Advisory Committee on Infant and Maternal Mortality

Meeting Minutes of December 14-15, 2021

Virtual Meeting via Zoom

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DAY ONE: Tuesday, December 14, 2021

Welcome, Call to Order & Introductions

***Vanessa Lee, M.P.H.*, Designated Federal Official, ACIMM**
***Edward Ehlinger, M.D., M.S.P.H.*, ACIMM Acting Chair**

Ms. Vanessa Lee welcomed participants to the meeting for the Advisory Committee on Infant and Maternal Mortality (ACIMM), formerly the Secretary's Advisory Committee on Infant Mortality (SACIM) and called the meeting to order.

Dr. Edward Ehlinger spoke about the continuing history of SACIM, which was established 30 years ago in 1991. At the recent 30th anniversary celebration of Healthy Start, Dr. Ehlinger, Ms. Lee, and Ms. Belinda Pettiford were asked to speak about SACIM. Dr. Ehlinger recalled a 1985 hearing on Senate bill 1209 for a National Commission to Prevent Infant Mortality, in which both he and Dr. Paul Wise testified. He recalled that they had addressed social determinants of infant health, social and racial disparities and inequities and the commitment needed to end the social injustices that underlie the survival and growth of infants and children.

Dr. Ehlinger said that it could be discouraging that the issues affecting infant mortality in 1985 persist today, but that, collectively, the Committee has helped change the trajectory of infant and maternal health and mortality. For instance, he stated, the Committee has helped shift the focus on clinical care to also include social determinants of health, racism, and historically underrepresented populations such as indigenous communities. He additionally noted that the Committee has helped highlight the unique needs of pregnant individuals and infants during a global pandemic and through a crisis at the southern border of the United States (U.S.). Dr. Ehlinger asked Committee members to recommit to the ACIMM charge to make the necessary changes needed to protect mothers and infants. He then welcomed ACIMM members and staff to introduce themselves.

The Committee unanimously passed a motion to approve the Minutes of the September 2021 meeting.

Federal Updates

***Kristen Zycherman, R.N., B.S.N.*, Centers for Medicare & Medicaid Services (CMS)**

Ms. Kristen Zycherman provided an update on the Maternal and Infant Health Initiative (MIHI), which was launched in July 2014 in response to expert panel recommendations to improve access to and quality of care for pregnant and postpartum individuals and their infants. Between 2019 and 2020, MIHI convened an expert working group to assess their progress and develop updated recommendations for improvement. She shared that based on these recommendations, MIHI now focuses on three key areas: increased use and quality of postpartum care visits, increased use and quality of infant well-child visits, and decreased rate of cesarean births in low-risk pregnancies. She noted that these three focus areas are interconnected and emphasize the importance of the mother-infant dyad and care throughout the life course.

Ms. Zycherman reviewed examples of risk factors that span all three focus areas. For instance, she noted that equity plays a significant role, with a maternal mortality rate of up to five times higher among Black and American Indian/Alaska Native (AI/AN) birthing persons. She stated that timing is also an important factor, with half of all maternal deaths occurring in the postpartum period and one-third of those occurring after the first postpartum week. These risk factors are also intertwined with Medicaid status. She cited studies of women enrolled in Medicaid that indicated that they are more likely to have co-morbidities, lower levels of education, higher levels of postpartum depression, and lower rates of postpartum care than uninsured or privately insured women. Ms. Zycherman reviewed the opportunities for improvement across both national and state levels.

She talked about the evolving concept of postpartum care based on the American College of Obstetrics and Gynecologists' (ACOG) recommendations to improve the quality and scope of services. She noted that this would include a care visit within the first three weeks postpartum and subsequent comprehensive visits focused not just on recovery, along with education, infant care and feeding, contraceptive care, and chronic disease screening and management. She stated that the evolving concept of postpartum care would also address the systemic inequities and social determinants of health that contribute to poor postpartum outcomes.

Ms. Zycherman described the MIHI Postpartum Care Learning Collaborative, which provides one-on-one and group training and technical assistance to improve the quality of postpartum care and the mortality rates in nine states. She shared that the next Learning Collaborative is focused on infant well-child visits. She explained that only 66 percent of children receive six or more well-child visits in the first 15 months of life, indicating a significant opportunity for improvement. She shared that MIHI also plans to launch a Learning Collaborative on reducing low-risk cesarean deliveries, which is a risk factor associated with maternal morbidity. She stated that CMS has not previously been able to publicly report the number of cesareans due to the low number of reporting states. She noted that in 2021, MIHI replaced the cesarean birth metric with one that measures low-risk delivery based on the Centers for Disease Control and Prevention (CDC) mortality data and CMS will calculate this on behalf of all states. In 2022, Ms. Zycherman explained, MIHI will provide a series of short videos and one-on-one coaching on tobacco cessation for pregnant and postpartum individuals

Ms. Zycherman reviewed other maternal and infant health activities at CMS, such as state guidance on postpartum coverage extension and the development of core measures to improve maternal and perinatal health in Medicaid and the Children's Health Insurance Program (CHIP). She shared that CMS also conducted an equity assessment on quality of care in the postpartum period among Medicaid and CHIP birthing persons, which led to a Challenge.gov competition for innovative strategies to improve postpartum care among Black and AI/AN individuals. She explained that CMS prioritizes maternal and infant health and has aligned their strategic priorities and goals with the Department of Health and Human Services (HHS) Maternal Health Action Plan.

Discussion

Dr. Paul Jarris addressed the term "effective use of contraception" and the importance of immediate postpartum contraception on birth spacing. He asked why this point seems to have been dropped. He was also concerned that the explanation of maternal mortality did not include impactful issues that fall outside of the medical environment, such as partner violence or drug overdose. Ms. Zycherman acknowledged that contraception was a focus area in the original phase of MIHI and in the next phase they developed two contraceptive care measures—one for all women and the other for postpartum women, which were wrapped into the concept of comprehensive quality postpartum care. She shared that MIHI has been working to unbundle Medicaid payments for long-acting reversible contraception (LARC), which has been a barrier, and it is exploring options for related measures, such as contraceptive counseling. She explained that these data rely on the CDC definition of severe maternal morbidity, which is based on 21 codes that are largely clinically-based. She noted that some states are beginning to calculate their own severe maternal morbidity rates and are including codes related to behavioral health, sexually transmitted disease (STD) and other metrics. She stated that intimate partner violence (IPV) may fall under different categories of pregnancy-related versus pregnancy-associated death, but MIHI does include IPV as part of quality postpartum screening, referral, and care.

Dr. Jeanne Conry commented on postpartum tubal ligation and the mandatory waiting period through Medicaid, which may represent a barrier or protection, depending on how one looks at it. She also suggested using gender-based and reproductive health-based measures that are reflections of preconception health, such as weight, blood pressure, tobacco use, or prenatal vitamin use. Ms. Zycherman agreed that healthy individuals become healthy pregnant individuals. She noted that while CMS is not able to directly address the preconception period, they do hope that extended postpartum care leads to healthier subsequent pregnancies. Dr. Conry added that the Women's Preventive Services Initiative (WPSI) recently updated their contraceptive guidelines, which will be made available soon.

Dr. Steve Calvin noted that Minnesota is not a participating state and asked what advice could be given to states that are lagging behind, both in terms of their participation and in improved outcomes. Ms. Zycherman answered that the reasons why a state does not participate varies and that it is often a matter of not having adequate resources. She shared that MIHI provides outreach to lower performing states to identify their challenges and technical assistance to states interested in quality improvement.

Dr. Magda Peck asked for clarification about the data gaps in CMS and not meeting the threshold of 25 participating states to publicly report on cesarean section data. She wondered if there were incentives for states to report or if there were other factors, such as capacity or a reluctance to report unfavorable data, that is keeping these states from reporting. Ms. Zycherman answered that they are limited somewhat by the statute that makes reporting voluntary. However, she noted that reporting on any measures related to the child core set and any behavioral health measures related to the adult core set will become mandatory in 2024. Currently, she stated that they are looking at data sources such as CDC WONDER or CMS census data to calculate these metrics on behalf of those states in order to meet threshold on some of the lesser reported metrics. Ms. Zycherman added that there is a process for recommending measures to their annual review.

Dr. Peck reiterated that it is essential to obtain these data for ACIMM to make data-informed recommendations as well as to link with related data, such as housing data or other upstream factors. She asked if CMS datasets were linked to other government agencies, particularly for housing. Ms. Zycherman answered that she was not aware of data linkages related to housing, but CMS is exploring data linkage with CDC.

