Report to the General Assembly: Illinois Task Force on Infant and Maternal Mortality Among African Americans (2021-2022)

December 2022

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EXECUTIVE SUMMARY

Maternal and infant mortality and morbidity remain significant indicators of national and state-level health. In addition, the crisis of non-Hispanic Black/African American infant and maternal mortality and morbidity in states, especially Illinois, mirrors the larger trends seen across the country. Non-Hispanic Black/African American women in Illinois are about three times as likely to experience a pregnancy-related death as White and Hispanic women.[1] Non-Hispanic Black/African American women also have the highest severe maternal morbidity (SMM) rate at 132.4 per 10,000 live births; this is more than two times the rate of non-Hispanic White women and significantly higher than Asian and Hispanic women.[1] There is an overwhelming volume of evidence highlighting how systemic racism throughout the health care system negatively impacts maternal morbidity and mortality for women of color.

For infants, those born to non-Hispanic Black/African American women die at rates more than double that of infants born to White, Hispanic, and Asian women in Illinois. Although the infant mortality rate (IMR) for infants born to non-Hispanic Black/African American women in Illinois decreased by 25% from 2000-2008, it did not significantly change from 2008 through 2018 (from 15.9 in 2000 to 13.7 in 2018). In contrast, the IMR decreased by 18% among infants born to White women (from 6.0 in 2000 to 5.0 in 2018) and by 29% among infants born to Hispanic women (from 7.4 in 2000 to 5.3 in 2018).[2] The stagnant high IMR among infants born to non-Hispanic Black/ African American women continues to highlight the need for targeted interventions that address underlying structural racism in a variety of contexts.

In July 2019, the Illinois General Assembly passed Public Act 101-0038, which created the Illinois Task Force on Infant and Maternal Mortality (IMMT) among African Americans Act (hereafter known as task force). The task force has been charged with working to identify and to present key strategies to decrease infant and maternal mortality among African Americans in Illinois. In this two-year report to the General Assembly, the task force presents the following:

[1] Illinois Department of Public Health. (2021). Illinois maternal morbidity and mortality report.
[2] IL Infant Mortality Data Report (illinois.gov)

KEY RECOMMENDATIONS

QUALITY IMPROVEMENT

1. **EVALUATIONS:** The state should ensure that organizations collaborating with the state maternal and child health (MCH) social service programs receive resources (i.e., personnel, financial, technical assistance, facilitators/ experts) necessary to measure their successes, gaps, and unmet needs. In addition, the state, through its various state agencies, should prioritize and fund independent evaluations of all statewide MCH programs to ensure they are reaching the intended populations, being implemented properly and efficiently, and positively impacting the community and MCH outcomes on consistent core measures. The evaluation team should include community members and individuals with "lived experience" to ensure the community voice is not only part of the decision making, in terms of metrics to assess, but also in the assessment itself.

2. **DATA COLLECTION AND SHARING:**

    a. The state should procure and implement a modernized and coordinated data system that connects all state-level MCH systems. This system should capture a core set of metrics within and across MCH systems, that is built upon federal mandates, requests of funders, and has community engagement in the planning and execution . Additionally, the core metrics should be built with input from women and families with lived experience.

    b. The proposed data system should have the capability of capturing data in multiple ways (e.g., manually, downloaded, and automatic transfer from electronic health records).

    c. The proposed data system should be flexible enough to allow state agencies to add additional data fields (across or within programs) as needed to generate standard, as well as customized reports, for the state agencies and the organizations that utilize the system.

    d. To build a unified, comprehensive, and coordinated data system that is statewide, resource allocation is essential from the state. This would include funding for personnel, workspace, review and evaluation of available systems, the cost of programming/software/hardware, etc. The task force recommends this be a priority in the fiscal 2024 Illinois budget planning process.

3. **COORDINATION:** The state should develop the infrastructure whereby all MCH efforts (e.g., government agency, community-based organization) can be catalogued and referenced by funder, communities, priority populations, scope of work, deliverables, metrics, and any other data point determined to be needed. This will allow for improved coordination, efficiency, transparency, and synergy to support the health of the most vulnerable and marginalized populations.

IMPACT AND EFFICIENCY

1. **GENERAL ASSEMBLY RECOMENDATIONS**

   a. The state should be proactive in assisting state residents who will be impacted by the sunset of the Public Health Emergency Act in 2023. It is estimated that as many as 25-35% of persons who have received Medicaid assistance during the pandemic years will lose coverage. This could impact their ability to receive health care, housing access, food access, and other forms of social supports. Assistance might include public service announcements informing the public of the imminent change, subsidizing navigators to assist those eligible for re-enrollment, advance notice to providers across the state, including medical, housing, childcare, social services and specialty care, shelter care, and others. The state should also provide resources to state agencies that will be potentially impacted by an influx of citizens seeking assistance as a result of the Public Health Emergency Act sunset. The state should consider allocating resources to birthing people even after the sunset of the Public Health Emergency Act. As research indicates, birthing people were significantly impacted by the COVID-19 pandemic, including experiencing poorer birth outcomes. Data further reflects, as is the focus of this task force, that these negative outcomes are more frequently and drastically experienced by African Americans.

   b. The state should adjust the timeframe for the task force to submit a report to the General Assembly to every two years as opposed to every year.

   c. This timeframe will afford the task force more time to collect and review data and input from key stakeholders; to create synergy between subcommittees and collaborators; and to generate thoughtful, impactful, and actionable recommendations that can be implemented statewide.

