

# Eliminating Racial Disparities in Maternal and Infant Mortality

A Comprehensive Policy Blueprint

By Jamila Taylor, Cristina Novoa, Katie Hamm, and Shilpa Phadke May 2019



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# Introduction and summary

If the fact that the United States has the highest maternal and infant mortality rates among comparable developed countries is not bad enough, the survival rates for African American mothers and their infants are even more dismal. African American women across the income spectrum and from all walks of life are dying from preventable pregnancy-related complications at three to four times the rate of non-Hispanic white women, while the death rate for black infants is twice that of infants born to non-Hispanic white mothers.

Maternal mortality affects U.S. women from all backgrounds; if a woman is able to become pregnant, she risks experiencing complications such as preterm labor, infections, gestational diabetes, and even death due to her pregnancy. Among women who survive pregnancy and childbirth, 50,000 women each year experience life-threatening pregnancy-related complications<sup>4</sup>, also known as severe maternal morbidity (SMM). Discussions of the maternal health crisis in the United States often exclude this condition that disproportionately affects women of color, with African American women twice as likely to experience SMM compared with non-Hispanic white women.<sup>5</sup> What's more, African American mothers are twice as likely to have an infant who dies by their first birthday.<sup>6</sup> Although other women of color also experience an elevated risk of poor outcomes—notably in American Indian and Alaska Native (AIAN) and some Latina communities—available data show that racial disparities between African Americans and non-Hispanic whites are the starkest.<sup>7</sup>

Pregnancy-related complications are closely tied to infant deaths as well. Nearly two-thirds of infant deaths occur during the first month after birth, often from congenital abnormalities and complications from preterm births. Preterm birth is a significant contributor to racial disparities in infant mortality. African Americans have the highest infant mortality rate of any racial or ethnic group in the United States, and higher rates of preterm births explain more than half of the difference, relative to non-Hispanic white women. AIAN and Puerto Rican women also have higher rates of infant mortality, and preterm births are a major driver for these groups as well. 10

Disparities in maternal and infant mortality are rooted in racism. Structural racism in health care and social service delivery means that African American women often receive poorer quality care than white women. It means the denial of care when African American women seek help when enduring pain or that health care and social service providers fail to treat them with dignity and respect. These stressors and the cumulative experience of racism and sexism, especially during sensitive developmental periods, trigger a chain of biological processes, known as weathering, that undermine African American women's physical and mental health. The long-term psychological toll of racism puts African American women at higher risk for a range of medical conditions that threaten their lives and their infants' lives, including preeclampsia (pregnancy-related high blood pressure), eclampsia (a complication of preeclampsia characterized by seizures), embolisms (blood vessel obstructions), and mental health conditions. The long-term psychological toll of the preclampsia (blood vessel obstructions), and mental health conditions.

Although racism drives racial disparities in maternal and infant mortality, it bears mentioning that significant underinvestment in family support and health care programs contribute to the alarming trends in maternal and infant health.<sup>13</sup> In the past decades, many programs that support families in need—such as Medicaid, Temporary Assistance for Needy Families (TANF), and nutrition assistance—have experienced a steady erosion of funding, if not outright budget cuts.<sup>14</sup> The fact that these cuts have a harmful impact on families of color, who are overrepresented in these programs due to barriers to economic opportunity in this country, can be attributed to structural racism.

Despite pervasive racial disparities in maternal and infant deaths, public attention has only recently focused on this issue as a public health crisis. <sup>15</sup> And the full extent of the crisis is not yet known due to incomplete data. <sup>16</sup> Compared with data on infant mortality, data on maternal mortality are less reliable and complete. <sup>17</sup> While the disparities in maternal mortality across race are clear within individual states, a reliable national estimate has not been possible because data have been inconsistent and incomplete across states. <sup>18</sup>

Behind these statistics are the stories of individuals and families. To bring the United States in line with the rest of the developed world, policymakers and health care providers must work together to eliminate these disparities.

This report provides a comprehensive policy framework to eliminate racial disparities in maternal and infant mortality. Too often, policy conversations about maternal and infant health take place separately despite the interdependence of pregnancy and birth outcomes. This report attempts to bridge that gap by considering solutions that address racial disparities in both maternal and infant mortality. The authors outline policy strategies in five areas and make the following recommendations to address the ongoing threat to African American mothers and their infants:

#### • Improve access to critical services:

- Strengthen existing health programs and support reproductive health care.
- Screen and treat women at risk for preterm birth.
- Eliminate maternity care deserts.
- Offer African American women tools to navigate the health care system.

#### • Improve the quality of care provided to pregnant women:

- Train providers to address racism and build a more diverse health care workforce.
- Create standardized assessments for mothers and infants.
- Adopt new models of care and link payment to quality.

#### Address maternal and infant mental health:

- Identify barriers to accessing maternal mental health services.
- Dismantle care barriers with a comprehensive approach.
- Screen for and address infant and early childhood mental health issues.

#### • Enhance supports for families before and after birth:

- Invest in and expand access to policies and programs that support families' basic needs.
- Invest in community programs that offer one-stop comprehensive services.
- Simplify enrollment across public benefit programs.
- Invest in home visiting.
- Fund community-based education and communications initiatives to support families.

#### Improve data collection and oversight:

- Standardize birth and death certificate data.
- Mandate and fund fetal and infant mortality review committees.
- Ensure equity in the review process.

Authors' note: Because of the significant number of acronyms used throughout this report, the authors have included an alphabetical listing in the appendix.

# Understanding racial disparities

#### How racism impacts health care and maternal and infant health

The maternal and infant mortality crisis cannot be adequately addressed without first understanding and then dismantling racism and bias in the health care system. African Americans have endured hundreds of years of racism in this country. This has occurred within the various systems and institutions that are part of American society—of which the health care system is just one. Racism, not race itself, is the driving force behind disparately high rates of maternal and infant deaths among African Americans, and the systemic barriers are fueled by both explicit and implicit bias.

For African Americans, the social determinants of health—including income level, education, and socio-economic status—are not protective factors as they are for white Americans when it comes to maternal and infant mortality. Social determinants of health are conditions that affect the health and quality of life of people in a given environment, including where a person lives, earns, works, or plays.<sup>20</sup> Racism is part and parcel of being black in the United States, and it compromises the health of African American women and their infants. Applying a racial justice lens to contextualize this urgent public health crisis is critical. Put simply, structural racism compromises health.<sup>21</sup>

Structural racism is defined as a system where public policies, institutional practices, and cultural representations work to reinforce and perpetuate racial inequity.<sup>22</sup> It is fueled by predominantly white power structures that perpetuate power imbalances among people of color. Policy solutions to the maternal and infant mortality crisis must be grounded in social justice frameworks that are intentionally designed to address these power imbalances.<sup>23</sup> One such framework is reproductive justice, which is a human rights-based structured approach that addresses the intersecting systems of oppression that prevent marginalized women, primarily women of color, from achieving complete bodily autonomy and parenting with dignity.<sup>24</sup> Reproductive justice recognizes that a woman's ability to determine her reproductive destiny is linked to the conditions in her community, including her access to

health care, affordable housing, economic opportunity, and other factors. Policy solutions, therefore, must prioritize communities of color and their realities to fully address racial disparities in maternal and infant mortality.<sup>25</sup>

Racism in health care can also manifest in other structural forms. This can include the concentration of people of color in communities that lack quality health facilities and providers; harsh environmental factors and toxins in predominantly African American neighborhoods;<sup>26</sup> inequality in the workplace; highly concentrated food insecurity within communities of color;<sup>27</sup> or draconian policy changes to health care programs that disproportionately serve people of color, such as Medicaid.

It should be noted that bias related to other social factors such as education level, income, sexual orientation, disability, and immigration status can also negatively affect patients' experiences in health care settings as well as their health outcomes. Furthermore, the intersectionality<sup>29</sup> of racism and sexism often result in women of color, particularly African American, Latina, AIAN, and Asian and Pacific Islander women, consistently reporting experiencing bias and discrimination based on their race and gender in health care settings. This compounded discrimination results in women, but especially women of color, feeling invisible or unheard when asking medical providers for help and when expressing issues with pain or discomfort during and after the birthing process. The social process of the social process of the pain or discomfort during and after the birthing process.

This report focuses on women and experiences of discrimination and health disparities at the intersection of race and gender. However, not all pregnant people identify as women, and transgender and nonbinary people face unique barriers to accessing quality health care. The authors recognize that the research reviewed here may not adequately make the distinction between cisgender and transgender women or recognize intersex people or people with nonbinary identities. This is partially due to the lack of available research that focusses on the pregnancy and parenting experiences of these populations. For the purposes of this paper, the authors focus their discussion on a robust body of research that predominantly refers to their participants as "women." The pregnancy and parenting experiences of transgender people, intersex people, and people who identify as nonbinary deserve more expansive future study and targeted interventions to eliminate barriers and improve the health of these communities.

The detrimental impact of racism on African American women's mental, emotional, and physical health throughout the lifespan is well documented.<sup>33</sup> It can also have deleterious effects on the health of their infants and families.<sup>34</sup> Health disparities

across maternal and infant health conditions, including maternal mental health, sudden infant death syndrome (SIDS), sudden unexpected infant deaths (SUID),<sup>35</sup> and cesarean section deliveries (C-sections), shed a light on how structural racism and bias can impact health outcomes. SIDS/SUID is one of the leading causes of infant mortality in the United States, and C-section deliveries are associated with higher rates of maternal mortality and severe maternal morbidity.<sup>36</sup> In 2017, the C-section rate for black women was 36 percent compared to 30.9 percent for non-Hispanic white women. And, in 2013, the SIDS/SUID rate for black women was about twice as high as that of non-Hispanic white women. Underinsurance and the lack of hospitals and facilities offering quality maternity and neonatal care in underserved communities are also key factors in these disparities.<sup>37</sup>

The sections that follow discuss policy recommendations to address structural racism in the health care and family support systems. Some of these recommendations are designed to rectify structural racism, while others provide additional supports and services to pregnant women and new mothers to ameliorate the impact that racism has on their respective experiences. Recommendations include strengthening existing health programs that largely serve communities of color, such as Medicaid and the Children's Health Insurance Program (CHIP); eliminating maternity care deserts; training health care providers to address racism and building a more diverse workforce; identifying barriers to accessing maternal mental health services; investing in community programs; as well as a host of others. In all cases, acknowledging racism as the underlying cause of maternal and infant deaths is critical to finding policy solutions that can effectively eliminate racial disparities. To adequately address the legacy and impact of racism, policy solutions should follow the theory of targeted universalism—an equity framework that employs targeted strategies to achieve a universal goal. This framework allows policy solutions to meet the needs of all populations—but have an intentional focus on those most in need—African American women and families. 38

# Improve access to critical services

Ensuring access to comprehensive, affordable, high-quality health care is vital in the effort to eliminate racial disparities in maternal and infant mortality. In doing so, policymakers should prioritize underserved populations, including women and infants of color, low-income communities, and those living in rural and medically underserved areas. Lack of access to both quality, affordable health care and insurance coverage fuel poor health outcomes and racial and ethnic health disparities. This section focuses on strengthening the existing health care system and ensuring quality care both in terms of health care outcomes and in treating patients with dignity—recognizing and respecting their autonomy and expertise related to their own experience.

# Strengthen existing health programs and support reproductive health care

Policymakers must work to strengthen the various parts of our nation's health care system—especially Medicaid, the Affordable Care Act (ACA), and CHIP—that provide health care coverage to millions of women and their children. Not only is comprehensive, affordable health care coverage important throughout women's lives, but it is also particularly critical to their health during pregnancy and after the birth of a child. Furthermore, when a woman has coverage of and access to maternity care, the positive health impacts can be long lasting to both her and her child. Without health care coverage, a woman may forgo the routine prenatal and postnatal care that is needed to identify health risks and prevent complications. According to reports from maternal mortality review committees (MMRCs) in partnership with the Centers for Disease Control and Prevention (CDC) Foundation, about 60 percent of maternal deaths are preventable. And among the most common conditions associated with maternal mortality, the percentages are even higher—cardiovascular and coronary conditions are 68 percent preventable, and hemorrhage is 70 percent preventable.

Access to maternity care, family planning, and other reproductive health care services is central to the constellation of services women need in order to have healthy pregnancies. Abortion and contraceptive coverage must be supported through both public and private sources of health insurance that are void of harmful funding restrictions or other measures that complicate a woman's ability to obtain comprehensive reproductive health care. Studies show that when women experience an unintended pregnancy and are forced to carry an unplanned pregnancy to term, they are likely to delay prenatal care. This can result in poor maternal and infant health outcomes. A woman's ability to choose if, when, and how to give birth is inextricably linked with her overall health and well-being; her economic security; and her educational attainment. 43

A crucial source of health insurance for pregnant women and mothers is Medicaid, a joint state and federal government funded program that provides health care coverage to millions of low-income Americans— 25 million of whom are women. The program covers almost half of all births in the country. And, in some states, the program covers more than half of births. Under the traditional Medicaid program, federal law requires states to provide pregnant women who have family incomes up to 138 percent of the federal poverty level (FPL) with pregnancy-related services through 60 days postpartum. These services are limited to prenatal care, delivery, postpartum care, and family planning. Many states voluntarily cover these services for women whose incomes exceed the 138 percent threshold.

However, states are not required to provide full Medicaid benefits under this eligibility pathway—which includes comprehensive coverage for all medically necessary services—to pregnant women and can limit their coverage to pregnancy-related services. As a result, a woman eligible for traditional Medicaid may receive services that vary widely from state to state depending on her eligibility pathway. Furthermore, certain pregnant women may also qualify for full Medicaid benefits if they meet other eligibility requirements.<sup>48</sup>

The ACA drastically improved coverage for women—including pregnant women—by expanding Medicaid eligibility to all adults with incomes up to 138 percent of the FPL. States that chose to expand their Medicaid programs must include coverage for essential health benefits as part of the benefits for the pregnancy pathway (although this is not necessarily true for other eligibility groups). The ACA statute required states to expand their programs to include this new eligibility category. But following the Supreme Court's 2012 decision on the constitutionality of key provisions of the ACA, Medicaid expansion was made optional for the states.<sup>49</sup> To date, 33 states and the District of Columbia have adopted Medicaid expansion.<sup>50</sup>

The ACA also expanded presumptive eligibility, which allows women to access needed care more quickly. As part of the ACA, Medicaid (as well as other plans participating in state health insurance exchanges) must cover 10 essential health benefits, including mental health services, chronic disease management, contraception, maternity and newborn care, and pediatric services for the expansion population. States must also cover certain maternity benefits such as prenatal visits, screenings, folic acid supplements, and breastfeeding supports and equipment rental, which must be provided with no cost sharing. States are provided with no cost sharing.

These services provide important supports to mothers and infants. Management of chronic disease ensures women receive ongoing treatment, minimizing the risk these conditions may pose throughout and after their pregnancy. Increased access to contraception helps avoid unplanned and often high-risk pregnancies. And guaranteed coverage of pregnancy and maternal care ensures women can access care that has been proven to lower the incidence of risk factors such as low birth weight and early term births. Taken together, the benefits of comprehensive health care have the potential to significantly improve women's health before and during pregnancy, which can greatly impact infant mortality.

Research shows that Medicaid expansion indeed saves lives; a study from the American Journal of Public Health found that Medicaid expansion states saw infant mortality rates decline, with the greatest decline among African American infants. 53 Using the same data source, the Center for American Progress estimates that expanding Medicaid in nonexpansion states would avert 141 infant deaths per year.<sup>54</sup> In the 17 states that have yet to fully expand their Medicaid programs, remaining restrictions on coverage and eligibility prevent pregnant women and new mothers from gaining the full benefits of health care coverage. At a minimum, federal law should require states to cover new mothers who receive coverage through the limited pregnancy pathway beyond 60 days postpartum to at least one year after giving birth and should require coverage for full Medicaid benefits during this period.55 These steps will increase access to comprehensive health care during an important time for new mothers. In particular, new mothers of color stand to gain both health and economic benefits from this extension of care. Because women of color are more likely to be covered by Medicaid, which covers almost half of all births in the United States, the program is essential to addressing racial disparities in maternal and infant mortality.