***Margaret Snyder, M.A.L.D.,* Office on Women's Health (OWH)**
Ms. Margaret Snyder presented on behalf of Dr. Dorothy Fink. She is a Lead Public Health Advisor for OWH and for the Office of the Assistant Secretary for Health (OASH). She reviewed Challenge.gov initiatives related to women's health. The Innovative Methods to Improve Postpartum Care for Black or African America and American Indian/Alaska Native Women challenge aims to improve postpartum care for Black, African American, and AI/AN low income beneficiaries of Medicaid or CHIP, with an emphasis on follow-up care for conditions associated with morbidity and mortality in the late postpartum period. The Innovative Methods to Address Endocrine-Disrupting Chemicals (EDCs) challenge aims to identify innovative ways to address the impact of EDCs on Black or African American women. Ms. Snyder shared that both challenges are in the phase one stage to identify programs that demonstrate effectiveness, sustainability, and replicability.

Ms. Snyder talked about a partnership with Premier, Inc that aims to develop a network of 220 birthing hospitals and has a two-pronged approach for advancing health equity: 1) to improve maternal and infant health data and 2) to implement and analyze evidence-based practices. She shared that the Maternal Morbidity and Mortality Data and Analysis Initiative will identify the key drivers of maternal and infant mortality and morbidity through standardized data collection processes. She explained that these data will represent a national baseline of maternal and infant health outcomes from 2008 and will explore the relationship between maternal and infant data and associations between demographics, co-morbidities, and other relevant data. Ms. Snyder shared that they will also conduct cost analyses and develop geographic maps to better understand disparities. She noted that the initiative will include data related to the COVID-19 pandemic and its impact on delivery-related outcomes. She pointed out that preliminary results from these data show a trend of an increased overall risk of an in-hospital delivery-related death and an increased risk of severe maternal morbidity for pregnant individuals with a COVID-19 diagnosis.

Ms. Snyder reviewed the Perinatal Improvement Collaborative that focuses on the implementation and analysis of evidence-based interventions towards improving maternal and infant health outcomes and reducing disparities. She explained that through the network of birthing hospitals and health systems, this multi-year initiative will support quality improvement through the collection and analysis of 150 measures of clinical and non-clinical factors (e.g., social determinants of health). These measures will come from three primary sources: the Perinatal Collaborative Outcome Dashboard, a virtual and onsite reliability assessments, and individualized improvement roadmaps. She shared that the collaborative partners with MoMMA's Voices and the National Birth Equity Collaborative to ensure that the initiative includes patient voices, is patient-centered, and provides equitable care.

Discussion
Dr. Ehlinger asked how the Perinatal Improvement Collaborative aligns with the HRSA Alliance for Innovation and Maternal Health (AIM). Ms. Snyder answered that the hospital improvement program is based on each hospital's priorities and that the collaborative is aligned with HRSA at the federal level.

Committee members discussed the diversity of location, size, and type across the participating hospitals. Dr. Calvin suggested including the critical access hospitals and birthing centers that feed into larger hospitals. Ms. Snyder agreed and said that diversity was a driving factor for choosing the participating hospitals. Dr. Janelle Palacios asked if the hospitals were diverse in size, which would affect diversity in the population that seeks care. For instance, Dr. Palacios explained, some of the rural hospitals that were included in the collaborative do not have level 3 hospitals, but Native American women tend to seek care only from a lower-level hospital. Ms. Snyder said that she would need to follow-up with this information. Dr. Palacios also asked if there was a plan to extend beyond the current list of participating hospitals. Dr. Snyder answered that they are focused on collecting and analyzing the data from the currently participating hospitals but that expansion may be part of future planning processes. Ms. Pettiford asked if there was a list of participating hospitals. Ms. Snyder said that there was a press release that included a list.

Dr. Peck asked if there was any likelihood of linkages of the hospitals' data with national-level databases to help provide a bigger picture of before and after the hospital experience, including mental health status, and social determinants of health. Ms. Snyder said that they are currently finalizing bringing the hospitals on board. They are in conversation with other federal agencies about collaboration and hopes to provide an update on data linkage in the future.

Ms. Pettiford asked for clarification on the partnership with MoMMA's Voices. Ms. Snyder answered that they were involved in the early planning stages and throughout the process to provide feedback for ensuring that the project was patient-centered. Ms. Pettiford asked if the hospitals were required to have a patient engagement component to capture lived experience. Ms. Snyder said that an important part of the initiative's aim is to change the culture of the hospitals. Because each hospital drives their own activities, Ms. Snyder explained that it is challenging to specify how they will address patient engagement but that partnering with MoMMA's Voices has been helpful.

Dr. Ehlinger asked if ACIMM's recommendations were included in the development of the White House Maternal Health Day of Action. Ms. Snyder said that that CMS and OWH were aware of ACIMM's recommendations as they developed the program.

Dr. Peck asked both presenters to comment on what success looks like five years from now and what change would result. Ms. Snyder said that the long-term impact of their two-pronged approach would be the identification of the drivers of maternal mortality and morbidity to better understand why women are dying, the reduction of maternal morbidity and mortality, and the implementation of solutions that make the U.S. the safest place to have a baby. Ms. Zycherman answered that their success would be that states would be equipped with the resources and infrastructure needed to reduce their rates of maternal morbidity and mortality and related disparities and that those practices would be disseminated to other states.

COVID-19 Follow-Up – What Have We Learned about Equity, Data, and Quality and Access to Care?

***Edward Ehlinger, M.D., M.S.P.H.*, ACIMM Acting Chair**

Dr. Ehlinger asked the Committee to discuss lessons learned and potential gaps since ACIMM's submission of COVID-19-related recommendations to the Secretary in June 2020. He also mentioned that the October 2021 Presidential COVID-19 Health Equity Task Force Final Report and Recommendations did not address pregnant individuals or infant health.

Dr. Palacios talked about observing her team struggle to manage the challenges of caring for a birthing person during the COVID-19 pandemic. She shared that nothing in their previous experience could adequately prepare them for the pandemic and they did not have access to counseling, research, or guidance. In a birthing hospital, she explained, they were no longer managing obstetrics alone. Rather, she said, it had become a multidisciplinary issue in which they needed to make decisions about an infectious disease and rapid deterioration, which shifted their strategies for triage and other care decisions. Going forward, Dr. Palacios stated that it will be important have a holistic view of care and a national plan in effect to guide an interdisciplinary team for these special circumstances.

Ms. Pettiford commented that an important lesson learned was the definition of the care team, which had limited birthing individuals to one support person, necessitating a decision between having a doula, spouse, or other support person in the room. She asserted that ACIMM should recommend that the definition of the care team not be limited to clinicians who work in the hospital. Dr. Calvin added that he had heard from mothers with low-risk pregnancies who had such negative experiences with the limitations that they would not consider having another baby unless they were certain that those restrictions would not be in place.

Dr. Palacios talked about certain higher-risk populations that were targeted with policies during the pandemic. She shared that while the policies may have been important at the beginning of the pandemic, when little was known about the disease, they could often result in negative consequences, such as separating the dyad from breastfeeding. She believes that it will be important to understand the consequences of such policies and to not criminalize a population for their high-risk status.

Dr. Peck suggested that there should be a systematic after-action review of outcomes from the COVID-19 response towards quality improvement. She stated that the pandemic is ongoing and evolving but now that the response is not in "catch-up" mode, there is an opportunity to conduct a standardized, systematic review of recommendations, actions, and outcomes, keeping at the forefront the birthing individuals, infants, and families who were directly affected. Dr. Paul Jarris asked whose authority might initiate such an after-action report. Dr. Michael Warren said the appropriate authority for an after-action review depends on the scope of the effort to determine whether the effort is placed onto a government or a non-government entity. Dr. Ehlinger asked how to move ACIMM's recommendations to the COVID-19 Health Equity Task Force to move those recommendations into action. Dr. Warren answered that ACIMM could request that they be passed to the Task Force.

Dr. Peck asked Dr. Warren if the Maternal and Child Health Bureau (MCHB) considers itself the locus of accountability for the health and wellbeing of all pregnant individuals and infants in the nation. Dr. Warren said that the MCHB mission is broad, but various facets of the pandemic response is larger than MCHB or even of the federal government. He stated that it will be important to define the specific questions before identifying the appropriate federal agency.

