

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

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.”<sup>1</sup>

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.

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### 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>

## 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.

#### *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.<sup>5</sup>

#### *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.

## 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<sup>6</sup> and have the highest rates of unintended pregnancy among all racial and ethnic groups.<sup>7</sup>

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.<sup>8</sup> 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.<sup>9</sup> These family planning-focused safety-net centers are the only source of health care for many low-income women who lack health insurance.<sup>10</sup>

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.<sup>11</sup> Three-quarters of the public money that goes toward family planning flows through the Medicaid program,<sup>12</sup> allowing women enrolled in the program to access contraceptive services, while state governments pays only 10% of the cost.<sup>13</sup> 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.<sup>14</sup>

### 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.<sup>15</sup>
- **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.<sup>16</sup>
- **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.<sup>17</sup> Centers with a reproductive health focus tend to have more contraceptive options available on site than clinics that focus on primary care.<sup>18</sup>

*“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

## 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.**<sup>19</sup> 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.<sup>20</sup> 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.<sup>21</sup> 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.



*“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

- **Monitor the accuracy of information that insurance companies provide to women about their rights to contraception.**<sup>22</sup> 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.
- **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.<sup>23</sup> 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.<sup>24</sup>
- **Allow a broader range of health professionals to provide contraception.**<sup>25</sup> 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.<sup>26</sup>



Brainstorming during the June 2015 Black Mamas Matter convening in Atlanta, GA.

## 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.<sup>27</sup> 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.<sup>28</sup> Youth of color have the highest risks of all,<sup>29</sup> and one in every 32 Black women in the United States will be diagnosed with HIV during her lifetime.<sup>30</sup>



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.<sup>31</sup> 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.**<sup>32</sup> 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.<sup>33</sup>
- **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.<sup>34</sup>

- **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.<sup>35</sup>

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.<sup>36</sup>

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 later ones,<sup>37</sup> and studies show that trained non-physician providers can perform them safely.<sup>38</sup> 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.<sup>39</sup> Advocates interested in exploring these measures can look to California, Washington, and Connecticut for examples.<sup>40</sup>
- **Ensure every woman has coverage for abortion care** (including public employees<sup>41</sup> 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.<sup>42</sup> 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.<sup>43</sup> 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.<sup>44</sup> In addition, several states force all private insurance companies to withhold coverage for abortion.<sup>45</sup> Other states, including Washington, have tried to proactively enact legislation that prohibits these discriminatory policies.<sup>46</sup> 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<sup>47</sup> and can delay women’s medical care, potentially pushing them past the legal limits for abortion in their state.<sup>48</sup>
- **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.<sup>49</sup>

*“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

## 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.<sup>50</sup> 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.<sup>51</sup>

#### *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.<sup>52</sup>

#### *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.<sup>53</sup> 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.<sup>54</sup> 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.**<sup>55</sup> 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.<sup>56</sup>
- **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.<sup>57</sup>

**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.

*“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

- **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 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>





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

- **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.

#### 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.<sup>65</sup> These conditions are also associated with high rates of morbidity.<sup>66</sup> 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.<sup>67</sup>
- **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.<sup>68</sup> 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.<sup>69</sup>

#### 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.<sup>70</sup> 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.<sup>71</sup>

#### 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.



*“[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

#### *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,<sup>72</sup> cesarean deliveries have increased sharply in recent years and are now used in one-third of all U.S. births.<sup>73</sup> 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.<sup>74</sup>
- **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.<sup>75</sup>
- **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).<sup>76</sup>
- **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.

## **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.<sup>77</sup>

*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.<sup>78</sup> Similarly, states that allow certified nurse-midwives (CNMs) to practice autonomously have lower rates of cesarean sections, preterm births, and low birthweight infants.<sup>79</sup> 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.
- **Direct state Medicaid agencies to amend their state plans and cover doula support** under the recently revised CMS Preventive Services Rule.<sup>80</sup> 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.<sup>81</sup>
- **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.<sup>82</sup> This model has been shown to improve birth outcomes among the low-income women and women of color it serves<sup>83</sup> and is designed to be easily duplicated.<sup>84</sup> Centering Pregnancy is another model that has been shown to improve birth outcomes and lower racial disparities through group prenatal care.<sup>85</sup> This model emphasizes self-care and confidence while building community among women who are experiencing pregnancy at the same time.<sup>86</sup>

**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<sup>87</sup> 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.<sup>88</sup> 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.

