

# **Table of Contents**

Dedication	2
Contributors	3
Acknowledgements	6
Notes About Language Choices	6
Letter from the Director	7
IDPH Commitment to Health Equity	8
Executive Summary	9
COVID-19 Pandemic and Maternal Health	10
Importance of Maternal Health	12
Maternal Morbidity	14
Chronic Disease During Pregnancy	14
Mental Health Conditions and Substance Use Disorders	23
Severe Maternal Morbidity	29
Maternal Mortality	34
Pregnancy-Associated Deaths	35
Pregnancy-Related Deaths	38
Examples of Maternal Deaths	54
Opportunities for Prevention	57
Recommendations	59
Momentum to Improve Maternal Health	65
Appendix A: Resources for Women and Their Families and Friends	69
Appendix B: Resources for Health Care Providers and Hospitals	71
Appendix C: Medical Terminology	72
Appendix D: Methods Notes for Statistical Analyses.	74

The Illinois Department of Public Health dedicates this report to the 263 Illinois women who died while pregnant or within one year of their pregnancy during 2018-2020, and to their loved ones and families.

We hope our efforts to better understand the causes of maternal mortality will prevent other women and families from suffering a similar fate by supporting systemic changes that promote maternal health and health equity.

#### **Contributors**

## Illinois Department of Public Health Staff

Amanda Bennett, PhD, MPH, Office of Women's Health and Family Services \*

Cara Bergo, PhD, MPH, Office of Women's Health and Family Services \*

Jelena Debelnogich, MPH, Office of Women's Health and Family Services \*

Trishna Harris, DNP, APN, WHNP-BC, CNM, Office of Women's Health and Family Services

Ashley Horne, MSPH, Office of Women's Health and Family Services

Julia Howland, PhD, MPH, Office of Women's Health and Family Services

Shannon Lightner, MSW, MPA, Chief Operating Officer \*

Nancy Martin, Office of Women's Health and Family Services

Lisa Masinter, MD, MPH, MS, Office of Women's Health and Family Services \*

Alexander Smith, BA, Office of Women's Health and Family Services

Natalia Vazquez Plaza, MPH, Office of Women's Health and Family Services

Sameer Vohra, MD, JD, MA, Director

Kelly Vrablic, MPH, Office of Women's Health and Family Services

## Other State Agency Staff

Lisa Cohen, MA, Illinois Department of Human Services

Karen Kasinger, MBA, MSN, APN, CPNP, Illinois Department of Healthcare and Family Services

Dawn R. Wells, BSN, RN, Illinois Department of Healthcare and Family Services

#### **Maternal Death Abstractors**

Angelique M. Muhammad, MSN, RN, IBCLC, University of Illinois at Chicago, College of Nursing

Elizabeth Richards, DNP, University of Illinois at Chicago, College of Nursing

Emily Schmid Lineberger, DNP, University of Illinois at Chicago, College of Nursing

Grace Yarnoff, DNP, University of Illinois at Chicago, College of Nursing

## **Perinatal Network Administrators**

Roma Allen, DNP, MSN-Ed, RNC-OB, Loyola University Medical Center

Daniell Ashford, DNP, MBA, NE-BC, RNC-OB, CEFM, FNP-BC, LNC, Northwestern Memorial Hospital

Peggy Cowling, APN, MSN, RNC-OB, C-EFM, CHSE, University of Chicago Medicine

Andrea Cross, RN, BS, MSHA, Cook County Health and Hospital System

Jodi Hoskins, DNP, MSN-Ed, RNC, Javon Bea Hospital

Joanne Sorce, MSN, RNC-OB, University of Illinois at Chicago

Dede Stewart, MSN, RN, CNL, CLC, HSHS St. John's Hospital

C. Susie Swain, BSN, RNC, C-EFM, OSF Healthcare System Saint Francis Medical Center

Connie Thompson, MSN-Ed, RNC-OB, C-EFM, SSM Cardinal Glennon Children's Hospital

Maripat Zeschke, RNC-EFM, MSN, Rush University Medical Center

<sup>\*</sup> Contributors to the writing, editing, and preparation of this report.

## Maternal Mortality Review Committee During Review of 2018-2020 Deaths

#### Chair

Robin L. Jones, MD, Obstetrics and Gynecology, Rush University Medical Center

#### Members

Robert Abrams, MD, Maternal-Fetal Medicine, Southern Illinois University

Timika Anderson Reeves, PhD, MSW, Community Integration, Access Family Health Center

David Arnolds, MD, Obstetric Anesthesiology, University of Chicago

Jennifer Banayan, MD, Cardiac and Obstetric Anesthesiology, Northwestern University

Deborah Boyle, MD, FACOG, BSN, Maternal Fetal Medicine, University of Chicago

Joan Briller, MD, FACC, FASE, FAHA, Cardiology with Obstetric Focus, University of Illinois at Chicago

Helen Cejtin, MD, MPH, Obstetrics and Gynecology, John H. Stroger, Jr. Hospital of Cook County

Stacey Chamberlain, MD, MPH, Emergency Medicine, University of Illinois at Chicago

Naida Cole, MD, Obstetric Anesthesia, University of Chicago

Lori Folken, DNP, RNC-OB, C-EFM, Obstetrics Nursing, Carle Health at Urbana

Stacie Geller, MPH, PhD, Women's Health Research, University of Illinois at Chicago

Charu Gupta, MD, Cardiology with Obstetric Focus, Northshore University Hospital

Catherine Harth, MD, Obstetrics and Gynecology, University of Chicago

Ashley Hunt, LCSW, MSW, Perinatal Psychotherapist, Crescent and Crown Therapy LLC

Patricia Lee King, PhD, MSW, Clinical Quality Improvement, Illinois Perinatal Quality Collaborative

Olga Lazala, PhD, APN, CNS, CNM, RNC-OB, Obstetrics and Gynecology, Advocate Health and UI Health

Kathryn Lindley, MD, Cardiology with Obstetric Focus, Washington University in St. Louis

Jerome Loew, MD, Pathology, Rush University Medical Center

Gary Loy, MD, MPH, Maternal Fetal Medicine, Rush University Medical Center

Tayo Mbande, Birth and Postpartum Doula, Chicago Birthworks Collective

Paula Melone, MD, Maternal Fetal Medicine, Loyola University

Neha Bhardwaj, MD, MS, Complex Family Planning & Obstetrics and Gynecology, University of Chicago

Heather Nixon, MD, Obstetric Anesthesiology, University of Illinois at Chicago

Brielle Osting, AM, MPP, Community Advocacy, Meridian, a WellCare Company

Jose Ortiz, MSW, MPH, Social Work, University of Chicago

Beth Plunkett, MD, MPH, Maternal Fetal Medicine, NorthShore University HealthSystem

Kirbi Range, MS, Maternal and Child Health Programs, EverThrive Illinois

Donald Reese, MD, Family Medicine with Obstetrics, Gibson Area Hospital

Candice Robinson, MD, MPH, Maternal and Child Health Medical Director, Chicago Department of Public Health

Sheila Sanders, Outreach and Education, EverThrive Illinois

Amy Sloan-Gray, MSW, CLC, CD(DONA), Social Work and Doula, Brightpoint (Children's Home and Aid)

Shirley Scott, DNP, WHNP-BC, C-EFM, CLS, Women's Health Nurse Practitioner, UI Health

Jennifer Seo, MD, JD, Maternal and Child Health Medical Director, Chicago Department of Public Health

Lee V. Smith, BA, Community-Based Programs for Case Management, Sinai Community Institute

Michael Socol, MD, Maternal Fetal Medicine, Northwestern University

Patrick Thornton, CNM, PhD, Nurse Midwifery, University of Illinois at Chicago

Paloma Toledo, MD, MPH, Obstetric Anesthesiology, Northwestern University

Elizabeth Ramsey Unal, MD, MSCR, Maternal-Fetal Medicine, Southern Illinois University

#### **Guest Contributors for COVID-19 Deaths**

Nevert Badreldin, MD, MS, Maternal-Fetal Medicine, Northwestern University

Sherry Jones, MD, MPH, FACOG, Obstetrics and Gynecology, Southern Illinois University Healthcare

Joana Lopes Perdigao, MD, Maternal-Fetal Medicine, University of Chicago Medicine

# Maternal Mortality Review Committee for Violent Deaths During Review of 2018-2020 Deaths

Chair

Robin L. Jones, MD, Obstetrics and Gynecology, Rush University Medical Center

#### **Members**

Alysan Anderson, CD(DONA), CLC, CPRS, Perinatal Harm Reduction, Rush University

Katherine Austman, MD, FASAM, Addiction Medicine, Family Medicine, Gibson Area Hospital

Ann Borders, MD, MSc, MPH, Maternal Fetal Medicine, NorthShore University HealthSystem & Illinois Perinatal Quality Collaborative

Deborah Boyle, MD, FACOG, BSN, Maternal Fetal Medicine, University of Chicago

Glendean Burton, MPH, BSN, RN, CLC, Maternal and Child Health Nursing and Programs, SIDS Illinois

Maria Criss, Certified Postpartum Doula & Addiction Recovery, Unity Point Hospital

Kara Driscoll, MD, ABPN, Psychiatry, The Allegro Center

Andrew Fisher, MD, Obstetrics & Gynecology, University of Chicago Medicine

Stacie Geller, MPH, PhD, Women's Health Research, University of Illinois at Chicago

Wilnise Jasmin MD, MBA, MPH, Medical Director of Behavioral Health, Chicago Department of Public Health

Katherine Kane-Willis, MA, Policy and Advocacy, Chicago Urban League

Jo Kim, PhD, Clinical Psychology, NorthShore University HealthSystem

Carrie Klima, CNM, PhD, FACNM, Nurse Midwifery, University of Illinois at Chicago

Karie E. Stewart, MPH, CNM, FACNM, Nurse Midwifery, University of Illinois Hospital & Health Services Systems

Erica Lavalle, MBA, Criminology, Special Agent, Illinois State Police

Jerome Loew, MD, Pathology, Rush University Medical Center

Bahakia Madison, PsyD, Substance Use Counseling, Oakton Community College

Denise McCaffrey, BSW, Child Abuse Prevention, Prevent Child Abuse Illinois

Michele L. McCay, DrPH, MPH, Health Policy, University of Illinois at Chicago

Tamela Milan-Alexander, MPPA, Community Engagement, EverThrive

Cindy Mitchell, RN, BSN, MSHL, Perinatal Network Administrator, HSHS St. John's Hospital

Bernadette Ray, MD, Family Medicine, Gibson Area Hospital

Jaclyn Rodriguez, BSN, BS, RN, SANE-A, SANE-P, Sexual Assault Nurse Examiner, Office of the Illinois Attorney General

Shirley Scott, DNP, WHNP-BC, C-EFM, CLS, Women's Health Nurse Practitioner, UI Health

Lita Simanis, LCSW, PMH-C, Perinatal and Postpartum Mental Health, Ascension Illinois/Alexian Brothers

Vickie Smith, BA, Domestic Violence Prevention and Services, Illinois Coalition Against Domestic Violence

Karen Tabb, PhD, MSW, Social Work, University of Illinois at Urbana-Champaign

Cheyenne Thompson, Criminology, Special Agent, Illinois State Police

Patrick Thornton, CNM, PhD, Nurse Midwifery, University of Illinois at Chicago

Amber Truehart, MD, MSc, Obstetrics and Gynecology, Family Planning Specialist, University of Chicago

Teresa Tudor, BS, Domestic Violence and Human Trafficking, Illinois Department of Human Services

Mary Uckerman MD, Pathology, Little Company of Mary Hospital and Health Care Centers

Carole Warshaw, MD, Psychiatry, National Center on Domestic Violence, Trauma and Mental Health

Elise Wessol, DO, Addiction Medicine, Heritage Behavioral Health Center

Maripat Zeschke, RNC-EFM, MSN, Perinatal Network Administrator, Rush University Medical Center

# Acknowledgements

## **Funding**

The work represented in this report was funded by the Enhancing Reviews and Surveillance to Eliminate Maternal Mortality (ERASE-MM) program of the Centers for Disease Control and Prevention, grant number 5 NU58DP006682-02-00.

The work represented in this report was funded in part by the Maternal and Child Health Services Block Grant to the States (Title V) program of the U.S. Department of Health and Human Services, Health Resources and Services Administration, grant number 6 B04MC47413-01-03.

## Other Support

Additional support was provided by the Centers for Disease Control and Prevention's Maternal and Child Health Epidemiology Program (MCHEP) and the Council of State and Territorial Epidemiologists Applied Epidemiology Program.

#### For more information

Contact the Illinois Department of Public Health, Office of Women's Health and Family Services at <a href="DPH.MCH@illinois.gov">DPH.MCH@illinois.gov</a>.

# **Notes About Language Choices**

#### "Women"

This report describes the experiences and outcomes of pregnant and postpartum "women." However, IDPH recognizes that not all people who have been pregnant or given birth identify as being a "woman." This report uses the term "women" as an intentional device to highlight the vulnerability of people who society typically identifies as being female. The use of "women" is not intended to exclude or silence those who do not identify as female, but to draw attention to the ways pregnant or postpartum people experience gender inequities because of their female gender assignment at birth.

## "Hispanic"

IDPH acknowledges that multiple terms can be used to describe the Hispanic population, including Latino/Latina or Latinx. A 2021 Gallup study of U.S. adults with Hispanic or Latino origins found that 57% preferred the term "Hispanic," 37% preferred "Latino" and 5% preferred "Latinx". IDPH has opted to use "Hispanic" throughout this report because it was the most preferred term.



525-535 West Jefferson Street • Springfield, Illinois 62761-0001 • www.dph.illinois.gov

The Illinois Department of Public Health (IDPH) is honored to share this third edition of the Illinois Maternal Morbidity and Mortality Report, which includes updated findings on maternal deaths that occurred during 2018-2020. Our first two reports (released in October 2018 and April 2021) shared detailed statewide data and recommendations to prevent maternal morbidity and mortality in Illinois, and we, as an agency, were proud of the action and programs sparked by the findings of those reports.

This report builds on the important work of two IDPH committees, the Maternal Mortality Review Committee (MMRC) and the Maternal Mortality Review Committee for Violent Deaths (MMRC-V). Our previous reports showed how the work of these committees spurred action from people from across the state, including community leaders, elected officials, clinical professionals, nonprofit organizations, and everyday Illinoisans. These individuals came together to push for improvements in the programs, policies, and systems that impact maternal health. Through this collective work, Illinois has become a national leader in maternal health. However, we know that more work needs to be done.

The goal of this third report is similar to the past two: describe patterns in maternal morbidity and mortality, identify opportunities for prevention, and direct recommendations to key partners to prevent the tragedy of maternal mortality. This report also expands into new territory by presenting deeper data on key topics like mental health and substance use disorders, discrimination and racism, social determinants of health, and community context. While these structural and systemic factors can feel daunting to address, they are critical pieces that need focus to improve health outcomes for Illinois women and families.

Despite the progress we have made, we still have a long way to go towards ensuring that all Illinoisans can have a safe and healthy pregnancy. We continue to see inequities in maternal mortality for Black women and women with lower socioeconomic status. Substance use disorders are the leading cause of pregnancy-related deaths and demonstrate that the opioid crisis is not behind us. The challenges of the COVID-19 pandemic affected pregnant women and families in many ways and the data in this report begins to demonstrate the extent of that impact. We continue to see disconnected, siloed health services, programs, and systems as a factor contributing to many maternal deaths.

Because of all this, we recognize that the dream of making Illinois the healthiest state to give birth is a work in progress. IDPH is committed to a culture of health equity and to working collaboratively with partners to promote maternal health. We will continue to support the MMRC and MMRC-V in their work to review maternal deaths and to ensure these reviews examine the root causes of inequities in our state.

IDPH is extremely grateful for the volunteers who serve on the MMRC and the MMRC-V, without whom we could not do this work. We cannot thank them enough for the expertise and passion they share with us, and for the thousands of collective hours they have dedicated to this important work.

Please join us in reviewing this report and being our new or continued partner. The work of building healthier futures for all Illinois residents requires all of us – connected, dedicated, and committed.

Yours in health,

James Johna

Sameer Vohra, MD, JD, MA

Director

## **IDPH Commitment to Health Equity**

According to the American Public Health Association (APHA), health equity is when "everyone has the opportunity to attain their highest level of health." The World Health Organization (WHO) defines health equity as "the absence of unfair and avoidable or remediable differences in health among population groups defined socially, economically, demographically or geographically." 2

The vision of the Illinois Department of Public Health (IDPH) is to see Illinoisans empowered and supported to achieve their optimal health with dignity and acceptance in diverse and thriving communities. Inequities in achieving optimal health are present for individuals, families, and communities across the entire state. IDPH is committed to health equity and the elimination of health inequities. IDPH seeks to address health equity issues through increased coordination between Illinois leadership, programs, and strategic partnerships. IDPH is committed to promoting health equity in all programs and policies, including the development of the public health and health care workforce.

This report demonstrates that Illinois' inequities in maternal health outcomes by race and ethnicity are persistent and unacceptable. These inequities are driven by structural racism, which is "a system consisting of structures, policies, practices, and norms—that assigns value and determines opportunity based on the way people look or the color of their skin." IDPH recognizes that racism has created a public health crisis within the state, and pledges to work diligently to do all it can to eradicate it and its detrimental effects on the physical and mental health of the IDPH staff and the communities served.

#### IDPH is committed to:

- Creating trained and knowledgeable staff who work to eliminate implicit, explicit, and cultural biases within and outside of IDPH.
- Evaluating the impact of policymaking on grantees and using this information to develop new policy initiatives that would promote a just and equitable disbursement of resources.
- Ensuring the principles of diversity, equity, inclusion, and justice are in place throughout IDPH to drive its work.

To frame and structure this work, IDPH developed the Diversity, anti-Racism, and Equity (DaRE) campaign to coordinate its activities related to race and inequality in an intentional way. Some of the ways that IDPH practically carries out this work include:

- *Health Equity Council.* Established in 2018, this council seeks to support the development of agency-wide standards to enhance health equity across programs.
- *Diversity, Equity, and Inclusion Committee.* This committee seeks to promote awareness around diversity, equity, inclusion, and justice within the agency to better serve the state's residents.
- State Health Improvement Plan (SHIP). The SHIP is the strategic plan for improving public health in the state and is being updated in 2023. One of the five priority areas to be addressed in this iteration of the plan is "racism as a public health crisis." Additionally, all five priority areas are tasks with addressing contextual factors that affect health equity, such as the social determinants of health, structural racism, and workforce needs.
- Workforce Development Grant. IDPH is the recipient of a new Centers for Disease Control and Prevention (CDC) Public Health Infrastructure Grant that will support public health workforce development in the state. IDPH is planning to further foster a diverse public health workforce through enhanced partnerships, improved job descriptions, implicit bias training, and mobility plans. IDPH will collaborate with health programs, schools, and community organizations to increase diverse applicants by recruiting staff with local insights, fostering partnerships, and creating pipelines for diverse candidates

Furthermore, the state established an Anti-Racism Commission in 2022 to identify and propose statewide policies to eliminate systemic racism, and to advance equitable solutions for Black and Brown people. IDPH will provide administrative support to the commission and coordinate its activities as the work gets underway. The future tasks of the commission will include assessing policy and procedures of all state agencies through a lens of racial equity and recommending policies that promote racial equity in economics, workforce development, and health.

Achieving health equity is an ongoing process and will not be accomplished overnight. It will take dedication and persistence to overcome generations of structural inequities. IDPH remains committed to doing what is necessary to help all Illinoisans live long, healthy lives that are free of avoidable, unfair differences in health outcomes. IDPH stands in solidarity with communities as it works to uproot and eliminate racism to improve conditions throughout the state.

- 1 American Public Health Association (APHA). (2023). Health Equity. Retrieved from <a href="https://www.apha.org/topics-and-issues/health-equity">https://www.apha.org/topics-and-issues/health-equity</a>
- 2 World Health Organization. (2023). Social Determinants of Health Health equity. Retrieved from <a href="https://www.who.int/health-topics/social-determinants-of-health#tab=tab\_3">https://www.who.int/health-topics/social-determinants-of-health#tab=tab\_3</a>
- 3 Illinois Department of Public Health. (2023). About IDPH. Retrieved from https://dph.illinois.gov/about.html
- 4 Centers for Disease Control and Prevention. (2023). Minority Health. Retrieved from: https://www.cdc.gov/minorityhealth/racism-disparities/index.html

## **Executive Summary**

Maternal morbidity and mortality continue to be a public health crisis in Illinois and nationwide. Severe pregnancy complications and maternal deaths are tragedies for women, families, and communities. There continues to be unequal experiences of poor maternal health outcomes for different racial, socioeconomic, and geographic groups in Illinois. Furthermore, in 2020 the COVID-19 pandemic upended not only health care systems but also everyday life, and there will continue to be ramifications for maternal health outcomes into the future. It is important to continue to study and to monitor maternal morbidity and mortality to better understand the causes of and contributors to this public health crisis.

The IDPH uses a variety of data sources to identify all deaths of women while pregnant or within one year of pregnancy (pregnancy-associated deaths), regardless of cause of death. Deaths are reviewed by two statewide maternal mortality review committees (MMRCs). The reviews aim to identify the cause of death, determine whether the death was pregnancy-related, determine whether the death was preventable, identify contributing factors to the death, and develop recommendations to prevent future deaths.

## **Key Findings**

All findings are for 2018-2020 unless otherwise noted.

#### **Chronic Disease During Pregnancy**

• From 2010 to 2020, maternal obesity increased 33%, maternal hypertension increased 103%, and maternal diabetes increased 68%.

#### **Mental Health Conditions**

• Of all live births, 8% had a maternal mental health condition recorded on the delivery hospital record. However, this was above 25% in some counties.

#### **Substance Use Disorders**

• Of all live births, 5% had a maternal substance use disorder recorded on the delivery hospital record. However, this was above 20% in some counties.

#### Severe Maternal Morbidity

- One out of every 115 deliveries had a severe maternal morbidity, with severe bleeding (hemorrhage) being the most common type of severe complication.
- Black women had a severe maternal morbidity rate more than two times that of White women.

#### **Maternal Mortality**

- An average of 88 women died while pregnant or within one year of pregnancy, with the highest number occurring during 2020 (110 deaths).
- 43% of women who died while pregnant or within one year of pregnancy died from a cause related to pregnancy.
- The leading cause of pregnancy-related death was substance use disorder, which comprised 32% of pregnancy-related deaths. The other most common causes of pregnancy-related death were cardiac and coronary conditions, pre-existing chronic medical conditions, sepsis, mental health conditions, and embolism.
- Black women were twice as likely to die from any pregnancy-related condition and three times as likely to die from pregnancy-related medical conditions as White women.
- More than half of pregnancy-related deaths occurred more than 60 days postpartum.
- The MMRCs determined 91% of pregnancy-related deaths were potentially preventable due to clinical, system, social, community, or patient factors.

# Key Recommendation Highlights

The preventable pregnancy-related deaths during 2018-2020 are the basis of recommendations in this report.

- Health care providers should know and follow best practices for high-quality maternal health care in the following key areas
  that are critical for reducing maternal mortality: cardiovascular disease, obesity, mental health conditions, substance use
  disorder, trauma-informed care, and contraceptive services.
- Hospitals and health systems should create protocols and practices to identify and address social determinants of health.
- Hospitals and health systems should develop standardized protocols and policies to assure implementation of high-quality delivery of maternal mental health and substance use care.
- Community-based organizations should partner with clinical systems to ensure health care providers know about available local social services and case management programs for pregnant and postpartum women.
- State agencies should implement plans of safe care for infants exposed to substances during pregnancy, including implementation of a notification and tracking system that is separate from child abuse/neglect reporting systems.

#### The COVID-19 Pandemic and Maternal Health

This report primarily focuses on maternal morbidity and mortality data from 2018-2020. During 2020, the landscape of maternal health and health care shifted immensely due to the pandemic of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), the virus that causes coronavirus 2019 disease (COVID-19). Most of this report focuses on findings from 2018-2020, which combines two years prior to the COVID-19 pandemic and the first year of the pandemic.