Birth Defects and Congenital Anomalies

***Tara Sander Lee, Ph.D.,* (Moderator)**
***Naomi K. Tepper, M.D., M.P.H., FACOG,* CDC**
***Julie S. Moldenhauer, M.D., FACOG, FACMGG,* University of Pennsylvania**

Dr. Naomi Tepper shared data about the impact of birth defects on infant mortality and potential opportunities to improve outcomes. She explained that birth defects cause one in five deaths during the first year of life. She shared that there are three specific categories of birth defects—congenital malformations, deformations, and chromosomal abnormalities—responsible for 4,301 infant deaths in the U.S. in 2019, which represents a mortality rate of 114.8 per 100,000 live births. She stated that the causes of infant death are not uniform across the first year of life. Congenital anomalies are the second leading cause of death in the neonatal period but the leading cause of death in the post-neonatal period. Despite an overall decline of infant mortality attributable to birth defects between 2003 and 2017, Dr. Tepper explained that the rate continued to be higher among non-Hispanic Black and AI/AN infants than Hispanic, non-Hispanic White, and Asian infants.

Dr. Tepper said that these overall declines may be related to improvements in prenatal care, infant medical care, and prevention measures. She shared that disparities among Black and AI/AN infants may be influenced by access to and utilization of health care, prenatal screening, and losses and terminations of pregnancies with fetal anomalies. She also stated that disparities may also be related to insurance status, with a higher mortality rates among deliveries covered by Medicaid.

She then reviewed opportunities to improve outcomes related to birth defects. She explained that most states conduct surveillance on birth defects to understand trends, conduct research, allocate appropriate resources, and provide referrals to families affected by birth defects. She shared that CDC is working towards a more modern data system to improve timeliness, accuracy and accessibility.

Dr. Tepper stated that research is another important opportunity to learn. She shared that CDC coordinates several multi-state studies to examine the causes and risks of birth defects, the findings of which are used to inform clinical and prevention practices, confirm observed associations, generate new hypotheses, and provide information on research outcomes to the public. She explained that the CDC study BD-STEPS aims to study risk factors that may be modifiable, such as medical conditions, medications, and other exposures.

Dr. Tepper stated that supporting prevention can bring about increased access to quality care, even though there are some challenges associated with preventing birth defects. For instance, Dr. Tepper said that most birth defects develop during the first trimester, often before the pregnancy is recognized, and the cause of most birth defects is unknown. Although it can be difficult to conduct studies on some modifiable risk factors, she explained that there are risk factors that are well-understood. She said, for example, it is known that promoting optimal folic acid levels can prevent spina bifida.

Finally, Dr. Tepper reviewed treatment opportunities. She explained that infants that are screened for congenital disorders can benefit from early treatment. She shared that the Recommended Uniform Screening Panel (RUSP) for infants currently includes 35 disorders and is estimated to have identified nearly 13,000 infants with a congenital disorders each year. Although all states screen for congenital disorders, she stated that their screening programs could benefit from systematic data collection processes to monitor the impact of early identification and treatment. She asserted that standardized treatment protocols would also help improve outcomes. Dr. Tepper summarized by reviewing how CDC is committed to understanding and addressing health disparities in infant mortality related to birth defects.

Dr. Julie Moldenhauer presented on fetal therapies, which is an intervention performed on the maternal-fetal dyad for the benefit of the fetus. She shared that it is a relatively new field, that is supported by a multidisciplinary team, and that it does not currently have a governing body. She spoke about the diagnostic aspect of fetal therapy, which has advanced considerably in recent years and provides an opportunity to not only diagnose in utero, but also treat. She explained that since the early 2000s, the number of fetal centers has grown exponentially and addresses many different issues and syndromes. She shared that historically, fetal surgery was conducted for conditions that were life-limiting or threatening. However, she explained, after the Management of Myelomeningocele (MOMS) Study, that paradigm has shifted to also include improving quality of life.

Dr. Moldenhauer reviewed the tenets that the field uses as guidance for deciding who is a candidate, how to make an accurate diagnosis, what the natural history is, and how to avoid the potential for fetal death or organ destruction. She reviewed several conditions that can be treated through fetal surgery, from less invasive procedures such as fetal cardiac arrhythmias to more invasive procedures such as fetoscopy. She explained that most anatomic defects lead to fetal death if left untreated, but the recent trend towards improving quality of life means they can also conduct surgery to reduce side effects of birth defects.

She reviewed the maternal risks associated with fetal surgery, which can impact not only the current pregnancy, but also future pregnancies. She explained that they carefully weigh risks and benefits for both the mother and infant. She noted that despite these risks, they can use their tenets to guide the most appropriate candidates, assess technical ability and experience of the surgeon, and obtain maternal informed consent that clearly outlines all risks and benefits of a procedure towards a beneficial outcome.

Dr. Moldenhauer provided several examples to better illustrate the impact of fetal surgery. In one example, she reviewed the treatment of complicated monochorionic twins, in which each twin shares one placenta. She explained that the complication arises from an unequal sharing of the placenta, as well as unequal sharing of vascular connections. That can lead to one twin pumping blood and amniotic fluid to the other and the other twin having to manage the excess fluid—putting both at risk. She noted that, if not managed aggressively, there is a low survival rate of approximately 10-30 percent. But if treated through fetoscopic selective laser photocoagulation, which separates the placental share and vascular connections, she explained that the likelihood of survival increases to approximately 70 percent.

She also reviewed the MOMS Trial of myelomeningocele, which is a form of spina bifida. She explained that the study randomized patients to either have prenatal closure or routine postnatal closure of the myelomeningocele. She shared that in the group that had prenatal closure, the half the risk of ventriculoperitoneal shunt placement, improved motor function, higher likelihood of reversal in hindbrain herniation, and higher likelihood of becoming an independent ambulator. To replicate the MOMS Trial, she noted that the North American Fetal Therapy Network sponsors the Fetal Myelomeningocele Consortium and created a registry that tracks outcomes from any participating center. She shared that this collaborative effort showed that real world fetal surgery can reproduce outcomes similar to the randomized MOMS Trial. However, she noted that the data also show significant disparities, in which most fetal surgery occurs among non-Hispanic White families. She additionally pointed out that there may also be cultural differences related to how fetal surgery is perceived.

Dr. Moldenhauer shared that going forward, they are working towards more minimally invasive procedures, gene therapies, stem cell transplantation, and artificial placenta use. She noted that one gap in the field is that many centers are not required to report their outcomes. Therefore, she stated, a focus on outcomes monitoring and transparency in reporting will help advance the field. She shared that in 2004, the Society for Maternal Fetal Medicine created a working group on fetal therapy. She said that this working group met with the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) and formed the North American Fetal Therapy Network (NAFTNet) in 2005 to track and follow fetal therapy outcomes. She explained that the mission of NAFTNet is to provide a cooperative clinical research network to study the natural history of fetal disease and to develop therapeutic interventions to improve outcomes. She shared that currently there are 40 NAFTNet member centers.

Discussion

Dr. Palacios talked about how there are no historical rates for birth defects in the AI/AN population from 2003 onward. She suggested that Indian Health Services (IHS) can provide that historical data and asked how CDC plans to conduct adequate surveillance of this population towards improving health equity. Dr. Tepper said that the data she presented came from the National Vital Statistics System (NVSS), which did not report on the AI/AN population. She stated that the data for race/ethnicity are available, although she is not certain how far back the data go. Dr. Danielle Ely added that the reason AI/AN data was not included is that, even though the infant mortality rate is very high, the numbers are very small, making the data unreliable for inclusion in research. She stated that mortality rates for congenital malformation are included in the 2019 infant mortality report, which was just released.

Dr. Ehlinger asked if CDC has specific activities for sickle cell anemia. Dr. Tepper said she would have to defer to her CDC colleagues at the Division of Blood Disorders who focus on sickle cell disease.

Dr. Calvin asked what anesthesia was used for both mother and baby during open procedures. Dr. Moldenhauer answered that more minimally invasive procedures involve intravenous sedation with local for the mother, an intramuscular injection for the baby, and in some cases general for the baby depending on fetal movement. She stated that in open fetal surgery, they apply general anesthesia to the mother, some of which is transferred to the baby via the placenta. Once the uterus is open, she explained, they also apply an intramuscular injection to the baby.