Loss of insurance coverage before and after childbirth is another factor that can adversely impact maternal and infant health outcomes. Coverage loss was a common and persistent occurrence prior to implementation of the ACA. <sup>56</sup> While half

of uninsured women were able to obtain Medicaid or CHIP coverage by the month of delivery, 55 percent of women with this coverage became uninsured in the six months following delivery.<sup>57</sup> Women most affected by the discontinuation or loss of insurance coverage were typically the sole caregiver in their homes or low-income mothers; Medicaid or CHIP recipients; and residents living in the Southern United States—a region of the country where most states have not expand Medicaid.<sup>58</sup>

After the implementation of the ACA, low-income women in expansion states who would otherwise have lost their eligibility for pregnancy-related Medicaid coverage became eligible to receive full Medicaid coverage. This led the uninsurance rate among new mothers (those who had given birth in the past year) in these expansion states to fall by 56 percent.<sup>59</sup> For new mothers residing in nonexpansion states, however, access to full Medicaid coverage was not as widespread, and the uninsurance rate only fell by 29 percent. 60 As of 2016, the difference in uninsurance rates between nonexpansion and expansion states was more than double—17.9 percent compared to 6.8 percent, respectively.<sup>61</sup>

CHIP is another vital insurance program that ensures pregnant women and their children who make up to 185 percent of the FPL have access to comprehensive health services, although most states exceed this threshold. CHIP covers children and pregnant women whose incomes are too high for Medicaid coverage, but for whom private health insurance may still be too expensive. CHIP benefits include comprehensive coverage for services such as routine checkups, immunizations, and dental and vision care, among others. 62 Currently, 40 states administer combined Medicaid and CHIP programs, 63 and many states have increased the 138 percent of FPL income threshold over the years to cover more low- to moderate-income children under Medicaid and CHIP. Today, the median income threshold is 250 percent of the FPL.<sup>64</sup>

#### Medicaid expansion a boon for women and families

Since the 2018 publication of the CAP report "Expanding Medicaid in All States Would Save 14,000 Lives Per Year," voters in an additional three states—Idaho, Nebraska, and Utah—passed ballot measures to adopt and implement Medicaid expansion, although expansion has yet to be implemented.<sup>65</sup> Of the remaining 14 states that have not expanded Medicaid, the majority are concentrated in the Southern region of the United States.<sup>66</sup> These are also states where women tend to lack access to vital health care services and have poorer health outcomes.<sup>67</sup> Because African American women and families are more likely to live in the South, the lack of Medicaid expansion in the region presents a missed opportunity in helping them gain insurance coverage and lead healthier lives.

Despite the Affordable Care Act's insurance coverage expansions, approximately 27.4 million nonelderly individuals remain uninsured.<sup>68</sup> People of color, especially non-Hispanic black and Hispanic populations, have significantly higher uninsured rates than non-Hispanic white people.<sup>69</sup>

There are also disparities in the quality of health care that African Americans and non-Hispanic white populations receive. This disparity begins in the earliest medical settings; both quantitative and qualitative studies reveal disparities in quality of care along racial and ethnic lines in neonatal intensive care units. In a large California study assessing racial disparity in quality of care between and within neonatal care units, researchers compared the care given to white infants to that given to nonwhite infants and found that white infants received higher quality of care on process measures (for example, timely eye examination, fewer health care-associated infections). Moreover, even within high-performing neonatal care units, white infants receive higher quality care. Utuality care of the attitudes, often based on stereotypes, that affect one's understanding, actions, and decisions in an unconscious manner—and lower quality of care, which in turn influences the patient-provider relationship and treatment or diagnosis decisions.

#### Screen and treat women at risk for preterm births

Preterm birth, which refers to when an infant is born before 37 weeks of pregnancy, is a leading cause of infant mortality and accounted for approximately 17 percent of all infant deaths in 2017. Deaths from complications like respiratory distress and bacterial infections are also much more likely to occur in infants born early. When all these preterm-related causes of death are taken together, they accounted for more than one-third—36 percent—of all infant deaths in 2013. However, significant disparities exist; the preterm-related infant mortality ratio (491 deaths per 100,000 live births) for infants born to African American mothers is more than three times as high as the infant mortality ratio (159 deaths per 100,000 live births) for infants born to white mothers. Higher rates of preterm-related causes of death account for more than half of the racial disparity in infant mortality between these two groups.

Because all the reasons why some infants are born early are not known or fully understood, the CDC is currently researching preterm birth. At the same time, the Health Resources and Services Administration (HRSA) is carrying out prevention efforts that it coordinates across federal agencies. At the state and local level, health agencies and other organizations are also taking action by experimenting with new ways to screen and treat parents at increased risk of preterm birth.

Although the underlying causes of preterm birth remain unknown, research links risk factors such as smoking, stress, certain health conditions (for example, infections, diabetes, blood clotting disorders), and some aspects of previous pregnancy history (prior preterm birth) to preterm birth. <sup>79</sup> Health care providers can easily screen for these risk factors through a questionnaire or medical history interview. Because obtaining accurate self-reported health history is nearly impossible in the absence of trust, it is critical that health care providers, including physicians, prenatal care educators, and others, conduct these screenings in a way that is supportive and free of judgment.

In addition to screening women for risk factors through interviews, recent research suggests that measuring the length of the cervix—the narrow passage forming the lower end of the uterus—can also help identify women who are at higher risk of spontaneous preterm birth.80 Because cervical shortening is one of the first steps in the process that leads to labor, using a sonogram to detect early cervical shortening during pregnancy may be a useful screening tool.81 In most states, Medicaid and private insurance pays for this procedure.82

To reduce the mortality and morbidity associated with preterm births, policymakers should make screening available to the full extent of current evidence-based guidelines and provide public funding to increase access to treatment through outreach, care coordination, and other supports. In all cases, health care providers should inform parents of this screening option as appropriate; work with patients to obtain informed consent; and then determine an appropriate course of action. If a woman is found to be at increased risk of preterm birth, either through a questionnaire or a cervical screening, doctors and other health care providers should ensure they help parents understand their treatment options and develop a plan to reduce their risk.

It is important to note, given the history of racism in U.S. medicine—including numerous examples of unethical, bordering on criminal, medical experimentation on African Americans—informed consent and respect for personal autonomy is crucial as these treatment plans are developed.

Examples of effective screening programs for preterm birth are found across the country. In Detroit, for example, the Make Your Date program seeks to educate the community about the risks of preterm birth and encourages women to undergo a sonogram test to screen for cervical shortening.<sup>83</sup> Women who join the program can enroll in free pregnancy education classes, receive transportation assistance, and seek help in securing insurance coverage. In Florida, state law requires every prenatal care provider to offer a Healthy Start Risk Screen to all pregnant women to assess risk for preterm birth. After completing this voluntary, one-page questionnaire, some women may be referred to Healthy Start, a federal program that offers care coordination and outreach, parenting education, and other supports that reduce the risk of preterm birth. All pregnant women in Florida who are at high risk of poor pregnancy outcomes—including preterm birth—are eligible to receive services, regardless of income. Since implementing this universal Healthy Start screening in 1991, Florida has seen its infant mortality rate fall from 8.9 per 1,000 live births to 6.2 per 1,000 in 2015.

In some cases, administering progesterone, a hormone that reduces uterus contractions and plays an important role in maintaining pregnancy, can reduce the risk of preterm birth. This strategy has emerged as a promising evidence-based intervention supported by the American College of Obstetricians and Gynecologists (ACOG) and the Society for Maternal-Fetal Medicine. Although not appropriate for all individuals—for example, progesterone cannot be used to prevent preterm birth for women with a multiple pregnancy—some research shows that both methods cut the risk of preterm birth by almost half. However, a recent study cast doubt on the effectiveness of the drug. As new data continue to emerge, the Centers for Medicare and Medicaid Services (CMS) should issue additional evidence-based guidance to states as well as guidance on reimbursement and coverage to providers.

#### Eliminate maternity care deserts

A maternity care desert is "a county in which access to maternity health care services is limited or absent, either through lack of services or barriers to a women's ability to access that care." Access to maternity care is determined by a combination of factors, including availability of hospitals and providers offering obstetric care and health insurance coverage for maternity care. In the United States, more than 12 percent of births take place in maternity care deserts or locations with limited access to maternity care.

A recent study found that more than half of rural counties lack obstetric services, and rural counties with more African American and low-income families were less likely to have hospital obstetric services. 95 However, maternity care deserts are not unique to rural settings; indeed, the closure of two maternity wards serving predominantly African American residents in Washington, D.C., has tremendously limited women's access to maternity care. 96 Moreover, women of color also lack access to high quality care. Particularly in urban settings, women of color have been shown to receive lower quality obstetric care and are more likely to deliver in a lower-quality hospital. 9798

States that have not participated in Medicaid expansion have seen higher rates of rural hospital closures, while the likelihood of closure significantly declined in states that expanded Medicaid, especially in rural areas. 99 Hospital closures as well as the closure of obstetric wards increase the distance that women must travel for maternity care. These closures create barriers to access and increase risk, especially for low-income women and women of color in both rural areas and cities. 100 Research confirms what common sense suggests; traveling long distances to seek health care negatively affects outcomes and imperils the lives of women and infants.<sup>101</sup>

To help eliminate maternity care deserts, policymakers should fully enforce the Improving Access to Maternity Care Act (Public Law No: 115-320), which was signed into law on December 17, 2018. The law requires the HRSA—an agency within the U.S. Department of Health and Human Services (HHS) that provides health care to underserved populations that are geographically isolated as well as medically and economically vulnerable—to identify and collect data on areas with a shortage of maternity care health professionals. 102 Policymakers should also go further and direct the HRSA to issue best practices and lessons learned from current programs, such as the Remote Pregnancy Monitoring Challenge. Such programs are designed to leverage technology to increase access to care in both low-income rural and urban settings to help inform these designations and the development of the best models of care to meet the needs of pregnant women in those areas. 103 Identifying maternity care deserts also provides critical information to the National Health Service Corps (NHSC), an organization central to filling workforce shortages in underserved areas through recruitment efforts, scholarships, and loan repayment programs for physicians, nurse practitioners, certified nurse midwives, and physician assistants. 104

As part of this effort, policymakers should also provide sufficient funding for the NHSC to recruit staff and implement a program to train and recruit health care personnel to serve communities of color. In these shortage areas, efforts must also be made to expand access to physicians, nurses, doulas (nonmedical professionals providing support during pregnancy, birth, and postpartum), midwives, and perinatal support workers—with a special focus on recruitment, training and certification of a workforce pipeline inclusive of people of color in order to meet the needs of the most affected communities. Another key component is building a workforce of health care providers that are substantively trained in cultural humility and who can be held accountable for providing patients with quality care that is equitable and unbiased. (see "The Cultural Humility Model")

#### Offer African American women tools to navigate health settings

Offering African American women more expansive choices in birthing options and prenatal care can lead to more positive birth experiences and healthy pregnancies. While some types of midwifery care are covered in state Medicaid programs, more can be done to fully integrate midwifery care into state health systems and expand insurance coverage of doula services. Both doula services and midwifery care are key to promoting birthing choice and reproductive autonomy for low-income women and women of color. These services should be available to all pregnant women, regardless of their source of insurance or income level. Health literacy and education can also support African American women and help them feel more autonomous over the health care decisions they make for themselves and their families.

#### Increase range of birth options

Women may benefit from a range of birth options that include hospitals, birthing centers, and planned home births that are attended by a physician, midwife, or doula. Regardless of where women give birth, access to a doula or midwife can provide additional support to women and potentially reduce C-section rates that put women and infants at risk. (see Figure 1)

International research shows that different birth settings and health care providers can lead to healthy births and positive birth outcomes for some mothers and infants.  $^{105}$  Although most investigations of planned home births show positive maternal outcomes—including fewer maternal complications, such as hemorrhage; greater satisfaction; and fewer medical interventions—infant outcomes are more mixed. 106 Evidence from countries such as Australia, Canada, Japan, and the Netherlands show similarly positive infant health outcomes across settings.<sup>107</sup> In the United States, however, studies suggest home births are associated with an increased risk of poor infant outcomes, including neonatal seizures; 108 low Apgar scores, a

scoring system used for rapid assessment of infant health shortly after birth; <sup>109</sup> and infant death. <sup>110</sup> Home births are safest when skilled midwives are in attendance; there are practice guidelines limiting home births to medically low-risk women following appropriate screening; and there are good working relationships between birth workers and transferring facilities. <sup>111</sup>

Reflecting on the complexity of literature on birth settings, midwife and medical anthropologist Melissa Cheyney explains, "[There is] no perfect option for birthing families in our country, and when no clear cut, risk-free option is available, we allow families to choose the option that fits best with their values, beliefs and desires."

Given that black women and other women of color often receive poorer quality care and are victims of racial bias in traditional health care settings, expanding birth options and increasing access to midwives and doulas in hospitals may lead to better outcomes for some populations. To this end, women should be given the full range of options and information before deciding the most appropriate setting for them. Opportunities to make nonhospital settings more accessible to women of color warrants further consideration.

Medicaid can help support more positive birth experiences among women by expanding free choice in birthing options. One way to expand birth options and support women's autonomy is to expand Medicaid coverage for home births and birthing centers for women with medically low-risk pregnancies. <sup>114</sup> Currently, 32 states cover birth center deliveries and 21 states cover home births under their Medicaid programs. <sup>115</sup> Oregon is an example of a state that uses Medicaid to support birth options; in a 2017 survey of states, it was the only state to cover births in birthing centers and home births as well as pay for doula services under the Medicaid program. <sup>116</sup> At the time the survey was conducted, Oregon also had one of the lowest infant mortality rates in the country at 5.4 per 1,000 live births. <sup>117</sup>

In the United States, there are about 35,000 births that take place at a woman's residence each year, which makes up about 0.9 percent of all U.S. births. The rate of home births has increased in recent years: Between 2009 and 2010, the rate of nonhospital births among white women jumped from 1.09 percent to 1.75 percent. In 2010, the rates for black and Hispanic women, by comparison, were 0.48 and 0.41 percent, respectively, pointing to barriers to accessing home births among women of color compared to white women. Among the contributing factors for this disparity is a dearth of black midwives. It is vital that efforts to expand birthing options include promoting diversity among the providers most involved in home births—midwives and doulas. It

#### Expand access to midwives and doulas

Medicaid can also support more positive birth outcomes by covering perinatal support services offered by certified midwives, doulas and other relevant providers, regardless of setting. When receiving Medicaid reimbursement, these individuals should be paid a livable wage for the health and support services they provide. <sup>122</sup> In New York's pilot program covering doula care under Medicaid, doulas are offered a minimal reimbursement rate of about \$600 per supported patient. <sup>123</sup> However, the typical payment for doulas working privately is, on average, \$1,200 per supported patient. <sup>124</sup> The ability to make a living wage is a concern for many doulas, particularly doulas of color, who often serve low-income women of color who do not have the ability to pay for their services. <sup>125</sup>

Doulas are not typically covered by either public or private health insurance. Minnesota and Oregon are the only states that currently cover doula services under their Medicaid programs, while New York, as previously noted, is testing a pilot program. <sup>126</sup> The support provided by doulas has been found to be more pronounced for low-income women, single women, and those with other social disadvantages. <sup>127</sup> Studies show that the one-on-one support of a trained doula not only helps women communicate their unique health needs and own their power in health care settings, but it also leads to positive birth outcomes for both mother and infant. <sup>128</sup>

All states cover the care of licensed midwives through their Medicaid programs, but the actual services provided vary by state due to licensure and the scope of practice requirements. <sup>129</sup> These variations have led to a patchwork of restrictions and regulations, which can be divided into three broad categories:

- Midwives must have physician supervision or a written collaborative agreement with a physician
- Midwives must have physician supervision in the provision of prescriptions
- Legislation governing the practice of midwifery both inside and outside of hospital settings<sup>130</sup>

Collaborative agreements hamper access to midwifery care when a midwife cannot identify a physician willing to sign the agreement. This can be cause for denial of payment, even if the services provided are within the midwife's scope. <sup>131</sup> The requirement of a formal agreement with a physician can also limit the availability of midwives in a particular state or hospital, leading to limitations on opportunities to practice midwifery as well as access to midwifery care for women and families in need. Similarly, the lack of authority to prescribe also imposes challenges for midwives as the requirement prevents

them from building independent practices. Lastly, regulations that stipulate the practice of midwifery in birthing centers or home births vary widely across states. Access to and the availability of midwifery care outside of hospital settings could be limited based on the state in which a woman and her family live.