#### 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.<sup>89</sup> 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,<sup>90</sup> 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.<sup>91</sup> 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.<sup>92</sup> Incarcerated pregnant women report mistreatment by correctional guards and staff during their pregnancies, lack of access to adequate nutrition and health care providers, and inhumane conditions during birth.<sup>93</sup> 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.<sup>94</sup>

*“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



*“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.

Reproductive-aged Black women in the United States have a significant risk of experiencing incarceration.<sup>95</sup> 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);<sup>96</sup> provide HIV testing, counseling, and referral upon release;<sup>97</sup> offer contraceptive counseling and LARC methods in a non-coercive manner prior to release;<sup>98</sup> 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.<sup>99</sup> However, disparities in these conditions of daily life give some people better opportunities to be healthy than others.<sup>100</sup> 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.<sup>101</sup>

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<sup>102</sup> 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.<sup>103</sup> 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.<sup>104</sup> 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.<sup>105</sup>
- **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.<sup>106</sup> When low-income people have access to public transportation, they are better able to access health care facilities, grocery stores, and recreation centers.<sup>107</sup> 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.<sup>108</sup>
- **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.<sup>109</sup> 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.<sup>110</sup>
- **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.<sup>111</sup> 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.<sup>112</sup> 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.

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.

*“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 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

### 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.<sup>113</sup> Because vital records collect data 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.<sup>114</sup> 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.<sup>115</sup>

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.<sup>116</sup> The U.S. standard death certificate, which is recommended for national use,<sup>117</sup> 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.<sup>118</sup>

*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.<sup>119</sup> 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.<sup>120</sup>

*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.<sup>121</sup> 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.<sup>122</sup> 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<sup>123</sup> 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.<sup>124</sup>
- **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.<sup>125</sup> These include deaths from violent injuries, drug overdoses, or motor vehicle accidents, and they may or may not be pregnancy-related.<sup>126</sup> 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?”)<sup>127</sup> 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.<sup>128</sup> 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.<sup>129</sup> 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.<sup>130</sup> AMCHP offers online access to the indicators and has provided intensive technical assistance to several states, including Louisiana, Mississippi, and Georgia.<sup>131</sup> 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.<sup>132</sup>

### Recommendations for advocates:

- **Develop participatory research models** that acknowledge community-based perspectives on care and can be used to set research agendas.<sup>133</sup> 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.



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

## 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.<sup>134</sup>



#### 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.<sup>135</sup> 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.<sup>136</sup> 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;<sup>137</sup> (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.<sup>138</sup>
- **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.<sup>139</sup> 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.<sup>140</sup>

### 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.<sup>141</sup> 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.
- **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.<sup>142</sup> 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.
- **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.<sup>143</sup> 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.<sup>144</sup>

*“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 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.”<sup>145</sup>

