes women of color around lived experiences and works to improve institutional policies and systems that impact the reproductive lives of marginalized communities; provides training in reproductive justice and provides a platform for movement members to work collaboratively toward shared policy goals, including advocacy on maternal health.

SPARK Reproductive Justice Now: builds new leadership, knowledge, and culture change in Georgia and the South to ensure individuals and communities have resources and power to make sustainable and liberatory decisions about their bodies, gender, sexualities, and lives; centers Black women, women of color, and queer/trans youth of color; focuses on civic engagement and policy advocacy around reproductive justice issues.

Endnotes - Advancing Maternal Health as a Human Rights Issue

[1] World Health Organization (WHO) et al., Trends in Maternal Mortality: 1990 to 2015 70-77 (2015) [hereinafter Trends in Maternal Mortality], http://apps.who.int/iris/bitstream/10665/194254/1/9789241565141_eng.pdf?ua=1.

[2] *Id.* The maternal mortality ratio (MMR) is a comparison of two numbers that provide information about the prevalence of maternal deaths in a given population. More specifically, it is defined as the number of maternal deaths during a given time period per 100,000 live births during the same time period. Some people use "ratio" and "rate" interchangeably to describe this relationship. However, the World Health Organization refers to it only as the maternal mortality ratio (MMR), distinguishing it from the MMRate which they define as the number of maternal deaths divided by person-years lived by women of reproductive age. *See* Trends in Maternal Mortality, 36.

[3] United Nations, The Millennium Development Goals Report 4, 6 (2015).

[4] *Goal 5: Improve Maternal Health,* United Nations, http://www.un.org/millenniumgoals/maternal.shtml (last visited Mar. 29, 2016).

[5] Trends in Maternal Mortality, *supra* note 1, at 76.

[6] Gopal Singh, U.S. Dep't of Health & Human Services, Health Resources & Services Administration, Maternal & Child Health Bureau, Maternal Mortality in the United States, 1935-2007: Substantial Racial/Ethnic, Socioeconomic, and Geographic Disparities Persist 2 (2010), http://www.hrsa.gov/ourstories/mchb75th/mchb75maternalmortality.pdf.

[7] Office of the United Nations High Commissioner for Human Rights et al., Summary Reflection Guide on a Human Rights-Based Approach to Health: Application to Sexual and Reproductive Health, Maternal Health, and Under-5 Child Health 3 (2015), *available at* http://www.ohchr.org/Documents/Issues/Women/WRGS/Health/RGuide_NHRInsts.pdf.

[8] *Adapted from* Human Rights Council, *Rep. of the Office of the United Nations High Commissioner for Human Rights on Preventable Maternal Mortality and Morbidity and Human Rights* (14th Sess., 2010), para. 12, U.N. Doc. A/HRC/14/39 (2010).

[9] *See, e.g.,* CERD Committee, *Concluding Observations: United States of America*, para. 15, U.N. Doc. CERD/C/USA/CO/7-9 (Sept. 25, 2014); Human Rights Committee, *Concluding Observations: Mali*, para. 14, U.N. Doc. CCPR/CO/77/MLI (2003); *Mongolia*, para. 8(b), U.N. Doc. CCPR/C/79/Add.120 (2000); *Peru*, para. 20, U.N. Doc. CCPR/CO/70/PER (2000); *Trinidad and Tobago*, para. 18, U.N. Doc. CCPR/CO/70/TTO (2000); Alyne v. Brazil, CEDAW Committee, Commc'n No. 17/2008, paras. 7.5-7.6, U.N. Doc. CEDAW/C/49/D/17/2008 (2011); CEDAW Committee, *Concluding Comments: Belize*, para. 56, U.N. Doc. A/54/38/Rev.1 (1999); ESCR Committee, *Concluding Observations: Brazil*, paras. 28-29, U.N. Doc. E/C.12/BRA/CO/2 (2009); *Dominican Republic*, para. 15, U.N. Doc. E/C.12/1/Add.16 (1997); CAT Committee, *Concluding Observations: Paraguay*, para. 22, U.N. Doc. CAT/C/PRY/CO/4-6 (2011); *Peru*, para. 15, U.N. Doc. CAT/C/PER/CO/5-6 (2013). *See also* Human Rights Council, *Rep. on Technical Guidance on the Application of a Human Rights-Based Approach to the Implementation of Policies and Programmes to Reduce Preventable Maternal Mortality and Morbidity* (20th Sess., 2012), para. 8, U.N. Doc. A/HRC/21/22 (2012) [hereinafter Human Rights Council, *Technical Guidance*].

[10] Committee on Economic, Social and Cultural Rights, *General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12)* (22nd Sess., 2000), *in* Compilation of General Comments and General Recommendations Adopted by Human Rights Treaty Bodies, at 81, 83, 86-87, and 89, paras. 14, 21, 22, 36 and 44(a), U.N. Doc. HRI/GEN/1/Rev.9 (Vol. I) (2008) [hereinafter ESCR Committee*, Gen. Comment No. 14*].