Like the care a trained doula provides, midwifery care is associated with lower C-section rates, reductions in preterm birth and neonatal loss, as well as a host of other positive health outcomes for mothers and infants.  $^{132}$  It should be noted that immigrant women and black women dominated the practice of midwifery in the United States until the early 20th century. 133 The medicalization of the practice—in addition to the onslaught of regulations, licensure requirements, and other stipulations—erected barriers to midwifery care and made it much harder and more costly for women of color to practice midwifery. Therefore, policy efforts to expand access and promote safer birth outcomes for African American women must include the elimination of barriers to both training and licensure for diverse populations without compromising the integrity of the midwifery care.

#### Midwifery paths in the United States

Certified nurse midwives (CNMs)<sup>134</sup> are trained in nursing with additional training in midwifery. Certified by the American Midwifery Certification Board (AMCB), they can legally practice in all 50 states and Washington, D.C. Medicaid coverage for CNMs is mandated in all states, and most private insurance covers CNMs. CNMs most often practice in hospitals and clinics, usually alongside a physician.

**Direct-entry midwives** primarily practice outside of the hospital setting. There is no national system for licensure of direct-entry midwives, and their legal ability to practice varies by state. 135 In 17 states, midwives can be criminally prosecuted for assisting a birth outside of a hospital.136

- Certified professional midwives (CPMs) make up the majority of direct-entry midwives. CPMs are certified through the North American Registry of Midwives and their training and practice are based primarily in home births and birthing centers.<sup>137</sup> As of January 2018, 31 states provide CPMs with a path to licensure, 13 states cover CPMs under Medicaid, and six states mandate private-insurance coverage for CPMs. 138
- Certified midwives (CMs) 139 are licensed through the same process as CNMs but are not required to be trained in nursing. Like CNMs, CMs primarily practice in hospital and clinic settings. CMs are currently only licensed to practice in five states, with three of those states providing Medicaid coverage for CMs.
- Some states have additional designations for direct-entry midwives, such as Licensed Midwife or Registered Midwife. These states generally require CPM certification and an additional in-state licensure process. 140

Lay midwives, or traditional midwives, work within communities and are not officially certified or licensed.<sup>141</sup> Historically, lay midwives have voiced concerns over the regulation of the profession, which has resulted in restricting the practice of midwives—often midwives of color—and has given the medical institution sole power over childbirth.<sup>142</sup>

One way to increase access to midwives and ensure high-quality maternity care is through the integration of midwifery care with primary health care. A study conducted by the Birth Place Lab in the Division of Midwifery at the University of British Columbia found that, for states with integrated midwifery care throughout health care systems, families were more likely to have full access to high-quality maternity care. 143 The study conceptualized integration as the ability of midwives to work fully in the scope of their practice autonomously and without unnecessary restrictions, within both traditional (hospitals) and nontraditional health settings (birthing centers and home births). 144 This work was done collaboratively with other health care professionals. Washington state, New Mexico, and Oregon were ranked highest for integration. 145 The states that were cited as being hostile to midwives were concentrated in the South and also had large African American populations. 146 In addition to coverage expansions and easing restrictive laws and regulations on the practice of midwifery, policymakers should do more to fully integrate both midwifery care and doula services in health systems, which could be particularly impactful in states with large African American populations or within states with high rates of maternal and infant mortality. Better integration could be achieved by ensuring the availability of skilled doulas and midwives in hospitals and birthing centers, with a focus on doulas and midwives of color, and ensuring close coordination and collaborative working partnerships with nurses and OB-GYNs.

Policymakers should also explore ways to address variations in licensure and restrictive regulatory requirements of midwifery across states. Experts such as the National Association of Certified Professional Midwives support a national, more uniform mechanism for certifying midwives and ensuring accountability aligned with safety standards and patient-centered health care practices. <sup>147</sup> This should be done in partnership with midwives and state licensing entities in ways that support expanding access to and opportunities for people of color who seek to practice midwifery.

Unlike midwives, who are health care providers, doulas provide nonmedical support and care, and receive training and certification through a variety of programs. States that provide Medicaid reimbursement for doulas have varying requirements for participating doulas. Coverage of midwifery care and doula services varies among private health insurance plans as well. In order to encourage birthing choice for women on private insurance and contribute to national strategies and plans to eliminate racial disparities in maternal and infant mortality, private plans should also expand coverage of these benefits.

Midwifery and doula services are not consistently covered under private insurance plans, particularly for those practicing outside of hospital settings. While most insurers cover CNMs, as of October 2017, only six states mandate private insurance coverage for CPMs, who practice in birthing centers and home births. 150 States do not currently mandate private insurance coverage for doula care, which can be costly for mothers and families to pay for out of pocket. 151 In addition, private insurance coverage for birthing centers varies widely. Under the ACA, Medicaid is required to provide coverage for licensed birth centers, but private insurers have no such mandate. 152 As a result, different private plans and insurers vary in whether they provide coverage at all for these services and if there are any in-network providers of nonhospital maternity care.

#### Black women-led models of maternal health care

"Black midwives have always been an essential element of the resistance and survival of Black people"—Nonkululeko Tyehemba<sup>153</sup>

#### The legacy of the granny midwife

Until the mid-20th Century, black midwives were the primary health care providers for black and low-income white pregnant women in the South. 154 These providers, known as granny midwives, have roots during the time of slavery in the United States. 155 The midwives passed their knowledge and skills down through apprenticeships, and in the Jim Crow South, when black communities did not have access to white medical institutions, granny midwives were often the sole providers of maternal and infant health care. Granny midwives were integral parts of their communities, engaging with families and the broader community beyond the birth itself.

However, as the practice of medicine became institutionalized, granny midwives became targets, scapegoated for the South's rising infant and maternal mortality rates and branded in thinly veiled racist attacks as being uneducated and unhygienic.<sup>156</sup> By the 1950s, a majority of births, once considered the purview of black midwives, took place in hospitals overseen by an overwhelmingly white, male medical profession.<sup>157</sup> New state licensing requirements for midwives upended the granny midwives' apprenticeship model for training, and they were largely pushed out of the profession.

In recent years, midwives, doulas, and community health workers have begun to regain popularity in the United States. Despite this resurgence, the institutionalization of the certification process and the legacy of delegitimizing granny midwives has led to a midwifery profession that is overwhelmingly white, with only 5 percent of U.S. midwives being women of color.<sup>158</sup> In addition, prohibitive cost and lack of information push midwifery and doula services out of reach for many women of color and low-income pregnant women. Although Medicaid and most private insurers provide coverage for hospital-based CNMs, there are very few coverage options for women seeking perinatal support outside of hospitals.

There is, however, a growing presence of black women-led models for prenatal, birth, and postpartum care. Black women are reclaiming their role as experts in maternity care and are working to make sure that women of color have healthy, positive birth experiences. These models, which are community-based, accessible, and patient-centered, work to build care teams that look like their patients and are making progress undoing the trauma and abuses inflicted by white medical institutions on black women. Two of these models are the JJ Way and Mamatoto Village.

#### The JJ Way

The JJ Way, created by midwife Jennie Joseph, is a patient-centered model of care that seeks to address disparities in maternal and infant health care and outcomes in part by building a health care team that is culturally competent, diverse, and accessible. The JJ Way works to reduce rates of preterm birth and low birth weight, helps women and families bond with their infants, and assists in successful breastfeeding.

By centering the agency and choices of pregnant women and including them as partners in their own care team, the JJ Way seeks to reduce barriers to care, especially for low-income women and women of color. It offers clinics where no one is turned away based on lack of insurance or inability to pay; assistance in navigating the health care system; and practical solutions and care plans based on each individual's life circumstances. 159 A 2017 evaluation of the model showed that women who received maternity care through The JJ Way in Florida had lower preterm birth rates and better low birth weight outcomes than the general population in Orange County and the state of Florida. 160 The JJ Way eliminated disparities in preterm birth, and significantly reduced low birth weights for at-risk populations. 161

Despite the success of patient-centered models such as the JJ Way, nonphysician members of the care team face restrictions in their ability to practice independently and outside of hospital or clinic settings. Although midwives in Florida face fewer restrictions than in many states, direct-entry midwives, including JJ midwives, must be certified through the state and can only practice autonomously for low-risk pregnancies. 162 In pregnancies with higher risk factors, midwives must have a practice agreement with a doctor, restricting their ability to provide autonomous care.

#### Mamatoto Village

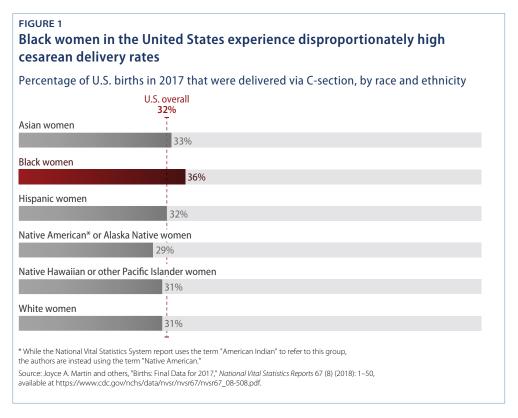
Based in Washington, D.C., Mamatoto village is a nonprofit organization that provides community support and health care services to women of color and their families, including supporting healthy pregnancy, childbirth, and postpartum experiences. Mamatoto Village believes that women are strengthened by other women from their communities and empowers women of color to become maternal health care providers, training community birth workers, perinatal community health and family support workers, and lactation specialists.

Mamatoto Village works to combat racial disparities in maternal and infant health by providing comprehensive, culturally competent services to women and families, including community birth workers; classes on childbirth, breastfeeding, and family wellness; and connections to community resources. <sup>163</sup> A 2017 review of women who received services through Mamatoto Village showed that 74 percent gave birth vaginally, 164 89 percent were able to breastfeed, 165 92 percent attended their six-week postpartum follow-up appointment, and there were zero maternal or infant losses.<sup>166</sup>

Women make their birthing choices or birthing plans, including the setting and supports that are best for them, in close consultation with their health care provider. Some women choose a home birth or a birthing center with the added support of a doula or midwife to have greater autonomy over their birthing decisions. At times, this choice is due to a lack of proximity to a hospital. For rural women, the closest hospital can be more than an hour away. For African American women, the choice to deliver at home could also be associated with the fact that the nearest hospital is a low-quality facility that lacks compassionate providers that adequately consider their lived experiences. Approximately 3 out of 4 black women will give birth at low-quality hospitals, where their risk for poor maternal health outcomes is the highest. African American women are more likely to live in segregated neighborhoods and the hospitals within those communities tend to be of lower quality, especially for maternity care. Women may also consider giving birth at home or in a birthing center due to the desire to have a vaginal birth as opposed to C-section. 169

#### Halt the overuse of C-sections in the United States

In a racially and ethnically diverse sample of Medicaid recipients, mothers who received prenatal education and childbirth support from trained doulas had lower odds of C-sections and preterm births compared to mothers who did not receive doula services, even after controlling for clinical and socio-demographic factors. <sup>170</sup> A C-section—where the fetus is removed through an incision in the woman's abdomen and uterus—is a major surgical procedure and is generally associated with greater risks than vaginal deliveries. <sup>171</sup> These risks can include surgical injury to the fetus, infection, postpartum hemorrhage, blood clots, and increased risks during future pregnancies. <sup>172</sup> The rates for maternal mortality and severe maternal morbidity are about three times higher for women who had C-sections versus vaginal deliveries. <sup>173</sup> In the United States, black women are more likely to undergo C-sections, even for low-risk pregnancies, when compared to other women of color groups and white women. <sup>174</sup> Some states, including Louisiana, Mississippi, and Florida, which have high percentages of African American residents, have C-section rates of more than 37 percent. <sup>175</sup>



Furthermore, the overuse of C-sections among U.S. women has been a cause for alarm among leading women's health care and infant health care experts in recent years. Cesarean deliveries are the most common major surgery performed in the United States—approximately 1 out of 3 infants are delivered via C-section each year. 176 Moreover, according to the World Health Organization, C-section rates greater than 10 percent at the population level are not associated with a reduction in maternal and infant mortality rates.<sup>177</sup> In 2014, the ACOG and the Society for Maternal-Fetal Medicine released an article outlining clinical and scientific considerations for reducing the rate of primacy care C-sections, which they reaffirmed in 2016. A key component in this article was the affirmation that the presence of support personnel for pregnant women, including a doula, is an important aspect in helping to improve labor and delivery outcomes as well as reducing the likelihood of receiving a C-section. 178 Health care providers should inform all patients of the risks associated with C-sections when compared to vaginal deliveries and use the ACOG's guidance to reduce C-section rates among women with low-risk pregnancies.

#### Ensure health literacy and childbirth education

Women of color-led, community-based organizations also play a key role in ensuring health literacy among pregnant and postpartum women of color. These education efforts are essential to help save lives by assisting mothers and families to attain a range of skills and competencies that help them seek and understand health information in order to make informed choices and reduce health risks. 179 For example, Ancient Song Doula Services, based in New York, offers an array of courses that include childbirth education, safety planning, and advocacy services and support groups. 180 These courses help women of color own their power, which translates to knowledge about their health and legal rights as well as the signs and symptoms of pain or distress. Advocacy services and support groups, such as Ancient Song Doula Services, give women the tools they need to exercise their rights while in the care of hospitals and other health care providers.

Policymakers should support grant funding in health literacy, education, and training for women of color-led, community-based organizations in order to sustain and expand these important programs. This funding can also help in the assessment and evaluation of these programs as well as duplication and modeling for broader communities and audiences. Policymakers and public agencies should also spearhead opportunities to make meaningful changes to the current health care system and traditional practices that improve health provider literacy. This includes developing policies, guidelines, and regulations that help practitioners to reduce persistent disparities and encourage them to seek out partnerships beyond traditional health and educational sectors to better engage and serve their patients and clients.<sup>181</sup>

# Improve the quality of care provided to pregnant women

Simply spending more on maternity care will not improve outcomes. Instead, policymakers must take a multifaceted approach that invests in building a diverse workforce; ensures there are standardized, evidence-based guidelines for care and assessments for new mothers; and builds a focus on preventive care, wellness, and mental health for expectant mothers. In addition, there should be payment incentives for health care providers to reward care that not only meets these standards but also improves mothers' experiences during and after their pregnancies.

This should go without saying, but women and families of color must be treated with dignity and respect when in the care of health providers. When pregnant and postpartum African American women express pain or discomfort, providers must recognize and respect their bodily autonomy by listening to them and addressing their health needs immediately. Interventions to address racism and bias in health care can work, but it takes commitment and concerted effort at the health systems level as well as at the individual level among health care providers. Achieving health equity—where every person has a fair and just opportunity to be healthier— must be the priority.<sup>182</sup> Getting to this goal requires removing barriers to care, such as poverty, discrimination, racism, sexism, and other societal ills. Hence, health care providers must consider the lived experiences of their patients and not only provide them with comprehensive and quality health care services but also compassion.

#### Train providers to address racism and build a more diverse health care workforce

Training health care professionals using a cultural humility model—where one is affirming of and sensitive to cultural differences—is critical to combating racism and unequal treatment in the health care system. Trainings to foster cultural humility should be implemented in both educational programs and licensing for staff and be embedded in regular ongoing trainings that occur in health care settings as a requirement of maintaining licensure. Policymakers must provide funding and support for

meaningful trainings on cultural humility<sup>183</sup> for all staff and personnel who interact with or engage pregnant women and families of color, including those not part of the medical team, such as emergency room or urgent care support staff. <sup>184</sup> OB-GYN residents should also receive cultural humility training. Critically, such training must be process-oriented, as opposed to a check-the-box model where superficial indicators or tasks are identified, and health care providers mark them on a list to fulfill cultural competency training as an end result. Of course, these trainings should be integrated with other trainings that ensure safety protocols and prioritize quality of care for all women.185

#### The Cultural Humility Model: An effective approach to addressing bias and racism

According to the article "Cultural Humility: Measuring Openness to Culturally Diverse Clients," cultural humility is the ability to have an interpersonal viewpoint that is open to those with different cultural backgrounds. 186 This model is viewed as a promising approach because it focuses on a life-long commitment to self-evaluation and self-critique—acknowledging that learning and commitment to embracing cultural differences are continual.

Another key aspect of the cultural humility model is to fix power imbalances. 187 In the context of maternal health care, power imbalances may be seen in women's interactions with OB-GYNs, nurses, and other health practitioners. These power imbalances may also be seen in a mother's interactions with her infant's pediatrician. It has been documented through the personal stories of black women that physicians, at times, ignore their requests for pain management or "talk down" to them during pre- and postnatal care visits. 188 Women should hold just as much, if not more, decision-making power as providers when it comes to their health care. In practical terms, a health care provider and patient should work together to collaborate and devise treatment plans that consider the personal history and health care preferences of that patient as well as the professional knowledge of the health care provider. This approach could have a positive impact in that it treats the patient and health care provider as equals.