While life looked very different in 2020 than in prior years, due to the small numbers of rare maternal outcomes, it is not statistically reliable to present single year estimates in this report, so generally 2020 is not compared to prior years. IDPH acknowledges the need to further study the impact of the pandemic on maternal health outcomes; this will be done in future reports when data is available for 2021 and beyond.

At the beginning of the pandemic, it was not clear whether pregnant women were more likely than non-pregnant women to have severe COVID-19 or whether there were additional maternal and infant health complications connected to SARS-CoV-2 infection. Over the last three years, much has been learned about the effect of COVID-19 on maternal health. The information below is not an exhaustive review of the scientific literature, but a few studies are cited to give examples of the current evidence in the field.

COVID-19 during pregnancy has been shown to be related to an increased risk of preeclampsia,<sup>5</sup> cesarean section,<sup>6</sup> preterm birth,<sup>7</sup> and stillbirth.<sup>8</sup> Several studies have shown that pregnant women had more severe COVID-19 than non-pregnant women, including higher rates of intensive care admission, invasive medical treatment, and death.<sup>9,10,11,12</sup> Some of these studies also showed that pregnant women who were older or who had underlying medical conditions, particularly diabetes and obesity, were at even higher risk of severe COVID-19.

Throughout the pandemic, Black and Hispanic people had higher rates of contracting SARS-CoV-2, more severe disease, and higher rates of death from COVID-19.<sup>13</sup> These racial inequities were also seen among pregnant women.<sup>14</sup> Studies around the U.S. found that Black and Hispanic pregnant women were disproportionately affected by and have higher rates of severe COVID-19.<sup>15</sup> Furthermore, COVID-19 vaccine acceptance was lower among pregnant people who were Black and Hispanic,<sup>16</sup> reflecting long-standing distrust of the medical community due to negative experiences and historic injustices against minoritized populations.

- 5 Conde-Agudelo, A., & Romero, R. (2022). SARS-CoV-2 infection during pregnancy and risk of preeclampsia: a systematic review and meta-analysis. American Journal of Obstetrics and Gynecology, 226(1), 68–89.e3. <a href="https://doi.org/10.1016/j.ajog.2021.07.009">https://doi.org/10.1016/j.ajog.2021.07.009</a>
- 6 Gurol-Urganci, I., Jardine, J. E., Carroll, F., et al. (2021). Maternal and perinatal outcomes of pregnant women with SARS-CoV-2 infection at the time of birth in England: national cohort study. American Journal of Obstetrics and Gynecology, 225(5), 522.e1–522.e11. https://doi.org/10.1016/j.ajog.2021.05.016
- Ko, J. Y., DeSisto, C. L., Simeone, R. M., et al. (2021). Adverse Pregnancy Outcomes, Maternal Complications, and Severe Illness Among US Delivery Hospitalizations With and Without a Coronavirus Disease 2019 (COVID-19) Diagnosis. Clinical Infectious Diseases: An Official Publication of the Infectious Diseases Society of America, 73(Suppl 1), S24–S31. https://doi.org/10.1093/cid/ciab344
- 8 DeSisto, C.L., Wallace, B., Simeone, R.M., et al. (2021). Risk for Stillbirth Among Women With and Without COVID-19 at Delivery Hospitalization United States, March 2020-September 2021. MMWR. Morbidity and Mortal Weekly Report. 70(47):1640-1645. doi: https://doi.org/10.15585/mmwr.mm7047e1
- 9 Jamieson, D. J., & Rasmussen, S. A. (2022). An update on COVID-19 and pregnancy. *American Journal of Obstetrics and Gynecology*, 226(2), 177–186. https://doi.org/10.1016/j.ajog.2021.08.054
- 10 Metz, T. D., Clifton, R. G., Hughes, B. L., et al. (2022). Association of SARS-CoV-2 Infection with Serious Maternal Morbidity and Mortality From Obstetric Complications. *JAMA*, 327(8), 748–759. <a href="https://doi.org/10.1001/jama.2022.1190">https://doi.org/10.1001/jama.2022.1190</a>
- 11 Brandt, J. S., Hill, J., Reddy, A., et al. (2021). Epidemiology of coronavirus disease 2019 in pregnancy: risk factors and associations with adverse maternal and neonatal outcomes. American journal of obstetrics and gynecology, 224(4), 389.e1–389.e9. https://doi.org/10.1016/j.ajog.2020.09.043
- 12 Zambrano, L. D., Ellington, S., Strid, P., et al. (2020). Update: Characteristics of Symptomatic Women of Reproductive Age with Laboratory-Confirmed SARS-CoV-2 Infection by Pregnancy Status United States, January 22-October 3, 2020. MMWR. Morbidity and mortality weekly report, 69(44), 1641–1647. https://doi.org/10.15585/mmwr.mm6944e3
- 13 Webb Hooper, M., Nápoles, A. M., & Pérez-Stable, E. J. (2020). COVID-19 and Racial/Ethnic Disparities. *JAMA*, 323(24), 2466–2467. https://doi.org/10.1001/jama.2020.8598
- 14 Allotey, J., Stallings, E., Bonet, M., et al. (2020). Clinical manifestations, risk factors, and maternal and perinatal outcomes of coronavirus disease 2019 in pregnancy: living systematic review and meta-analysis. BMJ (Clinical research ed.), 370, m3320. https://doi.org/10.1136/bmj.m3320
- 15 Sakowicz, A., Ayala, A. E., Ukeje, C. C., et al. (2020). Risk factors for severe acute respiratory syndrome coronavirus 2 infection in pregnant women. American Journal of Obstetrics & Gynecology MFM, 2(4), 100198. https://doi.org/10.1016/j.ajogmf.2020.100198
- 16 Rawal, S., Tackett, R. L., Stone, R. H., & Young, H. N. (2022). COVID-19 vaccination among pregnant people in the United States: a systematic review. American Journal of Obstetrics and Gynecology Maternal-Fetal Medicine, 4(4). <a href="https://doi.org/10.1016/j.ajogmf.2022.100616">https://doi.org/10.1016/j.ajogmf.2022.100616</a>

The COVID-19 pandemic changed the landscape of health care systems for everyone, including pregnant women. Medical offices were limiting appointments, patients delayed or skipped health care due to fear of COVID-19 exposure, and people could not bring support persons with them to appointments. At the same time, the pandemic forced health care delivery models to adapt and to increase the use of telemedicine, which may have eased health care access for some patients. Nationally, women received fewer prenatal care visits in 2020 than pre-pandemic, but prenatal care visits began to increase again during 2021. Postpartum visits were also reduced during the first year of the pandemic, especially among Black women, younger women, and those without insurance.

In addition to outpatient care changes, the birthing experience in hospitals changed during the pandemic, especially during the early stages when little was known about transmission pathways between mother and infant. Many hospitals limited the number of support persons who could accompany the pregnant woman and separated COVID-positive moms and babies to reduce transmission. Quality of care may have been negatively affected due to health care systems being overburdened and provider burnout.

In addition to changing health care delivery and utilization, the COVID-19 pandemic also led to many changes in public health systems and society at large. The COVID-19 pandemic exacerbated social determinants of health challenges, especially for marginalized populations. During the early stages of the pandemic, Hispanic adults reported the highest rates of stress due to not having enough food and unstable housing. <sup>19</sup> Pregnant and postpartum women were more likely to experience food insecurity during 2020 than pre-pandemic. <sup>20</sup> One survey found that compared to White women, Black pregnant women had a higher likelihood of having their employment negatively impacted, more worries regarding their prenatal care and birthing experience, and a higher prevalence of depression, but also higher resilience factors like self-reliance and emotional regulation. <sup>21</sup>

While this report includes data from 2020, it does not comprehensively assess the impact of the COVID-19 pandemic due to limited data availability for more recent years. In the sections that follow, this report examines important indicators of maternal morbidity and mortality and provides an overview of the maternal health landscape in Illinois. IDPH will continue to monitor these indicators into the future as it tracks changes in maternal health over time to better describe the full impact of the COVID-19 on maternal health outcomes.

<sup>17</sup> Martin, J. A., & Osterman, M. J. (2023). Changes in prenatal care utilization: United States, 2019-2021. *National Vital Statistics Reports*, 72(4). <a href="https://www.cdc.gov/nchs/data/nvsr/nvsr72/nvsr72-04.pdf">https://www.cdc.gov/nchs/data/nvsr/nvsr72/nvsr72-04.pdf</a>

<sup>18</sup> Bellerose, M., & Steenland, M. W. (2023). Association Between the Coronavirus Disease 2019 (COVID-19) Pandemic and National Disparities in Postpartum Visit Attendance. *Obstetrics and Gynecology*, 141(1), 170–172. https://doi.org/10.1097/AOG.000000000005014

<sup>19</sup> McKnight-Eily, L. R., Okoro, C. A., Strine, T. W., et al. (2021). Racial and Ethnic Disparities in the Prevalence of Stress and Worry, Mental Health Conditions, and Increased Substance Use Among Adults During the COVID-19 Pandemic — United States, April and May 2020. Morbidity and Mortality Weekly Report, 70(5): 162–166.

<sup>20</sup> Ujah, O. I., Olaore, P., Ogbu, C. E., & Kirby, R. S. (2023). Trends, Prevalence, and Risk Factors of Food Insecurity Among Pregnant and Postpartum Women in the United States: Findings from the 2019-2021 National Health Interview Survey. *Journal of Women's Health*, epub ahead of print. <a href="https://doi.org/10.1089/jwh.2023.0250">https://doi.org/10.1089/jwh.2023.0250</a>

<sup>21</sup> Gur, R. E., White, L. K., Waller, R., et al. (2020). The Disproportionate Burden of the COVID-19 Pandemic Among Pregnant Black Women. Psychiatry research, 293. https://doi.org/10.1016/j.psychres.2020.113475

# The Importance of Maternal Health

Maternal health refers to the health of women during or after pregnancy (postpartum period). During this time, women experience many rapid physical and psychological changes that can have lasting effects on their health and life. For example, the physiologic stress of pregnancy can exacerbate preexisting conditions and create new pregnancy-related health conditions.

Because women typically have more interaction with health care providers and the health care system and increased access to health and social services during pregnancy, pregnancy and the postpartum period provide an opportunity to identify, to treat, and to manage conditions to improve a woman's overall health.

#### Maternal Health in Illinois

Illinois ranks sixth in population in the United States with 12.7 million residents, including 2.5 million women of reproductive age (15-44 years).<sup>22</sup> Illinois is racially and ethnically diverse. Among the estimated 135,000 births in 2020, approximately 53% were born to non-Hispanic White women, 21% to Hispanic women, 17% to non-Hispanic Black women, 6% to Asian women, 0.3% to American Indian or Alaska Native women, less than 0.1% to Native Hawaiian or Pacific Islander women, and 1% to non-Hispanic women of other or multiple races. Illinois is also geographically diverse, with both large urban areas and sparsely populated rural communities, each with different systems and community factors that affect maternal health.

#### Maternal Health Continuum

There is a continuum of maternal health outcomes ranging from minor complications to maternal death (Figure 1). "Maternal morbidity" describes both short- and long-term health problems that are related to pregnancy or childbirth. "Maternal mortality" refers to the death of a woman during pregnancy or within one year of any pregnancy outcome. It is most common for women to experience a healthy pregnancy with no complications. Minor morbidities or pregnancy complications are somewhat common, but more severe complications are rare. The most severe and tragic outcome, maternal death, is very rare and affects less than 0.1% of pregnant or postpartum women.



Figure 1: The Continuum of Maternal Health Outcomes

Although rare, maternal mortality in the United States has been increasing and is 3 to 4 times more than in other developed nations, <sup>23</sup> and not all groups are at equal risk. In the United States, pregnancy-related deaths were almost three times higher for Black women than White women during 2017-2019. <sup>24</sup>

 $<sup>22 \</sup>quad U.S. \ Census \ Bureau. \ (2021). \ \textit{Explore Census data}. \ Retrieved \ from \ \underline{https://data.census.gov/profile/Illinois?g=040XX00US17}$ 

<sup>23</sup> GBD 2015 Maternal Mortality Collaborators (2016). Global, regional, and national levels of maternal mortality, 1990-2015: a systematic analysis for the Global Burden of Disease Study 2015. *Lancet (London, England)*, 388(10053), 1775–1812. https://doi.org/10.1016/S0140-6736(16)31470-2

<sup>24</sup> Division of Reproductive Health, National Center for Chronic Disease Prevention and Health Promotion. (2019). Pregnancy Mortality Surveillance System. Centers for Disease Control and Prevention (CDC). Retrieved from <a href="https://www.cdc.gov/reproductivehealth/maternal-mortality/pregnancy-mortality-surveillance-system.htm">https://www.cdc.gov/reproductivehealth/maternal-mortality/pregnancy-mortality-surveillance-system.htm</a>

Maternal health is not simply the result of an individual's biology or genetics but is influenced by social and systemic factors. Structural issues in the health care system, like health insurance access, health care availability and quality of services, affect maternal health and the health gap between Black and White women. Opportunities and access to information can affect decision-making and health behaviors. Laws and policies can create an unequal distribution of resources and power that may leave some groups disadvantaged and vulnerable to health risks. The social, political, and economic structures that produce inequities, combined with the lived, everyday experiences of individuals, are known as "social determinants of health." Social determinants of health deeply affect a woman's ability to thrive and be healthy. Some examples include poverty, quality of education, health literacy, employment, housing, availability of child care, transportation, community support, and neighborhood safety.

This is the third Illinois report on maternal morbidity and mortality. All three reports describe maternal deaths, including where they occurred, what contributed to them, and who was most affected. The three reports also specifically highlight the unacceptably high rates of pregnancy-related deaths for Black women. These reports serve as a foundation for informing ongoing efforts to eliminate preventable pregnancy-related mortality and highlight a variety of health outcomes along the maternal health continuum and the factors that influence these outcomes.

# **Maternal Morbidity**

In general, "maternal morbidity" describes any health problems that result from being pregnant or giving birth. This can include direct complications of a pregnancy, but also aggravation of underlying chronic health conditions during pregnancy. Maternal morbidities may be short- or long-term and range from mild to very severe and life-threatening. This report presents information on a variety of maternal morbidities experienced by Illinois women, including chronic diseases, mental health conditions and substance use disorders, and severe maternal morbidities.

## **Chronic Disease During Pregnancy**

Chronic diseases are health conditions that last more than one year, can limit the activities of daily living, and require ongoing medical attention. Genetic and environmental factors, such as violence, pollution, and food insecurity, can influence the development of chronic diseases. Many chronic diseases can also be influenced by tobacco use or exposure to secondhand smoke, poor nutrition, physical inactivity, and alcohol use. Common chronic diseases, including obesity, hypertension, and diabetes, may increase the risk of complications during pregnancy and the year postpartum. This section will focus on three common chronic diseases: obesity, hypertension, and diabetes. The data on chronic diseases were obtained from Illinois birth certificates, which are further described in Appendix D.

**Obesity** is having a weight higher than what is considered healthy for a given height. The American Medical Association passed a resolution in 2013 recognizing obesity as a chronic disease to promote improved medical approaches to prevention and treatment, while also reducing stigma.<sup>27</sup> Obesity carries risks of infant and maternal complications during pregnancy and delivery, including pregnancy loss, birth defects, preterm birth, stillbirth, preeclampsia, and gestational diabetes. Losing weight prior to pregnancy is the best way to decrease the risk of pregnancy complications related to obesity and to improve maternal health,<sup>28</sup> but this can be very difficult for many people.

Hypertension, or high blood pressure, occurs when the pressure in the arteries is too high. When high blood pressure in pregnancy or the postpartum period causes organ damage, it is known as preeclampsia. Hypertension and preeclampsia can cause pregnancy complications, including premature birth, low birthweight, and problems with the placenta. <sup>29</sup> Untreated hypertension or preeclampsia that remains into the postpartum period can cause fluid in the lungs, blood clots, seizures (eclampsia), or stroke. Women who have had preeclampsia can also have an increased risk of kidney disease, heart attack, stroke, and high blood pressure later in life. <sup>30</sup> The data on hypertension in this section includes both pre-pregnancy (chronic) and pregnancy-related hypertension, including preeclampsia/eclampsia.

<sup>25</sup> National Center for Chronic Disease Prevention and Health Promotion. (2022, July). *About Chronic Diseases*. Centers for Disease Control and Prevention (CDC). Retrieved from <a href="https://www.cdc.gov/chronicdisease/about/index.htm">https://www.cdc.gov/chronicdisease/about/index.htm</a>

<sup>26</sup> March of Dimes. (2019, March). Chronic health conditions and pregnancy. Retrieved from: <a href="https://www.marchofdimes.org/find-support/topics/planning-baby/chronic-health-conditions-and-pregnancy">https://www.marchofdimes.org/find-support/topics/planning-baby/chronic-health-conditions-and-pregnancy</a>

<sup>27</sup> Obesity Medicine Association. (2013, June 19). AMA House of Delegates Adopts Policy to Recognize Obesity as a Chronic Disease. Retrieved from <a href="https://obesitymedicine.org/ama-adopts-policy-recognize-obesity-disease/">https://obesitymedicine.org/ama-adopts-policy-recognize-obesity-disease/</a>

<sup>28</sup> The American College of Obstetricians and Gynecologists. (2023, January). Frequently Asked Questions: Obesity and Pregnancy. Retrieved from <a href="https://www.acog.org/Patients/FAQs/Obesity-and-Pregnancy">https://www.acog.org/Patients/FAQs/Obesity-and-Pregnancy</a>

<sup>29</sup> March of Dimes. (2019, February). *High Blood Pressure During Pregnancy*. Retrieved from <a href="https://www.marchofdimes.org/complications/high-blood-pressure-during-pregnancy.aspx">https://www.marchofdimes.org/complications/high-blood-pressure-during-pregnancy.aspx</a>

<sup>30</sup> The American College of Obstetricians and Gynecologists. (2023, April). Frequently Asked Questions: Preeclampsia and high blood pressure during pregnancy. Retrieved from: <a href="mailto:acog.org/womens-health/faqs/Preeclampsia-and-High-Blood-Pressure-During-Pregnancy">acog.org/womens-health/faqs/Preeclampsia-and-High-Blood-Pressure-During-Pregnancy</a>

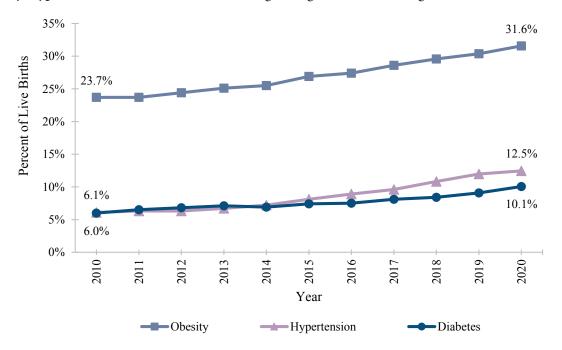
**Diabetes** is a condition in which a person's body cannot use the sugar from their diet because a hormone called insulin is not produced (type 1 diabetes) or the body doesn't adequately respond to insulin (type 2 diabetes). Some women develop diabetes during pregnancy (gestational diabetes), but their blood sugar may return to normal after pregnancy. Any type of diabetes during pregnancy can increase the risk of birth defects, stillbirth, preterm birth, or cesarean delivery. Gestational diabetes may increase the woman's risk of high blood pressure and preeclampsia during pregnancy, as well as diabetes later in life. The data on diabetes in this section includes chronic or gestational diabetes.

During 2010-2020, there were significant increases in the percent of live births to women with hypertension, diabetes, and obesity (Figure 2). Among live births in Illinois from 2010 to 2020:

- Maternal obesity increased 33% (from 23.7% in 2010 to 31.6% in 2020)
- Maternal hypertension increased 103% (from 6.1% in 2010 to 12.5% in 2020)
- Maternal diabetes increased 68% (from 6.0% in 2010 to 10.1% in 2020)

Some women may have presented with more than one of the three chronic conditions described in this section, therefore percentages in this section are not mutually exclusive groups.

Figure 2. Obesity, Hypertension, and Diabetes are Increasing among Women Delivering Live Births in Illinois.



In the following figures, rates of these chronic diseases are compared for different groups of Illinois women. For these analyses, three years of data were combined (2018-2020) so these analyses match the morbidity and mortality data presented later in this report.

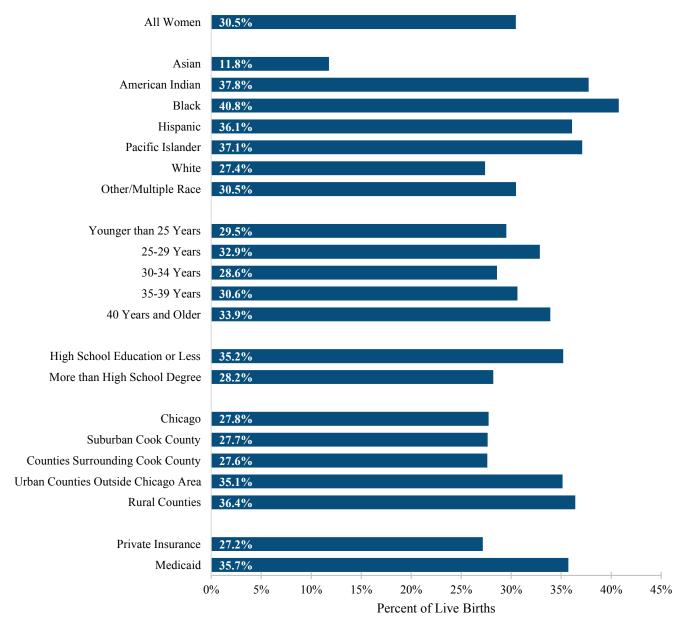
<sup>31</sup> Division of Reproductive Health, National Center for Chronic Disease Prevention and Health Promotion. (2018, June). Diabetes During Pregnancy. Centers for Disease Control and Prevention (CDC). Retrieved from <a href="https://www.cdc.gov/reproductivehealth/maternalinfanthealth/diabetes-during-pregnancy.htm">https://www.cdc.gov/reproductivehealth/maternalinfanthealth/diabetes-during-pregnancy.htm</a>

<sup>32</sup> Mayo Clinic. (2022, April). Gestational Diabetes. Retrieved from <a href="https://www.mayoclinic.org/diseases-conditions/gestational-diabetes/symptoms-causes/syc-20355339">https://www.mayoclinic.org/diseases-conditions/gestational-diabetes/symptoms-causes/syc-20355339</a>

#### **OBESITY**

During 2018-2020, 30.5% of live births were to women with obesity (Figure 3). Maternal obesity was highest among live births to women who were Black (40.8%), age 40 years and older (33.9%), had a high school education or less (35.2%), resided in rural counties (36.4%), and had Medicaid insurance (35.7%).

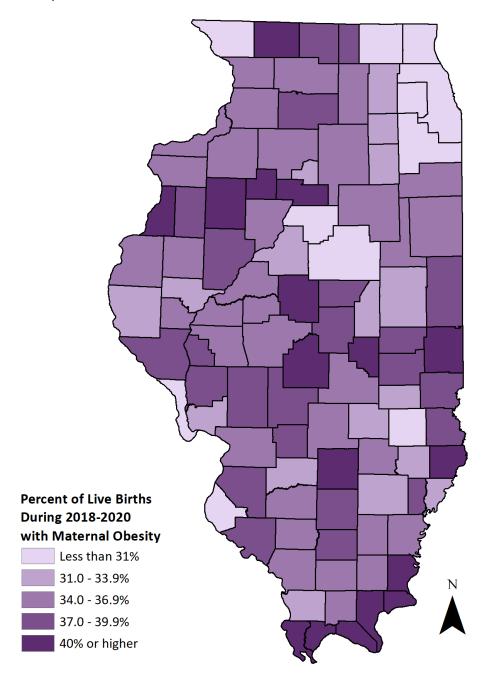
Figure 3. Maternal obesity is most common among Illinois women who are Black, age 40 years or older, have high school education or less, reside in rural counties, and have Medicaid insurance.