[11] *Id.* at 81 and 83, paras. 14 and 21.

[12] Universal Declaration of Human Rights, *adopted* Dec. 10, 1984, art. 3, G.A. Res. 217A (III), U.N. Doc. A/810 at 71 (1948); International Covenant on Civil and Political Rights, *adopted* Dec. 16, 1966, art. 6, G.A. Res. 2200A (XXI), U.N. GAOR, 21st Sess., Supp. No. 16, U.N. Doc. A/6316 (1966), 999 U.N.T.S. 171 (*entered into force* Mar. 23, 1976); Convention on the Rights of the Child, *adopted* Nov. 20, 1989, art. 6, G.A. Res. 44/25, Annex, U.N. GAOR, 44th Sess., Supp. No. 49, U.N. Doc. A/44/49 (1989) (*entered into force* Sept. 2, 1990); Convention on the Rights of Persons with Disabilities, *adopted* Dec. 13, 2006, art. 10, G.A. Res. A/RES/61/106, U.N. GAOR, 61st Sess., U.N. Doc. A/61/611 (*entered into force* May 3, 2008).

[13] Human Rights Committee, *General Comment No. 6: Right to Life (Art. 6)* (16th Sess., 1982), *in* Compilation of General Comments and General Recommendations Adopted by Human Rights Treaty Bodies, at 176, para. 1, U.N. Doc. HRI/GEN/1/Rev.9 (Vol. I) (2008) [hereinafter Human Rights Committee, *Gen. Comment No. 6*].

[14] *Id.* at 177, para. 5.

[15] Human Rights Committee, *General Comment No. 28: Article 3 (The Equality of Rights between Men and Women)* (68th Sess., 2000), *in* Compilation of General Comments and General Recommendations Adopted by Human Rights Treaty Bodies, at 229, para. 10, U.N. Doc. HRI/GEN/1/Rev.9 (Vol. I) (2008) [hereinafter Human Rights Committee, *Gen. Comment No. 28*].

[16] Human Rights Committee, *Gen. Comment No. 6*, *supra* note 13, at 177, para. 5; Human Rights Committee, *Gen. Comment No. 28, supra* note 15, at 229, para. 10; *see also* Special Rapporteur on Violence against Women, Its Causes and Consequences, *Rep. of the Special Rapporteur on Violence against Women, Its Causes and Consequences, Ms. Radhika Coomaraswamy, in Accordance with Commission on Human Rights Resolution 1997/44 – Addendum – Policies and Practices that Impact Women's Reproductive Rights and Contribute to, Cause or Constitute Violence against Women*, para. 66, U.N. Doc. E/CN.4/1999/68/Add.4 (Jan. 21, 1999) (noting "[g]overnment failure to take positive measures to ensure access to appropriate health-care services that enable women to safely deliver their infants as well as to safely abort unwanted pregnancies may constitute a violation of a woman's right to life…").

[17] ESCR Committee, *Gen. Comment No. 14*, *supra* note 10, at 80, para. 12.

[18] Alyne v. Brazil, CEDAW Committee, Commc'n No. 17/2008, para 7.5, U.N. Doc. CEDAW/C/49/D/17/2008 (2011).

[19] ESCR Committee, *Gen. Comment No. 14*, *supra* note 10, at 80 and 82, paras. 12(b) and 19.

[20] Human Rights Committee, *General Comment 18: Non-Discrimination* (37th Sess., 1989), *in* Compilation of General Comments and General Recommendations Adopted by Human Rights Treaty Bodies, at 27-28, paras. 6-12, U.N. Doc. HRI/GEN/1/Rev.1 (1994).

[21] Human Rights Council, *Technical Guidance*, *supra* note 9, at para. 12.

[22] ESCR Committee, *Gen. Comment No. 14*, *supra* note 10, at 80, para. 12.

[23] Convention on the Elimination of All Forms of Racial Discrimination, *adopted* Dec. 21, 1965, art 5(e)(iv), G.A. Res. 2106 (XX), Annex,

20 U.N. GAOR Supp. No. 14 at 47, U.N. Doc. A/6014 (1966), 660 U.N.T.S. 195 (*entered into force* Jan. 4, 1969); CERD Committee, *Concluding Observations: United States of America*, para. 15, U.N. Doc. CERD/C/USA/CO/7-9 (Sept. 25, 2014).

[24] CERD Committee, *Concluding Observations: United States of America*, para. 15, U.N. Doc. CERD/C/USA/CO/7-9 (Sept. 25, 2014).

[25] Human Rights Committee, *Rep. of the Working Group on the Universal Periodic Review: United States*, para. 176.316, U.N. Doc. A/HRC/30/12 (July 20, 2015).