Lastly, the model calls for the development of partnerships with individuals and entities that advocate on behalf of others. This can include family members, community partners, and perinatal support workers who also have a role in helping to dismantle structural racism and systemic inequality in partnership with health care providers.

A service-learning component should be part of all cultural humility trainings, which would require physicians and nurses to work in underserved communities to get a better sense of their patients' lived experiences. Perceptions about biological differences between racial groups, particularly those pertaining to African Americans—for example, that they have "tougher skin"—must be dismantled. 189 The trainings must be assessed and evaluated periodically by state and local health departments, including patient surveys and interviews. Over time, policymakers can use these results as part of broader efforts to align payment with quality, such as rewarding providers that successfully reduce racial disparities in maternal and infant mortality.

Additional research within actual health care settings is also needed to assess the impact of racism and bias on patient care and maternal and infant health outcomes. Policymakers should fund these additional research needs, allocating funds to the CDC and the National Institutes of Health (NIH). Moreover, grant-making should ensure diverse representation of researchers and project leads representative of the communities most heavily affected, with expertise in examining racism and bias within the health care system. Progress should be reported to Congress and the HHS in order to help inform national strategies to reduce maternal and infant mortality.

It is also critically important that national Culturally and Linguistically Appropriate Services (CLAS) standards are implemented adequately within health care settings in order to promote health equity, improve quality of care, and support women and families for whom English may not be their primary or preferred language. 190 These standards help address the need for respectful, quality health care services that are responsive to diverse populations. CLAS standards can also help reduce health disparities by helping to tailor health care service delivery in a way that supports individual health care preferences, varying competencies in health literacy, and cultural needs. Proper implementation of CLAS standards goes hand in hand with trainings in cultural humility and addressing bias and should be engrained throughout health care entities and systems.

In addition to training providers in cultural humility and bias, in order to confront high rates of maternal and infant mortality, it is equally vital to grow a diverse, culturally competent maternity care workforce. A report from the ACOG found that in 2016, only 11 percent of OB-GYNs were African American.<sup>191</sup> For women who choose to give birth in a hospital or clinic setting, a diverse medical team is important for building trust and understanding between a pregnant woman and her care team. This relationship is particularly important for black women, who have suffered a long history of obstetric violence and abuse in the medical system. 192 Pregnant

women must be able to trust that their providers will respect their autonomy and value them as experts of their own experience and needs. A diverse care team must also integrate doulas, midwives, and community-based perinatal health workers. The support of a care team that looks like their patients; will listen to women of color; look after their physical, mental, and emotional well-being; and see the totality of their life circumstances can play a significant role in helping women and infants not only survive but also have positive, empowering experiences.

#### Create standardized assessments for mothers and infants

Policymakers should consider convening a committee to explore the feasibility and utility of creating a standardized assessment for mothers and infants after delivery and at certain milestones, akin to the Apgar score, as a way to improve quality and trigger necessary medical interventions for mothers. Created in 1952 by Dr. Virginia Apgar as a method of assessing the clinical status of newborns in the minutes immediately after delivery, the Apgar score has been an accepted and convenient method for quickly assessing infant health for more than 60 years. 193 By focusing on five easily identifiable characteristics—heart rate, respiratory effort, muscle tone, reflex irritability, and color—the Apgar score introduces consistency in how infants are assessed and eliminates some of medical personnel's subjectivity and potential biases. Some research suggests that mothers whose infants have low Apgar scores are also more likely to be admitted to an intensive care unit (ICU). 194 To the authors' knowledge, no measure equivalent to the Apgar score exists for women after labor and delivery. Policymakers should facilitate further research into whether Apgar scores or similar standardized measures for mothers and infants can be implemented to help medical personnel avoid severe maternal morbidity and mortality. This research should include the benefit of maternal safety bundles and other action measures.<sup>195</sup>

#### Adopt new models of care and link payment to quality

Changing how Medicaid and other health care payers pay for maternity care is critical to improving quality. Adopting new models of care that focus on preventive care and care coordination—in part, by linking payment to quality and rewarding providers who offer high-quality, evidence-based, culturally competent care—can be an important tool to help reduce maternal mortality.

The default payment approach throughout the health care system has traditionally been fee-for-service payments, which pay doctors, hospitals, and other health care providers separately for different items and services furnished to the patient. This system rewards quantity over quality, especially for high-cost, high-margin services. For example, under the fee-for-service system, doctors will be paid more for delivering an infant via C-section regardless of the medical necessity of the procedure.

Health care payers, including Medicaid programs, are increasingly adopting reforms that flip these incentives and link payment to the quality of care provided and patient outcomes. In addition, these reforms are designed to encourage care coordination across different providers. In the maternity care context, policymakers can design reforms to encourage coordination between different providers and a greater focus on preventive care and mental health care throughout pregnancy. Studies show that integrated behavioral health and primary health care models not only lead to improvements in quality care and access but also to improved physical and mental health of patients.<sup>196</sup> Policymakers can also consider new models of payment that encourage care at birthing centers.

New payment and delivery models, for example, can reward health care practices that offer exceptional care. Evidence-based, consistently applied patient-reported outcome measures that evaluate experiences during pregnancy and delivery will help to incentivize the correct care behaviors. In addition, health care payers including Medicaid programs—should evaluate care coordination best practices, including any requirements to connect patients with local, culturally sensitive nutritional counselors; sleep and breastfeeding experts; and other health literacy and education programs.

Regardless of the specific model adopted, these reforms are designed to improve not just patient outcomes but also women's experiences as they move through the health care system during pregnancy.

#### Payment and delivery models

Patient-centered medical homes<sup>197</sup> are typically primary care practices that focus on preventive care, patient education, and care coordination between different health care providers. In the maternity care context, instead of a primary care physician, the woman's obstetrician is the primary provider during and after the pregnancy.

**Episode-based or bundled payments** are payments to a health provider for a bundle of services needed by a typical patient during an episode of care—in this case, a payment to an obstetrician that covers care needed throughout the woman's pregnancy and for a set postnatal period. Like the medical home model, the primary physician is then responsible for coordinating care and ensuring the patient receives all necessary services. If doctors provide high-quality care, as evidenced through meeting various quality measures, they can keep any amount that exceeds their costs.

#### Medical home and episode-based payment examples Wisconsin's Obstetric Medical Home Program

In order to address high costs and poor health outcomes, Wisconsin's Medicaid program launched the Obstetric Medical Home Program (OBMH). 198 Primarily targeting high-risk pregnant women, the medical home model included several measures to incentivize care coordination and improve overall care quality. Under the OBMH, each participating patient is assigned an obstetric practitioner to serve as the primary provider during their pregnancy, and patients are required to attend 10 prenatal visits and at least one postpartum visit within 60 days after the birth. All medical homes must also have designated care coordinators on site who develop care management plans for patients. Providers are eligible for up to \$1,000 in bonus payments for each patient that meets enrollment criteria in addition to receiving similar bonuses for each positive birth outcome.

In the case of a poor birth outcome (including low birth weight, preterm birth, neonatal death, or stillbirth), the medical home is required to provide follow up maternal and infant care for two years after the birth, including mental health services. 199 As of 2015, the state experienced an increased rate in postpartum care visits from 61.4 percent in 2013 to 85.5 percent in 2015 and increased delivery of timely postpartum care. 200

#### North Carolina's Pregnancy Medical Home

In 2011, Community Care of North Carolina partnered with the North Carolina Divisions of Medical Assistance and Public Health to launch the Pregnancy Medical Home (PMH) program in an effort to increase access to care and improve health outcomes for Medicaid recipients.<sup>201</sup> Under PMH, participating providers must perform risk screenings for each Medicaid patient seeing a participating provider for her pregnancy to determine if they are at risk for premature birth. Moreover, PMHs must refer at-risk patients to pregnancy care managers to develop individualized plans to prevent poor birth outcomes. In return, participating providers receive additional payments: \$50 per initial risk screening, \$150 per postpartum visit, and enhanced Medicaid reimbursement for vaginal deliveries.<sup>202</sup> As of 2017, there were 380 PMHs across 94 of the 100 counties in the state. About 80 percent of pregnant women complete risk screenings, and the state has seen a decline in elective deliveries (C-sections and induced labor) before 39 weeks.<sup>203</sup>

#### Arkansas and Tennessee episode-based payments for maternal care

In 2012, Arkansas launched perinatal episode payments under the Arkansas Health Care Payment Improvement Initiative (AHCPII), a statewide payment reform model. The perinatal episode payment model sets spending targets for each episode, covering prenatal care, labor and delivery, and postpartum maternal care. The physician who performs the delivery, or the Principal Accountable Provider (PAP), is responsible for excess costs but also is eligible to receive shared savings by meeting quality standards. Under the program, the state experienced a significant decrease in C-section births—dropping from 39 percent in 2012 to 32 percent in 2015, the most recent data available. Moreover, average costs per episode decreased from \$3,508 to \$3,413 over the same period. The National Bureau of Economic Research found that, in Arkansas, perinatal episode payments reduced spending by 3.8 percent relative to other states. Description of the payments reduced spending by 3.8 percent relative to other states.

Tennessee launched perinatal and other episode-based payments for the state's Medicaid program in 2014. Similar to Arkansas' model, perinatal episode-based payments under this model included prenatal care, labor, and delivery as well as 60 days of postpartum care. The PAP is eligible to receive shared savings if the episode met certain cost and quality thresholds. From 2014 to 2015, Tennessee experienced a 3.4 percent decrease in the cost of perinatal care, and gain-sharing payments (additional payments to providers who demonstrate cost-effective care) exceeded risk-sharing payments (which require providers to take on a portion of the cost in excess of the "acceptable threshold" for the cost of a procedure) by \$280,000. The combination with two other episode-based payments launched in 2014, the state achieved \$11.1 million in total savings from 2014 to 2015.

# Address maternal and infant mental health

Mental health services are covered by Medicaid and are part of a package of essential health benefits required for individual market and some employer-based health plans under the ACA. Yet accessing this care remains challenging—only 41 percent of adults living with a mental illness in the United States have received mental health treatment over the past year. 209 Access is especially limited for women of color, who are still woefully underserved by the mental health profession and relevant support services. In fact, black women are half as likely to receive mental health treatment and counseling as white women.<sup>210</sup>

Maternal depression and other perinatal mood disorders are linked to risk factors for maternal mortality and morbidity, including hypertension, 211 preeclampsia, 212 and gestational diabetes.<sup>213</sup> Mood disorders are prevalent among new mothers, particularly women of color who grapple with myriad stressors, including racism, coupled with the mental health strains resulting from motherhood daily. Studies show that African American and Hispanic mothers who experience maternal depression have higher rates of adversities than their white counterparts.<sup>214</sup>

Women of color are also least likely to have access to mental health care during pregnancy and in the postpartum period. 215 Barriers to accessing care manifest in different ways, and often involve problems related to the affordability, availability, and geographic accessibility of mental health services. Specifically, cost barriers (such as limited in-network providers and other structural costs); barriers due to provider shortages and long wait times; geographical disparities in access; barriers for women with disabilities; and a dearth of culturally sensitive care pose the greatest challenges to accessing care.

In contrast to maternal mental health, infant mental health remains less understood. However, research suggests it is no less important. Young infants can still show signs of depression such as inconsolable crying, sleep problems, and slow growth. <sup>216</sup> But infant mental health goes far beyond behavior. Early experiences are encoded in infants' brains as they are developing. Sensitive, responsive interactions with adults

and caregivers strengthen the rapidly forming neural connections in developing brains. However, often through no fault of their own, some parents may need support to provide these interactions. For example, mothers living with mental health challenges or experiencing depressive symptoms—exhaustion, sadness, distraction, irritability—could be less able to pick up on their infant's cues.<sup>217</sup> Similarly, a mother physically recuperating from a severe pregnancy or labor-related injury or complication, such as an infection, may be less able to quickly respond to her infant during her recovery, especially if she lacks access to adaptive parenting supports. <sup>218</sup> In the case of maternal death, the chance for any interactions with the mother disappears and the quality of interactions with other caregivers may also deteriorate as the surviving family grapples with grief and loss.

Each of these scenarios describes an adverse childhood experience (ACE): a potentially traumatic early experience that can lead to lasting negative effects. 219 Other scenarios that could instigate ACEs in a child, even in infancy, include exposure to violence within their neighborhoods; the loss of a parent to incarceration; homelessness; racial or ethnic discrimination; and income insecurity.<sup>220</sup> Given the long history of racism and bias in the United States, some communities of color are more likely to experience these traumatic events. In a recent survey, researchers found that nationally and across every region in the United States, the prevalence of ACEs is highest among African American children.<sup>221</sup>

ACEs can set in motion a child's stress reactions that—when activated repeatedly or for prolonged periods without relief—can disrupt normal physical and cognitive development. Research ties this sustained stress to chronic health conditions in adulthood such as diabetes, heart disease, and immune system dysfunction.<sup>222</sup> Importantly, research implicates many of these conditions in maternal and infant mortality. This means that a mother's death or near miss in the present may leave a lasting impact on her child's health as an adult. If this child grows up and wants to carry a child of her own, the trauma of her childhood can undermine her health, which in turn affects the health of her future children.

# Identify barriers to accessing maternal mental health services

Two of the greatest barriers preventing pregnant and postpartum women of color from accessing mental health care are the availability of providers and the resulting higher cost of care. <sup>223</sup> <sup>224</sup> The reasons are tied to low levels of provider participation in network plans as well as structural costs related to pursuing care. Mental health

providers have notably lower levels of participation in both private insurance and Medicaid. <sup>225</sup> A *Health Affairs* report found that only 42.7 percent of psychiatrists and 19.3 percent of nonphysician mental health care providers participated in private network plans in state-level markets. <sup>226</sup> The participation rates for Medicaid are not much better. In a 2015 survey of about 4,500 mental health providers, more than one-quarter of the respondents did not have a single Medicaid patient.<sup>227</sup> Mental health professionals are reluctant to participate in network plans due to heavy administrative burdens and other provider-side barriers specific to mental health that make the provision of care often financially and practically unfeasible. In fact, the incentive for providers to remain out-of-network is great: Commercial plans reportedly reimburse out-of-network mental health care providers 53 percent more for psychotherapy services compared to in-network providers.<sup>228</sup> Providers also cite Medicaid's low reimbursement rates and other time-consuming administrative processes, such as prior authorizations, as prohibitive and reasons for not participating in Medicaid.229

As a result, countless patients have at best inadequate insurance coverage for mental health services, forcing many to seek out-of-network care and absorb higher outof-pocket costs.<sup>230</sup> This is borne out by facts: According to a 2015 survey by the National Alliance on Mental Illness (NAMI), 1 in 4 respondents did not have a mental health therapist or prescriber in their health plan's network, compared to only 1 in 10 not having an in-network medical specialist. 231 About 70 percent of participants in the survey also reported facing difficulties when trying to find a prescriber that would accept their insurance. In terms of cost, 8 in 10 respondents had out-of-pocket costs topping \$200 for mental health services, including psychiatric hospital and residential mental health care. <sup>232</sup> Women of color are more likely to be enrolled in Medicaid than white women and continue to be uninsured at higher rates, meaning that these low participation rates and out-of-network costs are felt most keenly amongst them.<sup>233</sup>

Other cost barriers faced by pregnant and postpartum women of color are structural in nature. In a study that analyzed data from the Women's Employment Study, researchers explored the use of mental health and substance abuse treatment among a group of low-income women, 55 percent of whom were black.  $^{234}$  Among the cited barriers that resulted in increased cost of treatment were a lack of childcare, the cost of treatment itself, and a lack of transportation.<sup>235</sup> Taken together, these cost factors collude to make the affordability of mental health services difficult if not insurmountable for many women of color—a demographic that already faces systemic barriers to accessing structural supports related to childcare and transportation.

The shortage of mental health professionals throughout the United States poses a significant challenge related to the availability and accessibility of mental health care. A 2016 report by HRSA revealed that, by 2025, there will be significant shortages of psychiatrists, psychologists, social workers, and other mental health professionals. The lack of availability of mental health care is already leading to long wait times, causing patients to delay or forgo care altogether. Moreover, the few available providers are geographically clustered in certain parts of the country, leaving many counties with no local behavioral health providers. Rural areas are the most underserved, with some rural communities having virtually no access to mental health services. Regional differences are also stark. Almost 70 percent of counties in the New England region had access to a psychiatrist, while only 6 percent of counties in the West North Central region, including Oklahoma, Missouri, and North Dakota, had similar access.