2. **SUPPORT and RESOURCES:**
   The task force also strongly encourages the state to provide financial investment to support collaborations with key stakeholders to develop and to implement recommendations.

   a. **Illinois Department of Public Health (IDPH):** The state should enhance IDPH's capacity to support the activities of the task force and its affiliated subcommittees and workgroups by supporting 1-2 dedicated full-time equivalents within the Office of Women's Health and Family Services (OWHFS) for the duration of the task force. This recommendation was included in the January 2021 inaugural report provided to the General Assembly.

   b. **Other resources** (subcommittee leads, internal purposes only)

      I. Materials and support needed to engage and document community outreach. This includes stipends, transcriptions, and analysis of meetings with community residents that will inform the work of the task force.

      II. Funding the effort to coordinate the efforts in the state, as per above.

BACKGROUND

The Issue: Black/African American Infant and Maternal Mortality and Morbidity and its consequences

Maternal Mortality

Maternal and infant health outcomes are important indicators of the overall health status of a country, state, or community. Maternal mortality is the death of a woman during pregnancy, at delivery, or shortly after delivery. More specifically, pregnancy-related death is the death of a woman during pregnancy or within one year of the end of pregnancy that occurred due to a pregnancy complication, a chain of events initiated by the pregnancy, or the aggravation of an unrelated condition by the physiologic effects of pregnancy.[3,4] Between 1987-2018, data show a consistent rising trend in pregnancy-related mortality in the United States.[5] The United States has the highest maternal mortality rate among high-income countries at 17.4 maternal deaths per 100,000 live births.[6,7]

In contrast, severe maternal morbidity (SMM) encompasses unexpected outcomes during the pregnant and postpartum period that result in significant short-term and long-term impacts to a woman's health. The most recent national data on SMM reveal a worsening trend and show that more than 50,000 women are affected each year.[8] Considering SMM, in addition to maternal mortality, uncovers an even more extensive range of challenges as there are an estimated 70-80 cases of SMM for each maternal death, not including the morbidities that occur after delivery[9].

The crisis of non-Hispanic Black/African American infant and maternal mortality and morbidity is felt at the state level, mirroring larger trends seen across the country. Non-Hispanic Black/African American women in Illinois are about three times as likely to experience a pregnancy-related death as White and Hispanic women.[4] Non-Hispanic Black/African American women also had the highest SMM rate at 132.4 per 10,000 live births; this is more than two times the rate of non-Hispanic White women and significantly higher than Asian and Hispanic women.[4] There is an overwhelming volume of evidence highlighting how systemic racism throughout the health care system negatively impacts maternal morbidity and mortality for women of color.

Infant Mortality

Infant mortality is defined as the death of an infant before their first birthday. Like maternal mortality and morbidity, there is a stark racial disparity in infant mortality across the country and within Illinois. In 2020, the overall infant mortality rate (IMR) in the United States was 5.7 deaths per 1,000 live births. What's more, infants born to non-Hispanic Black women are 2.5 times likely to die before their first birthday than infants born to non-Hispanic White women.[10]

The most current available data indicates that the United States' international ranking among the Organization for Cooperation and Development (OECD) is 33rd out of 38 countries reporting infant mortality.[11] This reflects a slightly worse ranking compared to prior years.

The infant mortality rate in Illinois dropped from 6.5 deaths per 1,000 births in 2018 to 5.5 deaths per 1,000 births in 2020. This resulted in an improved ranking of 26th best IMR among U.S. states (previously 36/50 in 2018).[12] While there

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[3] Centers for Disease Control and Prevention. Maternal Mortality

[4] Illinois Department of Public Health. (2021). Illinois maternal morbidity and mortality report.

[5] Pregnancy Mortality Surveillance System | Maternal and Infant Health | CDC

[6] Maternal Mortality Maternity Care US Compared 10 Other Countries | Commonwealth Fund

[7] Other high-income countries used in this analysis were Australia, Canada, France, Germany, the Netherlands, New Zealand, Norway, Sweden, Switzerland, and the United Kingdom.

[8] Severe Maternal Morbidity in the United States | Pregnancy | Reproductive Health |CDC

[9] Severe Maternal Morbidity in the United States: A Primer | Commonwealth Fund

[10] Infant Mortality | Maternal and Infant Health | Reproductive Health | CDC

[11] Health Status: Maternal and infant mortality (oecd.org)

[12] Stats of the States - Infant Mortality (cdc.gov)

has been recent modest improvement, the IMR in Illinois remains above the Healthy People 2030 target of 5.0 deaths per 1,000 live births.[13] Continued infant mortality data collection over the next few years will determine if this improvement is sustained.

A concentrated effort is needed to eliminate the racial disparity in infant deaths in Illinois, as well as infant mortality overall. Specifically, infants born to non-Hispanic Black/African American women die at rates more than double that of infants born to White, Hispanic, and Asian women in Illinois.[14] Although the IMR for infants born to non-Hispanic Black/African American women in Illinois decreased by 25% from 2000-2008, it did not significantly change from 2008 through 2018 (from 15.9 in 2000 to 13.7 in 2018). In contrast, the IMR decreased by 18% among infants born to White women (from 6.0 in 2000 to 5.0 in 2018) and by 29% among infants born to Hispanic women (from 7.4 in 2000 to 5.3 in 2018).[14] The stagnant high IMR among infants born to non-Hispanic Black/African American women highlights the need for targeted interventions that address underlying structural racism in a variety of contexts.

