

# Racial Disparities in Prenatal Access in Maine

Report to the  
Maine Legislature



JANUARY 2022



**Permanent  
Commission**  
RACIAL, INDIGENOUS  
& TRIBAL POPULATIONS



**The communities themselves must inform and ideally perform the interventions, from the data collection to the programmatic work – with enough time and resources to support a community-driven process.**

# Introduction

In 2021, the Maine Permanent Commission on the Status of Racial, Indigenous, and Tribal Populations (referred to subsequently as “The Commission”) was directed to conduct a study on disparities in access to prenatal care in Maine. Specifically, LD 1113 directed the Commission to:

- “Study the extent of disparities in access to prenatal care for the State’s racial, indigenous, and tribal populations through data and other information;
- “Study the causes of the disparities in access to prenatal care, including through interviews with those women who had no prenatal visit until the last trimester or had no prenatal care at all; and
- “Recommend solutions to disparities in access to prenatal care in the State.”

There are many efforts underway in Maine to address this issue, from the establishment of culturally specific doula programs to collaborative public health initiatives, and through philanthropic efforts. This report seeks to acknowledge and uplift that existing work and provide baseline information to the Maine Legislature to support future efforts that center the experiences of the affected communities.

In addition to the overarching reflections on how to approach future work on maternal health, this report identifies a number of specific drivers that we believe are connected with prenatal access. Specifically, we explore the effects that racism, structural barriers, the social determinants of health, and community and cultural norms have in creating barriers to maternal health. Our

short- and long-term recommendations center on the following commitments:

“Do we invest in those systems that were meant to colonize... or do we build our own?”

**Expand community-led data gathering and align with statewide systems.**

“Listen to the direct needs of the folks and let them lead the direction of their pregnancy and birth.”

**Invest in relationship-centered care.**

“If you don’t know it’s available, it’s not available.”

**Address structural inequities.**

“There is a real need for community discussion to break that cultural barrier that increases the risks of negative outcomes during pregnancy.”

**Support community-led education.**

“The system was never built to include everyone.”

**Enhance statewide data collection to better serve communities.**

The timeline for this project has only allowed us to lay the groundwork for future efforts, but we expect it will help the Maine Legislature to develop an understanding of the landscape of maternal health and prenatal health access in Maine, and to identify next steps in view of improving the health of all Mainers.

# The Problem

The U.S. has the highest maternal mortality rate among developed nations.<sup>1,2</sup> While causes for these deaths vary, more than half are preventable.<sup>3, 4</sup> Complications that result in significant consequences to a birthing pregnant person's health (called severe maternal morbidity) are nearly 100 times more common than death.<sup>5</sup> Both mortality and morbidity have been increasing in recent years nationwide.<sup>6</sup>

**Systemic racism has created an environment in which maternal health outcomes— already among the worst in the world—are significantly worse for communities that are Black, Indigenous, and of color** (Black, Indigenous and People of Color are referred to throughout this report as BIPOC). Black and Indigenous women are at much higher risk of dying from pregnancy-related causes than non-Hispanic white women. In 2019, maternal mortality rates for Black women (44.0) per 100,000 live births were significantly higher than those for non- Hispanic white women (17.9) and for Hispanic women (12.6).<sup>7</sup> The rate of pregnancy-related deaths among American Indian/Alaska Native people was 28.3 for the years 2014-2017.<sup>8</sup> These disparities have persisted since maternal data collection related to this issue began in the early 20th century.<sup>9, 10, 11, 12, 13, 14, 15, 16</sup>

Still, we know that there are ways to address these disparities. While the causes for negative maternal health outcomes and disparities by race and ethnicity are complex and interrelated, **one factor that helps to improve maternal health outcomes for every population is access to uninterrupted,**

**high-quality prenatal care.** The sooner pregnant people access adequate prenatal care, the better the outcomes are for both parent and infant.

That care is not available to everyone who needs it. Pregnant people who are BIPOC may have poorer access to prenatal care, or access to only lower-quality prenatal care, and often have different and negative experiences with care providers.<sup>17, 18</sup> **BIPOC communities not only have worse maternal health outcomes in Maine than their white counterparts, they additionally have reduced access to prenatal care,** which is a key element in ensuring overall maternal health. This report explores the status of maternal health and prenatal access in Maine, the key drivers limiting that access, and recommendations for next steps.

**One factor that improves maternal health outcomes for every population is access to uninterrupted, high-quality prenatal care.**

# Method and Approach

In order to complete this report, the Commission contracted with the MWL Education Fund (MWLEF), a 501c3 nonprofit which exists to identify research, education, and action to address gender disparities in Maine.

The authorizing legislation, LD 1113, required a study on the extent of disparities, and a study on the causes of the disparities. It additionally required interviews with individuals “who had no prenatal visit until the last trimester or had no prenatal care at all.” However, in virtually all circumstances, conducting research with such individuals would require efforts that fall well outside the time constraints outlined in the bill, since it would require either gaining access to protected health information and/or the recruitment of the general public. Both approaches necessitate significant investments of time, whether in securing the approval of an Institutional Review Board<sup>19</sup> or in the process of coordinating with and building trust among members of the identified communities. For that reason, we approached this work with the support and perspectives of community experts and representatives, relying on them to provide diverse perspectives and feedback to complement mainstream data sources.

The project included three key efforts:

- To center the experiences of the communities most affected by racial disparities in maternal health, MWLEF convened an Advisory Group of stakeholders that provided feedback and resources for the initiative. The Advisory Group met three times: at the project launch in October, for an interim report in December, and to share final feedback and discuss next steps in January. The Advisory Group consisted of:

**Connie Adler**, Family Practitioner  
**Amanda Comeau**, Survivor Speak USA  
**Ambassador Maulian Dana**, Permanent Commission  
**Andrea Francis**, Maine Health Access Foundation  
**Kara Kaikini**, Maine State

Breastfeeding Association

**Carrie Louch**, Maine DHHS Women, Infants, and Children Program

**Morgan Miller**, Certified Midwives Association

**Hibo Omer**, New Mainers Public Health Initiative

**Cynthia Simpson** and **Laura Thomas**, Mano en Mano

**Lisa Sockabasin**, Wabanaki Public Health

**Odette Zouri**, In Her Presence

- MWLEF contracted with the Cutler Institute at the University of Southern Maine to conduct a literature review, assess and compile currently available quantitative data, interview key informants, and present a report to the Advisory Board, detailing the findings and opportunities for next steps. Key informants included:

**Katherine Ahrens, Ph.D.**, epidemiologist and assistant research professor in the Public Health Program at the USM Muskie School of Public Service

**Candy Henderly, M.D.**, Penobscot Nation Health Department Director

**Erika Lichter, Sc.D.**, Maternal and Child Health Epidemiologist at the Maine Center for Disease Control

**Hibo Omer, M.P.H.**, Program Director of the New Mainers Public Health Initiative

**Lisa Sockabasin, BSN, RN.**, Co-CEO Wabanaki Public Health & Wellness

- Where possible, Advisory Group members engaged in efforts to gather qualitative data from their communities. These efforts included the following:
  - In Her Presence conducted a community-based focus group. In Her Presence is organized and led by immigrant women living in Maine and strives to bring together immigrant women from across communities and generations to ensure that Maine’s economic agenda includes the aspirations and needs of immigrant women.
  - Mano en Mano engaged in participant interviews. Mano en Mano works to

allow farmworkers and immigrants in Maine to thrive. They envision a stronger, more inclusive Downeast Maine where the contributions of diverse communities are welcomed; access to essential services, education, and housing are ensured; and social justice and equity are embraced.

- Survivor Speak USA conducted a survey of members. Survivor Speak USA is a Maine-based, survivor-led organization working to end sex trafficking and exploitation through centering the experiences, healing, voices, and leadership of survivors.

It must be noted that Black and African Americans who trace their lineage to enslavement were not represented across these strategies, and therefore their voices are not significantly or meaningfully articulated in this report. This is due in large part to the lack of investment in the health of this community in Maine, where there is limited social infrastructure and built environment for and by Black and African American people. This systemic challenge in our state is the result of systemic racism, and it perpetuates the invisibility of the community. Future efforts must make every effort to engage with Black- and African American-led community groups such as NAACP Maine, Maine Black Community Development, and other initiatives.

The themes, trends, patterns, and recommendations identified across these efforts formed the basis for this final report. It should be noted that there are currently a number of other efforts underway in Maine related to racial disparities in maternal health and prenatal access. Where possible, these efforts are referenced throughout the report or relied upon as a source of information; future efforts should work in tandem with these existing initiatives.

“Data”—the facts and statistics that provide information or illumination—is often considered to mean “mainstream,” population-level, or numeric-driven

# Data: A Critical Tool and a Critical Gap

sets of information (such as tools like PRAMS, the Pregnancy Risk Assessment Monitoring System, a surveillance project of the Centers for Disease Control and Prevention<sup>20</sup>). **However, a focus on this data is uniquely harmful when it comes to addressing the BIPOC communities this report seeks to highlight.** As one of our Advisory Group participants noted: “The more that we look at existing data sets, the more we make the people with lived experience invisible. The existing datasets were designed to exclude the people who are most left out of the process and will be the ones not served by the existing data.” Another noted: “It’s not just about numbers, it’s about peoples’ lives.”<sup>21</sup>

Three ideas must be considered as part of the essential context for this report:

## LIVED EXPERIENCE AS DATA

Lived experience is real, and it can’t always be quantified or represented in traditional ways. While public health data shines a light on some aspects of our communities’ health and wellness, it falls short in helping us to understand and illustrate the nature and depth of the real experiences of the human beings within those communities. Surveillance data can point to disparities and trends but cannot help us to understand how that manifests with individuals.

Too often, these lived experiences are overlooked or ignored in the effort to gather data, but there is an opportunity to reassess the ways in which stories and experiences

can be meaningfully integrated into the larger data collection process. That said, this kind of qualitative data must be gathered with the utmost care. **Community trust, participatory research methods, and ethical human engagement all take time and care—resources that may themselves rarely be deployed in designing mainstream approaches, which tend to prioritize urgency and the supremacy of numbers over relationships.**

“It’s not just about numbers, it’s about people’s lives.”

It should also be noted that sharing lived experiences involves a form of emotional labor that pregnant and birthing people do not owe to the research community. The Advisory Group noted real “research fatigue” within their communities—that is, community members have expressed the sentiment that they do not have the capacity to continue offering up their stories and experiences for largely mainstream providers. In fact, one of our partners put their community-focused programming on hold for approximately six months because of community

fatigue related to surveys and study groups. Those findings will be available in the Spring of 2022.

## SOVEREIGNTY OF DATA

An understanding of the role of data ownership is essential in comprehending the data context and landscape described in this report. Mainstream data structures have often played a role in the colonization of people and the extraction of resources, contributing to their harm and even genocide. In the words of the First Nations Information Governance Centre (FNIGC, Canada) “First Nation peoples have always understood the need to protect our natural resources, and increasingly one of our most important resources today is information. Information is about more than numbers and surveys: it’s also about identity, heritage, and the right to self-determination.” For that reason, FNIGC has established OCAP, which outlines the approach to data Ownership, Control, Access, and Possession.<sup>22</sup>

While neither Maine nor the United States has developed a tool equivalent to OCAP, Maine Tribes are deeply invested in the sovereignty of their communities’ data. That means that the information may be protected from mainstream, white-centered efforts if those efforts are not meaningfully meeting the needs of the tribal community. As noted by one interviewee, “we need to develop different systems, we need to develop systems that are both developed, delivered, maintained by community, and this is doable.”

There are certainly shared efforts

# Enhancing Culturally Sensitive Data Collection

to articulate Maine’s public health data in relation to Tribal data. Resources such as the Maine Shared Community Health Needs Assessment and the Wabanaki Public Health Assessment are invaluable collaborations among public health agencies, healthcare providers, and citizens. Collaborations such as these provide readily available data and support data-driven health improvements for Mainers.

## LIMITATIONS OF MAINSTREAM DATA

Publicly available health data (and health data itself) lacks granularity when it comes to capturing the experiences of the communities the Permanent Commission has sought center in this investigation—that is, Black, Indigenous, and other people of color (BIPOC) in Maine. This is due in part to the challenges posed by working with smaller sample sizes, but it is also due to a longstanding lack of trust between BIPOC communities and white-centered systems.