# Dismantle care barriers with a comprehensive approach

Policymakers need to take a multipronged approach to address barriers to accessing care, which in many cases are interconnected. In the short term, policymakers should focus on encouraging existing mental health providers to participate in greater numbers in Medicaid as well as in other public and private insurances sources so that patients can access a greater breadth and quality of care and associated benefits. Higher Medicaid payment rates will encourage more behavioral health providers to participate in the program. Second, to help offset these costs for states, federal policymakers should increase the federal share of Medicaid payments for mental health care services. Higher payment rates are a critical first step in ensuring that all women enrolled in Medicaid can access vital benefits such as screenings for depression for pregnant and postpartum women. Additionally, public and private health insurers should consider covering nontraditional, alternative behavioral health therapies such as meditation or art therapy, which promote good mental health and patient choice in treatment options.

States should also increase access to mental health services that might not be readily available in a woman's neighborhood by encouraging the use of telehealth. Telehealth is a new field that brings together advances in technology with the growing demand for greater access to healthcare. The technology, accessible through mobile phones or computers, provides patients with access to health care services at the tip of their fingers and the ability to manage their health care, thereby cutting down on costs, unnecessary travel, and other barriers. As of 2017, providers are reporting a telehealth

adoption rate of 71 percent and are seeing great utility in using this technology to enhance their practice.<sup>241</sup> Its use for mental health services in particular has been adopted by the federal government: The U.S. Department of Veterans Affairs (VA) announced a rule last year that would allow VA doctors, nurses, and other providers to administer care to veterans using telehealth technology for, among other things, mental health services.<sup>242</sup> Telehealth lowers barriers to ensure veterans are better able to access care and is also beneficial to veterans living in rural settings, who may have been unable to access care because of logistical or transportation barriers. Likewise, telehealth can be used to improve maternal mental health outcomes, linking pregnant and postpartum women who may otherwise be unable to access vital mental health services with the care they need through digital avenues.

States can also increase access to mental health services by covering transportation costs to and from appointments. Medicaid currently provides enrollees with access to nonemergency medical transportation (NEMT), a benefit that is predominantly used for mental and behavioral health services. <sup>243</sup> Certain states, such as Arkansas and Massachusetts, have in recent years made efforts to limit NEMT while others, including Iowa and Indiana, have waived the benefit for their Medicaid expansion populations.<sup>244</sup> Thankfully, most states continue to make a commitment to provide NEMT to Medicaid enrollees, including those in expansion groups. A woman's ZIP code should not be the reason she lacks access to mental health services, particularly when she is grappling with the demands of parenthood as a new mother or while she is pregnant. These are the times when women are at increased risk of experiencing life stressors and mood disorders are more likely to arise.

In addition, the federal government should provide states with funding to implement patient safety bundled care. A concept introduced by the Institute for Healthcare Improvement (IHI), bundles offer a way to standardize care across hospital systems and practices while improving the quality of care and patient outcomes. The Council on Patient Safety in Women's Health Care took the concept a step further by proposing patient safety bundles primarily focused on improving maternal health outcomes, from maternal mental health to reductions in peripartum racial and ethnic disparities. 245 Maternal mental health recommendations include making mental health screening tools available in every clinical setting and educating staff on their use; providing patients and family members with perinatal depression and anxiety awareness education; and performing a comprehensive and multidisciplinary review in the event of adverse health outcomes.<sup>246</sup>

# Impact model

Similar to IHI's patient safety bundles, the University of Washington developed the Improving Mood-Providing Access to Collaborative Treatment (IMPACT) model, which uses a team-based approach to integrate depression treatment into primary health care as well as other medical settings.<sup>247</sup> After undergoing an assessment to determine impact, the model was shown to be more than twice as effective in treating depression and improving the physical health of patients when compared to other care.<sup>248</sup> It was also proven to reduce health care costs.

Mental health screenings, another key improvement to service delivery, should be routine and integrated into other health care settings for pregnant and postpartum women, as recommended by the U.S. Preventive Services Task Force (USPSTF).<sup>249</sup> USPSTF is an independent panel of national experts working to improve health by making evidence-based recommendations about preventive health services and medications.<sup>250</sup> Studies show that integrated behavioral health and primary health care models not only lead to improvements in quality care and access but also improved physical and mental health of patients.<sup>251</sup> The American Academy of Pediatrics (AAP), the ACOG, and the American Academy of Family Practitioners (AAFP) also advocate that perinatal depression screenings be conducted during pediatric developmental screenings to ensure women have increased access to mental health services during a natural point of engagement. Unfortunately, one-third of state Medicaid programs still do not permit reimbursement for maternal depression screenings provided during pediatric visits. 252 253

While routinized screening, integration, and expansions in coverage have helped some people gain access to important mental health services, evidence suggests that more can be done on this front. Barriers to accessing behavioral health providers and treatment, including prescription drugs, therapy sessions, and alternative therapies, still exist for many and have a disproportionate impact on people of color with mental health challenges. Policymakers should fund research to examine the barriers to screenings, the uptake of follow-up mental health care, as well as whether disparities exist in the implementation of mental health services.

These changes are certainly important short-term interventions, but federal policymakers must also make longer-term investments to build a more robust, welltrained behavioral health care workforce that can provide culturally appropriate care. Proposals to accomplish this include expanding federal and state loan repayment programs for mental health professionals to practice in underserved areas and expanding the numbers of midlevel and paraprofessional providers added to the workforce. For example, federal policymakers should increase funding for the Substance Abuse and Mental Health Services Administration (SAMHSA) Minority Fellowship Program.<sup>254</sup> SAMHSA, an agency within the HHS, aims to reduce the impact of substance abuse and mental health in America, and its Minority Fellowship Program is a grant initiative that provides funding to organizations to build out a pool of mental health practitioners that can serve communities of color. In addition, programs run by nonprofit, community-based organizations such as Mamatoto Village are also vital to addressing mental health conditions amongst pregnant and postpartum women, particularly women of color, because they are rooted in the community and are committed to crafting solutions that meet a woman where she is.<sup>255</sup> By increasing funding for these programs, not only can mental health professionals attain proper training, but more mental health professionals of color can also enter the workforce, which is key to ensuring the development and implementation of culturally sensitive mental health treatment.

The stigma associated with mental health is yet another barrier preventing many women from seeking mental health care. That being the case, policymakers should fund education campaigns and other efforts that work to change the culture and thinking around mental health that contribute to its stigmatization. New York City's ThriveNYC mental health initiative does just that. Spearheaded by New York City's first lady Chirlane McCray, in partnership with historically black organizations, the initiative aims to train 10,000 African Americans in mental health first aid with the goal of increasing mental health awareness and dismantling mental health stigma within the African American community.<sup>256</sup> It is also important to continue spreading awareness about the protections offered by the Americans with Disabilities Act and Section 504 of the Rehabilitation Act for women with mental health disabilities. Policymakers should ensure that pregnant and postpartum women with disabilities, including mental health disabilities, are provided accommodations to access mental health care—a right that is protected under these important federal civil rights laws.

Health care providers and communities must be educated about the importance of access to and utilization of mental health care among African American women. Good mental health should be acknowledged as an essential part of overall wellness. The supported education campaigns should reach local and national audiences and must prioritize the lived experiences of pregnant and postpartum African American women, including the need to dismantle the perception that black women must be strong at all times and do not need the space to be vulnerable, also known as strong

black woman syndrome<sup>257</sup>. These efforts must also help African American women to recognize the signs and symptoms associated with mood disorders and address the ways that racism, ableism, and gender discrimination impact mental health. Policymakers should issue grants for such campaigns and work with an array of entities, including religious organizations, women of color-led groups at the national and state level, disability justice groups, and community-based organizations.

# Screen for and address infant and early childhood mental health issues

Adverse childhood experiences and childhood trauma can have devastating, longterm consequences for children's future health and development. However, research also shows that forming strong, supportive relationships with adults is key to helping children overcome this trauma.<sup>258</sup> Recognizing that prevention and timely intervention is critical, most states' Medicaid programs cover socio-emotional screening and infant and early childhood mental health services in the home, pediatric, or early learning settings. 259 Nevertheless, several states understand that more can be done. To this end, a few states and territories have recognized the key role of local governments in detecting ACEs and quickly connecting families to treatment. In 2011, Washington state became the first state to enact legislation aimed at this issue, passing a law that required a multistakeholder group to identify ways to reduce and prevent ACEs.<sup>260</sup> More recently, California Gov. Gavin Newsom (D) released a state budget that includes significant investments in early developmental screening, including screening for ACEs, and trauma-informed care. 261 Gov. Newsom's appointment of Dr. Nadine Burke Harris as the state's first surgeon general is also significant. As a black woman and expert in ACEs and social determinants of health, Dr. Burke Harris can use her lived experiences to reach and inform families across the state.<sup>262</sup> As the impact of these state-level policies becomes clearer, federal policymakers should look to effective policies as models for national action.

# Enhance supports for families before and after birth

All parents with infants need support to thrive, especially during the critical time before and after birth. Many parents' joy at welcoming a new infant is tinged with anxiety and exhaustion as they navigate the new, constantly shifting terrain of pregnancy and a child's first months. This period can be especially stressful for African American mothers, who may have experienced complications during pregnancy and delivery and who also carry the physical and emotional impact of structural racism. Mothers without enough physical and emotional support may miss critical pre- and postpartum medical care and can develop physical complications (for example, hypertension or gestational diabetes) and mental health complications (for instance, postpartum depression) that endanger her long-term health as well as the health and development of her infant.<sup>263</sup>

As many new mothers are still physically recuperating from childbirth, they also face the demands of caring for an infant at a moment when two critical resources—money and time—are especially scarce. Because parents of infants are often early in their careers, they earn less and have less savings on which to draw. In the first year of life, an average family expects to spend \$12,000 on child-related expenses. 264 The financial squeeze following the birth of a child is particularly pronounced for African American families, who own only one-tenth the wealth of white families, a long-term consequence of racist social and economic policies, racial segregation, and slavery.<sup>265</sup>

As parents encounter the financial strain of a new infant, they find themselves waking throughout the night to feed and care for their infant, which leaves them sleep deprived or exhausted throughout the day. Postpartum sleep difficulties are common and insidious, and research points to a vicious cycle between sleep and postpartum depression.<sup>266</sup> Financial strain and poor sleep mean that the perinatal period is ripe for mental health challenges for many families. It should come as no surprise then that perinatal mood disorders affect approximately 20 percent to 25 percent of mothers from all backgrounds.<sup>267</sup> As maternal mental health plays a role in maternal and infant health, its prevalence is a potential public health concern. However, there are few programs that treat it as such.

A lack of investment in critical pre- and postpartum programs means that adjusting to parenthood can be especially difficult for the 1 in 5 families of infants and tod-dlers living in poverty. The racial and gender wage gap, along with educational and job discrimination, mean that African American women are twice as likely to live in poverty, as compared to non-Hispanic white women. In addition, hourly earners and low-wage workers—with women of color and black women over represented in both categories—are less likely to have paid leave. Programs that help families afford the basics, such as Medicaid, housing assistance, and nutrition assistance programs, are often underfunded, making them unable to serve all eligible families. For example, the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC)—which provides nutritious food, formula, and other services to pregnant women, postpartum women, and children under age 5—served just over half of all eligible people in 2014. Program for 2014.

To be sure, maternal and infant mortality rates are elevated for black women and infants across the socio-economic spectrum and, as mentioned above, education and income do not guard against maternal and infant mortality. At the same time, poverty is correlated with maternal and infant deaths. Poverty can be understood as another mechanism through which racism results in disparities in maternal and infant mortality.

Ultimately, to improve the well-being of African American families across the socioeconomic spectrum, targeted interventions should be embedded in a larger system of robust, universal, and appropriately financed services.<sup>272</sup> To prevent the physical and mental health complications that contribute to maternal and infant mortality—especially among African American women and infants—the United States must create conditions that support a broader notion of community health. This first means ensuring that all families can meet their basic needs and easily access the care and resources that support their health. Next, it means promoting a dense network of positive social supports and connections, especially for new families. These connections can help protect against the emotional and physical effects of traumatic events and improve mental well-being.<sup>273</sup> Social support is especially critical for African American women, who are more likely to experience trauma due to systematic racism and bias. Finally, it requires that services and supports be delivered via community-based solutions. Community leaders already working with those most affected by maternal and infant mortality should spearhead these programs. This approach helps address the systematic bias that has undermined the efficacy of support programs, fostering trust and reciprocal help in its place.

# Invest in and expand access to policies and programs that support families' basic needs

The federal government funds several benefit programs that provide income, housing, nutrition, and other supports to families. These programs improve maternal and infant health by providing basic living supports essential to the immediate safety and well-being of families.<sup>274</sup> Doing so improves stability and security—the building blocks of healthy families and a necessary ingredient in children's cognitive development and long-term educational success.<sup>275</sup> Although not explicitly designed to address maternal and infant health, research shows that many of these programs nevertheless improve health. For example, studies show that participation in nutrition assistance programs such as WIC and the Supplemental Nutrition Assistance Program (SNAP) is associated with a decline in low birth weight births<sup>276</sup> and higher rates of breastfeeding.<sup>277</sup> To improve maternal and infant health, policymakers should invest in nutrition programs, including switching to the low-cost food plan from the thrifty food plan to increase SNAP benefits, <sup>278</sup> boosting the supports families receive.

The Title V Maternal and Child Health Block Grant also represents a significant source of funding dedicated to improving the health and wellness of the nation's pregnant women, mothers, infants, and children. In 2017, Title V grants were dispersed to 59 states and jurisdictions and provided funding for health care services for 56 million Americans.<sup>279</sup> As one of the largest federal block grant programs, it is vital that Title V funding is provided to grantees based on selection criteria that are grounded in evidence-based solutions and not influenced by ideology or partisanship.

Many of these programs have experienced an erosion of funding and subsequent reduction in number of families served.<sup>280</sup> Experts argue that current federal investments offer only minimal support for the most vulnerable families with young children.<sup>281</sup> In order to provide more families with the services they need to thrive, Congress should fully fund these programs and resist efforts to impose barriers to eligibility such as work requirements, which kick participants off the program.<sup>282</sup>

# Invest in community programs that offer one-stop comprehensive services

Families looking for additional support face a fragmented system, beginning with where services are located. A family seeking housing or food assistance must begin by visiting a social service office during regular business hours. This can require taking time off work, arranging for child care (or bringing children to appointments), and securing transportation—often with no guarantee that, in the end, they will receive the necessary supports. In many cases, they must repeat this entire process for each benefit.<sup>283</sup> Because the application process is complex and time consuming, some families may be deterred from seeking services altogether.<sup>284</sup> This may be especially true for families with young infants who, as described earlier, experience significant barriers to accessing care during the perinatal period.

A promising strategy to simplify families' application process and thereby increase access to services is to invest in "one-stop" resource centers. 285 These one-stop programs deliver a comprehensive portfolio of services in a single location.<sup>286</sup> When services and programs are housed together, families avoid the complicated logistics needed to make multiple visits to different locations. In addition, when these programs are integrated in the community and staffed by caring, culturally sensitive workers, staff can be a valuable source of social support that help families weather stressful events in their lives. Although frontline workers can perpetuate stigma and racism, hiring, training, and promoting empathic, sensitive workers from within the community to staff these programs can help increase social support for women of color and their children.