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[29] *See* Human Rights Council, *Technical Guidance*, *supra* note 9.

[30] Adapted from the following sources: National Economic and Social Rights Initiative (NESRI), *What are the Basic Principles of the Human Rights Framework?*, http://www.nesri.org/programs/what-are-the-basic-principles-of-the-human-rights-framework; Human Rights Council, *Technical Guidance*, *supra* note 9; CHANGE, *supra* note 28.

[31] Human Rights Council, *Technical Guidance*, *supra* note 9, at para. 9

[32] NESRI, *supra* note 30.

[33] CHANGE, *supra* note 28, at 22.

[34] Human Rights Council, *Technical Guidance*, *supra* note 9.

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[36] Asian Communities for Reproductive Justice, *supra* note 35.

[37] Loretta Ross, “What is Reproductive Justice?” *in* Reproductive Justice Briefing Book: A Primer on Reproductive Justice and Social Change, *available at* http://protectchoice.org/downloads/Reproductive%20Justice%20Briefing%20Book.pdf.

[38] *E.g.* Ross, *Understanding Reproductive Justice*, *supra* note 35; Asian Communities for Reproductive Justice, *supra* note 35.

[39] *See e.g.* Ross, *Understanding Reproductive Justice*, *supra* note 35; Center for Reproductive Rights et al., *Reproductive Injustice: Racial and Gender Discrimination in U.S. Health Care (A Shadow Report for the UN Committee on the Elimination of Racial Discrimination)* (2014), http://www.reproductiverights.org/sites/crr.civicactions.net/files/documents/CERD_Shadow_US.pdf; *Trust Black Women Statement of Solidarity with Black Lives Matter*, Trust Black Women, http://trustblackwomen.org/solidarity-with-black-lives-matter.

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Endnotes - Research Overview of Maternal Mortality and Morbidity in the United States

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[4] *The WHO Near-Miss Approach*, WHO, http://www.who.int/reproductivehealth/topics/maternal_perinatal/nmconcept/en/ (last visited Apr. 1, 2016).

[5] William M. Callaghan et al., *Severe Maternal Morbidity among Delivery and Postpartum Hospitalizations in the United States*, 120 Obstet. Gynecol. 1029, 1034 (2012) [hereinafter Callaghan et al., *Severe Maternal Morbidity among Hospitalizations*].

[6] WHO, Trends in Maternal Mortality: 1990 to 2015 70-77 (2015), http://apps.who.int/iris/bitstream/10665/194254/1/9789241565141_eng.pdf [hereinafter Trends in Maternal Mortality].

[7] *Id.* In addition to the 169 countries that have reduced their MMR, one (Canada) has held constant, neither reducing nor increasing its rate.

[8] *Id.*; *Reproductive Health: Pregnancy Mortality Surveillance System*, CDC, http://www.cdc.gov/reproductivehealth/MaternalInfantHealth/PMSS.html (last updated Jan. 21, 2016) [hereinafter *Pregnancy Mortality Surveillance System*].

[9] Trends in Maternal Mortality, *supra* note 6. *See also Pregnancy Mortality Surveillance System*, *supra* note 8 (showing that the CDC also tracks trends in maternal mortality and stating their estimate for the 2012 U.S. average pregnancy-related mortality ratio—the last year data is available—at 15.9 deaths per 100,000 live births, with the ratio for Black women at 41.1). Because there is no mandatory, centralized system for collecting and analyzing maternal mortality surveillance data in the U.S., estimates of the MMR can vary.

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[12] Elliott K. Main, *Maternal Mortality: New Strategies for Measurement and Prevention*, 22 Current Opinion in Obstet. Gynecol. 511, 511 (2010); *see also Pregnancy Mortality Surveillance System*, *supra* note 8.

[13] Callaghan et al., *Severe Maternal Morbidity among Hospitalizations*, *supra* note 5, at 1034. *See also* William M. Callaghan et al., *Identification of Severe Maternal Morbidity during Delivery Hospitalizations, United States, 1991-2003*, 199 Am. J. Obstet. Gynecol. 133.e1 (2008).

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[15] *Reproductive Health: Severe Maternal Morbidity in the United States*, CDC, http://www.cdc.gov/reproductivehealth/maternalinfanthealth/severematernalmorbidity.html (last visited Mar. 29, 2016).

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[22] *See, e.g.* New York City Dep't of Health & Mental Hygiene, Bureau of Maternal, Infant & Reprod. Health, Pregnancy-Associated Mortality: New York City, 2006-2010 9 (2015) [hereinafter Pregnancy-Associated Mortality: New York City], http://www.nyc.gov/html/doh/downloads/pdf/ms/pregnancy-associated-mortality-report.pdf (showing that in New York City, Black women are 12 times more likely than White women to die of pregnancy-related causes); Singh, *supra* note 21, at 5 (showing that during 2003-2007, the MMR in the District of Columbia was 41.6).

