DEPARTMENT OF HEALTH

# Stillbirth Advisory Workgroup Report

MATERNAL AND CHILD HEALTH ADVISORY TASK FORCE

DECEMBER 2022

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# Summary of Recommendations

In 2016-2017, the Maternal and Child Health Advisory Task Force convened a working group on stillbirths in Minnesota with the aim to release recommendations to prevent future stillbirths. The recommendations below represent the Stillbirth Workgroup's final list of four actionable recommendations:

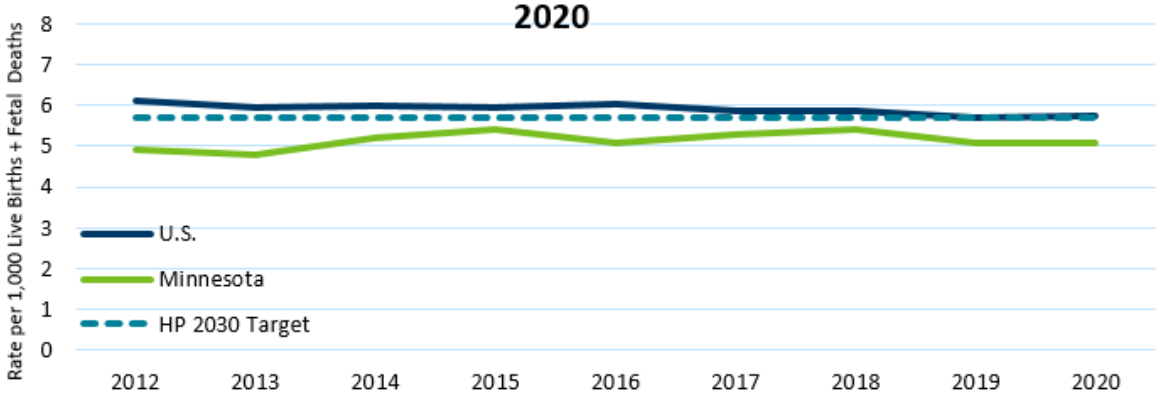
1. Track and publish Minnesota stillbirth data in the annual MDH Vital Statistics Report by sociodemographic information such as hospital of birth, county of birth, gestational age, and infant, maternal, and paternal race/ethnicity.
2. Establish a service like the former Minnesota SID Center that provides support, information, and assistance to families who have experienced a stillbirth.
3. Reinstate ongoing Fetal and Infant Mortality Reviews (FIMR) to provide information about the circumstances and underlying contributing factors associated with fetal deaths/stillbirths.
4. Conduct a root cause analysis on every fetal death that aims to inform how the 39 weeks policy is being implemented, rapid appeals process when medically indicated deliveries prior to 39 weeks of gestation are denied, and shared patient-provider decision making about scheduled deliveries prior to 39 weeks of gestation including all relevant fetal, maternal, and newborn risks and benefits.

# Introduction

Much attention has been given in the last few years, and rightly so, to addressing infant mortality in the U.S. The U.S. has a much higher infant mortality rate than other industrialized societies with similar levels of access to health care and health-promoting resources. However, there is another hidden loss, rarely highlighted or discussed, but similarly devastating: stillbirths.[1] A stillbirth is a fetal loss that occurs at or after 20 weeks gestation either in utero or at the time of delivery. Stillbirths are a cause for concern because they can have life-altering and devastating consequences for individuals, families, and communities, including prolonged grief, anger, fear, pain, guilt, depressive symptoms, anxiety, social isolation, loss productivity, and financial hardship.[2]

In 2020, there were 20,854 stillbirths in the U.S., resulting in a stillbirth rate of 5.7 per 1,000 live births plus fetal deaths — a rate which did not change from 2019 (Figure 1).[3] During the same year, 326 stillbirths occurred in Minnesota, resulting in a stillbirth rate of 5.1 per 1,000 live births plus fetal deaths. Both the nation and state have already met the Healthy People target of 5.7 fetal deaths at 20 or more weeks gestation per 1,000 live births plus fetal deaths by 2030 (Figure 1). Despite these achievements, disparities persist.