Examples of these programs can be found throughout the country but are still not the norm for most families seeking financial support for their basic needs. In Washington, D.C., Mary's Center is a community health center—a nonprofit, consumer-directed heath care organization—that provides families with services such as family-centered health care through Medicaid and early education in a single location.<sup>287</sup> In Tulsa, Oklahoma, Union Public Schools operates a community school model that connects students and their families with nutrition assistance and operates full-service medical clinics on site. 288 For expectant mothers enrolled in the school, accessing comprehensive mental and reproductive health services in a familiar setting can help them receive the medical and social supports they need. And across the country, Head Start and Early Head Start are designed to link families to services beyond early learning, including parenting and health education, crisis intervention, mental health services, and housing assistance. In rural communities, where fewer services are available, Head Start plays an outsize role in connecting families to resources.<sup>289</sup>

Research shows that this community-based, one-stop approach can promote healthy behaviors and reduce negative outcomes associated with maternal and infant mortality. At least one study found that community health centers such as Mary's

Center might increase mothers' postpartum care use<sup>290</sup> and reduce low weight births. Indeed, one study showed that although African American women continued to experience higher rates of preterm birth compared to white women, community health centers nearly cut the disparity in half.<sup>291</sup>

Federal policymakers can promote these comprehensive programs by first building upon investments in existing programs such as community health centers, Title V, and Head Start. Appropriators should guarantee robust funding for these programs and invest in research on how these programs can continue to improve access to service and service delivery. State and local policymakers, particularly mayors and county executives, can also prioritize building integrated student supports into local schools. Doing so may be a powerful way to address future generations' health, as some community schools lead to better educational outcomes that are correlated with better maternal and infant health.<sup>292</sup>

## Simplify enrollment across public benefit programs

Locating comprehensive social services in a single location is only one way to increase access to services. Many states require families to complete lengthy, duplicative application forms for each program, often requiring families to repeatedly verify their claims through documents such as pay stubs and proof of residence.<sup>293</sup> Simplifying the application process could be a useful way to increase the likelihood that families access the resources and services they need in a timely manner. As discussed earlier, increasing access to comprehensive services is a key to improving maternal and infant health.

Recognizing that information collected by one benefit program can be used in others, some states and localities are already experimenting with ways to screen and enroll families more efficiently. Various localities are part of the Advancing Strategies to Align Programs (ASAP) initiative, an advocacy initiate that aims to streamline enrollment through information sharing and program coordination.<sup>294</sup> Additionally, in 33 states and the District of Columbia, people eligible for Supplemental Security Income (SSI) are automatically enrolled in the state's Medicaid program without having to apply separately.<sup>295</sup> And for families who receive SNAP, children are automatically eligible for free or reduced-price school meals. <sup>296</sup> For low-income families navigating pregnancy and parenthood, simplifying the application process and receiving benefits faster can help them avoid crises such as housing loss that can derail family well-being. <sup>297</sup> Simplifying the application process can increase access

to care in several ways. First, simplifying application and enrollment removes some of the burden from families in need. Simplifying the application process not only increases families' access to the benefits they need, it also prevents "churn," where families gain and then lose access repeatedly because of paperwork issues. Second, it can reduce the time families must wait to receive benefits, a crucial priority. Finally, it can help families access all benefits for which they are eligible, including ones they may not be aware of. <sup>299</sup>

State and local policymakers should identify opportunities under federal law to use eligibility determinations in one program to simplify the application and enrollment process in others. State policymakers can facilitate cross-enrollment through measures such as improving data matching algorithms and notifying program participants of their potential eligibility for other programs. Policymakers too can foster linkages between programs where none yet exist. For example, the Earned Income Tax Credit (EITC) is a large income support program with no existing linkages with other benefit programs such as nutrition or housing assistance. To increase enrollment across programs, policymakers can provide training to staff on eligibility rules and processes for the EITC in order to ensure families applying to traditional benefit programs also have an opportunity to enroll in others.<sup>300</sup>

## Invest in home visiting

Home visiting is a voluntary, evidence-based program that delivers comprehensive family services in the home. Program models vary in duration, intensity, and targeting criteria; some include a few visits for all families, while others deliver intensive services to targeted families from pregnancy through the child's early years. Program models also vary by home visitors' characteristics and focus area. In some models, a certified nurse partners with parents and focuses on child health and family stability. In others, a parent educator delivers services focused on education and infant mental health. Ultimately, the aim of these program models is to bring the necessary supports directly to mothers, infants, and young children and to connect families to programs already available in the community. Due to limited resources, most federally funded programs prioritize serving specific families: families with low incomes; pregnant women under age 21; families with a history of child welfare system involvement or substance abuse; tobacco users; military families; and families of children with developmental delays or disabilities.

Home visiting works to improve maternal and infant health by providing emotional support in addition to another opportunity to link families to the services and education they need. Home visitors in intensive programs can become trusted advisers to families and a source of social support to help soften the stress that comes with navigating pregnancy and parenthood. By developing deep relationships with families, home visitors can also help introduce and cultivate norms and attitudes that promote health. For example, many programs provide lactation education and support in culturally appropriate contexts. This has important consequences for infant health, as breastfeeding is associated with lower risk of SIDS/SUID.<sup>304</sup> Many models—such as the Family Spirit Model or HealthConnect One community-based doula model—have deep cultural connections to the community and are staffed by community members.<sup>305</sup>

Research shows home visiting is an effective intervention that addresses many of the causes and correlates of maternal and infant mortality. Previous studies show home visiting increases families' referrals and enrollment in community services<sup>306</sup> including contraception and other family planning services;<sup>307</sup> adult education;<sup>308</sup> employment; and transportation services.<sup>309</sup> Other studies show positive impacts on maternal mental health, including greater self-efficacy<sup>310</sup> and lower depression.<sup>311</sup> Beyond improved mental health, there is noted improvement with maternal physical health, with some home visiting models showing an association with decreased pregnancy-related hypertension<sup>312</sup> and fewer delivery complications.<sup>313</sup>

Additionally, mothers who participate in home visiting are more likely to breastfeed<sup>314</sup> and adopt healthy eating habits<sup>315</sup> and less likely to take up behaviors such as drinking alcohol or smoking during or after pregnancy.<sup>316</sup> Positive outcomes also spanned beyond mothers' health and well-being. Infants whose mothers were enrolled in home visiting were less likely to be born preterm or at a low birth weight<sup>317</sup> and had fewer emergency room hospitalizations. <sup>318</sup> These positive health outcomes are associated with better outcomes for mothers and infants and result in significant health care savings. For example, fewer delivery complications and preterm births reduce the length of hospital stays for mothers and infants. Given that Medicaid pays for nearly half of all U.S. births and almost two-thirds of all births to African American mothers, 319 any intervention that reduces hospital stays has significant cost-saving potential for states and the federal government.

Although a recent national evaluation—the Maternal and Infant Home Visiting Program Evaluation (MIHOPE) study—showed little effect on known correlates of infant mortality such as birth weight, the authors found that home visiting

nevertheless contributed to other positive outcomes, including fewer emergency department visits, improved home environments, and improved maternal mental health.<sup>320</sup> Importantly, the study still showed positive effects at a time when families generally have access to more community services and prenatal care, making it difficult to detect significant differences in outcomes between families who are enrolled in home visiting and those who are not.<sup>321</sup> Even in light of these findings, previous studies have found home visiting resulted in fewer subsequent pregnancies with adverse birth outcomes, suggesting home visiting services confer long-lasting benefits through improved maternal health and economic self-sufficiency.<sup>322</sup>

# Universal home visiting

Although most home visiting programs in the United States target families with high needs, a few evidence-based universal home visiting programs have developed in recent years.

#### **Family Connects**

Family Connects is designed to bridge the gap between family needs and community resources for parents of newborns. All families, regardless of income, are eligible to receive between one to three free home visits from a registered nurse and are referred to further services as needed. Families characterize these nurse visits as a valuable source of support during a tumultuous time. 323 A randomized control trial conducted with a representative, racially diverse sample in Durham, North Carolina, found that participant families had 50 percent less total emergency care utilization and that mothers were 28 percent less likely to report possible clinical anxiety. 324 In addition, participant mothers reported significantly more positive parenting behaviors with their infant, utilized higher-quality child care, and were rated as having higher quality home environments.<sup>325</sup> The program more than paid for itself, saving over \$3 for every \$1 spent as a result of the reduction in postnatal hospitalization costs alone.<sup>326</sup> These benefits are becoming more widely recognized, as the Family Connects model is now in use in 16 programs in 10 states.327

#### **Welcome Baby**

Welcome Baby is a free, voluntary home visiting program locally designed and implemented in Los Angeles. Originally launched in one downtown Los Angeles community and offering services to all families giving birth within a five-mile radius of the local hospital, the program now serves families throughout the county. In contrast to Family Connects, Welcome Baby offers prenatal services delivered by a parenting coach. Studies show participation in Welcome Baby is associated with positive outcomes, including stronger maternal responsiveness, lower parenting stress, and greater social and communication skills for children. These effects persisted up to three years after the intervention.<sup>328</sup>

#### **United Kingdom Health Visiting**

The United Kingdom has a long history of home visiting (known as "health visiting") dating to the Victorian-era philanthropic public health movement. Over time, it moved from the private, voluntary sector into public health, eventually finding a home in the National Health Service (NHS) in 1974.<sup>329</sup> Today, health visitors are qualified nurses or midwives who receive additional training in community public health nursing.<sup>330</sup> Evidence-based services are offered to all families at different levels of intensity, according to family need. For example, a family facing a complex, long-term challenge, such as postpartum depression, will receive more intensive supports than a family experiencing temporary short-term feeding difficulty.<sup>331</sup>

The United Kingdom has also taken bold steps to ensure that pregnant women and new mothers receive care that prioritizes their well-being. British pregnant women and mothers also receive care that spans from the prenatal period to well after birth and is highly standardized and regulated. For more detailed discussion, see "Improve Data Collection and Oversight."

The federal government supports home visiting through the Maternal, Infant, and Early Childhood Home Visiting (MIECHV) program, which has strengthened state programs by supporting services, research, and local infrastructure since its inception in 2010.<sup>332</sup> However, current MIECHV funding—\$400 million annually—allows the program to serve only 156,000 parents and children.<sup>333</sup> This is a tiny fraction of the approximately 3.5 million families with infants or the 4.6 million families in poverty that could benefit from the program.<sup>334</sup>

As part of the next reauthorization, Congress should significantly increase MIECHV funding to provide evidence-based services to all high priority families, including families in poverty and families of infants. This funding should also be flexible enough to support innovative, promising community-based approaches that do not yet have enough evidence to qualify as evidence-based.335

In addition to directly increasing home visiting funding by increasing MIECHV dollars, federal policymakers can help states leverage other resources such as Medicaid to augment dedicated home visiting funds.<sup>336</sup> Specifically, the federal government should clarify the relationship between the MIECHV grant program and Medicaid funding; provide technical assistance to states on billing; and issue waiver templates for states wishing to expand services.<sup>337</sup> Using Medicaid funds to support home

visiting services helps prevent costly services later, including emergency room visits and lengthy hospital stays, representing potential cost savings for Medicaid.

Finally, Congress should consider establishing grants to support innovations in home visiting. First, it should increase research funding for rapid-cycle evaluations of home visiting models to better understand what aspects of these services work best for specific populations, including families of color and families that have individuals with a disability.<sup>338</sup> This type of research—which the MIHOPE study authors endorse as a way to tailor services and improve program delivery—can help programs better understand what works for a family and ensure services meet the specific cultural and social needs of a community. Second, Congress should establish pilot programs that implement universal home visiting in a geographic area, such as Family Connects. Research shows that the majority of families need additional support after the birth of a child, 339 and experts contend that a universal approach is an effective way to find and serve families who are in greatest need.<sup>340</sup>

# Fund community-based education and communications initiatives to support families

While racial disparities in maternal and infant mortality are persistent across the country, the solutions are often most successful when they are localized to reflect a community's strengths and needs and implemented by local leaders trusted in the community. Across the country, communities launch educational campaigns and communication initiatives to address specific areas for improvement. For example, an earlier section discussed New York City's ThriveNYC mental health initiative, championed by first lady Chirlane McCray. (see "Address maternal and infant mental health") Local leaders know the community's needs intuitively, and when they have access to high-quality data related to maternal and child health (see "Improve data collection and oversight"), they can make data-informed decisions about where to invest valuable resources.

To support these efforts, policymakers should ensure diverse representation in grant-making to community-based organizations to establish or support these initiatives. Programs should identify a clear need in the community that is unmet and develop a concrete plan to address this need through leveraging community resources. These grants can provide initial funding for promising community-based solutions that can be sustained in the long term through increased local investment.

# Baltimore's B'more for Healthy Babies

In 2009, Baltimore had the fourth-highest infant mortality rate among comparable U.S. cities, and black infants were dying at five times the rate of white infants.<sup>341</sup> Faced with that reality, the Baltimore City Health Department partnered with local health providers, community partners, home visiting programs, public agencies, private donors, and academics. After an extensive period of community engagement and analysis of local needs, initiative leaders developed a locally driven initiative to reduce instances of premature birth, low birth weight, and unsafe sleep.<sup>342</sup> The initiative, B'more for Healthy Babies, which launched in 2009, focused on building policy support, making service improvements, promoting community engagement, and conducting outreach to families and individuals across the city. <sup>343</sup> Key components of the program include:

- Safe sleep campaign: As in other parts of the country, Baltimore has significant racial disparities in deaths from SIDS/SUID.<sup>344</sup> Although the underlying reasons for these deaths are still poorly understood, there is abundant evidence that modifying sleep practices helps avoid future cases.<sup>345</sup> To this end, Baltimore implemented a campaign aimed at educating parents, caregivers, and community members about the "ABCDs" of safe sleep ("Alone, on their Back, in a Crib, Don't smoke"). 346 Other practices recommended by the AAP include placing infants on a firm surface and removing loose bedding and soft objects, such as pillows and stuffed animals, that can obstruct an infant's breathing.<sup>347</sup> The campaign includes educational videos around safe sleep tha are shown to every family in the hospital after an infant is born as well as in other community hubs, such as court houses and health care centers. 348 The campaign also engages a diverse set of ambassadors to spread the safe sleep message through creating videos featuring fathers, family caregivers, and professional athletes as well as through training community health workers to discuss safe sleep in places such as barbershops and libraries. As individuals with deep knowledge of the community, community health workers are especially well-positioned to listen to parents' concerns about safe sleep and help families to develop plans that both suit their individual needs and preferences while mitigating unsafe practices. The initiative also distributes free cribs to eligible families to promote safe sleep.
- **Home visiting:** Over several years, Baltimore transitioned its home visiting program to two evidence-based home visiting models: Nurse Family Partnership (NFP) and Healthy Families America (HFA).<sup>349</sup> The city has centralized its home visiting referral system to create a single point of entry for pregnant women to receive services. This centralized system is managed by a local nonprofit that receives referrals from various health care providers, including doctors, hospitals, and community-based programs. The city developed a prenatal risk assessment tool to identify the women who were most at risk for poor birth outcomes and ensure that they received appropriate home visiting services. Women who did not qualify for the limited number of home visiting

slots are referred to the less intensive Baby Basics program.

• **Prenatal education and support groups:** The city developed a health literacy program, Baby Basics, for pregnant mothers and their families. The curriculum includes comprehensive prenatal care information, tools for navigating the health care system, and discussions of complex social, economic, and cultural challenges that pregnant women often face. The materials were designed to be used as part of prenatal education and support groups called Moms Clubs. Community-based health programs and clinics also utilize the Baby Basics materials as a mechanism to improve quality of services.

By 2015, Baltimore had the lowest infant mortality rate in the city's history, declining by 38 percent. <sup>350</sup> B'more for Healthy Babies also reduced sleep related deaths by over 50 percent.<sup>351</sup> While Baltimore significantly reduced the racial disparity between black and white infants, in 2015, black infants were still two times more likely to die than white infants. Unfortunately, the city has recently seen a spike in sleep related infant deaths, although it remains too soon to determine the cause. Nevertheless, these deaths have prompted conversations about how to respond. 352 The program therefore serves as an example of the potential, opportunities, and challenges associated with implementing effective programs and sustaining successful outcomes over time.

# Improve data collection and oversight

Public health practitioners have long understood that data are critical to illustrate the prevalence and concentration of maternal and infant mortality. In public health, this process is known as public health surveillance: The "systematic collection, analysis, interpretation, and dissemination of health data on an ongoing basis" to uncover patterns of disease or death in a community in order to prevent future cases. However, data on health events that affect women—particularly women of color—are not always prioritized. This is most clearly seen in the United States' inability to publish an official maternal mortality rate since 2007, a fact researchers lament as a "national embarrassment." It has taken high-profile stories such as Serena Williams' near-death experience and sustained media attention from reporting sources such as ProPublica to increase awareness of this fact. 355

Collecting and disseminating reliable, consistent data on maternal and infant mortality is essential to developing solutions. But progress on this front has not been uniform. Data have not always been collected in a consistent manner, and not all states have effective systems for collecting the type of data that can help inform action to avoid future deaths.