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[25] Trends in Maternal Mortality, *supra* note 6 (showing that in 2015, the MMRs for the occupied Palestinian territory, Mexico and Egypt were 45, 38, and 33 respectively).

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ciated Mortality at the End of the Twentieth Century: Massachusetts, 1990-1999, 57 J. Am. Med. Women's Assoc. 140, 140 (2002).

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[30] *Id.*

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[47] *Id.*

[48] *Id.*

[49] Algernon Austin, Center for Global Policy Solutions, Obamacare Reduces Racial Disparities in Health Coverage 6-7, (Dec. 2015), http://globalpolicysolutions.org/wp-content/uploads/2015/12/ACA-and-Racial-Disparities.pdf (last visited April 6, 2016).

[50] *Who is Impacted by the Coverage Gap in States that Have Not Adopted the Medicaid Expansion?*, Kaiser Family Foundation (KFF) [hereinafter *Who is Impacted?*], http://kff.org/slideshow/who-is-impacted-by-the-coverage-gap-in-states-that-have-not-adopted-the-medicaid-expansion/ (last updated Jan. 2016).

[51] *Id.*

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[53] *Who is Impacted?*, *supra* note 50.

[54] U.S. Dep't. of Health & Human Servs. (HHS), Agency for Healthcare Research and Quality, 2012 National Healthcare Disparities Report Chapter 9 (2013) [hereinafter 2012 National Healthcare Disparities Report], http://archive.ahrq.gov/research/findings/nhqrdr/nhdr12/chap9.html.

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[56] Usha Ranji et al., KFF, Women's Health Care Chartbook 32 (2011), https://kaiserfamilyfoundation.files.wordpress.com/2013/01/8164.pdf.

[57] Guttmacher Inst., Fact Sheet: Unintended Pregnancy in the United States (July 2015), http://www.guttmacher.org/pubs/FB-Unintended-Pregnancy-US.html [hereinafter Unintended Pregnancy in the United States]; Denise D'Angelo et al., *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*, MMWR Surveillance Summaries, CDC (Dec. 14, 2007), http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5610a1.htm.

[58] Unintended Pregnancy in the United States, *supra* note 57 (showing that rates of unintended pregnancy for women at or higher than 200% of the poverty line have been consistently declining for three decades; meanwhile the rate for women below 100% of the poverty line rose from 1981 to 2008, before declining in 2011, though still remaining higher than the 1981 rates).

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[60] 2012 National Healthcare Disparities Report, *supra* note 54.

[61] *Uninsured Rates for the Nonelderly by Race/Ethnicity, 2014*, KFF, http://kff.org/uninsured/state-indicator/rate-by-raceethnicity/#map (last accessed Feb. 19, 2016); Jessica Stephens et al., *Health Coverage and Care in the South in 2014 and Beyond,* The Kaiser Commission on Medicaid and the Uninsured: Issue Brief (KFF, Menlo Park, CA), updated June 2014, https://kaiserfamilyfoundation.files.wordpress.com/2014/04/8577-health-coverage-and-care-in-the-south-in-2014-and-beyond-june-2014-update.pdf.

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among pregnant Black women. *See* Howell et al., *supra* note 14, at 122.e3.

[63] *E.g.* HHS, Agency for Healthcare Research and Quality, Disparities in Healthcare Quality among Minority Women: Findings from the 2011 National Health care Quality and Disparities Reports 5 (2012), http://archive.ahrq.gov/research/findings/nhqrdr/nhqrdr11/minority-women.pdf (stating that 60.4% of Black women receive prenatal care in the first trimester, compared to 76.7% of non-Hispanic White women, 64.7% of Hispanic women, 76.5% of Asian/Pacific Islander women, and 55.1% of American Indian and Alaskan Native women); Nat'l Insts. of Health, Off. of Research on Women's Health, Women of Color Health Data Book 103 (4th ed. 2014), http://orwh.od.nih.gov/resources/policyreports/pdf/WoC-Databook-FINAL.pdf (stating that 12% of American Indian, Alaskan Native, and Black women receive prenatal care only in the third trimester or not at all, compared to 9% for Hispanic women and 5% for Asian/Pacific Islander and non-Hispanic White women).

[64] Coeytaux et al., *supra* note 36, at 190.

[65] HHS, Agency for Healthcare Research and Quality, 2013 National Healthcare Disparities Report 14 (2014), http://www.ahrq.gov/sites/default/files/wysiwyg/research/findings/nhqrdr/nhdr13/2013nhdr.pdf.

[66] Agrawal, *supra* note 20.

