

AN ACT concerning State government.

**Be it enacted by the People of the State of Illinois,
represented in the General Assembly:**

Section 1. Short title. This Act may be cited as the Task Force on Infant and Maternal Mortality Among African Americans Act.

Section 5. Findings. Based upon an April 11, 2018 New York Times article on "Why America's Black Mothers and Babies Are in a Life-or-Death Crisis", the General Assembly finds the following:

(1) From 1915 through the 1990s, amid vast improvements in hygiene, nutrition, living conditions and health care, the number of babies of all races who died in the first year of life dropped by over 90% – a decrease unparalleled by reductions in other causes of death. But that national decline in infant mortality has since slowed. In 1960, the United States was ranked 12th among developed countries in infant mortality. Since then, with its rate largely driven by the deaths of black babies, the United States has fallen behind and now ranks 32nd out of the 35 wealthiest nations. Low birth weight is a key factor in infant death, and a new report released in March by the Robert Wood Johnson Foundation and the University of Wisconsin suggests that

the number of low-birth-weight babies born in the United States – also driven by the data for black babies – has inched up for the first time in a decade.

(2) Black infants in America are now more than twice as likely to die as white infants – 11.3 per 1,000 black babies, compared with 4.9 per 1,000 white babies, according to the most recent government data – a racial disparity that is actually wider than in 1850, 15 years before the end of slavery, when most black women were considered chattel. In one year, that racial gap adds up to more than 4,000 lost black babies. Education and income offer little protection. In fact, a black woman with an advanced degree is more likely to lose her baby than a white woman with less than an eighth-grade education.

(3) This tragedy of black infant mortality is intimately intertwined with another tragedy: a crisis of death and near death in black mothers themselves. The United States is one of only 13 countries in the world where the rate of maternal mortality – the death of a woman related to pregnancy or childbirth up to a year after the end of pregnancy – is now worse than it was 25 years ago. Each year, an estimated 700 to 900 maternal deaths occur in the United States. In addition, the Centers for Disease Control and Prevention reports more than 50,000 potentially preventable near-deaths per year – a number that rose nearly 200% from 1993 to 2014, the last year for

which statistics are available. Black women are 3 to 4 times as likely to die from pregnancy-related causes as their white counterparts, according to the Centers for Disease Control and Prevention – a disproportionate rate that is higher than that of Mexico, where nearly half the population lives in poverty – and as with infants, the high numbers for black women drive the national numbers.

(4) In her 2014 testimony before the United Nations Committee on the Elimination of Racial Discrimination, Monica Simpson, the Executive Director of SisterSong, the country's largest organization dedicated to reproductive justice for women of color, testified that the United States, by failing to address the crisis in black maternal mortality, was violating an international human rights treaty. Following this testimony, the committee called on the United States to "eliminate racial disparities in the field of sexual and reproductive health and standardize the data-collection system on maternal and infant deaths in all states to effectively identify and address the causes of disparities in maternal and infant-mortality rates". No such measures have been forthcoming. Only about half the states and a few cities maintain maternal-mortality review boards to analyze individual cases of pregnancy-related deaths. There has not been an official federal count of deaths related to pregnancy in more than 10 years. An effort to standardize the national count has been financed

in part by contributions from Merck for Mothers, a program of the pharmaceutical company, to the CDC Foundation.

(5) The crisis of maternal death and near-death also persists for black women across class lines.

(6) The reasons for the black-white divide in both infant and maternal mortality have been debated by researchers and doctors for more than 2 decades. But recently there has been growing acceptance of what has largely been, for the medical establishment, a shocking idea: for black women in America, an inescapable atmosphere of societal and systemic racism can create a kind of toxic physiological stress, resulting in conditions – including hypertension and pre-eclampsia – that lead directly to higher rates of infant and maternal death. And that societal racism is further expressed in a pervasive, longstanding racial bias in health care – including the dismissal of legitimate concerns and symptoms – that can help explain poor birth outcomes even in the case of black women with the most advantages.

(7) Science has refuted the theory that high rates of infant death in American black women has a genetic component. A 1997 study published by 2 Chicago neonatologists, Richard David and James Collins, in The New England Journal of Medicine found that babies born to new immigrants from impoverished West African nations weighed more than their black American-born counterparts and were

similar in size to white babies, and were more likely to be born full term, which lowers the risk of death. In 2002, the same researchers further found that the daughters of African and Caribbean immigrants who grew up in the United States went on to have babies who were smaller than their mothers had been at birth, while the grandchildren of white European women actually weighed more than their mothers had at birth. It took just one generation for the American black-white disparity to manifest.

(8) Though it seemed radical 25 years ago, few in the field now dispute that the black-white disparity in the deaths of babies is related not to the genetics of race but to the lived experience of race in this country. In 2007, Richard David and James Collins published an even more thorough examination of race and infant mortality in the American Journal of Public Health, again dispelling the notion of some sort of gene that would predispose black women to preterm birth or low birth weight. Based upon his years of research and study on the subject, David, a professor of pediatrics at the University of Illinois-Chicago, stated that for "black women...something about growing up in America seems to be bad for your baby's birth weight".