The reason for the United States' poor data on maternal mortality can partly be explained by a 2003 change in how maternal deaths have been reported. The CDC releases revised death certificate standards to all states every 10 to 15 years. The last revisions, issued in 2003, included a checkbox to identify whether a person was pregnant at the time of death or had been pregnant within specified time periods (for example, within 42 days of death or within one year of death). The reason for this update is that previous ways of reporting maternal mortality failed to identify all cases, leading to systematic underestimation of maternal deaths. To complicate the labor- and time-intensive process of collecting and analyzing new data, states were also transitioning to or updating electronic birth registration systems as they were rolling out the revised death certificate forms. This process required additional staff training and investments in data infrastructure. This process required additional staff training states with large African American populations, such as Maryland,

Alabama, and North Carolina—delayed implementing the revised death certificates for more than a decade.<sup>357</sup> As a result, individual states' reported mortality rates were not comparable across state lines or from year to year until 2017, when all states finally began including the pregnancy checkbox. Even now, with all states in compliance, doubts about the data's reliability make health officials hesitant to publish an official mortality rate. 358

# Current sources of maternal and infant mortality information

The CDC administers several national data sources for estimating maternal and infant mortality, which can lead to confusion when reporting or investigating longitudinal trends or international comparisons. Each of these sources uses slightly different measures to count deaths, especially maternal or pregnancy-related deaths, and not all are compatible with methods used by organizations such as the World Health Organization (WHO) or the Institute for Health Metrics and Evaluation. 359 Although each of these data sources provide valuable information about the causes of death and associated risk factors at a population level, states' data collection practices may vary, as discussed previously.<sup>360</sup> More importantly, these data cannot be used to identify factors that contributed to individual deaths; determine whether these deaths were preventable; or identify opportunities for improving how health care and social service are delivered.<sup>361</sup>

#### National program sources

The National Center for Health Statistics (NCHS) administers the National Vital Statistics System, the source of official United States' maternal and infant mortality statistics used for both state and international comparisons.<sup>362</sup> When a vital event, such as a live birth or death, occurs, the state registers the event by issuing a certificate or record. The center collects these vital statistics from 57 records jurisdictions: 50 states, five territories, the District of Columbia, and New York City.<sup>363</sup> These data are then used to produce maternal mortality ratios (MMRs) and infant mortality ratios (IMRs).<sup>364</sup> As explained earlier, however, several states delayed in implementing the pregnancy checkbox. This has serious implications for states' ability to identify maternal deaths, as research shows check boxes are highly effective in identifying them.<sup>365</sup>

The Pregnancy Mortality Surveillance System (PMSS) is a supplemental CDCadministered public health surveillance system and a source of maternal mortality data in the absence of official NCHS estimates. In contrast to the NCHS, the PMSS collects data on pregnancy-related deaths—the death of a person while pregnant or within one year of pregnancy termination—from 50 states, the District of Columbia, and New York City. To do so, the CDC requests the 52 reporting areas to voluntarily send copies of death certificates for all women who died within a year of being pregnant as well as copies of the matching birth or fetal death certificate.<sup>366</sup> Medically trained epidemiologists summarize this information and use it to identify pregnancy-related deaths and calculate the pregnancy mortality ratio.<sup>367</sup> Although the PMSS provides more information on risk factors than the NCHS, it cannot shed light on what social factors (such as housing instability) or aspects of clinical practice (for example, lack of coordination between providers) contributed to an individual death. 368

Pregnancy Risk Assessment Monitoring System (PRAMS), a joint public health surveillance project of the CDC and state health departments, collects state-specific data on maternal attitudes and experiences before, during, and shortly after pregnancy. Unlike the previous programs, rather than collect data on the entire population of women, PRAMS only collects information from a sample of women who have had a live birth in the last year. Moreover, not all states participate; only 47 states, the District of Columbia, New York City, and Puerto Rico participate. As a result, PRAMS represents only about 83 percent of U.S. births. Within those states, however, it can be used to identify groups of women and infants at higher risk for health problems, monitor changes in health status, and measure progress towards reducing maternal and infant mortality.<sup>369</sup>

In addition to these data sources, some states and localities have conducted extensive and systematic reviews of maternal and infant deaths. Unlike the CDC surveillance programs described above, these review programs are more localized and are designed to elicit information that can inform improvement plans. Moreover, they often integrate interviews with affected families in order to capture important context not readily available through vital statistics, medical records, or survey data.

#### State program sources

The maternal mortality review committee (MMRC) is a comprehensive review process operating at the state level that identifies and analyzes maternal deaths; disseminates findings; and develops recommendations. For example, after establishing its MMRC in 2006, California found that maternal hemorrhage was among the most common preventable causes of maternal deaths. Health care experts in California then developed an evidence-based toolkit for health care providers with guidance on how to monitor blood loss and put together a "hemorrhage cart," a portable rolling cart

with medication and tools to manage a hemorrhage. <sup>370</sup> Researchers estimate that MMRCs can reduce maternal deaths by 20 percent to 50 percent.<sup>371</sup> Although the number of states with MMRCs has increased significantly since 2010, approximately 13 states still have no active MMRCs at the time of this writing.<sup>372</sup>

Fetal and infant mortality review (FIMR) committees are similar to MMRCs with a few important differences. Unlike MMRCs, FIMRs are usually organized at the local or county level and are typically composed of two teams: a community review team (CRT) that reviews cases and a community action team (CAT) that helps disseminate findings and implement improvements.<sup>373</sup> Like MMRCs, FIMRs are a powerful tool to address infant mortality. For example, Baltimore's local mortality review committee determined that unsafe sleep practices such as using loose bedding or too-soft surfaces were contributing to high infant mortality rates. In 2009, the city's health department, in partnership with a local nonprofit, launched a public education campaign that contributed to a 71 percent decrease in sleep-related infant deaths and a 64 percent decrease in the black-white disparity in infant mortality. (see "Enhance supports to families pre- and postpartum")<sup>374</sup> According to the National Center for Fatality Review and Prevention, 28 U.S. states currently operate FIMR programs.<sup>375</sup>

Other countries—notably the United Kingdom—have robust national programs in place similar to MMRCs and FIMRs. The United Kingdom's Confidential Enquiry into Maternal Deaths (CEMD) process, long seen as a "global standard," entails a systematic review of maternal and infant deaths; an assessment of care quality; the identification of areas in need of improvement; and the provision of standardized care guidelines.<sup>376</sup> For example, postpartum hemorrhage guidelines are provided to all NHS hospitals and updated regularly by leading national medical agencies such as the Royal College of Obstetricians and Gynecologists and the National Institute for Health and Care Excellence.<sup>377</sup> In contrast, the United States has relegated this responsibility to states. With passage of the Preventing Maternal Deaths Act (H.R. 1318) in 2018—a bill designed to support states' MMRCs—the United States took an important step in bringing the nation in line with the rest of the developed world. (see text box below)

# **Preventing Maternal Deaths Act (PMDA)**

In order to support states in establishing or expanding MMRCs, Congress passed the Preventing Maternal Deaths Act (H.R. 1318) on December 21, 2018. The bill, which was signed into law after unanimously passing both chambers of Congress, represents an important first step toward addressing the maternal mortality crisis. The Preventing Maternal Death Act:

- Authorizes the HHS to provide grants to states to establish and strengthen MMRCs to investigate the causes of pregnancy-related deaths
- Requires MMRCs to be composed of multidisciplinary and diverse experts and community members
- · Supports the collection of consistent, standardized data
- Ensures that state departments of health develop a plan to prevent maternal mortality and widely share the findings and recommendations of MMRCs.<sup>378</sup>

Importantly, this bill does not contain provisions to collect data on infant deaths. To date, Congress has not passed comparable legislation to support data collection for infant mortality.

Despite the importance of this legislation, more work is needed. Review committees rely on accurate vital statistics data in order to identify cases to review and recommend improvements, but states too often inconsistently report this information. Moreover, not all states have review committees, and even among states with established committees, underfunding compromises the efficacy of their work. Given the recent legislative advances on collecting data on maternal mortality, it will be especially important that policymakers at all levels ensure that data collection efforts around fetal and infant mortality keep pace. Given the racial disparity in both maternal and infant mortality, states need to better incorporate equity in their review processes.

#### Standardize birth and death certificates

The first step in developing robust, effective mortality committees is collecting accurate and comprehensive vital statistics. However, as a result of inconsistent public health surveillance practices across states, the United States has not published an official maternal mortality rate since 2007.<sup>379</sup> At the international level, this has led to a dearth of information on maternal health in the United States at a time of increased attention on maternal mortality.<sup>380</sup> And, at the state level, poor reporting has serious implications for how mortality review committees identify cases to examine and then use the information gleaned to develop recommendations.

To improve the quality of vital statistics and thereby support state mortality review committees, Congress should ensure adequate funding to the NCHS, and states should significantly invest in their vital statistics systems in order to ensure rapid implementation of the next round of birth and death certificates from the CDC. In a report from Marian MacDorman and colleagues analyzing the impact of the 2003 death certificate revisions on maternal mortality, the authors claim that chronic underfunding contributed to significant delays in the adoption of revised birth and death certificates.<sup>381</sup> One reason some states were unable to implement the pregnancy checkbox after the 2003 death certificate revisions was that the NCHS which enters into contracts with reporting jurisdictions to obtain data—lacked the funding to pay states to collect additional data.<sup>382</sup> At the same time, states had to delay implementing the pregnancy checkbox until they had sufficient funds to reengineer their electronic records systems and train hospital staff on the new system.<sup>383</sup> Federal and state investments in vital statistics systems will be critical to ensure that future efforts to standardize birth and death certificates are successful.

As part of the revision process, federal and state policymakers can work together to address several challenges that plague vital statistics systems by developing technical assistance plans and resources. First, policymakers should provide technical assistance on ways to improve completeness of data, amend records, and account for incomplete data in analyses. During analyses, cases with incomplete data might be excluded, which could potentially leave out some of the mothers and infants who were at the highest risk of infant mortality. For example, one California study found an association between incomplete birth certificates—those that are missing important information such as gestational age, number of prenatal visits, or maternal education—and infant mortality.<sup>384</sup> Specifically, women who were at high risk for poor perinatal outcomes were more likely to have incomplete birth certificates, and incomplete certificates were associated with increases in infant mortality rates.<sup>385</sup> Technical assistance to improve data quality will help state and local programs improve data quality, which helps communities develop plans to address racial disparities in mortality.

Second, policymakers should also provide funding for technical assistance on ways to reduce misclassification of race on medical and mortality records. Doing so will help states more accurately measure racial disparities and avoid underestimating maternal and infant mortality for certain communities. Physicians and coroners,

who often determine racial identity on maternal and infant death certificates, frequently neglect to confirm a person's self-identification through an informant or family member.<sup>386</sup> Moreover, the CDC standard practice is to only consider maternal race when assigning infant race, thereby underestimating and obscuring important patterns in infant mortality. As a result, racial misclassification is common, especially for AIAN communities, who may trace tribal membership through either parent. To address this issue, policymakers can provide technical assistance on certain practices such as linking data from tribal registries and hospital records, which can reduce racial misclassification in mortality data.<sup>387</sup>

Finally, in consultation with experts, advocates, and a diverse array of stakeholders, policymakers should consider ways of collecting data on birth and death certificates that are inclusive of a broad range of gender identities. The pregnancy and parenting experience of transgender, intersex, and nonbinary individuals deserves robust study, which is currently undermined by a dearth of adequate data.<sup>388</sup>

### Mandate and fund fetal and infant mortality review committees

It is important to note that legislation on collecting fetal and infant mortality data has not advanced in the wake of the passage of the Preventing Maternal Deaths Act. Whereas MMRCs operate in nearly 40 states, only about half of states operated FIMR programs in 2017, according to the National Center for Fatality Review and Prevention.<sup>389</sup> Even some states that do have active FIMR sites arguably operate too few; for example, only one of Colorado's 64 counties operates a local FIMR program.<sup>390</sup> As review committees share staff time across numerous projects, reports can take years to complete.<sup>391</sup>

To address this issue, Congress should, at a minimum, increase funding for Healthy Start and the Title V Maternal and Child Health Services Block Grant, two important funding sources for FIMR programs. 392 In locales with existing FIMRs or FIMRs that have not published recent reports, these funds can pay for staff to review cases, analyze findings, and publish comprehensive reports in a timely manner. In locales without FIMRs, this additional funding can be used to train staff in existing child fatality review committees—which operate in all 50 states and investigate deaths throughout childhood and adolescence—on ways to use components of the FIMR process to more effectively review infant deaths.<sup>393</sup>

Federal policymakers should also consider establishing a new grant program to create or improve FIMRs. Doing so would help to ensure that federal investments in states' infant mortality review programs are brought in line with the increased investments in maternal mortality review programs articulated by the Preventing Maternal Deaths Act. Like the Preventing Maternal Deaths Act, funding should be contingent on programs' plans to ensure adequate representation and participation by representatives of communities most affected by infant mortality, including women of color. Funding should be directed to states that do not currently have FIMRs or have too few programs to serve their states.

## Ensure equity in the review process

California and the United Kingdom have been praised as examples of using data to prevent maternal deaths. However, these examples also shed light on the limitations of such an approach. Although California was able to dramatically reduce its overall maternal mortality—it is currently one-third the national average—
African American mothers in the state are still nearly four times more likely to die from causes related to pregnancy or childbirth as non-Hispanic white mothers. Similarly, the United Kingdom's review process has not succeeded in reducing the nation's racial disparities; compared to white women, the pregnancy mortality ratio for Asian women is twice as high, whereas the pregnancy mortality ratio for black women is a staggering five times higher.

These examples make clear that collecting data alone is not enough. U.S. policy-makers need to implement comprehensive interventions that address the complex social determinants of health and use data to monitor what is working. State review boards can support these interventions if they are able to better integrate equity in their efforts. In order to accomplish this, Congress should, first, ensure that state review boards have funding to support the collection of qualitative interviews that illuminate the role of racism, sexism, and other social determinants of health on outcomes. The Black Mamas Matter Alliance—a black women-led cross-sectoral policy, research, and advocacy alliance—argues that qualitative data provide insight into the impact of racial discrimination on the care women receive and perceptions of quality. Similarly, state FIMR programs describe maternal interviews as a key strategy to understand how women of color's lived experience can influence maternal and child health outcomes. However, budget limitations curtail the ability of MMRCs and FIMRs to collect these qualitative data. Indeed, in a recent survey of FIMR programs nationwide, half reported that a lack of funding represents a signifi-

cant barrier to conducting a maternal interview.<sup>398</sup> Additional funding will help state MMRCs and FIMR committees pay for staff time and training to ensure interviews are conducted in ways that center the experiences of families most affected by maternal and infant mortality and morbidity.

Second, as part of the implementation of the Preventing Maternal Deaths Act and any comparable legislation for infants, Congress should ensure that states have funds to cover technical assistance around incorporating equity and social determinants of health into their review process.<sup>399</sup> For example, Congress could provide technical assistance to incorporate promising analyses such as geocoding, which is the process of converting addresses to geographic coordinates. Geocoding where a death occurs and triangulating that information with publicly available data from the American Community Survey (ACS) or Area Health Resource File (AHRF) can illuminate the connection between geographic location and the uneven distribution of resources such as hospitals. These socio-spatial indicators can help review committees describe community factors that contribute to inequality and complement qualitative data. 400

Whereas spatial analysis can help a community describe access to care, interviews can describe the quality of care. Spatial analysis can measure a community's racial segregation, but it cannot describe the ways racism and discrimination undermine health. Technical assistance to program staff can help programs collect any type of data that can inform improvements.

Finally, as states and localities establish or expand their MMRCs and FIMR committees, local policymakers must ensure that they include people affected by maternal and infant mortality at all levels. Community engagement has been an integral part of the FIMR process since its inception, and MMRCs are beginning to more thoughtfully integrate representation in the review process. For example, both Washington, D.C., and Maryland have recently introduced legislation that would better integrate community voices by requiring that review boards include individuals directly affected by maternal mortality or severe maternal morbidity.<sup>401</sup>

# Other key initiatives to ensure African American mothers and infants survive and thrive

Ensuring workplace supports and humane treatment within the criminal justice system are also vital to eliminating racial disparities in maternal and infant mortality. Pregnant and postpartum African American women deserve accommodations, benefits, and protections that help lead to positive health outcomes for themselves and their infants, regardless of the settings within which they live or work.

