



Once Upon a Premie: Policy Note 2.0

Maternal Health Equity. Neonatal Equity.

Once Upon a Premie, Inc. (OUAP) is a non-profit organization that advocates on behalf of Black mothers and Black premature babies across the nation with an emphasis on advancing equity in NICUs through the transformation of care delivery and lifting up lived experiences.

INTRODUCTION

The United States is experiencing an ongoing maternal and infant health care crisis that disproportionately impacts Black communities. Black women are three times more likely than white women to die from pregnancy-related complications. The mortality rate of Black infants is double the rate of white infants, with the leading cause of death being preterm birth.ⁱ

In the United States, one in five Black babies are born preterm at 37 weeks or sooner. Babies who are born preterm, or premature, are at greater risk of adverse health outcomes later in life and have higher rates of mortality than infants born at full term.ⁱⁱ

Unsurprisingly, the same historical patterns of inequities that are associated with the Black maternal health crisis, are also associated with the disproportionately high rates of Black infant prematurity across the country. These historical patterns of inequities include systemic racism, economic disenfranchisement, and discrimination in the healthcare system.

TOO MANY BLACK MOTHERS ARE DYING TOO SOON AND TOO MANY BLACK BABIES ARE BORN TOO SOON

The maternal health and wellbeing of Black women is associated with Black infant health outcomes.ⁱⁱⁱ Black women are more likely to experience pregnancy related complications than white women and the preterm birth rate for Black women is 50 percent higher than that of all other racial groups.^{iv} In comparison to white women, Black women, despite education or income levels, are more likely to experience preterm labor, and as such, Black infants are more likely to require admission to the NICU than babies of any other racial group.^v

WHEN YOUR BABY IS BORN TOO SOON

As a healthcare executive and advocate for healthy lifestyles and health equity, OUAP's founder Jenné Johns found herself advocating for the needs of her prematurely born son. Although Jenné had over a decade of experience working in the health field, an advanced degree, and access to the best health insurance and timely prenatal care, that was not enough to prepare her for the life changing, traumatic, and inequitable journey her family experienced in the Neonatal Intensive Care Unit (NICU).

Shamefully, nearly 17 percent of Black babies are born premature each year.^{vi} There are many factors that impact preterm birth, including socioeconomic status. However, socioeconomic status alone cannot explain the stark disparities in preterm birth. A growing body of research points to racism, a chronic stressor, as a key variable in understanding preterm birth disparities. Data shows that college-educated Black women are more likely to experience maternal and infant mortality than white women with high school diplomas.^{vii}

Black babies are 50 percent more likely to be born premature than white babies and have higher rates of NICU admissions.^{viii} Similarly, to the wider healthcare system, the NICU is a place where racism undermines the wellbeing of Black infants. When admitted to the NICU, Black infants are subject to discrimination and are more likely than white preemie babies to lack concordant care, which is associated with better health outcomes for Black infants.^{ix}

There are also stark differences in the quality of care received by Black infants in the NICU in comparison to white infants. Data shows that when Black preemie babies are admitted to NICUs in Black serving hospitals, these healthcare systems have fewer resources, thus creating greater disparities in breastfeeding rates and quality indicators.^x However, while majority serving hospitals are better resourced, they lack culturally relevant care, racially concordant care, and have high rates of implicit bias and discrimination. Black families regularly report being dissatisfied with patient care provider communication, family centered care, and respectful care in NICUs.^{xi} Although healthcare institutions are encouraged to complete annual cultural competency training, as recommended by the Office of Minority Health in the National Culturally and Linguistically Appropriate Services (CLAS) Standards, this is not enough to address the persistent differences in health outcomes and bias that permeates Black NICU families' experiences.

BLACK MATERNAL AND NEONATAL HEALTH EQUITY CAN BE IMPROVED THROUGH STRONG LEGISLATION.

To meaningfully address disparities in Black maternal and infant health, the healthcare system must be transformed to deliver patient-centered care that is equitable in nature and culturally relevant to the needs of Black mothers and infants. Innovations in Black maternal and neonatal health care requires centering Black Mothers lived experiences, acknowledging prematurity in the black population, and developing comprehensive policy solutions that are grounded in reproductive justice frameworks.

Innovative and equitable policy solutions are paramount to improving the quality of care and safety of Black mothers and their infants. To improve Black Maternal and Neonatal health care, these solutions must be firmly rooted in the lived experiences of Black families with preemie babies and culturally appropriate healthcare workers, such as Doulas, that successfully deliver care pre, during, and post delivery.

