2020 Report to the General Assembly: Illinois Task Force on Infant and Maternal Mortality Among African Americans

January 2021

Contents

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Executive Summary

Maternal and infant mortality and morbidity are significant indicators of national health. In the most recent estimates available, Illinois reports a pregnancy-related mortality rate of 23 maternal deaths per 100,000 live births, a severe maternal morbidity rate of 51.4 per 10,000 births, and an infant mortality rate of 6.5 infant deaths per 1,000 live births, ranking 36th out of 50 states and the District of Columbia. In all of these categories, non-Hispanic Black/African American mothers and infants die or are injured at significantly higher rates than their non-Hispanic, White counterparts. Systemic racism in health care and chronic health conditions negatively impact infant and maternal morbidity and mortality.

In July 2019, the Illinois General Assembly passed Public Act 101-0028, creating the Illinois Task Force on Infant and Maternal Mortality among African Americans Act (hereafter known as "Task Force"). The Task Force was charged with working to identify and to present key strategies to decrease infant and maternal mortality among African Americans in Illinois. In its initial annual report, the Task Force presents the following:

Key Recommendations

- PROVIDER EDUCATION: Health care systems should require standardized implicit bias, racial equity, and trauma-informed care education for all providers who work with pregnant and postpartum patients to enhance the level of competency across the state.

- ACCESS AND EQUITABLE CARE – TELEHEALTH: (1) The state, through the Illinois Department of Healthcare and Family Services (HFS), should expand and standardize the acceptability, accessibility, utilization, and best practices for telehealth, including phone visits for reproductive-age, pregnant and postpartum women and their infants up to age 1; and (2) Managed care organizations (MCOs) and third-party payors should establish standards of care utilizing telehealth as a vital modality of contact and ensure that all patients have access to equitable and quality preconception, prenatal, labor and delivery, and postpartum care.

- ACCESS AND EQUITABLE CARE - BIRTHING CENTERS: (1) The state should complete its evaluation of the demonstration program authorized by the Alternative Health Care Delivery Act [210 ILCS 3] and enhance its support of free-standing birthing centers to address maternity deserts in Black/African American communities; and (2) Community organizations should explore opportunities to establish free-standing birthing centers to address maternity deserts in Black/African American communities.

- POSTPARTUM MEDICAID REIMBURSEMENT: The state through HFS should reimagine the current framework of bundled Medicaid reimbursement for obstetric care by unbundling the postpartum visit from prenatal care and labor and delivery services. Specifically, the state should support the implementation of a universal early postpartum visit within the first three weeks and a comprehensive visit within 4-12 weeks postpartum. This will improve postpartum access to care and positively impact the incidence of maternal morbidity and mortality in the postpartum period.

- DOULA CERTIFICATION AND COVERAGE: (1) The state should support the increased utilization and reimbursement of doula services for prenatal and postpartum care, which includes supporting the development of an educational infrastructure for the certification of community-based doulas across the state; and (2) Academic institutions and community-based organizations should establish community-based doula certification programs that develop a workforce able to provide prenatal and postpartum care in Black/African American communities and, subsequently, improving infant and maternal health.

- IDPH SUPPORT: The state should enhance the Illinois Department of Public Health's (IDPH) capacity to support the activities of the Task Force and its affiliated subcommittees and workgroups by supporting 1-2 dedicated full-time equivalents (FTEs) within the Office of Women's Health and Family Services (OWHFS) for the duration of the Task Force. The Task Force also strongly encourages the state to provide financial investment to support collaborations with key stakeholders to develop and to implement recommendations.

Background

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

United States. Maternal and infant health outcomes are common 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 caused or aggravated by the pregnancy[1]. In contrast, severe maternal morbidity (SMM) encompasses unexpected outcomes that result in significant short-term and long-term impacts to a woman's health[2]. The most current available data indicates that the United States' international ranking among the 37 countries of the Organization for Cooperation and Development (OECD) is 25th for maternal mortality and 32nd for infant mortality[3]. The United States reports the highest maternal mortality rate out of 10 of the wealthiest countries in the world at 14 maternal deaths per 100,000 live births[4]. The most recent national data on SMM reveal an increasing trend and show that more than 50,000 women were affected in 2014[5]. Between 1987-2017, data show a rising trend in pregnancy-related mortality in the United States and during 2014-2017, non-Hispanic Black/African American women experienced a 3-3.5 higher ratio of pregnancy-related death than non-Hispanic White and Hispanic or Latina women[6].