Sample sizes are uniquely challenging in Maine, one of the least populous and most homogeneous states in the country. According to the 2020 Census, about 91 percent of Maine’s population identifies as white alone.<sup>23</sup> In a state with just 1.36 million residents, this means that the sample sizes of specific subpopulations may be so small that sharing data can result in an infringement of individual privacy. Indeed, in some cases, small samples cannot be shared out in an ethical fashion. Finally, smaller population sizes can also present a challenge with respect to large margins of error, statistically insignificant data, data collection techniques that prioritize white citizens and deprioritize racial and ethnic subgroups, a lack of distinction when collecting data, and more.<sup>24, 25</sup>

Compounding the problem of small sample sizes is a lack of trust. After centuries of racism, many members of BIPOC communities simply do not trust researchers enough to share personal health information when asked. Having observed and suffered the consequences of the misuse of data by providers and researchers, a lack of informed consent, data

## RECOMMENDATIONS

- 1. Invest in and value qualitative data, storytelling, and the sharing of lived experiences as an essential means of data collection, and engaging communities in meaningful, community-led discussions about experiences with prenatal care and maternal health, and data collection more broadly.**
- 2. Support the development of initiatives that honor the ability of communities to gather their own data, investing in efforts that ensure the health and sovereignty of that data.**
- 3. Invest in efforts that allow productive and mutually beneficial data sharing between mainstream public health systems and community-led data initiatives.**
- 4. Invest in improvements to public health data collection and data analysis that result in more robust racial and gender breakdowns.**
- 5. Understand that the systemic changes and trust that are required to support these recommendations is the work of years.**

exploitation, and a host of other factors, this can hardly come as a surprise.<sup>26, 27</sup> The well-known (and well-justified) vaccine hesitancy among the Black population is one example of this distrust.<sup>28</sup> Another participant noted: “Our work is based on relationships, and when you have datasets that are essentially federally or state-led, -collected, -analyzed, if you will, shared out, usually based on a survey, an interview... Black and Brown, Indigenous people don’t have those relationships with the very systems that were set up to target them; it only makes sense that that data is going to be of poor quality.”<sup>29</sup>

# Key Findings on Maternal Outcomes in Maine

## MAPPING MATERNITY IN MAINE

Maine has the highest median age of any state at 44.7.<sup>30</sup> Children under 18 years of age comprise 18.5 percent of the state's population, which is lower than the national level of 22.1 percent.<sup>31</sup> The number of births in Maine has been declining steadily, with an 18.5 percent decrease in births from 2006 to 2020. Maine is one of four states in the United States where deaths outnumber births.<sup>32</sup>

Between 2000 and 2020, the percentage of births to people who were born outside of the United States increased by 81 percent, an average of 2.84 percent per year. In 2016-2020, about 9 percent of Maine infants had birth parents who were born outside of the United States (though Androscoggin and Cumberland counties each has about 17 percent).<sup>33</sup>

Between 2016-2020, there were 60,593 births in Maine. The vast majority were at a hospital (97.7 percent), with 2.0 percent (1,228) of births taking place at home, and very few at birthing centers (0.2 percent) or other locations (0.1 percent).<sup>34</sup>

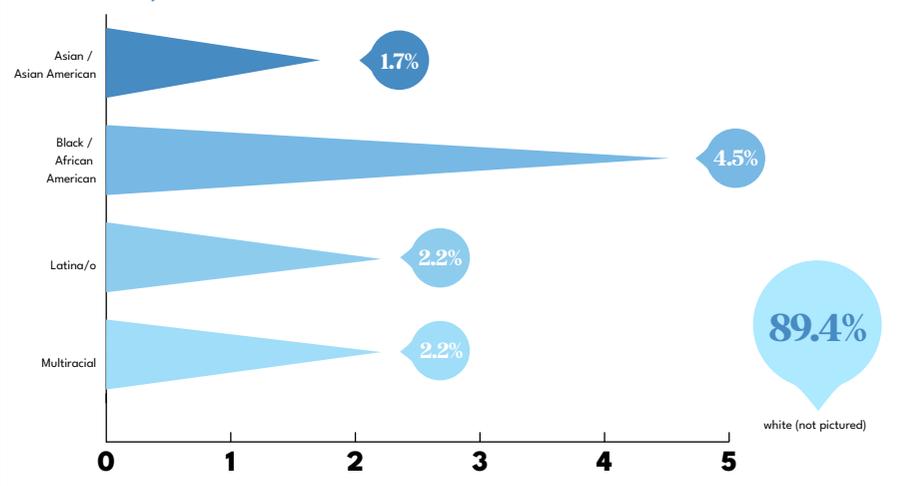
Maine has 25 birth hospitals located across the state, with most being small community hospitals that provide basic-level care. The state's two largest hospitals, Maine Medical Center (MMC) and Northern Light Eastern Maine Medical Center (EMMC) both have Neonatal Intensive Care Units.<sup>35</sup> Since 1998, seven hospitals have stopped providing obstetric services. Most of these were rurally located, considerably limiting access to birthing facilities in some of Maine's most rural areas.<sup>36</sup>

Between 2018-2020, there were 35,605 live births to Maine residents with 20 pregnancy-associated deaths during that period.<sup>37</sup> Pregnancy-associated mortality is defined as "any death of a person while pregnant or within one year of the end of pregnancy, regardless

of cause."<sup>38</sup> For the 14 pregnancy-associated deaths between 2018-2019,<sup>39</sup> one-third were due to medical complications related to the pregnancy, and two-thirds to injuries and indirect causes the risk of which increases in pregnancy.<sup>40</sup> Almost two-thirds of deaths occurred among women with a high school diploma or less education.<sup>41</sup>

In addition to reviewing mortality, maternal morbidity—which includes serious complications that can include near-death—is an important indicator of maternal wellness. Nationally, severe maternal morbidity has been increasing over recent years,<sup>39</sup> yet Maine data from 2016-2019 show relatively similar annual numbers (roughly 60 per year), with a total of 248 morbidities reported in that period of time.<sup>42</sup> Additionally, the