Dr. Peck said she was struck by the language used in the presentation that described the mother as a willing, innocent bystander who agreed to take on risk. She asked for more detail on the risk for maternal mortality, severe maternal morbidity, and the subsequent reproductive life course. Dr. Moldenhauer described how she approaches counseling the mother, which involves talking about every possible negative outcome. She explained that there is also a two-day process in which the mother has a diagnostic workup, receives counseling, and meets with all of the clinicians involved. She shared that if the mother is engaged and genuinely wants to move forward after this process, only then does it represent informed consent. She stressed that major complications after minimally invasive procedures are rare, and the likelihood of a complication, such as uterine rupture, that affects the reproductive life course is low. She explained that open fetal surgery involves incision at the thicker part of the uterus, which can affect not only the index pregnancy, but also every future pregnancy. She noted that data from the myelomeningocele registry showed a 10 percent incidence of uterine rupture and, of those, two babies were lost and one mother suffered major complications. She pointed out that the risk is not insignificant and should not be taken lightly. She concluded that mothers with high risk factors, such as cardiac arrhythmia or poorly controlled diabetes, would not be a good candidate for fetal surgery because the risk is too high.

Dr. Peck asked what insurance pays for this procedure. Dr. Moldenhauer answered that both private insurance and Medicaid pays. She stated that at Children's Hospital of Philadelphia, they have philanthropic funds from former patients to fund patient travel and housing. She reiterated that their data is skewed toward a population of educated White individuals who may have a stronger support system than others.

Dr. Colleen Malloy talked about her observation as a neonatologist that mothers only hear about the option for fetal surgery through their obstetrician or midwife. She stated that every family has a right to know that this is an option. Dr. Moldenhauer agreed.

State and Community Projects on Maternal Health

***Steve Calvin, M.D.,* (Moderator)**
***Tammy Murphy*, First Lady, State of New Jersey; Founder, NURTURE NJ**
***Elliot Main, M.D.,* Stanford University**
***Connie Mitchell, M.D., M.P.H.,* California Department of Public Health**

Ms. Tammy Murphy launched Nurture New Jersey in 2019, which is a statewide awareness campaign committed to reducing maternal and infant mortality and ensuring equitable care. In January, she unveiled the Nurture New Jersey Maternal and Infant Health Strategic Plan. As First Lady of New Jersey, she listened to increasingly frequent stories from Black mothers and other mothers of color who had lost their babies, and from fathers who had lost their life partners. She shared that a common theme of these stories is of mothers not being listened to and cared for when they were at their most vulnerable.

She outlined their comprehensive approach to understanding the scope of New Jersey's maternal health crisis, which has made significant, often groundbreaking, policy changes. She shared that among their accomplishments are being one of the first states to establish a statewide universal newborn home visitation program, expanding Medicaid coverage to 365 days postpartum, and reimbursing Medicaid for doula care. Despite these accomplishments, she stressed that the crisis is just as urgent as before. She highlighted that the structural changes needed to address the institutional racism that causes significant disparities in Black maternal and infant outcomes will require persistence and dedication.

Ms. Murphy said the state's goal is to not simply improve maternal health statistics, but to ensure that every mother and baby in New Jersey is put on a trajectory for a full and healthy life. She shared that the Nurture New Jersey Maternal and Infant Health Strategic Plan is the culmination of more than a year of collaboration with relevant organizations, community representatives, clinical professionals, and mothers and their families. She explained that the Strategic Plan is their blueprint for making New Jersey the most safe and equitable state in the nation for delivering and raising a baby, which will be accomplished by meeting the specific needs of individuals in their communities. She noted that the Strategic Plan aims to make broad reforms to dismantle structural racism with recommendations ranging from increasing prenatal care and support for mothers of color to creating a groundbreaking Maternal Health Research and Innovation Center. She shared that their goal is to reduce the maternal mortality rate by 50 percent in five years and eliminate health disparities in birth outcomes.

Ms. Murphy said that Nurture New Jersey meets quarterly with their interdepartmental maternal and infant health workgroup. She shared that they have held six family festivals to bring together state, county, and local resources to over 5,500 families from cities representing the highest rates of maternal and infant mortality. Recently, she stated, they held their fourth annual Black Maternal and Infant Health Leadership Summit, which hosted over 350 participants including doulas, nonprofits, state agencies, and mothers. She shared that Governor Phil Murphy has signed 37 maternal health-related pieces of legislation representing small and large changes, all of which created major impact. She noted that these accomplishments have put New Jersey on the path towards tackling systemic racism. She hopes their success will lead the nation onto the same path.

Dr. Elliott Main is the Director of the California Maternal Quality Care Collaborative (CMQCC) and chairs multiple national committees on maternal quality care. He explained that California has a large and diverse population with nearly 500,000 births every year, representing 12 percent of all U.S. births. He shared that the CMQCC is a public-private entity formed by the California Department of Public Health (CDPH) and established in 2006 to address their rising maternal mortality rates. He stated that their mission is to translate statewide maternal mortality reviews into action.

He provided an example of their work. By reviewing data comparing rates of first birth low-risk cesarean rates in California to that of the U.S., both of which were at 26 percent in 2014, California's dropped significantly in the five years following statewide changes implemented through the collaborative. He shared that the rate of unexpected newborn complications did not change despite the reduced number of cesareans. He highlighted that the CMQCC process for creating this change, at scale, is synergistic and involves combining data from maternal mortality reviews, hospital quality improvement collaboratives, quality improvement toolkits, and the participation of pregnant individuals. He explained that the project concurrently engages with health plans, Medicaid, and other purchasers; rewards hospitals that achieve target metrics; and provides transparent reporting of outcomes to the public.

Dr. Main cited that the Quality Improvement Toolkits provide a "how-to" for improving and designing hospital care for specific obstetric conditions. He explained that the toolkits are paired with Quality Improvement Collaboratives between hospitals and community groups to work together to address a specific issue. He highlighted that underlying these processes is their Maternal Data Center, which translates birth certificates into quality improvement tools. He explained that they link every birth certificate in California to hospital discharge diagnosis files and use these data to calculate benchmark quality metrics that are stratified by race/ethnicity. He shared that the Maternal Data Center is supported through a modest fee paid by each of the participating hospitals to increase access to comprehensive, timely data and reduce siloes.

He said that as a private-public collaborative, CMQCC benefits from engaging a wide range of stakeholders and active partners, including professional groups, public consumer and community organizations, and health plans (which are particularly important because they can provide incentives for participation and target achievement). He explained that they also engage with national partners such as the Joint Commission, CMS, HRSA, and CDC to promote guidance, safety bundles, and quality collaboratives. He shared that CMQCC collaboratives have been able to reduce maternal mortality among all racial groups in California, but they have not yet closed the gap in disparities. He remarked that quality improvement cannot be achieved without reaching health equity, suggesting that this may stem from lack of key connections between community and health systems, between public health and clinical health approaches, and between in-patient and outpatient environments.

Dr. Main summarized that the CMQCC drives change to improve care at scale by using data surveillance and patient stories; mobilizing a range of public, private, and community partners; creating a system of rapid-cycle maternal-infant data; implementing a series of data-driven and large-scale quality improvement projects; and addressing equity. All of this is enacted simultaneously and transparently.

Dr. Connie Mitchell is an emergency medicine physician and Deputy Director for the CDPH Center for Family Health and was critical to the development of the pregnancy-associated mortality reviews in California. She spoke about the CDPH approach to addressing the rising rate of maternal mortality in California. She shared that this project began by generating hypotheses, one of which was that obstetric care was contributing to the rise in maternal deaths. She explained that they looked at medical records, approaching the investigation not as an oversight activity, rather as a collaborative quality improvement endeavor to maintain goodwill and trust. CMQCC provided the bridge between CDPH and the hospitals to develop guidance documents and toolkits and to gather real-time data to determine if they were making progress.

She reviewed a slide comparing the U.S. maternal mortality rate to that of California, from 1999 to 2016. She noted that from 1999 to around 2006, California rates were aligned with those of the nation. After 2006, when the CMQCC was initiated, California's maternal mortality rate began to sharply decline. Dr. Mitchell suggested that this decline may have resulted from many small, simultaneous changes that collectively accumulated impact.

She pointed out that, this trend does not represent the whole story. She reviewed data illustrating that the maternal mortality rates differ by how the rate is calculated (i.e., by death certificate alone versus from multiple sources) and by time (up to 42 days after pregnancy versus after 365 days). She explained that using multiple sources increases the rate, as does calculating the rate up to 365 days after pregnancy, suggesting that a snapshot of maternal mortality rates is not sufficient to describe the impact of policy and programmatic efforts. She shared that, furthermore, data that is stratified by race/ethnicity indicates significant disparities that persist despite their efforts. She stated that, importantly, by extending data out to one year, it reflects a wideningof the disparities between Black and White maternal mortality. She shared that social determinants of health also play a key role in disparities, with the highest mortality rates occurring in the most disadvantaged communities in California.