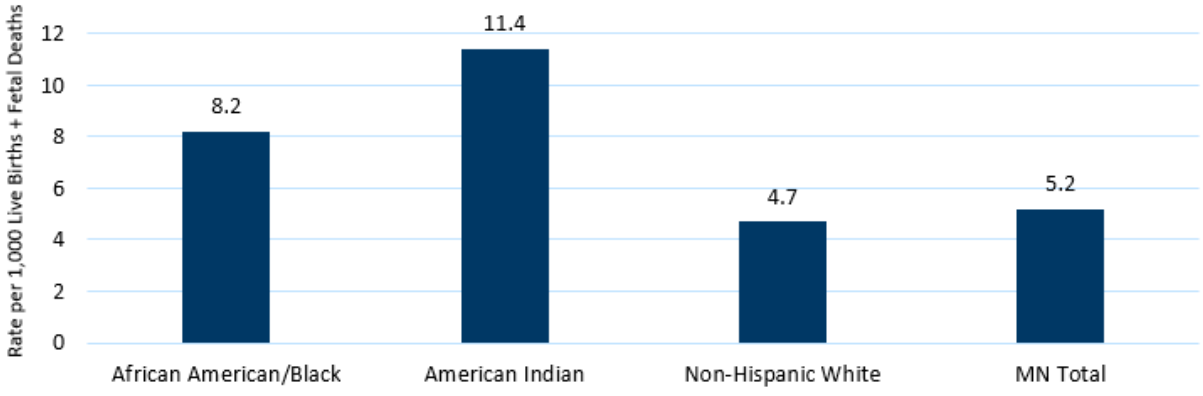
**Figure 1: Fetal Death Rates in the U.S.[1] and Minnesota[2], 2016-2020**




Sources: [1]United States Department of Health and Human Services (US DHHS), Centers for Disease Control and Prevention (CDC), National Center for Health Statistics (NCHS), Division of Vital Statistics (DVS). National Vital Statistics System, Fetal Death Records 2005-2020, on CDC WONDER Online Database. Data are compiled from data provided by the 57 vital statistics jurisdictions through the Vital Statistics Cooperative Program. [2]Minnesota's Final Resident Birth and Fetal Death File.

In Minnesota, disparities in stillbirth rates are evident and troubling. Of particular concern are persistent disparities in fetal loss by race/ethnicity. Black/African American and American Indian pregnant women and birthing people are at greater risk of experiencing a fetal loss than White pregnant women and birthing people. Between 2018 and 2020, the stillbirth rate for Black/African American and American Indian birthing people was 1.7 and 2.4 times the rate for Non-Hispanic White birthing people, respectively (Figure 2).

**Figure 2: Stillbirth Rates by Race/Ethnicity: Minnesota, 2018-2020**




Source: Minnesota Department of Health - Final Resident Birth and Fetal Death File

# Legislative Charge

# Identifying Issues for Workgroup Activities

To execute its legislative charge, MDH held an initial listening session on July 13, 2015, to gain a better understanding of the concerns and issues. Families who had experienced a stillbirth, organizations that offered support to families who experienced stillbirths, and medical and health care providers attended the meeting along with interested legislators, MCHATF members, and other stakeholders. During the meeting, Lindsey Wimmer, Executive Director of Star Legacy Foundation (https://starlegacyfoundation.org/), a local advocacy and research organization that focuses on stillbirths, provided an overview of the most current stillbirth research, data, and prevention strategies. Additionally, personal stories of loss were shared and discussed, and concerns related to families' experiences with navigating multiple systems (e.g., health care and public health) after suffering a loss also emerged. The specific concerns reported during the listening session were:

- The change in health coverage policy to reduce early elective inductions may have led to an increased rate of stillbirths by preventing or discouraging necessary early elective inductions
- Families do not receive information during pregnancy regarding how to monitor their pregnancies for problems. Specifically mentioned was a lack of education about the risk of stillbirth and how to monitor their pregnancy for changes that could indicate a problem.
- The lack of information provided to families regarding the value of performing an autopsy after a stillbirth, and in some cases, offering it as an option. Families subsequently learned, through their own research, about what information could be gathered from an autopsy about the cause of death.
- While health care providers are compassionate and committed, the system does not always provide a means of recognizing parents' grief and need for resources and support.