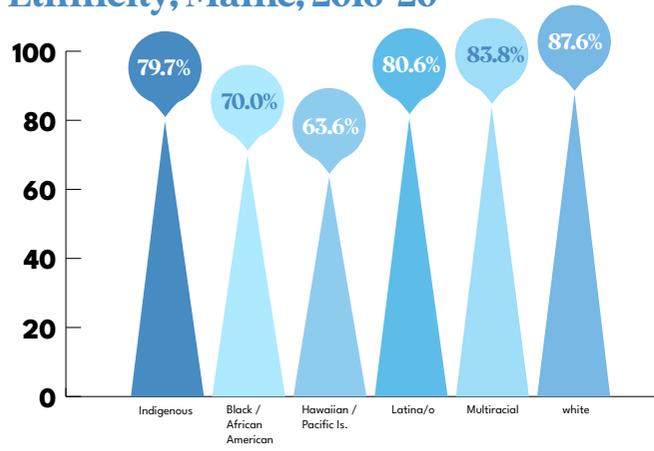
## Births to Birthing Parents by Race, Maine, 2010



2016-2019 morbidity rate for Maine was 85.7 per 10,000 deliveries, which is significantly lower than the 2016-2017 national rate of 140 per 10,000 deliveries.<sup>43</sup>

**Still: during that time period, the severe maternal morbidity rate was 176 percent higher among African American delivery hospitalizations than among white delivery hospitalizations in Maine (50.1 per 10,000 deliveries).<sup>44</sup>**

## Adequate Prenatal Care by Race / Ethnicity, Maine, 2016-20



In 2019, Maine’s infant mortality rate (IMR), or the number of infant deaths for every 1,000 live births, was the second highest in New England, but was the 18th lowest nationally.<sup>45</sup> Maine’s infant mortality rates vary by county. In 2014-2018, Lincoln County had the highest rate (9.1), and Hancock County had the lowest (3.9).<sup>46</sup> More than 60 percent of the 2019 deaths occurred during the first seven days of life (the early neonatal period) and the most common causes of infant deaths were directly related to being preterm (born before 37 weeks of pregnancy)<sup>47</sup> Preterm and low birthweight infants have a much higher risk of death compared to infants that are full-term and have normal birth weights. Maine’s percentage of infants born preterm rose between 2012 (7.7 percent) and 2019 (9.0 percent), though it remains lower than the U.S. rate (10.2 percent).<sup>48</sup> Between 2018-2019, Maine’s smallest county by population, Piscataquis County (96 percent white), had the highest rates of low birthweight and preterm births.

## Maine women of reproductive age are less likely to be insured.

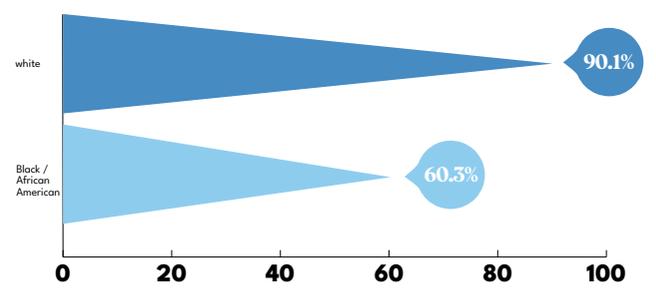
In 2019, 20.9 percent of Maine women of reproductive age were insured through Medicaid, and 65.2 percent had private insurance compared to 37.0 percent and 70.3 percent among all Mainers, respectively.<sup>49</sup> According to data collected on Maine birth certificates, MaineCare paid for 39 percent of births to Maine residents between 2016-2020. In births for which MaineCare was the primary payer, the vast majority were to white women (20,040). However, MaineCare was the primary payer for three in four births to Black/African Mainers and more than three in five births to American Indian/Alaska Natives, Native Hawaiian or Other Pacific Islanders, and to women that identify as being of two or more races.

## MAPPING DISPARITIES

As discussed, access to uninterrupted prenatal care is a key factor that can improve maternal outcomes and is the primary focus of this legislation. The “Adequacy of Prenatal Care Utilization Index (APNCU)” measures adequacy of care—“births for which the [pregnant person] received at least adequate prenatal care for birth, based on date prenatal care began, number of prenatal care visits, and infant’s gestational age at birth, as recorded on the birth certificate”.<sup>50</sup> In 2016-2020, 86.6 percent of women in Maine received adequate prenatal care.<sup>51</sup> This average is 10 percentage points higher than the national percentage, but rates vary greatly by race, ethnicity, and maternal country of birth.<sup>52</sup>

White pregnant people in Maine are more likely to receive adequate prenatal care than BIPOC pregnant people, as noted in the chart. The widest disparity exists between white women (87.6 percent) and Native Hawaiian or Other Pacific Islanders (63.6 percent), while virtually every non-white population also experienced decreased access to care (Black/African American (70.0 percent),

## “Got Prenatal Care as Early as Wanted,” Maine PRAMS, 2019



“Other” race (77.9 percent), American Indian/Alaska Native (79.7 percent), Hispanic/Latinx ethnicity (80.6 percent), and those born outside of the United States (78.2 percent).

The other population-wide source that shows access to prenatal care is Maine’s Pregnancy Risk Assessment Monitoring System (PRAMS). It is a population-based surveillance system “designed to identify groups of women and infants at high risk for health problems, to monitor change in health status, and to measure progress towards goals in improving the health of mothers and infants.”<sup>53</sup> For the data point in which respondents indicated they got prenatal care as early as they wanted, publicly available PRAMS data only includes a racial breakdown of white, Black or African American, and other. Maine PRAMS data from 2019 show that 91.1 percent of white women received prenatal care as early as wanted, while only 60.3 percent of Black or African American women did.<sup>54</sup>

# Disparity Drivers

Many factors drive the disparities we observe in maternal health outcomes among BIPOC communities. This section groups them into four broad categories—racism, structural barriers, the social determinants of health, and community norms—and summarizes the national and local research.

