Department of Health and Human Services
Maine People Living
Safe, Healthy and Productive Lives
Paul R. LePage, Governor
Ricker Hamilton, Commissioner

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June 4, 2018

Senator Eric L. Brakey, Chair
Representative Patricia Hymanson, Chair
Joint Committee on Health and Human Services
#100 State House Station
Augusta, Maine 04333-0100

Dear Senator Brakey, Representative Hymanson and members of the Joint Standing Committee on Health and Human Services:

Enclosed is the *Maine Maternal Fetal Infant Mortality Review Panel Report for fiscal year 2017.*

The Maternal Fetal Infant Mortality Review Panel statute (22 M.R.S.A. Chapter 101 §261) directs the Panel to submit an annual report to the Department of Health and Human Services and to the Joint Standing Committee of the Legislature having jurisdiction over health and human services. The report will identify factors contributing to maternal and infant deaths in the State, determine the strengths and weaknesses of the current maternal and infant health care delivery system and make recommendations to the Department to decrease the rate of maternal and infant death.

If you have any questions or would like further information, please feel free to contact Bruce Bates, D.O., Director, Maine Center for Disease Control and Prevention at (207) 287-3270 or bruce.bates@maine.gov.

Sincerely,

Ricker Hamilton
Commissioner

RH/klv

Enclosure

cc: Bruce Bates, D.O., Director, Maine Center for Disease Control and Prevention, DHHS

Maine Maternal, Fetal and Infant Mortality Review Panel

July 1, 2016 - June 30, 2017

Submitted to the Joint Standing Committee on Health and Human Services

2017 Annual Report

Department of Health and Human Services
Maine People Living Safe, Healthy and Productive Lives

Paul R. LePage, Governor

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Maine Centers for Disease Control and Prevention
Maternal, Fetal and Infant Mortality Review Panel
2017 Annual Report to the Legislature

TABLE OF CONTENTS

INTRODUCTION

The Maternal, Fetal, Infant Mortality Review (MFIMR) Panel resides within the Maine Center for Disease Control and Prevention (Maine CDC) and is a multidisciplinary group of health care and social service providers, public health officials, and other persons with professional expertise in maternal and infant health and mortality. All Panel members are volunteers. The Panel's purpose is to gain an understanding of the factors associated with fetal, infant and maternal deaths in order to expand the state's capacity to direct prevention efforts and to be able to take actions to promote the health of mothers and infants. Using a public health approach, the program's goal is to strengthen community resources and enhance state and local systems and policies affecting women, infants and families, in order to improve health outcomes in this population and prevent maternal and infant mortality.

This 2017 report summarizes relevant data contributing to perinatal outcomes, challenges, activities and plans for the MFIMR Panel.

BACKGROUND

In 2005, the 122nd Legislature passed *An Act to Establish a Maternal and Infant Death Review Panel.* In 2010, the 124th Legislature amended this statute to authorize the Maternal and Infant Death Review Panel to review fetal deaths occurring after 28 weeks gestation (stillborn infants). With this change, the Panel was referred to as the Maternal, Fetal and Infant Mortality Review (MFIMR) Panel. The Legislature also repealed the Panel's sunset provision allowing the Panel to continue its work beyond the original end date of January 1, 2011.

In 2017, an amendment to modify the MFIMR statute was approved to become effective on November 1, 2017. The changes to the statute are as follows:

- It formally changes the Maternal and Infant Death Review Panel to the Maternal, Fetal and Infant Mortality Review Panel;
- It provides that the term, "director" (as it pertains in the laws governing the Panel), refers to the medical director of the Maine CDC;
- It allows the Panel Coordinator to obtain, without the family's consent, the health information of a woman who died during pregnancy or within 42 days of giving birth, a child who died within one year of birth or a mother of a child who died within one year of birth, including fetal deaths after 28 weeks of gestation; and
- It requires the Panel to meet at least twice per year.

