

## 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.<sup>1</sup> 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.<sup>2</sup>

### 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.<sup>3</sup> The sustainable development agenda that will now follow the MDGs includes a renewed commitment to further reduce the MMR.<sup>4</sup> 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.<sup>5</sup> 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.<sup>6</sup> 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.<sup>7</sup> 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.<sup>9</sup> As a result, ensuring adequate reproductive and maternal health care is considered a core government obligation.<sup>10</sup> “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.<sup>11</sup>

### 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.<sup>8</sup>

### The right to life

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

## 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”).<sup>17</sup> 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.<sup>18</sup>

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.<sup>19</sup>

*“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.<sup>20</sup>

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

## 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.<sup>23</sup> 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.<sup>24</sup>
- 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.<sup>25</sup> 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.<sup>26</sup> 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.<sup>27</sup>

mortality. Instead, this approach empowers all women to claim their full set of human rights in order to live the healthiest lives possible.<sup>21</sup> It recognizes that discrimination plays a role in undermining women's and girls' 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.<sup>22</sup>

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.<sup>28</sup> However, a comparable commitment to improving maternal health within the U.S. is currently lacking.

## A Human Rights Based Approach to Improving Maternal Health<sup>30</sup>

**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.<sup>29</sup> 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,<sup>31</sup> non-discrimination, universality,<sup>32</sup> and equity,<sup>33</sup> 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.<sup>34</sup>

## 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.<sup>35</sup> 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.”<sup>36</sup> This includes the right to have children, to not have children, to parent one’s children, and to control one’s birthing options.<sup>37</sup>

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.<sup>38</sup> 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.<sup>39</sup>

### 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.<sup>40</sup>

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

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.<sup>2</sup> Accessibility has four overlapping dimensions: non-discrimination, physical accessibility, economic accessibility, and information accessibility.<sup>3</sup> 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.<sup>4</sup>

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<sup>58</sup> 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.<sup>59</sup> More than a third of women in the United States experience rape, physical violence, or stalking by an intimate partner during their lifetime.<sup>60</sup> For some women, IPV escalates during pregnancy.<sup>61</sup> 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.<sup>62</sup> Others have passed laws that require health care professionals to complete training in domestic violence and IPV.<sup>63</sup> A few states require protocols for the standard of care and information that IPV survivors are provided.<sup>64</sup>

- **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