Infant mortality is the death of an infant before their first birthday and, similar to maternal mortality, the infant mortality rate (IMR) is a key indicator of national health[7]. According to the Centers for Disease Control and Prevention (CDC), in 2018, more than 21,000 infants in the United States died before their first birthday, resulting in an IMR of 5.7 deaths per 1,000 live births.

Illinois. The crisis of Black/African American infant and maternal mortality and morbidity is felt at the state level as well. Illinois reports a pregnancy-related mortality rate of 23 maternal deaths per 100,000 live births, with non-Hispanic Black/African American mothers dying from pregnancy-related causes at more than six times the rate of non-Hispanic White mothers[8]. Additionally, Illinois' severe maternal morbidity (SMM) rate is 51.4 per 10,000 births and, compared to White women, Black/African American women are nearly three times more likely to

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[1] Centers for Disease Control and Prevention (CDC). (2020). Pregnancy mortality surveillance system. Retrieved from https://www.cdc.gov/reproductivehealth/maternal-mortality/pregnancy-mortality-surveillance-system.htm

[2] Centers for Disease Control and Prevention (CDC). (2020). Maternal mortality. Retrieved from https://www.cdc.gov/reproductivehealth/maternal-mortality/index.html

[3] Organization of Economic Cooperation and Development. OECD.Stat, Health Status: Maternal and infant mortality. Retrieved from https://stats.oecd.org/index.aspx?queryid=30116

[4] Gunia, M. Z., Tikkanen, R., Seervai, S., & Collins, S. R. (2018 December 19). What is the status of women's health and health care in the U.S. compared to ten other countries? *The Commonwealth Fund*. Retrieved from https://www.commonwealthfund.org/publications/issue-briefs/2018/dec/womens-health-us-compared-ten-other-countries

[5] Centers for Disease Control and Prevention (CDC). (2020). Severe maternal morbidity in the United States. Retrieved from https://www.cdc.gov/reproductivehealth/maternalinfanthealth/severematernalmorbidity.html

[6] Centers for Disease Control and Prevention (CDC). (2020). Pregnancy mortality surveillance system. Retrieved from https://www.cdc.gov/reproductivehealth/maternal-mortality/pregnancy-mortality-surveillance-system.htm

[7] Centers for Disease Control and Prevention (CDC). (2020). *Infant mortality.* Retrieved from https://www.cdc.gov/reproductivehealth/maternalinfanthealth/infantmortality.htm

[8] Illinois Department of Public Health. (2018). *Illinois maternal morbidity and mortality report*.

experience SMM[9]. Systemic racism in health care and chronic health conditions negatively impact maternal morbidity and mortality[10].

Illinois has a long and pervasive history of racial disparities in infant mortality and these disparities continue. In 2018, the IMR in Illinois was 6.5 infant deaths per 1,000 live births and Illinois ranked 36th out of 50 states and the District of Columbia in infant mortality[11]. Not only does the Illinois IMR exceed the Healthy People 2030 IMR target of 5.0, significant racial disparities persist in the rate of infant deaths in Illinois[12]. Specifically, Black/African American infants have an IMR two-to-three times as high as that of White, Hispanic, and Asian infants in Illinois[13]. Although the IMR among Black/African American infants 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)[14]. In contrast, the IMR decreased by 18% among White infants (from 6.0 in 2000 to 5.0 in 2018) and by 29% among Hispanic infants (from 7.4 in 2000 to 5.3 in 2018)[15]. Leading causes of infant death include prematurity and fetal malnutrition, congenital and chromosomal abnormalities, SIDS (Sudden Infant Death Syndrome)/SUID (Sudden Unexplained Infant Death), and pregnancy and delivery complications. The significantly higher IMR in non-Hispanic Black/African American infants highlights the need for targeted interventions[16].

Legislative Mandate

In July 2019, the Illinois General Assembly passed Public Act 101-0028, establishing the Illinois Task Force on Infant and Maternal Mortality among African Americans (hereinafter referred to as "Task Force"). The Task Force 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.

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[9] Ibid.

[10] Illinois Department of Public Health. (2018). *Illinois maternal morbidity and mortality report*.; Bey, A., Brill, A., Porchia-Albert, C., Gradilla, M., & Strauss, N. (2019). *Advancing birth justice: Community-based doula models as a standard of care for ending racial disparities*. Retrieved from https://everymothercounts.org/wp-content/uploads/2019/03/Advancing-Birth-Justice-CBD-Models-as-Std-of-Care-3-25- 19.pdf

[11] CDC. (2020). *Infant mortality by state*. Retrieved from https://www.cdc.gov/nchs/pressroom/sosmap/infant_mortality_rates/infant_mortality.htm

[12] Centers for Disease Control and Prevention (CDC). (2020). *Infant mortality.* Retrieved from https://www.cdc.gov/reproductivehealth/maternalinfanthealth/infantmortality.htm

[13] Illinois Infant Mortality Report. Illinois Department of Public Health. (December 2020). Retrieved from http://www.dph.illinois.gov/sites/default/files/publications/illinois-infant-mortality-data-report-2020-december.pdf

[14] Ibid.