The leading causes of infant death in Illinois include prematurity and/or fetal malnutrition, congenital and chromosomal abnormalities (birth defects), sudden unexpected infant death (SUID), and pregnancy and delivery complications. Among the leading causes of death, the largest racial/ethnic disparity occurs in SUID deaths and prematurity/malnutrition deaths, where infants born to non-Hispanic Black/African American women are six times and three times as likely to die as infants born to non-Hispanic White women, respectively. In the last 20 years, approximately two-thirds of all infant deaths in Illinois occurred during the neonatal period (0-27 days after birth).[14]

LEGISLATIVE MANDATE

In July 2019, the Illinois General Assembly passed Public Act 101-0038, establishing the Illinois Task Force on Infant and Maternal Mortality among African Americans (hereinafter referred to as "task force"). The task Ffrce is charged with identifying best practices to decrease infant and maternal mortality among African Americans in Illinois. More specifically, it is charged with the following:

1. Reviewing research that substantiates the connections between a mother's health before, during, and between pregnancies, as well as that of her child across the life course.
2. Reviewing comprehensive, nationwide data collection on maternal deaths and complications, including data disaggregated by race, geography, and socioeconomic status.
3. Reviewing the data sets that include information on social and environmental risk factors for women and infants of color.
4. Reviewing better assessments and analysis on the impact of overt and covert racism on toxic stress and pregnancy-related outcomes for women and infants of color.
5. Reviewing research to identify best practices and effective interventions for improving the quality and safety of maternity care.
6. Reviewing research to identify best practices and effective interventions, as well as health outcomes before and during pregnancy, in order to address pre-disease pathways of adverse maternal and infant health.
7. Reviewing research to identify effective interventions for addressing social determinants of health disparities in maternal and infant health outcomes.
8. Producing an annual report detailing findings, including specific recommendations, if any, and any other information the task force may deem proper in furtherance of its duties.

[13] Infants - Healthy People 2030 | health.gov
[14] IL Infant Mortality Data Report (illinois.gov)

TASK FORCE ON INFANT AND MATERNAL MORTALITY AMONG AFRICAN AMERICANS (TASK FORCE)

Membership
The legislation required the task force to consist of 22 members representing various qualifications and clinical backgrounds. Members include state agency representatives, hospitals partners, pediatricians, obstetricians, maternal and child health advocates, neonatal professionals, public health experts, insurance industry representatives, and community members.

For more information on the composition of the task force, see **Appendix 1.**

Meetings and Activities
The task force is required to meet quarterly, a minimum of four times per year. In 2021, the Task Force met six times and, in 2022, the task force met five times.

2021 Meetings

In 2021, the task force began the year focused on drafting by-laws to provide guidance and set expectations for the voting members and the officers leading the overall task force and its respective subcommittees. The by-laws were finalized and approved by the task force at a special meeting in July 2021.

Other meetings focused on presentations and discussions regarding IDPH's 2021 Maternal Morbidity and Mortality Report, Illinois Department of Healthcare and Family Services' (HFS) Medicaid expansion, COVID-19 and pregnant and breastfeeding women, doula services and Medicaid reimbursement, and implicit bias training for all individuals that interface with pregnant persons and babies in the health care system. For the final meeting of 2021, the task force featured Arthur R. James, MD, FACOG, discussed how history and past discriminatory practices contributed to racial disparities in infant mortatlity, emphasized the importance of structural determinants, and challenged Illinois to make a concerted effort to decrease infant mortality among Black babies born in the state.

2022 Meetings

In 2022, the task force began with two assignments. The first was to discuss with HFS the new provider types that could be covered by Medicaid reimbursement during the postpartum period. More specifically, the task force provided insight on the "public health nurse" and "medical caseworker" categories. The second assignment focused on analyzing the task force's strengths, weaknesses, opportunities, and desired outcomes (SWOD analysis).

For more information on the SWOD analysis, see **Appendix 2**.

Other activities covered in the remaining meetings included discussions with the key partners and stakeholders. The task force had a presentation from a subcommittee of the Illinois Maternal Health Task Force (IMHTF), which is part of the University of Illinois' federal grant with the Health Resources and Services Administration (HRSA). IMHTF's Roots and Structural Causes of Health Inequity Subcommittee shared it's three key strategies, which include addressing homelessness and pregnant women. This subcommittee highlights how the task force collaborated with others. Dara Basley who sits on the task force, also served as the chair of the IMHTF subcommittee.

The task force also had presentations and discussions regarding the UI Health Two-Generation Clinic, the Chicago South Side Birthing Center, and Chicago Department of Public Health's Family Connects. The goal of the UI Health clinic is to increase access to high quality care, serve families with limited access, and provide wraparound services. The primary care clinic touches on the entire family unit and not just mothers and babies. The Chicago South Side Birthing Center will be an independent Black led birth center that provides intergenerational care through a holistic approach. According to an information sheet from lead contact, Jeanine Logan, a certified nurse midwife and member of the task force, the

birth center will offer a low-risk option for birth and mixed risk option for reproductive health care to people in their neighborhood and community with hopes of closing the disparity amongst Black birthing people and children on the South Side of Chicago. Family Connects Chicago is a pilot in-home nurse service available to Chicago families with newborns. A registered nurse visits people's home at no cost around three weeks after birth to check on the birthing person, baby, and the whole family. Anyone with a newborn can participate, including foster and adoptive parents. The service is implemented by Chicago Department of Public Health (CDPH) in partnership with Humboldt Park Health, Rush University Medical Center, Mount Sinai Hospital, and University of Chicago Medicine. The CDPH plans to explore expansion beyond these hospitals in future.