## RACISM

### Structural racism.

There are numerous barriers related to structural racism that specifically affect BIPOC people’s access to care and experience when receiving care.<sup>55, 56, 57</sup> Research has shown that these disparities between Black and white populations persist even when their personal and community characteristics (e.g., income, insurance coverage) are the same.<sup>58, 59, 60, 61, 62</sup> Various studies have linked these persisting disparities to provider behavior and discrimination, miscommunication and lack of trust between patient and provider, and differences in care-seeking behavior by BIPOC patients that is likely connected to the deterrent effect of previous negative experiences with the medical system.<sup>63, 64</sup>

### Poorer quality of care.

Research has found that Black women often receive poorer- quality prenatal care than do white women. This intersection of racism and sexism means that BIPOC women are also more likely to report being treated disrespectfully by medical providers, feel a lack of agency and not having decision autonomy during labor and delivery, or feel pressured into having a cesarean birth.<sup>65</sup> When expressing concerns about their health and requesting medical attention and treatment, BIPOC women are more likely to have their concerns dismissed or be denied care, which may delay diagnosis and care and thus contribute to complications or death that could have been prevented.<sup>66, 67, 68, 69</sup> These issues may be exacerbated for some BIPOC immigrant women, especially if a language barrier makes it harder for them to communicate directly with providers and to advocate for themselves.<sup>70</sup>

**Racist policing patterns may contribute to the racial disparity in preterm births.**

### Chronic stress associated with the effects of racism.

Racism-related stress may more largely contribute to social determinants of health for BIPOC than socio- economic factors, including in areas like premature births and birth outcomes.<sup>71, 72, 73, 74, 75, 76</sup> Chronic stress related to the experience of racism or trauma may negatively affect overall health, as well as maternal health outcomes, due to high levels of stress-related hormones like cortisol that may cause inflammation or affect the immune system.<sup>77, 78</sup> Similarly, refugees and asylum seekers often have elevated maternal cortisol levels due to trauma and stress related to migration, and are more likely to experience prenatal and post-partum depression.<sup>79, 80</sup> A recent study of policing in Minneapolis found that police contact was associated with preterm birth for both Black and white pregnant people. The study suggests that, because Black pregnant people were more likely to be exposed to police in their neighborhoods than white pregnant people, racist policing patterns may contribute to the racial disparity in preterm births.<sup>81, 82</sup>

**“Mistrust of the system makes some of the women not want to go to those appointments.”**

### Structural racism.

Research has found that delays in accessing prenatal care are associated with past experiences of bias and racism. BIPOC pregnant people cite attitudes of providers as a potential barrier to accessing prenatal care.<sup>83, 84</sup> As noted by one Advisory Group participant, “The mistrust of the system makes some of the women not want to go to those appointments.”<sup>85</sup> One participant noted that many BIPOC women have a heightened fear of child welfare involvement (at the national level BIPOC communities are in fact overrepresented in the child welfare system,<sup>86</sup> though that trend is less clear in Maine).<sup>87</sup> It was also noted that some pregnant people who struggle with addiction “don’t want to see a doctor because of the stigma and fear of losing their babies in the hospital instead of bonding.”<sup>88</sup>

# STRUCTURAL BARRIERS

## Lack of Providers.

Maine has an average of 67 primary care providers per 100,000 people. In more urban counties, there are more than 85 providers per 100,000 people, while in more rural counties there are fewer than 45 providers. Maine's least populated county, Piscataquis County, has only 18 primary care providers per 100,000 people.<sup>89</sup>

A 2016 national study found that racial and ethnic minorities made up only 12.3 percent of the physician workforce, despite comprising nearly 40 percent of the total population in the U.S.<sup>90</sup> Cultural competency trainings have a limited impact on patient outcomes without also focusing on a patient-centered approach.<sup>91</sup> A more diverse health care workforce would increase minority patients' opportunities to see a provider of their own race, ethnicity, or cultural background and research suggests this would also create a larger pool of culturally competent providers and ensure that BIPOC perspectives are taken into account throughout the healthcare system.<sup>92</sup> This could increase minority patients' trust in the healthcare system, increase their use of health care, and improve their experience and adherence to treatment plans.<sup>93</sup>

## Lack of Insurance.

As of 2019, nonelderly American Indians/Alaskan Natives, Hispanic, Native Hawaiian and Other Pacific Islanders, and Black/African American people continue to lack health insurance more often than is the case for their white counterparts in the United States.<sup>94</sup> Additionally, research has shown that Black, Indigenous, and Hispanic women experience disruptions in their health insurance coverage before, during, and after pregnancy at much higher rates than white women.<sup>95</sup>

While all major health insurance plans cover pregnancy and prenatal care in Maine, women of reproductive age (15-49) are more likely than the population at large to be uninsured (10.8 percent as opposed to 7.9 percent). They are also less likely to have private insurance (65.2 percent had private insurance compared to 70.3 percent of all Mainers).<sup>96</sup> In 2021, state legislation was passed for MaineCare to increase coverage up to 12 months after delivery, but cost barriers to care end up limiting access to health care regardless of coverage; about one in nine Mainers reports that cost is a barrier to seeking necessary medical care. That proportion increases to one in four Black or African American people in Maine and one in five Indigenous people in Maine.<sup>97</sup>

**“Receiving a bill for care received and not being able to afford it is one of the biggest fears that keeps people from seeking care even though they need it.”**

**Barriers related to insurance and cost were echoed throughout our work.** In the report from the community focus group conducted by In Her Presence, it was noted that “Receiving a bill for a care received and not being able to afford it is one of the biggest fears that keep people from seeking care even though they need it. Most asylum seekers are not qualified for state and local insurance to support their health care.”<sup>98</sup> A survey respondent also noted that “Some doctors won't take women that... have different insurance or if you are uninsured or waiting for MaineCare.”<sup>99</sup> People with uncertain immigration status may also avoid healthcare systems, for fear of jeopardizing their status or family stability.

**MaineCare was also cited as a challenging system to navigate.** It was noted “If you don't know it's available, it's not available;” “They deny you first;” and that it takes a few times to get access to MaineCare even when qualified. “The system takes a lot of navigation.”<sup>100</sup> Pregnancies may have progressed into the second or third trimester by the time MaineCare coverage begins.

## Location.

Among Mainers, living a greater distance away from a primary care provider has been associated with delayed diagnosis of serious health conditions.<sup>101</sup> Additionally a 2020 report by the Maine CDC listed accessing obstetric care and family planning services as key challenges to the maternal health of rural Mainers, as well as lack of birthing hospitals due to recent closures.<sup>102</sup> Likewise, when speaking about Tribal members' access to prenatal care, **a community leader emphasized the effects of rurality related to the shortage of rural providers, which means that Native and Indigenous women travel for hours to receive the care they need,** particularly for higher-level care beyond routine prenatal care.<sup>103</sup>

## Citizenship and political status.

As noted, pregnant people with uncertain citizenship status may actively avoid engagement with the healthcare system. The fear of harmful contact with systems is a pervasive reality for people in Maine with a range of different immigration statuses.