[15] Ibid.

[16] Ibid

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.

Task Force on Infant and Maternal Mortality Among African Americans (Task Force)

Membership

The legislation required the Task Force to consist of 14 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. To date, there have been five meetings with the first meeting occurring January 28, 2020 and the fifth meeting occurring December 15, 2020.

The initial Task Force meeting consisted of convening the members, reviewing the charge, voting on the chair and co-chair, and establishing three subcommittees to help address the Task Force's various responsibilities. The three subcommittees are: (1) Community Engagement; (2) Systems; and (3) Programs and Best Practices.

The second and third quarter meetings focused on subcommittee updates and presentations on potential collaborations with other committees/task forces focusing on infant and maternal health within the state. In particular, the Task Force considered collaboration with the Illinois Maternal Health Task Force, which is part of a Health Research and Services Administration (HRSA) grant funded project at the University of Illinois at Chicago, School of Public Health.

It is important to note that shortly after the start of the new year, the first cases of COVID-19 were reported in the United States. Illinois felt the impact of the pandemic in early March and IDPH and local health departments had to shift most of their efforts to address the impact and consequences of the pandemic. This shift of focus impacted the Task Force as evident in the

emergency meeting convened in April. During this meeting, the Task Force received an IDPH COVID-19 update and discussed the following issues:

- Separation of COVID-19 positive pregnant women from their baby for 14 days.
- Presumption of pregnant women being COVID-19 positive while laboring and putting the women in isolation away from their partners or support person(s).
- Disproportionate impact of COVID-19 on access to maternity care, delivery services and postpartum care in communities of color.
- Data on the effect of COVID-19 on the Black/African American community.
- Impact of COVID-19 on postpartum depression.
- Strategies employed by other states to address maternal health during the pandemic.

Although the initial year of the Task Force was significantly impacted by the COVID-19 pandemic, members of the Task Force and subcommittees remain committed to the Task Force's charge and continue to convene to generate recommendations and strategies to reduce disparities and address health inequities resulting in Black/African American infant and maternal mortality.

Task Force Subcommittees

In addition to the five Task Force meetings that occurred in 2020, the individual subcommittees met multiple times to address their assigned components of the legislative mandate. It should be noted that some of the activities of the subcommittees are distinct, but many of their areas and activities will overlap and complement each other.

For more information on the composition of the Task Force Subcommittees, see **Appendix 2.**

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
Westside Healthy Start Community Action Network, Coordinator
Access Warren Health Center

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 reviewed data on social and environmental risk factors with a specific focus on toxic stress, including covert and overt racism and their effects

on Black/African American infant and maternal health. The subcommittee members expressed a desire to identify both protective and risk factors by engaging the community and capturing their voice regarding these factors within the community. To support the understanding of social and environmental factors that contribute to toxic stress and to amplify and engage the voices and perspectives of Black/African American mothers, the subcommittee will do the following:

- Review existing research regarding the social and environmental factors (including covert and overt racism) on toxic stress and pregnancy outcomes among Black/African American mothers and infants.
- Gather data regarding the experiences of Black/African American mothers during preconception, pregnancy, labor and birth, and postpartum through listening sessions (focus groups) and targeted surveys.

The subcommittee will use this information to inform the Task Force's final recommendations for improving pregnancy and birth outcomes and meet its assigned scope of the Task Force's charge.

For a draft of the Listening Session Guide, see **Appendix 3.**

The subcommittee piloted its proposed questions with key stakeholders from November through December 2020 and expects to launch a series of listening sessions in early 2021. Potential partners for distributing and conducting the listening sessions and surveys include:

- Illinois Title V Maternal and Child Health Family Councils
- Community-Based Organizations (e.g., EverThrive Illinois and Illinois Healthy Starts)
- African American Greek Sororities (e.g., Alpha Kappa Alpha Sorority, Inc., and Delta Sigma Theta Sorority, Inc.)

Programs and Best Practices Subcommittee

Lead: Dara M. Gray-Basley, MA, LCSW
Health & Community Integration Program Manager
Access Community Health Network

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 developed a tool to identify programs and best practices for addressing the issues of Black/African American infant and/or maternal health. Members used the tool to review research and programs and presented their findings to the subcommittee.