Another notable activity during 2022 was the task force's viewing of the 22-minute short film entitled "Toxic: A Black Woman's Story." The film created a dramatization of the various issues Black/African American women/families encounter on a regular basis, such as chronic stressors, micro aggressions, and re-encountering of past stresses. Many members expressed how the different aspects of the film resonated with them and shared their personal stories. The task force plans to explore ways to help women self-advocate when they know that something is wrong with their pregnancy or after pregnancy, and how do women get their providers to listen and respond accordingly.

For its final 2022 meeting, the task force held nominations for new officers. After the nomination committee presented the candidates to the full task force, Angela Ellison and Tamela Milan-Alexander were re-elected to their offices as chair and co-chair, respectively. They will serve an additional three years in these positions, 2023 through 2025.

TASK FORCE SUBCOMMITTEES

The task force subcommittees have continued to help address the legislative charge by engaging in various activities and providing recommendations that focus on Black/African American infant and maternal health. Many of their activities overlap and complement each other.

For more information on the composition of the task force subcommittees, see **Appendix 3.**

Community Engagement Subcommittee

Co-Leads: Shirley Fleming, BSN, MN, CNM, MDiv, DrPH
Co-Director of the Center for Faith and Community Health Transformation
Director, Faith Health Promotion, Retired
Office of Community Engagement and Neighborhood Health Partnerships
University of Illinois at Chicago

Tamela D. Milan-Alexander, MPPA
Community Engagement Director
EverThrive Illinois

Objectives of Overall Task Force Assigned to the Subcommittee

1. Research regarding women's health before, during, and between pregnancies.
2. Review data on social and environmental risk factors for women and infants of color.

Activities

The Community Engagement Subcommittee focused on capturing the voices of women with lived experiences. They partnered with the University of Illinois Chicago (UIC) to incorporate the voice of reproductive age women of color in the storytelling and listening sessions. In 2022, the subcommittee hosted listening sessions in Chicago, East St. Louis, and Rockford. These listening sessions sought to gather data about the experiences of Black/African American women/families during preconception, pregnancy, labor and birth, and postpartum. The sessions in Chicago and East St. Louis were held in a physical location while the Rockford session was held virtually to reach more people across the central part of the state. The committee is looking to continue this work into 2023 and include a session focused on women with a private insurance.

The subcommittee leveraged its relationship with UIC to secure partial financial support for and student assistance in conducting and analyzing the results from the listening sessions. Currently, the qualitative data is being analyzed and the subcommittee expects to have a report of the findings in 2023. This information will inform the task force's final recommendations for improving pregnancy and birth outcomes.

Another noteworthy subcommittee activity was its partnering with an IDPH epidemiology fellow to design and to conduct an environmental scan of the social/environmental context in which Black/African American mothers live, work, and play before, during, and after pregnancy.

While the subcommittee has made progress in capturing the voices of the community, challenges still exist, including recruiting participants for the listening sessions as well as identifying and securing human resources to perform administrative and logistics for the sessions, data gathering, and analysis. To address these issues, the subcommittee strongly recommends funding for the task force to support the engagement of Black/African American childbearing families in the assessment of practices and experiences.

Future activities for the Community Engagement Subcommittee include:

- Reviewing the environmental scan data, storytelling, and data from the listening sessions to expand understanding of the experiences and wisdom of Black/African American women/ families (before, during, and after pregnancy) and their infants.
- Integrating the perspectives and wisdom of Black/African American women/families in developing policy recommendations that promote equity before, during, and after pregnancy. This activity seeks to change the paradigm of treating Black/African American women/families as objects without voices or agency, but rather treat them as subjects with agency that proactively partner and contribute to policy development.
- Partnering with the Programs and Best Practices Subcommittee to research national models for promoting health equity in the birth outcomes of Black/African American women/families and infants.

Programs and Best Practices Subcommittee

Co-Leads: Dara M. Basley, MA, LCSW
Director of Health Equity
Access Community Health Network

Patricia Ann Lee King, PhD, MSW
State Project Director and Quality Lead
Illinois Perinatal Quality Collaborative

Objectives of Overall Task Force Assigned to the Subcommittee

1. Identify best practices to improve quality and safe maternity care.
2. Identify effective interventions to address the social determinants of health disparities in maternal and infant outcomes.

Activities

The Programs and Best Practices Subcommittee has focused on identifying programs and best practices for addressing the issues of Black/African American infant and maternal health. After discussing a handful of programs in 2020, the subcommittee concluded that no single program could decrease maternal or infant mortality on its own, but rather, combining elements from multiple programs may best achieve the goal. To begin compiling the elements, the group searched for published evaluation reports. Unfortunately, there was a paucity of evaluations (especially those of community-based programs) available to determine the programs' success or lack thereof.