A conversation with the Director of the Penobscot Nation Health Department provided insight into access to care for some Native women in Maine. Tribal membership is a political designation; a person may self-identify as Native American but lack the political status needed to meet eligibility criteria for prenatal and other health services provided by the Penobscot Nation Health Department through the Indian Health Service. Therefore, while they are geographically located near this care, they cannot access these services and may experience lack of care or gaps in care. “When we talk about gaps in care, there are people who self-identify as Native who cannot access Native healthcare systems because they lack that political standing.”<sup>104</sup>

**“There are people who self-identify as native who cannot access native healthcare systems because they lack that political standing.”**

## SOCIAL DETERMINANTS OF HEALTH

### Socioeconomic factors.

Socioeconomic barriers to accessing care can include the cost of care, the cost or lack of access to transportation or childcare for other children, employment that does not allow pregnant people to attend prenatal appointments during the day, and not being able to afford to take time off work to receive care. A national study found that large and persistent socioeconomic disparities between racial and ethnic groups are a primary contributor to racial and ethnic disparities in access to prenatal care, specifically the disparities in access to care between Black and white women.<sup>105, 106</sup> Data for Maine shows a similar pattern. Mainers that are BIPOC are more likely to live below the poverty line and Maine mothers with income under \$16,000 are less likely than higher-income women to get prenatal care as early as they want it.<sup>107</sup>

## Maternal age.

Nationally, women under the age of 20 are least likely to receive prenatal care early, with only 61 percent accessing prenatal care in the first trimester of their pregnancy (compared to 81 percent of women aged 30-34), and are most likely to receive prenatal care late or not at all.<sup>108, 109</sup> Births to 15-19-year-olds in Maine have been steadily declining since 2011, but there are wide differences in adolescent birth rates across different subpopulations (Native Hawaiian or other Pacific Islanders have the highest adolescent birth rate (43.5), followed by American Indian/Alaska Native teens (22.1), teens that identify as more than one race (18.5), Black or African American teens (15.7), and then white teens (12.5) and Asian teens (2.2).<sup>110</sup>

Early maternal age may contribute to lack of prenatal care due to the stigma associated with teen birth, as well as simple lack of knowledge about the signs of pregnancy. As noted from one survey respondent who did not have access to prenatal care: “[It was because of my young] age, not knowing that I was pregnant and almost six months along.”<sup>111</sup>

**“[It was because of my young] age, not knowing that I was pregnant and almost 6 months along.”**

### Regional Factors.

There are also social determinants of health that may affect pregnant people based on regional challenges. The Penobscot Dept. of Health Direction noted that “...living on Reservation provides that community support, that cultural support, spiritual support, but in return you also have issues with accessing clean drinking water. It’s kind of a tradeoff, you know, but that is specific to residency on Tribal land.” The close grouping of New Mainers in two urban areas also means they are especially subject to the health effects of their regions.

**“We come from a place where unless you are sick, you don’t go to the hospital.”**

# COMMUNITY AND CULTURAL NORMS

While Maine is the most racially homogenous state in the country, more than 95 percent of Maine's total population growth is due to non-white populations, primarily people born outside the United States and arriving as immigrants, refugees, or asylum seekers.<sup>112</sup> This means that immigrants make up a substantial portion of Maine's non-white population.

## “Pregnancy is not a sickness.”

In some immigrant communities, a preference for curative care instead of preventative care may prevent people from seeking prenatal care. A leader in the community shared that, in addition to Somali women not accessing prenatal care without a sickness, they need to know why they are going. “We come from a place where unless you are sick, you don't go to the hospital... women come to me [and say] ‘Well I am not sick, why would I go there [to a prenatal appointment]’... it's a really hard sell.” – Excerpt from conversation with a Leader in Maine's Somali Community.

## Skepticism about U.S. practices.

In some community focus groups in Lewiston, Somali women in Maine report thinking that U.S. providers rushed labor and were quick to introduce medical interventions such as C-sections. In a 2015 group, some women expressed fears of dying during a cesarean birth. Many of them had spent time in refugee camps before immigrating to the U.S. and may have experienced C-sections to be unsafe there. This fear of C-sections may lead women to delay going to the hospital until they are in advanced labor in hopes of avoiding a cesarean birth.<sup>113</sup>

## Competing priorities.

Many New Mainers are overwhelmed with handling a difficult living situation or dealing with competing priorities, like housing, food insecurity, employment, care for other children, or financial constraints related to the cost of care, transportation, or childcare.<sup>113</sup> A community leader added that, since many community members do



not view preventative prenatal care as strictly necessary, they are less willing to take time off work to attend a prenatal appointment and instead prefer to prioritize earning money to prepare for the time after the baby is born and only seek care if issues arise.

## Structural barriers.

Many immigrants in Maine lack knowledge about navigating an unfamiliar health care system (for example, not knowing about available services, how to find a provider, how to pay for care, and how to navigate the bureaucracy of establishing care).<sup>114, 115, 116</sup> As noted by a community focus group, “Some concepts like informed consent, family health history and so on are pretty new or unknown to some immigrants. Since these are common, important components to health assessment and plan of care, they can limit the quality of care received by immigrants. There is a very deep cultural awareness to raise among immigrants about how the healthcare system works here, especially when it comes to prevention of some cardiovascular diseases that increase the risk of maternal death, such as diabetes and hypertension. The absence of health records makes it necessary to make a lot of different appointments with specialists to prevent or diagnose early signs and symptoms.”

Language barriers can increase these challenges, with the language line falling short in helping people manage the logistics and specifics of care, as well as to establish trusting, consistent relationships with providers.

# Implications and Recommendations

This report should be considered the groundwork for future efforts, which hold the experiences, voices, and needs of BIPOC communities at their center. Our conclusions span five different areas, each offering opportunities for further reflection.

1.

“Do we invest in those systems that were meant to colonize... or do we build our own?”

**EXPAND COMMUNITY-LED DATA GATHERING AND ALIGN WITH STATEWIDE SYSTEMS.**

2.

“Listen to the direct needs of the folks and let them lead the direction of their pregnancy and birth.”

**INVEST IN RELATIONSHIP-CENTERED CARE.**

3.