For more information regarding the tool, see **Appendix 4.**

The subcommittee reviewed 14 programs and research projects and was unable to identify one program that provided all the elements necessary to address infant and maternal mortality.

Consequently, the subcommittee elected to identify key elements of programs and selected best practices rather than recommend specific programs in their entirety. Key elements identified included:

- Using a health equity, holistic lens/framework, and screening of social determinants of health.
- Meaningful interactions between patients and providers.
- Doula support.
- Black/African American representation among provider pool.
- Continuity of care.
- Use of telehealth and virtual counseling.
- Insurance coverage through the postpartum period, universal postpartum support and follow up.
- Universal behavioral health screening and care, and universal monitoring of chronic conditions (hypertension, obesity).
- Health literacy.
- Care coordination throughout the life course, health continuum and the perspective of transitions from childhood to adolescence to adulthood, and two-generation clinics (integration of pediatrics with postpartum care).

Systems Subcommittee

Co-Leads: Catherine Harth, MD
Physician
Associate Professor of Obstetrics and Gynecology
University of Chicago Medicine

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

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 subcommittee received an IDPH presentation on data relevant to the issue and identified additional data sources that could be helpful to access as the subcommittee and overall Task Force in formulating recommendations. These additional data sources included Pregnancy Risk Assessment Monitoring System (PRAMS) data, information from the upcoming IDPH Maternal Morbidity and Mortality Report, an IDPH report on racial/ethnic outcomes in severe maternal morbidity and infant mortality scheduled to be completed by early 2021, and the Illinois Title V Databook.

Three workgroups were created: (1) Health Care Partner Engagement; (2) Education; and (3) Funding Activities and Opportunities. The workgroups met various times and explored many ideas that could lead to Task Force recommendations.

Health Care Partner Engagement Workgroup. This workgroup discussed the following ideas:

- Conducting community focus groups to obtain shared stories and care experiences in collaboration with the Community Engagement Subcommittee.
- Expanding the work of MCOs to address social determinants of health (e.g., fund food insecurity, housing instability, transportation issues, behavioral health concerns, substance use, intimate partner violence).
- Partnering with formal and informal community leaders, like elected officials, religious leaders, and community service providers, through repeated and sustained communication.

Education Workgroup. This workgroup discussed the following ideas:

- Leveraging educational opportunities targeting various audiences and covering a range of topics.
    - Health care providers - Trauma informed care, implicit bias, racial equity and impact on health and health outcomes.
    - Health care providers and patients - Impact of co-morbidities and chronic conditions before, during, after, and between pregnancies, and the importance of collaborative, wrap-around care.
- Supporting the implementation of Illinois' Maternal Mortality Review Committee's recommendations involving education and including enforcement mechanisms.

Funding Opportunities Workgroup. This workgroup discussed the following ideas:

- Improving access to quality care for interpersonal violence (IPV), substance use disorder, and mental illness, such as perinatal depression.
- Extending Medicaid coverage from 60 days to one- year postpartum for all pregnant women.
- Increase access and support of services and programs, such as the Maternal, Infant and Early Childhood Home Visiting Program (MIECHV), Healthy Start, Family Connects, the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC).
- Supporting funding and reimbursement for paraprofessionals, such as breastfeeding peer support counselors, doulas, and lactation counselors.
- Protecting, supporting, and advocating for a range of comprehensive reproductive health services for all women of reproductive health age, regardless of health insurance status.
- Improving access to care through innovative approaches, such as telehealth.
- Exploring new, creative means of conducting health visits that are reimbursed and offer greater access to care.

Key Recommendations

For this inaugural report, the Task Force presents recommendations in five key areas and identifies existing opportunities the state can leverage in implementing the recommendations.

PROVIDER EDUCATION

Health care systems should require standardized implicit bias, racial equity, and trauma-informed care education for all providers who work with pregnant and postpartum patients to enhance the level of competency across the state. Health care professionals participating in the delivery of prenatal and postpartum care should receive a standardization of clinical education and care in facilitating equitable care to Black/African American women across the state.

Leveraging existing opportunities: Leveraging existing opportunities: The Task Force recommends supporting the Illinois Perinatal Quality Collaborative (ILPQC) Birth Equity Initiative and sustainability plan for a minimum of two years. This initiative is expected to launch in 2021 and is referenced in Public Act 101-390 (c). It aims to support hospital capacity to facilitate systems and culture change to achieve birth equity through four key drivers: social determinants of health, data usage, patient and partner engagement, and provider engagement and education. The initiatives' specific objectives include the following: appropriate screening and linking patients to resources and support of social determinants of health, increasing the proportion of women reporting positive obstetric care experiences, and accurately recording patient race and ethnicity data. IDPH actively encourages hospitals to participate in ILPQC's Birth Equity Initiative (or a comparable quality improvement birth equity training program).