## 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.)

## Endnotes

- <sup>1</sup> WORLD HEALTH ORGANIZATION (WHO), Constitution of the World Health Organization, *signed* July 22, 1946 (*entered into force* Apr. 7, 1948) [hereinafter WHO, Constitution].
- <sup>2</sup> Committee on Economic, Social and Cultural Rights (ESCR Committee), *General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12)* [hereinafter ESCR Committee, *Gen. Comment No. 14*], para. 12, U.N. Doc. E/C.12/2000/4 (2000).
- <sup>3</sup> *Id.*
- <sup>4</sup> 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 Morbidity and Mortality* [hereinafter Human Rights Council, *Technical Guidance*], U.N. Doc. A/HRC/21/22 (2012).
- <sup>5</sup> THE ASSOCIATION FOR MATERNAL AND CHILD HEALTH PROGRAMS (AMCHP), *Health for Every Mother: A Maternal Health Resource and Planning Guide for States* 84 [hereinafter AMCHP, *Health for Every Mother*] (2015), [http://www.amchp.org/programsandtopics/womens-health/Focus%20Areas/MaternalMortality/Documents/Health-for-Every-Mother\\_FINAL\\_WebOptimized.pdf](http://www.amchp.org/programsandtopics/womens-health/Focus%20Areas/MaternalMortality/Documents/Health-for-Every-Mother_FINAL_WebOptimized.pdf); *See also* ASSOCIATION OF STATE AND TERRITORIAL HEALTH OFFICIALS, *State Options for Enhancing Health Information and Exchange for MCH Systems*, (2012), <http://www.astho.org/Maternal-and-Child-Health/Collaborations/MCH-and-Health-Information-Exchange-Issue-Brief/>.
- <sup>6</sup> *See* Christine Dehlendorf et al., *Disparities in Abortion Rates: A Public Health Approach*, 103 AM. J. PUB. HEALTH 1772, 1774 (2013) (citing Joyce C. Abma et al., *Teenagers in the United States: Sexual Activity, Contraceptive Use, and Childbearing, 2006-2010 National Survey of Family Growth*, 23 Vital Health Stat. 31 (2011)).
- <sup>7</sup> *Fact Sheet: Unintended Pregnancy in the United States*, GUTTMACHER INST. (Mar. 2016) (citing Lawrence B. Finer & Mia R. Zolner, Shifts in Intended and Unintended Pregnancies in the United States, 2001-2008, 104 AM. J. OF PUB. HEALTH S43 (2014)), <https://www.guttmacher.org/fact-sheet/unintended-pregnancy-united-states>.
- <sup>8</sup> *Fact Sheet: Publicly Funded Family Planning Services in the United States*, GUTTMACHER INST. (July 2015), [http://www.guttmacher.org/pubs/fb\\_contraceptive\\_serv.html](http://www.guttmacher.org/pubs/fb_contraceptive_serv.html) [hereinafter *Publicly Funded Family Planning Services*].
- <sup>9</sup> *Id.*
- <sup>10</sup> *Id.* (stating that four in ten women who receive care at clinics that specialize in contraception do not have other sources of health care).
- <sup>11</sup> *Id.*
- <sup>12</sup> 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>.
- <sup>13</sup> *Publicly Funded Family Planning Services*, *supra* note 8.
- <sup>14</sup> *Id.*
- <sup>15</sup> Jennifer Frost et al., Contraceptive Needs and Services, 2013 Update, GUTTMACHER INST. (July 2015), <http://www.guttmacher.org/pubs/win/contraceptive-needs-2013.pdf>.
- <sup>16</sup> AMCHP, *Health for Every Mother*, *supra* note 5, at 70.
- <sup>17</sup> *Publicly Funded Family Planning Services*, *supra* note 8.
- <sup>18</sup> *Id.*
- <sup>19</sup> 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](http://www.leginfo.ca.gov/pub/13-14/bill/sen/sb_1051-1100/sb_1053_bill_20140925_chaptered.pdf).
- <sup>20</sup> 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>.
- <sup>21</sup> *Id.*
- <sup>22</sup> 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-con->

trol-coverage-get-wrong-messages-from-insurers-survey-finds/.

<sup>23</sup> 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](http://journals.lww.com/greenjournal/Abstract/2011/03000/Number_of_Oral_Contraceptive_Pill_Packages.8.aspx).

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

<sup>25</sup> Bills introduced in Washington, California, and Oregon have included registered nurses, nurse practitioners, nurse-midwives, physician assistants, naturopathic physicians, and pharmacists.

<sup>26</sup> 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.

<sup>27</sup> 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.reproductivejustice.org/sites/crr.civicactions.net/files/documents/CERD\\_Shadow\\_US.pdf](http://www.reproductivejustice.org/sites/crr.civicactions.net/files/documents/CERD_Shadow_US.pdf).

<sup>28</sup> *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).

<sup>29</sup> 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>.

<sup>30</sup> *HIV Among African Americans*, CDC (Feb. 4, 2016), <http://www.cdc.gov/hiv/group/raciaethnic/africanamericans/index.html> (last visited Apr. 1, 2016).

<sup>31</sup> *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).

<sup>32</sup> Human Rights Council, *Technical Guidance*, *supra* note 4, at 31.

<sup>33</sup> *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.reproductivejustice.org/sites/crr.civicactions.net/files/documents/US-PAPS-Compendium-final-SM.pdf>.

<sup>34</sup> *Sexuality Education Justice Framework*, ASIAN COMMUNITIES FOR REPRODUCTIVE JUSTICE (ACRJ), <http://strongfamiliesmovement.org/sej-framework> (last visited Apr. 1, 2016).

<sup>35</sup> Susan A. Cohen, *Abortion and Women of Color: The Bigger Picture*, 11 GUTTMACHER POL’Y REV. 3 (2008), [https://www.guttmacher.org/sites/default/files/article\\_files/gpr110302.pdf](https://www.guttmacher.org/sites/default/files/article_files/gpr110302.pdf).

<sup>36</sup> WORLD HEALTH ORGANIZATION (WHO), *Safe Abortion: Technical & Policy Guidance for Health Systems* 2 (2015), [http://apps.who.int/iris/bitstream/10665/173586/1/WHO\\_RHR\\_15.04\\_eng.pdf?ua=1](http://apps.who.int/iris/bitstream/10665/173586/1/WHO_RHR_15.04_eng.pdf?ua=1).