[67] *Id.*

[68] *See, e.g.* F. L. Lucas et al., *Race and Surgical Mortality in the United States*, 243 Annals of Surgery 281, 285 (2006) (showing that hospitals treating a large proportion of Black patients had higher mortality rates for a wide range of surgical procedures); Lenny López and Ashish K. Jha, *Outcomes for Whites and Blacks at Hospitals that Disproportionately Care for Black Medicare Beneficiaries*, 48 Health Services Research 114, 122-124 (2013) (showing that hospitals treating a large proportion of Black patients had higher mortality rates for heart attacks); Leo S. Morales et al., *Mortality among Very Low-Birthweight Infants in Hospitals Serving Minority Populations*, 95 Am. J. Pub. Health 2206, 2210-2211 (2005) (showing that hospitals treating a large proportion of Black patients had higher mortality rates for very low-birthweight infants); Andreea A. Creanga, *Performance of Racial and Ethnic Minority-Serving Hospitals on Delivery-Related Indicators*, 211 Am. J. Obstet. Gynecol. 647.e1, 647.e5-e7 (2014) (showing that Black-serving hospitals performed worse than White- or Hispanic-serving hospitals on 12 of 15 delivery-related indicators).

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[70] *Id.* at 122.e5.

[71] *Id.* at 122.e5-122.e6.

[72] *See, e.g.* Brian D. Smedley et al., Inst. of Medicine of the Nat'l Academies, Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care 162-174 (2003), *available at* http://www.nap.edu/catalog/10260/unequal-treatment-confronting-racial-and-ethnic-disparities-in-health-care (providing an overview of the "limited but growing" body of research about the ways that biased or prejudicial attitudes among health care providers can manifest in interactions with patients); Joshua H. Tamayo-Sarver et al., *Racial and Ethnic Disparities in Emergency Department Analgesic Prescription*, 93 Am. J. Public Health 2067, 2071 (2003) (showing that physicians have demonstrated a lower likelihood of prescribing opioids to Black patients for migraines and back pain); Janice A. Sabin and Anthony G. Greenwald, *The Influence of Implicit Bias on Treatment Recommendations for 4 Common Pediatric Conditions: Pain, Urinary Tract Infection, Attention Deficit Hyperactivity Disorder, and Asthma*, 102 Am. J. Public Health 988, 991 (2012) (showing that pediatricians' implicit attitudes and stereotypes about race affect their decisions about children's pain management, with their likelihood of prescribing narcotic pain medication to Black patients decreasing as their pro-White bias increased); Kevin A. Schulman et al., *The Effect of Race and Sex on Physicians' Recommendations for Cardiac Catheterization*, 340 N. Engl. J. Med. 618, 621-625 (1999) (showing that race and sex independently influence physicians' decisions about how to manage patients complaining of chest pain, with Black women being significantly less likely to be referred for cardiac catheterization than White men).

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[74] Somnath Saha et al., *Patient-Physician Racial Concordance and the Perceived Quality and Use of Health Care,* 159 Arch. Intern. Med. 997, 997-998 (1999) *available at* http://archinte.jamanetwork.com/article.aspx?articleid=485025 (stating that Black patients with Black physicians were more likely than those with non-Black physicians to report receiving preventative care and all needed medical care).

[75] *Id.* at 998, 1000-1002 (stating that Black patients with Black physicians were more likely than those with non-Black physicians to rate their physicians as excellent and that, of the variables used to measure patient satisfaction, the strongest association with racial concordance appeared in the higher ratings that Black patients gave to Black physicians for treating them with respect).

[76] Laura Castillo-Page, Association of American Medical Colleges, Diversity in the Physician Workforce: Facts & Figures 2006 10 (2006), http://www.rwjf.org/content/dam/farm/reports/charts/2006/rwjf12748 (stating that "race-concordant visits were longer, by about 2.2 minutes, and had higher ratings of positive patient affect").

[77] *Diversity in the Physician Workforce: Facts & Figures 2014 – Section II: Current Status of the U.S. Physician Workforce*, Association of American Medical Colleges (Dec. 3, 2014), http://aamcdiversityfactsandfigures.org/section-ii-current-status-of-us-physician-workforce/.

