WHITE PAPER

Equitable Pregnancy Outcomes for Black and Brown New Yorkers
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Page</th>
<th>Section</th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td>Executive Summary</td>
</tr>
<tr>
<td>5</td>
<td>Maternal Mortality and Morbidity</td>
</tr>
<tr>
<td>11</td>
<td>Maternal Health in New York City</td>
</tr>
<tr>
<td>16</td>
<td>Infant Mortality</td>
</tr>
<tr>
<td>20</td>
<td>The Pregnancy and Birthing Experience of TGNC Individuals</td>
</tr>
<tr>
<td>26</td>
<td>Support and Resources</td>
</tr>
<tr>
<td>28</td>
<td>Policy Recommendations</td>
</tr>
<tr>
<td>31</td>
<td>Acknowledgments</td>
</tr>
</tbody>
</table>
EXECUTIVE SUMMARY

The maternal health crisis in the United States disproportionately impacts Black, and Indigenous pregnant persons, with stark disparities at the local level in New York City. This problem has significantly affected Black women, who have been more likely to die during childbirth than white women for more than a century.¹ Currently, Black women and Native American women are 3 times more likely than white women to die from pregnancy-related causes,² and Black women are twice as likely as white women to experience maternal morbidity.³ Although the data at the national level on maternal health outcomes for Hispanic women is mixed, studies show that certain subgroups of Hispanic women, including Puerto Rican women, experience higher rates of maternal mortality compared with non-Hispanic white women.⁴ Studies also demonstrate higher rates of maternal morbidity for Hispanic women in comparison to white women.⁵ The maternal health crisis is rooted in racism and medical discrimination, which, when combined with a lack of access to adequate healthcare and lack of information on one’s rights during pregnancy, creates a clear inequity in pregnancy outcomes for women of more color. And although there is a clear lack of data on the experiences and outcomes of LGBTQ and TGNC birthing people, there is evidence of the discrimination that these individuals face in accessing pregnancy-related care and health care in general.⁶

3 Elmman, Nora. Community-Based Doulas and Midwives. https://www.americanprogress.org/issues/women/reports/2020/04/14/483114/community-based-doulas-midwives/#:~:text=Multiple%20studies%20have%20found%20better%20outcomes%20of%20maternal.
4 Elmman, Nora. Community-Based Doulas and Midwives. https://www.americanprogress.org/issues/women/reports/2020/04/14/483114/community-based-doulas-midwives/#:~:text=Multiple%20studies%20have%20found%20better%20outcomes%20of%20maternal.
5 Ibid.
6 Ibid.
Effectively addressing the maternal health crisis and the inequities in pregnancy outcomes for birthing people of more color requires a multifaceted approach that centers the needs of Black and Brown pregnant persons. This approach means mandating and increasing anti-bias trainings for medical staff with regard to race and gender, ensuring the availability and accessibility of midwifery and doula services, and improving reporting on maternal mortality and morbidity cases. This approach would require a collective and concerted effort between New York City’s municipal government, New York State government, and the federal government.
MATERNAL MORTALITY AND MORBIDITY

At the center of the maternal health crisis is maternal mortality and morbidity. Maternal mortality refers to the death of a woman during pregnancy, at delivery, or soon after delivery.\(^7\) The term is used to refer to the death of a pregnant woman within 42 days of the end of pregnancy,\(^8\) whether it be delivery, miscarriage, termination, or ectopic pregnancy.\(^9\) Maternal morbidity, also known as severe maternal morbidity, or SMM, refers to the unexpected outcomes of labor and delivery that result in significant short-term or long-term consequences to a woman’s health.\(^10\) SMM includes life-threatening complications due to pregnancy and delivery. The maternal mortality and morbidity rates in the United States demonstrate a racial disparity within the maternal health crisis.

In the United States, Black women are 3 times more likely to die from a pregnancy-related cause than white women.\(^11\) Research shows that cardiovascular conditions, hemorrhage, and pulmonary embolism are among the primary causes of pregnancy-related deaths.\(^12\) Hypertensive disorders, which accounted for 6.6% of pregnancy-related deaths in the U.S. between 2014 and 2017,\(^13\) include pre-eclampsia and eclampsia.\(^14\) It has been reported that pre-eclampsia and eclampsia are 60% more common in African-American women than in white women, and also more severe.\(^15\)

The causes of the stark disparities in pregnancy-related mortality rates can include access to care, quality of care, prevalence of chronic diseases, structural racism, and implicit biases.\(^16\) From 2014 to 2017, the pregnancy-related mortality ratios were:\(^17\)

\(^8\) Maternal deaths. [https://www.who.int/data/gho/indicator-metadata-registry/imr-details/4622](https://www.who.int/data/gho/indicator-metadata-registry/imr-details/4622)
\(^13\) Ibid.
\(^14\) Ibid.
\(^15\) Roeder, Amy. “America is Failing its Black Mothers.” [https://www.hsph.harvard.edu/magazine/magazine_article/america-is-failing-its-black-mothers/](https://www.hsph.harvard.edu/magazine/magazine_article/america-is-failing-its-black-mothers/)
\(^17\) Ibid.
41.7 deaths per 100,000 live births for non-Hispanic Black women

28.3 deaths per 100,000 live births for non-Hispanic American Indian or Alaska Native women

13.8 deaths per 100,000 live births for non-Hispanic Asian or Pacific Islander women

13.4 deaths per 100,000 live births for non-Hispanic White women

11.6 deaths per 100,000 live births for Hispanic or Latina women

Health issues represent just one of the factors that contribute to these disparities. Chronic conditions, structural racism, and implicit bias are other factors. In the 1970s, researchers examined the issue of Black women having a higher risk of maternal and newborn health complications through the lens of genetics, behavioral and cultural differences, and access to healthcare. Then, in 1984, former Secretary of Health and Human Services Margaret Heckler convened the first task force of experts to conduct a comprehensive study of the health status of minority populations, known as the Report of the Secretary’s Task Force on Black and Minority Health, which was released the following year.