ACCESS AND EQUITABLE CARE

Telehealth - **(1) The state through the Illinois Department of Healthcare and Family Services (HFS) should expand and standardize the acceptability, accessibility, utilization, and best practices for telehealth, including phone visits for reproductive-age, pregnant and postpartum women and their infants up to age 1; and (2) Managed care organizations (MCOs) and third party payors should establish standards of care utilizing telehealth as a vital modality of contact and ensure that all patients have access to equitable and quality preconception, prenatal, labor and delivery, and postpartum care.**

Leveraging existing opportunities: Given the COVID-19 pandemic, the increased prevalence of maternity deserts and rural maternal health crisis, the Task Force recommends that the state, through HFS, support the continued Medicaid, MCO, and private insurance coverage and reimbursement of telehealth services for all aspects of obstetric care (i.e., preconception, prenatal, labor and birth, and postpartum services).

Birthing Centers - **(1) The state should complete its evaluation of the demonstration program authorized by the Alternative Health Care Delivery Act [210 ILCS 3] and enhance its support of free-standing birthing centers to address maternity deserts in Black/African American communities; and (2) Community organizations should explore opportunities to establish free-standing birthing centers to address maternity deserts in Black/African American communities.** Access to quality maternity service in the neighborhoods of Black/African American women is critical to providing equitable care.

Leveraging existing opportunities: Illinois passed the Safe Birthing Act of 2007 (also listed as an amendment of the Alternative Health Care Delivery Act) which allows for the establishment of 10 free-standing birthing centers. To date, there are two existing birthing centers: Birth Center at PCC Community Wellness Center in Berwyn and Birth Center of Bloomington-Normal. Two additional birthing centers are expected to open in Burr Ridge and in Chicago within the year. The Task Force recommends that the state, through IDPH, evaluate the demonstration program and further encourage the establishment of quality birthing centers by convening existing birthing centers to share knowledge and experience with other key stakeholders interested in establishing future birthing centers.

POSTPARTUM MEDICAID REIMBURSEMENT

The state, through HFS, should reimagine the current framework of bundled Medicaid reimbursement for obstetric care by unbundling the postpartum visit from prenatal care and labor and delivery services. Specifically, the state should support the implementation of a universal early postpartum visit within the first three weeks and a comprehensive visit within 4-12 weeks postpartum. This will improve postpartum access to care and positively impact the incidence of maternal morbidity and mortality in the postpartum period. Currently, women receive one postpartum visit that is included in the delivery bundle. However, the American College of Obstetricians and Gynecologists (ACOG) recommends that patients have more than one postpartum visit, including an early maternal health safety check visit to assess and identify risk factors that may develop during the early postpartum period[17].

Leveraging existing opportunities: Currently, the billing and reimbursement for postpartum health visits are combined with prenatal and delivery services in the delivery bundle. The Task Force recommends the state encourage and support the unbundling of the prenatal/delivery/ postpartum bundle and the creation of a new bundle specific to postpartum care. It is recommended that this new bundle include Medicaid coverage and reimbursement of: (1) earlier and more frequent access to postpartum care; and (2) postpartum care services rendered by community-based (certified) doulas, certified lactation counselors, international board-certified lactation consultants, public health nurses, certified nurse midwives, community health workers, and other peer navigators.

DOULA CERTIFICATION AND COVERAGE

(1) The state should support the increased utilization and reimbursement of doula services for prenatal and postpartum care, which includes supporting the development of an educational infrastructure for the certification of community-based doulas across the state; and (2) Academic institutions and community-based organizations should establish community-based doula certification programs that develop a workforce able to provide prenatal and postpartum care in Black/African American communities and, subsequently, improving infant and maternal health. Doulas are trained professionals that provide services including, but not limited to, "continuous physical, emotional, and informational support to a [patient] before, during, and shortly after childbirth[18]." Doula provided care can

[17] American College of Obstetricians and Gynecologists. (2018). Optimizing postpartum care: ACOG committee opinion no. 736. *Obstetrics and Gynecology, 131*(5), :e140–50.
[18] DONA International. (2020). What is a doula? Retrieved from https://www.dona.org/what-is-a-doula/

increase access to necessary services that can improve labor and delivery, promote positive birth outcomes, such as reduced preterm birth and low birth weight, and reduce negative feelings about birth experiences[19]. The Task Force recommends that as a part of the educational infrastructure there would be an emphasis on the matriculation of Black/African American women into doula programs. It has been shown that having support that reflects the very women it intends to serve makes a difference in empowering women to make their voices heard and respected[20,21].