[78] *See, e.g.* Cheryl L. Giscombé & Marci Lobel, *Explaining Disproportionately High Rates of Adverse Birth Outcomes among African Americans: The Impact of Stress, Racism, and Related Factors in Pregnancy*, 131 Psychol. Bull. 662, 667-668 (2005) and Nancy Krieger, *Racial and Gender Discrimination: Risk Factors for High Blood Pressure?*, 30 Soc. Sci. Med. 1273, 1277-1278 (1990) (showing that racism acts as a form of chronic stress in the lives of Black American women); Nancy Krieger and Stephen Sidney, *Racial Discrimination and Blood Pressure: The CARDIA Study of Young Black and White Adults*, 86 Am. J. Pub. Health 1370, 1373-1376 (1996) (showing an association between racial discrimination and responses to unfair treatment and elevated blood pressure among Black adults); Robert L. Goldenberg et al., *Bacterial Colonization of the Vagina during Pregnancy in Four Ethnic Groups*, 174 Am. J. Obstet. Gynecol. 1618, 1619-1620 (1996) and Jennifer F. Culhane et al., *Maternal Stress is Associated with Bacterial Vaginosis in Human Pregnancy*, 5 Maternal and Child Health J. 127, 127, 129-132 (2001) and Aziz R. Samadi and Robert M. Mayberry, *Maternal Hypertension and Spontaneous Preterm Births among Black Women*, 91 Obstet. Gynecol. 899, 902 (1998) (showing that Black women have significantly higher rates during pregnancy of bacterial vaginosis, which is associated with chronic stress in pregnant women, and of hypertensive disorders); Hope Landrine and Elizabeth A. Klonoff, *Racial Segregation and Cigarette Smoking among Blacks: Findings at the Individual Level*, 5 J. Health Psychology 211, 217-218 (2000) and Irene Yen et al., *Racial Discrimination and Alcohol-Related Behavior in Urban Transit Operators: Findings from the San Francisco Muni Health and Safety Study*, 114 Pub. Health Reps. 448, 449, 454-455 (1999) (showing that segregation and racial discrimination are associated

with negative health effects and unhealthy coping behaviors).

[79] Amani Nuru-Jeter et al., *It's the Skin You're In: African-American Women Talk about their Experiences of Racism. An Exploratory Study to Develop Measures of Racism for Birth Outcome Studies*, 13 Matern. Child Health J. 29, 30 (2009).

[80] Fleda Mask Johnson et al., *Contextualized Stress, Global Stress, and Depression in Well-Educated, Pregnant, African-American Women*, 22 Women's Health Issues e329, e330 (2012).

[81] *Id.* at e329-e330.

[82] Arline T. Geronimus, *Black/White Differences in the Relationship of Maternal Age to Birthweight: a Population-Based Test of the Weathering Hypothesis*, 42 Soc. Sci. Med. 589, 591-592, 594-595 (1996).

[83] *Id.* at 594-596.

[84] *US Spends More on Health Care than Other High-Income Nations but Has Lower Life Expectancy, Worse Health*, The Commonwealth Fund (Oct. 8, 2015), http://www.commonwealthfund.org/publications/press-releases/2015/oct/us-spends-more-on-health-care-than-other-nations.

[85] Creanga et al., *Maternal Mortality and Morbidity*, *supra* note 14, at 6.

[86] *See* Marge Koblinsky et al., *Maternal Morbidity and Disability and Their Consequences: Neglected Agenda in Maternal Health*, 30 J. Health Population & Nutrition 124-130 (June 2012).

[87] *Pregnancy-Related Deaths*, *supra* note 1.

[88] Singh, *supra* note 21, at 2.

[89] Belle Taylor-McGhee, *'We Simply Don't Know' Why Black Moms Die More Often*, Women's eNews (Dec. 14, 2012), http://womensenews.org/2012/12/we-simply-dont-know-why-black-moms-die-more-often/.

Featured Quotations

Page 21: Cynthia Greenlee, *Why Don't More People Care About Black Maternal Deaths?*, Rewire (Oct. 25, 2013, 10:41 AM) (emphasis in original), https://rewire.news/article/2013/10/25/why-dont-more-people-care-about-black-maternal-deaths/.

Page 26: Elizabeth Dawes Gay, *In the U.S., Black Mothers Need More Than Health Care*, Maternal Health Task Force Blog (Nov. 11, 2015), https://www.mhtf.org/2015/11/11/in-the-u-s-black-mothers-need-more-than-health-care/.

SisterSong Story Circles took place in April and May of 2014, in Atlanta, Ga. and Jackson, Miss. All names for Story Circle participants are pseudonyms.

Endnotes - A State Policy Framework for the Right to Safe and Respectful Maternal Health Care

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[8] *Fact Sheet: Publicly Funded Family Planning Services in the United States*, Guttmacher Inst. (July 2015), http://www.guttmacher.org/pubs/fb_contraceptive_serv.html [hereinafter *Publicly Funded Family Planning Services*].

[9] *Id.*

[10] *Id.* (stating that four in ten women who receive care at clinics that specialize in contraception do not have other sources of health care).

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[12] Adam Sonfield & Rachel Benson Gold, Public Funding for Family Planning, Sterilization and Abortion Services, FY 1980–2010, Guttmacher Inst. (Mar. 2012), http://www.guttmacher.org/pubs/Public-Funding-FP-2010.pdf.

