HB0001

101ST GENERAL ASSEMBLY

State of Illinois

2019 and 2020

HB0001

Introduced 1/9/2019, by Rep. Mary E. Flowers

SYNOPSIS AS INTRODUCED:

New Act

Creates the Task Force on Infant and Maternal Mortality Among African Americans Act. Creates the Task Force on Infant and Maternal Mortality Among African Americans. Provides for the membership of the Task Force. Provides for the election of a chairperson of the Task Force. Requires the Department of Public Health to provide technical support and assistance to the Task Force and to be responsible for administering its operations and ensuring that the requirements of the Act are met. Provides that members of the Task Force shall receive no compensation for their services as members of the Task Force. Provides for the meetings and duties of the Task Force. Provides that 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. Provides findings. Effective immediately.

LRB101 04044 RJF 49052 b

A BILL FOR

1 AN ACT concerning State government.

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

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

7 Section 5. Findings. Based upon an April 11, 2018 New York
8 Times article on "Why America's Black Mothers and Babies Are in
9 a Life-or-Death Crisis", the General Assembly finds the
10 following:
11 (1) From 1915 through the 1990s, amid vast improvements
12 in hygiene, nutrition, living conditions and health care,
13 the number of babies of all races who died in the first
14 year of life dropped by over 90% — a decrease unparalleled
15 by reductions in other causes of death. But that national
16 decline in infant mortality has since slowed. In 1960, the
17 United States was ranked 12th among developed countries in
18 infant mortality. Since then, with its rate largely driven
19 by the deaths of black babies, the United States has fallen
20 behind and now ranks 32nd out of the 35 wealthiest nations.
21 Low birth weight is a key factor in infant death, and a new
22 report released in March by the Robert Wood Johnson
23 Foundation and the University of Wisconsin suggests that

1 the number of low-birth-weight babies born in the United
2 States — also driven by the data for black babies — has
3 inched up for the first time in a decade.
4 (2) Black infants in America are now more than twice as
5 likely to die as white infants — 11.3 per 1,000 black
6 babies, compared with 4.9 per 1,000 white babies, according
7 to the most recent government data — a racial disparity
8 that is actually wider than in 1850, 15 years before the
9 end of slavery, when most black women were considered
10 chattel. In one year, that racial gap adds up to more than
11 4,000 lost black babies. Education and income offer little
12 protection. In fact, a black woman with an advanced degree
13 is more likely to lose her baby than a white woman with
14 less than an eighth-grade education.
15 (3) This tragedy of black infant mortality is
16 intimately intertwined with another tragedy: a crisis of
17 death and near death in black mothers themselves. The
18 United States is one of only 13 countries in the world
19 where the rate of maternal mortality — the death of a woman
20 related to pregnancy or childbirth up to a year after the
21 end of pregnancy — is now worse than it was 25 years ago.
22 Each year, an estimated 700 to 900 maternal deaths occur in
23 the United States. In addition, the Centers for Disease
24 Control and Prevention reports more than 50,000
25 potentially preventable near-deaths per year — a number
26 that rose nearly 200% from 1993 to 2014, the last year for

1 which statistics are available. Black women are 3 to 4
2 times as likely to die from pregnancy-related causes as
3 their white counterparts, according to the Centers for
4 Disease Control and Prevention — a disproportionate rate
5 that is higher than that of Mexico, where nearly half the
6 population lives in poverty — and as with infants, the high
7 numbers for black women drive the national numbers.
8 (4) In her 2014 testimony before the United Nations
9 Committee on the Elimination of Racial Discrimination,
10 Monica Simpson, the Executive Director of SisterSong, the
11 country's largest organization dedicated to reproductive
12 justice for women of color, testified that the United
13 States, by failing to address the crisis in black maternal
14 mortality, was violating an international human rights
15 treaty. Following this testimony, the committee called on
16 the United States to "eliminate racial disparities in the
17 field of sexual and reproductive health and standardize the
18 data-collection system on maternal and infant deaths in all
19 states to effectively identify and address the causes of
20 disparities in maternal and infant-mortality rates". No
21 such measures have been forthcoming. Only about half the
22 states and a few cities maintain maternal-mortality review
23 boards to analyze individual cases of pregnancy-related
24 deaths. There has not been an official federal count of
25 deaths related to pregnancy in more than 10 years. An
26 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

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

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

24 (9) People of color, particularly black people, are
25 treated differently the moment they enter the health care
26 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