IDPH SUPPORT

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 (FTEs) within the Office of Women's Health and Family Services (OWHFS) for the duration of the Task Force. The Task Force also strongly encourages the state to provide financial investment to support collaborations with key stakeholders to develop and implement recommendations. Given the persistent disparities in Black/African American infant and maternal morbidity and mortality and the urgency in addressing this epidemic, the Task Force will continue to meet quarterly, and the subcommittees will meet monthly to review evidence, engage the community, and develop strategies and key recommendations. These activities will continue until the General Assembly sets a sunset date for the Task Force.

Future Activities

The Task Force expects to build upon its recommendations and activities in future annual reports. It is noted that this inaugural report focused heavily on maternal health, however, future activities and recommendations will address both maternal and infant health for Black/African Americans. Below are a few of the activities planned for the Task Force and its subcommittees when they resume meetings in 2021.

- Listening Sessions (Focus Groups): The Task Force will collect the perspectives of women with "lived" experiences though listening sessions. These listening sessions will be conducted throughout the state with Black/African American community members. The Task Force will use the data to make additional recommendations to the General Assembly regarding interventions to improve Black/African American infant and maternal health outcomes.

- Provider Education: The Task Force will collaborate with ILPQC to inform provider education on implicit bias, racial equity, and trauma-informed care. It will also identify other key topics that should be standardized to enhance competency and address infant

[19] Expecting Justice. (n.d.). Expecting Justice Annual Report. Retrieved from https://pretermbirthca.ucsf.edu/sites/g/files/tkssra2851/f/wysiwyg/Expecting%20Justice%20Annual%20Report%202020 18-19_v2web.pdf

[20] Gruber, K. J., Cupito, S. H., & Dobson, C. F. (2013). Impact of doulas on health birth outcomes. *The Journal of Perinatal Education*, *22*(1), 49–56. http://dx.doi.org/10.1891/1058-1243.22.1.49

[21] Hardeman, R. R., & Kozhimannil, K. B. (2016). Motivations for entering the doula profession: Perspectives from women of color. *Journal of Midwifery & Women's Health, 61*(6): 773–780. http://dx.doi:org/10.1111/jmwh.12497

and maternal mortality. The Task Force will also explore other opportunities and identify additional partners to engage in educational activities for providers and the Black/African American community.

- Doula Certification and Coverage: The Task Force will identify and recommend standard doula training requirements and doula certification programs. The Task Force will also identify ways to advocate for Medicaid reimbursement of comprehensive doula services of prenatal through postpartum care, including identifying other state models that are reimbursing comprehensive doula services.

- 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 (established through the HRSA Maternal Health Innovation Grant managed by the University of Illinois at Chicago), and the Illinois Title V Program. Additionally, the Task Force will seek to work with the Chicago Collaborative for Maternal Health (CCMH), which was established through the Merck for Mothers grant managed by EverThrive Illinois and the Alliance Chicago, the Fetal and Infant Mortality Review (FIMR) program, and the Governor's Office of Early Childhood Development.

Conclusion

The Task Force has and will continue to advise and 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. It is recognized that this inaugural report focuses heavily on maternal health, however, 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 9/22/2020)

Committee Member	Specialty/Sub-Specialty/Occupation	Affiliation
(3) 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
Open	Director of Healthcare and Family Services or Designee	Illinois Department of Healthcare and Family Services
LaTanya Law, MA	Secretary of Human Services or Designee	Illinois Department of Human Services
Two (2) Medical Providers (infant and community health)		
Richard David, MD	Professor (Pediatrics)	University of Illinois at Chicago
Cheryl Wolfe, MD, MS	Physician, Vice Chair of Obstetrics and Section Director of Ambulatory Services	Rush University and Medical Center
Two (2) 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 (2) 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 (2) Registered Nurses		
Virginia Julion, RN, MPH	Fetal and Infant Mortality Review Coordinator (Retired)	University of Chicago
Jerrilyn Pearson, RN, BSN, MSN, EdD	CEO, President	First Step to Excellence Health Care Training Academy