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[14] *Id.*

[15] Jennifer Frost et al., Contraceptive Needs and Services, 2013 Update, Guttmacher Inst. (July 2015), http://www.guttmacher.org/pubs/win/contraceptive-needs-2013.pdf.

[16] AMCHP, *Health for Every Mother*, *supra* note 5, at 70.

[17] *Publicly Funded Family Planning Services*, *supra* note 8.

[18] *Id.*

[19] In 2014, California fully removed these particular hurdles by passing the Contraceptive Coverage Equity Act. It requires that all FDA-approved contraceptive drugs, devices and products be covered without cost sharing and without extra approvals. S.B. 1053, 2014 Leg., Reg. Sess. (Cal. 2014), http://www.leginfo.ca.gov/pub/13-14/bill/sen/sb_1051-1100/sb_1053_bill_20140925_chaptered.pdf.

[20] United States Department of Labor, FAQs about Affordable Care Act Implementation (Part XXVI), May 11, 2015, http://www.dol.gov/ebsa/faqs/faq-aca26.html.

[21] *Id.*

[22] In Washington, advocates conducted a "secret shopper" survey to determine whether insurance companies selling health plans through their state's online marketplace were complying with the ACA's contraceptive coverage mandate. When they found that insurance companies were misinforming women about their right to expanded access to birth control, they released a report. As a result of these efforts, the WA State Insurance Commissioner began meeting with carriers to discuss the findings and improve compliance and information. Northwest Health Law Advocates & NARAL Pro-Choice Washington, *Contraceptive Coverage in Washington State's Qualified Health Plans* (Apr. 2015), http://www.nohla.org/infoAnalysis/advPolicy/ExSumNoHLA-NARALConCov.pdf; JoNel Aleccia, *Women Getting Bad Info on Birth-Control Coverage from ACA Insurers*, The Seattle Times (Apr. 16, 2015), http://www.seattletimes.com/seattle-news/health/women-seeking-birth-control-coverage-get-wrong-messages-from-insurers-survey-finds/.

[23] Diana Greene Foster et al., *Number of Oral Contraceptive Pill Packages Dispensed and Subsequent Unintended Pregnancies*, 117 Obstet. Gynecol. 3 (2011), http://journals.lww.com/greenjournal/Abstract/2011/03000/Number_of_Oral_Contraceptive_Pill_Packages.8.aspx.

[24] S.B. 5034, 2013 Leg., 2nd Spec. Sess. (Wash. 2013), http://apps.leg.wa.gov/documents/billdocs/2013-14/Pdf/Bills/Senate%20Passed%20Legislature/5034-S.PL.pdf.

[25] Bills introduced in Washington, California, and Oregon have included registered nurses, nurse practitioners, nurse-midwives, physician assistants, naturopathic physicians, and pharmacists.

[26] In Oregon and California, new laws allow women to get prescriptions for hormonal contraceptives (patch, pill, ring) directly from the pharmacist. To ensure patient safety, women must first fill out a self-screening checklist. If a woman has any risk factors that indicate hormonal contraception is not a good choice for her, she will be referred to a doctor or clinic.

[27] *See* Christine Dehlendorf et al., *supra* note 6; The Center's own work is consistent with those findings. In May 2014, the Center partnered with SisterSong Women of Color Reproductive Justice Collective to document stories from Black women in Mississippi and Georgia. The women who shared their experiences frequently cited a lack of information about sexuality and sexual health, and a lack of access to sexual and reproductive health care. When they were able to obtain such care, many of these women described it as poor quality and compromised by discrimination. The results of these conversations were included in a shadow report submitted to the UN Committee on the Elimination of Racial Discrimination in August 2014. *See* Center for Reproductive Rights (CRR) et al., *Reproductive Injustice: Racial and Gender Discrimination in U.S. Health Care (A Shadow Report for the UN Committee on the Elimination of Racial Discrimination)* (2014), http://www.reproductiverights.org/sites/crr.civicactions.net/files/documents/CERD_Shadow_US.pdf.

[28] *Sexual Risk Behaviors: HIV, STD, & Teen Pregnancy Prevention*, Centers for Disease Control and Prevention (CDC) (Feb. 16, 2016), http://www.cdc.gov/HealthyYouth/sexualbehaviors/ (last visited Apr. 1, 2016).

[29] *E.g. 2014 Sexually Transmitted Diseases Surveillance, STDs in Racial and Ethnic Minorities,* CDC (last updated Nov. 17, 2015), http://www.cdc.gov/std/stats14/minorities.htm (last visited Apr. 20, 2016); *Unintended Pregnancy Among Young People in the United States*, Advocates for Youth (citing Kathryn Kost & Stanley Henshaw,

U.S. Teenage Pregnancies, Births and Abortions, 2010: National and State Trends by Age, Race and Ethnicity, Guttmacher Inst. (May 2014)), http://www.advocatesforyouth.org/publications/1909-unintended-pregnancy-among-young-people-in-the-united-states.