Support from Doulas have demonstrated improved health outcomes should be mandated by government sponsored and commercial insurers as a free-service for the first year of life. Also most critical, efforts to improve Black Maternal and Neonatal health care should address systemic racism as the root cause of disparities in health outcomes, including the preterm labor rate for Black women, and the quality of care delivered to Black infants in the NICU.

To assist policymakers in promoting maternal and neonatal health equity across the country, Once Upon a Premie has developed the following recommendations:

Priority #1: Federal funding should support policies that mandate implicit bias training to address discrimination in maternal and neonatal health care.

Black women and infants are more likely than their white counterparts to experience discrimination in the healthcare system, which is shown to impact health outcomes. Despite the disproportionately high rate of Black patients in NICUs, providers are unprepared to deliver care that is culturally relevant. Research indicates that too many Black NICU families have reported experiencing discrimination in the NICU.^{xii} Therefore, implicit bias training is essential to combating discrimination and improving Black Maternal and Neonatal health care. Providers should be equipped with the relevant training to address implicit bias in practice through an expanded curriculum that unpacks root causes of inequities in care delivery and solutions to close quality and disparity gaps at the bedside, and within the larger healthcare system.

Nearly 90% of healthcare professionals who completed the Once Upon A Premie Academy eLearning training program reported seeing challenges around health and racial equity in their workplace.

Over 80% of these same healthcare professionals also reported increased competency in implicit bias post Once Upon A Premie trainings.

We must mandate implicit bias training policies will to combat discrimination in the healthcare system, by equipping healthcare professionals with the skills to deliver culturally relevant, respectful, and equitable maternal and neonatal care.

Policy Recommendations:

- Fund and mandate continuous implicit bias training for perinatal, neonatal, and community health care professionals who serve Black birthing and NICU admitted women;
- Include an anti-bias curriculum in all provider credentialing requirements and continued education;
- Fund programs and establish mechanisms for pregnant, NICU admitted, and postpartum women to report instances of discrimination and bias.
- Establish and fund Respectful Maternity Care Compliance and NICU Equity programs to address bias and promote accountability;
- Fund technology-enabled learning modules that provide training on implicit bias.

Priority #2: To improve maternal and neonatal health outcomes, healthcare systems must collect accurate data. Healthcare systems must consistently collect, analyze and report health outcomes by race, ethnicity, and language. A critical step in promoting health equity is the standardization of data collection across the healthcare space for better analysis and reporting of quality metrics, including key demographics and patient experience. Further, robust data collection is needed to understand the full scope of the maternal and neonatal crises so that interventions may be better tailored.

“Healthcare organizations should collect information on patients’ race and ethnicity in order to measure disparities in care.”
- American Hospital Association

Policy Recommendations:

- Mandate the standardized collection of expanded race, ethnicity, and language categories;
- Institutionalize the tracking, trending, and reporting of patient level race, ethnicity, and language data;
- Fund the standardized collection and disaggregation of self-reported race, ethnicity, and language data;
- Require race, ethnicity, and language data analysis by quality improvement metrics, patient satisfaction, and patient trust measures.

Priority # 3: To improve the health of Black preemie babies, we must increase and expand pathways to diversify the maternal and neonatal workforce. Research indicates that Black infants with complex health conditions fare better when they are treated by Black providers.^{xiii} Provisions to expand the perinatal workforce should also apply to the neonatal workforce. Diversification of the maternal and infant workforce will increase concordant care and improve health outcomes, improve Black patient experiences, increase trust between Black patients and providers, and increase the number of care providers who can offer culturally relevant care.

Policy Recommendations:

- Provide guidance on the development and expansion of racially and professionally diverse care teams;
- Provide funding to establish and scale programs that will grow and diversify the maternal and neonatal health workforce;
- Study the barriers that prevent Black professionals from entering the maternity and infant care workforce and receiving fair compensation;
- Create funding for undergraduate training programs to expose Black students to careers in perinatal and neonatal health.

Priority #4: Black mothers and infants need access to high quality, culturally relevant and appropriate care, regardless of insurance status. Access to high quality health care is associated with better health outcomes. Clinical guidelines recommend that mothers have access to high quality health care that is ongoing and routine for at least one year postpartum, but without a federal mandate, too many Black mothers fall into coverage gaps.^{xiv}

Policy Recommendations:

- Expand Medicaid postpartum coverage extension to at least one year after birth;^{xv}
- Expand access to and support on-the-ground evidence-based interventions that increase access to mental health care for pregnant, NICU admitted and postpartum women;
- Ensure providers are held accountable for delivering equitable and culturally appropriate care to postpartum and NICU admitted women during the expanded coverage periods.
- Encourage all maternity and neonatal care settings to participate in governing bodies tasked with quality improvement and equity measures.