Two (2) Certified Nurse Midwives		
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 (4) 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
Pamela Roesch, MPH	Epidemiologist/Director of Health Equity	Sinai Health System
Karyn Stewart, PhD	Professor, Sociology	DePaul University
One (1) Member Representative of Hospital Leadership		
Debra Wesley, MSW	President and Chief Executive Officer	Sinai Health System
One (1) Member Representative of Health Insurance Company		
Open		
One (1) African American Woman of Childbearing Age (experienced traumatic pregnancy)		
Tamela Milan-Alexander, MPPA (Co-Chair)	Westside Healthy Start Community Action Network, Coordinator	Access Warren Health Center
One (1) 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 (1) Physician Representative of the Illinois Chapter of AAP (ICAAP)		
Daniel Johnson, MD	Pediatrician/Pediatric Infectious Disease Specialist	University of Chicago Medicine

Appendix 2: Subcommittee Members, Meeting Attendees and Meeting Dates

Community Engagement Subcommittee	
Shirley Fleming, Co-Lead*	March 20, 2020
Tamela Milan-Alexander, Co-Lead*	April 28, 2020
Bisola Bello	May 7, 2020
Cheryl Floyd*	June 10, 2020
Wandy Hernandez	July 8, 2020
Stephanie James*	July 22, 2020
Virginia Julion*	August 19, 2020
Jessica Lamberson	September 2, 2020
Kelsie Landers	September 19, 2020
Jasmine Martin*	September 30, 2020
Pamela Roesch*	October 14, 2020
Judith Stewart	October 28, 2020
Karyn Stewart*	November 18, 2020
Kathy Waligora	December 9, 2020
Debra Wesley*	
Programs and Best Practices Subcommittee	
Dara Gray-Basely, Lead	May 26, 2020
Nelson Agbodo	June 23, 2020
Michele Brown	August 4, 2020
Angela Ellison*	August 25, 2020
Veronica Halloway	September 29, 2020
Michelle Hoersch	October 26, 2020
Virginia Julion*	November 17, 2020
Patti Lee King	
Jessica Lamberson	
Gordon Mayer	
Jasmine Martin*	
Kenya McRae*	
Jennie Pinkwater	
Santina Wheat*	
Cheryl Wolfe*	
Systems Subcommittee	
Glendean Burton, Co-Lead	April 3, 2020
Catherine Harth, Co-Lead*	May 6, 2020
Timika Anderson Reeves	June 8, 2020
Brenda Blasingame	July 13, 2020
Ann Borders	August 10, 2020
Glenda Burnett	September 25, 2020
Kathy Chan	October 12, 2020
Shondra Clay	October 30, 2020
Jessica Davenport	November 9, 2020
Arden Handler	December 14, 2020
Daniel Johnson*	
Bakahia Madison	
Cindy Mitchell	
Angelique Muhammad	
Ashley Phillips	
Virginia Reising	
Cynthia Wilson	

**Task Force Members*

Appendix 3: Listening Guide

IMMT – Community Engagement Subcommittee Listening Session Questions
(v.11/06/20)

Key questions the subcommittee would like covered if there are time constraints are marked with an (*) at the end.

I. Before Pregnancy Section

A.1. In the year before you found out you were pregnant, were there things that happened that made you or a mother you know feel stressed or overwhelmed? *

A.2. Can you describe the top 2 or 3 things that were the major reasons that you or a mother that you know felt stressed or overwhelmed in the year before you found out you were pregnant? *

A.3. How do you feel about the way that you or a mother you know were treated by the doctors, nurses, or other health care providers who cared for you in the year before you found out you were pregnant? What did the providers do or say to make you feel this way? *

A.4. How did your providers include you in your care? *

A.5. In the year before you found out you were pregnant, what things helped you feel well and manage stress? *

II. During Pregnancy Section

B.1. During your last pregnancy, were there things that happened that made you or a mother you know feel stressed or overwhelmed? *

B.2. Can you describe the top 2 or 3 things that were the major reasons that you or a mother that you know felt stressed or overwhelmed during pregnancy? *

B.3. How do you feel about the way that you or a mother you know were treated by the doctor, nurse, or other health care provider who cared for you during your pregnancy before your birth? What did the provider do or say to make you feel this way? *

B.4. How did the provider include you or the mother you know in your care?

B.5. Can you share with me your thoughts on whether or not the things the health provider suggested you do in order to have a healthy pregnancy were things that you or the mother you know could actually do? If they were not things you could do, what were some of the challenges? *

B.6. In what ways did your provider connect you or the mother you know with the resources that you needed? If the provider did not connect you with resources, what was needed that was not provided?

B.7. If you had the option, would you have chosen a different provider to care for you during your pregnancy if you could go through pregnancy again? Why or why not? *

B.8. Now we want to talk about those things that helped you feel well during your pregnancy. As a reminder, when we talk about being well, we mean wellness overall – your physical, mental, and spiritual wellbeing.