Dr. Mitchell said that the major challenges the CDPH faces include addressing the systemic racism and social determinants of health that underlie disparities, using a life course approach to understand risk and resilience the continuum of childhood to parenthood, increasing support for other related health risks, promoting health literacy for all, and continuing to improve the quality of care across the continuum of reproductive health. She reviewed opportunities for federal agencies to improve maternal health, including addressing equity-based COVID-19 recovery assistance for families and women, prioritizing the rising maternal morbidity rate, creating a national collaborative to improve health outcomes for Black mothers, addressing social determinants of health and social supports as a part of routine care, promoting a national vision that child-rearing is a shared responsibility, incentivizing a diverse reproductive health workforce, and improving data quality and standard reporting procedures. Dr. Mitchell reviewed the Guiding Principles for Maternal Health Policy Change document, which calls out the need to improve health care access and quality, address underlying determinants of health, eliminate systemic discrimination, ensure accountability, and promote inclusion and empowerment.

Discussion

Dr. Ehlinger asked how both New Jersey and California were able to build the political will and facilitate the sharing of data between hospitals. Ms. Murphy answered: people throughout the country are unified in support of this topic. She suggested that potential opponents/outliers be included in the process form the outset, breaking down communication siloes inside and outside the state. Dr. Main added that their first five or six years were spent communicating, promoting the benefits, and providing rewards and incentives.

Dr. Peck commented on the data for foreign-born mothers and asked why this particular population had better outcomes than non-Hispanic White mothers. Dr. Mitchell said that it is important to engage the community and include their perspectives to identify and understand their strengths. CDPH recently wrote a report on AI/AN, asking the community to interpret the data and how those findings relate to what they see. Similarly, he said, CDPH will engage the community in a report on Black infant and maternal health. Dr. Main added that there are strengths in the Latin community that are not reflected in traditional metrics, which looks at factors like personal wealth. Additionally, Latina women have far fewer comorbidities than other racial groups.

Dr. Palacios asked if the data for the AI/AN community will be included in the CDPH initiatives and what kind of partnerships would support that data collection. Dr. Main answered that they stratified their data by race/ethnicity, but they were initially concerned about including AI/AN communities due to the very small numbers. He shared that they have since changed that and the most recent report will include AI/AN mothers, as well as guidance on how to interpret small numbers. If multiracial birthing persons were included in the data, he explained, it would more than double the AI/AN rates. Dr. Palacios reiterated that capturing the community's experience is key.

Summary of Day One

***Edward Ehlinger, M.D., M.S.P.H.*, ACIMM Acting Chair**

Dr. Ehlinger provided a recap of the day, suggesting that, while medical approaches can be well-funded and researched through federal agencies such as the National Institutes of Health (NIH), the community and social side is not as well-funded or supported by any one agency. He asserted that this day's presentations have demonstrated the importance of community in maternal and infant health outcomes, and there is a need for better balance between clinical and community approaches.

DAY TWO: Wednesday, December 15, 2021

Narrative Development – Healthy Mothers, Healthy Babies, Healthy Society

***Edward Ehlinger, M.D., M.S.P.H.*, ACIMM Acting Chair**

Dr. Ehlinger reminded the Committee of President Lincoln's statement that one who controls public sentiment by shaping the narrative is more influential than one who enacts statutes or pronounces decisions. He stated that, today, social media and other media outlets have powerful influence over creating the narrative that shapes public opinion. He asserted that it is, therefore, important for the Committee to focus on creating and advancing a narrative about the importance of maternal and infant health to the success of our society. He shared that Vice President Kamala Harris contributed to this narrative when, in her opening remarks at the White House Maternal Health Day of Action, she said that "a healthy economy requires healthy mothers and healthy babies."

He described how narrative is not simply one story, rather it is a set of stories based on the context of values, lived experiences, and affiliations. He stated that narratives inform our identities and shape how we function in society. He reiterated his aim to develop an ACIMM report that shapes the narrative about the importance of mothers, babies, and families that leads to the long-term success of the country and helps change local, state, and federal program investment and policy strategies.

He stated that the first two steps in the process are to identify the dominant narrative and then create an alternative narrative. He reviewed some ideas that may shape the dominant narrative, including that health is an individual responsibility, anyone can choose to be healthy, and health care will "cure" illness and injury. He shared that the alternative narrative includes ideas such as health care is a community responsibility, historical trauma and health equity are current challenges, investments in medical and public health should be balanced, and the government has a role in protecting the public good.

Dr. Ehlinger applied both of these narratives to maternal and child health, with the dominant narrative including ideas that parents carry sole responsibility for the health of their children, private sector markets meet the needs of children, and disparities result from parental inadequacies. He stated that the alternative narrative for maternal and child health includes ideas that child rearing is a family and community responsibility, vitality of society requires community investment and prioritization of children, and some families endure structural disadvantages and need additional support.

He said that the next step involves advancing the alternative narrative. He stated that three sources of information help to advance this narrative: 1) the proposed actions put forward at the White House Maternal Health Day of Action, 2) elements of the Build Back Better Act that invest in public policies to strengthen maternal and child health, and 3) Dr. Laurie Zephyrin's article "Changing the Narrative and Accelerating Action to Reduce Racial Inequities in Maternal Mortality," published in the *American Journal of Public Health*. He highlighted the step in Dr. Zephyrin's article about determining *why* Black pregnant and birthing people do not receive risk-appropriate care based on standards. He asserted that it is at this step that the dominant narrative for maternal and child health constrains advancing health equity, because it is built on the idea that health comes from personal choices and medical care, not from structural processes and social determinants of health.

Dr. Ehlinger reviewed Dr. Robert Milstein's framework of navigating public health work, which outlines both a charity narrative and a social justice narrative for impacting health. He stated that over the last few years, ACIMM has been slowly changing the narrative from a focus on programs and medical care to a focus on policies and social determinants of health. He asked the Committee to review and provide feedback on these ideas on dominant and alternative narratives.

Discussion

Dr. Peck cautioned against viewing narratives as "either/or", rather they can be a "both/and" view that embraces all layers of narratives as essential for change. She pointed out that a narrative can be focused on structural change and justice without sacrificing a narrative focused on access to, quality of, or innovation in health care. Dr. Ehlinger agreed that there is no right or wrong narrative—all are necessary. However, there is often greater focus on resources and funds for health services and less focus on social justice or factors.

Dr. Warren said that the "both/and" perspective is also reflected in the updated ACIMM charter and name, which now includes both mother and child. He asserted that there cannot be healthy infants and mothers without considering the lifecycle and how upstream factors influence the next generation of offspring. In terms of developing a narrative, he stated, it is important to remember that states and communities operate very differently. Advancing ACIMM's work will require not holding onto preconceived ideas but instead understanding and meeting people where they are.

Dr. Jarris reflected on the challenge of broadening language to be more accessible to a wider audience. He asserted that the current state of politics has created systems in which certain words cannot be used. For instance, he said, the words "structural racism" cannot be used in some universities' course descriptions. He pointed out that at the fundamental level, everyone cares about mothers and babies, but the language is going to be important. He suggested identifying people who can contribute to the development of language that will reach different views. Dr. Ehlinger pointed out that Dr. Jarris is a good model for using language that reaches different audiences, such as his use of "goodness and fairness" rather than "equity and disparities." He also highlighted how the term "birthing people" may have seemed strange a year ago, but with consistent use has become normalized.

Dr. Palacios agreed that diplomacy in word choice is important but that it can be a double-edged sword. She asserted that there is a risk of having to talk in code, which can have a real impact on what is being measured and, ultimately, what is being funded. She stated that terms that are used to mask the word "racism," for instance, do not describe the fundamental issue and will not achieve the intended change. Dr. Ehlinger agreed and provided an example of how his use of the term "structural racism" as a state health commissioner helped to change the conversation. He asked the Committee to continue thinking about narrative during the remaining presentations.

Health of Indigenous Mothers and Babies

***Janelle Palacios, Ph.D., C.N.M., R.N.,* Moderator**
***CAPT Suzanne England, D.N.P., A.P.R.N.,* Great Plains Area Indian Health Service**
***Alida Montiel,* Inter Tribal Council of Arizona**
***Stephanie Bustillo, M.P.H.,* Inter Tribal Council of Arizona**

Dr. Palacios introduced the second part of a panel on indigenous mothers and babies. The first part took place at the September 2021 ACIMM meeting. She reviewed the presentations of the first meeting, which addressed the systemic policies that removed indigenous people from their land and caused intergenerational transmission of trauma. This trauma continues to affect the populations' health, the history and background of the Indian Health System (IHS), and the unique needs of the 574 recognized tribes and the ongoing challenges that hinder their health outcomes.