In the early 1990s, researchers identified a physiological mechanism that could explain “weathering,” a term coined by Arline Geronimus, a public health researcher and professor. Weathering refers to the ways social disadvantages corrode health. The researchers asserted that weathering happened due to a physiological mechanism called allostatic load. The human bodies respond to threats with a physiological stress response. Stress hormones flood the body, sending blood flowing to the muscles and the heart to help the body operate faster and harder. These processes funnel energy from other bodily systems not normally engaged in

---


19 Roeder, Amy. “America is Failing its Black Mothers.” [https://www.hsph.harvard.edu/magazine/magazine_article/america-is-failing-its-black-mothers/](https://www.hsph.harvard.edu/magazine/magazine_article/america-is-failing-its-black-mothers/)

20 Ibid.

21 Ibid.

22 Ibid.

23 Ibid.
the fight-or-flight response, including those that support healthy pregnancies. According to an article from the Harvard Public Health Magazine, this issue may not be an imminent threat in the short-term because the body’s homeostasis returns to normal. However, for individuals who face chronic threats and socioeconomic hardships, such as struggling to pay bills on a minimum wage job or witnessing and/or being a victim of police brutality, the fight-or-flight response may never subside. As a result, health risks rise at increasingly younger ages for chronic health conditions like hypertension and type 2 diabetes. Depression and sleep deprivation also tend to become more common. These conclusions tell us that women and persons planning to become pregnant in minority groups, namely Black women, may be living in such a stressful environment and facing social issues that has made their state of health worse by the time they are in their 20s and 30s, which is when most individuals begin to have children, than in their teens.

Weathering can also happen with minority groups in higher socioeconomic classes. Geronimus led a study in Detroit among low-income individuals of multiple races and ethnicities. In the study population, poor white individuals experienced more weathering than poor minority populations, and Hispanics with extensive education experienced more weathering than those with less education. Social isolation and feeling estranged from one’s community, whether due to differences in career or educational levels, along with daily exposure to discrimination in new, predominantly white, middle-class environments, may contribute to why a person of more color with more education experience weathering.

24 Ibid.
25 Ibid.
26 Ibid.
27 Ibid.
28 Ibid.
29 Ibid.
30 Ibid.
31 Ibid.
32 Ibid.
Stress related to immigration status also affects pregnancy outcomes. Researchers in New York City comparing rates of preterm birth before and after the 2016 presidential election found a statistically significant increase among Hispanic women and pregnant persons born outside of the U.S living in New York City. According to researchers and policy experts with the City’s Department of Health and Mental Hygiene, the increase in preterm births was attributed to anti-immigrant rhetoric used during and after the election season, in addition to federal immigration raids that also could have increased stress among immigrant populations.

Medical discrimination is another factor that effects pregnancy outcomes. According to The New York Times’ initiative, The 1619 Project, it is not uncommon for medical personnel to hold antiquated, racist misconceptions that date back to the 1800s, such as the idea that there are physiological differences between Black people and white people. These theories, which vary from Black people having thicker skin than white people, to Black individuals having less lung capacity than white individuals, are still being taught to medical students and are included in textbooks. Another area that is often viewed through a racial lens is pain tolerance. Medical journals have reported that white patients receive more and better pain treatment than African Americans and Hispanics. Studies show that although African Americans and Hispanics have higher pain scores, they were less likely than white patients to receive any pain medication and more likely to receive lower doses of pain medication.

34 Ibid.
35 Ibid.
37 Ibid.
39 Ibid.
These theories demonstrate that the discrimination and biases that exist in healthcare settings are the remnants of structural racism. And unfortunately, racism has reared its head in maternal health, with several cases of maternal mortality among Black and Brown women across the United States. Kira Johnson, a 39-year-old woman in Los Angeles who did not have any major health problems, went to the hospital in 2016 for her scheduled Cesarean section. After the procedure, she expressed experiencing severe pain in her abdomen. Her family asked the doctor and medical staff to address her symptoms and run tests. She was in pain for more than 10 hours. When the doctor finally took her into emergency surgery, 3 liters of blood had been found in her abdomen. The doctors had lacerated her bladder during the C-section and Kira had been bleeding internally ever since. She died on the operating table.

Shalon Irving was a 36-year-old epidemiologist at the Centers for Disease Control and Prevention in Atlanta when she learned she was pregnant with her first child in 2016. Three weeks after giving birth, Shalon collapsed and died due to complications of high blood pressure. The federal agency tasked with understanding why so many American women, mainly Black American women, die or nearly die from complications of pregnancy and childbirth, had lost one of its own staff members to the maternal mortality crisis. Shalon’s background, with a number of degrees - including a dual Ph.D - her top-notch insurance coverage, and a solid family support system, shows that this crisis impacts all Black women, regardless of educational level and socioeconomic class.