Consequently, in 2021, the subcommittee decided to complete a more in-depth review of each program. To facilitate this review, the subcommittee designed a form that helped review any available program evaluations, developed key questions to ask existing program staff, and invited program administrators and staff to share their insight on the operations and impact of their respective programs.

For more information regarding the tool and discussion questions for programs, see **Appendix 4.**

To date, the subcommittee has reviewed the state supported family case management (FCM) program. It invited the Illinois Department of Human Services (DHS) and staff members from one of the organizations that offers FCM to families in the Chicagoland area to a subcommittee meeting. During the meeting, the subcommittee was able to hear different perspectives on implementing and administering FCM. They learned about key issues encountered, which included caseloads, the Cornerstone system, and data collection and reporting. To address some of these issues, the subcommittee recommends the state carry out the following:

- Prioritize the evaluation of all statewide MCH programs.
- Ensure social service programs receive the necessary resources (i.e., personnel, financial, technical assistance, facilitators/experts) to measure their successes, gaps, and unmet needs.
- Develop and implement an updated and coordinated data system that connects all state-level MCH programming.
- Develop a process to coordinate and share data across state agencies, including setting core metrics within and across MCH programs that organizations must report to their state funding agency(ies).

Future activities for the Programs and Best Practices Subcommittee include:

- Reviewing all Family Connects programs in Illinois. This will include inviting staff to meetings to share their insight on the operations and impact of their respective programs.
- Leveraging information from the Community Engagement Subcommittee regarding women/family experiences and interactions with the various programs.

Systems Subcommittee

Co-Leads: Glendean Burton, MPH, BSN, RN, CLC
Maternal and Child Health (MCH) Nurse Consultant
Maternal, Infant, and Early Childhood Home Visiting (MIECHV) Illinois
Sudden Infant Death Services (SIDS) of Illinois

Catherine Harth, MD
Physician
Associate Professor of Obstetrics and Gynecology
University of Chicago Medicine

Objectives of Overall Task Force Assigned to the Subcommittee

1. Identify key areas and gaps in the educational, political, and social systems that impact the health and wellbeing of Black/African American women and babies.
2. Review nationwide data on maternal deaths and complications, including data by race, geography, and socioeconomic status.
3. Identify best practices to improve quality and safe maternity care.

Activities

The Systems Subcommittee convened workgroups of various stakeholders to identify key system issues and programs that can help the task force address infant and maternal mortality. This approach illustrates the value the subcommittee has placed on including an array of voices with different perspectives at the table.

The subcommittee held four open meetings between April and December 2021 to discuss doulas and their services. Participants included doulas with various levels of training and focus as well as staff from IDPH and HFS. HFS provided a question guide to assist individuals and groups in elicitation of comment on critical areas within the rulemaking process related to doulas. The group discussed ideas about training, certification, scope of care, and reimbursement and was able to provide HFS with insight information.

The subcommittee also held several open calls to discuss the Adverse Pregnancy Outcomes Reporting System (APORS) and the High-Risk Infant Follow-up (HRIF) Program. Topics discussed included referrals, challenges of follow ups, increasing community awareness of services, and workforce challenges.

Telehealth was another key issue the subcommittee focused on in 2021 and 2022. The subcommittee collaborated with UIC's Illinois Maternal Health Task Force (IMHTF) under the federally-funded I PROMOTE-IL grant. The subcommittee contributed to the content of a telehealth brief that defines telehealth and impresses upon the reader the importance of continuing to support telehealth services beyond the COVID-19 pandemic. Also, the two groups worked on a one-page telehealth infographic for patients to enhance their understanding of telehealth and its importance. Currently, the document is being finalized and will be shared with HFS for comment and consideration in 2023.

Future activities for the Systems Subcommittee include the following:

- Delving more into infant mortality and developing a definition for pediatric deserts.
- Continuing to explore the state's APORS and HRIF services and alternative care services. This may include exploring training registered nurses on remote physical assessment to complete HRIF visits as well as working with the other subcommittees
- In light of the one-year postpartum coverage extension, working with the overall task force and its subcommittees to promote strategies that increase Black/African American women/families' participation in postpartum care and emphasizing the importance of the state to track and report on the rate of participation.

KEY RECOMMENDATIONS

For this report, the task force recommends the following:

QUALITY IMPROVEMENT

1. **EVALUATIONS:** The state should ensure that organizations collaborating with the state MCH social service programs receive resources (i.e., personnel, financial, technical assistance, facilitators/ experts) necessary to measure their successes, gaps, and unmet needs. In addition, the state, through its various state agencies, should prioritize and fund independent evaluations of all statewide MCH programs to ensure they are reaching the intended populations, being implemented properly and efficiently, and positively impacting the community and MCH outcomes on consistent core measures. The evaluation team should include community members and individuals with lived experience to ensure the community voice is not only part of the decision making in terms of metrics to assess, but also in the assessment itself.