1 these assumptions, researchers blamed not individual
2 prejudice but deeply ingrained unconscious stereotypes
3 about people of color, as well as physicians' difficulty in
4 empathizing with patients whose experiences differ from
5 their own. In specific research regarding childbirth, the
6 Listening to Mothers Survey III found that one in five
7 black and Hispanic women reported poor treatment from
8 hospital staff because of race, ethnicity, cultural
9 background or language, compared with 8% of white mothers.
10 (11) Researchers have worked to connect the dots
11 between racial bias and unequal treatment in the health
12 care system and maternal and infant mortality; however,
13 based upon the preceding findings, it is clear that more
14 must be done, and the General Assembly finds that a Task
15 Force is necessary to work to establish best practices to
16 decrease infant and maternal mortality among African
17 Americans in Illinois.

18 Section 10. Task Force on Infant and Maternal Mortality
19 Among African Americans.
20 (a) There is hereby created the Task Force on Infant and
21 Maternal Mortality Among African Americans to work to establish
22 best practices to decrease infant and maternal mortality among
23 African Americans in Illinois.
24 (b) The Task Force shall consist of the following members:
25 (1) the Director of Public Health, or his or her

1 designee;
2 (2) the Director of Healthcare and Family Services, or
3 his or her designee;
4 (3) the Secretary of Human Services, or his or her
5 designee;
6 (4) two medical providers who focus on infant and
7 community health appointed by the Director of Public
8 Health;
9 (5) two obstetrics and gynecology (OB-GYN) specialists
10 appointed by the Director of Public Health;
11 (6) two doulas appointed by the Director of Public
12 Health. For the purposes of this paragraph (6), "doula"
13 means a professional trained in childbirth who provides
14 emotional, physical, and educational support to a mother
15 who is expecting, is experiencing labor, or has recently
16 given birth;
17 (7) two nurses appointed by the Director of Public
18 Health;
19 (8) two certified nurse midwives appointed by the
20 Director of Public Health;
21 (9) four community experts on maternal and infant
22 health appointed by the Director of Public Health;
23 (10) one representative from hospital leadership
24 appointed by the Director of Public Health;
25 (11) one representative from a health insurance
26 company appointed by the Director of Public Health; and

1 (12) one African American woman of childbearing age who
2 has experienced a traumatic pregnancy, which may or may not
3 have included the loss of a child, appointed by the
4 Director of Public Health.
5 (c) The Task Force shall elect a chairperson from among its
6 membership and any other officer it deems appropriate. The
7 Department of Public Health shall provide technical support and
8 assistance to the Task Force and shall be responsible for
9 administering its operations and ensuring that the
10 requirements of this Act are met.
11 (d) The members of the Task Force shall receive no
12 compensation for their services as members of the Task Force.

13 Section 15. Meetings; duties.
14 (a) The Task Force shall meet at least once per quarter
15 beginning as soon as practicable after the effective date of
16 this Act.
17 (b) The Task Force shall:
18 (1) review research that substantiates the connections
19 between a mother's health before, during, and between
20 pregnancies, as well as that of her child across the life
21 course;
22 (2) review comprehensive, nationwide data collection
23 on maternal deaths and complications, including data
24 disaggregated by race, geography, and socioeconomic
25 status;

1 (3) review the data sets that include information on
2 social and environmental risk factors for women and infants
3 of color;
4 (4) review better assessments and analysis on the
5 impact of overt and covert racism on toxic stress and
6 pregnancy-related outcomes for women and infants of color;
7 (5) review research to identify best practices and
8 effective interventions for improving the quality and
9 safety of maternity care;
10 (6) review research to identify best practices and
11 effective interventions, as well as health outcomes before
12 and during pregnancy, in order to address pre-disease
13 pathways of adverse maternal and infant health;
14 (7) review research to identify effective
15 interventions for addressing social determinants of health
16 disparities in maternal and infant health outcomes; and
17 (8) produce an annual report detailing the Task Force's
18 findings based upon its review of research conducted under
19 this Section, including specific recommendations, if any,
20 and any other information the Task Force may deem proper in
21 furtherance of its duties under this Act.

22 Section 20. Report. Beginning December 1, 2020, and for
23 each year thereafter, the Task Force shall submit a report of
24 its findings and recommendations to the General Assembly. The
25 report to the General Assembly shall be filed with the Clerk of

1 the House of Representatives and the Secretary of the Senate in
2 electronic form only, in the manner that the Clerk and the
3 Secretary shall direct.

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