Dr. Suzanne England provided a brief overview of the U.S. tribal obligations, starting with the Constitution to the 2010 Indian Healthcare Improvement Act. She highlighted the accomplishments of IHS nurse, Eleanor Greg, who started the nursing division of IHS that specifically aimed to improve maternal and child health in the 1920s and the first Chief of Nurse Midwifery Service in IHS, Lucille Woodville in the 1970s. Dr. England also spoke about the Great Plains area, in which she serves, and the Pine Ridge Midwifery Program that started in the early 1970s.

She reviewed the IHS mission, vision, and strategic goals and its different Divisions, Area Offices, and tribally-operated and urban Indian health care services throughout the U.S. She shared that IHS serves more than 2.56 million people and its appropriations increase as the population increases. She explained that the IHS 2020 budget appropriation was $6 billion representing an expenditure of approximately $4,000 per user population. She stated that in comparison, the average health care expenditure in the U.S. is $9700. She pointed out that IHS provides several health care provider career paths and offers loan repayment programs to aid recruitment.

Dr. England reviewed IHS accomplishments including an increased age of mothers giving birth to their first child, access to care that is close to families' homes, public health nurse visits, postpartum visits and well-child checks, and partnerships with ACOG to provide quality improvement and education opportunities ensuring provision of evidence-based care. In terms of challenges, she stated, IHS is working to improve access for families living in rural areas and food deserts, address high poverty rates and generational trauma, improve recruitment to address health care provider positions in rural areas, and reduce substance use. She explained that another ongoing challenge is that IHS statistics come primarily from people who live on the reservations and receive care from IHS hospitals, even though many families live off the reservation. Therefore, she stated, there is a need for IHS to understand and address the specific needs of Native American populations at both rural and urban areas, on and off reservations.

She then addressed challenges in maternal and child health, specifically in rural areas. She explained that many birthing persons will receive prenatal care in a health center that does not have delivery capacity. She highlighted that they must travel a great distance to give birth, often battling weather conditions. She pointed out that this challenge is compounded when a birthing person is considered high-risk because they will then need to travel further to a level 2 or 3 facility. Often, she explained, this means that families are unable to join them or must travel a great distance. She said that telemedicine or specialists who travel to local facilities can help overcome some of these challenges, but long distances and the shortage of health care professionals continues to negatively affect access to care. She explained that emergency departments in rural areas are now trained for emergency childbirth and to assess high-risk conditions such as preeclampsia or uncontrolled diabetes.

Ms. Alida Montiel directs the Inter Tribal Council of Arizona (ITCA) health and human services. She provided an overview of ITCA and maternal and infant health programs and outcomes in American Indian communities in Arizona. She shared that ITCA was established in 1952 during a termination era in which tribal governments came together as a united voice to address common issues. She explained that in 1975, the ITCA achieved nonprofit status. She shared that its members comprise the highest elected tribal officials to provide a comprehensive view of the conditions and needs of their communities. She highlighted that they work with federal agencies, specifically IHS and the Bureau of Indian Affairs, to address health, education, environment, and voting initiatives. She explained that of the 12 IHS facilities across the nation, three are located in Arizona.

Ms. Montiel talked about the AI/AN traditional practices that view wellness as a balance of mind, body, and spirit with the environment. She shared that these traditional practices focus on prevention and risk reduction and have been shown to improve outcomes in maternal and infant health. She explained that cultural consideration for these traditional practices should be acknowledged, accepted, and integrated into their medical and community health setting that serve the AI/AN community. Currently, she stated, these practices have been integrated into some IHS/Tribal/Urban Health (I/T/U) programs but are not yet covered by Medicaid. She explained that their Medicaid agency, the Arizona Health Care Cost Containment System (AHCCCS), hosts a Traditional Healing Workgroup that has been advocating for the inclusion of a Traditional Healing Waiver for I/T/U facilities through the Section 1115 Demonstration Waiver. As of December 2020, this request is still under negotiation.

She compared obstetric, labor, and delivery best practices that are provided through the IHS system with traditional AI/AN practices. She shared that IHS best practices provide low-risk family-centered birthing centers that offer different birthing options, anesthesia consultations, and lactation support. She shared that aligning those practices with traditional AI/AN practices includes honoring and incorporating protocols that permit feathers, tobacco, medicine bundles, teas, prayers, songs, and other rituals into the birthing plan.

She noted that IHS created a policy to address the high rate of AI/AN maternal mortality and plans to establish a multidisciplinary Maternal Mortality Review Committee. She shared that ITCA has a Steering Committee of community health representatives, maternal health coordinators, nurse midwives, OB-GYNs, and traditional healers to guide and support maternal health strategies, improve maternal morbidity and mortality, and evaluate maternal health outcomes. Ms. Montiel reviewed an issue in which a labor and delivery facility in Phoenix was temporarily closed for maintenance during the pandemic. She explained that this closure compounded concerns for long travel distance, covered services, and staff shortages and prompted demonstrations from the AI/AN community. She noted that ITCA has therefore prioritized the backlog of the maintenance and repair of their IHS facilities, advocating for increased funding through IHS appropriations and working to reopen the Phoenix facility.

Ms. Stephanie Bustillo reviewed data from a recent ITCA report on severe maternal mortality providing background for the scope of maternal mortality and morbidity in Arizona. She stated that the CDC Pregnancy Mortality Surveillance System indicates the AI/AN women have the second highest mortality rate, of which an estimated 60 percent are considered preventable. She shared that CDC also indicates that the overall rate of severe maternal morbidity has increased nearly 200 percent from 1993 to 2014, with blood transfusions accounting for the majority of that increase.

Ms. Bustillo pointed out that ITCA serves Arizona, Nevada, and Utah but Arizona's rate of maternal mortality and severe morbidity in AI/AN is far higher than the other two states. She explained the results of her comparison analysis of Arizona's rates to that of IHS across the nation. She noted that IHS's rate of maternal mortality and severe morbidity between 2011 and 2015 was 246.1 per 10,000 live deliveries as compared to Arizona's rate of 292.6. Although there were some limitations in this analysis, including the distinction between maternal morbidity and severe morbidity, she affirmed that the data still depicts a concerning issue for birthing individuals in Arizona.

She then reviewed the ITCA action items for addressing this disparity from a social-ecological perspective. These include at the *individual level*, initiating and continuing prenatal care and seeking postpartum care; at the *tribal community level*, advertising resources for these services; at the *tribal health care provider level*, educating individuals about maternal mortality and morbidity and promoting the CDC Hear Her campaign; at the *tribal leader and non-public health* *level*, improving AI/AN surveillance data with tribes, IHS, state registries, and tribal epidemiology centers; and at the *ITCA level*, continuing to analyze and report more current data using the IHS Epidemiology Data Mart. Ms. Bustillo provided a link for the ITCA maternal and child health reports.

Discussion
Dr. Jarris asked about the difference between the number of diagnostic codes and procedure codes in the ITCA analysis. Ms. Bustillo answered that both codes were identified by CDC. She explained that one potential reason for the disparity was that blood transfusions indicate that something else is going on and it would be interesting to identify the diagnostic codes associated with those blood transfusions.

Dr. Calvin asked the presenters to address the travel distance to high-quality services and the what the ideal balance of those services with local community care might be. Ms. Monteil suggested looking to the Alaska Native medical center model, which provides places for patients to stay close to facilities. She explained that Alaska is a huge state with a lot of transfer of care needs. She pointed out that ITCA looked at the resources Alaska provides to bring patients closer to delivery services to make recommendations for Arizona in the future.

Dr. Wanda Barfield asked the presenters to address risk appropriate care, and the models of care for meeting the needs of patients living in huge geographic regions. Ms. Monteil said that one challenge identified by their tribal health leaders is that the systems can lose track of a patient who received prenatal care locally but is transferred a long-distance for delivery. Dr. England added that many who experience challenges with travel and finances will not continue with postpartum care. She shared that providing postpartum programs, in combination with well-child checks for instance, could address their needs for parenting education, contraception, and health care follow-ups. Additionally, she said, the referral facilities are often not aware of cultural considerations and would benefit from education to provide culturally appropriate care. Ms. Bustillo said that ITCA is aware data gaps of American Indian individuals who may not be registered or who deliver outside of IHS and is working to improve data linkages.