**Data interpretation example:** The bar on the chart referring to "High School Education or Less" means that among live births occurring to women with a high school education or less, 35.2% had maternal obesity.

The percent of live births to women with obesity varied substantially across Illinois counties (Figure 4). During 2018-2020, the lowest maternal obesity percent was in DuPage County (22.2%) and the highest maternal obesity percent was in Henderson County (45.7%). Eighteen counties had a maternal obesity percent of 40% or higher (Alexander, Christian, Edgar, Gallatin, Hardin, Henderson, Knox, Lawrence, Logan, Marion, Marshall, Massac, Moultrie, Pope, Pulaski, Stark, Stephenson, and Vermilion).

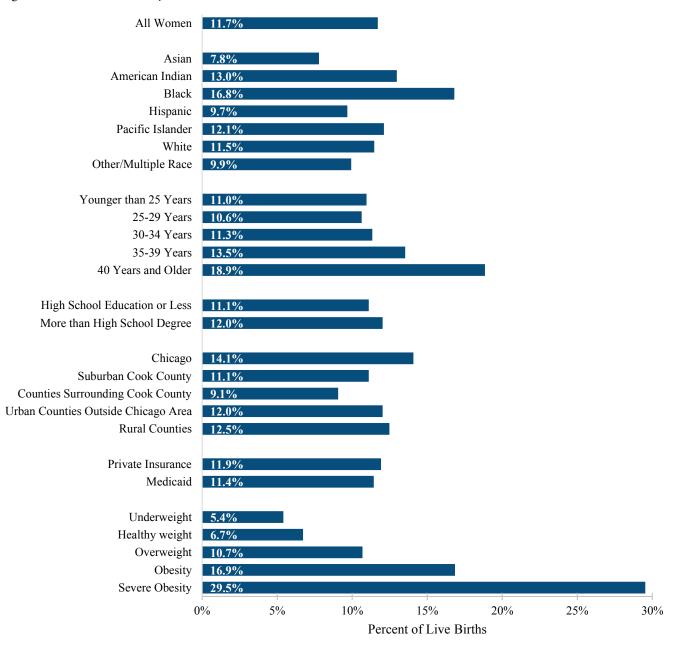
Figure 4. Maternal obesity varies across Illinois and was most common for residents of rural counties.



#### **HYPERTENSION**

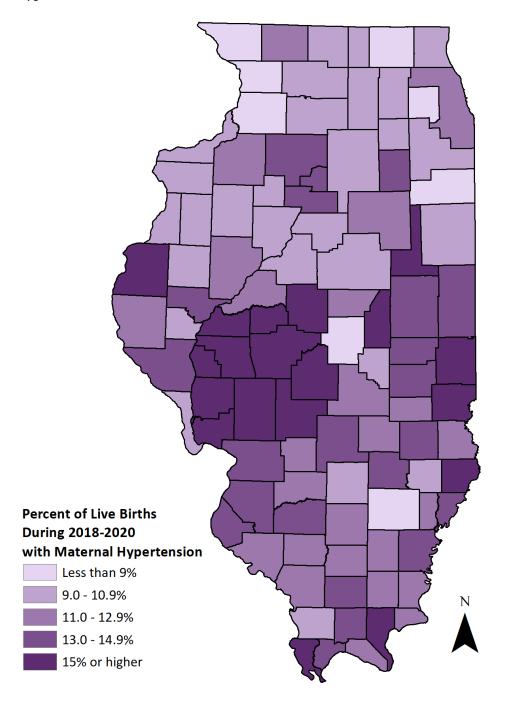
During 2018-2020, 11.7% of live births were to women with hypertension (Figure 5). Maternal hypertension was highest among live births born to women who were Black (16.8%), age 40 years and older (18.9%), and resided in Chicago (14.1%). Maternal hypertension increased with increasing body mass index; 29.5% of births to women with severe obesity had maternal hypertension. There were only small differences in maternal hypertension by level of education or insurance type.

Figure 5. Maternal hypertension is most common among Illinois women who are Black, age 40 years or older, reside in Chicago, and have severe obesity.



The percentage of live births to women with hypertension varied substantially across counties (Figure 6). During 2018-2020, maternal hypertension was lowest in Jo Daviess County (5.9%) and highest in Scott County (25.2%). Nineteen counties had a maternal hypertension percent of 15% or higher (Alexander, Cass, Christian, Clark, Edgar, Ford, Greene, Hancock, Jersey, Lawrence, Logan, Macoupin, Menard, Montgomery, Morgan, Piatt, Pope, Sangamon, and Scott).

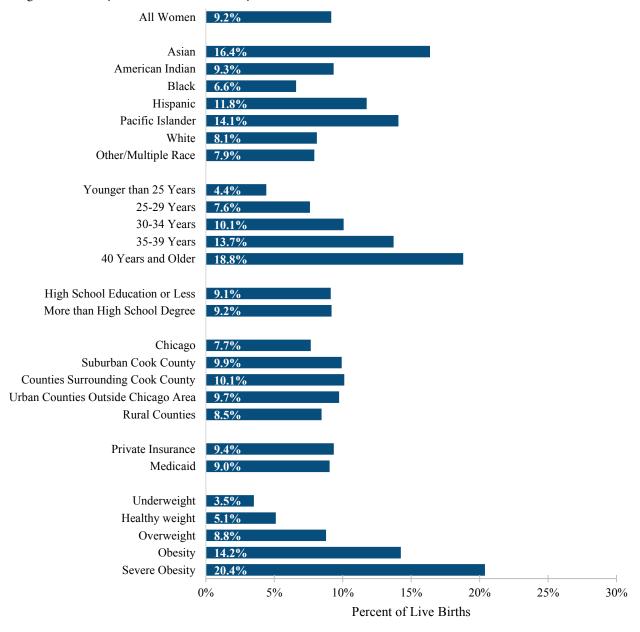
Figure 6. Maternal hypertension varies across Illinois and was most common for residents of counties located in central Illinois.



#### **DIABETES**

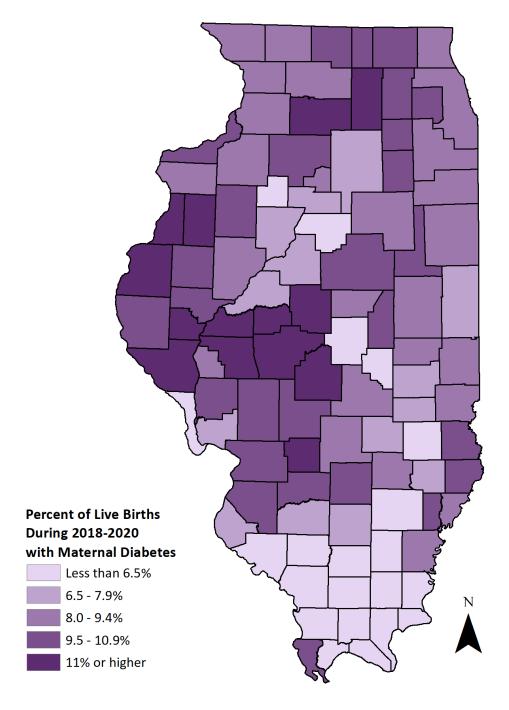
During 2018-2020, 9.2% of live births were to women with diabetes (Figure 7). Maternal diabetes was highest among live births born to women who were Asian (16.4%), age 40 years and older (18.8%), and resided in counties surrounding Cook County (10.1%). Maternal diabetes increased with increasing body mass index; 20.4% of births to women with severe obesity had maternal diabetes. Rates of maternal diabetes were similar regardless of education level or insurance type.

Figure 7. Maternal diabetes is most common among Illinois women who are Asian, age 40 years or older, reside in counties surrounding Cook County, and have severe obesity.



The percentage of live births to women with diabetes varied substantially across counties (Figure 8). During 2018-2020, maternal diabetes was lowest in Pulaski County (1.9%) and highest in Menard County (16.6%). Fourteen counties had a maternal diabetes percent of 11% or higher (Bond, Brown, Cass, Christian, DeKalb, Hancock, Henderson, Lee, Logan, Menard, Morgan, Pike, Sangamon, and Warren).

Figure 8. Maternal diabetes varies across Illinois and was most common for residents of counties in central and western Illinois.



#### **Chronic Disease Prevention**

Given the relationship between chronic conditions and adverse maternal health outcomes, it is important that all women of reproductive age have access to routine preventive and reproductive health care to optimize their health as much as possible before pregnancy. Women with chronic health conditions, especially those planning to become pregnant, should receive care from appropriate specialists to ensure their chronic conditions are properly managed and have access to patient-centered reproductive health services.

Chronic diseases have long been characterized as outcomes that are solely the product of individual behavior, whether from a lack of exercise, poor diet, irregular doctor visits, or all the above. While many (but not all) chronic diseases can be prevented or minimized by eating healthy foods, being active, and maintaining a healthy weight status, not all people have equal opportunities to make these choices. The social determinants of health influence the development of chronic diseases as well as a person's ability to successfully manage their condition and experience favorable health outcomes.

Some social determinants of health that affect chronic diseases include economic stability, food security, geography, and trauma. <sup>33,34</sup> People who have low incomes may struggle to afford things like healthy foods, housing, and health care. Programs that focus on reducing poverty can improve the overall health and well-being for women of reproductive age and their families. Access to healthy food and education on how nutrition impacts health outcomes are key to reducing poor health outcomes. Geography, or where a patient lives and works, plays a large role in various factors affecting health like access to health care, exposure to environmental hazards, and experience of violence. <sup>35</sup> Trauma, such as experience of adverse childhood events (ACEs), <sup>36</sup> also affects chronic disease outcomes by increasing stress levels and causing long-term physical changes in the body. Numerous studies suggest that social determinants of health account for between 30-55% of health outcomes. <sup>37</sup>

Improving the health of reproductive-aged women will take a systemic approach to address the social and structural determinants of health that affect women's ability to be healthy. This will require health care to incorporate screenings and interventions for chronic disease and social determinants of health into routine women's health visits, while improving community-based health promotion and education.<sup>38</sup>

<sup>33</sup> Cockerham, W. C., Hamby, B. W., & Oates, G. R. (2017). The Social Determinants of Chronic Disease. *American Journal of Preventive Medicine*, 52(1S1), S5–S12. https://doi.org/10.1016/j.amepre.2016.09.010

<sup>34</sup> Berkowitz, S. A., Meigs, J. B., DeWalt, D., et al. (2015). Material need insecurities, control of diabetes mellitus, and use of health care resources: results of the Measuring Economic Insecurity in Diabetes study. JAMA Internal Medicine, 175(2), 257–265. https://doi.org/10.1001/jamainternmed.2014.6888

<sup>35</sup> Office of Disease Prevention and Health Promotion. (n.d.). *Healthy People 2023*. U.S. Department of Health and Human Services. Retrieved from <a href="https://health.gov/healthypeople/objectives-and-data/social-determinants-health">https://health.gov/healthypeople/objectives-and-data/social-determinants-health</a>

<sup>36</sup> National Center for Injury Prevention and Control, Division of Violence Prevention. (2023, June). Fast Facts: Preventing Adverse Childhood Experience. Centers for Disease Control and Prevention (CDC). Retrieved from <a href="https://www.cdc.gov/violenceprevention/aces/fastfact.html">https://www.cdc.gov/violenceprevention/aces/fastfact.html</a>

<sup>37</sup> World Health Organization (WHO). (n.d.). Social Determinants of Health. Retrieved from <a href="https://www.who.int/health-topics/social-determinants-of-health">https://www.who.int/health-topics/social-determinants-of-health</a>

<sup>38</sup> Barfield, W. D., & Warner, L. (2012). Preventing chronic disease in women of reproductive age: opportunities for health promotion and preventive services. Preventing Chronic Disease, 9, E34. https://doi.org/10.5888/pcd9.110281

#### Mental Health Conditions and Substance Use Disorders

Mental health conditions and substance use disorders are common diseases that affect people from all backgrounds and often co-occur. Mental health conditions and substance use disorders are serious, but treatable. Given these diseases can be worsened by or induced by pregnancy, it is important to consider how they may be affecting maternal health in Illinois.

Mental health conditions affect a person's thinking, feeling, behavior, or mood.<sup>39</sup> These conditions are common and regularly affect daily living. Many mental health conditions are not caused by a singular event, but a group of linked causes, including traumatic experiences, environmental factors, genetics, and family history of mental health conditions. Different ongoing or acute stressors can make some people more susceptible. Common mental health conditions include mood disorders, such as depression or anxiety, and psychotic disorders, including schizophrenia. Mental health conditions can lead to complications, such as disrupted personal and family relationships, trouble maintaining a job, and even suicide. Receiving an early diagnosis and connecting to evidence-based mental health treatment is the best way to decrease the risk of any complications related to mental health conditions during and after pregnancy.

Substance use disorder refers to the recurrent use of substances that causes distress and clinically significant impairment. Substance use disorders can range in severity, in terms of the extent it affects daily living and overall health.<sup>40</sup> Common risk factors for substance use disorders are similar to other mental health conditions, including genetics, family history of substance use disorders, environmental factors, and trauma. Substance use prevention, strategies to reduce harms from substance use, and evidence-based, consistent treatment are all important for reducing the impact of substance use disorders on pregnant and postpartum women.

This section of the report will focus on mental health conditions and substance use disorders among women giving birth using data from hospital discharge records for delivery hospitalizations. Detailed information about the definitions used for this analysis are available in Appendix D.

Throughout this section, there will be reference to the percent of live births where mental health conditions or substance use disorders were recorded by the delivery hospital as an acknowledgement that the true experience of these conditions may be higher than what is submitted by hospital billing data for a delivery hospitalization.

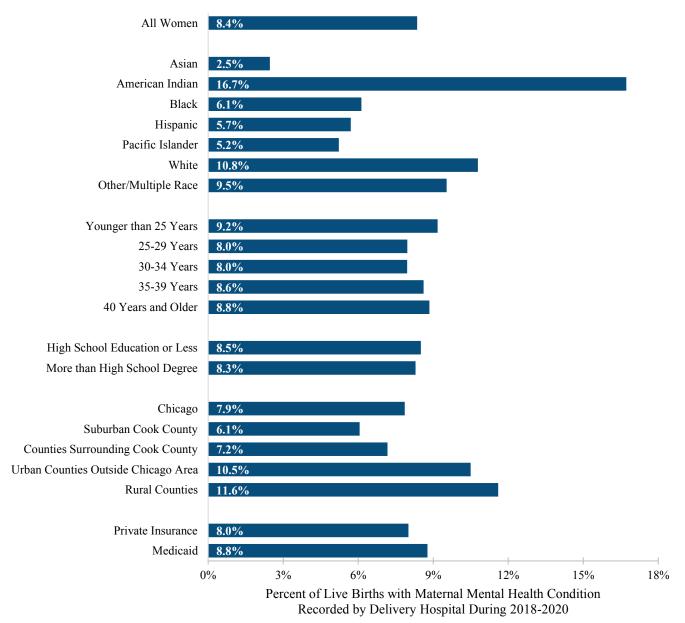
<sup>39</sup> National Alliance on Mental Illness. (n.d.). *Mental Health Conditions*. Retrieved from <a href="https://www.nami.org/About-Mental-Illness/Mental-Health-Conditions">https://www.nami.org/About-Mental-Illness/Mental-Health-Conditions</a>

<sup>40</sup> Substance Abuse and Mental Health Services Administration. (2023, June). *Mental Health and Substance Use Disorders*. U.S. Department of Health and Human Services. Retrieved from <a href="https://www.samhsa.gov/find-help/disorders">https://www.samhsa.gov/find-help/disorders</a>

#### Maternal Mental Health Conditions Recorded by Delivery Hospital

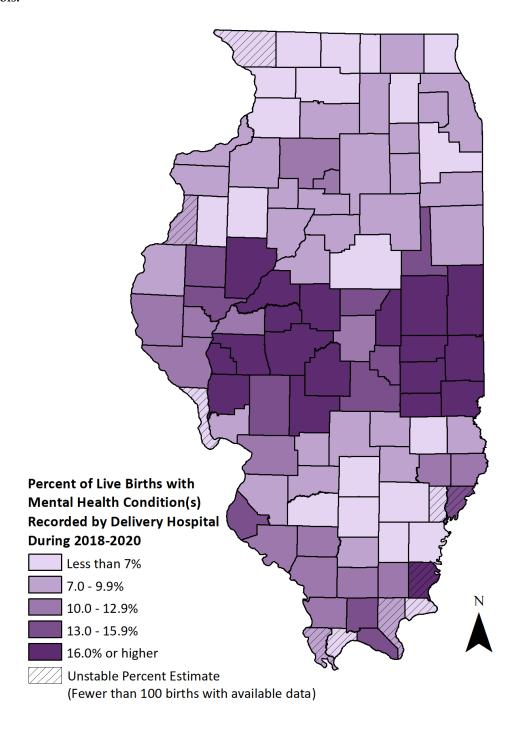
During 2018-2020, 8.4% of live births had a maternal mental health condition recorded by the delivery hospital (Figure 9). Maternal mental health conditions were recorded by the delivery hospital most often for live births born to women who were American Indian (16.7%) and who lived in urban counties outside the Chicago area (10.5%) or rural counties (11.6%). There were only small differences in maternal mental health conditions recorded by the delivery hospital with respect to age, level of education, or insurance type.

Figure 9. Maternal mental health conditions were most often recorded by the delivery hospital for Illinois women who were American Indian and who lived in counties outside the Chicago area.



The percentage of live births with a maternal mental health condition recorded by the delivery hospital varied across counties (Figure 10). During 2018-2020, maternal mental health conditions recorded by the delivery hospital were lowest in Jo Daviess County (2.5%) and highest in Fulton County (31.4%). Nineteen counties had a maternal mental health condition recorded for 16% or more of their live births (Champaign, Christian, Clark, Coles, Cumberland, Douglas, Edgar, Fulton, Gallatin, Greene, Logan, Mason, Menard, Montgomery, Morgan, Piatt, Sangamon, Scott, and Vermilion).

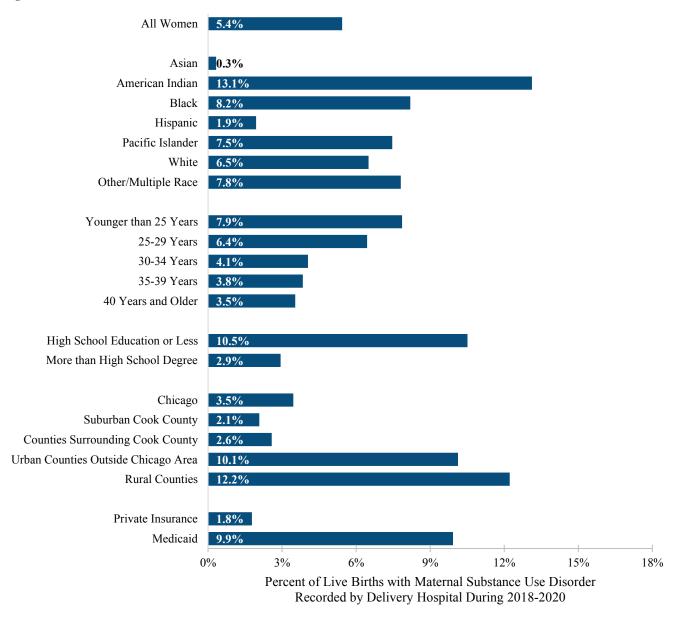
Figure 10. Maternal mental health conditions were most often recorded by the delivery hospital for residents of counties in central Illinois.



#### Maternal Substance Use Disorders Recorded by Delivery Hospital

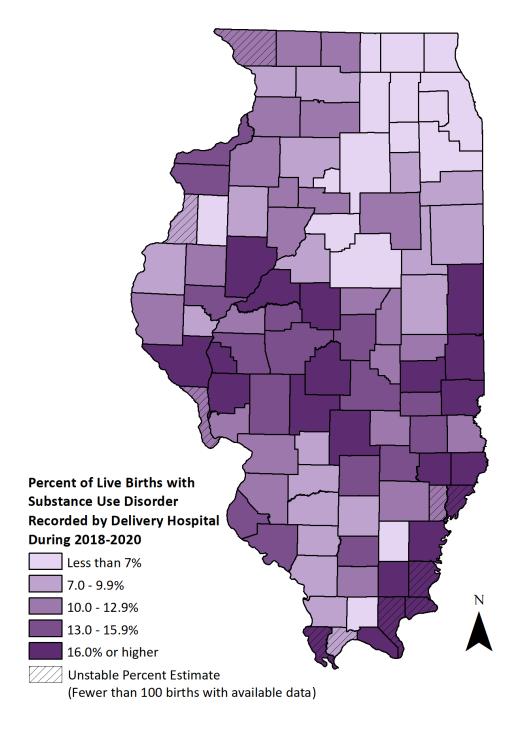
During 2018-2020, 5.4% of live births had a maternal substance use disorder recorded by the delivery hospital (Figure 11). Maternal substance use disorders were recorded by the delivery hospital most often for women who were American Indian (13.1%), younger than 25 years (7.9%), had a high school education or less (10.5%), lived in urban counties outside the Chicago area (10.1%) or rural counties (12.2%), and who had Medicaid insurance (9.9%).

Figure 11. Maternal substance use disorders were most often recorded by the delivery hospital for Illinois women who were American Indian, younger than 25 years, had a high school education or less, lived in counties outside the Chicago metropolitan area.



The percentage of live births with a maternal substance use disorder recorded by the delivery hospital varied across counties (Figure 12). During 2018-2020, maternal substance use disorders recorded by the delivery hospital were lowest in DuPage County (1.4%) and highest in Edgar County (24.3%). Twenty-three counties had a maternal substance use disorder recorded for 16% or more of their live births (Alexander, Christian, Clark, Coles, Edgar, Fayette, Fulton, Gallatin, Greene, Hardin, Lawrence, Logan, Mason, Massac, Montgomery, Pike, Pope, Richland, Saline, Scott, Vermilion, Wabash, and White).

Figure 12. Maternal substance use disorders were most often recorded by the delivery hospital for residents of counties in central and southeastern Illinois.



#### Prevention, Treatment and Recovery

As many Illinois women are affected by mental health conditions and substance use disorders, it is important to also consider their impact on other maternal health outcomes. In this report, the connection of mental health conditions and substance use disorders to severe maternal morbidity (see page 31) and pregnancy-related death (see page 43) is shown.

Addressing social determinants of health, including poverty and structural racism, may prevent mental health conditions and substance use disorders from developing and may mitigate the effects if these disorders do occur. In addition, experiences of trauma, such as community and domestic violence, childhood neglect, and sexual violence, are also associated with mental health conditions and substance use disorders. Family support programs designed to address childhood and family trauma are critical for preventing mental health conditions and substance use disorders. School and community-based programs designed to develop emotional intelligence, resilience, and conflict resolution in children and adolescents have also demonstrated positive effects on mental wellbeing.

Women with mental health conditions and substance use disorders, especially those seeking to become pregnant, need access to evidence-based care with appropriate specialists before, during, and after pregnancy to ensure their conditions are properly identified and treated, just as they would for any other chronic disease. Experts, including the American College of Obstetricians and Gynecologists, recommend universal screening for mental health and substance use disorders as part of prenatal care, with verbal screening for substance use disorders. If substance use disorders are identified in pregnant women, treatment should be offered that is accessible, responsive to family and parenting needs, and evidence-based, including access to medication-assisted recovery (MAR) services for patients with opioid use disorder. Unfortunately, many pregnant and postpartum women may not receive mental health care or substance use disorder treatment due to multiple barriers in accessing behavioral health services.

Many barriers to receiving mental health and substance use treatment are structural and social factors. Inadequate supply of mental health and substance use treatment providers can create long wait times for appointments and cause delays in receiving care. Patients, especially those in rural areas, may need to travel long distances to get to a mental health provider. Other transportation barriers can also make it difficult to access mental health care, such as lack of access to a vehicle, lack of access to frequent and reliable public transit, or the inability to afford public transit or alternative transportation, such as rideshares or taxis. Child care barriers can also lead to inability to receive mental health care. Pregnant and postpartum women also may not seek medical care due to stigma and fear of losing custody of their child(ren). Furthermore, health care providers may not be screening all patients for mental health conditions or substance use disorder and, even if they do, they may not know how to treat or where to refer patients.