# Ensure workplace supports for pregnant women and new mothers

Workplace policies that support pregnant women and new mothers can improve maternal and infant health, leading to better birth outcomes and fewer instances of mortality and morbidity. Unfortunately, many women of color tend to work in lowwage jobs that lack the protections and benefits afforded to high-wage workers. 402 Policymakers working on maternal and infant health disparities must make the connection between the health of pregnant women and new mothers and the workplace supports they receive. For example, about one-quarter of both black and Hispanic workers reported that during "the last two years that they needed or wanted to take time away from work for parental, family or medical reasons but could not."403 Women, more so than men, were unable to take leave in the last two years when they needed or wanted to.404

There are several ways to support pregnant workers and working mothers, including adopting a comprehensive national paid family and medical leave policy; ensuring access to high-quality affordable child care; and enforcing and expanding the Pregnancy Discrimination Act. Whereas most of the aforementioned programs may benefit women across the socio-economic spectrum, it is nevertheless important to recognize that poverty is a powerful predictor of health throughout the lifespan. Moreover, institutional racism has made African American women overrepresented in the lower end of the socio-economic spectrum. Although research makes it abundantly clear that poverty is not the only factor when it comes to African American

women and infants' poor health outcomes, 405 reproductive justice nonetheless demands that policymakers tackle poverty and wealth inequality through economic policies such as increasing the minimum wage, ensuring equal pay for equal work, and more progressive tax policies. 406

#### Address pregnancy discrimination

Experiencing pregnancy discrimination in the workplace can also be detrimental to maternal and infant health. According to the National Partnership for Women and Families, about 3 in 10 pregnancy discrimination claims were filed by African American women from 2011–2015, double the proportion of black women ages 16 to 54 in the labor force. 407 This discrimination takes many forms, including firing and denial of promotions or pay raises to pregnant women; inadequate maternity leave; and being subject to harsh conditions or extreme manual labor during pregnancy. Pregnancy discrimination can have severe health consequences. An investigation by The New York Times included a review of thousands of documented cases in the public record where pregnant women suffered miscarriages and premature labor after being denied accommodations in the workplace, especially in positions requiring manual labor. 408 This type of discrimination hits black women particularly hard, in part, due to stereotypes, including those that distort black women's tolerance for pain and capacity for physical labor. In addition, the systematic devaluation of their contributions to the workplace and their overrepresentation in low-wage jobs that lack workplace protections and policies contribute to black women's disproportionate experiences of pregnancy discrimination. 409 No one should be forced to choose between their livelihood and a healthy pregnancy.

#### Adopt comprehensive paid family and medical leave

The absence of paid family leave is particularly troubling, given nearly two decades of research outlining the benefits of paid leave on maternal and infant health. Studies indicate that having access to paid family leave contributes to fewer low birth weight infants, fewer infant deaths, higher rates of breastfeeding, improved mental health, longer parental lifespan, and long-term achievement for children. 410

Unfortunately, most U.S. workers do not have access to paid leave to either take care of themselves or a loved one, including a new infant. Only 17 percent of American workers have paid leave; 411 nearly three-quarters of mothers who worked during pregnancy return to work within six months of giving birth; 412 and nearly 1 in 4 mothers return to work less than two weeks after giving birth to their infants.<sup>413</sup>

When it comes to women of color, those numbers are even more alarming. From CAP Senior Fellow Jocelyn Frye:

Women of color are less likely to have access to any form of paid leave, although the differences vary—44 percent of Latinas, 40 percent of Asian American women, 37 percent of African American women, and 36 percent of white women do not have access to paid leave.414

And less than one-third of black working mothers are eligible for and can afford unpaid leave through the Family Medical Leave Act (FMLA).<sup>415</sup> The economic consequences of this difference is stark: African American women with family caregiving responsibilities are estimated to spend 41 percent of their annual income on expenses related to caregiving such as medical and travel expenses. 416 In contrast, white caregivers—both male and female combined—spend approximately 14 percent of their annual income on caregiving expenses.<sup>417</sup>

Pregnant women and new mothers also need access to paid sick days, which allow them time off work to care for themselves—such as attending prenatal doctor appointments—or their new child. Yet, 34 million people do not have access to paid sick days, 418 and this disparity is worse for workers of color, especially Latinos. 419 Paid sick days help lessen the severity and length of workers' illnesses<sup>420</sup> and allow workers to access health care to prevent and quickly address health problems.

#### Support breastfeeding

Workplace support for breastfeeding is critical to supporting women in breastfeeding for the six months recommended by the AAP. 421 Studies show that returning to work can pose barriers for some women to breastfeed, which can lead to stress and anxiety for new mothers. 422 State paid leave policies have been shown to raise rates and duration of breastfeeding. 423 The benefits of breastfeeding not only support the unique nutritional and health needs of infants, but also manifest in better maternal health outcomes for mothers. 424 Furthermore, exclusive breastfeeding helps address infant mortality by reducing risk for SIDS/SUID, gastrointestinal infections, respiratory infections, and other chronic conditions. 425 Black women have consistently had lower rates and shorter periods of breastfeeding, in part, influenced by earlier returns to work and a lack of breastfeeding support from health care providers. 426 A CDC study found that hospitals in areas with higher percentages of black residents were less likely to provide adequate breastfeeding information and support to new mothers.427

For new mothers working in low-wage jobs, manual labor, or the service industry, which disproportionately represent women of color, workplace breastfeeding supports can be even harder to obtain. Because disparities still exist in breastfeeding trends, policymakers must do more to incentivize the implementation of policies already in place to support adequate space and time for new mothers to express breast milk while at work. The ACA mandated workplace supports for breastfeeding mothers, including a requirement that employers provide break time<sup>428</sup> and private space for mothers to express breast milk. 429 The ACA also requires that insurers cover breastfeeding support, counseling, and supplies at no cost—vital coverage that can help reduce disparities in breastfeeding along racial and economic lines. 430 Women covered by Medicaid and those participating in the WIC program also have access to breastfeeding supports and education. Policymakers could go even further by requiring such support for all workers, regardless of employer size or industry.

#### Make high-quality child care affordable

When parents return to work, they need access to affordable, quality child care options that keep children safe. However, the high cost of licensed child care is out of reach for many families. The average price of a licensed child care center or home is around \$10,000 per year, much higher than what most working families can easily afford. 431 When faced with limited child care options, parents may opt for a patchwork of family and friends or unlicensed child care. Sometimes these options are ideal for the parent, child, and caregiver. Other times, these arrangements create significant stress for parents without a regular child care arrangement or parents who worry about their children's safety.

For families of color, the challenges of finding affordable child care are even more pronounced. Among African American families, 3 in 4 children have all available parents in the workforce, as compared to 66 percent for children across all races. 432 However, the average child care center tuition rate is \$18,000 per year, which accounts for 42 percent of the median income for African American households, making child care unaffordable for many families. 433 To make quality, affordable child care a reality for all families, the United States needs a comprehensive solution with adequate funding that limits what families must pay, improves quality, and increases wages for early educators.

#### Eliminate harmful work requirements

Both traditional Medicaid and Medicaid expansion should be implemented without so-called work requirements, which serve as harsh time limits that disproportionately harm women of color. These policies—which the National Academy

of Sciences finds are "at least as likely to increase as to decrease poverty" 434—do nothing to invest in job creation or raise wages and, in fact, may make it harder for people to find work.<sup>435</sup> While African American women have the highest labor force participation rates among women, they are also more likely to be unemployed or experience long periods of unemployment when compared to white women. 436 They are also more likely to work in low-wage jobs, 437 which are especially likely to have the volatile schedules and irregular hours that lead to coverage losses when work requirements are in place. Because of this, they could risk losing access to vital health care. For example, in Arkansas—a state that recently imposed a work requirement of 80 hours per month—more than 18,000 people have already lost coverage due to work requirements, and fewer than 2,000 of those individuals reenrolled.

#### Implement tax supports for families

Tax credits also represent a critical support for families at the birth of a child. The current Child Tax Credit—which is not available to the families without sufficient earnings—leaves far too many of the country's lowest income families behind families that are especially likely to be headed by women of color. Investing in these families requires improving the Child Tax Credit by making it fully refundable; making it available on a monthly basis to cover basics such as formula and diapers; and providing a boost for families with children under age 6.438

# Ensure humane treatment of pregnant and postpartum women in the criminal justice system

Women of color are disproportionately represented in the criminal justice system. 439 Nearly 80 percent of incarcerated women are mothers (overwhelmingly single mothers), the majority of whom have been jailed for minor offenses. 440 They also tend to be low-income, survivors of violence, and predisposed to trauma.<sup>441</sup> Incarcerated pregnant women are not only vulnerable to poor physical and mental health, but also violence and substance abuse. 442 The overrepresentation of women of color has significant consequences for their children as well. Specifically, parental incarceration is classified as an ACE. Importantly, African American children are more than twice as likely as non-Hispanic white children to have an incarcerated parent or guardian due to decades of racial discrimination and predatory sentencing practices in the criminal justice system.<sup>443</sup>

Incarcerated women endure many routines and procedures that impact them negatively, including the practice of shackling. Outlawed in 2008 by the Federal Bureau of Prisons, shackling is still practiced in most state and local jails and prisons as well as in Immigration and Customs Enforcement (ICE) detention. 444 The number of detained immigrants and arrests of immigrants with no criminal records have increased since 2016.445 Since late 2017, ICE has been detaining more pregnant women, and in March 2018, it formally ended the Obama-era policy of "presumption of release" for pregnant immigrants, under which a pregnant woman would only be detained if mandated by law or under extraordinary circumstances. 446 Pregnant women in ICE detention have reported stress, miscarriage, and stillbirth as a result of shackling, and ICE reported that over fiscal years 2017 and 2018, 28 women had a miscarriage while in custody.447

Twenty-eight states and ICE use restraints on pregnant women while they are in labor, during transport, and during recovery in the postpartum period.<sup>448</sup> Furthermore, because prisons and prison staff are often ill-equipped to support women's health care needs, pregnant women in the criminal justice system often experience high-risk pregnancies and lack access to comprehensive, compassionate health care during pregnancy and in the postpartum period.<sup>449</sup>

#### Ban shackling of pregnant and postpartum women

Shackling is inhumane and can be a source of trauma for women in the criminal justice system as well as a host of other health-related issues. According to the ACOG, shackling can lead to dangerous health effects for incarcerated pregnant women, including a delay in the assessment of vaginal bleeding and hypertensive disease, which can in turn lead to maternal deaths. 450 The practice has been referred to by a number of social justice organizations as an unconstitutional human rights violation and can be viewed as a form of obstetric violence.<sup>451</sup>

Reproductive justice groups have worked tirelessly to end shackling. In 2018, the work of SisterSong and Forward Justice resulted in North Carolina abandoning the practice of shackling incarcerated pregnant women during childbirth. 452 Shackling has been strongly opposed by not only social justice groups but also by medical organizations, including the ACOG, the American College of Nurse-Midwives (ACNM), and the American Medical Association (AMA). 453

As noted earlier, U.S. immigration policy and the criminal justice system target women of color. This can be seen in recently implemented draconian policy changes and attacks on immigrant communities 454 as well as the persistent criminalization of black and brown women for minor offenses. As a consequence, there is an overrepresentation of these populations within both ICE detention centers and in prisons and jails across the country. Addressing the practice of shackling and the criminalization of women of color are key to broader criminal justice reform efforts. Policymakers should issue a total ban on shackling of incarcerated pregnant women in both public and private prisons as well as those in ICE custody. 455

#### Ensure high-quality health care in the criminal justice system

Policymakers must also ensure access to comprehensive, quality health care for pregnant and postpartum women in the criminal justice system. In doing so, they must hold public and private prisons accountable in the provision of quality care. Poor quality of care and negligent procedures can contribute to already high levels of stress experienced by incarcerated pregnant black women in particular. 456 Dozens of states do not require medical examinations or prenatal nutrition counseling for pregnant women who are incarcerated and fail to offer guidance on recommended activity levels or safety measures during pregnancy.<sup>457</sup>

Reproductive health care, voluntary family planning, screening for HIV and sexually transmitted infections (STIs), substance abuse treatment, and mental health care are all vital aspects in the spectrum of health care services pregnant and postpartum incarcerated women need. Health care staff serving the prison population must operate under the highest standards and offer incarcerated women quality care. Policymakers should mandate bonding time for incarcerated new mothers after the birthing process, which has been shown to have positive health effects for the infant.<sup>458</sup>

# Conclusion

The needless, preventable deaths of African American mothers and infants is a national tragedy and disgrace. Eliminating racial disparities in maternal and infant mortality must be a priority for the United States. As articulated in this report, there is no single policy solution that will solve this public health crisis—the approach must be comprehensive and multipronged.

The Center for American Progress has recommended a set of policy strategies that includes improving access to critical services; improving the quality of care provided to pregnant women; addressing maternal and infant mental health; ensuring supports for families before and after birth; and improving data collection and oversight. If implemented fully, these policy strategies will allow African American women to navigate a more compassionate and woman-centered health care system and do so freely with the bodily autonomy they deserve. The policy strategies also promote the overall health and well-being of families of color, helping to instigate better health outcomes for African American infants and ensure that they thrive throughout childhood.

Eliminating racial disparities in maternal and infant mortality cannot be done without prioritizing African American women and infants and substantively addressing inequality and racism within America's structures and institutions. And despite the shameful historical foundations of racism upon which this country was built, concrete policy strategies, as laid out in this report, can address the manifestations of racism and how they instigate poor maternal and infant health outcomes. The lives and health of African American mothers and infants depend on it.

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## Acknowledgements

The authors would like to thank Maura Calsyn, Osub Ahmed, Nora Ellmann, Madeline Twomey, Danyelle Solomon, and Rejane Frederick for their assistance on this report.

# **Appendix**

## Acronyms

**AAFP:** American Academy of Family Practitioners

**AAP:** American Academy of Pediatrics

**ACA:** Affordable Care Act

**ACE:** Adverse Childhood Experience

**ACNM:** American College of Nurse-Midwives

ACOG: American College of Obstetricians and Gynecologists

**ACS:** American Community Survey

**AHCPII:** Arkansas Health Care Payment Improvement Initiative

AHRF: Area Health Resource File

AIAN: American Indian and Alaska Native

AIMM: Access Integration Maternity care Mapping

**AMA:** American Medical Association

AMCB: American Midwifery Certification Board

**C-Section:** Cesarean Section

**CAP:** Center for American Progress

**CDC:** Centers for Disease Control and Prevention

**CEMD:** Confidential Enquiry into Maternal Deaths (*United Kingdom*)

**CAT:** Community Action Team

**CHIP:** Children's Health Insurance Program

**CLAS:** Culturally Linguistically Appropriate Services

**CM**: Certified Midwife

CMS: Centers for Medicaid and Medicare Services

**CNM:** Certified Nurse Midwife **CRT:** Community Review Team

**CPM:** Certified Professional Midwife

**EITC:** Earned Income Tax Credit

FIMR: Fetal and Infant Mortality Review Committee

FMLA: Family Medical Leave Act

FPL: Federal Poverty Level

**HFA:** Healthy Families America

**HHS:** Department of Health and Human Services

**HRSA:** Health Resources and Services Administration

**ICE:** Immigration and Customs Enforcement

**ICU:** Intensive Care Unit

**IMPACT:** Improving Mood—Providing Access to Collaborative Treatment

**IMR:** Infant Mortality Ratio

MIECHV: Maternal, Infant, and Early Childhood Home Visiting Program

**MMR:** Maternal Mortality Ratio

**MMRC:** Maternal Mortality Review Committee

NAMI: National Alliance on Mental Illness

**NCHS:** National Center for Health Statistics

**NEMT:** Non-Emergency Medical Transportation

**NFP:** Nurse Family Partnership

**NHS:** National Health Service (*United Kingdom*)

**NHSC:** National Health Service Corps

NIH: National Institutes of Health

**OB-GYN:** Obstetrician-Gynecologist

**OBMH:** Obstetric Medical Home Program

**PAP:** Principal Accountable Provider

**PMDA:** Preventing Maternal Deaths Act

PMH: Pregnancy Medical Home

**PMSS:** Pregnancy Mortality Surveillance System

**PRAMS:** Pregnancy Risk Assessment Monitoring System

**SAMHSA:** Substance Abuse and Mental Health Services Administration

**SIDS:** Sudden Infant Death Syndrome

**SMM:** Severe Maternal Morbidity

**SNAP:** Supplemental Nutrition Assistance Program

**SSI:** Supplemental Security Income

**STI:** Sexually Transmitted Infection

**SUID:** Sudden Unexpected Infant Death

**USPSTF:** United States Preventative Services Task Force

WIC: Special Supplemental Nutrition Program for Women, Infants, and Children

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