41 Ibid.
42 Ibid.
43 Ibid.
44 Ibid.
46 Ibid.
and socioeconomic class.\textsuperscript{47} Shalon had a history of clotting disorder, a fibroid surgery, 36 years of weathering as a Black woman in America, weight issues, in addition to high blood pressure, but managed to keep it under control during her pregnancy and delivery without medication.\textsuperscript{48} Where things went wrong, however, was in her postpartum care, when her blood pressure kept spiking and falling, one of her legs swelled, and she gained weight - 9 pounds in 10 days to be exact.\textsuperscript{49} She kept going to see the doctors and telling them that she did not feel fine and knew something was wrong with her body.\textsuperscript{50} But after her tests for pre-eclampsia came back negative, they told her there was nothing they could do and sent her home with a prescription for blood pressure medication.\textsuperscript{51} An autopsy report revealed that Shalon’s heart showed signs of damage that correlated with hypertension and attributed her death to complications of high blood pressure.\textsuperscript{52}

Both Kira and Shalon’s deaths could have been prevented. Kira’s internal bleeding, which was identified way too late, could have been averted if doctors had listened to her family’s concerns and treated her sooner. Shalon’s high blood pressure could have been averted if doctors had listened to her, had more frequent check-ups and ran more tests, given her medical history. One doctor even said that it would have made sense to have admitted her to a hospital for a chest X-ray, an echocardiogram to check for heart failure, and a titration of her medication to get her blood pressure to normal range.\textsuperscript{53} At the root of these two cases is medical neglect. Unfortunately, too many Black and Brown pregnant people report the same treatment, which reveals the existence of unconscious bias and racism in healthcare facilities.

\textsuperscript{47} Ibid.  
\textsuperscript{48} Ibid.  
\textsuperscript{49} Ibid.  
\textsuperscript{50} Ibid.  
\textsuperscript{51} Ibid.  
\textsuperscript{52} Ibid.  
\textsuperscript{53} Ibid.
In New York City, Black women are 8 times more likely than white women to die from a pregnancy-related cause, and nearly 3 times more likely to experience severe maternal morbidity than white women. In 2017, Black women gave birth to 23% of New York City babies, yet accounted for 55% of maternal deaths. Pregnancy-related illness is much more common in women of color in New York City. For each maternal death, about 100 women will suffer a life-threatening and often life-changing event during or after childbirth. Examples of SMM include heavy bleeding, blood clots, kidney failure, stroke, or heart attack. Hispanic women are twice as likely to experience SMM as white women. In New York City, maternal mortality and morbidity impacts women of color, regardless of socioeconomic status. A Black mother with a college education is at 60% greater risk of maternal death than a white mother with less than a high school education. Black women who live in high-income communities experience SMM at 4 times the rate of white women who live in very low-income communities. Black women with a college education have higher rates of severe pregnancy-related outcomes than all other women who did not complete high school.

In 2018, New York City began investing $12.8 million in a comprehensive five-year plan to reduce maternal mortality and morbidity. The funding goes towards four initiatives:

55 Ibid.
57 Ibid.
58 Ibid.
61 Ibid.
64 Ibid.
Engaging relevant private and public health care providers across the City in adopting implicit bias training - the unconscious attitudes or stereotypes that can affect behaviors, decisions and actions in their treatment of women of color who are pregnant.

Supporting private and public hospitals to enhance data tracking and analysis of severe maternal mortality and maternal morbidity events to improve quality of care and eliminate preventable complications.

Enhancing maternal care at NYC Health + Hospitals' facilities.

Expanding public education in partnership with community-based organizations and residents.

As part of the plan, Health + Hospitals introduced a new medical simulation training to educate providers on best practices in managing maternal hemorrhage, one of the top causes of pregnancy-related deaths for women of color. The training also aims to prevent implicit bias. Health + Hospitals announced the expansion of the training in 2020. Six H+H facilities (Bellevue, Elmhurst, Harlem, Kings County, Jacobi, and Lincoln) were outfitted with their own OB simulation lab to help replicate life-threatening health conditions during labor, such as embolisms, massive hemorrhages, and eclampsia. Using high-tech, full-body mannequins-of-color, OB physicians, anesthesiologists, nurse practitioners, midwives, and physician assistants from each of the 11 hospitals in the H+H system will participate in simulations that will further help identify a potentially life-threatening condition during labor and childbirth. The goal is to have more than 85 percent of H+H’s labor and delivery personnel complete a range of OB emergency simulations on an ongoing, rolling basis in the new labs. The New York City Council has also allocated funding towards addressing this issue. For


66 Ibid.


68 Ibid.

69 Ibid.

70 Ibid.
Fiscal Year 2022, the City Council allocated $3,192,818 to maternal and child health services, with $1.3 million of that funding going to the Department of Health and Mental Hygiene and the rest going to community-based providers and health care facilities.\(^{71}\)