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[31] *State Policies on Sex Education in Schools*, National Conference of State Legislatures (Feb. 2, 2016), http://www.ncsl.org/research/health/state-policies-on-sex-education-in-schools.aspx (last visited Apr. 1, 2016).

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[33] *State Policies on Sex Education in Schools*, National Conference of State Legislatures (Feb. 2, 2016), http://www.ncsl.org/research/health/state-policies-on-sex-education-in-schools.aspx (last visited Apr. 1, 2016) (demonstrating that definitions of "medically accurate" vary by state); Oregon, California, Washington, Vermont, and Colorado offer a range of legislative approaches to this issue. *See* CRR, *Moving in a New Direction: A Proactive State Policy Resource for Promoting Reproductive Health, Rights, and Justice* 32-33 [hereinafter CRR, *Moving in a New Direction*] (2015), http://www.reproductiverights.org/sites/crr.civicactions.net/files/documents/US-PAPS-Compendium-final-SM.pdf.

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[42] *See* H.R. 2264, 105th Cong. §§509-510 (1997).

[43] Haw. Admin. Rules § 17-1722.3-18(c)(3); Md. Code Regs. §§§ 09.02.04(G), 09.34.04(A)(5), 09.34.04(B)(2); N.Y. Soc. Serv. Law § 365-a(2); Wash. Rev. Code Ann. §9.02.160.

[44] Guttmacher Inst., *Restricting Insurance Coverage*, *supra* note 41.

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[55] *Id.* at 70.

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[77] Choices in Childbirth et al., *supra* note 73, at 6-7.

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[135] Duties of an MMR committee can include examining the medical and non-medical circumstances of women's deaths that occur during or around the time of pregnancy; identifying gaps in services and systems that should be improved to prevent future deaths; disseminating review results to health care practitioners and facilities; making recommendations to help prevent future deaths and improve maternal health; identifying systems problems; and identifying strengths in systems of care that should be encouraged or expanded. The scope of the committee's work will be determined in part by the definitions chosen. ACOG and the CDC have crafted definitions that differentiate between *pregnancy-related* and *pregnancy-associated* deaths. Pregnancy-associated deaths include a wider range of causes. AMCHP recommends that states use a standardized case review form to facilitate discussions, and that they adopt the CDC pregnancy-related mortality cause of death classification system. *Id.* at 19.

[136] *Id.* at 16; ACOG, *Improving Pregnancy Outcomes*, *supra* note 111, at *Drafting Your MMR Bill: Legislative Considerations* 4.

[137] *See CDC/AMCHP Assessment of Maternal Mortality Review Processes in the United States* (2012), http://www.amchp.org/programsandtopics/womens-health/Focus%20Areas/MaternalMortality/Documents/MMRCAssessmentSumary.pdf.

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[140] *Id.* at 17-18.

[141] *Id.* at 19.

[142] CDC & AMCHP, *Assessment of Maternal Mortality Review Processes in the United States*, http://www.amchp.org/programsandtopics/womens-health/Focus%20Areas/MMR/Documents/2012-CDC-AMCHP-MMR-Assess-Summary.pdf; AMCHP, *Health for Every Mother*, *supra* note 5, at 25.

[143] Human Rights Council, *Technical Guidance*, *supra* note 4, at 25.

[144] Other state-level government stakeholders may include public health departments, state Title V maternal and child health agencies, state Title X family planning programs, social services programs that serve women (family planning, WIC, domestic violence and substance abuse), and the medical examiner's office. ACOG, *Improving Pregnancy Outcomes*, *supra* note 111, at *Drafting Your MMR Bill: Legislative Considerations* 3-4.

[145] Vermont Workers' Center & National Economic and Social Rights Initiative, *Proposal for Public Participation in State Budget and Revenue Policy* (Aug. 2012), http://www.nesri.org/resources/proposal-for-public-participation-in-state-budget-and-revenue-policy (last visited Apr. 15, 2016).

Featured Quotations

Page 43: Alicia Walters, *Policing African-American Motherhood from Every Angle*, Rewire (Jan. 22, 2013, 7:46 AM), https://rewire.news/article/2013/01/22/policing-african-american-motherhood-from-every-angle/.

Page 52: *Black Mamas Matter*, Center for Reproductive Rights (Sept. 1, 2015), http://www.reproductiverights.org/feature/black-mamas-matter.

Page 63: Dr. Joia Crear-Perry, *Our Quest to Save Mothers' Lives Is Just Beginning*, Women's E-News (Oct. 22, 2015), http://womensenews.org/2015/10/our-quest-to-save-mothers-lives-is-just-beginning/.

SisterSong Story Circles took place in April and May of 2014, in Atlanta, Ga. and Jackson, Miss. All names for Story Circle participants are pseudonyms.

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