Priority #5: To reduce disparities in maternal and infant health, the wellbeing of Black Mothers and preemie babies must be centered in maternal health legislation.

The social risk factors that are associated with maternal mortality and morbidity are also associated with poor infant health outcomes including prematurity. Black women are more likely than white women to experience “weathering” from racism throughout the course of their life.^{xvi} To reduce disparities and improve maternal and infant health outcomes, legislation should develop a social safety net that will enable all families to thrive.

Policy Recommendations:

- Establish a mechanism to coordinate federal efforts to address social determinants of health for pregnant, NICU admitted, and postpartum women;
- Provide and scale programs that improve access to nutritious food, breastfeeding services, diapers, and transportation services to pregnant, NICU admitted, and postpartum women;
- Provide funding to community-based organizations to expand access to holistic and culturally tailored care for pregnant, NICU admitted, and postpartum women;
- Expand access to early childhood development experts in pediatric offices for low-income individuals;
- Invest in digital tools, including telehealth, to increase access to healthcare for families living in underserved areas.

Priority # 6: Expand access to Postpartum Doulas and Community Health Workers to support Black preemie families admitted to the NICU.

Historically, Doulas have supported black families by delivering culturally appropriate birthing, emotional, and practical support pre, during, and post delivery. Research has shown that access to Doulas improves outcomes for successful births and healthy babies and has lowered the odds of Postpartum Depression and Postpartum Anxiety by about 58 percent.^{xvii} Furthermore, research indicates that support from Doulas can save Medicaid and private insurers \$1,000 per birth.^{xviii} Therefore, given proven research, lived experiences, and recent federal priorities placed on increasing access to Doulas, no black birthing woman in the US should be left behind. Expanding access to doula care and community health workers for black preemie families is essential to ensuring the delivery of high quality, culturally appropriate and family centered care that Black birthing families require.

Policy Recommendations:

- Expand Doula services for one year post-partum for NICU admitted families and include these services as a covered benefit by government sponsored and commercial insurers.
- Mandate accredited implicit bias training for healthcare providers to understand the important role and value of Postpartum Doulas for patient safety, quality, and delivering culturally competent care.
- Ensure that Postpartum Doulas are provided substantial funding as a partner in the delivery of high quality, culturally appropriate and respectful care.
- Educate and empower birthing women and NICU admitted families about the benefits of Doulas to support their postpartum and NICU journey.

Priority # 7: Provide mental health and social service support for Black Premie Families.

Having a premature infant is a life changing and traumatic experience that for some women lasts a lifetime. Each minute a premie spends in the NICU can seem like an eternity for parents. Many times, mental health disorders and depressive symptoms do not present themselves immediately upon a baby's admission to the NICU. Additionally, many women's need for mental, emotional, and social support goes underrecognized, or misdiagnosed. This difficult time is unfortunately exacerbated for Black families because of systemic, systematic and societal racism coupled with unconscious bias, and a lack of culturally appropriate mental health screening tools. As America Builds Back Better, we need to address this disparity to improve outcomes for families with premature infants.

Policy Recommendations:

- Provide free mental health and social service support to families with a premature infant or who experienced infant loss for one year leveraging the medicaid expansion of postpartum care benefits.
- Mandate that mental health and social service providers receive training in delivering culturally appropriate screening tools and implicit bias training.
- Mandate the implementation of fully funded, culturally appropriate hospital and community-based support groups, led by peers and community-based organizations with lived experience. Support groups should be a safe space where families feel comfortable openly discussing any mental, emotional or bias-based issues they are experiencing from their healthcare providers.

CONCLUSION

A society's well being is measured by the ability of its population to thrive. However, far too many Black Mothers and Black babies experience higher rates of morbidity and mortality. Black Mothers and Black newborns die at three times the rate of their white counterparts. This is the unfortunate reality of a society that devalues the lives of Black women.^{xix} These health disparities can be addressed through policy levers. Without urgent action, Black mothers and infants will continue to experience poor health outcomes, high premature birth rates, and discrimination in the healthcare system.

Once Upon a Premie urges Congress to act now by enacting comprehensive policy solutions that are centered on the needs of Black Mothers and Black Premie Babies. Let's work together to combat these health disparities by creating equitable Maternal and Infant health care solutions for all premie families.



Once Upon A Premie is committed to improving the health outcomes of Black mothers and babies, unpacking disparities in NICU admissions, advancing equity in NICUs across the country, and educating NICU providers through anti-bias training. Once Upon a Premie advocates for the acknowledgement and integration of the needs of Black premie parents in Congressional bills that support eliminating disparities for maternal and infant health. Once Upon a Premie calls on policymakers to prioritize Black maternal and neonatal health through strong legislative action.

ENDNOTES

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