These areas of concern were used to shape the content of subsequent meetings and later helped the workgroup formulate its recommendations. They also informed the Stillbirth Workgroup's goal or purpose.

The Stillbirth Workgroup identified the underlying goal for their work: Many stillbirths are preventable, and we can do better at preventing them.

# Initial Findings/ Recommendations

Following the initial listening session, the workgroup further explored and discussed the topics of concern. Presentations were made by medical researchers, advocates, health care providers, and epidemiologists related to the identified topics. The presentations and discussions covered:

- Minnesota data and birth defects monitoring of stillbirths.
- Current fetal death collection methods.
- Supports currently available to families experiencing a stillbirth in Minnesota.
- Evaluating perinatal deaths.

- Hospital implementation of early elective induction coverage policies across the state.
- Medical Assistance/MinnesotaCare coverage policy regarding early elective inductions.

The presentations, as well as the stories shared by families and advocates about their own lived experiences with loss not only generated rich discussions during each meeting, but also helped the group prioritize their initial list of 42 recommendations to a shorter list of seven findings and overarching recommendations. These are the workgroup's key findings and recommendations:

1. Implement effective antenatal monitoring including increased fetal surveillance between 32-34 weeks and from 39 weeks on, educate parents about the risk of stillbirth, and provide shared decision making with parents about early delivery.
2. Provide good control of chronic conditions prior to and during pregnancy.
3. Provide grief counseling in hospitals and support organization(s) for grieving parents.
4. Follow up on abnormal conditions/lab results from previous pregnancies in subsequent pregnancies.
5. Address disparities in the Black/African American and American Indian populations, where stillbirth rates are 2-3 times higher for African American/Black and American Indian birthing people than for white people in Minnesota.
6. Identify the causes of stillbirths and implementing ongoing Fetal and Infant Mortality Reviews (FIMR), as well as birth defects registry and autopsies to better understand and reduce contributing causes
7. Improve access to autopsies such as addressing insurance barriers and making assistance available to increasing opportunities for families to have answers, ensuring that labor and delivery staff prepare placental and other labs accurately for analysis, and gathering information from autopsies to inform and address causes.

## Final Recommendations

In December 2017, the workgroup's findings and recommendations were presented to the MCHATF for review and consideration before sending them to the Commissioner of Health. The MCHATF reviewed the initial full list of 42 recommendations and voted to forward the full list as well as the shorter list of seven recommendations on to the Commissioner with their support. Following a recommendation by the MCHATF, the group met subsequently to give more specificity to some of the recommendations to make them actionable. The recommendations below represent the Stillbirth Workgroup's final list of four actionable recommendations:

1. Track and publish Minnesota stillbirth data in the annual MDH Vital Statistics Report by sociodemographic information such as hospital of birth, county of birth, gestational age, and infant, maternal, and paternal race/ethnicity.
2. Establish a service like the former Minnesota SID Center that provides support, information, and assistance to families who have experienced a stillbirth.
3. Reinstate ongoing Fetal and Infant Mortality Reviews (FIMR) to provide information about the circumstances and underlying contributing factors associated with fetal

deaths/stillbirths. FIMR includes case record information collected from clinics, hospitals, and freestanding birth centers, to conduct an annual systematic stillbirth review event to better understand the causes of fetal deaths from a clinical care delivery perspective.