Despite the City’s efforts to address this issue in recent years, the racial disparities in the maternal health crisis remain stark. In April of 2020, a 26-year-old pregnant woman named Amber Rose Isaac died after having an emergency Cesarean section to deliver her son.\(^{72}\) Prior to giving birth, Amber and her partner witnessed a lack of communication between the doctors’ offices throughout her pregnancy, and on numerous occasions when they went to her scheduled appointments at Montefiore Hospital, they found out that her appointments had never been scheduled at all.\(^{73}\) Instead of being seen in person, doctors’ appointments were done through virtual calls due to the onset of the COVID-19 pandemic, and the mother-to-be was told to buy her own blood pressure monitor.\(^{74}\) According to Amber’s partner, the couple felt judged by the OBGYN at their very first appointment for being unmarried.\(^{75}\) At one point during Amber’s pregnancy, the couple discovered that her platelet levels were decreasing and her pregnancy had been deemed high-risk.\(^{76}\) While it was unclear what had caused the decrease in her platelet levels at the time,


\(^{76}\) Ibid.
Amber knew something was wrong with her health.\footnote{Ibid.} She had been having trouble breathing, and her job as an early childhood education teacher required her to carry children up and down the stairs frequently, which also took a toll on her health.\footnote{Ibid.} When Amber communicated this to her OBGYN, the doctor responded by saying “Well, there are pregnant women who are squatting and lifting in this office. Why can’t you do the same?” This reaction was outright neglect and disregard.\footnote{Ibid.}

Doctors later discovered that Amber’s platelet count was decreasing because she had HELLP syndrome,\footnote{Ibid.} which is a serious complication of high blood pressure during pregnancy. HELLP stands for Hemolysis (which is the breaking down of red blood cells), Elevated Liver enzymes (EL), and Low Platelet count (LP).\footnote{Preeclampsia Foundation. Hellp Syndrome. https://www.preeclampsia.org/hellp-syndrome} A pregnant person can survive HELLP syndrome if treated in time.\footnote{Ibid.} Evidently, if Amber’s OBGYN had listened to her when she said she had difficulty breathing, if her doctors scheduled more in-person check-ups, and if certain laboratory tests were ordered, she could have been diagnosed and treated early, which would have subsequently saved her life.

Unfortunately, Amber is not the only Black woman in recent years who has lost her life after experiencing medical neglect and discrimination from healthcare providers in New York City. Shamony Gibson died of a pulmonary embolism in October of 2019, two weeks after giving birth to her second child.\footnote{Ibid.} She was only 30 years old.\footnote{Ibid.} According to Shamony’s mother, her daughter had been experiencing breathing problems a few days before she died.\footnote{Ibid.} She felt fine over the next 2 days, but then she went into
cardiac arrest while at home with her partner and children.\textsuperscript{86} When first responders arrived at their house, Shamony’s mother mentioned the possibility of pulmonary embolism and said her suggestion was dismissed.\textsuperscript{87} First responders asked her several times if her daughter used drugs, even though she had already informed them that Shamony had recently given birth.\textsuperscript{88} Shamony’s mother said that 12 hours later, while at the hospital, her daughter died.\textsuperscript{89} The cause of death was pulmonary embolism.\textsuperscript{90} The inconsideration that the first responders showed to Shamony’s mother is very similar to the disregard that Kira Johnson’s family experienced when they told doctors about the pain she was having. The experiences both women and their families endured reflect medical neglect, and demonstrate the extent to which discrimination is a leading cause in the maternal health crisis. Shamony’s mother stated that while the hospital to which her daughter was admitted treated her well, it was not equipped to handle the medical issue that she had.\textsuperscript{91} If the first responders listened to her, they could have brought her daughter to a hospital that would have been able to order not only lab tests, but X-rays, ultrasounds, CT scans, MRIs, and other tests that are typically done to diagnose pulmonary embolism.\textsuperscript{92} If caught early enough, treatment - whether through medication or surgery - would have saved Shamony’s life.

\textsuperscript{86} Ibid.
\textsuperscript{87} Ibid.
\textsuperscript{88} Ibid.
\textsuperscript{89} Ibid.
\textsuperscript{90} Ibid.
\textsuperscript{91} Ibid.
\textsuperscript{92} Mayo Clinic. Pulmonary Embolism. \url{https://www.mayoclinic.org/diseases-conditions/pulmonary-embolism/diagnosis-treatment/drc-20354653}
\textsuperscript{93} Ibid.
Infant mortality refers to the death of an infant before their first birthday. In 2018, the infant mortality rate in the United States was 5.7 deaths per 1,000 live births. Over 21,000 infants died in the United States that year. The five leading causes of infant death in 2018 were birth defects, preterm birth and low birth weight, maternal pregnancy complications, sudden infant death syndrome, and injuries, such as suffocation. In 2019, the states that had the highest infant mortality rates were Alabama (7.89), Louisiana (8.07), Mississippi (9.07), and North Dakota (7.35). New York’s infant mortality rate that year was 4.26.

The gap between infant mortality rates for Black infants and white infants is wider now than it was during slavery. Reports show that in 2018, when disaggregated by race and ethnicity, the non-Hispanic Black demographic had the highest infant mortality rate, at 10.8 per 1,000 live births. The infant mortality rate for the American Indian or Alaska Native demographic was 8.2 per live births. The infant mortality rate for the Hispanic demographic was 4.9, and the rate for the non-Hispanic white demographic was 4.6. This data demonstrates that although other women of more color experience an elevated risk of poor outcomes, racial disparities between Black and non-Hispanic white individuals remain the most stark.