It is important to address these barriers to mental health and substance use disorder care for pregnant and postpartum women. Removing barriers to treatment is a first step in addressing the systemic issues that impact the mental health of reproductive aged women.

<sup>41</sup> Cleveland Clinic. (2023). Adverse Childhood Experiences. Retrieved from: https://my.clevelandclinic.org/health/symptoms/24875-adverse-childhood-experiences-ace

<sup>42</sup> Child Welfare Information Gateway. (n.d.) Evidence-Based Practice in Family Support and Preservation Services. Retrieved from <a href="https://www.childwelfare.gov/topics/supporting/resources/evidence/">https://www.childwelfare.gov/topics/supporting/resources/evidence/</a>

<sup>43</sup> Collaborative for Academic, Social, and Emotional Learning. (2023). What Does the Research Say? Retrieved from <a href="https://casel.org/fundamentals-of-sel/what-does-the-research-say/">https://casel.org/fundamentals-of-sel/what-does-the-research-say/</a>

<sup>44</sup> American College of Obstetricians and Gynecologists. (2017, August). Opioid Use and Opioid Use Disorder in Pregnancy: Committee Opinion Number 711. Retrieved from <a href="https://www.acog.org/clinical/clinical-guidance/committee-opinion/articles/2017/08/opioid-use-and-opioid-use-disorder-in-pregnancy">https://www.acog.org/clinical/clinical-guidance/committee-opinion/articles/2017/08/opioid-use-and-opioid-use-disorder-in-pregnancy</a>

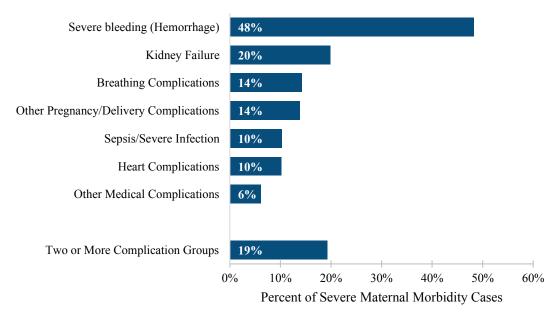
## **Severe Maternal Morbidity**

"Severe maternal morbidity" or SMM refers to a group of potentially life-threatening, unexpected maternal conditions or complications that occur during labor and delivery. Some types of severe maternal morbidity may cause long-lasting health problems that extend beyond the pregnancy. For this report, a woman was classified as having severe maternal morbidity if any of 20 types of severe complications were listed on the billing record for her delivery hospital stay. 45

During 2018-2020, an average of 1,151 women each year experienced a severe maternal morbidity during their delivery, which translates to approximately one case of severe maternal morbidity for every 115 deliveries.

Figure 13 shows the types of severe complications experienced by women with severe maternal morbidity. Of the women who experienced a severe maternal morbidity, 48.3% had a severe bleeding (hemorrhage) complication, 19.8% had kidney failure, 14.2% had breathing complications, 13.8% had other pregnancy/delivery complications, 10.3% had sepsis (a severe infection),10.2% had a heart complication, and 6.2% had other medical complications. Overall, 19.3% of women who experienced a severe maternal morbidity had medical issues in two or more of these complication categories.

Figure 13. Severe Bleeding, Kidney Failure, and Breathing Issues were the most common categories of severe maternal morbidity complications for Illinois women.

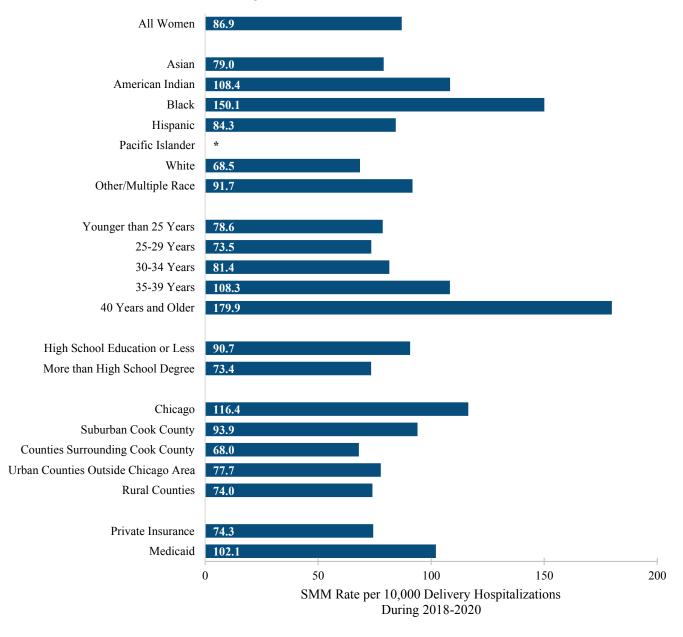


NOTE: Some women experienced more than one of the severe maternal morbidity complications, therefore the percentages in figure 13 are not mutually exclusive and add up to more than 100%.

<sup>45</sup> Since the last Maternal Morbidity and Mortality Report, the way SMM was calculated was slightly changed to align with changes to national standards, so SMM rates in this report are not comparable to past reports. For more information about how severe maternal morbidity was calculated, see Appendix D.

During 2018-2020, Illinois' severe maternal morbidity rate was 86.9 per 10,000 deliveries. Severe maternal morbidity varied significantly by race/ethnicity, age, education level, region of residence, and insurance type (Figure 14). Severe maternal morbidity was most common among women who were Black (150.1 per 10,000 births), age 40 years and older (179.9 per 10,000 births), had a high school education or less (90.7 per 10,000 births), resided in Chicago (116.4 per 10,000 births), and had Medicaid insurance (102.1 per 10,000 births). Notably, Black women had a severe maternal morbidity rate more than two times that of White women.

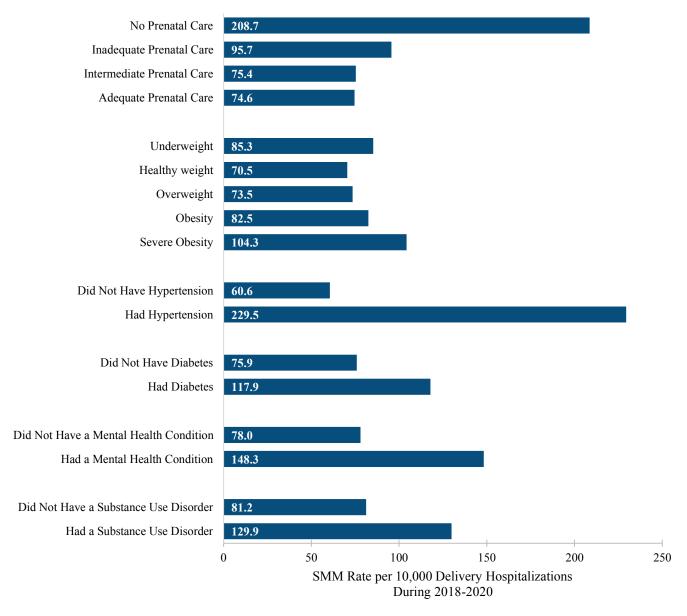
Figure 14. Severe maternal morbidity (SMM) is most common among Illinois women who are Black, age 40 years or older, have Medicaid insurance, and who live in Chicago.



<sup>\*</sup>Data were suppressed due to fewer than 10 cases of severe maternal morbidity during this time period, resulting in an unstable rate estimate.

Severe maternal morbidity during 2018-2020 also varied according to the level of prenatal care received, weight status, and whether the woman had hypertension, diabetes, mental health conditions, and substance use disorders (Figure 15). Women with no prenatal care had a severe maternal morbidity rate that was nearly three times that of women with adequate prenatal care. Women with severe obesity had the highest rate of severe maternal morbidity compared to other weight groups. Women with hypertension and diabetes had severe maternal morbidity rates that were higher than women without these conditions. Women with a mental health condition or substance use disorder recorded by the delivery hospital also had higher rates of severe maternal morbidity than women without these conditions.

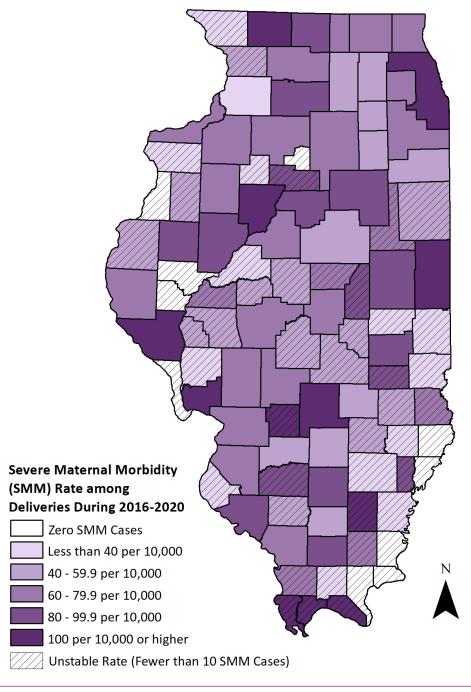
Figure 15. Severe Maternal Morbidity (SMM) rates are higher among Illinois women who get no or inadequate prenatal care, women who had severe obesity, hypertension, or diabetes, and women who had a mental health condition or substance use disorder.



To explore county differences in a rare event like severe maternal morbidity, five years of data were combined to improve statistical reliability. <sup>46</sup> During 2016-2020, 49 of Illinois' 102 counties had at least 10 cases of severe maternal morbidity to support reliable rate estimates; only these 49 counties are described below.

During 2016-2020, the severe maternal morbidity rate varied across counties (Figure 16), ranging from a low of 39.0 per 10,000 births in Whiteside County to a high of 119.8 per 10,000 births in Pike County. Seven counties had a severe maternal morbidity rate of at least 100 per 10,000 births (Cook, Fayette, Jersey, Peoria, Pike, Stephenson, and Vermilion).

Figure 16. Severe maternal morbidity varies across Illinois but has no clear geographic pattern.



<sup>46</sup> For the map in Figure 16, 2016-2020 data were combined to increase statistical reliability; note this differs from the time period (2018-2020) used for the rest of this section, including Figures 13, 14, and 15.

#### **Severe Maternal Morbidity Prevention**

Severe maternal morbidity can have long-term effects on a woman's health and future maternal health outcomes. To prevent severe pregnancy complications, women need to have access to routine preventive and reproductive health care to help them identify risks that can be mitigated before pregnancy and to help plan their pregnancies if desired. It is important for women to receive quality health care between pregnancies, including access to contraception. Pregnant women also need access to prenatal care to manage their chronic diseases, including substance use or mental health conditions. These care points are opportunities to reduce the risk of severe pregnancy complications.

# **Maternal Mortality**

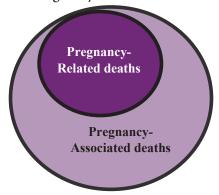
Maternal mortality is the death of a woman during or after pregnancy. Several definitions of maternal mortality are used to track and analyze deaths in different contexts, but Illinois uses the following standard definitions from the CDC:<sup>47</sup>

Pregnancy-Associated Death = The death of a woman during pregnancy or within one year of the end of a pregnancy from any cause.

Pregnancy-Related Death = The death of a woman during pregnancy or within one year of the end of a pregnancy from a pregnancy complication, a chain of events initiated by pregnancy, or the aggravation of an unrelated condition by the physiologic effects of pregnancy.

Pregnancy-related deaths are a subset of pregnancy-associated deaths (Figure 17).

Figure 17: Relationship Between Pregnancy-Associated and Pregnancy-Related Deaths.



Identifying all pregnancy-associated deaths is essential to tracking and understanding maternal mortality. Deaths are identified from a variety of public health data sources. Following identification, IDPH and the two MMRCs review the deaths to closely examine the cause of death and determine whether it was pregnancy-related. The review process then identifies factors that influenced the death and creates recommendations to prevent future deaths.

The process Illinois uses to identify pregnancy-associated deaths, collect information, and review cases was described in detail in the 2018 version of the Illinois Maternal Morbidity and Mortality Report.<sup>48</sup>

<sup>47</sup> Centers for Disease Control and Prevention (CDC). (2021, November). Maternal Mortality Review Committee Facilitation Guide. Retrieved from <a href="https://www.reviewtoaction.org/national-resource/maternal-mortality-review-committee-facilitation-guide">https://www.reviewtoaction.org/national-resource/maternal-mortality-review-committee-facilitation-guide</a>

<sup>48</sup> Illinois Department of Public Health (IDPH). (2018, October). Illinois Maternal Morbidity and Mortality Report. Retrieved from <a href="https://dph.illinois.gov/topics-services/life-stages-populations/maternal-child-family-health-services/maternal-health/mmmr.html">https://dph.illinois.gov/topics-services/life-stages-populations/maternal-child-family-health-services/maternal-health/mmmr.html</a>

## **Pregnancy-Associated Deaths**

During 2018-2020, the years included in the detailed data analyses for this report, 263 pregnancy-deaths occurred, an average of 88 pregnancy-associated deaths each year.

Figure 18 shows that since 2015, the annual number of pregnancy-associated deaths among women have ranged from 70 (in 2019) to 116 (in 2021- preliminary data only).



Figure 18: An average of 88 pregnancy-associated deaths occurred each year during 2018-2020.

 $*preliminary\ data,\ subject\ to\ change\ after\ final\ MMRC\ review$ 

Some national studies using different data sources have suggested increases in maternal mortality during the COVID-19 pandemic. 49,50 An analysis of Illinois' preliminary pregnancy-associated deaths data also suggests increases during 2020-2022. During the five years prior to the pandemic (2015-2019), there was an average of 84 pregnancy-associated deaths each year. Figure 18 also shows that during 2020-2022, the number of pregnancy-associated deaths was well above this average, particularly for 2020 and 2021. According to death certificate information, most of the increase in pregnancy-associated deaths during these years appears to be related to higher numbers of medical deaths among Black residents of Chicago and overdose deaths for both Black and White women throughout the state. The provisional data also suggest that pregnancy-associated deaths in 2022 were lower than in 2020-2021, a positive sign that the number of deaths may decline as the effects of the pandemic wane.

Future reports will combine the final 2020-2022 data and be better suited to look for changes in maternal mortality outcomes related to the COVID-19 pandemic.

<sup>49</sup> Thoma, M. E., & Declercq, E. R. (2022). All-Cause Maternal Mortality in the US Before vs During the COVID-19 Pandemic. *JAMA Network Open*, 5(6), e2219133. https://doi.org/10.1001/jamanetworkopen.2022.19133

<sup>50</sup> United States Government Accountability Office. (2022, October). Maternal Health: Outcomes Worsened and Disparities Persisted During the Pandemic. Retrieved from <a href="https://www.gao.gov/products/gao-23-105871">https://www.gao.gov/products/gao-23-105871</a>

### Reviewing and Assessing Maternal Deaths

The CDC recommends a review of pregnancy-associated deaths by a multidisciplinary committee to gather additional information about how the woman died, whether the death was pregnancy-related, whether the death was preventable, and how to prevent future deaths. Illinois has two statewide committees that review maternal deaths. To ensure consistency, both committees have the same purpose, vision, and chairperson.

	Maternal Mortality Review Committee (MMRC)	Maternal Mortality Review Committee for Violent Deaths (MMRC-V)		
History	Began in 2001	Began in 2015		
Scope*	Pregnancy-associated deaths from medical conditions that are potentially related to pregnancy.	Pregnancy-associated deaths due to homicide, suicide, unintentional drug overdose, or other drug-related conditions.		
Example	Postpartum bleeding	Substance use disorder		
Causes of	High blood pressure	Postpartum mood disorders		
Death	Complications of asthma during pregnancy	Depression		
	Infection	Intimate partner violence		
Vision	Eliminate preventable pregnancy-related deaths in Illinois			
Purpose	Determine contributing factors to maternal mortality and identify potential interventions to prevent future maternal deaths			
*Deaths that do not fall within the scope of the committee reviews (i.e., deaths related to cancer or motor vehicle crashes) are still counted as pregnancy-associated deaths but are reviewed internally by IDPH and confirmed to be not related to pregnancy.				

More information on how IDPH has implemented national best practices within the committees, including how cases are identified,

data is collected, and how the case abstracts are created for review, is available in the 2021 version of the I*llinois Maternal Morbidity* and Mortality Report.<sup>51</sup>

To guide the case review discussion, both MMRC and MMRC-V use a standardized data collection form developed by the CDC called the "Committee Decision Form." This form walks the committees through key questions about each death, including the following:

- 1. What was the cause of death?
- 2. Was the death related to pregnancy?
- 3. Was the death potentially preventable?

If the death is related to pregnancy and preventable, the committees address:

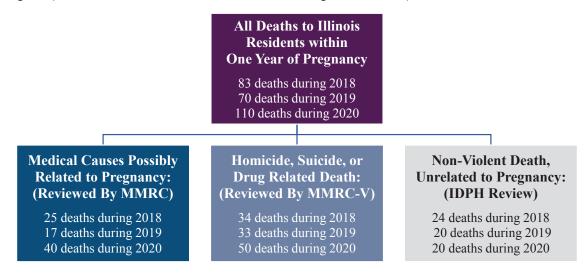
- 4. What factors contributed to the death?
- 5. What recommendations could be implemented to prevent future deaths?

The Illinois MMRC and MMRC-V completed the reviews of the 2018-2020 pregnancy-associated deaths between October 2020 and March 2023. Of the 263 pregnancy-associated deaths to Illinois residents during this time frame, 199 deaths were reviewed, 82 by the MMRC and 117 by the MMRC-V (Figure 19). The remaining 64 pregnancy-associated deaths were reviewed internally by IDPH because they were due to non-violent causes unrelated to pregnancy.

<sup>51</sup> Illinois Department of Public Health (IDPH). (2018, October). *Illinois Maternal Morbidity and Mortality Report*. Retrieved from <a href="https://dph.illinois.gov/topics-services/life-stages-populations/maternal-child-family-health-services/maternal-health/mmmr.html">https://dph.illinois.gov/topics-services/life-stages-populations/maternal-child-family-health-services/maternal-health/mmmr.html</a>

<sup>52</sup> Centers for Disease Control and Prevention (CDC). (2022). Maternal Mortality Review Committee Decisions Form. Retrieved from <a href="https://reviewtoaction.org/national-resource/mmria-committee-decisions-form-and-additional-guidance">https://reviewtoaction.org/national-resource/mmria-committee-decisions-form-and-additional-guidance</a>

Figure 19. Pregnancy-Associated Deaths to Illinois Residents during 2018-2020, by Review Committee.



The next section of this report presents data from reviews for pregnancy-related deaths of women that occurred during 2018-2020. This builds upon the data presented in the first two state reports by presenting the most recent years of data and expanding upon the themes identified in these past reports. The three-year combined estimates provide larger case counts and improve the reliability of the statistical analyses, allowing this report to present a more detailed analysis of issues related to racial inequities and causes of death.

The "pregnancy-related mortality ratio" (PRMR) is reported throughout this section to compare how frequently pregnancy-related deaths occur. The PRMR is interpreted as the number of deaths that occurred for every 100,000 live births within a specific group of women. Because it standardizes the population size, the PRMR is the preferred way to compare likelihood of death for different groups (instead of using case counts).

The reviews of 2021-2022 deaths have not yet been completed by the MMRCs, so it is not known how many deaths during these years were pregnancy-related. As the MMRCs review the 2021-2022 maternal deaths, they will be able to determine the specific factors that contributed to deaths during the pandemic, including both the direct effects of SARS-CoV-2 infection and the indirect effects of the COVID-19 pandemic on maternal health.<sup>53</sup>

It will remain critically important to discuss the social determinants of health that impacted each woman's death, such as access to care, finances, employment, and social support, and how these factors were affected by the societal changes brought on by the pandemic. Understanding the broad reaching effects of the pandemic on maternal health will help systems better prepare for future public health emergencies.

<sup>53</sup> Metz, T. D., Collier, C., & Hollier, L. M. (2020). Maternal Mortality from Coronavirus Disease 2019 (COVID-19) in the United States. Obstetrics and Gynecology, 136(2), 313–316. https://doi.org/10.1097/AOG.00000000000004024

# **Pregnancy-Related Deaths**

Pregnancy-related deaths are deaths where the MMRCs determined that the cause of death was related to the pregnancy. The MMRCs have used the same standardized approach and definitions to review deaths since the 2015 death reviews, allowing this report to compare data back to 2015.

Figure 20 shows the number of pregnancy-related deaths identified by the MMRCs each year from 2015-2020. The number of pregnancy-related deaths each year ranged from a low of 22 in 2016 to a high of 52 in 2020.

60 Focus of Past Reports Focus of This Report 50 40 30 20 10 26 37 52 38 2015 2016 2017 2018 2019 2020 Year

Figure 20: Number of Pregnancy-Related Deaths, Illinois 2015-2020.

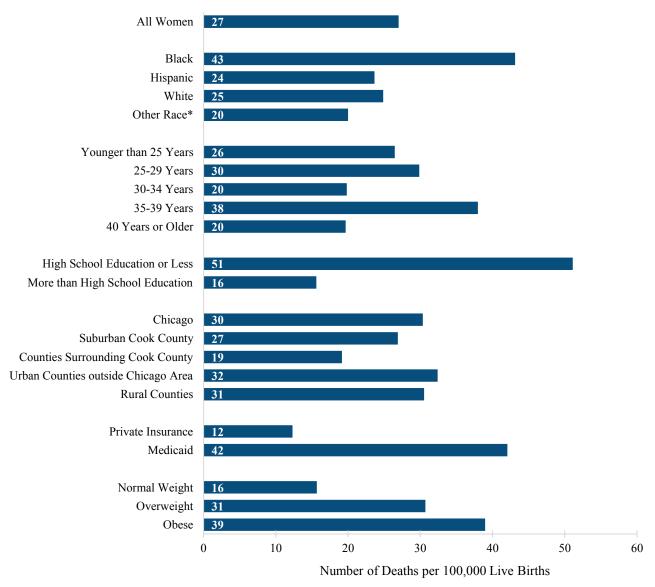
### Pregnancy-Related Deaths During 2018-2020

Of all pregnancy-associated deaths during 2018-2020, 43% (or 113 deaths) were determined to be pregnancy-related. This translates to 27 pregnancy-related deaths for every 100,000 live births among Illinois residents.

Pregnancy-related mortality is not equally experienced by all groups of women. Figure 21 shows the pregnancy-related mortality ratios for residents during 2018-2020 according to different demographic characteristics. There were substantial differences in pregnancy-related mortality based on race/ethnicity, age, education level, location of residence, insurance type, and body mass index (BMI).

- Black women were nearly twice as likely as White women to die from a pregnancy-related cause.
- Pregnancy-related mortality increased with age, with women 35-39 years old being 46% more likely to die from a pregnancy-related cause than women younger than 25 years old.
- Women with a high school education or less were more likely to die from a pregnancy-related cause than women with more than a high school education.
- Pregnancy-related mortality was lowest for counties surrounding Cook County (Lake, Kane, DuPage, and Will County) and
  the highest for residents of urban counties outside Chicago and rural counties.
- Women on Medicaid during pregnancy were over three times as likely to die from a pregnancy-related cause as women with private insurance.
- Obese women had a higher pregnancy-related mortality than normal weight and overweight women.

Figure 21. Pregnancy-related mortality among Illinois residents during 2018-2020 is most common among Illinois women who are Black, age 35-39, have a high school education or less, have Medicaid insurance, and who are obese.



\*Other races could not be reported separately due to small sample size (fewer than 5 deaths for group)

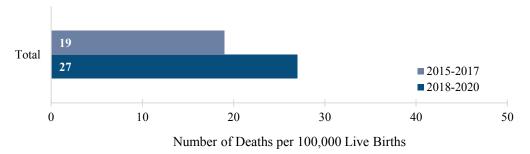
**Data interpretation example:** The bar on the chart referring to Chicago women means that for every 100,000 births among Chicago residents, 30 Chicago women experienced a pregnancy-related death.