Dr. Wise asked if there is a primary narrative integrating the three presentations that would facilitate direct action. Dr. Ehlinger responded that he is working with MCHB to host the next in-person meeting on tribal land. He asked the Committee and the Health Equity Work Group to consider the AI/AN narrative towards the planning of that meeting. He also mentioned looking forward to the ACOG evaluation report of IHS.

Housing Insecurity, Eviction, and Birth Outcomes

***Magda Peck, Sc.D.,* Moderator**
***Richard Cho, Ph.D.,* Department of Housing and Urban Development (HUD)**
***Gracie Himmelstein, M.D., M.A.,* Princeton University; University of California, Los Angeles**
***Alison Cernich, Ph.D., APBPP-Cn,* National Institute of Child Health & Human Development (NICHD)**

Dr. Peck said that housing is a key social determinant of health that impacts maternal and infant health outcomes. She talked about Matthew Desmond's book, *Eviction*, which described eviction as a sentinel event. She shared that the systems that create housing instability are complex, multifaceted, and intergenerational and can lead to long-lasting effects on families and, in particular, negatively impacts infant and child health and wellbeing.

She pointed out that despite aggressive advances in clinical medicine and innovations to improve access to quality health care, there is growing evidence that upstream factors such as racism and environmental exposure impact health outcomes. She shared that these presentations will focus on the upstream factor of housing and its impact on health. She indicated that the White House just hosted a forum on housing, bringing together stakeholders across the health sector to spotlight the impact of housing on health equity and to issue a call for action.

Dr. Richard Cho is a senior advisor to Ms. Marcia Fudge, the HUD Secretary, and was a lead presenter at the December 2021 White House forum on housing. He shared that HUD's mission is to create strong, sustainable, inclusive communities and quality affordable homes for all. He pointed out that HUD understands that to achieve that mission, it must also address the health needs of people in their housing programs. He explained that though it is currently a small agency, the President's proposed Build Back Better Act would significantly increase their budget.

Dr. Cho's role at HUD is to address the intersection of housing and health. He reviewed the Department's definition of housing security, which is housing that is physically and environmentally safe; has physically adequate space; is affordable (representing no more than 30 percent of gross income); is based on choice; and is stable through the protection of local, state, and federal housing laws. He explained that the definition of housing insecurity spans multiple experiences including homelessness, risk of homelessness, rent burden (paying more than 30 percent of gross income), risk of eviction or foreclosure, severely inadequate living conditions, and worst case housing needs (renter households that are experiencing rent burden and severely inadequate conditions).

He then reviewed the scope of housing insecurity. He shared that statistics from the Household Pulse Survey collected during the COVID-19 pandemic show that, from September to October 2021, nearly 7 million renters in the U.S. reported being behind in rent and more than 3 million reported fear of imminent eviction. He noted that pre-pandemic data indicated that more than 580,000 people had experienced homelessness, an increase of 6 percent since 2016. He pointed out that data from 2019 indicated that 7.77 million households had experienced worst case housing needs, representing a 2 percent increase among non-Hispanic Black households and a decrease among non-Hispanic White households.

Dr. Cho shared that over the course of the pandemic the number of households experiencing housing insecurity varied from month to month, with higher numbers associated with increasing numbers of infections and lower numbers associated with the rollout of the American Rescue Plan and COVID-19 vaccinations. He stated that, the overall rate of housing insecurity remained high affecting approximately 5 million households at any given time during the pandemic and disproportionately affecting non-White households.

Dr. Cho noted that 70 percent of individuals in HUD-assisted programs are women. Of those, 77 percent identify with a racial/ethnic minority group. He shared that approximately 50,000 babies are born each year to HUD-assisted women. He explained that children comprise 35.5 percent of all HUD-assisted persons, including 900,000 children aged 0-5. He stated that data on health status indicate that both women and children in the HUD programs are more likely to have high risk factors for COVID-19.

He shared that research indicates that that infancy is the most likely period of life to live in a homeless shelter. He highlighted that approximately half of homeless families have a child aged 0-5 and 10 percent have a child under 12 months of age. He pointed out that homelessness is associated with higher odds of low birth weight, preterm delivery, and poor infant health, as well as worse maternal physical and mental health outcomes.

Dr. Cho reviewed some promising interventions for the coordination of housing assistance and maternal and child health. He cited the Ohio Healthy Beginnings at Home study, which showed that a combination of rental vouchers and maternal health services resulted in a greater number of newborns born at full term, fewer newborns admitted to NICU, and fewer days spent in NICU for newborns who required it. He shared that another 12-year study found that providing a housing voucher to homeless families with young children resulted in fewer child separations, decreased maternal distress, decreased economic stress, fewer child behavior issues, and decreased food insecurity. He also pointed to the Boston Healthy Start in Housing Program which is tracking how the provision of public housing and maternal health services improves maternal health status.

Going forward, he stated that HUD is committed to improving outcomes for mothers, children, and families through increased education and outreach, cross-agency data linkages, partnerships with maternal and child health stakeholders, and connecting health care providers with housing providers. He further emphasized that HHS can facilitate a stronger link with housing programs by including HUD in its conversations and embedding housing screening and resources with their existing programs.

Dr. Gracie Himmelstein is part of the Eviction Lab team. She said that health at birth is a major determinant of health across the life course and one key driver of poor health at birth is maternal disadvantage. She shared that eviction is both a cause and a consequence of maternal disadvantage. She noted that there has been a rising eviction crisis in the past two decades, with median rent increasing by 13 percent and median income increasing by less than half a percent. She cited that in 2016 over 6 percent of renter households had an eviction filing, and in 2017 more than half of poor tenants in the U.S. were considered rent burdened. She explained that these data do not represent a one-time event, but rather an epidemic of chronic financial insecurity in renters.

She noted that during the COVID-19 pandemic, the CDC issued a moratorium on evictions, preventing over 1.5 million evictions. She explained that, in states and localities that did not continue a moratorium policy, eviction rates increased, resulting in increased rates of COVID-19 infection, morbidity, and mortality. She highlighted that there are racial and gender disparities in eviction risk, with eviction rates higher among Black renters and women. Notably, she pointed out, the eviction filing rate against Black women (the same population at highest risk for adverse birth outcomes) is nearly twice that of White women.

Dr. Himmelstein presented eviction and birth data from Georgia. Comparing women during their pregnancy and the time outside of pregnancy, she explained that those individuals were exposed to eviction during gestation had significantly worse birth outcomes, including lower birth rate and increased probability of premature birth. She shared that the second and third trimester were found to be particularly vulnerable times for eviction. She stated that eviction rates vary across the U.S. and are dependent on state and local policies. She concluded that research suggests that policy intervention such as legal assistance, affordable housing, rental assistance, and increased minimum wage and public benefits can significantly reduce the frequency of eviction.

Discussion

Mr. Lee Wilson said that MCHB has been engaging with HUD to bridge services. Dr. Cho has spoken at Healthy Start meetings and they are looking at the potential of a housing voucher program for Healthy Start grantees.

Dr. Ehlinger asked what policy changes occurred in the 1980s that led to a dramatic increase in homelessness. Dr. Cho said that the idea that the deinstitutionalization of mental health institutions in the 1960s and 1970s led to an increase in homelessness is an oversimplification. He explained that there were also slum clearance policies, reduced numbers of affordable housing, and a significant shift in HUD's budget that contributed to homelessness. Of these, he stated, the decades of disinvestment in housing programs coupled with significant housing costs has been the biggest driver of homelessness rates. He explained that the American Rescue Plan and the Build Back Better Act are opportunities to make up for the many decades of disinvestment.

Dr. Peck asked if Dr. Cho had a wish list from ACIMM. Dr. Cho said that continued conversation is key to increasing understanding and awareness of this issue and recommended build collaborations between health and housing programs. He shared that HUD is excited to support partnership with HRSA.

Dr. Peck asked Dr. Himmelstein to describe the Eviction Lab and why it exists. Dr. Himmelstein said that eviction results in a cascade of adverse outcomes affecting employment, education, and health. She shared that the Eviction Lab exists to address these cascading events of insecurity and to use the data to understand the who, where, and what that result from eviction.

Dr. Tara Sander Lee asked what type of policies are needed for a pregnant individual and across what timeline would those policies be most effective. Dr. Himmelstein said that understanding that the second and third trimesters are the most vulnerable for eviction provides a window of time in the first trimester to intervene. She explained that providing a medical and legal partnership early in the pregnancy and identifying those at highest risk would have significant impact.