The Maine CDC MFIMR Panel did not meet between SFY 2014 and SFY 2016. In 2016, it was identified that modifications were needed to improve the function of the MFIMR Panel process, which included the following:

- The process of contacting families for interviews and obtaining consent for record reviews was revamped and families were contacted using this new process;
- Records were reviewed for the few cases for which family consent was obtained; and
- The Office of Child and Family Services was tasked with conducting interviews for families interested in sharing their experience with delivery of care, challenges they encountered, and recommendations for improvement.

Recommendations from Previous Years

The Panel had previously identified the following issues as needing in-depth investigation:

- Factors that contribute to preterm birth, pregnancy loss and strategies for prevention;
- Barriers to delivery of the highest risk infants (e.g., very low birth weight, premature infants) at hospitals with appropriate facilities and resources to provide the best chance of survival for the infant (i.e., Level III facilities);
- Sudden Infant Death Syndrome (SIDS) and Sudden Unexpected Infant Death (SUID) as emerging issues, including sleep related deaths;
- Increasing awareness of the MFIMR Panel and related activities and resources for healthcare providers and bereaved families; and
- Determining which of the recommendations from the National Fetal Infant Mortality Review Technical Assistance to implement in order to improve the MFIMR system.

MFIMR PANEL ACTIVITIES IN STATE FISCAL YEAR 2017

The MFIMR Panel reconvened in March 2017 with participation of some past Panel members as well as new members. The statutory requirements for the Panel were reviewed and the Panel Coordinator described the new processes used to contact families for permission to review records and offer family interviews. Information regarding fetal/infant deaths in Maine was reviewed by an epidemiologist from the Maine CDC. These data demonstrated that Maine's infant mortality rate peaked in 2013, but has been declining since then. In the period of 2012-2014, Maine ranked 36th in the U.S. for infant mortality. Pre-term related conditions are the leading cause of infant mortality, followed by congenital anomalies. Maine has not seen an increase in prematurity or low birth rates over the past seven years. Conditions related to infants most at risk were reviewed, and it was noted that there has been an increase in the number of drug-affected babies; smoking during pregnancy also remains an area of concern.

The Panel met again in June 2017 and reviewed an infant death case. Information regarding the Perinatal Periods of Risk (PPOR) Approach for Preventing Infant Mortality was presented by a Maine CDC epidemiologist. This approach is used to help identify potential areas of focus for infant and fetal mortality reviews.

Legislation was passed that will allow the Panel Coordinator to have access to health care records (effective November 2017) without the express permission of next of kin. This legislation will remove a barrier to accessing and reviewing cases to identify trends or issues with prenatal or postnatal care of mothers, fetuses, and infants.

Challenges Experienced by the MFIMR Panel

Maternal death reviews are challenging, for a number of reasons, including the following:

- It can be difficult to ascertain where the mother may have had pre- and post-natal care;
- It can be challenging to determine which family member to contact for an interview; and
- Case ascertainment requires linking death certificates of women of reproductive age with birth and fetal death records.

The statutory requirement mandating a 4-month waiting period prior to contacting the family to extend an invitation for an interview is problematic. Other states do not have this requirement as it is a prolonged amount of time to wait to reach out to a grieving family.

PLANS FOR MFIMR PANEL FOR STATE FISCAL YEAR 2018

With the legislative changes in 2017, the Panel Coordinator will be able to obtain, review, and abstract medical records without consent of the family starting in November 2017. This information is confidential to the Panel Coordinator, and is de-identified when case abstractions are presented to the Panel members. It is expected that many more cases will be reviewed by the Panel which will provide more meaningful information upon which recommendations may be made to improve systems and processes, and decrease mortality in these groups.

The Panel is required to meet a minimum of two times in state fiscal year 2018. The first meeting is scheduled for November 2017 and subsequent meeting times will be determined with Panel member input.

The Panel will continue to monitor statistical data for trends in maternal, fetal, and infant mortality. Specifically, the Panel will look at the timing and adequacy of prenatal care, access to care for pregnant teens, impact of substance abuse, and the appropriateness of care for infants with very low birth weight, including distance from a Level III facility.