### Changes to Pregnancy-Related Mortality Over Time

The three most recent years of data (2018-2020) were compared to the prior three-year period (2015-2017) to identify how pregnancy-related mortality has changed over time.

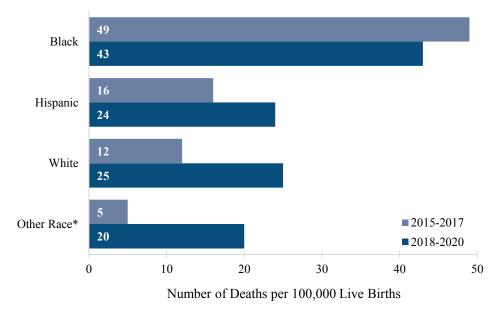
Pregnancy-related deaths significantly increased from 19 per 100,000 live births in 2015-2017 to 27 deaths per 100,000 live births in 2018-2020 (Figure 22).

Figure 22. Pregnancy-related mortality in Illinois was higher in 2018-2020 than in 2015-2017.



Pregnancy-related mortality varies by race/ethnicity and trends over time have not been the same for all racial groups (Figure 23). In 2018-2020, Black women continued to have the highest pregnancy-related mortality ratio compared to all other racial/ethnic groups, even though Black women experienced a slight decline in pregnancy-related mortality compared to 2015-2017. Hispanic, White, and other race women had similar pregnancy-related mortality ratios to each other in 2018-2020, but these three racial groups all experienced increases in pregnancy-related mortality compared to 2015-2017.

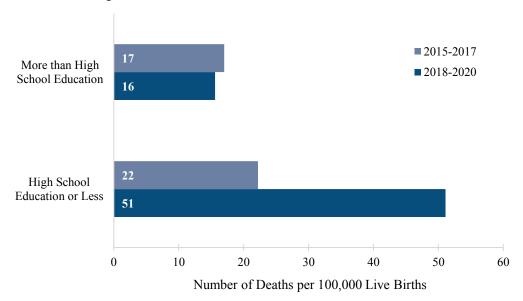
Figure 23. Pregnancy-related mortality in Illinois remains the highest for Black women, despite a decrease in recent years.



\*Other races could not be reported separately due to small sample size (fewer than 5 deaths for group)

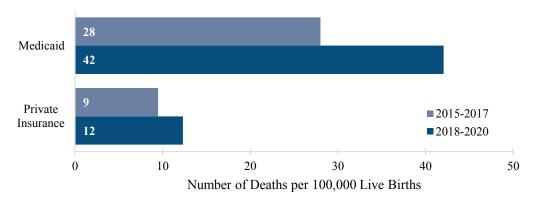
Women with a high school education or less experience a higher level of pregnancy-related death than women with more than a high school education, but these differences were exacerbated in 2018-2020 (Figure 24). When comparing 2015-2017 to 2018-2020, pregnancy-related deaths for women with a high school education or less more than doubled, but there was no substantial change for women with more than a high school education.

Figure 24. Pregnancy-related mortality more than doubled among women with lower education levels, but did not change among women with more than a high school education.



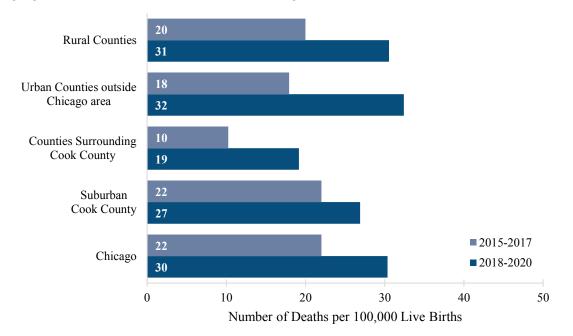
Women with Medicaid insurance experience a higher level of pregnancy-related death compared to women with private insurance and this inequity widened during 2018-2020 (Figure 25). When comparing 2015-2017 to 2018-2020, pregnancy-related deaths for women with Medicaid increased by about 50% while there was only a slight increase for women with private insurance.

Figure 25. Pregnancy-related mortality increased among women on Medicaid, but did not significantly change for women with private insurance.



When comparing 2015-2017 to 2018-2020, pregnancy-related mortality increased across all geographic regions (Figure 26). Because pregnancy-related death is a rare health outcome, individual county-level data cannot be reported and are instead reporting based on groups of counties. Urban counties outside of the Chicago area experienced the highest pregnancy-related mortality ratio during 2018-2020 and a large increase in pregnancy-related deaths from 2015-2017 to 2018-2020 (18 to 32 deaths per 100,000 live births). Counties surrounding Cook County also experienced a large increase from 10 to 19 deaths per 100,000 live births from 2015-2017 to 2018-2020.

Figure 26. All geographic areas in Illinois had an increase in pregnancy-related death between 2015-2017 and 2018-2020.



### Causes of Pregnancy-Related Deaths

To better understand pregnancy-related deaths, the MMRC evaluates the underlying cause of death, which is defined as the event that started the chain of events that led to the death. More information about how we classified categories of underlying cause of death is available in Appendix D.

Table 1 shows the top categories of the underlying causes of pregnancy-related death during 2018-2020. The most common underlying cause of pregnancy-related deaths was substance use disorder, which caused 36 deaths over the three-year period. The next most common causes of pregnancy-related deaths over the three-year period were cardiac and coronary conditions, pre-existing chronic medical conditions, sepsis, and mental health conditions resulting in suicide.

Table 1. Substance use disorder was the leading cause of pregnancy-related death in Illinois during 2018-2020.

Cause of Death Category	Number of Pregnancy-Related Deaths	Percent of Pregnancy- Related Deaths
Substance Use Disorder	36	32%
Cardiac and Coronary Conditions	16	14%
Pre-existing Chronic Medical Condition*	13	12%
Sepsis (blood stream infection)	10	9%
Mental Health Conditions resulting in suicide**	9	8%
Thrombotic Embolism (blood clot)	8	7%
Hemorrhage (postpartum bleeding)	6	5%
Cardiomyopathy (heart muscle disease)	5	4%
COVID-19	4	3%
Homicide	2	2%
Amniotic Fluid Embolism	2	2%
Hypertensive Disorder of Pregnancy	1	1%
Stroke	1	1%

<sup>\*</sup> These deaths were related to health conditions that women were known to have prior to pregnancy, including autoimmune disease, sickle cell disease, diabetes, connective tissue disease, seizure disorder, lupus, liver disease, and end-stage renal disease. These deaths are included as "non-cardiovascular deaths" by the CDC PMSS.

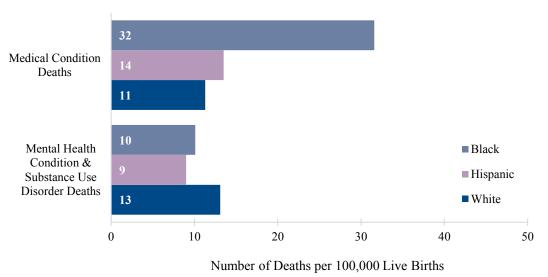
<sup>\*\*</sup> Includes deaths due to depression, schizophrenia, and bipolar disorder.

To compare the factors influencing different causes of death, deaths were combined into two groups: 1) mental health conditions and substance use disorders and 2) all medical conditions. Other injury deaths (homicides) are not included in the comparisons that follow because there were fewer than four during 2018-2020.

For all pregnancy-related deaths during 2018-2020, 58% were caused by medical conditions and 40% were caused by mental health conditions and substance use disorders. The pregnancy-related mortality ratio for medical conditions was 16 deaths per 100,000 births. The pregnancy-related mortality ratio for mental health conditions and substance use disorders was 11 deaths per 100,000 births.

When splitting pregnancy-related deaths by cause of death, the racial/ethnic patterns become more striking than the overall PRMR indicates (Figure 27). For medical causes of death, Black women had a pregnancy-related mortality ratio nearly three times that of White women. In contrast, for mental health conditions and substance use disorders, all racial/ethnic groups had similar pregnancy-related mortality ratios.

Figure 27. Black women are more likely to experience pregnancy-related death due to a medical condition while all racial groups have similar ratios of pregnancy-related deaths from mental health conditions and substance use disorders.

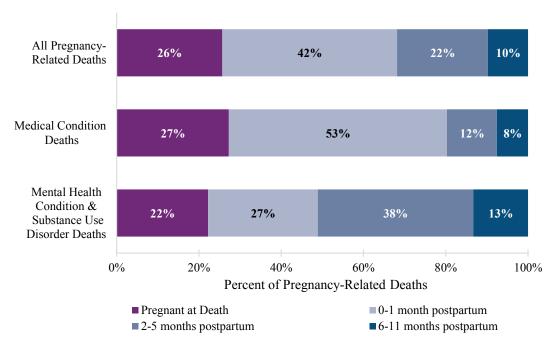


### Timing of Pregnancy-Related Deaths

Of the 113 pregnancy-related deaths that occurred during 2018-2020, 26% occurred during pregnancy, 42% occurred less than two months postpartum, 22% occurred 2-5 months postpartum, and 10% occurred 6-11 months postpartum (Figure 28). These data demonstrate the value of tracking maternal deaths to one year postpartum, as approximately one-third of pregnancy-related deaths occurred two or more months after pregnancy.

Timing of death varies by type of pregnancy-related death (Figure 28). Pregnancy-related deaths from medical causes were most likely to occur during the first two months postpartum while pregnancy-related deaths from mental health conditions and substance use disorders were most likely to occur two or more months postpartum. Of deaths due to medical conditions, 27% occurred while women were pregnant, 53% occurred less than two months postpartum, 12% occurred 2-5 months postpartum, and 8% occurred 6-11 months postpartum. Of deaths due to mental health conditions, including substance use disorder, 22% occurred to women while they were pregnant, 27% occurred less than two months postpartum, 38% occurred 2-5 months postpartum, and 13% occurred 6-11 months postpartum.

Figure 28. Timing of pregnancy-related deaths differs by cause of death, with medical deaths occurring close to pregnancy.



### Preventability of Pregnancy-Related Deaths

After discussion of the cause of death for pregnancy-related deaths, the MMRCs determine whether the death was potentially preventable. Deaths are considered "preventable" if reasonable changes to any provider, facility, patient, community, or system factors may have helped prevent the death. The definition of preventability is not limited to clinical factors, but also considers the social and community factors influencing the death.

It is important to recognize that among these "preventable" deaths, the chance of preventing that death can range from a "very good chance" to "slight chance." The number and types of factors that contribute to each case greatly influence the chance of preventability.

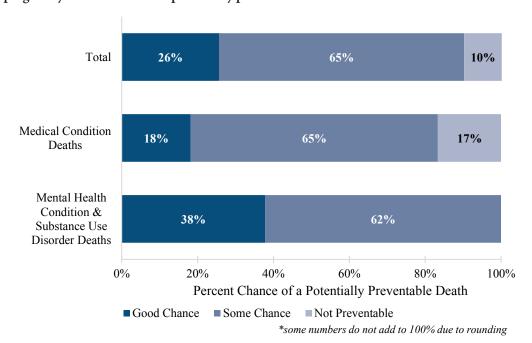
For example, a death where the hospital did not have enough blood available to treat a hemorrhage might have a "good chance" of being prevented because it was one specific protocol change that would have altered the outcome. On the other hand, the death of a woman with a complicated medical condition who was receiving treatment, but did not receive a referral to a specialist, might have had a "slight chance" of being prevented because she might have died even with that referral. However, all preventable deaths have at least one issue that the MMRCs identified as a potential way to change the course of the woman's health outcome.

Deaths that are deemed "not preventable" had no reasonable factors identified that could have changed the sequence of events or medical condition that led to the death. An example of a death that was "not preventable" is a woman who suffers from a sudden, severe brain bleed during pregnancy but had no known risk factors that would have reasonably led preventative treatment for this condition prior to its occurrence.

For pregnancy-related deaths, the MMRCs determined there was at least "some chance" of the death being prevented for 65% of the deaths and "good chance" of being prevented for 26% of all pregnancy-related deaths (Figure 29). The preventability of pregnancy-related deaths was similar across racial/ethnic groups.

The preventability of pregnancy-related deaths differed across cause of death. For pregnancy-related deaths due to medical conditions, about 4 of 5 were potentially preventable but only 1 of 5 had a "good chance" of being prevented. However, for pregnancy-related deaths due to mental health conditions and substance use disorders, all were potentially preventable, and 2 of 5 had a "good chance" of being prevented.





### Discrimination as a Contributing Factor to Pregnancy-Related Deaths

Discrimination can be a contributing factor to poor maternal health outcomes, including pregnancy-related deaths, by creating barriers to health care and negatively influencing health status. Understanding how discrimination influences a woman's ability to have a healthy pregnancy can promote equitable outcomes for all women. Pregnancy-related death is a complex problem, and recognizing the impact of discrimination and working to address and eliminate discrimination is essential to achieving health equity.

For every pregnancy-related death, the MMRCs discuss and determine whether discrimination was a contributing factor. Discrimination, according to the CDC definition for MMRCs, <sup>54</sup> can include any of the following:

**Discrimination:** Treating someone less or more favorably based on the group, class, or category they belong to resulting from biases, prejudices, and stereotyping. It can manifest as differences in care, clinical communication, and shared decision-making. <sup>SS</sup>

- The Illinois MMRCs identified discrimination based on race, language, weight status, and substance use disorder status as a contributing factor in deaths during 2018-2020.
- Examples of discrimination in pregnancy-related deaths include:
  - Blaming language about the patient in the medical chart, such as "frequent flier" or "non-compliant."
  - Minimizing patient complaints and consistent lack of action by providers to appropriately evaluate, treat, or refer patient to necessary health care due to their substance use disorder.

**Interpersonal racism:** Discriminatory interactions between individuals based on differential assumptions about the abilities, motives, and intentions of others, and resulting in differential actions toward others based on their race. It can be conscious as well as unconscious.<sup>56</sup>

The Illinois MMRCs did not identify interpersonal racism as a contributing factor in deaths during 2018-2020. This may be
due to the difficulty detecting specific, blatant references in the types of records available to the MMRCs. This finding might
not reflect lived experience of the women who died.<sup>57</sup>

**Structural racism:** The systems of power based on historical injustices and contemporary social factors that systematically disadvantage people of color and advantage White people through inequities in housing, education, employment, earnings, benefits, credit, media, health care, criminal justice, etc.<sup>58</sup>

- The Illinois MMRCs identified structural racism related to community indicators, such as a lack of health care providers, violent crime, unstable housing, lack of transportation, and high poverty.
- The information provided by the Community Vital Signs Dashboard, first made available in 2018 for all maternal mortality reviews nationally, has been critical for discussions about structural racism. (For more information, see the section entitled *Community Context in Pregnancy-Related Deaths* on page 53).
- Examples of structural racism in pregnancy-related deaths include:
  - Inability to access needed health care in a timely manner.
  - Systems of care and services not available in languages other than English.
  - Community has high level of racial segregation, crime, and poverty.

<sup>54</sup> Hardeman, R. R., Kheyfets, A., Mantha, A. B., et al. (2022). Developing Tools to Report Racism in Maternal Health for the CDC Maternal Mortality Review Information Application (MMRIA): Findings from the MMRIA Racism & Discrimination Working Group. Maternal and Child Health Journal, 26(4), 661–669. https://doi.org/10.1007/s10995-021-03284-3

<sup>55</sup> Institute of Medicine (US) Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care, Smedley, B. D., Stith, A. Y., & Nelson, A. R. (Eds.). (2003). Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care. National Academies Press (US).

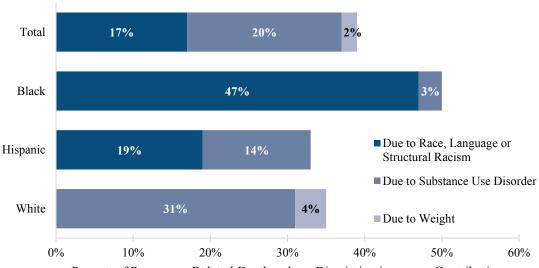
<sup>56</sup> Jones C. P. (2000). Levels of racism: a theoretic framework and a gardener's tale. *American Journal of Public Health*, 90(8), 1212–1215. https://doi.org/10.2105/ajph.90.8.1212

<sup>57</sup> Mohamoud YA, Cassidy E, Fuchs E, et al. Vital Signs: Maternity Care Experiences — United States, April 2023. MMWR Morb Mortal Wkly Rep 2023;72:961–967. DOI: http://dx.doi.org/10.15585/mmwr.mm7235e1

<sup>58</sup> Bailey, Z. D., Krieger, N., Agénor, M., et al. (2017). Structural racism and health inequities in the USA: evidence and interventions. *Lancet (London, England)*, 389(10077), 1453–1463. https://doi.org/10.1016/S0140-6736(17)30569-X

Overall, discrimination, including structural racism, contributed to 39% of pregnancy-related deaths during 2018-2020 (Figure 30). Discrimination was more likely to be a contributing factor to pregnancy-related deaths among Black women (50%) than among White women (35%) and Hispanic women (33%), and the types of discrimination contributing to the death varied across groups. Among Black women, 47% experienced discrimination due to race, language, or structural racism and 3% experienced discrimination due to substance use. Among Hispanic women, 19% experienced discrimination due to race/ethnicity, language, or structural racism, and 14% experienced discrimination due to substance use. Among White women, 31% experienced discrimination due to substance use disorder and 4% experienced discrimination due to weight status.

Figure 30. Discrimination was more likely to be a contributing factor to pregnancy-related deaths among Black women than among other races.



Percent of Pregnancy-Related Deaths where Discrimination was a Contributing Factor

### Past Trauma for Women Experiencing Pregnancy-Related Deaths

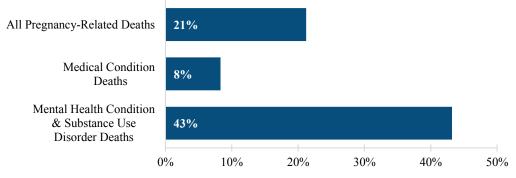
A traumatic event is defined by the National Institute of Mental Health as a shocking, scary, or dangerous experience that can affect someone emotionally and physically. Traumatic events can include violence, such as sexual, physical, or emotional abuse. These events can manifest in acute and chronic health conditions affecting one's mental and physical health.

The MMRCs review information on the history of past trauma when it is available in the records for maternal deaths. Identifying past trauma is the first step in better understanding the entirety of events leading to the death. Data limitations, including a lack of screening and hesitancy to disclose information to a provider, may lead to an underreporting of past events. Trauma was present if any reviewed records noted a history of adverse childhood events, abuse (sexual, physical, or emotional), human trafficking, or other events described as traumatic.

Based on the records available during review of 2018-2020 pregnancy-related deaths, about 1 in 5, experienced a traumatic event (Figure 31). Almost half of women who had a pregnancy-related death due to mental health conditions and substance use disorder experienced trauma.

In general, health care providers do not routinely screen for trauma. For example, there are inconsistent practices in documenting and screening for intimate partner violence even though it has been recommended since 2018 by the U. S. Preventive Services Task Force. On the other hand, some facilities and providers did document specific past events, such as childhood abuse, and worked to support their patient in getting needed help. It is important for providers to be informed about how past trauma can influence their patients' ongoing physical and mental health. The MMRCs have made recommendations focused on trauma-informed care, identifying social determinants of heath, and connecting women to needed resources.

Figure 31. About 1 in 5 women who experienced a pregnancy-related death had past trauma in their life, and past trauma was more common for women who experienced a death due to mental health conditions and substance use disorder.



Percent of Pregnancy-Related Deaths who experienced trauma in their life

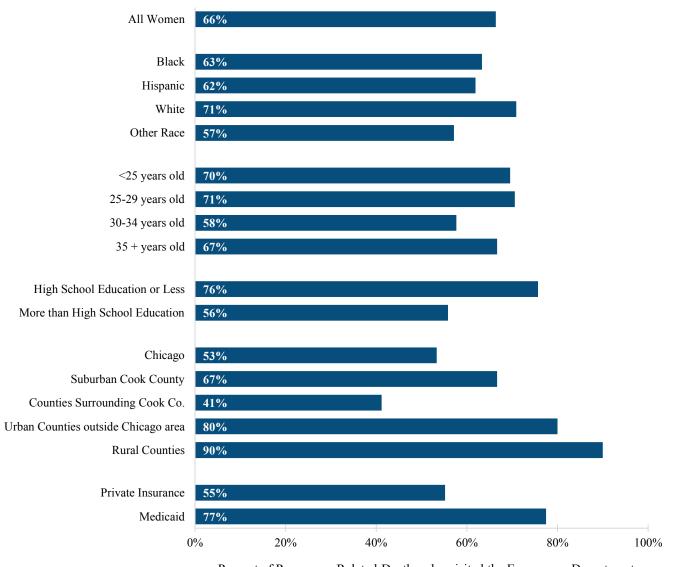
<sup>59</sup> National institute of Mental Health. (2023, May). Coping with Traumatic Events. U.S. Department of Health and Human Services. Retrieved from <a href="https://www.nimh.nih.gov/health/topics/coping-with-traumatic-events">https://www.nimh.nih.gov/health/topics/coping-with-traumatic-events</a>

### **Emergency Department Use Among Pregnancy-Related Deaths**

During the reviews of pregnancy-related deaths, the MMRCs recognized a common pattern of hospital emergency department use. Visits to the emergency department were sometimes for urgent issues, but also included visits for mental health care, substance use treatment, primary care issues, and prenatal care.

Among the pregnancy-related deaths during 2018-2020, 2 out of 3 women visited the emergency department at least once during pregnancy or postpartum, not including the death event (Figure 32). While this seems high, equivalent data for women who did not experience a pregnancy-related death are not available, so it is not known if emergency department visits were more common among the deaths than among all pregnant/postpartum women. Emergency department visits were most common among the pregnancy-related deaths of White women, women under the age of 30, women with a high school education or less, women residing in rural counties, and women with Medicaid insurance. The strongest variation in emergency department use was by geography; 90% of pregnancy-related deaths for rural county residents had an emergency department visit during pregnancy or postpartum, compared to 53% of pregnancy-related deaths for Chicago residents.

Figure 32. Emergency department use was common among pregnancy-related deaths and was most common among deaths to women who were White, under the age of 30, had a high school education or less, lived in rural counties and had Medicaid insurance.



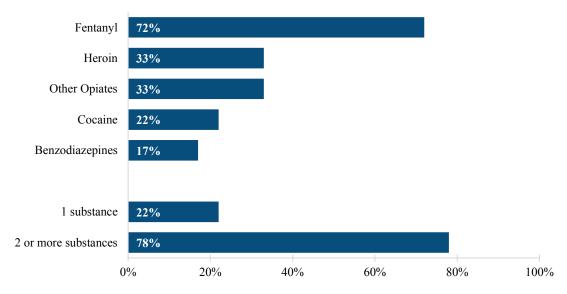
Percent of Pregnancy-Related Deaths who visited the Emergency Department

The MMRCs have made recommendations focused on how the emergency department can help identify and connect women to necessary care. Collaboration with emergency departments will support effective implementation and hopefully lead to women connecting with ongoing care and reduce the need to visit the emergency department for non-emergency issues.

### Pregnancy-Related Deaths Related Due to Substance Use Disorder

For substance use disorder deaths, toxicology tests during an autopsy are used to determine the substances involved. For 46 out of the 50 drug overdose tests, toxicology results were available to the MMRC-V and a summary of the most common substances involved in the deaths is shown in Figure 33. The most common substances found in toxicology were fentanyl (72%), heroin (33%), other opiates (33%), cocaine (22%), and benzodiazepines (17%). These groups are not mutually exclusive since multiple substances were often found in toxicology results. Among the pregnancy-related deaths due to substance use disorder, 78% had two or more substance types involved in the death. Any opiate (fentanyl, heroin, and other) in combination with benzodiazepines was the most common combination of two or more substances among these deaths. The high prevalence of polysubstance use highlights the need to improve education related to drug interactions.

Figure 33. Most pregnancy-related deaths due to substance use disorder involved opioids, specifically fentanyl, and were due to two or more substances.