<sup>37</sup> GUTTMACHER INST., *Fact Sheet: Induced Abortion in the United States* (Mar. 2016) (citing Rachel K. Jones & Jenna Jerman, *Abortion Incidence and Service Availability in the United States*, 2011, 46 PERSP. ON SEXUAL & REPROD. HEALTH 1(2014)), <https://www.guttmacher.org/fact-sheet/induced-abortion-unit-ed-states>.

<sup>38</sup> NATIONAL ABORTION FEDERATION, *Clinical Policy Guidelines* (2014), <http://prochoice.org/wp-content/uploads/2014NAFCPGs.pdf>.

<sup>39</sup> GUTTMACHER INST., *State Policies in Brief: An Overview of Abortion Laws* (Mar. 1, 2016), [https://www.guttmacher.org/sites/default/files/state\\_policy\\_overview\\_files/spib\\_oal.pdf](https://www.guttmacher.org/sites/default/files/state_policy_overview_files/spib_oal.pdf).

<sup>40</sup> A.B. 154, 2013 Leg., Reg. Sess. (Cal. 2013), [http://leginfo.legislature.ca.gov/faces/billNavClient.xhtml?bill\\_id=201320140AB154](http://leginfo.legislature.ca.gov/faces/billNavClient.xhtml?bill_id=201320140AB154); Wash. Op. Att’y Gen. No. 1 (Jan. 5, 2004), <http://www.atg.wa.gov/ago-opinions/authority-advanced-registered-nurse-practitioners-arnps-prescribe-or-furnish-abortion>; Conn. Op. Att’y Gen. No. 15 (July 2, 2001), <http://www.ct.gov/ag/cwp/view.asp?A=1770&Q=281848>.

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<sup>43</sup> 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.

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<sup>47</sup> See “*Crisis Pregnancy Centers*” (CPCs), NARAL PRO-CHOICE AMERICA, <http://www.prochoiceamerica.org/what-is-choice/abortion/abortion-crisis-pregnancy-centers.html> (last visited Apr. 1, 2016) (listing all affiliate investigative reports on CPCs).

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<sup>49</sup> *Women’s Health Protection Act*, ACT FOR WOMEN! <http://www.actforwomen.org/the-womens-health-protection-act/>.

<sup>50</sup> U.S. Department of Health and Human Services (HHS), Health Resources and Services Administration, Maternal and Child Health Bureau, Understanding Title V of the Social Security Act, available at <http://www.amchp.org/AboutTitleV/Documents/UnderstandingTitleV.pdf>

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<sup>52</sup> Trust for America’s Health, Investing in America’s Health: A State-by-State Look at Public Health Funding and Key Health Facts, Apr. 2013, <http://healthyamericans.org/report/105/>.

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<sup>55</sup> *Id.* at 70.

<sup>56</sup> *Id.*; See also Daniel Frayne et al., *Health Care System Measures to Advance Preconception Wellness*, 0 OBSTETRICS & GYNECOLOGY 1-10 (2016) (providing recommendations for preconception wellness measures as a metric to monitor performance of preconception care practice in health systems).

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<sup>59</sup> FUTURES WITHOUT VIOLENCE, *The Facts on Reproductive Health and Partner Abuse*, [http://www.futureswithoutviolence.org/userfiles/file/Children\\_and\\_Families/Re-productive.pdf](http://www.futureswithoutviolence.org/userfiles/file/Children_and_Families/Re-productive.pdf).

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<sup>78</sup> *Id.* at 1.

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<sup>90</sup> Victoria Law, *U.S. Prisons and Jails Are Threatening the Lives of Pregnant Women and Babies* (Sept. 28, 2015), IN THESE TIMES, <http://inthesetimes.com/article/18410/u.s.-prisons-are-threatening-the-lives-of-pregnant-mothers-and-newborns> (last visited Apr. 18, 2016).

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- <sup>133</sup> Andrea Cornwall & Rachel Jewkes, *What is Participatory Research?*, 41 SOC. SCI. MED. 12 (1995), [http://www.civitas.edu.pl/pub/nasza\\_uczelnia/projekty\\_badawcze/Taylor/what\\_is\\_participatory\\_research.pdf](http://www.civitas.edu.pl/pub/nasza_uczelnia/projekty_badawcze/Taylor/what_is_participatory_research.pdf).
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- <sup>135</sup> 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.
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- <sup>143</sup> Human Rights Council, *Technical Guidance*, *supra* note 4, at 25.
- <sup>144</sup> 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*.
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## Featured Quotations

Page 15: 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 24: *Black Mamas Matter*, CENTER FOR REPRODUCTIVE RIGHTS (Sept. 1, 2015), <http://www.reproductiverights.org/feature/black-mamas-matter>.

Page 35: 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.