Dr. Sanders Lee referred to Mathew Desmond's book and suggested it referred to eviction not only as a sentinel event, but as one that is self-perpetuating. She asked what tools might help an individual who has been in the cycle for a while. Dr. Himmelstein agreed that the data show serial evictions but that the effect on infant health is the same whether the eviction occurs once or serially. She said that pregnancy is a time in which there is increased contact with social workers and clinicians. This provides an opportunity for intervention.

Dr. Peck said that it is important to understand the historical, contemporary dynamics of housing and the relationship of housing insecurity and stress to inform recommendations for action. She asked Dr. Alison Cernich to address the effect of stress on housing. Dr. Cernich answered that social determinants of health can provoke biological shifts in the body. Additionally, she noted, many at risk individuals experience multiple disadvantages that impact where they live, regardless of eviction status. She shared that longitudinal research shows that there is intergenerational transmission of these disadvantages. She stated that even genetically, stress responses are passed through generations. She concluded that the time period of impact is not only the pregnancy, but across the life of the parent and child.

Planning for a Future Evidence Review and Discussion on the Impact of Abortion on Infant and Maternal Mortality

***Edward Ehlinger, M.D., M.S.P.H.*, ACIMM Acting Chair**

Dr. Ehlinger said that, although many people view abortion as an issue of values and morality, there are also public health implications related to the health of mothers and infants. He asked the Committee to consider a framework for which objective data on the impact of abortion on maternal and infant mortality can inform a productive discussion. He reviewed ACIMM's charge to remind the Committee of its scope and then invited Dr. Glenda Eoyang to review a process for objectively asking questions.

Dr. Eoyang talked about the process of inquiry, which provides a path forward for complex topics that can become "stuck." She explained that inquiry helps to turn judgment into curiosity so that conflict and defensiveness can move to shared exploration. She stated that the process of inquiry involves framing a specific question to focus on, collecting sources of evidence or objective questions, and using those questions to design a framework for future conversation.

Dr. Eoyang asked Committee members to share their questions. Questions were written in the Zoom chat function and then read out loud.

Questions asked:

- What is the impact of restricting access to abortion on maternal health and maternal mortality -- morbidity, mortality? (Dr. Conry)
- What are the socioeconomic effects of having access to abortion or not having access to abortion for women, families, communities, and populations? (Dr. Palacios)
- What are the links between abortion and contraception access and use? (Dr. Palacios)
- How is infant mortality defined? I understand the definition of mortality between birth and one year. So, we have agreement on a definition? (Dr. Conry)
- Does anyone really feel that this process will immunize SACIM from intense, likely lethal controversy, particularly if the less progressive Congress is elected in the mid-term? (Dr. Wise)

- What are the dangers to women in having an abortion and what are the risks to future pregnancies and impact on preterm birth? (Dr. Sander Lee)
- How does the death of a mother impact the health of her family and community? (Dr. Conry)
- What is the impact on individuals and families related to abortion services access?
- (Dr. Pettiford)
- Do prior preterm or do prior pregnancy outcomes impact preterm birth risk?" (Dr. Calvin)
- What are the dangers to women in having an abortion and what are the risks to future pregnancies and impact on preterm birth? (Dr. Conry)
- What are the dangers to women in having an abortion and what are the risks to future pregnancies and impact on preterm birth? (Dr. Peck)
- What is the evidence source? (Dr. Conry)
- Who gets to decide what's evidence and what if we can't agree on the same set of facts here within SACIM? (Dr. Peck)
- If MCHB staff are available to really assist in formulating a literature search and then doing comprehensive scientific research that includes ranking the evidence and the quality of the studies? (Dr. Jarris)
- What are the risks of abortion? (Dr. Conry)
- What about risks that lead to preterm birth, which can include various published factors, including history of surgical abortion? (Dr. Malloy)
- How does access to abortion help reduce infant mortality? (Dr. Sander Lee)
- Over time, how has policy changes regarding abortion affected women, children, families, communities, and populations? (Dr. Palacios)
- How does the discussion and deliberation of ACIMM change, given the expanded duties to address maternal mortality and morbidity? How has it changed now that the committee has shifted from an exclusive focus on infant health to a mandate to look at maternal health and morbidity? (Dr. Peck)
- How and who makes the risk benefit decisions, given that any medical intervention has a risk and a benefit? (Dr. Jarris)
- How does global research impact United States understanding or interpretation of data? (Dr. Conry)

Dr. Ehlinger said that he will form a small work group to curate these questions, in order to create a session for framing this topic at the April 2022 meeting. Dr. Sanders Lee pointed out that this extensive approach has not been taken with any other topic. Dr. Malloy added that a discussion on preterm birth, which includes abortion, as it relates to maternal and infant mortality is reasonably within the scope of the ACCIM charge and has a body of evidence that does not require a different approach. Dr. Ehlinger reiterated that the topic is controversial, and this process is to determine if there is potential for objective discussion. Dr. Jarris said that he is grateful for this process because it allows him to better understand the topic so that Committee members can come to the conversation with similar knowledge backgrounds.

Public Comment

***Vanessa Lee,* Acting Designated Official, ACIMM**

Ms. Lee said that the Committee did not receive written comments. There was one request for oral public comment from Dr. Jen Villavicencio, who is an OB-GYN and the lead for equity transformation at ACOG. Dr. Villavicencio said that abortion is a complex issue but also a common, normal, and safe part of reproductive lives, whereas restricting abortion has dire consequences. She shared that ACOG's statement of policy on abortion is that induced abortion is an essential component of women's health care. She elaborated that it also states that all medical decisions regarding abortions should be made by patients in consultation with their health care providers without undue interference by outside parties. She explained that part of her practice includes compassionate and fact-based counseling, including informing each individual of the risks, benefits, and alternatives associated with all medical procedures, including pregnancy termination. She stated that the science on the safety of abortion and both its short- and long-term impacts on mental and physical health is settled and was reinforced recently by the National Academies of Science, Engineering, and Medicine in their 2018 consensus report *The Safety and Quality of Abortion Care in the United States*.

Dr. Villavicencio affirmed that ACOG strongly recommends that the Committee thoroughly review the conclusions of this report. She stated that the conclusions outlined in the report reinforce that the Committee's time is best spent focusing on developing recommendations for the Secretary to address pressing drivers of maternal and infant mortality, including inequities in outcomes resulting from individual and systemic racism and social determinants of health. She added that there are also data from the Turnaway Study demonstrating that women who are turned away from a needed abortion and subsequently give birth experience an increase in household poverty (and related outcomes, such as an increase in evictions) that lasts at least four years. She concluded that as the Committee considers its next steps, ACOG strongly urges it to consider the negative impacts that legislative restrictions have on maternal and infant mortality, as well as the body of evidence affirming the safety of abortion.

Discussion and Next Steps

***Edward Ehlinger, M.D., M.S.P.H.*, ACIMM Acting Chair**
***Vanessa Lee,* Acting Designated Official, ACIMM**

Ms. Lee reviewed the language of the 2021-2021 ACIMM charter, which has been updated to include maternal mortality and severe morbidity, tribal and territorial governments, and the MCHB Title V Block Grants. She shared that the updated charter also includes formalized language for the Committee to consider private and voluntary sectors and to look beyond medical factors to include policy-, program-, and system-level changes. She stated that the Committee bylaws have also been approved by HRSA and will be included in the next briefing book. She explained that HRSA anticipates appointing eight to nine new Committee members by the next meeting. She noted that they are exploring an offsite, in-person meeting on April 5, 6, and 7, 2022, depending on any government policy in place at that time. Ms Lee talked about their intention to have a more experiential meeting, but they will monitor the state of the COVID-19 pandemic and will keep the Committee posted.

Dr. Ehlinger anticipates the next two meetings will also focus on recommendations for indigenous health and provide a warm handoff from retiring Committee members to new Committee members. Ms. Lee shared that the annual deadline to file the ethics review is May, which is the same for regardless of start date and will be required to complete in order to participate in the June meeting. Dr. Peck asked if there will an opportunity to bundle recommendations for housing, COVID-19, or immigration with those for indigenous health. Dr. Ehlinger said there would and that finalizing the recommendations by June will be the last opportunity for some Committee members to see this work through. Dr. Peck recommended asking new Committee members to join workgroups as a transition process.

Ms. Lee shared that she will on maternity leave in January and that Mr. Wilson will serve as acting DFO. Ms. Anne Leitch will act as program lead in her absence.

Adjourn

In closing, Dr. Ehlinger asked the Committee to consider addressing the impact of violence on maternal and infant mortality. He then asked Committee members to summarize their takeaways from the meeting and adjourned the meeting at 4:00 p.m.