Pregnancy-related complications have been tied to infant mortality rates. According to a report from the Center for American Progress, about two-thirds of infant deaths

95 Ibid.
96 Ibid.
98 Ibid.
101 Ibid.
102 Ibid.
occur during the first month after birth, often because of congenital abnormalities and complications from preterm births. Preterm birth is also a significant contributor to racial disparities in infant mortality. The most prevalent, severe congenital anomalies are heart defects, neural tube defects, and Down syndrome. Common causes of preterm birth include multiple pregnancies (i.e. being pregnant with twins), infections and chronic conditions (i.e. diabetes, high blood pressure). Some preterm births happen because of early induction of labor or caesarean section, whether it be for medical or non-medical reasons. There could also be a genetic influence. Oftentimes, no cause is identified. Interestingly enough, the United States was among the top 10 countries with the highest number of preterm births at 517,400 in 2010.

At the local level, racial disparities exist within rates of infant mortality. In New York City, non-Hispanic Black babies are three times more likely to not survive their first year of life than non-Hispanic white babies. These racial disparities exist within infant mortality because pregnancy-related complications are a contributing factor. The racial disparities that exist within maternal morbidity are causing those that exist in infant mortality. These disparities are also cited in other birth outcomes that affect the lives of mothers and their babies, such as Cesarean birth, preterm birth (which takes place before 37 weeks of pregnancy), and low birthweight (which is classified as less than 5 pounds, 8 ounces). Women who undergo Cesarean deliveries have a greater risk of dying or developing severe complications of their pregnancy, and their babies

104 Ibid.
105 Ibid.
108 Ibid.
109 Ibid.
111 Ibid.
have a greater risk of developing chronic conditions such as asthma, diabetes, and obesity. In 2016, Black women in New York City had the highest proportion of Cesarean births out of all racial and ethnic groups. Moreover, while infants born to Black mothers accounted for 19% of all births in 2016, they made up 28% of all low-birthweight babies and 26% of all preterm births that year. These statistics are essential in understanding the racial disparity in this issue because low-birthweight infants and preterm birth are key drivers of infant mortality.

Location also plays a role in why there are racial inequalities with regard to infant mortality. New York City neighborhoods are extremely segregated by race and socioeconomic class, which significantly impacts birth outcomes. Neighborhoods with predominantly Black and Hispanic populations, and where many residents live below the poverty line have some of the highest rates of severe maternal morbidity and infant mortality in the City. These neighborhoods include East Flatbush and Brownsville in Brooklyn, Williamsbridge and Mott Haven in the Bronx, and Jamaica in Queens. From 2013 to 2014, the rate of severe maternal morbidity was 92.4 for every 10,000 live births in Borough Park, Brooklyn, whereas it was 567.7 for every 10,000 live births in East Flatbush. Neighborhoods that are made up predominantly of people of more color have higher rates of SMM and infant mortality than neighborhoods that are predominantly white because those individuals are more likely to experience structural racism and medical neglect during pregnancy and delivery.

Although racial disparities in infant mortality are a stark reminder of the racial inequities in the healthcare system, some research shows that having a Black doctor

112 Ibid.
113 Ibid.
114 Ibid.
115 Ibid.
116 Ibid.
117 Ibid.
118 Ibid.
119 Ibid.
care for newborn babies reduces mortality rates.\textsuperscript{120} According to research reported in The Washington Post, after examining the records of 1.8 million hospital births in Florida between 1992 and 2015, researchers found that when the doctor of record for Black newborns was also Black, their mortality rate, in comparison to white newborns, was cut in half.\textsuperscript{121} Researchers found an association, not causation, so the reason behind this finding has not yet been determined.\textsuperscript{122} They said more studies are needed to understand what effect, if any, a doctor’s race could have on infant mortality.\textsuperscript{123} This information could very well serve as a catalyst for Black mothers to seek Black doctors - pediatricians, neonatologists, and family practitioners - to care for their newborns, but unfortunately supply does not meet demand.\textsuperscript{124} According to the Association of American Medical Colleges, only 5% of doctors and 4.5% of pediatricians identify as Black. Given that there were 579,174 Black babies born in 2018, representing 15% of all births, there are limited options for Black families seeking Black providers for their infants.\textsuperscript{125}

\begin{flushleft}

\textsuperscript{121} Ibid.

\textsuperscript{122} Ibid.

\textsuperscript{123} Ibid.

\textsuperscript{124} Ibid.

\textsuperscript{125} Ibid.
\end{flushleft}
THE PREGNANCY AND BIRTHING EXPERIENCE OF TGNC INDIVIDUALS

Although most data currently collected on pregnancy outcomes and maternal health is primarily of cisgendered identified women, the information that does exist with regard to transgender or gender nonconforming individuals shows disparities in access to health care and quality medical attention. Quality medical attention begins with creating a welcoming and safe environment for TGNC individuals who are expecting.

Current data suggest that 0.6% of the American population identifies as transgender or gender nonconforming. A TGNC person is one whose gender identity differs from that which was assigned at birth. If an individual's gender identity does not fit within the male/female dichotomy, the description “nonbinary gender identity” can be utilized. Most of the discourse around trans birth and parenting center on the challenges faced by trans men. Oftentimes, the nonbinary community is left out of the conversations. With more and more people identifying along different points along the gender spectrum, members of the TGNC community say medical institutions need to keep up, which entails not only knowing that various gender identities exist but also the medical issues that TGNC individuals may face.