“If you don’t know it’s available, it’s not available.”

**ADDRESS STRUCTURAL INEQUITIES.**

4.

“There is a real need for community discussion to break that cultural barrier that increases the risks of negative outcomes during pregnancy.”

**SUPPORT COMMUNITY-LED EDUCATION.**

5.

“The system was never built to include everyone.”

**ENHANCE STATEWIDE DATA COLLECTION TO BETTER SERVE COMMUNITIES.**

## Expand community-led data gathering and align with statewide systems.

- Invest in systems that support community-led and culturally specific fact finding, story gathering, and qualitative data gathering. As noted earlier in this paper, **Maine’s data and information systems need to be expanded and improved to meaningfully center the experiences of BIPOC communities.** Prioritizing ongoing efforts to move this initial work forward is essential. It is time, as one interviewee noted, “to allow the power to be held where it should be held, and not by the government, simply within the communities.”
- Consult with the Maine Centers for Disease Control, including the Maine CDC MCH Director; the Maine Departments of Health and Human Services and DHHS Child Health Officer; and the Maine Perinatal System of Care Workgroup to **ensure that efforts in the state are aligned.**
- Continue **increasing the alignment between statewide systems and community-led and culturally specific programming** in order to identify needs and recommendations.

## Invest in Relationship-Centered Care.

- “Listen to the direct needs of the folks and let them lead the direction of their pregnancy and birth while also providing optimum support.”<sup>117</sup> One method to do this is to **expand access to doula and pregnancy support programs**, already increasing in recent years. Doulas are trained, non-medical pregnancy support people, who focus on offering guidance and support to the birthing person (sometimes throughout the pregnancy and recovery, in addition to labor). Their duty is to the birthing person and their specific plan and needs, and research has shown a decrease in cesarean births, shorter labors, decreased use of medications, and more satisfaction with the birth process.<sup>118</sup> There are several culturally and community-specific doula programs in Maine, including one hosted through In Her Presence, and a Wabanaki Doula Fund through the Eastern Maine Rematriation Collective. Several states have considered including doulas as eligible services in Medicaid,<sup>119</sup> and Maine should consider the same.
- **Expand access to midwifery and non-hospital births.** One survey respondent noted that the best part of their prenatal care was “Having a midwife service.”<sup>120</sup> One Advisory Group member noted: “Certain immigrant populations are more drawn to CNMs [certified nurse midwives] and CPMs [certified professional midwives] for

similar models of care offered internationally. Help to build bridges and foster cooperation between CNMs, CPMs and physicians providing obstetric care particularly around the care of BIPOC parents. Birth centers and home birth practitioners should be included in program development alongside hospitals.” A survey participant agreed: “If I could do it again, I would give birth at home.”

- **Build trust between providers and pregnant people.** There are several innovative models that focus on supporting open, trusting relationships between pregnant people and their practitioners. These have been shown to have a range of positive outcomes such as fewer numbers of preterm births and higher birth weights. Three sites using the Centering Pregnancy model are currently accredited in Maine at Mid Coast Women’s Health in Brunswick, York Hospital in York, and Waterville and Augusta Women’s Care in China Village. The programs focus on providing relationship- centered care and support, and empowering families through education and taking an active role in care. They have been shown to increase access to high-quality preventive health care. Maine should continue this expansion across the state, especially in communities most likely to serve populations with higher risk factors.
- **Provide support for communities before, during, and after pregnancy.** Healthy pregnancies and healthy community connections begin before the pregnancy. Building trusted programs to help people navigate community resources and care can address some of those concerns. One interviewee shared “I didn’t have as many appointments because I had a hard time setting up the appointment.... Communication with families and making sure families are in the loop of what’s going on [would support better prenatal care.]. I had missed an appointment because I had forgotten the appointment and I never got a call back to reschedule. If I hadn’t called back, I wouldn’t have had another appointment made.”<sup>121</sup> **Culturally specific community liaisons could help bridge the trust gap for communities**, and a new expansion of community health workers in Maine could provide an important resource in connecting pregnant and birthing people with care before, during, and after they give birth.<sup>122</sup>

## Address Structural Inequities.

- **Address the critical health insurance gaps that limit people’s access to care.** Health insurance was repeatedly cited as a major barrier to accessing maternal care, and while Maine has made progress in recent years—including by expanding access to MaineCare up to 12 months after giving birth—we must have access to continuous health insurance coverage before, during, and after pregnancy. Specifically,

this should include expanding access to MaineCare for pregnant people at higher income levels, covering New Mainers regardless of citizenship status, and finding other ways to ensure that all people in Maine can access the care they need to support their health and wellness.

- **Increase the accessibility of prenatal care and providers.** Geography and provider shortages both exacerbate the challenges with access, and both need to be addressed. Some solutions could include:
  - Support mobile health services and providers that bring specialized care to women in or near their homes,<sup>123</sup> including prenatal and postnatal medical home visits.<sup>124</sup>
  - Improve structures and fund the technology needed for telehealth programs.
  - Increase access to hospital and non-hospital birthing programs.
- **Ensure the workforce is adequate and appropriate.** Maine needs more healthcare providers who can provide care to birthing women, and we must increase the number of community- and culturally specific providers, and providers that reflect the race and ethnicity of those they serve.
  - **Earmark funding for workforce development and educational opportunities** in Maine’s health care force for BIPOC communities. One possible support for this is tuition programs. In October 2021, Governor Janet Mills announced a tuition remission program that will provide financial support to help employees attain healthcare credentials via funding from the Maine Jobs & Recovery Plan.<sup>125</sup>
  - **Engage BIPOC communities to explore the best ways to reduce racism within healthcare settings,** whether through increased implicit bias training, policy development, proactive measures to address discrimination, or other methods.
  - **Identify ways to include community liaisons in healthcare settings.** One Advisory Group member noted: “The best practice would include a community resource person with a cultural competency skill to understand and establish the connection between the healthcare industry and the immigrant population with the same cultural background. That would bring some understanding and mutual acceptance and reduce the distrust between the immigrants and the caregivers.”