Percent of Maternal Deaths due to Substance Use Disorder

### Community Context in Pregnancy-Related Deaths

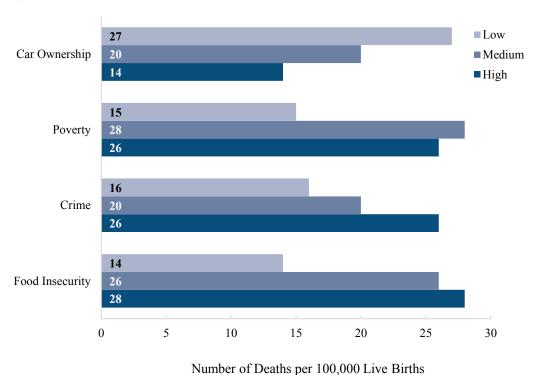
Since starting to review the 2018 deaths, the MMRCs have included a "community vital signs dashboard" for all reviews. These dashboards, developed by Emory University in partnership with the CDC, provide county- and neighborhood-level data on various social determinants of health. <sup>60,61</sup> The dashboards provide information based on the woman's last known address, giving insight into the community context in which she lived, worked, and accessed health care. This information helps the MMRCs deepen their discussion around social determinants of health and community-level factors contributing to the death.

At the population level, understanding how community context is related to maternal mortality can help identify vulnerable communities for public health interventions. Because maternal death is a rare health outcome, individual county-level data on pregnancy-related mortality cannot be examined. However, geographies that have similar characteristics can be grouped to assess how that characteristic is related to pregnancy-related mortality.

To analyze community context, four key county-level indicators from the community vital signs dashboards were selected and counties were sorted into three levels (low, medium, high) for each of the indicators. The PRMR within these groups of counties was then compared (see Appendix D for more methods details.).

Figure 34 shows that county-level car ownership, poverty, crime, and food insecurity were all associated with pregnancy-related mortality. Counties with the lowest rates of car ownership had higher PRMRs than counties with higher rates of car ownership. Counties with high rates of poverty, crime, and food insecurity had higher PRMRs than counties with low rates of those indicators. Counties with medium rates of poverty and food insecurity had similar PRMR to counties with high rates of those indicators.

Figure 34. Counties with high food insecurity, crime, poverty, and low car ownership have higher pregnancy-related mortality ratios, Illinois 2015-2020.



<sup>60</sup> Kramer, M. R., Strahan, A. E., Preslar, J., et al. (2019). Changing the conversation: applying a health equity framework to maternal mortality reviews. American Journal of Obstetrics and Gynecology, 221(6), 609.e1–609.e9. <a href="https://doi.org/10.1016/j.ajog.2019.08.057">https://doi.org/10.1016/j.ajog.2019.08.057</a>

<sup>61</sup> Emory University. (2023). ERASE-MM Community Vital Signs Project. Retrieved from https://www.erase-mm-cvsproject.org/

These data are a step towards understanding the relationship of community context and maternal mortality. The data in this section are not based on individual-experiences of the social determinants of health, but on the environment where the woman lived at the time of her death. While an individual's issues of car ownership, poverty, crime, and food insecurity can contribute to her maternal death, the community data here focus on collective experiences and show how maternal deaths are not randomly occurring throughout the state. Instead, there are patterns of experiences that influence which communities are most prone to the tragedy of pregnancy-related mortality. Identifying communities with high levels of poverty, high levels of food insecurity, high crime, and low car ownership could offer a way to geographically focus maternal mortality prevention efforts.

# **Examples of Maternal Deaths**

The following section includes five real examples of Illinois women who died during 2018-2020 while pregnant or within a year of pregnancy. Although names have been changed and details have been omitted to respect the privacy of the woman and her family, these summaries stay true to the main events of each death.

Each example led to rich discussion during the MMRC meetings and important lessons were learned from each woman's death. These examples represent major themes that were identified across reviewed deaths. The examples were selected to illustrate many different factors that could be addressed to prevent maternal mortality.

#### Anne's Story

Anne was a White woman in her 30s with a history of substance use disorder. She was on methadone for her substance use disorder for several years until she moved to Illinois from another state during her first trimester. She started prenatal care in Illinois during her second trimester and during one visit was given information to contact nearby substance use treatment facilities. Throughout the rest of her pregnancy, the prenatal care provider did not have any further discussions with her about substance use treatment. During her third trimester, she had a positive urine drug screening, but no treatment information was provided. After delivery, she had another positive urine drug test, and her baby was taken into Illinois Department of Children and Family Services (DCFS) care. At discharge from her delivery hospitalization, Anne was not connected with any substance use disorder treatment or recovery services. In the weeks that followed, Anne had multiple emergency department visits for heart problems where she disclosed substance use but did not receive referrals to substance use treatment or outpatient cardiology. Two months after delivery, she passed away from heart failure related to her substance use.

### What can we learn from Anne's death?

Lack of proper coordination into substance use disorder treatment programs for pregnant and postpartum women continues to be an issue for Illinois women. Anne disclosed her substance use to providers in many different health care settings, including during multiple emergency department visits, but did not receive a warm handoff to treatment or recovery services. Community-based support services are beneficial for women with substance use disorder to ensure they receive necessary referrals and care coordination to specialty providers. Clinical professionals interacting with women during pregnancy should have knowledge of community-based resources and support connecting patients to them.

### Tasha's Story

Tasha was a Black woman in her late teens. She entered prenatal care early in her pregnancy and had the recommended number of prenatal care visits at a community health center. Late in her second trimester, she went to the emergency department for chest pain where the providers prioritized a urine drug test (which was negative), and she was discharged home with no specific diagnosis or treatment. About two months later, she again went to the hospital with chest pain and shortness of breath. She was again tested for drugs without a specific basis for doing so. After further testing, she was diagnosed with a heart condition and had an emergency cesarean section. She went home from the delivery hospital with heart medications and was told to follow-up with cardiology in 3 to 5 days for her heart condition, but the hospital did not make her a follow-up appointment directly. She attended a postpartum visit one week after delivery and was told to follow-up with cardiology, without assistance making an appointment. Three weeks after delivery, she went to the emergency department with chest pain and shortness of breath. The emergency department did not ask if she had recently been pregnant. This time, she was discharged home with a cardiology appointment scheduled for the next month. One week later, around one month postpartum, she went to the same emergency department with the same complaints, then quickly became unresponsive and died from cardiomyopathy.

### What can we learn from Tasha's death?

On multiple occasions in the emergency department, Tasha received a urine drug test without a reason for this test, indicating potential discrimination due to her race and young age. Providers may not have intentionally treated her differently or unfairly, but implicit bias can affect patient care. In clinical settings, there are many opportunities to provide equitable and respectful care to all patients. Hospitals can improve bias training for providers, evaluate policies and procedures, and gather feedback from patients to improve respectful care practices. There were also multiple missed opportunities to connect Tasha to the specialty care she needed, both in the emergency room and after her delivery. When a pregnant or postpartum woman is diagnosed with a serious medical condition, she should be directly

connected to the specialists she needs, rather than putting the burden of follow-up on the patient. Tasha would have benefited from patient navigation support to ensure she attended a cardiology appointment as soon as possible. Finally, emergency departments should have a policy in place to ask women about whether they have recently been pregnant, because a recent pregnancy can increase the risk of severe complications, such as cardiac disease. If the emergency department had recognized Tasha's recent pregnancy when evaluating her symptoms, they may have ensured more urgent follow-up with a cardiologist.

#### Valerie's Story

Valerie was a White woman in her 20s from a rural community. She had a history of depression but started experiencing hallucinations very early in her pregnancy. She started prenatal care in her first trimester and saw a psychiatrist throughout pregnancy. She was on several psychiatric medications during pregnancy, but she continued to hallucinate and have suicidal thoughts. After she gave birth, her medications were changed to be safe for breastfeeding. When Valerie was discharged from the hospital, she was told to not be alone with the infant and to follow up with a psychiatrist but did not receive active follow-up or care coordination. About a week after delivery, she had an early postpartum visit with her obstetrician and said she felt about the same as during delivery. No further psychiatric follow-up was discussed at this postpartum appointment. Within a few days, she went to the emergency department with worsening suicidal thoughts. She was transferred to an inpatient facility for about two weeks, then discharged home with new medications that may not have been appropriate for her psychotic symptoms. She was scheduled for a medication management follow-up appointment in more than one week. However, before this appointment date, she died by suicide at approximately one month postpartum.

#### What can we learn from Valerie's death?

It is important that women with mental health disorders receive ongoing appropriate medications and are directly connected to mental health services. While Valerie received some ongoing psychiatric care, her psychosis symptoms were not well controlled. Additionally, she had several changes to her medications in the first month postpartum, which may have caused withdrawal symptoms and left her even more vulnerable to perinatal psychosis. Her health care providers could have consulted with experts in perinatal psychiatry to ensure they were prescribing the optimal medications. Additionally, given the severity of Valerie's symptoms, she would have benefitted from closer follow-up in the days after hospital discharge for medication adjustments. Hospitals can ensure continuity of care by providing intensive outreach and case management to patients with severe mental illness after discharge from a hospitalization or emergency department visit.

#### Crystal's Story

Crystal was a Black woman in her 30s with a history of substance use disorder, anxiety, and bipolar disorder. She had been raised in foster care due to her parents being incarcerated. Throughout prenatal care there was no documentation of referrals or treatment for her mental health. The medical record notes from providers included undertones of blaming language surrounding her "unwillingness" to quit her substance use and classifying her as a "known drug user." Around her sixth month of pregnancy, Crystal went to the emergency department with abdominal pain. A hospital social worker told her that DCFS would be contacted due to her positive urine drug test. Crystal became upset and started to cry due to the fear of losing her children and asked to be discharged. She then left the hospital against medical advice. The social worker reported her to DCFS after the hospital stay. In her prenatal care visits after this emergency department visit, there was no documented follow-up for Crystal's substance use disorder or other mental health conditions. She later gave birth to a full-term healthy baby. From the hospital records available, it seems the infant was not taken into DCFS care after birth. After delivery, there is no record of Crystal receiving a postpartum visit or any other care. She died two months postpartum of a drug overdose from a combination of fentanyl and cocaine.

### What can we learn from Crystal's death?

Women who have substance use disorder can experience stigma and bias related to their substance use, especially during pregnancy. This can result in some women avoiding medical care during or after pregnancy due to the fear of DCFS reporting and the potential to lose custody of their child(ren). Health care providers should seek out training to further understand the impact stigma related to substance use affects care to improve respectful care practices for all patients. While it is currently Illinois law to report positive urine drug screens to DCFS after an infant is born, there is no mandated reporting for drug screenings during pregnancy prior to the baby's birth. Crystal's health care providers did not assess her readiness for substance use disorder treatment nor connect her to

available treatment and recovery services. Women with substance use disorder can benefit from care coordination and patient navigation to ensure they are receiving the treatment and recovery support that they need. Furthermore, the clinical team should work with the pregnant patient prior to delivery to create a plan of safe care, a plan designed to ensure the safety and well-being of an infant with prenatal substance exposure following his or her release from the care of a health care provider by addressing the health and substance use treatment needs of the infant and affected family or caregiver that encourages ongoing treatment and promotes the best outcomes for both the woman and her infant.

### Morgan's Story

Morgan was a Black woman in her 30s. She entered prenatal care in her first trimester and had a normal pregnancy with few complications. At about three months pregnant, she was diagnosed by her OB with asthma and given an inhaler. About a month later, she was referred to a maternal-fetal medicine specialist due to persistent shortness of breath but did not attend an appointment. She arrived at the hospital for labor and delivery with a dry cough and a positive COVID-19 test. She delivered a healthy baby and was discharged home two days after delivery because her provider thought she was stable enough, even though her oxygen saturation was worsening, and she still reported shortness of breath. Morgan was given a blood pressure cuff to take home and education on postpartum warning signs. She was scheduled for a blood pressure check appointment 10 days after discharge but was not given follow-up care or education regarding her COVID-19 infection. At five days postpartum, Morgan died from COVID-19 at home.

#### What can we learn from Morgan's death?

Lack of appropriate assessment and understanding of urgent maternal warning signs for potential pregnancy and postpartum complications contributed to Morgan's death. Even with worsening COVID-19 symptoms during delivery, she was discharged from the hospital where she could have been better monitored and cared for. Providers need to prioritize helping patients monitor symptoms and how to identify when to return for further care. Morgan also missed an appointment for her ongoing shortness of breath. Hospitals can implement screening for social determinants of health to identify barriers to attending prenatal, postpartum, and other medical appointments and provide care coordination services to address those barriers.

# **Opportunities for Prevention**

During the maternal mortality review process, the MMRCs determine whether the death was potentially preventable. If a death is pregnancy-related and preventable, the MMRCs identify contributing factors to the maternal death and create recommendations to address those factors and prevent future deaths.

Contributing factors, as identified by the MMRCs, are modifiable factors that impacted a woman's health outcome in a meaningful way, even if that factor did not directly or solely cause the death. Contributing factors can occur at multiple levels, including system, community, hospital, provider, or family/patient.

In the deaths occurring during 2018-2020, the MMRCs identified several common contributing factors that represent opportunities for prevention. The most common contributing factors to pregnancy-related deaths included poor quality of care, poor coordination of care, lack of access to services, lack of screening, and lack of community knowledge regarding postpartum warning signs. These common contributing factors are summarized below and can inform maternal mortality prevention efforts. All themes and factors must be addressed using an equity lens, since the burden of maternal deaths is not equally distributed across groups.

### 1. Poor Quality of Care

Improving the quality of health services provided to pregnant and postpartum women can vastly impact their health outcomes. Delays in appropriate and necessary care stem from the inadequate quality of health services. In addition, the inaccurate identification of illnesses is a major problem leading to the poor quality of care provided to pregnant patients. Maternal deaths highlight the need for better communication between patient and provider and the improvement of patient education when patients interact with the health care system. The MMRCs' recommendations aim to improve quality of care for the pregnant and postpartum population through implementation of clinical best practices and the development of new protocols and procedures. Steps to improve the quality of care can occur at all health care levels, including providers, hospitals, and health systems.

Care for mental health conditions and substance use disorders continues to be insufficient. Pregnant and postpartum women with these conditions specifically lacked screenings, access to appropriate treatment, and appropriate medication management. Many of the maternal deaths needed to be linked to or started on medication-assisted recovery services for their substance use disorder. There is a consistent lack of timely referrals and follow-up appointments to monitor treatment. Recommendations from the MMRCs highlight quality improvement initiatives, increasing screening, and training providers on current treatment opportunities.

### 2. Poor Coordination of Care

Synchronizing the delivery of care from multiple providers and systems is vital to achieve effective care for pregnant and postpartum women. The MMRCs found that many women were being referred to specialists without any support in getting an appointment. Some women were seeing multiple providers that were not communicating with each other. There is a lack of resources to help women navigate the complicated health care system to get the care they need. When referrals are provided, they are often done with passive information that puts the burden on the patient for scheduling and follow-up. In many cases, providers and hospital systems failed to contact patients for follow-up after a visit, especially during the postpartum period. The MMRCs' recommendations address how to enhance coordination of care for pregnant and postpartum women throughout pregnancy and in the postpartum period. Services such as social work, case managers, and other community-based supportive programs can help women navigate these complex systems.

#### 3. Lack of Access to Services

Availability and ease of access to services for pregnant and postpartum women is important for improving maternal health outcomes. Women with chronic conditions, including mental health conditions and substance use disorders, need ongoing and attentive care throughout their pregnancy to ensure a healthy outcome. Specifically, in rural areas, women faced barriers to finding needed specialty care, especially for treatment of substance use disorders, mental health services, and other chronic conditions. These barriers included a lack of providers and a long distance to services. Ability to access health care services, such as specialists and substance use disorders treatment in timely and consistent manner, greatly affects the well-being of pregnant and postpartum women.

#### 4. Lack of Screening

Pregnancy and the postpartum period are an opportunity to screen for a wide variety of conditions that could affect pregnancy outcomes and the long-term health of the woman and her infant. Health risk factors continue to not be properly identified, screened, diagnosed, or treated. Screening during the prenatal care period for chronic conditions, substance use disorders, and social determinants of health is essential to connecting the woman with needed treatment and resources to ensure she is healthy during and after pregnancy. For example, for substance use disorder ACOG recommends universal, routine verbal screening to reduce bias, yet selective and unequal urine toxicology screening tends to be completed most frequently in pregnancy-related deaths. Several of the MMRCs' recommendations address ways to ensure that pregnant and postpartum women are properly screened.

### 5. Lack of Community Knowledge Regarding Postpartum Warning Signs

Communities and families need resources to help them know about services that are available and about the warning signs of severe pregnancy complications. The MMRCs identified that many patients delayed seeking medical attention for severe pregnancy complications because they had not been adequately educated on warning signs and when to seek emergency care. Specifically related to substance use disorders, communities can work to better understand harm reduction interventions, such as how to use opioid antagonists like Naloxone, to prevent overdose. It is the responsibility of everyone, including those outside of the health care field, to educate both women and their families about postpartum health. Several of the MMRCs' recommendations focus on key actions that can be taken to improve the community and family's knowledge of warning signs and resources to help.

#### Recommendations

During the review of each maternal death, the MMRC and MMRC-V developed specific, actionable recommendations that could have prevented death. IDPH recorded recommendations developed in response to each reviewed case, which totaled more than 200 unique recommendations for the three years of reviews. The MMRCs then reviewed and prioritized these recommendations based on importance, feasibility, and potential impact.

Based on the themes that emerged from the review of maternal deaths during 2018-2020, the MMRC and MMRC-V made recommendations specifically tailored towards hospitals and health systems, health care providers, health insurance plans, including Illinois Medicaid, state agencies, and community-based organizations. The MMRCs also shared information for women and their families and friends. All these groups have a shared role in the promotion of women's health and the prevention of maternal mortality.

#### Recommendations for Hospitals and Health Systems

Hospitals are one of the many critical partners in reducing maternal mortality. Implementing best practices and creating protocols and patient-centered policies can improve maternal health outcomes and racial equity. Hospitals and health systems can prevent delays in diagnosis and treatment, ensure appropriate consultation, and coordinate care. Hospitals and health systems can implement a more holistic approach to maternal care that considers the broader social context in which pregnant and postpartum individuals live.

#### For *hospitals and health systems*, the MMRCs recommend:

- 1. Incorporate best practices for timely identification and assessment of all pregnant and postpartum women in the emergency department with clear policies for emergency department providers to treat pregnant and postpartum women related to:
  - a. Implementing specific processes to identify pregnancy within the last year.
  - b. Establishing when to seek consultation from an obstetrical provider.
  - c. Describing the process for initiating transport to a facility with an appropriate level of maternal care.
- 2. Create protocols and practices to identify and address social determinants of health, such as:
  - a. Implementing universal, routine screening for social determinants of health during prenatal care, delivery admission, and postpartum.
  - b. Employing qualified and trained staff to conduct and document psychosocial needs assessments. 62
  - c. Developing processes for actively linking patients to resources and support services in their communities that provide care coordination and support.
  - d. Providing care coordination services to address barriers to attending prenatal, postpartum, and other medical appointments.
- 3. Promote birth equity through:
  - a. Participating in ongoing state and regional birth equity initiatives.
  - b. Developing and evaluating processes for patient reported experience measures that include opportunities to report if patients are receiving respectful care and report discrimination.
  - c. Engaging patient/community partners or advisory panels with hospital quality improvement teams to gather patient and community input on hospital efforts focused on birth equity.

<sup>62</sup> American College of Obstetrics and Gynecologists. (2018, January). Importance of Social Determinants of Health and Cultural Awareness in the Delivery of Reproductive Health: Committee Opinion Number 729. Retrieved from <a href="https://www.acog.org/clinical-guidance/committee-opinion/articles/2018/01/importance-of-social-determinants-of-health-and-cultural-awareness-in-the-delivery-of-reproductive-health-care">https://www.acog.org/clinical/clinical-guidance/committee-opinion/articles/2018/01/importance-of-social-determinants-of-health-and-cultural-awareness-in-the-delivery-of-reproductive-health-care</a>

- 4. Develop standardized protocols and policies to assure implementation of high-quality delivery of maternal mental health and substance use care, such as:
  - a. Implementing patient safety bundles<sup>63</sup> for mental health and substance use disorders.
  - b. Participating in state and regional quality improvement initiatives on these topics.
  - c. Adopting a universal, validated, self-reported screening tool for substance use in prenatal care, on admission for delivery and during emergency department visits.
  - d. Training emergency department and obstetric providers on initiating medication-assisted recovery services during pregnancy and linking patients to outpatient recovery treatment, peer support services, and ongoing coordination of care through Illinois Helpline/MARNow.<sup>64</sup>
  - e. Providing intensive outreach and case management after discharge from an inpatient hospitalization or emergency department visit related to severe mental illness or substance use disorder.
  - f. Collaborating with pregnant and postpartum women with substance use disorders to develop plans of safe care and share lists of services and supports within their community.<sup>65</sup>
  - g. Engaging in the Drug Overdose Prevention Program  $(DOPP)^{66}$  to be able to provide free opioid antagonists, including naloxone, at the point of care for all patients.

### **Recommendations for Health Care Providers**

Health care providers who care for women before, during, and after pregnancy have a critical role to play in preventing maternal mortality. Knowing best practices for care regarding chronic disease and other conditions that can heighten risk during pregnancy is essential for providers to ensure quality care. Addressing racial and ethnic bias, stereotypes, stigma, and discrimination is essential to improving equity among maternal health outcomes.

#### For *health care providers*, the MMRCs recommend:

- 1. Know and follow best practices for high-quality maternal health care in the following key areas that are critical for reducing maternal mortality:
  - a. *Cardiovascular disease*, especially as related to ensuring evaluation for cardiac symptoms and coordinated referral to an appropriate medical specialist, such as a cardiologist, during prenatal and postpartum period.<sup>67</sup>
  - b. *Obesity,* especially as related to patient education and referral to a dietician for comprehensive counseling services and linking patients to nutrition and food access resources.<sup>68</sup>
  - c. *Mental health conditions*, especially as related to screening with a validated tool, prescribing anti-depressants, and linking patients to mental health services using the Illinois Moms Line and Illinois DocAssist.<sup>69</sup>

<sup>63</sup> American College of Obstetricians and Gynecologists. (2021). Safe Health Care for Every Woman. Retrieved from https://safehealthcareforeverywoman.org/

<sup>64</sup> Illinois Helpline. (n.d.). MAR Now. Retrieved from helplineil.org

<sup>65</sup> A plan of safe care is a plan designed to ensure the safety and well-being of an infant with prenatal substance exposure following his or her release from the care of a health- care provider by addressing the health and substance use treatment needs of the infant and affected family or caregiver.