Gender dysphoria is a condition in which a person experiences psychological distress resulting from the incongruence between one's assigned sex at birth and one's gender identity. Pregnancy-related gender dysphoria can be a common issue for

---


127 Ibid.

128 Ibid.

129 Ibid.


131 Ibid.

132 Ibid.

133 Ibid.
TGNC birthing people.\textsuperscript{134} Trans and gender-nonconforming people have to navigate an additional layer of healthcare discrimination to have a supportive birthing experience. There are often issues around respecting one's gender, the degree to which a TGNC individual has to educate the healthcare provider about their body, whether or not staff will use the correct pronouns and respect one's choices for their children, whether or not the doctor will provide tools to help manage pregnancy-related dysphoria, and if there will be support for breast or chestfeeding if one pursues it.\textsuperscript{135} Most doctors, nurses, and administrators may not fully understand the negative impact that using the wrong pronouns can have, but studies show that misgendering can cause psychological harm.\textsuperscript{136} Another issue that TGNC birthing people, namely those who are transgender men or trans-masculine, have expressed is being told that they do not belong in certain medical settings for pregnant women.\textsuperscript{137} One transgender man reported that he was even offered an abortion at 28 weeks of pregnancy by healthcare professionals,\textsuperscript{138} which indicates the existence of discrimination towards trans birthing people in certain healthcare settings.

All birthing people, regardless of gender, share the same goals, which include finding healthcare providers and a setting that will support a healthy pregnancy and allow them to have a supportive birthing experience.\textsuperscript{139} This means making decisions about who to include on a care team, such as obstetricians, certified nurse-midwives,
BEING AN ALLY MEANS THAT DISCUSSIONS ARE SPECIFICALLY FOCUSED ON THE CULTURE OF CARRYING A CHILD, RATHER THAN REDUCING IT TO GENDER.

midwives, doulas, and where to give birth. These decisions can be especially difficult for trans and gender nonconforming people, who have to navigate a layer of health care discrimination throughout pregnancy and birth.

Even when health care providers have obtained LGBTQ-centric education, pregnant people may meet with multiple care providers over the course of their perinatal care, and sometimes do not know who will be delivering their child when the day of delivery approaches. This lack of clarity is due to the fact that many hospitals and birthing centers adopt a rotational schedule, rather than requesting specific providers. In other words, the doctor who uses the correct pronoun and creates a gender-affirming environment for a gender non-conforming birthing person may not end up being the person who delivers their child, but rather a doctor who has not received the right training or simply does not know the specific needs of a TGNC pregnant person. Lack of this important knowledge can lead to the discomfort of TGNC patients. For example, there is a great degree of physical contact during birthing, such as vaginal or cervical exams. In many hospitals, this physical contact happens without discussion or consent, which can be traumatic for any individual but especially for a trans person dealing with acute dysphoria or a nonbinary person who may be in an environment where misgendering and disrespect is taking place. Some TGNC patients find touching of or discussion around their genitals very upsetting, as it can lead to dysphoria or memories of past trauma. When this happens in the context of a highly emotional situation, like delivery, it can exacerbate distress, which is not beneficial for the patient or the infant. An OB-

140 Ibid.
141 Ibid.
142 Ibid.
143 Ibid.
144 Ibid.
145 Ibid.
146 Ibid.
GYN at an LGBTQ-focused health center in Boston suggests establishing effective communication and consent before pregnancy, with preconception counseling and continuing said counseling through postpartum visits, where medical professionals ask questions about what changes the patient has noticed in their body and how they are feeling. This also requires having conversations throughout pregnancy with patients to prepare them for the experience of labor and delivery. The objective is to create a safe and gender affirming experience for them. In certain situations, that may include an elective Cesarean section for patients who feel unprepared for vaginal birth. According to a piece in Rewire News Group, acknowledging names and pronouns, consulting with patients before touching them, and using language about genitals and gender that correlates with the wants and needs of patients can create a respectful environment for everyone on the gender spectrum. This practice should be applied in hospitals, birthing centers, and home birth settings. Friends and family can also create a better environment for TGNC pregnant people by changing the discourse. Instead of centering the conversations on motherhood, center the conversation on “parenthood.” Being an ally means that discussions are specifically focused on the culture of carrying a child, rather than reducing it to gender.

Maintaining health insurance and coverage can be an obstacle for transgender people, which can impact their pregnancy, birthing, and postnatal experience. According to the 2015 U.S. Transgender Survey, which surveyed 28,000 people, 25% of respondents experienced a problem in the preceding year with their insurance because of their transgender identity, such as being denied coverage for routine care because they were transgender. In the previous year, 23% of respondents did not see a doctor when they needed to for fear of being mistreated as a transgender person, and 33% did not see a doctor when they needed to because they could not afford it.