## Support Community-Led Education.

- Identify dedicated funding for **community outreach and prenatal education programming** for Maine’s immigrant populations to improve health literacy, increase knowledge around the benefits of preventative prenatal care, and to address misconceptions or fear around certain medical procedures. This outreach must be done by members of the BIPOC communities themselves to ensure acceptance and appropriateness.
- Identify funding to **compensate immigrant- centered organizations and educators and support their existing efforts.**
- Identify funding to **support community-focused and community-led educational teaching materials,** make materials available in multiple languages, and use multiple channels and methods (such as video, social media, peer outreach, and more). Consider participatory programs, such as micro-grants, requests for proposals, or contests to develop materials uniquely suited to communities.
- Expand **education and outreach specifically for younger people about pregnancy and pre-pregnancy** to promote early identification and support.

## Enhance Statewide Data Collection to Better Serve Communities.

- Identify the importance of and support methods to **collect qualitative data to provide more granular and richer insights** into the experiences of BIPOC women in Maine.
- Update quantitative data collection methods to better capture the experience of care for BIPOC women. One example is adding questions about new mothers’ experience of racism before, during and/or after pregnancy to the Pregnancy Risk Assessment Monitoring System (PRAMS) survey.
- Develop **research and evaluation approaches that center participatory efforts** to strengthen maternal health data collection and community involvement. It should be noted that participatory research takes time, trust, and resources to compensate participants for their commitment and labor. Any such efforts should be part of a statewide investment.
- Ensure **new and ongoing community health needs assessment processes** which include health professionals, experts, and members of Maine’s BIPOC communities.

# Additional Maine & Tribal Resources

## Alliance for Innovation on Maternal Health (AIM)

Maine has recently started participating in [AIM](#), the Alliance for Innovation on Maternal Health, and will begin working with hospitals on quality improvement projects for populations at greater risk for hypertension. The project begins in January 2022. Future collaborations should include this group to ensure outreach and efforts are aligned.

## CradleME

CradleME is a referral service that connects pregnant persons and new parents to Public Health Nursing, Maine Families, WIC Nutrition Program, MaineMOM and Child Developmental Services Early Intervention Program.

## Culturally Specific Doula and Birthing Programs

There are several culturally and community-specific doula programs in Maine, including one hosted through In Her Presence, and a Wabanaki Doula Fund through the Eastern Maine Rematriation Collective.

## Early Head Start Home Visiting

Many Maine Head Start programs offer Early Head Start, which provides early care and education for infants and toddlers up to age three, and to pregnant women and their families who have incomes below the federal poverty level. Early Head Start uses the evidence-based Parents as Teachers model.

## Maine Families Home Visiting Program (MFHV)

MFHV is offered to all families in Maine that are expecting or have a new baby at home. This free program involves family visitor staff going to families' homes on a monthly up to weekly basis. The website Welcome Video is available in English, Somali, Portuguese, Spanish, French, Arabic, and Kinyarwanda. The program's goals include: "Nurturing families and their relationships, Promoting positive and effective parenting, Encouraging healthy living, considering all aspects of development, Providing guidance in creating positive and creative learning environments, Protecting children from violence, abuse and neglect, Protecting children from preventable illness and injury; Providing connections to needed resources and the community; Encouraging family self-sufficiency."<sup>126</sup>

Since 2000, MFHV has provided universal home visiting to eligible families in every Maine county. The program’s annual satisfaction survey shows that participants have a high overall satisfaction with the program and staff. In 2018, women who were enrolled in the program prenatally were more likely than women who enrolled postpartum to receive more than 80 percent of expected prenatal care visits. Program enrollment has decreased by 19 percent since 2018, and is serving 6.6 percent of children under age two in Maine.<sup>127</sup>

When looking specifically at engaging racially and ethnically diverse populations in Maine, the MFHV October 2020 Needs Assessment stated, “Families served by MFHV are more diverse than Maine’s population in general. MFHV programs report making a concerted effort to engage Maine’s BIPOC communities and new Mainer populations, though they recognize there is room for improvement with the cultural sensitivity and adaptability of their programming and the need to employ more individuals from these diverse communities. Future research efforts should include working with the MFHV to learn whether they recruit and employ diverse staff fluent in languages spoken most frequently in Maine.

### Public Health Nursing Home Visiting Program

The Public Health Nursing Program of the Maine CDC works to ensure positive birth outcomes for all Mainers.<sup>128</sup> The Maine CDC website describes Public Health Nurses as,

“registered professional nurses, working to improve, preserve, and protect the health and quality of life for all Maine citizens. Using nursing theory, research, evidence-based practice and the nursing process (assessment, diagnosis, planning, implementation and evaluation), Public Health Nurses continually work to improve the health of individuals, populations, cultures and communities.”<sup>129</sup> According to the NIECHV October 2020 Needs Assessment Update, there are 28 field nurses that work with women, infants, and children with an identified health need.<sup>130</sup> Future research should investigate the diversity of this group, the languages spoken, and outreach to BIPOC communities.

### Maine Perinatal Quality Collaborative (PQC4ME)

[PQC4ME, a multidisciplinary team](#), works to improve outcomes for maternal and infant health. The group does this by identifying and implementing quality improvement projects to improve maternal and newborn health with representation from medical providers across the State of Maine. PQC4ME has a Diversity, Equity and Inclusion Subcommittee. This committee is relatively new, but is in the process of developing its mission, vision, and goals. Future work should include collaborating with this group to align efforts.

## Maine Perinatal Systems of Care Workgroup

The Maine DHHS Child Health Officer leads an effort to bring providers together to establish a perinatal system of care. More discussion of the components of Maine's ideal perinatal system care can be found in [Understanding and Addressing the Drivers of Infant Mortality in Maine](#). The [efforts of this group and the ensuing report](#) contributed to the momentum for [LD113](#).

## Maine WIC Nutrition Program

[Maine WIC](#) is a nutrition program supporting thousands of Maine families. Anyone living in Maine, including migrants working in Maine, can apply. WIC supports pregnant or breastfeeding women, women who had a baby in the last six months, infants and children up to five (including adoptive and foster children) to receive food benefits, nutrition education, and healthcare referrals at no cost.

## Wabanaki Maine Families

Penobscot Nation, through Indian Health Services, runs an evidence-based family home visiting program for new parents and children up to age 3. Home visitors provide culturally responsive, best practice learning activities for parents and children. Future research efforts should include learning more about this home visiting program as a potential model, learning whether the other tribes in Maine run similar programs, and investigating whether there are other tribes nationwide with programs that could serve as case models.<sup>131</sup>



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