<sup>66</sup> Illinois Department of Human Services. (n.d.). IDHS/SUPR Drug Overdose Prevention Program. Retrieved from <a href="https://www.dhs.state.il.us/page.aspx?item=58142">https://www.dhs.state.il.us/page.aspx?item=58142</a>

<sup>67</sup> American College of Obstetrics and Gynecologists. (2019, May). Pregnancy and Heart Disease: Practice Bulletin Number 212. Retrieved from <a href="https://www.acog.org/clinical/clinical-guidance/practice-bulletin/articles/2019/05/pregnancy-and-heart-disease">https://www.acog.org/clinical/clinical-guidance/practice-bulletin/articles/2019/05/pregnancy-and-heart-disease</a>

<sup>68</sup> American College of Obstetrics and Gynecologists. (2021, June). Obesity in Pregnancy: Public Bulletin Number 230. Retrieved from <a href="https://www.acog.org/clinical-guidance/practice-bulletin/articles/2021/06/obesity-in-pregnancy">https://www.acog.org/clinical-guidance/practice-bulletin/articles/2021/06/obesity-in-pregnancy</a>

<sup>69</sup> University of Massachusetts Medical School. (2019, November 15). Lifeline for Moms Perinatal Mental Health Toolkit. Retrieved from <a href="http://hdl.handle.net/20.500.14038/44263">http://hdl.handle.net/20.500.14038/44263</a>

- d. *Substance use disorder*, especially as related to adopting a validated self-reported screening tool, initiating medication-assisted recovery (MAR) services, providing opioid antagonist, such as naloxone, with counseling, and referring patients to the Illinois Helpline/MARNow program for ongoing recovery services, peer support, and care coordination.<sup>70,71,72</sup>
- e. *Trauma-informed care*, especially as related to understanding how the experience of intimate partner violence, adverse childhood experiences, emotional abuse, and trauma can affect physical health, mental health, and risk for substance use disorder.<sup>73</sup>
- f. *Contraceptive services*, especially as related to providing access to full range of contraceptive options and promoting reproductive justice through shared medical decision-making.<sup>74</sup>
- 2. Educate patients and their loved ones using culturally relevant informational materials at an appropriate literacy level on the following topics:
  - a. Urgent maternal warning signs: How to recognize warning signs and when to seek emergency care.
  - b. *Perinatal mental health conditions*: How to recognize symptoms and the importance of getting mental health services.
  - c. *Harm reduction strategies for substance use disorder and emerging substances:* How to and where to access drug checking programs and get life-saving resources like opioid antagonists (such as naloxone) and test strips for fentanyl and xylazine.<sup>75</sup>
- 3. Seek out trainings, beyond those required, to further understand the impact of racism, implicit bias, and stigma in health care<sup>76</sup> and participate in ongoing hospital birth equity initiatives to improve respectful care practices.<sup>77</sup>
- 4. Collaborate with pregnant and postpartum patients with substance use disorders to develop plans of safe care<sup>78</sup> for postpartum patients and their infants after delivery.
- 5. Ensure that pregnant and postpartum women with complex social or medical conditions, including mental health conditions and substance use disorders, receive comprehensive, multi-disciplinary, coordinated care, referral to community-based support services, 79 and case management services. 80

<sup>70</sup> Alliance for Innovation on Maternal Health. (n.d.) Care for Pregnant and Postpartum People with Substance Use Disorder Patient Safety Bundles. Retrieved from <a href="https://saferbirth.org/psbs/care-for-pregnant-and-postpartum-people-with-substance-use-disorder/">https://saferbirth.org/psbs/care-for-pregnant-and-postpartum-people-with-substance-use-disorder/</a>

<sup>71</sup> American College of Obstetrics and Gynecologists. (2021). Opioid Use and Opioid Use Disorder in Pregnancy: Committee Opinion Number 711. Retrieved from <a href="https://www.acog.org/clinical-clinical-guidance/committee-opinion/articles/2017/08/opioid-use-and-opioid-use-disorder-in-pregnancy">https://www.acog.org/clinical-clinical-guidance/committee-opinion/articles/2017/08/opioid-use-and-opioid-use-disorder-in-pregnancy</a>

<sup>72</sup> Illinois Helpline. (n.d.). MAR Now. Retrieved from <u>helplineil.org</u>

<sup>73</sup> American College of Obstetrics and Gynecologists. (2021, April). Caring for Patients Who Have Experienced Trauma: Committee Opinion Number 825.

Retrieved from <a href="https://www.acog.org/clinical/clinical-guidance/committee-opinion/articles/2021/04/caring-for-patients-who-have-experienced-trauma">https://www.acog.org/clinical/clinical-guidance/committee-opinion/articles/2021/04/caring-for-patients-who-have-experienced-trauma</a>

<sup>74</sup> Office of Population Affairs. (2017). *Quality Family Planning*. U.S. Department of Health and Human Services. Retrieved from <a href="https://opa.hhs.gov/grant-programs/title-x-service-grants/about-title-x-service-grants/quality-family-planning">https://opa.hhs.gov/grant-programs/title-x-service-grants/about-title-x-service-grants/quality-family-planning</a>

<sup>75</sup> Illinois Department of Public Health. (2023, August 1). Illinois Xylazine Best Practices for Health Care Providers. Retrieved from <a href="https://www.chicagohan.org/alert-details/46680078?p\_rp\_categoryId=undefined">https://www.chicagohan.org/alert-details/46680078?p\_rp\_categoryId=undefined</a>

<sup>76</sup> Implicit bias awareness training, 20 ILCS § 2105-15.7 (2021). https://www.ilga.gov/legislation/ilcs/documents/002021050K2105-15.7.htm

<sup>77</sup> Illinois Perinatal Quality Collaborative. (2021). Birth Equity-BE. Retrieved from https://ilpqc.org/birthequity/

<sup>78</sup> A plan of safe care is a plan designed to ensure the safety and well-being of an infant with prenatal substance exposure following his or her release from the care of a health- care provider by addressing the health and substance use treatment needs of the infant and affected family or caregiver.

<sup>79</sup> Community-based support services include, but are not limited to: patient navigation, home visiting programs, community health workers, doulas, and lactation consultants.

<sup>80</sup> Healthy Families Illinois, Nurse Family Partnership, Family Connects

### **Recommendations for Health Insurance Plans**

Health insurance plans, including Illinois Medicaid, are integral in promoting maternal health and providing access to comprehensive and affordable medical services essential for pregnant and postpartum women to obtain the care they need. By adopting policies that address education, accessibility, and support services, health insurance plans can contribute to more informed decision-making, increased access to care, and improved maternal health outcomes. The MMRCs also emphasized the need for continued reimbursement for telehealth to ensure women throughout the state can access care during and after pregnancy.

For *health insurance plans*, including Illinois Medicaid, the MMRCs recommend:

- 1. Educate providers and the public about the case management and support services provided by the insurance plan to enrolled pregnant and postpartum women.
- 2. Continue reimbursement for telehealth regardless of patient or provider location within the state, including phone-based services, for clinical services not widely geographically available in Illinois.
- 3. Educate providers and the public about nutrition counseling services covered (including telemedicine visits) for all patients.

### **Recommendations for State Agencies and Partners**

State agencies help develop and sustain many of the programs that affect how women access health care and other services. Their policies, programs, regulations, and leadership can address systemic injustices and promote equitable approaches in improving maternal health. The MMRCs identified several key opportunities for the state to create an environment where maternal health is prioritized, and pregnant and postpartum individuals have access to resources and services they need for healthy pregnancy outcomes. These recommendations address a variety of needs, ranging from mental health conditions and substance use to emergency preparedness and infant care, ultimately working to prevent maternal mortality.

#### For *state agencies*, the MMRCs recommend:

- 1. Create or expand community-based support services<sup>81</sup> that are available to all pregnant or postpartum women.
- 2. Improve coordination and continuity of community-based support services for all pregnant and postpartum women and ensure their coordination with health care systems/providers.
- 3. Implement strategies to disseminate information to providers and the community about state-funded resources that support pregnant and postpartum women with mental health conditions or substance use disorders.
- 4. Ensure that emergency preparedness efforts are inclusive of the needs of pregnant and postpartum women, including tailoring public messages, communicating with obstetric care providers, and, as needed, prioritizing pregnant and postpartum women for treatment and specific response efforts, to build upon lessons learned from the COVID-19 pandemic in future public health emergencies.
- 5. Implement plans of safe care<sup>82</sup> for infants exposed to substances during pregnancy, including implementation of a notification and tracking system that is separate from child abuse/neglect reporting systems.

<sup>81</sup> Community-based support services include, but are not limited to patient navigation, home visiting programs, community health workers, doulas, and lactation consultants.

<sup>82</sup> A plan of safe care is a plan designed to ensure the safety and well-being of an infant with prenatal substance exposure following his or her release from the care of a health care provider by addressing the health and substance use treatment needs of the infant and affected family or caregiver.

### Recommendations for Community-Based Organizations

Community-based organizations are unique and effective partners in the reducing maternal mortality due to their understanding of community needs and dynamics. Because of their established trust within their community, these organizations are positioned to share information and to educate in culturally appropriate ways to empower women in health care settings. The MMRCs' recommendations aim to improve health outcomes through education, support, awareness, collaboration, and access to essential services.

### For *community-based organizations*, the MMRCs recommend:

- 1. Provide education on the urgent maternal warning signs for potential pregnancy and postpartum complications and develop supportive programs to help women get prenatal care early in pregnancy and attend postpartum visits.
- 2. Inform the community about the importance of pre-conception and inter-conception health, especially in the context of chronic disease, develop safe exercise spaces to promote physical activity, and increase access to healthy food through community gardens, farmer's markets, and other healthy food programs including the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC).
- 3. Expand substance use harm reduction and peer support programs, educate communities about contamination of the drug supply (such as fentanyl and xylazine), promote the Drug Overdose Prevention Program (DOPP) for access to opioid antagonists, including naloxone, inform the community about the Illinois Helpline/MARNow, and help community members learn how to use harm reduction interventions to prevent opioid overdose.
- 4. Educate the community about the signs and symptoms of postpartum depression and psychosis, the importance of mental health treatment, and resources available in the community.<sup>83, 84, 85</sup>
- 5. Partner with clinical systems to ensure health care providers know about available local social services and case management programs for pregnant and postpartum women.
- 6. Connect pregnant and postpartum women to existing case management, intensive outreach, and other supportive programs to help them get the health care they need.
- 7. Provide linkage to supportive housing services and programs that accommodate women earlier in pregnancy, including those with substance use disorder.

<sup>83</sup> Perinatal Family Support Center. (n.d.). *Perinatal Depression Program*. NorthShore University Health System. Retrieved from <a href="https://www.northshore.org/pediatrics/specialty-programs/neonatology/perinatal-family-support-center/perinatal-depression-program/">https://www.northshore.org/pediatrics/specialty-programs/neonatology/perinatal-family-support-center/perinatal-depression-program/</a>

<sup>84</sup> Health Resources and Services Administration. (2023, June). *National Maternal Mental Health Hotline*. Retrieved from <a href="https://mchb.hrsa.gov/national-maternal-mental-health-hotline">https://mchb.hrsa.gov/national-maternal-mental-health-hotline</a>

<sup>85</sup> Postpartum Depression Alliance of Illinois. (2020). Retrieved from <a href="https://ppdil.org/">https://ppdil.org/</a>

### Information About Maternal Health for Pregnant and Postpartum Women and their Families

- 1. **Pre-Pregnancy Health Matters**. Annual check-up visits with primary care providers can help identify and manage any chronic conditions, including obesity, to keep women as healthy as possible before or between pregnancies.
- 2. **Postpartum Health Matters.** Early (< 3 weeks) and routine (6-12 weeks) postpartum care visits are important to stay healthy after the baby is born. After pregnancy, it is also important to connect with a regular primary care doctor for continued medical care beyond the postpartum visit.
- 3. **Tell Providers About Pregnancy.** When discussing concerns with any health care provider, it is important for them to know about current pregnancy or a pregnancy in the last year, even if you do not think it is relevant. This information helps them look for things that might be more dangerous or only happen during or after pregnancy.
- 4. **Speak Up about Symptoms.** During and after pregnancy it is important to talk to health care providers about anything that doesn't feel right. It may be physical symptoms, but could also include feelings of sadness, anxiety, and exhaustion that make it difficult to complete daily care activities for. Learn more about <u>urgent maternal warning signs</u>.
- 5. **It's OK to Ask Questions.** Here is a <u>simple guide</u> to help start a conversation with health care providers. If possible, bring a friend or family member with you to appointments to help ask the questions. Every person deserves to understand what is being told to them.
- 6. **Help is Available.** Mental health conditions and problems with drugs and alcohol are ongoing medical conditions and help is out there. These services can help women find whatever support they need:
  - <u>National Maternal Mental Health Hotline</u> 1-833-TLC-MAMA (1-833-852-6262)
  - <u>Illinois Perinatal Depression Line</u> 1-866-364-MOMS (1-866-364-6667)
  - <u>Illinois Helpline</u> / <u>MARNow</u> 1-833-234-6343 or text "HELP" to 833234
  - National Suicide and Crisis Lifeline: Call or text 988
- 7. **There Are Ways to Reduce Risk of Overdose.** Small strips of paper (fentanyl test strips) can be used to detect fentanyl in drugs and provide people who use drugs with important information. Overdose reversal medications, such as naloxone, help prevent death in someone experiencing an opioid overdose. Anyone can get naloxone without a prescription at pharmacies or other community locations. By learning how and when to use naloxone and fentanyl test strips, you could save lives.<sup>86</sup>

<sup>\*</sup> See Appendix A for more information about services and programs available to the public. \*

<sup>86</sup> Academy of Perinatal Harm Reduction. (2023, June). *Illinois Pregnancy and Substance Use: A Harm Reduction Toolkit.* Retrieved from <a href="https://www.perinatalharmreduction.org/pcc">https://www.perinatalharmreduction.org/pcc</a>

# Momentum to Improve Maternal Health

The first two *Illinois Maternal Morbidity and Mortality Reports*<sup>87</sup> served as a powerful tool to monitor important maternal health indicators, to build momentum in addressing maternal health, and to solidify Illinois' commitment to reducing racial and social inequities in maternal health. Since the second report was published in April 2021, there have been many continued efforts to improve maternal health across the state by implementing the recommendations in the report.

Some key maternal health initiatives since 2021 include:

#### **Medicaid Innovations**

- Medicaid Postpartum Expansion. In April 2021, Illinois was the first state to extend full Medicaid benefits through 12 months postpartum with continuous eligibility and regardless of how the pregnancy ends, with the federal Centers for Medicare & Medicaid Services (CMS) approval of an 1115 waiver. In fall 2021, Illinois became the first state to offer this extended coverage regardless of immigration status with federal CMS approval of a CHIP Health Services Initiative (HSI). Extending Medicaid coverage through 12 months postpartum was a key recommendation from the first report and a major accomplishment for the state.
- Doula and Home Visiting Reimbursement. In April 2021, the governor signed the Illinois Legislative Black Caucus Healthcare Pillar Bill (HB 158), adding doulas and evidence-based home visiting programs as new Medicaid provider types and covered services. The Illinois Department of Healthcare and Family Services (HFS) has collaborated with community doulas and home visiting organizations on a statewide level to develop certification requirements that will be utilized in the implementation process. Currently, HFS is in the process of establishing reimbursement rates for these services and developing Medicaid billing trainings in partnership with the Medicaid Technical Assistance Center, which was created by the same legislation. This was a recommendation from the second report.
- Postpartum Visits and Services. In October 2021, P.A. 102-0665 was enacted to require Illinois Medicaid to provide reimbursement for two postpartum visits –within 0 and 3 weeks postpartum and within 4 to 12 weeks postpartum. This was a recommendation from the second report. The act also added new provider types and covered services during the postpartum period, including certified lactation consultants and medical caseworkers. <sup>89</sup> The FY23 Medicaid omnibus legislation also added licensed certified professional midwives as a new Medicaid provider type and covered service. HFS is working to implement these new provider types and covered services, which build on the implementation of the 12-month postpartum extension.
- Family Planning Coverage. In November 2022, Illinois Medicaid launched a new partial benefit eligibility group for comprehensive coverage of family planning and related services for people otherwise not eligible for Medicaid. This program has a higher income eligibility threshold than the regular Medicaid program and includes services such as an annual preventive exam, family planning counseling, Food and Drug Administration approved methods of contraception, permanent methods of birth control, and basic infertility counseling. HFS and IDPH staff are coordinating to maximize access to family planning coverage between the Medicaid and IDPH Title X family planning programs, which have different eligibility criteria.
- Policy Innovation Program. Illinois was 1 of 8 states accepted into the National Academy of State Health Policy (NASHP) Maternal and Child Health Policy Innovation Program (MCH PIP) in April 2021. IDPH and HFS staff participated in this two-year initiative to collaborate on issues related to Medicaid policy, reimbursement, and innovations. Key accomplishments from this project included implementing the HEDIS Prenatal and Postpartum Care (PPC) quality measure as the Medicaid Managed Care Organization Performance Improvement Program measure, holding partner meetings to inform Medicaid reimbursement of new provider types (e.g., doulas), and improved data. Illinois will continue participating in the NASHP MCH PIP during 2023-2025, focusing on social determinants of health.

<sup>87</sup> Illinois Department of Public Health. (2021, April). *Illinois Maternal Morbidity and Mortality Report*. Retrieved from <a href="https://dph.illinois.gov/topics-services/">https://dph.illinois.gov/topics-services/</a> <a href="https://dph.illinois.gov/topics-services/">https://dph.illinois.gov/topics-services/</a> <a href="https://dph.illinois.gov/topics-services/">life-stages-populations/maternal-child-family-health-services/maternal-health/mmmr.html</a>

- 1115 Healthcare Transformation Waiver Request. The HFS 1115 Healthcare Transformation waiver request seeks to bring federal Medicaid matching dollars to Illinois to test Medicaid coverage of Health-Related Social Needs (HRSN) benefits, including housing supports and nutrition services. The waiver request includes pilot programs providing HRSN benefits to pregnant and postpartum people to address social determinants of health. The waiver request went through a state public comment period and was submitted to federal CMS for consideration in June 2023.
- Medicaid Quality Pillars. HFS established five quality pillars for the Medicaid program, including Maternal Child Health
  quality and Equity quality. These pillars require results to be broken out by race, ethnicity, and geography to identify and to
  address health disparities.

### Improving Clinical Practice and Health Care Provider Training

- Statewide Birth Equity Initiative. The Illinois Perinatal Quality Collaborative launched a statewide birth equity initiative in June 2021 that aims to support hospital capacity to facilitate systems and culture change to achieve birth equity. This initiative is financially supported by IDPH.
- Maternal Levels of Care. Over the last two years, IDPH convened workgroups to develop draft administrative rules for the implementation of maternal levels of care. These draft rules align with national policy guidelines from the American College of Obstetrics and Gynecology and Society for Maternal-Fetal Medicine<sup>91</sup> and are in the final stages of revision before starting the public comment process.
- Implicit Bias Training. In April 2021, a state law was passed to require a one-hour implicit bias awareness training for health care professionals who have continuing education requirements, effective January 1, 2023.<sup>92</sup>
- Birthing Hospital Training. In compliance with state laws, birthing hospitals continue to provide annual continuing education for health care providers on the management of severe maternal hypertension, obstetric hemorrhage, and other leading causes of maternal mortality. This includes education for providers and staff of the emergency department and other staff who may care for pregnant and postpartum people.
- Emergency Department Training. Innovations to ImPROve Maternal OuTcomEs in Illinois (I PROMOTE-IL) at the University of Illinois at Chicago is convening partners from across the state to develop a comprehensive training on maternal health issues for emergency department providers. During 2023, IDPH is financially supporting the pilot implementation and evaluation of this training.

#### Addressing Maternal Mental Health and Substance Use

- Perinatal Depression Hotline. IDPH continues to fund the state perinatal depression hotline through NorthShore University Health System, which provides perinatal depression crisis interventions, consultations, resources, education, and referrals for women who have screened positive for symptoms of perinatal depression.
- Illinois Helpline. Illinois continues to maintain a 24/7 Illinois Helpline<sup>93</sup> for assisting the public with finding substance use treatment and recovery services.
  - In September 2022, the Helpline launched the MAR Now program, <sup>94</sup> which provides medication on demand to residents seeking opioid use disorder treatment. Callers can speak directly with a provider over the phone, immediately receive a prescription or expedited in-person appointment, and get transportation assistance to a pharmacy or clinic through one phone call. After induction on MAR, patients are referred to community-based care for ongoing treatment.

<sup>90</sup> Illinois Perinatal Quality Collaborative. (2021). Birth Equity-BE. Retrieved from https://ilpqc.org/birthequity/

<sup>91</sup> American College of Obstetrics and Gynecologists. (2023, April). Levels of Maternal Care: Obstetric Care Consensus Number 9. Retrieved from <a href="https://www.acog.org/clinical-clinical-guidance/obstetric-care-consensus/articles/2019/08/levels-of-maternal-care">https://www.acog.org/clinical-clinical-guidance/obstetric-care-consensus/articles/2019/08/levels-of-maternal-care</a>

<sup>92</sup> Department of Professional Regulation Law, 20 ILCS § 2105/2105 (2000). https://www.ilga.gov/legislation/ilcs/ilcs5.asp?ActID=325

<sup>93</sup> Illinois Helpline. (n.d.). Retrieved from <a href="https://helplineil.org/app/home">https://helplineil.org/app/home</a>

<sup>94</sup> Illinois Helpline. (n.d.). MAR Now. Retrieved from <a href="https://e.helplineil.org/mar-now/">https://e.helplineil.org/mar-now/</a>

- Guidelines for Treatment in Pregnancy. The Illinois Department of Human Services (IDHS) continues to provide education to community-based substance use treatment and recover programs about the unique needs of pregnant and postpartum women. For example, in June 2022, IDHS developed and disseminated guidelines for methadone use during pregnancy.<sup>95</sup>
- Pregnant and Postpartum Women Pilot Treatment/Illinois Families in Recovery Program. The IDHS Division of Substance Use Prevention and Recovery (IDHS/SUPR) has continued to support a three-year pilot program to provide integrated family-based prenatal/postpartum care and substance use disorder treatment for families in central Illinois.
- Pregnant and Postpartum Women with Opioid Use Disorders and Stimulant Use/Misuse Disorders Pilot Project.
   IDHS Substance Use Prevention and Recovery funded a program to increase access to medication assisted recovery (MAR) services for pregnant and postpartum women. Four agencies are funded to provide family-based services to postpartum women with substance use disorder, including specialized screening, referral, family-based treatment interventions, and recovery support services.

### **Expanding Maternity Care Providers**

- Birth Center Licensure. In August 2021, the Illinois Birth Center Licensing Act created a process by which an independent birth center can be licensed by IDPH.<sup>96</sup> Previously, freestanding birth centers were allowed only through a demonstration program authorized by the Alternative Health Care Delivery Act, but this strictly limited the number of birth center sites in the state. The new law will expand licensing to more freestanding birth centers and establish standards for monitoring health care quality in birth centers.
- Certified Professional Midwives Licensure. In December 2021, a state law was passed to allow certified professional midwives to become licensed.<sup>97</sup>

### Protecting and Expanding Reproductive Health Care

- Complex Abortion Navigation Program. In August 2023, Illinois launched a hotline called Complex Abortion Referral Line
  for Access (CARLA) to aid patients with complex medical needs in scheduling abortion services with hospital systems when
  they need a higher level of care than can be provided at free-standing abortion clinics.<sup>98</sup>
- **Reproductive Health Public Navigation Hotline.** IDPH is in the process of developing a new hotline that will aid patients, including those travelling from out of state, in finding and navigating reproductive health care in Illinois.

### **Coordinating Maternal Health Efforts**

- Maternal Health Summits. IDPH hosted two Illinois Maternal Health Summits in September 2021 and October 2023. These two conferences each had more than 300 participants and highlighted key maternal health topics, such as structural racism, substance use in pregnancy, maternal mental health, and community-engagement approaches. The summits also included peer-sharing roundtables for organizations to share their maternal health program successes. Each summit concluded with an action planning session that aimed to move participants towards collective action to improve maternal health.
- Convening Maternal Health Leaders. Since the first Maternal Health Summit, IDPH continues to convene quarterly meetings with state maternal health leaders to ensure that groups are mutually informing each other of their programs and initiatives. The group aims to forge connections between these leaders and set up opportunities for improved coordination, collaboration, and synergy.

<sup>95</sup> Illinois Department of Human Services Division of Substance Use Prevention and Recovery (HIS/SUPR). (2022, May). Guideline: Methadone in Pregnancy for Opioid Use Disorder (OUD). Retrieved from

https://www.dhs.state.il.us/OneNetLibrary/27896/documents/SUPR/Guidelines/GuidelineMethadoneinPregnancy2.pdf

<sup>96</sup> Birth Center Licensing Act. LRB102 14648 CPF 21906 b (2021). https://www.ilga.gov/legislation/publicacts/fulltext.asp?Name=102-0518

<sup>97</sup> Licensed Certified Professional Midwife Practice Act. LRB102 14708 SPS 20061 b (2022). https://www.ilga.gov/legislation/publicacts/102/102-0683.htm

<sup>98</sup> Rush University Medical Center. (n.d.). Complex Abortion Referral Line for Access (CARLA). Retrieved from <a href="https://www.rush.edu/complex-abortion-referral-line-access-carla">https://www.rush.edu/complex-abortion-referral-line-access-carla</a>

- Coordinating Advisory Committees. Multiple state advisory committees advise IDPH on issues of maternal health and perinatal care. IDPH coordinates the efforts of these groups to increase their collective impact through ensuring communication with workgroup chairpersons, facilitating joint meetings between committees, and ensuring there is not duplication of projects. Such advisory committees include:
  - Perinatal Advisory Committee (PAC): Advises IDPH on all issues related to perinatal health and the regionalization of
    perinatal health care. PAC has four sub-committees, including the two MMRCs, which collectively counsel IDPH on the
    establishment and implementation of policies related to perinatal health and the birthing hospitals.
  - Task Force on Infant and Maternal Mortality Among African Americans (IMMT): Legislatively created in 2020 and charged with identifying key strategies to decrease infant and maternal mortality among African Americans in Illinois. IMMT has three subcommittees with cross-membership from other state workgroups and seeks to align efforts across groups and with the Illinois Title V Maternal and Child Health program.