147 Ibid.
148 Ibid.
149 Ibid.
150 Ibid.
151 Toler, Sarah. “What it’s like to be pregnant as a transmasculine person?” https://helloclue.com/articles/lgbt/what-it-s-like-to-be-pregnant-as-a-transmasculine-person
153 Ibid.
In addition to difficulties accessing health care, there are issues with administrative procedures. Intake forms and informational websites often include gendered language that communicates an assumption that all birthing parents are women who use she/her pronouns. Some trans men and nonbinary people have described their reproductive experience as difficult, including ordeals of painful and traumatic insemination, or getting so sick that they did not begin to show until their third trimester. Facing these challenges, along with being misgendered, are hard for members of the TGNC community who want to expand their families, which is why many of them turn to doulas for support throughout their pregnancy. Although TGNC pregnant persons may have the benefit of doula support, medical facilities need to do more to guarantee these individuals can give birth in a safe environment. While it is important to ensure that the language on paperwork and website information is gender inclusive, practitioners also need to understand that not every trans person is the same, which means no two trans people will require identical care. Transgender health care education needs to be targeted to folx who have already done the relevant training and are practicing, and trying to make sure that their practices are inclusive, welcoming, and affirming. It is also important to understand that cisnormative beliefs about reproduction can make gender presentation and pregnancy status difficult for transgender men or people with masculine gender expressions through pregnancy and birth.

While data on pregnancy outcomes and obstetric complications in transgender males is limited, a study of eight transgender male parents found that they

155 Ibid.
156 Ibid.
157 Ibid.
158 Ibid.
reported preterm labor (10%), placental abruption (10%), anemia (7%), and hypertension (12%). Another finding was an increased preference for elective cesarean among transgender males who had previously used testosterone. Although masculinizing hormone therapies must be stopped during pregnancy, providers should be aware that transgender males may experience mood swings, worsening of gender dysphoria, or worsening of underlying mental health disorders due to stopping the therapies. Pregnant transgender males and transmasculine individuals also have pregnancy hormones, in addition to the estrogen that they were born with, which could affect their body in ways that may be difficult to adapt to. Transgender males may opt to control their gender presentation by dressing as an overweight male or binding their breasts. Breast binding during pregnancy could interfere with lactation and increase the risk of complications, such as mastitis. Birth workers, whether they be OB-GYNs or midwives, need to have knowledge of this information in order to best serve their TGNC patients.

161 Ibid.
162 Ibid.
164 Ibid.
Despite the medical neglect and discrimination Black and Brown pregnant persons may face from doctors in hospital settings, there are safe alternatives. Doulas, midwives and birthing centers are an adequate, culturally competent option for women and pregnant persons who choose to forego hospital care. Doulas are individuals trained to provide non-medical physical, emotional, and informational support to birthing people and their families. Doula care has been linked to lower rates of Cesarean birth, preterm birth, low birth weight, and postpartum depression, as well as increased rates of breastfeeding, and greater patient satisfaction with maternity care. A midwife is a trained, typically certified birth attendant who provides a comprehensive range of services. These services include primary care; gynecologic care and family planning services; preconception care; care during pregnancy, childbirth, and postpartum period; and care of the newborn during the first 28 days of life. A birthing center is a healthcare facility for childbirth where care is provided in the midwifery and wellness model. The World Health Organization (WHO) recommends midwives as an evidence-based solution to reducing maternal mortality. Many systematic reviews have found that midwifery-led care for women with healthy pregnancies is comparable or preferable to physician-led care. Midwifery care has led to better maternal and neonatal outcomes, including lower maternal mortality and morbidity, as well as reduced stillbirths and preterm births. It has led to lower use of potentially harmful interventions like C-sections for low-risk

166 Ibid.
168 Ibid.
169 American Association of Birth Centers. What is a Birth Center? https://www.birthcenters.org/page/bce_what_is_a_bc
171 Ibid.
172 Ibid.
deliveries, epidurals, and instrument-assisted births.\textsuperscript{173} Midwifery care has also been reported to improve patient satisfaction and maternal psychosocial well-being outcomes, including those for postpartum depression.\textsuperscript{174} If a pregnant person has a low risk pregnancy, they can choose to have a midwife care for them during pregnancy.\textsuperscript{175} Although midwifery is a proven alternative to obstetricians and physicians for maternal care, they are often inaccessible for pregnant women who are low-income because a midwife must be enrolled with the Department of Health (DOH), Medicaid Management Information Systems (MMIS), in order to be able to receive payment for services provided to a Medicaid eligible recipient.\textsuperscript{176} In other words, if a midwife is not enrolled in Medicaid, then a pregnant person who has Medicaid would have to pay out of pocket for the midwife’s services. And while New York City has the Brooklyn-based “By My Side” program that offers doula services free of charge, most services are also not usually covered by insurance.\textsuperscript{177} This means their support is only accessible to women who are aware of it and can afford to pay for it. There are 15 midwifery service providers,\textsuperscript{178} 2 freestanding birthing centers,\textsuperscript{179} and 20 homebirth midwives\textsuperscript{180} in NYC. These numbers tell us that not only do midwives in New York City not have the bandwidth to take on the amount of births happening on a regular basis, but that there could also very well be a lack of availability of midwifery services for women who would prefer to give birth under the care of midwives.

