



# Once Upon a Premie: Policy Note

## ***Maternal Health Equity. Neonatal Equity.***

*Once Upon a Premie (OUAP) is a Black woman led 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.*

## 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. Black infants double the mortality rate of white infants, with the leading cause of death being preterm birth. <sup>i</sup>

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 in later life and have higher rates of mortality than infants born at full term. <sup>ii</sup>

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 health care system.

### When your baby is born too soon

As a health care executive and advocate for healthy lifestyles and health equity, OUAP 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, 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).

## 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. <sup>iii</sup> Black women are more likely to experience pregnancy related complications than white women and the preterm birthrate for Black women is 50 percent higher than for all racial other groups. <sup>iv</sup> In comparison to white women, Black women, despite education or income levels, are more likely to experience pre-term labor, and as such, Black infants are more likely to require admission to the NICU than babies of any other racial group. <sup>v</sup>



Shamefully, nearly 17 percent of Black babies are born premature each year.<sup>vi</sup> There are many factors that can impact preterm birth, but 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 show that college-educated Black women are more likely to experience maternal and infant mortality than white women with high school diplomas.<sup>vii</sup>

Black babies are 50 percent more likely to be born premature than white babies and have higher rates of NICU admissions.<sup>viii</sup> Similarly, to the wider health care system, the NICU is a place where racism undermines the wellbeing of Black infants. Black infants are subject to discrimination in the NICU and are more likely than white preemies to lack concordant care which is associated with better health outcomes for Black infants.<sup>ix</sup>

There are also stark differences in the quality of care received by Black infants in the NICU in comparison to white infants. Data show that when Black preemies are admitted to NICU's in Black serving hospitals, the systems have fewer resources, thus creating greater disparities in breastfeeding rates and quality indicators.<sup>x</sup> 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 provider communication, family centered care, and respectful care in NICUs.<sup>xi</sup> 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 it is not enough to address the ongoing discrimination and bias that permeate Black NICU families' experiences.

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## Black Maternal and Neonatal Health Equity Can be Improved Through Strong Legislation.

To meaningfully address disparities in Black maternal and infant health, the health care 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 develop comprehensive policy solutions that are grounded in reproductive justice frameworks. And most critical, efforts 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 trainings to address discrimination in maternal and neonatal health care.**

Black women and infants are more likely than white women to experience discrimination in the health care 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. Implicit bias training is necessary because too many Black NICU families have reported experiencing discrimination in the NICU.<sup>xii</sup> Providers should be equipped with the relevant training to address implicit bias in practice through an expanded curriculum that unpacks discrimination in the health care system and at the bedside.

Policy Recommendations:

- Fund and mandate continuous implicit bias training for perinatal and neonatal 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, postpartum women to report instances of discrimination;
- Establish and fund Respectful Maternity Care Compliance and NICU Equity programs to address bias and promote accountability;
- Develop and fund technology-enabled learning modules that cover trainings on implicit bias.

**Priority #2: To improve maternal and neonatal health outcomes health care systems must collect accurate data.**

Healthcare systems must consistently collect, analysis and report health outcomes by race, ethnicity, and language. A critical step in promoting health equity is the standardization of data collection, across the health care 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.

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 preemies 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.<sup>xiii</sup> 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 babies 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.<sup>xiv</sup>

Policy Recommendations:

- Expand Medicaid postpartum coverage extension to at least one year after birth;<sup>xv</sup>
- 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 post-partum and NICU admitted women during the expand 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 Mother’s 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 across the life course.<sup>xvi</sup> To reduce disparities and improve maternal and infant health outcomes, legislation should develop a social safety net so that all families can 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 health care for families living in underserved areas.

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## Conclusion

A society’s wellbeing is measured by the ability of its population to thrive, yet far too many Black Mother’s and Black babies experience morbidity and mortality. Black Mother’s 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.<sup>xvii</sup> Health disparities can be addressed through policy levers. Without urgent action, Black mothers and babies will continue to experience poor health outcomes, high premature birth rates, and discrimination in the health care system.

**Once Upon a Premie urges Congress to act now by enacting comprehensive policy solutions that center the needs of Black Mothers and Black Premie Babies.**





## 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

- <sup>i</sup> Centers for Disease Control and Prevention. (2022, February). *Maternal mortality rates in the united states, 2020*. <https://www.cdc.gov/nchs/data/hestat/maternal-mortality/2020/maternal-mortality-rates-2020.htm>; Office of Minority Health. (2021, July). *Infant mortality and african americans*. <https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=4&lvlid=23>; Ely D, Driscoll A. (2019). *Infant Mortality in the United States, 2017: Data from the Period Linked Birth/Infant Death File*. [https://www.cdc.gov/nchs/data/nvsr/nvsr68/nvsr68\\_10-508.pdf](https://www.cdc.gov/nchs/data/nvsr/nvsr68/nvsr68_10-508.pdf). from: [https://www.cdc.gov/nchs/data/nvsr/nvsr68/nvsr68\\_10-508.pdf](https://www.cdc.gov/nchs/data/nvsr/nvsr68/nvsr68_10-508.pdf).
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