The Panel will complete a comprehensive analysis of data related to preterm births, including relevant risk factors such as smoking, substance abuse, and chronic disease, such as diabetes. The review of this analysis will identify opportunities for reducing preterm births and other causes of infant death.

The Panel will work with the Maine CDC and DHHS leadership to follow up on recommendations and develop plans to implement system improvements.

MFIMR: EPIDEMIOLOGY REPORT

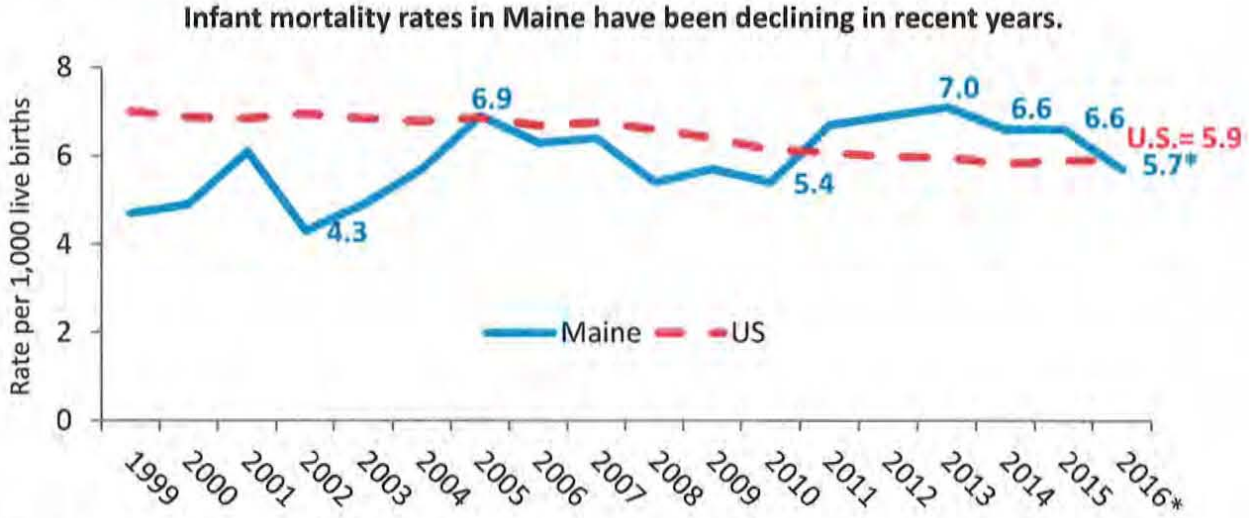
In support of the MFIMR Panel, funding is provided for epidemiologic analyses of maternal, infant and fetal mortality to help the Panel understand patterns and trends associated with maternal, fetal and infant deaths. In the previous year, MFIMR epidemiologist activities included:

- Conducting analyses of infant mortality causes and trends and presenting the results to the MFIMR panel;
- Obtaining provisional quarterly birth and infant death data from Maine CDC's Data, Research and Vital Statistics program to monitor infant mortality and associated risks on a quarterly basis; and
- Conducting a Perinatal Period of Risk (PPOR) Analysis to identify potential areas of focus for the MFIMR panel.

Below is a summary of data related maternal, fetal and infant mortality, including results from Maine's PPOR analysis.

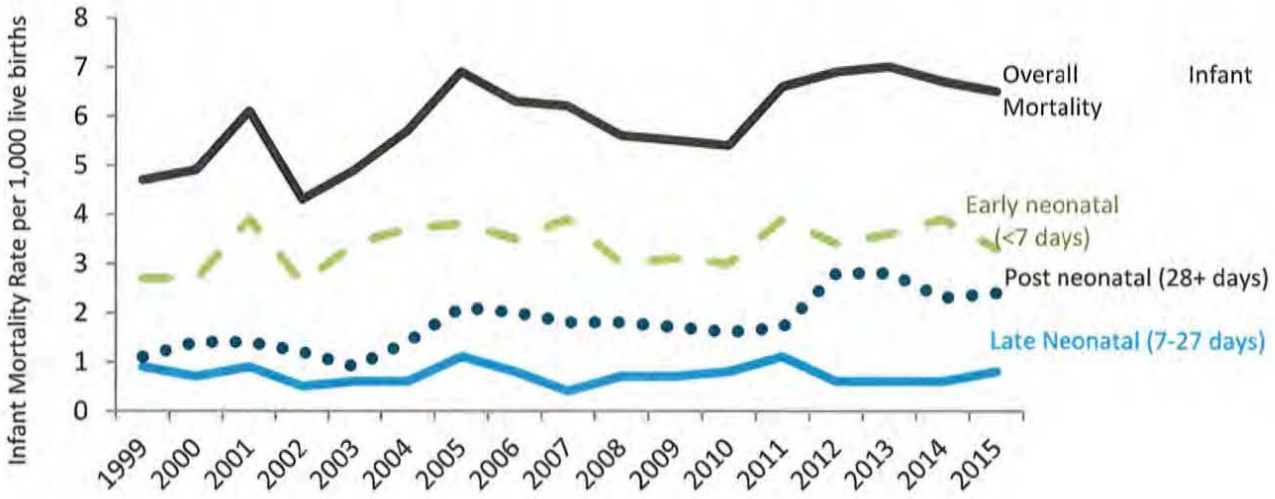
Infant Mortality

About 80 infants die each year in Maine and there are about 56 fetal deaths annually. Maine's infant mortality rate peaked in 2013, but has been declining since that time. In 2015, Maine's infant mortality rate ranked 31st highest in the U.S.[1]



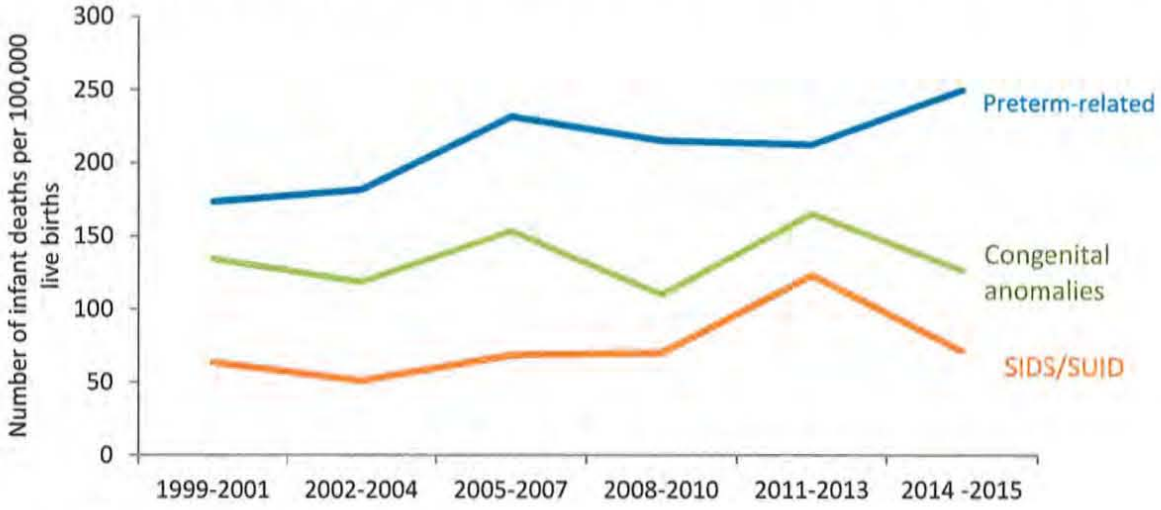
*Data are provisional and subject to change
Sources: 1999-2015 linked birth –infant death files, CDC Wonder; 2016: Maine: Maine CDC provisional death certificate and birth certificate data (non-linked); U.S.: Death certificate and natality data (non-linked)

The majority of infant deaths occur in the neonatal period, the first seven days of life (50%), followed by the post-neonatal period (37%).



Source: Maine CDC Death Certificate data.

Preterm-related conditions continue to be the leading cause of infant mortality in Maine, followed by birth defects and SIDS/SUID deaths.



Source: Maine CDC death certificate data.

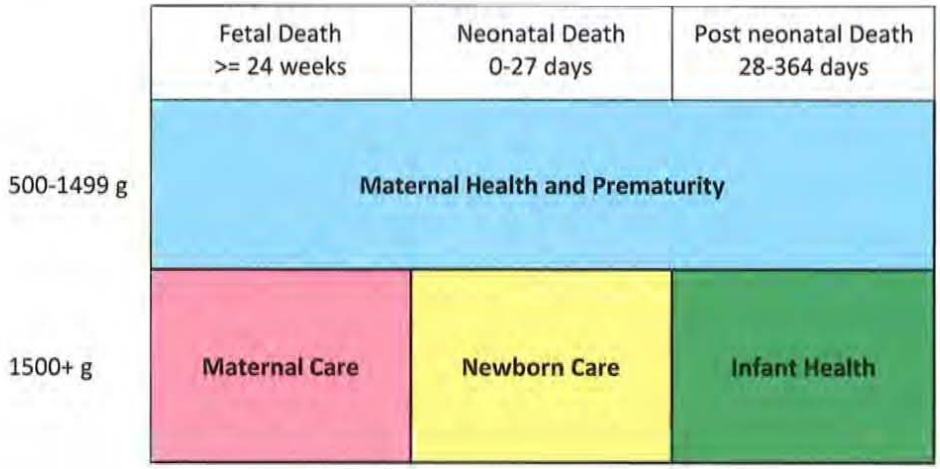
Fetal deaths

There were 65 fetal deaths in 2015; about half of these deaths occurred after 27 weeks gestation. Maine's fetal death rate for 2015 was 5.1 fetal deaths per 1,000 live births. The U.S. fetal death rate in 2015 was 6.0 fetal deaths per 1,000 live births. [2]

Risk Factors for Infant Mortality: Perinatal Period of Risk

In order to gain a better understanding of infant and fetal deaths in Maine, a Perinatal Period of Risk (PPOR) Analysis was conducted in 2017 using data from August 2013 to December 2015.[3] Maine switched to the 2003 standard birth certificate in August 2013. To examine risk factors across years, only cases identified after August 2013 were included. PPOR is a data analysis method that allows states and communities to identify the "risk period" in which infant and fetal deaths are higher than would be expected.[3] In conducting a PPOR analysis, infant and fetal deaths are divided into four groups, based on the age and birthweight at death.

- **Maternal Health and Prematurity**: This period includes all deaths of infants and fetuses between 500 and 1,499 grams. To prevent deaths in this weight group, the focus is generally on preconception health and health behaviors such as smoking during pregnancy.
- **Maternal Care**: This period includes fetal deaths greater than 24 weeks gestation that weigh 1,500 grams or more. Prevention strategies in this period focus on prenatal care, ensuring appropriate referrals for high-risk infants, and adequate obstetric care.
  Newborn Care: This period includes deaths of infants 0 and 27 days of age who weighed 1,500 grams at birth or more. Prevention efforts for this group focus on perinatal management and NICU care.
- **Infant Health**: This period includes deaths of infants between 28 and 364 days of age who weighed 1,500 grams or more at birth. Prevention strategies for infants in this group focus on safe sleep practices, injury prevention, and infection prevention and management.



For the PPOR, a reference population (e.g., lower risk group) is chosen and compared to all other infant and fetal deaths. By comparing the reference group to the higher risk group, excess deaths are calculated to determine which period of risk contributes the most to the overall rate of excess deaths.

In Maine, the selected reference group was women who were between the ages of 20-34 with at least 13 years of education who were White. Nationally, these women tend to have the best birth outcomes. The infant mortality rate of the reference group was subtracted from the infant mortality rate of all other women to determine the excess mortality in each period of risk. These excess mortality rates are presented below.