Through these efforts, IDPH remains committed to building upon the work already underway in Illinois. IDPH will continue to identify and to review maternal deaths to ensure new recommendations are identified to further advance maternal health and health equity. IDPH welcomes efforts to disseminate and to implement the recommendations from this report and looks forward to engaging diverse partners about innovative strategies to improve maternal health.

# APPENDIX A: Resources for Women and Their Families and Friends

If you or someone you know is having suicidal thoughts, immediately contact:

988 Suicide and Crisis Lifeline\* Text/Call to 988

National Suicide Crisis Text Line Text HOME to 741-741

For help with depression or other mental health concerns:

Illinois Perinatal Depression MOMSline 866-364-MOMS (6667)
Postpartum Support International\* 800-944-4PPD (4773)

Postpartum Depression Alliance of Illinois 847-205-4455

National Maternal Mental Health Hotline\* 833-TLC-MAMA (852-6262)

National Institute of Mental Health\* 866-615-6464

To find treatment for substance use disorders or for questions about naloxone:

Illinois Helpline for Opioids and Other Substances\* 833-234-HELP (6343) -or-

Text HELP to 833234

SAMHSA's National Hotline\* 800-662-HELP (4357)

Illinois Tobacco Quitline\* 866-784-8937

Map of Illinois Substance Use Treatment Facilities

https://public.tableau.com/app/profile/lina.cook/viz/IllinoisSUDMap/Sheet1

For support and services related to domestic violence:

Illinois Domestic Violence Helpline\* 877-863-6338
National Domestic Violence Hotline\* 800-799-7233

For support and services related to sexual assault:

National Sexual Assault Hotline\* 800-656-4673

For concerns regarding human trafficking:

National Human Trafficking Hotline\* 888-373-7888 -or- Text 233733

To find birth control or women's health care services:

Illinois Women's Health Line\* 888-522-1282

Planned Parenthood 877-200-PPIL (7745) -or-

Text PPNOW to 774636

Federally Qualified Health Centers

https://npidb.org/organizations/ambulatory\_health\_care/federally-qualified-health-center-fqhc\_261qf0400x/il/

For other postpartum and parenting questions, concerns, and support:

4th Trimester Project Self-Care Resource <a href="https://www.newmom.health/">https://www.newmom.health/</a>

(general information for new parents)

La Leche League International 877-452-5324

(breastfeeding support)

Erikson Institute's Fussy Baby Network\* 888-431-2229

(support for families struggling with fussy babies)

Compassionate Friends 877-969-0010

(support group for parents who have lost a child)

To determine whether you or your family qualify for state programs:

Medicaid, WIC, Food Stamps (SNAP)*	800-843-6154
Temporary Assistance for Needy Families (TANF)*	800-843-6154
Child Care Assistance Program (CCAP)*	312-823-1100
Illinois Cares RX (assistance with medications)	800-252-8966

Illinois Home Visiting Collaborative 312-793-1476 <a href="http://igrowillinois.org/">http://igrowillinois.org/</a>

All Kids (Health Care coverage) 866-255-5437

For other state health programs:

HIV/AIDS Hotline\* 800-243-2437 Immunization Program and I-Care 217-785-1455

For emergency, short-term child care:

Crisis Nurseries <a href="http://www.dhs.state.il.us/page.aspx?item=55909">http://www.dhs.state.il.us/page.aspx?item=55909</a>
Safe Families <a href="https://safe-families.org/get-help/">https://safe-families.org/get-help/</a>

For legal assistance

Legal Aid agencies throughout Illinois <a href="https://shdh.illinois.gov/legal-assistance.html">https://shdh.illinois.gov/legal-assistance.html</a>

<sup>\*</sup>Available in Spanish

# **APPENDIX B: Resources for Health Care Providers and Hospitals**

For consultation about mental health and substance use concerns for perinatal patients:

Illinois DocAssist 866-986-ASST (2778)
Postpartum Support International 800-944-4773, ext. 4

https://www.postpartum.net/

MCPAP for Moms 855-MOM-MCPAP (666-6272)

https://www.mcpapformoms.org/Toolkits/Toolkit.aspx

The Joint Commission's Toolkit on detecting suicidal ideation

https://www.jointcommission.org/assets/1/18/SEA\_56\_Suicide.pdf

For questions regarding safe medications during pregnancy and breastfeeding:

Infant Risk Center 806-352-2519

For questions regarding best practices for birth control options:

U.S. Medical Eligibility Criteria (MEC) for Contraceptive Use

https://www.cdc.gov/mmwr/volumes/65/rr/rr6503a1.htm?s cid=rr6503a1 w

For information about participation in statewide perinatal quality initiatives:

Illinois Perinatal Quality Collaborative

https://ilpqc.org/

For information on maternal patient safety bundles, toolkits, and quality care standards:

National Council on Patient Safety in Women's Health Care

AIM | Alliance For Innovation On Maternal Health (saferbirth.org)

National Center on Domestic Violence, Trauma, and Mental Health - Coercion toolkit

https://ncdvtmh.org/toolkit/coercion-related-to-mental-health-and-substance-use-in-the-context-of-intimate-partner-violence/

To learn about naloxone and get patient education materials:

Illinois Department of Public Health

https://dph.illinois.gov/topics-services/opioids/naloxone.html

For screening families for the social determinants of health:

American Academy of Family Physicians recommended SDOH screening tool

https://innovation.cms.gov/Files/worksheets/ahcm-screeningtool.pdf

For materials to support warm handoffs:

Agency for Healthcare Research and Quality Warm Handoff Intervention tools

https://www.ahrq.gov/patient-safety/reports/engage/interventions/warmhandoff.html

For implicit bias training tools:

Innovations to ImPROve Maternal OuTcomEs in Illinois Implicit Bias Training Inventory

https://ipromoteil.org/implicit-bias-training-inventory/

# **APPENDIX C: Medical Terminology**

### **Body Mass Index**

Body mass index (BMI) is a measure to look at body weight proportional to body size. BMI equals weight (in kilograms) divided by height (in meters) squared. A BMI of 18.5-24.9 is considered normal weight, a BMI of 25.0-29.9 is considered overweight, and a BMI of 30.0 or higher is considered obese.

#### Cardiomyopathy

Cardiomyopathy is a condition in which the chambers of the heart can no longer pump blood like they normally do, leading to heart failure. Peripartum related cardiomyopathy is defined as heart failure occurring towards the end of pregnancy or within five months following delivery. The cause is currently unknown, but risk factors include age greater than 30 years, pregnancy with multiple fetuses, African descent, and maternal cocaine use.

#### Coronavirus Disease 2019 (COVID-19)

COVID-19 is an infectious disease caused by the SARS-CoV-2 virus. The virus usually causes mild-to-moderate respiratory illness. Most people with COVID-19 do not need special treatment, but some will become seriously ill and require medical attention. Anyone can get sick with COVID-19 and become seriously ill or die at any age, but older people and those with underlying medical conditions are more likely to develop serious illness.

#### **Diabetes**

Diabetes is a condition in which insulin is not produced (type 1 diabetes) or the body doesn't respond to insulin well (type 2 diabetes), preventing the cells in the body from using the sugar a patient eats in their diet. This results in sugar remaining in the blood rather than being taken into the cells. People with diabetes must monitor their blood glucose frequently and take insulin injections or other medications to make sure their blood sugar stays in a normal range to prevent long-term health complications.

#### Hypertension

Hypertension is high blood pressure, which can be present before, during, or after pregnancy. When high blood pressure develops during pregnancy or during the postpartum period and is accompanied by organ damage, most commonly to the liver or kidneys, it is called preeclampsia. Damage to the kidneys results in protein being discarded in the urine. Eclampsia occurs when a woman with preeclampsia begins to have seizures. This is a life-threatening emergency and warrants immediate delivery of the baby.

#### **Maternal Morbidity**

A maternal morbidity is a complication from pregnancy that results in significant short- or long-term consequences to a woman's health.

#### **Maternal Mortality**

A maternal mortality is the death of a woman during pregnancy or close in time to pregnancy.

### **Opioids**

Opioids are compounds similar in structure to opium, an addictive drug made from poppies. It is a narcotic and, in medicine, is used as a pain reliever.

#### Substance Use Disorder

Substance use disorder (SUD) is a condition in which there is a pattern of uncontrolled use of a substance despite poorly affecting the person's ability to function in day-to-day life, including a failure to fulfill major obligations at school, work, or home. The most severe SUDs are sometimes called addictions.

### Postpartum Mental Health

Because of hormonal changes during and around the time of pregnancy, it is normal for women to feel "down" or sad after delivery, sometimes called the postpartum blues. These may last up to four weeks postpartum. However, when certain symptoms, such as sleep disturbance, lack of interest, feelings of guilt, low energy, poor concentration, or altered appetite, persist after four weeks, a woman may be diagnosed with postpartum depression. Some women with postpartum depression may also have feelings of wanting to hurt themselves (self-harm) or wanting to die (suicidal ideation). Rarely, a condition called postpartum psychosis develops in which a woman may develop delusions, hallucinations they see or hear, and rapid mood swings.

#### Pregnancy-Associated Death

The death of a woman during pregnancy or within one year of the end of pregnancy, regardless of the cause of death.

#### **Pregnancy-Related Death**

The death of a woman during pregnancy or within one year of the end of pregnancy from a pregnancy complication, a chain of events initiated by pregnancy, or the aggravation of an unrelated condition by the physiologic effects of pregnancy.

#### Preventable Death

A death is considered preventable if the MMRC/MMRC-V determines that there was at least some chance of the death being averted by one or more reasonable changes to patient, family, provider, facility, system and/or community factors.

### **Kidney Failure**

Kidney failure is a condition when the kidneys are no longer able to remove waste from the blood. This can result in a build-up of potentially harmful substances and chemical imbalances in the blood. Chronic diseases like diabetes can cause renal failure, but a common cause of renal failure among pregnant and postpartum women are hypertensive disorders of pregnancy.

#### Sepsis

When the body is exposed to an infection, it sends many chemicals into the body that damage various organ systems. If a woman enters septic shock, her blood vessels become unable to adequately pump blood and blood pressure drops dramatically. Without the pressure propelling the blood to organs, many organs die from oxygen starvation.

#### **Severe Maternal Morbidity**

Severe maternal morbidity represents a group of potentially life-threatening unexpected maternal conditions or complications that occur during labor and delivery. It is sometimes referred to as "near miss" morbidity, meaning that the woman came very close to dying from her condition.

# **APPENDIX D: Methods Notes for Statistical Analyses**

### **Demographic Definitions**

#### Race/Ethnicity

In each of the data sources used in this report, race and ethnicity are collected as two separate fields, in alignment with the U.S. Census. Women were hierarchically classified into one of four racial/ethnic groups: American Indian/Alaska Native (including those who were Hispanic or multiple races), Hispanic, non-Hispanic Black, non-Hispanic Asian, non-Hispanic Native Hawaiian or Other Pacific Islander, non-Hispanic White, and non-Hispanic Other race (includes multi-racial women who were not American Indian). The shorthand of "American Indian," "Hispanic," "Black," "Asian," "Pacific Islander," "White," and "Other Race" is used throughout this report. For the maternal mortality data, there were zero or very few deaths to women who were American Indian, Asian, Pacific Islander, or Other races, therefore these subgroups cannot be reported separately and are combined into one "other race" group for that analysis.

### Location of Residence

A woman's location of residence was used to group women into 1 of 5 geographic categories:

- Chicago: Residential ZIP code within Chicago boundary
- Suburban Cook County: Residence in Cook County, but ZIP Code not within Chicago boundary
- · Counties Surrounding Cook County: Residence in DuPage, Kane, Lake, McHenry, or Will counties
- Urban Counties Outside Chicago Area: Residence in Champaign, DeKalb, Kankakee, Kendall, McLean, Macon, Madison, Peoria, Rock Island, Sangamon, St. Clair, Tazewell, or Winnebago counties
- Rural Counties: Residence in all other counties not referenced above (93 counties)

#### Insurance Status

Insurance status was classified based on the payer for during pregnancy or delivery.

#### **Body Mass Index**

Pre-pregnancy body mass index (BMI) was classified based on the pre-pregnancy height and weight using the formula weight (kg) / height2 (m). BMI is categorized into the following categories: underweight (<18.5), normal (18.5-24.9), overweight (25.0-29.9), obesity (30.0-39.9), and severe obesity (40.0 or higher). For some analyses, obesity and severe obesity are combined.

#### Adequacy of Prenatal Care

Adequacy of prenatal care was classified using the Adequacy of Prenatal Care Utilization Index,<sup>99</sup> which measures prenatal care received into four categories (inadequate, intermediate, adequate, and adequate plus) by combining information about the timing of prenatal care, the number of visits, and the infant's gestational age.

#### **Chronic Disease Methods**

The data in this section comes from live birth certificates for Illinois residents. In addition to information about the baby, the birth certificate records a variety of demographic and health-related information about the mother. Chronic diseases were identified from the birth certificates in the following ways:

**Obesity:** Pre-pregnancy height and weight as recorded on the birth certificate were used to calculate body mass index (BMI) using the formula weight (kg) / height2 (m). BMI is categorized into the following categories: underweight (<18.5), normal (18.5-24.9), overweight (25.0-29.9), obesity (30.0-39.9), and severe obesity (40.0 or higher). The indicator for percent obesity combines those in the obesity and severe obesity groups (BMI of 30.0 or higher).

**Hypertension:** Women with hypertension diagnosed prior to pregnancy, hypertension diagnosed during pregnancy (including pregnancy-induced hypertension or preeclampsia), or severe preeclampsia were defined as having hypertension.

**Diabetes:** Women with diabetes diagnosed before or during pregnancy were defined as having diabetes.

<sup>99</sup> Kotelchuck, M. (1994). An Evaluation of the Kessner Adequacy of Prenatal Care Index and a Proposed Adequacy of Prenatal Care Utilization Index. American Journal of Public Health, 84(9), 1414-1420. https://doi.org/10.2105/ajph.84.9.1414

To study trends in these conditions, single-year estimates were calculated for 2010-2020. The revised Illinois birth certificate was implemented in 2010, so it is not possible to obtain comparable data from older birth certificates.

To better understand how chronic disease impacts different subgroups of Illinois women, the percent of live births to women with hypertension, diabetes, and obesity were each calculated separately by various demographic characteristics on the birth certificates for 2018-2020 combined. The maps of obesity, hypertension, and diabetes were generated using county of residence from the birth certificate.

#### Mental Health and Substance Use Disorder Methods

Hospital discharge records with any International Classification of Diseases version 10 diagnosis code for mental health and/or substance use disorders were selected based on Clinical Classification Software (CCS) categories 650-652, 660-661, and 656-670. Using a probabilistic approach, birth certificates were matched to hospital discharge data for the maternal delivery hospitalization based on name, date of birth, date of delivery, and hospital name. The percentage of live births with a mental health condition or substance use disorder code on the maternal record was calculated based on the linked files.

To better understand how mental health conditions and substance use deliveries were recorded differentially for subgroups of Illinois women, the percent of live births to women with each condition type were calculated separately by various demographic characteristics for 2018-2020 combined.

- Race/ethnicity and geography/county of residence were determined from the birth certificate, but if missing on the birth record, then determined from the hospital discharge record.
- Age and education level were determined from the birth certificate.
- **Insurance type** was determined from the hospital discharge record.

Hospital discharge data are collected primarily for billing purposes but routinely used for state and national disease surveillance and research, including studies of maternal medical conditions and pregnancy complications. Using hospital discharge data to examine pregnancy-related mental health conditions and substance use disorders can be limited due to under-reporting. For example, during hospital stays for a birth/delivery, mental health and substance use disorders may be less likely to be included as a billing code than other medical conditions, especially conditions directly related to pregnancy, like preeclampsia. Due to this limitation, the rates of mental health and substance use disorders are likely underestimated by the hospital discharge data. However, hospital discharge data are the only statewide data source that can provide population-based estimates of mental health and substance use disorders among all deliveries, so this information is presented despite its limitations.

### **Severe Maternal Morbidity Methods**

The term "severe maternal morbidity" represents a group of potentially life-threatening unexpected maternal conditions or complications that occur during labor and delivery. The CDC developed a standard method to identify severe maternal morbidity from International Classification of Diseases, Version 10 (ICD-10) diagnosis and procedure codes representing 21 types of pregnancy complications associated with high risk of maternal death. To align with the definition of the severe maternal morbidity indicator used by CDC and the Maternal and Child Health Bureau, this report does not include blood transfusion as a severe maternal morbidity condition. Because ICD-10 codes slightly change over time to accommodate new billing procedures, there were slight edits to the algorithm of codes to identify delivery hospitalizations and severe maternal morbidity cases. Therefore, the data presented in this report are not comparable to previous reports.

For this report, 2016-2020 hospital discharge data from Illinois, Wisconsin, and Missouri hospitals were combined to identify delivery hospitalizations to Illinois residents occurring in any of these three states. Previous reports included only Illinois hospital data, so the data from this report are not comparable to previous reports. For most analyses, 2018-2020 data were used (involving more than 397,000 records), however for the county-level map, 2016-2020 data were used to generate more stable estimates for as many Illinois counties as possible. For deliveries occurring in Illinois hospitals, a probabilistic approach was used to match birth certificates to hospital discharge data for the maternal delivery hospitalization based on name, date of birth, date of delivery, and hospital name.

Severe maternal morbidity rates were calculated by dividing the number of severe maternal morbidity cases by the number of total deliveries and multiplying by 10,000. This gives a rate that represents the number of women experiencing severe maternal morbidity out of every 10,000 deliveries.

To better understand how chronic disease impacts different subgroups of Illinois women, severe maternal morbidity rates were calculated separately by various demographic and maternal health characteristics for 2018-2020 combined.

- Race/ethnicity and geography/county of residence were determined from the birth certificate, but if missing on the birth record, then determined from the hospital discharge record.
- Education level, adequacy of prenatal care, pre-pregnancy weight status, hypertension, and diabetes were determined from the birth certificate.
- Age and insurance type were determined from the hospital discharge record.

### Pregnancy-Associated and Pregnancy-Related Mortality Methods

The data presented throughout this section come from multiple sources, including death certificates, birth certificates, fetal death certificates, medical records, autopsy reports, coroner reports, police reports, and MMRC decision forms.

In this report, three years of mortality data are presented together to improve the reliability of the statistics. Because maternal mortality is a relatively rare event, case counts from a single year may be too small to draw meaningful conclusions, especially if the data are broken down into specific subgroups. Because of the small case counts, there may be random fluctuation from year to year; interpretation is improved when multiple years are combined.

### **Pregnancy-Related Mortality**

The "pregnancy-related mortality ratio" (PRMR) is displayed to allow for comparisons of the likelihood of mortality for different groups. The PRMR is calculated by dividing the number of pregnancy-related deaths by the number of live births and then multiplying by 100,000. The PRMR is interpreted as the number of pregnancy-related deaths that occurred for every 100,000 live births within a specific group of women. Because they standardize the population size, the PRMR is more meaningful than case counts for comparing the likelihood of death for different groups.

To better understand how maternal mortality impacts different subgroups of Illinois women, pregnancy-related mortality ratios were calculated separately by various demographic and maternal health characteristics for 2018-2020 combined.

- Race/ethnicity, education level and geography/county of residence were determined from the birth certificate, but if missing
  on the birth record, then determined from other medical records. Only information on women who were Illinois residents at
  the time of death are presented in this report.
- Age and insurance type were determined from the birth certificate. If the insurance information was not available from the birth certificate, medical records were used to identify insurance during pregnancy.
- Body mass index (BMI) was calculated from the live birth or fetal death certificate for the most recent pregnancy. If the height and weight information were not available on the birth or fetal death certificate, medical records were used to identify the pre-pregnancy height and weight and weight were not available in medical records, height and weight from the earliest known point in pregnancy were used.

The underlying cause of death was first classified as either injury, mental health conditions, or one of 10 medical conditions defined by the CDC's Pregnancy Mortality Surveillance System (PMSS): hemorrhage, infection, amniotic fluid embolism, thrombotic pulmonary embolism, hypertensive disorders of pregnancy, anesthesia complications, cerebrovascular accident, cardiomyopathy, other cardiovascular conditions, and other non-cardiovascular conditions. Next, further "mental health conditions" were divided into two sub-categories for analysis: one for deaths related to substance use disorder and one for other mental health conditions. The PMSS category "other non-cardiovascular deaths" was further divided into two sub-categories for analysis: one for deaths related to pre-existing chronic medical conditions and one for other conditions in pregnancy.

#### Discrimination

The data in this section comes from the 2018-2020 MMRCs review decisions on pregnancy-related deaths. Since the review of the 2018 deaths, the MMRCs have answered the question "Did discrimination contribute to the death?" Discrimination encompasses discrimination, interpersonal racism, and structural racism. This question is included in the standardized data collection form developed by the CDC called the "Committee Decision Form."

Among 2018-2020 deaths where the committee identified discrimination as a contributing to the death, a determination was made according to case review notes whether discrimination was due to race, language, structural racism, substance use disorder status, or weight status. There were no other types of identified discrimination. Pregnancy-related deaths were then categorized by race/ethnicity and type of discrimination.

#### Past Trauma

The data in this section includes Illinois Maternal Mortality Review Committee data between the years 2018 to 2020. Data was compiled from the social determinants of health checklist to capture information about the social and community context, education and language, health care barriers, and economic stability for each death reviewed by the MMRCs. This checklist allows the committee to specifically identify social, economic, and environmental factors that may have contributed to the death and to develop data-driven policy recommendations to address them. However, because medical records are not designed to capture detailed social histories, it is likely that the checklist underestimates the true experience of these issues. The data from these checklists therefore represent a conservative estimate of the extent to which each factor affected maternal deaths.

The social determinants of health checklists for pregnancy-related deaths were used to identify past trauma among pregnancy-related deaths. Trauma was present if any reviewed records noted a history of adverse childhood events, abuse (sexual, physical, or emotional), human trafficking, or other events described as traumatic. The data further examines patterns of past trauma by cause of death, previously defined.

#### Emergency Department Usage among Pregnancy-Related Deaths

The data in this section includes MMRC data between the years 2018 to 2020. Data was compiled from the death abstracts of the MMRCs to better identify emergency department use among pregnancy-related deaths. Emergency department use was identified if a woman visited the emergency department for any type of care, outside of the birth or death hospitalization, during or after pregnancy prior to her death. The data further examines patterns of emergency department use by demographic characteristics earlier described.

#### Pregnancy-Related Mortality Due to Substance Use Disorder

The data in this section includes information from toxicology reports for pregnancy-related deaths due to substance use disorder between the years 2015 to 2020. The data examines which substances were identified in each toxicology report and if there were one or more substances identified.

### **Community Context Data**

The county-level indicators for this analysis were downloaded from the Community Vital Signs Dashboard from 2017, which represented the midpoint of the period for the mortality analysis (2015-2020). The raw data for the indicators came from County Health Rankings (food insecurity, crime) and the American Community Survey (car ownership, poverty).

For each indicator, the 102 Illinois counties were ranked and divided into three equal groups of 34 counties (tertiles), which were labeled as low, medium, and high. The PRMR for 2015-2020 combined was calculated for each tertile group.