2. **DATA COLLECTION AND SHARING:**

   a. The state should procure and implement a modernized and coordinated data system that connects all state-level MCH systems. This system should capture a core set of metrics within and across MCH systems that is built upon federal mandates, requests of funders, and has community engagement in the planning and execution. Additionally, the core metrics should be built with input from women and families with lived experience.

   b. The proposed data system should have the capability of capturing data in multiple ways (e.g., manually, downloaded, and automatic transfer from electronic health records).

   c. The proposed data system should be flexible enough to allow state agencies to add additional data fields (across or within programs) as needed to generate standard, as well as customized reports for the state agencies and the organizations that utilize the system.

   d. To build a unified, comprehensive, and coordinated data system that is statewide, state resources are essential. This would include funding for personnel, workspace, review and evaluation of available systems, the cost of programming/software/hardware, etc. The task force recommends that this be a priority in the fiscal 2024 Illinois budget planning process.

3. **COORDINATION:** The state should develop the infrastructure whereby all MCH efforts (e.g., government agency, community-based organization) can be catalogued and referenced by funder, communities, priority populations, scope of work, deliverables, metrics, and any other data point determined to be needed. This will allow for improved coordination, efficiency, transparency, and synergy to support the health of the most vulnerable and marginalized populations.

IMPACT AND EFFICIENCY

1. **GENERAL ASSEMBLY RECOMMENDATIONS**

    a. The state should be proactive in assisting state residents who will be impacted by the sunset of the Public Health Emergency Act in 2023. It is estimated that as many as 25-35% of persons who have received Medicaid assistance during the pandemic years will lose coverage. This could impact the ability to receive health care, housing access, food access, and other forms of social supports. Assistance might include public service announcements informing the public of the imminent change, subsidizing navigators to assist those eligible for re-enrollment, advance notice to providers across the state, including medical, housing, childcare, social services and specialty care, shelter care, and others. The state should also provide resources to state agencies that will be potentially impacted by an influx of citizens seeking assistance as a result of the Public Health Emergency Act sunset. The state should consider allocating resources to birthing people even after the sunset of the Public Health Emergency Act. As research indicates, birthing people were significantly impacted by the COVID-19 pandemic, including experiencing poorer birth outcomes. Data further reflects, as is the focus of this task force, that these negative outcomes are more frequently and drastically experienced by African Americans.

    b. The state should adjust the timeframe for the task force to submit a report to the General Assembly to every two years as opposed to every year.

    c. This timeframe will afford the task force more time to collect and review data and input from key stakeholders, to create synergy between subcommittees and collaborators, and to generate thoughtful, impactful, and actionable recommendations that can be implemented statewide.

2. **SUPPORT and RESOURCES**
The task force also strongly encourages the state to provide financial investment to support collaborations with key stakeholders to develop and to implement recommendations.

    a. **IDPH:** The state should enhance IDPH's capacity to support the activities of the task force and its affiliated subcommittees and workgroups by supporting 1-2 dedicated full time equivalents within the Office of Women's Health and Family Services (OWHFS) for the duration of the task force. This recommendation was included in the January 2021 inaugural report provided to the General Assembly.

    b. **Other resources** (subcommittee leads, internal purposes only)

        I. Materials and support needed to engage and document community outreach. This includes stipends, transcriptions, and analysis of meetings with community residents that will inform the work of the task force.

        II. Funding the effort to coordinate the efforts in the state, as per above.

FUTURE ACTIVITIES

The task force expects to build upon its recommendations and activities in future annual reports. It is noted that the task force has focused most of its efforts on maternal health. However, future activities and recommendations will address both maternal and infant health for Black/African Americans (e.g., the Systems Subcommittee is beginning to explore issues with pediatric deserts). Below are a few of the activities planned for the task force and its subcommittees when they resume meetings in 2023.

- Listening Sessions: The task force will continue to collect the perspectives of women/ families with lived experiences though the listening sessions. The sessions will be conducted throughout the state with Black/African American community members. Existing and newly collected data will be analyzed to make recommendations regarding interventions that could potentially improve Black/African American infant and maternal health outcomes.

- Program Reviews: The task force will continue to invite administrators and staff from key MCH programs to share information regarding their programs. It is anticipated that the task force will take an in-depth look at four Illinois-based programs in 2023 (e.g., Family Connects).

- Doula Certification and Coverage: The task force will continue to provide insight and to collect input regarding doula training and certification. The task force will also identify ways to advocate for Medicaid reimbursement of comprehensive doula services of prenatal through postpartum care.

- Collaborations/Partnerships: In its efforts to address the impact of racism on pregnancy-related outcomes and identify effective interventions and system changes that would improve outcomes for Black/African American women and infants, the task force will collaborate with interested and engaged maternal and child health partners across the state. Collaborations include working with the Illinois Maternal Mortality Review committees, Illinois Maternal Health Task Force (UIC I-PROMOTE IL Task Force), and the Illinois Title V Program. Additionally, the task force will seek to work with the Fetal and Infant Mortality Review (FIMR) Program, the Governor’s Office of Early Childhood Development, Illinois Perinatal Quality Collaborative (ILPQC), and the various state agencies.

CONCLUSION

The task force has and will continue to advise and to assist IDPH regarding Black/African American infant and maternal mortality. Considering the COVID-19 public health emergency, the task force has made significant progress on reviewing data, evidence, best practices, and interventions. While this report focuses heavily on maternal health, future reports will address infant health as well. This is just the first of many steps in addressing these issues. Much work lies ahead. Work that will challenge the status quo, identify and confront underlying structures and institutions that facilitate inequities in care, and produce recommendations for programs, research, and interventions that will improve Black/African American infant and maternal health outcomes in Illinois.