(9) People of color, particularly black people, are treated differently the moment they enter the health care system. In 2002, the groundbreaking report "Unequal

Treatment: Confronting Racial and Ethnic Disparities in Health Care", published by a division of the National Academy of Sciences, took an exhaustive plunge into 100 previous studies, careful to decouple class from race, by comparing subjects with similar income and insurance coverage. The researchers found that people of color were less likely to be given appropriate medications for heart disease, or to undergo coronary bypass surgery, and received kidney dialysis and transplants less frequently than white people, which resulted in higher death rates. Black people were 3.6 times as likely as white people to have their legs and feet amputated as a result of diabetes, even when all other factors were equal. One study analyzed in the report found that cesarean sections were 40% more likely among black women compared with white women.

(10) In 2016, a study by researchers at the University of Virginia examined why African-American patients receive inadequate treatment for pain not only compared with white patients but also relative to World Health Organization guidelines. The study found that white medical students and residents often believed incorrect and sometimes "fantastical" biological fallacies about racial differences in patients. For example, many thought, falsely, that blacks have less-sensitive nerve endings than whites, that black people's blood coagulates more quickly and that black skin is thicker than white. For

these assumptions, researchers blamed not individual prejudice but deeply ingrained unconscious stereotypes about people of color, as well as physicians' difficulty in empathizing with patients whose experiences differ from their own. In specific research regarding childbirth, the Listening to Mothers Survey III found that one in five black and Hispanic women reported poor treatment from hospital staff because of race, ethnicity, cultural background or language, compared with 8% of white mothers.

(11) Researchers have worked to connect the dots between racial bias and unequal treatment in the health care system and maternal and infant mortality; however, based upon the preceding findings, it is clear that more must be done, and the General Assembly finds that a Task Force is necessary to work to establish best practices to decrease infant and maternal mortality among African Americans in Illinois.

Section 10. Task Force on Infant and Maternal Mortality Among African Americans.

(a) There is hereby created the Task Force on Infant and Maternal Mortality Among African Americans to work to establish best practices to decrease infant and maternal mortality among African Americans in Illinois.

(b) The Task Force shall consist of the following members:

(1) the Director of Public Health, or his or her

designee;

(2) the Director of Healthcare and Family Services, or his or her designee;

(3) the Secretary of Human Services, or his or her designee;

(4) two medical providers who focus on infant and community health appointed by the Director of Public Health;

(5) two obstetrics and gynecology (OB-GYN) specialists appointed by the Director of Public Health;

(6) two doulas appointed by the Director of Public Health. For the purposes of this paragraph (6), "doula" means a professional trained in childbirth who provides emotional, physical, and educational support to a mother who is expecting, is experiencing labor, or has recently given birth;

(7) two nurses appointed by the Director of Public Health;

(8) two certified nurse midwives appointed by the Director of Public Health;

(9) four community experts on maternal and infant health appointed by the Director of Public Health;

(10) one representative from hospital leadership appointed by the Director of Public Health;

(11) one representative from a health insurance company appointed by the Director of Public Health;

(12) one African American woman of childbearing age who has experienced a traumatic pregnancy, which may or may not have included the loss of a child, appointed by the Director of Public Health;

(13) one physician representing the Illinois Academy of Family Physicians; and

(14) one physician representing the Illinois Chapter of the American Academy of Pediatrics.

(c) The Task Force shall elect a chairperson from among its membership and any other officer it deems appropriate. The Department of Public Health shall provide technical support and assistance to the Task Force and shall be responsible for administering its operations and ensuring that the requirements of this Act are met.

(d) The members of the Task Force shall receive no compensation for their services as members of the Task Force.

Section 15. Meetings; duties.

(a) The Task Force shall meet at least once per quarter beginning as soon as practicable after the effective date of this Act.

(b) The Task Force shall:

(1) review research that substantiates the connections between a mother's health before, during, and between pregnancies, as well as that of her child across the life course;

(2) review comprehensive, nationwide data collection on maternal deaths and complications, including data disaggregated by race, geography, and socioeconomic status;

(3) review the data sets that include information on social and environmental risk factors for women and infants of color;

(4) review better assessments and analysis on the impact of overt and covert racism on toxic stress and pregnancy-related outcomes for women and infants of color;

(5) review research to identify best practices and effective interventions for improving the quality and safety of maternity care;

(6) review research to identify best practices and effective interventions, as well as health outcomes before and during pregnancy, in order to address pre-disease pathways of adverse maternal and infant health;

(7) review research to identify effective interventions for addressing social determinants of health disparities in maternal and infant health outcomes; and

(8) produce an annual report detailing the Task Force's findings based upon its review of research conducted under this Section, including specific recommendations, if any, and any other information the Task Force may deem proper in furtherance of its duties under this Act.

Public Act 101-0038

HB0001 Enrolled

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Section 20. Report. Beginning December 1, 2020, and for each year thereafter, the Task Force shall submit a report of its findings and recommendations to the General Assembly. The report to the General Assembly shall be filed with the Clerk of the House of Representatives and the Secretary of the Senate in electronic form only, in the manner that the Clerk and the Secretary shall direct.

Section 99. Effective date. This Act takes effect upon becoming law.