\textsuperscript{173} Ibid.
\textsuperscript{174} Ibid.
\textsuperscript{175} HealthPartners. Choosing a midwife for pregnancy care: Who they are, what they do and when one may be right for you. https://www.healthpartners.com/blog/when-does-it-make-sense-to-choose-a-midwife-for-your-pregnancy/
\textsuperscript{177} Thomas, Mary-Powel. “Doula Support for Women in Underserved Communities.” https://www.publichealthpost.org/research/doula-support-for-women-in-underserved-communities/
\textsuperscript{178} NYC Midwives. Find a Midwife. https://www.nycmidwives.org/find-a-midwife/page-1
\textsuperscript{179} Brooklyn Birthing Center. Jazz Birth Center of Manhattan. https://brooklynbirthingcenter.com/
\textsuperscript{180} Crear-Perry, Joia, Bandele, Monifa, and Porchia-Albert, Chanel, panelists. Panel discussion. Black Mothers Matter Panel, 16 April 2020, Office of the Public Advocate.
POLICY RECOMMENDATIONS

The Office of the Public Advocate has the following specific legislative and policy recommendations:

- **The New York City Council needs to pass the Public Advocate's maternal health legislative package, which includes:**
  - Intro 2370: A Local Law to amend the administrative code of the city of New York, in relation to education about city standards for respectful care at birth, health care proxy forms and patients’ rights.
  - Intro 2369: A Local Law to amend the administrative code of the city of New York, in relation to requiring employers to hold an onboarding meeting to discuss an employee’s reintegration back into the workplace after parental leave.

- **New York City needs to expand its comprehensive plan to reduce maternal death from 5 years to 10 years.** The City should invest more funding and effort in the first point of the plan, which focuses on engaging private and public health care providers in adopting implicit bias training, to ensure that the training is effective. Health care professionals have identified methods that make implicit bias training in health care successful, which include gaining support from the leadership team of a medical facility and providing clear takeaways from the training.\(^\text{181}\) It is important that medical staff complete their training with a clear takeaway that is uniquely tailored to their implicit biases in regard to providing care.\(^\text{182}\) A clear call to action enables hospital staff to see patients differently and address disparities in access to care.\(^\text{183}\)

---


\(^\text{182}\) Ibid.

\(^\text{183}\) Ibid.
New York City’s Health + Hospitals Corporation needs to incorporate the World Health Organization’s recommendations for improving outcomes of preterm births. State legislatures in every state need to pass legislation mandating that their hospital systems incorporate WHO’s recommendations. The guidelines include interventions provided to the pregnant person, such as steroid injections before birth, antibiotics when the birthing person’s water breaks before the onset of labor, and magnesium sulfate to prevent future neurological impairment of the child. The guidelines also include interventions for the infant, such as thermal care, feeding support, kangaroo mother care, safe oxygen use, and other treatments to benefit a baby’s breathing.184 State legislatures in the South and mid-Atlantic region of the U.S. would benefit from having their hospitals incorporate these guidelines because they have higher infant mortality rates.

**New York City Health + Hospitals needs to include information on maternal mortality rates and the number of severe maternal morbidity cases, disaggregated by age, race or ethnicity, gender identity, health condition, and borough of residence in its annual Community Health Needs Assessment report.** Every locality’s hospital system has a yearly Community Health Needs Assessment (CHNA). Unfortunately, hospitals are not required to prioritize maternal and infant health in their CHNA, which means the inclusion of this information is left to the hospitals’ discretion. In the NYC Health + Hospitals’ 2019 CHNA, there is information on the disproportionate rate of infants who are born with low birthweight and to how many women, the distribution of encounters by facility by pregnant women, the race and ethnicity of pregnant women, the age distribution of pregnant women, the distribution of infants’ birthweight, and the breakdown of the numbers of encounters of pregnant women. There is no information on maternal mortality rates however. It is essential for the public to know the number of cases in which women are experiencing life-threatening complications from delivery and the maternal mortality rates across the City. At the moment, there is no public record of this information, which makes it all the more difficult to determine how to effectively address the maternal mortality issue in our City.

184 Preterm birth. [https://www.who.int/news-room/fact-sheets/detail/preterm-birth](https://www.who.int/news-room/fact-sheets/detail/preterm-birth)
The New York State legislature needs to pass, and the Governor needs to sign, legislation that would require public and private health care facilities to incorporate a biannual anti bias training focused on racial bias to create a respectful environment for women and birthing people of more color, as well as a biannual training that is focused on creating trans-inclusive, gender affirming environments for TGNC patients.

The New York State legislature needs to pass, and the Governor needs to sign, legislation that would require health insurance plans to provide free coverage of midwifery and doula services to expectant persons, regardless of gender identity, and ensure that midwives and doulas are reimbursed at a liveable wage.

The U.S. Congress needs to pass and the President needs to sign the Black Maternal Health Momnibus Act.
ACKNOWLEDGMENTS

**Lead Author:** Anika Michel, Policy and Legislative Associate.

**Co-Authors:** Casie Addison, Director of Legislation & Policy; Xamayla Rose, Deputy Public Advocate for Civic and Community Empowerment; Kadeem Robinson, Senior Policy and Legislative Associate; Kim Watson-Benjamin, LGBTQ Coordinator; Veronica Aveis, Chief Deputy Public Advocate for Policy; and Nick E. Smith, First Deputy Public Advocate.

**Design and Layout:** Leticia Theodore-Greene, Director of Public Affairs; Luiza Teixeira-Vesey, Graphic Designer.

The Public Advocate would like to thank those who participated in our Black Maternal Health Roundtable, Sevonna Brown (Black Women’s Blueprint), Dawn Godbolt (NBEC), Nana Adjeiwa-Manu (NBEC), Meghan Racklin (A Better Balance), Dana Bolger (A Better Balance), Dr. Christina Pardo (OB-GYN at SUNY Downstate) and the Council’s Women’s Caucus, who contributed invaluable information to this report.