Appendix 1: Task Force Committee Membership (as of 12/08/2022)

Committee Member	Specialty/Sub-Specialty/Occupation	Affiliation
Three Members from the various State Departments		
Kenya D. McRae, JD, PhD	Director of Public Health or Designee	Illinois Department of Public Health, Office of Women's Health and Family Services
Dawn R. Wells	Director of Healthcare and Family Services or Designee	Illinois Department of Healthcare and Family Services
Marie Versher, MSW	Secretary of Human Services or Designee	Illinois Department of Human Services
Two Medical Providers (infant and community health)		
Dara M. Basley, MA, LCSW	Manager of Health Equity	Access Community Health Network
Lisa Green, DO, MPH	Chief Executive Officer // Attending Physician	Family Christian Health Center
Two OB/GYN Specialists		
Catherine Harth, MD, FACOG	Physician and Associate Professor Section of General Obstetrics and Gynecology	University of Chicago Medicine
Gloria L. Elam, MD, MPH	Physician, Labor and Delivery Medical Director, and Associate Professor of Clinical Obstetrics and Gynecology	University of Illinois at Chicago
Two Professionally trained Doulas		
Stephanie James, CD, CLC	Doula Specialist, Lactation Counselor	Peaceful Birth Practices, LLC
Jasmine Martin, BS	Doula	Children's Home and Aid
Two Registered Nurses		
Virginia Julion, RN, MPH	Fetal and Infant Mortality Review Coordinator (Retired)	University of Chicago
Glendean Burton, MPH, BSN, RN, CLC	Maternal and Child Health (MCH) Nurse Consultant; Maternal, Infant, and Early Childhood Home Visiting (MIECHV), Sudden Infant Death Services (SIDS) of Illinois	IDHS/Children's Home and Aid; SIDS of Illinois
Two Certified Nurse Midwives		

Committee Member	Specialty/Sub-Specialty/Occupation	Affiliation
Shirley Fleming, BSN, MN, CNM, MDiv, DrPH	Co-Director of the Center for Faith and Community Health Transformation; Director, Faith Health Promotion, Retired	University of Illinois at Chicago, Office of Community Engagement and Neighborhood Health Partnerships
Jeanine Logan, MPH, MSN, CNM	Certified Nurse Midwife, Birth Assistant/Registered Nurse	PCC Community Wellness Center
Four Community Experts on Maternal and Infant Health		
Angela Ellison, PhD, MS.Ed (Chair)	Senior Director	University of Illinois at Chicago, Office of Community Engagement and Neighborhood Health Partnerships
Cheryl Floyd, MS.Ed	Director, Center for Health Promotion and Wellness	Winnebago County Health Department
OPEN		
Paula Brodie, MS	Vice President Support Services	Southern Illinois Healthcare Foundation
One Member Representative of Hospital Leadership		
OPEN		
One Member Representative of Health Insurance Company		
OPEN		
One African American Woman of Childbearing Age (experienced traumatic pregnancy)		
Tamela Milan-Alexander, MPPA (Co-Chair)	Community Engagement Director	EverThrive Illinois
One Physician Representative of the Illinois Academy of Family Physicians		
Santina Wheat, MD, MPH, FAAFP, AAHIVS	Program Director, Family Physician with OB	Erie Family Health Centers
One Physician Representative of the Illinois Chapter of AAP (ICAAP)		
Daniel Johnson, MD	Pediatrician/Pediatric Infectious Disease Specialist	University of Chicago Medicine

Appendix 2: Task Force SWOD Analysis

S W O ~~T~~ D ANALYSIS

Strengths
- Passion/commitment
- Going beyond the silos – collaborate with others and seek synergy (connections with the other MCH related task forces and groups)
- Diversity of education and experiences – has helped balance perspectives
- Diverse representation; ability to work on a number of initiatives because of the work of the Sub-committees
- Broad expertise
- Lived experience
- Focused and committed to African American women and families
    - Seeing women as individuals as opposed to numbers (more humanizing)
    - Amplify the AA experience
- Connected to a state agency (IDPH)
- Focusing on strengths and challenges (assets and barriers/deficits)
- Timing of existence
- Shined a light on the issue

Weaknesses/ Challenges
- We do not have women engaged in services as group members
- Lack of funding to support activities
- Members are all volunteers
- Pandemic has posed many challenges (virtual meetings, work challenges, own health)
- Limited interaction with the community (e.g., listening sessions)
- Work well with others, but have not crafted a strategic plan to work with other on maternal and infant mortality
- The overlapping of terms and responsibilities.
- Needing to understand the economic lens to address the issues around maternal and infant mortality. Knowing the terms and language
- Things that have worked well have stopped and unable to highlight (Challenges in identifying and implementing best practices)
- Have not conducted a deeper dive for the whole state. Need more holistic view of the state.
- we are splintered in our approach. Also, it sometimes feels like we are brought in at the tail end (like after legislation is adopted), to clarify, to figure out how to make something work, vs leading the charge
- Policy makers not at the table
- Legislation language is limiting and there are other key players that should be at the table (housing, education, criminal justice system, communities of faith)

S W O ~~T~~ D ANALYSIS

Opportunities
- Hold a joint meeting/conversation to bring those key players not in the legislation together. Special meeting. Policy makers could call the meeting.
- Look into these other committees to create a strategic plan that specifically address AA women.
- Conduct the deep dive across all of Illinois
- Bring in key people from the community to join a special meeting or attend the meetings on a regular basis.
- Develop real stories that put a face and experience to the purpose and passion of the task force.
- Request funding and additional support for the Task Force.