4. Conduct a root cause analysis on every fetal death (critical event review) that aims to inform when:
    a. there is variability in how the 39-week policy is being implemented by health systems, providers, and payers, including administrative process and different implementation of what risk factors constitute medically necessary criteria for an early elective delivery. Policies should be reviewed to ensure that the process is not burdensome, lengthy, narrow, or rigid such that it deters legitimately medically necessary early scheduled deliveries.
    b. requests to schedule medically indicated deliveries (inductions and cesarean sections) prior to 39 weeks of gestation are made, and the indication for the delivery does not meet the hospital guidelines, hospital policy should encourage and support a rapid appeal process that includes a medical review of the case, with the hospital's obstetrical leadership, to reconsider the medical necessity of the requested induction.
    c. scheduled deliveries (inductions and planned cesarean sections) prior to 39 completed weeks of gestation are considered by obstetrical providers and shared decision making should be employed. The patient should be informed of all relevant fetal, maternal, and newborn risks and benefits, and likewise be informed of how these risks and benefits change with the timing of the planned procedure.

## Next Steps

The Maternal and Child Health Section at MDH is in the process of drafting a perinatal health plan, which articulates a vision and outlines goals and accompanying strategies to improve perinatal health outcomes in Minnesota within the next five years. Final recommendations in this plan that have not already been implemented by MDH or partners/stakeholders since the Stillbirth Workgroup concluded, will be considered among a list of priority strategies to be included in the plan.

## Citations

[1] MacDorman, M. F., Gregory, E. C. W. Fetal and perinatal mortality: United States, 2013. *National Vital Statistics Reports*; Vol. 64, No. 8. Hyattsville, MD: National Center for Health Statistics. 2015.

[2] Heazell, A. E. P., Siassakos, D., Hanna, B., et. al. Stillbirths: economic and psychological consequences. *Lancet* 2016: 387: 604-616.

[3] What is Stillbirth? National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention. Retrieved on 3 August 2022.

# Appendix A

## List of Stillbirth Advisory Workgroup Members

| Name | Organization |
|---|---|
| Ken Bence | Medica Director of Government Programs, Chair of the MCH Advisory Task Force |
| Laura Dean | OB/GYN, ACOG Representative |
| Peter Dehnel | Medical Director, Blue Cross Blue Shield |
| Chris and Amanda Duffy | Family advocates |
| Kathleen Fernbach | Director, MN Sudden Infant Death Center |
| Dale and Carrie Fuller | Family advocates |
| Stephanie Graves | Workgroup Chair, Minneapolis Department of Health, MCH Advisory Task Force member |
| Representative Alice Hausman | MN State Legislature, House of Representatives |
| Lisa Hiltz | Minnesota Hospital Association Representative |
| Butch Hudson | Assistant Medical Examiner, Ramsey County |
| Shauna Libsack | Operations Director, Star Legacy Foundation |
| Rich Lussky | Perinatologist |
| Kelly McDyre, Jenna Rogers | Executive Director, Faith's Lodge |
| Fritz Ohnsorg | Agency Policy Specialist, Minnesota Department of Human Services |
| Jenny Oliphant | Research Associate, University of MN Healthy Youth Development Prevention Research Center |
| Lindsey Wimmer | Executive Director, Star Legacy Foundation |
| Maggie Diebel | MDH – Director of Community and Family Health |
| Susan Castellano | MDH – Maternal and Child Health Section, Workgroup Co-chair |
| Michelle Chiezah | MDH – State Infant Health and Mortality Reduction Specialist |
| Sook Ja Cho | MDH – Birth Defects Monitoring & Analysis Unit |
| Barbara Frohnert | MDH – Birth Defects Monitoring & Analysis Unit |
| Gloria Haluptzok | MDH – Office of the State Registrar |
| Katie Linde | MDH – Women and Infant Health Unit |
| Bonika Peters | MDH – MCH Assistant Section Manager |
| Mira Grice Sheff | MDH – State MCH Epidemiologist |
| Cecilia Wachdorf | MDH – Women's Health Consultant |

*Note: This list contains the names of people who attended one or more workgroup meetings. Some members may have changed their affiliation since participating in the workgroup.*