The PPOR indicated that the excess infant and fetal deaths were most likely to occur in the Maternal Care (59%), Maternal Health/Prematurity (19%) and Infant Health (14%) periods of risk. Overall, based on the birth outcomes of the reference population, 36 deaths could have been prevented between 2013 and 2015.

Maternal Care: The deaths during this period are primarily stillbirths (infants weighing more than 1,500g that occur during the pregnancy). Known risk factors for fetal demise include: maternal hypertension, uncontrolled diabetes, obesity, smoking during pregnancy, substance use, birth defects, inadequate prenatal care, and stress.

Maternal Health: The deaths in this period are very low birth weight infants (Less than 1,500g) who died during pregnancy or within the first year of life. The PPOR analyses determined that, in our target population, the excess deaths were primarily caused by a higher frequency of very low birth weight infants compared to the reference population. Maternal risk factors for premature, very low birth weight infants include smoking during pregnancy, low weight gain during pregnancy, inadequate prenatal care, pre-pregnancy diabetes, substance use, and previous preterm birth.

Infant Health: This period represents deaths among infants greater than 1,500 grams that occurred after the first 28 days of life. The excess deaths in this period were driven by injury and SIDS deaths. Risk factors for deaths during this period include maternal depression, child maltreatment, unsafe sleep conditions, and car seat use.

The table below highlights some of the risk factors contributing to excess deaths in Maine. Maine's rates of smoking during pregnancy, obesity prior to pregnancy, pre-pregnancy depression, and neonatal abstinence syndrome are areas for potential prevention and intervention efforts.

	Maine	U.S.	Year
Percent of women who smoke during pregnancy[4]	16%	8%	2015
Percent of women with diabetes during pregnancy[5]	6.6%	6.5%	2015
Percent of women who were obese prior to pregnancy[6]	30.1%	25.6%	2015
Percent of women who received late or no prenatal care[4]	3%	6%	2015
Percent of new mothers told by a provider they had depression before pregnancy[7]	17.2%	11.7%	2013
Percent of infants born low birth weight[i] (<2,500 grams)[4]	6.9%	8.1%	2015
Percent of infants born very low birth weight (<1,500 grams)[4]	1.2%	1.4%	2015
Percent of infants born premature (<37 weeks gestation)[4]	9%	11%	2015
Incidence of neonatal abstinence syndrome[9]	47.5 per 1,000	10.7 per 1,000	2014
Percent of infants most often laid on back to sleep[7]	78.2%	86.1%	2013
Percent of infants who rarely or never sleep in same bed with someone else[10]	63.6%	NA	2014
Percent of births to women with less than a high school education[8]	7%	15%	2015
Enrolled in MaineCare during pregnancy[7]	43%	38%	2013

Based on the PPOR analyses, prevention efforts should be focused on:

- Reducing the number of very low birth weight births;
- Preventing injury and SIDS/SUID deaths; and
- Reducing risk factors associated with fetal demise (smoking, inadequate prenatal care, parental substance use, obesity).

These are factors that will be considered during MFIMR Panel reviews of infant and fetal deaths.

Maternal Mortality

There are several different ways to measure and monitor maternal deaths.[11] Maine's MFIMR Panel staff are working with the Maine Center for Disease Control and Prevention's Data, Research and Vital Statistics Program to follow best-practices for maternal mortality case ascertainment.[12] Best practice involves linking death certificates of women of reproductive age to birth certificates from the 12 months prior to the death to determine if the woman was pregnant at the time of death or within 12 months of the birth. This linkage will be conducted at least twice a year to identify cases of maternal death for the Panel to review. The first linkage will occur in early 2018 to identify 2017 maternal deaths.

To date, a provisional examination of death certificates was conducted using the pregnancy checkbox that was added to Maine's death certificate in 2010. Based on this checkbox, 21 women died within one year of being pregnant between 2014 and 2016 - approximately seven women each year. Eleven (52%) of these deaths were during pregnancy; six deaths occurred within 42 days of pregnancy (29%); and four deaths occurred between 43 days and one year of pregnancy.

Of the 21 maternal deaths, nine deaths were related to or aggravated by pregnancy. These types of deaths are often related to cardiovascular diseases, infection, hemorrhage, cardiomyopathy, and embolism.[13] Twelve of the deaths were due to injury (e.g., overdose, homicide, suicide, car crash).

This past year, Maine's maternal and child health epidemiologists have also been conducting analyses on maternal morbidities using Maine's hospital discharge data. Results from these analyses are being reviewed to determine how they can be used to inform the MFIMR panel, we well as birthing hospitals.

[1] United States Department of Health and Human Services (US DHHS), Centers of Disease Control and Prevention (CDC), National Center for Health Statistics (NCHS), Division of Vital Statistics (DVS). Linked Birth / Infant Death Records 2007-2015, as compiled from data provided by the 57 vital statistics jurisdictions through the Vital

Statistics Cooperative Program, on CDC WONDER On-line Database. Accessed at http://wonder.cdc.gov/lbd-current.html.

[2] Gregory ECW, Drake P, Driscoll A, Martin J. *User Guide to the 2015 Fetal Death Public Use File.* Division of Vital Statistics, National Center for Health Statistics, Centers for Disease Control and Prevention, Department of Health and Human Services.
ftp://ftp.cdc.gov/pub/Health_Statistics/NCHS/Dataset_Documentation/DVS/fetaldeath/2015FetalUserGuide.pdf

[3] CityMatCH. *What is PPOR?* http://www.citymatch.org/perinatal-periods-risk-ppor-home/what-ppor

[4] The Annie E. Casey Foundation, KIDS COUNT Data Center, http://datacenter.kidscount.org.

[5] United States Department of Health and Human Services (US DHHS), Centers of Disease Control and Prevention (CDC), National Center for Health Statistics (NCHS), Division of Vital Statistics (DVS). Natality Records 2007-2015, as compiled from data provided by the 57 vital statistics jurisdictions through the Vital Statistics Cooperative Program, on CDC WONDER On-line Database. Accessed at http://wonder.cdc.gov/

[6] Deputy NP, Dub B, Sharma AJ. Prevalence and Trends in Prepregnancy Normal Weight — 48 States, New York City, and District of Columbia, 2011–2015. MMWR Morb Mortal Wkly Rep 2018; 66:1402–1407.
DOI: http://dx.doi.org/10.15585/mmwr.mm665152a3

[7] Centers for Disease Control and Prevention, Pregnancy Risk Assessment Monitoring System. Selected 2012 and 2013 Maternal and Child Health Indicators.

[8] Centers for Disease Control and Prevention, National Center for Health Statistics.
2015 national and state-level estimates are from the National Center for Health Statistics (NCHS), National Vital Statistics Reports or can be accessed through the CDC Wonder system.

[9] Health Resources and Services Administration, Maternal and Child Health Bureau. Title V State-Federal Partnership, National Outcome Measures.
https://mchb.tvisdata.hrsa.gov/PrioritiesAndMeasures/NationalOutcomeMeasures.

[10] Maine Center for Disease Control and Prevention, Pregnancy Risk Assessment Monitoring System. 2014.
http://www.maine.gov/dhhs/mecdc/public-health-systems/data-research/prams/tables2014/73-sleepbed14.pdf

[11] MacDorman MF, Declercq E, Cabral H, Morton C. Is the United States maternal mortality rate increasing: Disentangling trends from measurement issues. *Obstetrics and Gynecology* .2016. 128(3): 447-455.

[12] Building U.S. Capacity to Review and Prevent Maternal Deaths. (2017). Report from maternal mortality review committees: a view into their critical role. Retrieved from
https://www.cdcfoundation.org/sites/default/files/upload/pdf/MMRIAReport.pdf.

[13] Centers for Disease Control and Prevention. *Pregnancy Mortality Surveillance System.*
https://www.cdc.gov/reproductivehealth/maternalinfanthealth/pmss.html

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