B.9 During your last pregnancy, what things helped you feel well and manage stress?

III. Birth and Postpartum Section

C.1. During your birth at the hospital, in your home, or at another location, were there things that happened that made you or a mother you know feel stressed or overwhelmed? Can you describe what happened during birth to make you or the mother you know feel this way? *

C.2. Now, how about in the months and year after birth? Were there things that happened that made you or a mother you know feel stressed or overwhelmed?

C.3. Can you describe the top 2 or 3 things that were the major reasons that you or a mother that you know felt stressed or overwhelmed in the months and year after birth?

C.4. Thinking back to your birth specifically, how do you feel about the way that you or a mother you know were treated by the doctor, nurse, or other health care providers who cared for you during your birth? What did the providers do or say to make you feel this way? *

C.5. If you had the option, would you have chosen a different provider or provider type – like a midwife – to care for you or another hospital to go to for your birth if you could do it again? Why or why not?

C.6. Were you able to return to your doctor, nurse, or other health care provider for a follow-up visit after birth? Why or why not? *

C.7. For those who were able to return to your provider or clinic after birth, how do you feel about the way that you or a mother you know were treated by the doctor, nurse, or other health care providers? What did the providers do or say to make you feel this way?

C.8. Can you share with me your thoughts on whether or not the things the health provider suggested you do in order to have a healthy recovery from pregnancy or birth were things that you or the mother you know could actually do.

C.9. In what ways did your provider connect you or the mother you know with the resources that you needed? If the provider did not connect you with resources, what was needed that was not provided?*

C.10. Now, I want to talk about those things that helped you feel well in the months and year after you delivered. As a reminder, think about wellness overall – your physical, mental, and spiritual wellbeing.

C.11. In the months and year after your birth, what things helped you manage stress and feel well?

IV. Wrap Up Section: In the months and year after your birth, what things helped you manage stress and feel well?

Appendix 4: Programs and Best Practices Subcommittee Tool

Task Force for Infant and Maternal Mortality Among African Americans

Health among African American Women
Programs and Best Practices Subcommittee

Research and Effective Programs/Interventions Information Gathering Tool

Deadline to Submit

Purpose of Tool:
The Illinois Department of Public Health (IDPH) has convened the Task Force for Infant and Maternal Mortality Task Force Among African Americans (IMMT) to respond to legislative mandates to better understand and address maternal morbidity and mortality disparately impacting African American women. Three subcommittees have been created to distribute the work amongst the members. The Programs and Best Practices (P&BP) Subcommittee is charged with identifying and assessing key research and effective programs that have been initiated at the state level (within and outside of Illinois) as well as at the national level. The subcommittee's findings will inform the content of the Task Force's annual report, including specific recommendations to the State on new initiatives and action plans.

Instructions: Please complete this form and help us to identify the following:

- **Effective programs and interventions to address the social determinants of health disparities in maternal and infant outcomes (past or present)**
- **Key research findings regarding women's health before, during, and after/between pregnancies**

Name of person submitting form: _____

Name of organization/individual conducting program/research: _____

Title of program/research: _____

Type (please check one): Program _____ Research _____

Target population (community, geography, and demographics – age, race/ethnicity):

Program components/Research variables and how measured:
Key outcomes or takeaways of the program/research:

Programs Reviewed

Program/Research (Author/Organization)	Reviewed	To Be Reviewed
Effectiveness of prenatal care on birth outcomes (Agbodo, N. V., 2019)	X	
Reduction of Peripartum Racial/Ethnic Disparities (The Council on Patient Safety in Women's Health Care Alliance for Innovation on Maternal Health (AIM))	X	
California Birth Equity Collaborative Pilot (California Maternal Quality Care Collaborative)	X	
Birth Equity Initiative (ILPQC)	X	
Mother's Voices Driving Birth Equity (National Birth Equity Collaborative (NBEC)	X	
Family Management (DHS)	X	
Healthworks (DHS)	X	
The Luke Project 52 Clinic	X	
Disparities Research for Change: A Roadmap to Reduce Racial and Ethnic Disparities in Health Care (RWJF)	X	
Family Connects (CDPH)	X	
APORS	X	
HRIF	X	
Supportive Pregnancy Care Program (March of Dimes)	X	
Centering Pregnancy	X	
Healthy Start		X
Better Birth Outcomes		X
EverThrive Programs		X
Listening to Women		X
Abundant Birth Project		X
Expecting Justice		X
The JJ Way		X
Faith Community Nursing (OSF St. Francis Medical Center College of Nursing, Peoria)		X