Desired Outcomes
- Health care of AA women be better.
- Provide an opportunity to use our voices to change systems that are bias or negatively impact AA women health. Real policy changes so that health care gets better.
- Make recommendation of at least 5 best practices for AA women
- Fully funded staff and support for activities
- Routine opportunity to listen to the voices of women (state-wide systematic process to collect the experiences of the women – likes and dislikes). Have the voices of the consumer drive the policy.
- Have the committee and medical system understand the importance and value of doula and CHW services to AA women.
- The decreasing the gap between AA and White women/birthing persons and increase awareness of the gap.
- Make such an impact that a committee is not needed. Permanent changes that structures and support are already in place for ALL.

Appendix 3: Subcommittee Members, Meeting Attendees, and Meeting Dates

Community Engagement Subcommittee	
Shirley Fleming, Co-Lead* Tamela Milan-Alexander, Co-Lead* Cheryl Floyd* Marie Versher* Shirley Scott Tia Britton Virginia Julion*	Meetings: • 9 meetings in 2021 • 7 meetings in 2022
Programs and Best Practices Subcommittee	
Dara Gray-Basely, Co-Lead* Patricia Lee King, Co-Lead Angela Ellison* Cheryl Wolfe* Cynthia Price Ellen Mason Gloria Elam* Joanna Su Jose Ortiz Kenya McRae* Santina Wheat*	Meetings: • 7 meetings in 2021 • 5 meetings in 2022
Systems Subcommittee	
Catherine Harth, Co-Lead* Glendean Burton, Co-Lead* Angelique Muhammad Ann Borders Arden Handler Bakahia Madison Cindy Mitchell Cynthia Wilson Daniel Johnson* Glenda Burnett Jeanine Logan* Jessica Davenport Jessica Lamberson Paula Brodie* Sarah Bier Shondra Clay Timika Anderson Reeves	Meetings: • 10 meetings in 2021 • 9 meetings in 2022

**Task Force Members*

Appendix 4: Program Review Form and Program Questions

Task Force for Infant and Maternal Mortality Among African Americans

Programs and Best Practices Subcommittee:

Program Review

NAME OF PROGRAM:

ORGANIZATION LEADING PROGRAM:

PURPOSE OF PROGRAM/BRIEF STATEMENT ON THE IMPORTANCE OF PROGRAM:

SOCIAL DETERMINANTS OF HEALTH ADDRESSED BY PROGRAM:

___ Published Evaluation

___ Unpublished Evaluation

___ General Report

___ Other

___ Existing Program

___ Historical Program

___ Temporary program

TARGET POPULATION & AREA OF IMPLEMENTATION:

Age	
Race/Ethnicity	
State	
County (if Illinois)	
Rural/Urban Setting	
Income Level	
Other Special Characteristics of Target Populations	

TIMEFRAME OF PROGRAM:

WHEN IS A PERSON ELIGIBLE FOR THE PROGRAM -PROVIDE PERINATAL STAGE / EVENT (AS APPLICABLE)?		HOW LONG DOES THE PROGRAM LAST?
Stage/Event	*(x) all that apply*	
Child-Bearing Age		
Prenatal		
Labor and Delivery		
Post-Partum		
Full Perinatal lifespan		
Other		

OBJECTIVE OF PROGRAM:

OBJECTIVE (AIM) #	DESCRIPTION

INPUTS:

	DESCRIPTION (SPECIFICS)
Staff Delivering Program and Roles:	
Funding Resources:	
Direct Resources to participants:	
Resources leveraged by the program for its use (non-monetary): (tools?)	
Other:	

ACTIVITIES/COMPONENT OF PROGRAMS:

ACTIVITY/COMPONENT *(capture all touch points)*	PURPOSE OF ACTIVITY	FREQUENCY OF ACTIVITY (INCLUDE MIN AND MAX)

Provide any notes on how quality is defined and captured:

OUTPUTS: What products (i.e., materials, units of services delivered) are produced by the activities?

OUTCOMES/RESULTS:

SHORT-/MID-TERM OUTCOMES	LONG-TERM OUTCOMES

Note:

Results:

Conclusions:

DATA COLLECTION:

a. How was Data Collected

TYPE OF DATA	HOW COLLECTED (E.G., SELF-REPORT, OBSERVATION)

b. *How is/was success measured? Discuss who determined it was successful (funder/program/etc.)? Does the subcommittee agree with how the program was measured and whether it was successful or not (Please keep in mind how the study was designed)?*

STRENGTHS OF PROGRAM *(Discuss what was in the write up as well as thoughts of the subcommittee)*:

CHALLENGES/CRITIQUES/LIMITATIONS OF PROGRAM *(Discuss what was in the write up as well as thoughts of the subcommittee)*:

WHAT ARE SOME KEY TAKE AWAYS FROM THE PROGRAM?

a. Are their key elements that need to be noted?

ELEMENT/OTHER NOTEWORTHY ITEMS	WHY IS THE ELEMENT/ITEM IMPORTANT?

b. Opportunities of Program (What can be leveraged?):

PROGRAM CONTACT:

Name of Primary Contact:

Email address:

Phone number:

Website: