### **Advisory Committee on Infant and Maternal Mortality**

**DRAFT** Meeting Minutes of September 13-15, 2022

**Hybrid (In-Person and Virtual) Meeting** 

These minutes will be formally considered by the Committee at its next meeting.

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### DAY ONE: Tuesday, September 13, 2022

### **Drum/Flag Ceremony and Invocation**

### **Imnizska Drum Group:**

Ozzie Nelson, Sisseton Wahpeton Oyate Sage Demarce, Spirit Lake Nation David Nelson, Sisseton Wahpeton Oyate David Stier Chelsea Thompson, Leech Lake Band of Ojibwe Amy Nelson, Bois Forte Band of Chippewa

### **Veteran Group:**

Barry Welch, Shakopee Mdewakanton Sioux Community, SMSC Flag Warren Stade, Shakopee Mdewakanton Sioux Community, Amos & Rose Crooks Family Eagle Staff

Cody Seaboy, Mandan-Hidasta-Arikara, American Flag

#### **Invocation:**

# Leonard Wabasha, Shakopee Dakota, Director of Cultural Resources at Shakopee Mdewakanton Sioux Community

Mr. Leonard Wabasha talked about the US-Dakota war of 1862 and invited attendees to visit the Hocokata Ti Cultural Center to learn more about the event and Dakota life. He opened the meeting with the Dakota invocation prayer.

### Welcome

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

Mr. Lee Wilson called the Advisory Committee on Infant and Maternal Mortality (ACIMM) to order and welcomed both in-person and virtual attendees. Dr. Edward Ehlinger welcomed attendees to the sacred tribal land in which they could work towards the betterment of Indigenous mothers and babies across the country.

### **Tribal Welcome**

# Joanna Bryant, Shakopee Dakota, Tribal Public Health Administrator, Shakopee Mdewakanton Sioux Community

Ms. Joanna Bryant welcomed attendees to the Shakopee Mdewakanton Sioux Community and thanked the Committee for recognizing the importance of bringing people together to hear the different voices and inputs—not only from the policymakers and advocates, but also from those who are affected by policies and the Committee's recommendations. She thanked the Committee for their dedication to improving the lives of mothers and infants.

### **Welcoming Remarks and HRSA Perspective**

### Carole Johnson, Administrator, HRSA, HHS

Ms. Carole Johnson thanked the Committee for their commitment to maternal and infant health and their leadership to deeply investigate the challenges that are faced by American Indian and Alaska Native (AI/AN) women. She echoed the importance of the voices of the community for informing the Committee's critical work. She recognized the Committee, the Health Resources and Services Administration (HRSA) Maternal and Child Health Bureau (MCHB), and Indian Health Services (IHS) leadership for their partnership to bring cultural humility to the work of maternal and child health. It is unacceptable that infant mortality rates are more than 75 percent higher among AI/AN infants and that maternal mortality rates are more than two times higher among AI/AN women. She expressed hope that the panelists' input and the Committee's work will make progress in reversing these rates. She acknowledged the burden placed on communities when they are asked to bring forward their stories and expressed hope that the way forward will reflect both the community's trauma and resilience.

Ms. Johnson said that the Biden-Harris Administration has prioritized the maternal mortality crisis and directed Department of Health and Human Services (HHS) to address the crisis across all of its agencies and bureaus. One of the challenges in improving health care outcomes among AI/AN is workforce needs, which HRSA addresses through several focused efforts. For instance, HRSA's National Health Service Corps supports the growth of the primary care workforce to communities in the United States (US) with limited access to health care (including tribal communities) through scholarships, loan repayment, and clinician placements. HRSA endeavors to support a health care workforce that is respectful of tribal traditions and trusted by tribal communities. HRSA's Teaching Health Center Graduate Medical Education Program, which provides clinician training in hospitals and communities, has tribal partners to ensure that clinicians have more exposure to and understanding of tribal communities.

Ms. Johnson highlighted MCHB programs that provide federal resources to US states, tribes, and other jurisdictions towards advancing the health and wellbeing of women, children, and families. The Maternal Infant and Early Childhood Home Visiting Program (MIECHV) partners with the Administration for Children & Families (ACF) to support the Tribal Maternal, Infant, and Early Childhood Home Visiting Program (TMIECHV), which identifies needs during home visits and connects individuals to services. The Healthy Start program has recently partners with the Inter-Tribal Council of Michigan and the Great Plains Tribal Chairmen's Health Board to determine how Healthy Start can best to serve their tribal communities. HRSA has also focused on cultural competence within its Maternal Mental Health Hotline, which provides 24/7 support for pregnant and postpartum individuals experiencing mental health challenges.

HRSA also supports pediatric mental health by providing <u>training</u> for pediatricians to ensure that they are equipped to identify and meet children's mental health needs. The program currently has two tribal partners—the Chickasaw Nation and the Red Lake Band of Chippewa Indians. The Bipartisan Safer Communities Act included a significant investment to this program and HRSA

will use the funds to expand its reach to tribal partners. HRSA recently hosted listening sessions that included several tribes to better understand the cultural and linguistic needs of Indigenous communities toward improved and increased access to pediatric mental health services.

HRSA is also working to simplify its grant application processes so that more communities are able to apply. HRSA recognizes that tribes may not have access to a dedicated grant writer and will continue to identify and advance the technical support needed to make HRSA's resources more accessible to all. HRSA strives to be an agency that reduces barriers to funding and engages new grantees with cultural humility. The Committee is at the forefront of this goal through its creativity and innovation in its recommendations for policy change. Ms. Johnson highlighted a Committee recommendation to expand Medicaid programs for one year postpartum that many states have implemented.

#### **Discussion**

Dr. Ehlinger emphasized the importance of social determinants of health in the AI/AN communities and asked how HRSA interfaces with other federal agencies to address the impact of these determinants on maternal and child health. Ms. Johnson said that Vice President Kamala Harris convened a Cabinet Meeting focused on maternal mortality to include herself; HHS Secretary Xavier Becerra; and leadership from other agencies such as the Centers for Medicare and Medicaid Services (CMS), the Department of Labor (DOL), the Department of Housing and Urban Development (HUD), and the Department of Transportation (DOT) to work collectively on the social determinants of health that affect maternal health. Social determinants of health were also the foundation for the White House Blueprint for Addressing the Maternal Health Crisis, which is a whole-of-government response to maternal mortality in the US.

Ms. Belinda Pettiford asked if the program that provides resources to family volunteers was national or statewide. Ms. Johnson answered that MIECHV is a national program that is supported by funding that HRSA provides to states. The TMIECHV is a version of MIECHV that specifically serves tribal communities.

### **HHS Secretary's Remarks**

Xavier Becerra, Secretary, HHS (Virtual)

Secretary Xavier Becerra thanked MCHB Associate Administrator Dr. Michael Warren, Dr. Ehlinger, and the Shakopee Mdewakanton Sioux Community for hosting this important meeting on tribal land. He also thanked the Committee and all those in attendance, who likely come to their leadership roles through lived experience and understanding of what is needed to address maternal and infant mortality and morbidity. He acknowledged the rich, but painful, history of the tribal community and conveyed HHS's resolve to capitalize on their input and the championship from the White House to make a real difference. There are unprecedented federal resources to focus on maternal and infant health in the US, including overcoming the barriers of mental health challenges and inequities. He urged the Committee members to "never be mild" because they are in a place to make the greatest difference, whether for maternal and infant

mortality and morbidity, the crisis of missing and murdered Indigenous people, the preservation of language and culture, or the assurance of health care for all.

### **Discussion**

Dr. Ehlinger thanked Secretary Becerra for his acknowledgment of the efforts from Dr. Warren and Mr. Wilson to conduct this meeting on tribal land. He invited Dr. Janelle Palacios, an Indigenous Committee member, to lead the discussion with Secretary Becerra.

Dr. Palacios talked about the number of federal reports demonstrating that the provision of health care borne from treaty rights are not meeting the needs of Native people. There is chronic underfunding, dilapidated facilities, outdated technology, and a lack of necessary equipment needed to support a stable and robust workforce. Dr. Palacios asked Secretary Becerra and Ms. Johnson to address to two major issues in supporting maternal and infant health among Indigenous communities. First, better data are needed among Native populations, in which there are regional and local differences. Depending on the year and source of data, Native women may die between two and seven times the rate of White women. While data are essential for defining health challenges in any population, there is question of how data on Native populations are collected, analyzed, and used. Native communities across the country have raised the idea of sovereignty over the collection, ownership, and application of its own data. There is a need for the meaningful participation of Indigenous people in the development of data collection, analyses, and dissemination. There is also a need for the inclusion of data related to historical and generational trauma, racism, and discrimination. Second, it is essential to provide greater resources and sufficient political will to support IHS and related frontline health and health care systems to ensure that they can provide reliable, accessible, and highest-quality health care for all Indigenous women and infants.

Secretary Becerra said that it is an HHS priority to obtain quality, disaggregated data to better understand how different Indigenous communities are doing. He added that President Biden has requested that funding for IHS is classified as mandatory and not discretionary so that there would be a clear, automatic allocation of resources every year. If Congress does not approve mandatory funding, they will seek to secure advanced discretionary appropriations so that Indian country can conduct some budgetary forecasting without having to guess each year on the resources they might receive. Government shutdowns put all discretionary programs, including IHS, at risk of closing, but advanced appropriations would at least provide IHS with funding in advance of a year or two. The President's budget has provided a record investment in IHS and, although it is not where it should be, it is far more than has been provided before.

Ms. Johnson said that HRSA understands that census data in insufficient to appropriately capture Indian country and has responded by opening up programs and processes for tribes to deliver data directly. It may not be ideal or efficient to require tribes to collect data and repeatedly provide it. Therefore, HRSA is looking to identify more systemic data collection processes and welcomes the Committee's recommendations and insights toward that goal. She said that Secretary Becerra has also been an incredible champion for increasing the IHS budget and that there has never before been a proposal for a consistent, well-defined budgeting process than what he and President Biden have proposed.

Dr. Ehlinger spoke about how Dr. Palacios's membership on the Committee had brought indepth insights about a population that would not otherwise be well-understood. He said that one of the Committee's recommendations will be to include more Indigenous members—both on this Committee and on committees across the federal government. It is important to build the diverse workforce and leadership needed to change the course of public health in the US.

Dr. Magda Peck commented that the championship from the HHS Secretary is historic. That both Secretary Becerra and Ms. Johnson described the maternal and infant mortality as an acute crisis speaks to the increasing visibility of the important maternal-infant dyad. Although the Committee has existed for more than three decades, the rates of maternal and infant mortality have not budged—particularly in Indian country. This is an opportunity to leverage the wave of attention and interest to raise up the context of families and communities and deliver on the Committee's charge.

Dr. Marie Ramas thanked Secretary Becerra and the administration for their action in health equity, particularly for Indigenous people. She highlighted three opportunities to address. First, there is an opportunity to sustain, maintain, and retain pediatricians, family physicians, and other primary care clinicians in support of continuity of care from healthy women to healthy pregnancies and infants. Second, she challenged Secretary Becerra to take the next step in maternal and child home visits by making them mandatory The programs are known to be beneficial to both mother and infant, and so it should be an automatic program for all. Finally, as technology and telehealth increase access to health care, it is critical to address the unequal access to broadband and cellular coverage, particularly in Indigenous communities.

Ms. Pettiford reiterated that it was important for the Committee to consider unintended consequences, such as the potential for telehealth to increase inequities without equal access to broadband.

Ms. ShaRonda Thompson was struck by the discussion about the need for a diverse Committee and Dr. Peck's comment that the Committee had been in existence for more than three decades. As a community member, she had only learned about the Committee a few years ago. She asked how to involve the public more so that they trust the Committee with their stories. Dr. Ehlinger answered that it can be a slow process. He challenged Committee members to share information about the Committee and their recommendations with their communities, organizations, senators and representatives, and governors. It is contingent upon the Committee members to conduct outreach and upon HRSA to develop a communication strategy to move the work into communities.

Dr. Palacios asked that the Committee consider that the mandatory funding requests for IHS does not mean that it will be sufficient to fill the needs of the Indigenous people. There has been such chronic underfunding that the community distrusts the use of IHS. If the COVID-19 pandemic had not occurred, IHS would not have seen the recent increase in funding. It will take much more than funding because the issue requires systemic changes throughout the US.

### **Introductions of ACIMM Members: Appointed and Ex-Officio**

#### **ACIMM Members**

Dr. Ehlinger invited Committee members to report on what they hope to bring to and learn from this meeting.

Ms. Thompson said that she hoped to hear about personal experiences and life stories to help the Committee make their recommendations.

Dr. Ramas said that the Committee's recommendations should reflect the needs, desires, and lived experiences of the people they represent.

(Speaker 7) said that there should be a removal of the invisibility in small numbers that are needed to drive recommendations and to acknowledge the weight of the task ahead that could fundamentally change the native and Indigenous communities that have been long ignored and hidden.

Dr. Peck hoped that the Committee could not only see the data, but feel the stories that would bring to life the issues and to unlearn the convenient stories that have preserved systems of power and oppression so that the changes can be made to help mothers and infants thrive.

### **Remarks from Minnesota Lieutenant Governor**

Peggy Flanagan, White Earth Ojibwe, Lieutenant Governor, Minnesota (Video Statement)
Lieutenant Governor Peggy Flanagan welcomed the Committee to Minnesota and thanked the Shakopee Mdewakanton Sioux Community for hosting the meeting. She and Minnesota Governor Tim Walz are dedicated to addressing maternal health disparities in Minnesota, specifically for Black and Indigenous mothers and infants. They have been working to address the maternal health crisis through expanding access to doula care, investing in a home visiting program, providing medical assistance coverage for children, and passing the Dignity and Childbirth Act. They have partnered with the Black Maternal Health Caucus, the People of Color and Indigenous Caucus, tribal leaders and staff, clinicians, health officials, and community organizations and hope to partner with the Committee to improve maternal health outcomes for people in Minnesota and across the US.

### **Remarks by Federal and State Officials**

Loretta Christiansen, M.D., M.B.A., MSJ, FACS, Navajo, Chief Medical Officer, IHS (Virtual) on behalf of Elizabeth A. Fowler, Comanche Nation with descendancy from the Eastern Band of Cherokee, Acting Director, IHS

Dr. Loretta Christiansen thanked Secretary Becerra and the Committee for their continued focus on improving maternal and child safety, health outcomes, and wellbeing. She talked about the IHS initiatives to address health disparities that lead to poor health status across Indian country. One of the aims of the IHS Maternal and Child Health Program is to improve health through risk reduction and health promotion. Hypertensive disorders of pregnancy have become increasingly common and are among the leading causes of maternal morbidity and mortality in the US. In

early 2022, IHS launched a pilot program at six IHS sites to expand the utilization of self-monitored blood pressure management equipment among pregnant individuals.

IHS has also strengthened their perinatal addiction services for individuals with substance use disorders and expanded access to medications for opioid use disorder to pregnant individuals. IHS plans to expand their Opioid Surveillance Dashboard, which is a data collection tool to help target opioid interventions, enhance clinical decision support, and create professional practice evaluation strategies. Dr. Christiansen commended the Portland Indian Health Board clinicians and people in recovery in their development of the Safe Care Toolkit to address substance use disorder in new parents. IHS also developed mandatory trauma-informed care training to ensure that the organization implements best practices in providing trauma-responsive services and access to care support. IHS trains its clinical professionals to identify and manage early warning signs in pregnant individuals through the use of the American College of Obstetricians and Gynecologists (ACOG) Alliance for Innovation on Maternal Health (AIM) bundles. IHS also collaborates with tribal leaders and other partners to conduct site visits to improve rural obstetric care and provides Advanced Life Support and Obstetrics (ALSO) courses to their staff.

#### **Discussion**

Dr. Ehlinger expressed frustration that IHS was not able to attend this important Committee meeting in person. He commented on the Committee's struggle to obtain the information they need from IHS to understand the scope of maternal and infant morbidity and mortality among Indigenous people. He asked Dr. Christiansen how the Committee could best work with IHS to obtain this information in its effort to make data-informed and appropriate recommendations for this community Dr. Christiansen said that IHS has a new maternal and child health consultant and that she hopes to continue interacting with the Committee to improve their relationship. She explained that there were multiple time commitments that impede the ability to attend meeting in person but that she is committed to working with the Committee to achieve their shared goals.

Dr. Peck said that she appreciated Dr. Christiansen's interaction with the Committee in their June 2022 meeting. She suggested that this particular meeting was an historic moment that she had expected would be a priority for IHS. She asked for clarification about the partnership between IHS and ACOG, which has been in existence for more than 50 years, and its outcomes. Dr. Christiansen said that IHS seeks to maintain patient safety and quality care and utilizes the expertise of ACOG to critically evaluate IHS maternal and obstetric care. Therefore, the relationship with ACOG is one of oversight and evaluation to identify areas of improvement and ensure the highest quality of care. IHS has similar partnerships with other organizations, such as the American College of Surgeons and the Committee on Native American Child Health.

Dr. Palacios said that the Committee is interested in reading historical reports about the IHS partnerships with ACOG and other organizations, but those reports have not been made available. She can obtain some information from the Government Accountability Office (GAO) or from the very few reports that IHS releases. As a Committee charged with improving the health of native women and children, there is a need to have data and information. She understands that tribes may be protective of their data and that IHS may not have funds for a statistician. She asked about the basis of these external evaluation partnerships if there were no

available reports of data that are vital to the Committee's charge. Dr. Christiansen answered that one of her priorities was to evaluate how IHS aggregates, analyses, and discloses information. The maternal and child health consultant will also be working to update their information sharing processes. There are some overarching parts of ACOG reports that can be shared and IHS is in process of gathering those data. IHS will have to carefully consider disclosing other parts of the reports that contain granular-level patient information and the sovereignty of that tribal data. Dr. Christiansen reiterated her commitment to working with the Committee and to finding the best pathways for sharing information going forward.

### Amy Klobuchar, U.S. Senator, Minnesota (Video Statement)

Senator Amy Klobuchar thanked Secretary Becerra and the Committee for their efforts to reduce maternal mortality in AI/AN people and reviewed the dire statistics. In Minnesota, only 55 percent of AI/AN women see a provider during their first trimester of pregnancy, as compared to 87 percent of White women. Only 47 percent of AI/AN women report receiving adequate prenatal care, as compared to 82 percent of White women. AI/AN women are early eight times as likely to die from pregnancy-related complications than White women. Of these deaths, approximately 60 percent are preventable. Senator Klobuchar talked about the successful fight to include extended postpartum health coverage for women on Medicaid and CHIP in the American Rescue Plan, which supported approximately 7,000 Minnesotan women with access to a full year of postpartum coverage. Minnesota Senator Tina Smith's Rural Maternal and Obstetric Modernization of Services (MOMS) Act was an important lifesaving step to increase funding for rural providers.

Senator Klobuchar talked about her commitment to the health care workforce. There is a need for nurses, midwives, and doulas, but in Minnesota alone, there are more than 30,000 unfilled nurse positions. Therefore, she is fighting for legislation to invest in high school career and technical education and community college to help students enter this essential high demand field. Senator Klobuchar said that there is much yet to do to provide AI/AN women with the culturally appropriate health care for safe deliveries and she looks forward to the Committee's recommendations.

### **Meeting Objectives and Format**

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

Dr. Ehlinger said that the purpose of this unique meeting was to gather knowledge to help strengthen and improve the Committee's recommendations for the Secretary. To ensure that the recommendations are impactful, it is important that they represent the issues, perspectives, and stories from Indigenous people. Therefore, Dr. Ehlinger asked the presenters to not only describe their program activities, but to also include a personal story to help the Committee enhance their report of recommendations with context. He asked Committee members to listen to these stories as they consider what is needed to understand the scope of the issue and the future issues that the Committee should focus on.

## **Setting the Context for Addressing Birth Outcomes for Indigenous Mothers and Infants**

Jackie Dionne, Turtle Mountain Chippewa, Director of American Indian Health, Minnesota Ms. Jackie Dionne talked about her work at the Minnesota Department of Health to address the systems that affect tribes and urban American Indian communities. The system is made up of people who make decisions about other people, but these decisions are often made from assumptions. For instance, there are assumptions that tribes do not want to partner or that a tribe is one voice that represents a collective answer. Therefore, those inside the system need to be educated about what an external partnership with tribes would look like. Ms. Dionne said that American Indian women historically have had to rely on the government to survive. In Minnesota, 80 percent of American Indian women who give birth do so under a public program. From the time of conception to the provision of care for the child, there are a number of systems that interact with the family. But when American Indian women interact with these systems, the message they receive is that they do not matter, and these experiences lead to mistrust.

It is not that no one in the system cares, but that policies within the system create restrictions. Policies are typically enacted by a legislator or administrator who assumes that they do not have permission to obtain data needed to make informed decisions, but tribal health directors are able to speak on behalf of tribes at the same level as these decision-makers. It is important for tribal maternal and child health data to be public so that it can be actionable through decisions and policies. Minnesota is a state with some of the best health outcomes overall, but the worst health disparities among American Indians. There is something inherently wrong with how decisions have been made and how funding is allocated. Although the population is small, the level of trauma that has been inflicted on the population is not. Rather than trying to change people, there should be a change in the systems to accommodate people where they are.

## Stacy Hammer, RDN, LDN, Bdewakantunwan Dakota, Director of Community Health, Community Health Officer, Lower Sioux Health Care Center

Ms. Stacey Hammer talked about the challenges that she has observed as a tribal health director. She emphasized the importance of relationship-building and the differences between funding partners who have never visited the community and only require reports of quantitative data and the partners who visit the community and learn about their history. She thanked the Committee for their effort to learn about the community, the inclusion of an American Indian Committee member, and their draft of recommendations. Her tribal nation does not have an IHS facility and has only recently opened its first ever tribal clinic. Ms. Hammer talked about how her father could not be born into his community because the family had to drive two hours to the nearest IHS facility.

Despite the profound difference the tribal clinic has made on the community, there are still several challenges. Although they hold quarterly meetings with the tribal health directors and Ms. Dionne, they do not talk to or even know anyone from IHS. There is also a disconnect between federal and state or county relationships. For instance, SNAP is a federal program that is written in such a way that it does not recognize income from their county-level benefit program. Even though they hired a SNAP outreach coordinator to help guide people through the process, the federal government continued to deny SNAP benefits to their community members.

Ms. Hammer talked about a young mother who had to travel two hours every Friday for six weeks to receive specialty care. She also talked about how the federal government provided a sudden influx of funding during the COVID-19 pandemic with a strict time limit to spend it. Fortunately, they had completed a strategic plan the year prior to the pandemic and knew that food insecurity was a significant need that could be quickly addressed with the additional funds. Ms. Hammer said that staffing is always a challenge and there is a need for clinical workforce development among AI/AN people. She talked about a new assisted living facility that had to be closed after only two years because of the lack of staffing. They also need capacity to hire expertise such as a statistician or epidemiologist. Although they have a grant-funded Family Spirit maternal and child health program, they do not have adequate staffing with Indigenous people who can conduct home visits and train others. Finally, Ms. Hammer said that there are many elders who are raising their grandchildren and great grandchildren and need support.

### **Department of Health**

# Socia Love-Thurman, M.D. Cherokee/Yuchi/Delaware, Chief Health Officer, Seattle Indian Health Board, Urban Indian Health Institute

Dr. Socia Love-Thurman talked about her experience as the Chief Health Officer for the Seattle Indian Health Board and as a family physician that provides obstetrics and postpartum care. She provided the Committee with several recommendations for the 76 percent of AI/AN people who live in urban areas. These urban communities were established through federal termination and removal policies in the 1950s, which led to socioeconomic disparities. Native pregnant women lost long-standing traditional birthing practices and experience barriers to care from a lack of transportation, financial means, and fear of stigma and discrimination from a system that was not made for them and that actively harms them. The system often over-medicalizes obstetrical care for native women, leading to invasive interventions and negative outcomes. Unfortunately, urban Indian organizations only receive one percent or less of the entire IHS budget.

Dr. Love-Thurman said that the Seattle Indian Health Board advocates for increased funding and programmatic support for urban AI/AN, not through a diversion of funding bur from carve-outs from state allocations. The inclusion of legislative language for tribes, tribal organizations, and urban Indian organizations could initiate funding mechanisms to sustainably provide culturally-attuned health care for mothers and infants. The Seattle Indian Health Board has been providing community resources and cultural activities to honor and celebrate their community. They recently opened a clinic that offers a larger proportion of AI/AN people with behavioral health case management and substance use disorder treatment. They host maternal and infant health groups that are rooted in traditional practices that are known to decrease infant mortality.

Dr. Love-Thurman talked about the <u>Healthy Native Babies</u> project that provided culturally-appropriate safe sleeping practices, but was discontinued by National Institutes of Health (NIH) when their contract ended in May 2022. The Seattle Indian Health Board recommends that the Healthy Native Babies program be reinstated through the Centers for Disease Control and Prevention (CDC) Division of Reproductive Health or the Administration for Children and Families (ACF). They also advocate for a permanent extension of WIC flexibility waivers, increased funding for WIC state grants to cover administrative costs that are currently unfunded,

decreased administrative burdens through reduced WIC grant reporting requirements, and increased funding for the WIC breastfeeding peer counselor program. Seattle Indian Health Board requests prioritized funding for outreach and training to potential AI/AN providers, including lactation consultants and doulas who can strengthen traditional birthing practices. Although HRSA announced a \$4.5 million <u>carve-out</u> for hiring, training, certifying, and compensating doulas in areas with high rates of adverse maternal health outcomes, the funding is not available to urban AI/AN organizations.

Dr. Love-Thurman is on the advisory committee through the Hummingbird Indigenous Family Services program in Seattle to roll out a guaranteed basic income pilot for AI/AN expecting woman. They also serve pregnant AI/AN who experience intimate partner violence, housing insecurity, and substance use—all of which are predictors of maternal mortality. She urged the Committee to recommend funding for culturally appropriate intervention programs, such as inpatient treatment and specialized services, for pregnant or parenting AI/AN who face these threats. The Urban Indian Health Institute has developed community health profiles for urban AI/AN to include data on metrics such as maternal and child health, births, breastfeeding, Cesarean sections, infant mortality, low birth weight, maternal mortality, maternal smoking, NICU admission, and premature birth. There is a need to develop best practices for AI/AN data collection for institutional data reform. The Seattle Indian Health Board also recommends that HHS enforce workforce development approaches to fill critical provider roles with representation from AI/AN providers, including support for the National Tribal Budget Formulation workgroup 2023 recommendation to invest \$1 billion in the Indian Health Care Improvement Act for workforce development.

Dr. Love-Thurman closed with a story about Stephanie Snook, an Indigenous woman who was pregnant with twin. Given her twin pregnancy and congenital heart defect, she was transferred to a maternal fetal medicine specialty clinic at a nearby hospital. She had developed unusual symptoms such as shortness of breath, but was not taken seriously by her health care team. She and her twins died, leaving the community devastated and sowing further mistrust in the health care system. Before she died, she had agreed to take part in an <a href="NBC feature">NBC feature</a> on maternal mortality among AI/AN. Another mother who was featured in the NBC feature also died within a month following her delivery. Dr. Love-Thurman emphasized that this was the reality of the community and asked the Committee to recommend the return of care and funding back to the community that best knows how to care for its people.

### Discussion

Dr. Ehlinger talked about the importance of partnerships between tribes and the federal government and his experience hiring Ms. Dionne in a leadership position to help create that relationship.

Ms. Thompson asked Ms. Dionne to talk about what could be done about the lack of trust at the national level. Ms. Dionne answered that a White mother's birth experience is not the experience that the AI/AN mother will have. There are low rates of first trimester prenatal care among AI/AN because they are going to their mothers or grandmothers instead of clinical care. Talking about pregnancy and birth is very intimate and it is difficult to talk about challenges such as

abuse because it may be reported into the system. Even if the doctor is compassionate and receptive, the experiences are so common that the mistrust is applied to the entire system. Therefore, the system, which was built to support White people, needs to change. There is often an argument that a system should not be changed for one. However, positive changes for one lead to positive changes for all. For example, curb cuts were created to accommodate people in wheelchairs, but they also support mothers with strollers and other people who have difficulty stepping up to curbs.

Ms. Thompson asked Ms. Hammer to talk about having a workforce that matches the community and what the Committee could do to increase the entrance of Indigenous people. Ms. Hammer said that this was a difficult challenge. The interest begins in the home, but the home is often a place that has experienced a lot of related trauma or insufficient support. Without education support, the community's children might not graduate high school. The challenge therefore requires a holistic approach where families are supported at home and in the school system. The children and youth need to recognize that there are opportunities beyond the reservations. Her clinic offers job shadowing. There needs to be investment in getting members of the community excited about programs that lead to jobs that do not require four-year college degrees, such as medical laboratory technicians.

Ms. Thompson asked. Dr. Love-Thurman if the negative outcomes for those who did trust the medical system resulted from a lack of advocacy or from their wishes and concerns not being taken seriously. Dr. Love-Turman said that stigma and systemic racism begins as soon as the native person enters the door. Even as an obstetrician, she experienced barriers in a system that was heavily focused on funding and the fear of litigation. Since she left her clinical practice, she has been working with the native community to consider different ways of birthing. Hospital birth is not for everyone, but there is such a culture of fear surrounding birth in the US that some women feel that it is the only way. There are many ways in which native women are low risk, but become high risk as a result of the racism. The Committee should focus on alternative birth practices. There should be a focus on competent certified nurse midwives without the barriers that many Indigenous midwives face. Seattle is looking into creating birthing centers that do not feel as institutionalized and she expressed hope that there would be more of these conversations.

Dr. Kathryn Menard suggested that the conversation about workforce development should start to center on workforce development systems rather than compartmentalized training programs for clinicians, midwives, or doulas. She asked the panel to comment on what was missing in the system that could be addressed with team training approaches. Dr. Love-Thurman said that native people feel comfortable in a clinic where they are treated by native people, but the moment that they are asked to go outside of that environment, there is fear of what will happen to them. There is a need to build relationships with specialists so that they know they are sending patients to a safe place and will be treated with the same care and respect that they would with native providers. There is a need for advocates or doulas to attend these specialty visits with the patient, but advocates and doulas are underfunded and/or overworked. The Urban Indian Health Institute has offered to provide more training and to look at hospital data to identify where microaggressions are happening. There is often clear clinical documentation of false accusations

of drug use or looking too tired. But this work should not be done for free. The more that native people are asked to share, the more funding they need.

Ms. Dionne said that, while it is ideal to cultivate a workforce within the native community, it is a reality that there will always be non-native providers working in the community. Caring about the community is not something that can be trained, but there is a need to integrate that compassion across the entire workforce. Youth on the pathway from high school into the clinical workforce have to face multiple systems that communicate that they are not cared about. Dr. Love-Thurman added that native people are resourceful. For instance, during the pandemic, clinical staff began training medical assistants on the job. The program was so effective in filling staffing gaps that there is now a waitlist for the program. The native students that they trained are now moving into nursing and physician assistant programs.

Dr. Palacios talked about how her life changed when an assistant secretary at her high school suggested that she apply to <u>Indians Into Medicine</u> program, which piqued her interest into becoming a medical professional. These resources are available, but they need increased funding and awareness.

## Tribal, State, and Local Challenges and Approaches to Improving Indigenous Birth Outcomes

### Marisa Miakonda Cummings, Umonhon/Omaha, President/CEO, Minnesota Indian Women's Resource Center

Ms. Marisa Miakonda talked about the Minnesota Indian Women's Center, whose mission is to empower native women and families to exercise their cultural values with integrity and to achieve sustainable life ways, while advocating for justice and equity. The center is located in the Phillips neighborhood in Minneapolis, which houses the third largest urban Indian population in the US. Ms. Miakonda said that the root cause of disparities among native people is the colonialism and white supremacy that built its wealth from the extraction of native land, resources, and free labor. Hundreds of years of federal policies and a lack of resources have had a horrific effect on the health and wellbeing of native people. Native people have been taught to live with a scarcity mindset in a country that hoards its wealth and resources.

The Phillips neighborhood is a historically native community that evolved from the relocation era as a survival mechanism for recently displaced American Indian people. The neighborhood organized an environment of support and resources, much of which was funded by native nonprofits. However, the community is still underfunded and under-resourced—struggling with the highest opioid overdose rate in Minnesota, two to three funerals per week from overdose or gun violence, carjacking, and sex work and trafficking. Many women go to the Minnesota Indian Women's Center for basic life resources, housing, crisis intervention, mental health services, substance use management, healing from generational trauma, and skill development. Ms. Miakonda said that IHS has not been the answer for the health needs of their community and to suggest that American Indian people did not have health services before IHS is disrespectful to their ancestors who carried traditional medicines and practices. She shared her experiences of traditional birthing practices, from being named at birth by her great grandmother (who was a midwife) to later acting as a doula to other family members.

Ms. Miakonda shared her recommendations with the Committee. First, it is important to understand the reality of native people's experiences in the health care system by including more native people on the Committee. Second, in the Committee's recommendations for workforce expansion and diversity, there should be consideration for a non-IHS model, such as apprenticeship programs for traditional birth work that they conduct with young native women. Finally, there needs to be an acknowledgement that the native people have traditional wisdom and know best how to care for their own communities. However, they need funding that is equitable to the disparities that have been forced on them for over 200 years.

### Joni Buffalohead, Ph.D., Bdewákhathuŋwaŋ Dakota, Chair, Minneapolis Indian Health Board

Dr. Joni Buffalohead said that urban Indian health clinics exist as a result of the Indian Relocation Act of 1956, which moved native people to cities in order to assimilate them and take over their land for profit. At the time, the average life expectancy of native people was 44 years, but even today native people are at the bottom of health and socioeconomic measures. For instance, AI/AN infants have a mortality rate twice that of White infants. AI/AN youth have the highest rates of obesity and the lowest rates of high school graduation. Intimate partner violence affects between 11 and 21 percent of AI/AN high school seniors. AI/AN people have the highest rates of unemployment and are incarcerated nine time more often that White people.

Dr. Buffalohead talked about what she had learned from interviewing the medical director, maternal health care providers, and pediatricians from the Indian Health Board in Minneapolis. One of their challenges is the inability to access data from other systems, making it difficult to understand what is or is not working. Native families need safe housing, access to birth control and reproductive health care, education about alcohol use in women of child-bearing age, and transportation to health care. The Indian Health Board provides two vans to the Phillips neighborhood to bring people to clinics, but many have moved outside of the neighborhood because of crime and drug use. Providers also witness the origins of the missing and murdered Indigenous women crisis as they see drug dealers and sex traffickers entering encampments. The challenge is knowing what is happening prior to this vulnerability and what can be done as an alternative path. There is mistrust of the system and a loss of traditional health practices, making it difficult to access native youth and build the trusting relationships needed to provide them with health care, education, and supports.

The Indian Health Board made several recommendations for the Committee to consider. First, it is important to interview caregivers and capture their stories. The Board also wanted the Committee to help them understand the root causes of infant mortality and to support the development of standardized testing for risk factors such as drug-dependence in newborns. They asked the Committee to support education for youth on pregnancy, health, and housing safety. The suggested engaging retired providers who are familiar with maternal health to help with workforce challenges in rural areas and developing holistic care protocols, including for behavioral health. The Board also talked about the loss of tradition and connection to elders in young men, who often suffer from a lack meaningful employment and a sense of belonging.

There is a need to make maternal and infant health programs more culturally relevant and aligned with traditional community practices.

Dr. Buffalohead shared a personal story about her sister who had become pregnant but was convinced to give her baby up for adoption. She subsequently became suicidal, dropped out of school, and struggled with alcoholism. She died at the age of 44, having experienced a system that had failed her.

## Lynn Lane, Diné, Tribal Maternal Health Innovation Program Manager, Arizona Department of Health Services

## *Heidi Christensen*, Maternal Health Innovation Program Manager, Arizona Department of Health Services

Ms. Lynn Lane talked about the maternal health efforts in Arizona and their purposeful partnership and inclusion of tribal communities to better understand maternal health outcomes in AI/AN communities. For instance, they sought to include the participation of tribal communities in Arizona's Maternal Mortality Review Committee. In Arizona, AI/AN women account for nearly 12 percent of all pregnancy-associated deaths and reviews of those deaths showed that the overwhelming majority of these were preventable. For every 10,000 delivery hospitalizations in Arizona, there are 303 cases of several maternal morbidity in AI/AN, which is more than three times the rate of morbidity in non-Hispanic White women.

Ms. Lane reviewed the three pillars of their Tribal Maternal Health Improvement Program, which are to 1) establish a state-focused Tribal Maternal Health Task Force to create and implement a strategic plan; 2) improve the collection, analysis, and application of state-level data on maternal mortality and severe maternal morbidity (e.g., upholding and championing the sovereignty of AI/AN data); and 3) promote and execute innovation in maternal health (e.g., awareness, access to care, workforce capacity, and systems of care). In early 2021, the maternal health team met with tribal communities to identify community champions in birth work. The result of these conversations was the development of maternal and family wellness training sessions that were based on Indigenous perspectives. To date, they have held more than 200 sessions, reaching more than 2,000 community members. Their Indigenous doula and breastfeeding trainings consistently have waitlists of more than 300 people. Ms. Lane emphasized that people were hungry for information and wanted to improve birth outcomes in their community. She also spoke about the challenges she faced in reaching the tribal community and their fear that the Arizona Department of Health would want to claim their information.

Arizona's Tribal Maternal Health Task Force has multisectoral representation from executive directors, doulas, community health workers, people with lived experience, and providers. The Task Force meets quarterly to discuss activities across four priority areas: improved access to and early participation in prenatal care; increased patient and provider awareness of chronic disease and associated perinatal risks; improved access to behavioral health resources, substance use treatment, breastfeeding support, and oral health; and built capacity among tribal leaders and non-tribal public health work to improve AI/AN surveillance data with tribes, IHS, state registries, and tribal epidemiological centers.

During the pandemic, three gap areas were identified in maternal health: 1) COVID-19 vaccination during pregnancy and breastfeeding, 2) oral health during pregnancy, and 3) AI/AN health in urban Arizona. Notably, the Tribal Maternal Health Task Force was not notified of the sudden closure during the pandemic of the Phoenix Indian Medical Center obstetrics services. Pregnant women in active labor went to the center, not knowing that it had closed, and were only told to go somewhere else. Ms. Lane expressed frustration that no explanation was ever provided by IHS and that they could have helped the community with alternatives if they had known what was happening.

The Arizona Department of Health had a critical partnership with Diné College, Northern Arizona University, the Navajo Nation Epidemiology Center, and the InterTribal Council of Arizona to develop the first ever Tribal Maternal and Child Health Needs Assessment, which was incorporated into the overall Title V Needs Assessment, and the 2020 Navajo Maternal and Child Health Needs Assessment. In addition, their Maternal Health Innovation Program has a contract with the InterTribal Council of Arizona and another contract with Diné College and the Navajo Department of Health to develop infrastructure. They also have a tribal liaison to help encourage transparency and engagement and are intentional with their efforts to keep funding within tribal communities. Ms. Lane provided some examples of how Diné College and Navajo Nation have utilized the needs assessment to improve maternal health outcomes. For instance, Diné College developed four strategic priority areas and the InterTribal Council of Arizona is in the final stages of drafting their strategic plan for maternal health. There is also an effort to translate messaging into tribal languages, both as a way to extend information to the communities but also to support the revitalization of those tribal languages. There is also audio messaging through podcasts and radio stations. Additionally, Arizona has two tribal hospitals that are part of the AIM initiative.

Ms. Lane reviewed their foundational principles for working with tribes including: 1) flexibility for tribes to develop community-driven solutions; 2) tribal approvals for translations; 3) use of practice-based, community-driven, and cultural humility in language (rather than an evidence base for Indigenous practices, which is scarce); 4) partnership with tribal communities; and 5) inclusion of a tribal liaison to assist with strengthening partnerships. She also spoke about their effort to provide radical transparency. It is important to remember the history of the relationship between the US government and tribal nations and the need to be humble, listen with intention, say what will be done and do it, ensure the right people are in the room, and provide stable and reliable funding and guidance.

Ms. Heidi Christensen talked about their program's professional development, which aims to align health professionals with cultural values, increase Indigenous and community-based providers, promote compassionate care, and provide implicit bias training to clinical staff. Ms. Christensen noted that there was a difference in the types of training that communities wanted in facilities on tribal lands versus hospital systems outside of tribal lands. Within tribal land, the clinical community was interested understanding the people they were serving and their birthing traditions. Hospitals in urban settings recognized that their clinicians were not going to serve may AI/AN and would need to learn how to ask open-ended, thoughtful questions.

Ms. Christensen said that their access to care efforts focus on high-risk perinatal programs and consultations, accessible and high-quality medical care and coverage (including more time with patients), increased numbers of mobile clinics, engagement with families through doula services and home visits, and the reopening of the Phoenix Indian Medical Center. Their efforts to integrate and coordinate care include incorporating traditional practice and cultural values in to the health care system, identifying opportunities for engagement and access to traditional and cultural practices, safe and affordable child care and transportation options, family-engaged prenatal care with doulas and home visits, increased awareness of chronic disease and associated perinatal risks, increased preconception and prenatal education, reduced stigma around substance use and mental health, and education for advocating for appropriate health care.

Ms. Christensen said that community unity and empowerment (i.e., engagement with grandmothers, support circles, and listening sessions) could lead to positive system changes. Ms. Lane added that they have recently focused on data surveillance and sovereignty, trying to identify champions who could understand these principles, develop questions or standards for capturing Indigenous determinants of health, and create training for organizations that collect AI/AN data.

## Noya Woodrich, Athabaskan, Director, Child and Family Health Division, Minnesota Department of Health

Ms. Noya Woodrich talked about her work and how infant mortality has been the focus of her career in maternal and child health programs. She talked about one of her first clients, an 11-year-old girl who was pregnant as a result of being raped during a party that her mom was hosting. She was so young that her mother would not let her walk three doors away to Ms. Woodrich's building by herself; but had to help her through pregnancy and parenthood. Ms. Woodrich also talked about her experience in the first Indian infant mortality review process with the Minnesota Department of Health. It was the first time in which the majority of people at the table were American Indian. She emphasized that the infant mortality rate during this time was the same as it is today. Nothing has changed. However, if only three native infants were saved every year in Minnesota, there would be no disparity. Data show that if an American Indian woman obtains a master's degree, her birth outcomes are better than any other woman's. The solutions are available, but more needs to be done.

Ms. Woodrich reviewed some of the challenges that she has experienced in Minnesota. First, there is never enough funding. Their work is largely driven by Title V MCHB Block Grants, but the funds are not enough. They currently have grant writers who have been successful with obtaining additional funds to support tribes and community organizations, but there is a need for consistently increased funding. Second, there is a need for more American Indian staff. She has seen many native people work in the system but leave because it is too difficult to be a person of color in public service. There is a need to help these people do the important work by increasing knowledge and awareness of the American Indian people so that they are recognized as an active part of society. Third, there is not enough support at the policy level. It is clear that when maternal mortality for American Indian people is addressed, outcomes will improve for everyone. There is a need for community engagement with government organizations to better understand the challenges and identify practical solutions.

Ms. Woodrich talked about some of the department's recent efforts. The Minnesota Department of Health recently published their first ever <u>Maternal Mortality Report</u>. Unfortunately, despite the value of these reviews, Minnesota no longer has a statute for infant mortality review. They will be updating their 2021 <u>American Indian Maternal and Child Health</u> fact sheet. They also have a grant to work with and promote doulas in the community and will continue to seek grants to provide funding to American Indian communities.

### Pressing Issues for Indigenous Women: Incarceration and Violence

### **Prison Doula Project**

### Rebecca Shlafer Ph.D., M.P.H., Associate Professor, University of Minnesota's Medical School and School of Public Health

Dr. Rebecca Shlafer provided context to the issue of the incarceration of Indigenous women. Since 1980, there has been a nearly 700 percent increase in the number of women incarcerated in the US. Most of these women are of childbearing age and have high rates of chronic health conditions. Women of color are disproportionately represented in both the criminal and child welfare systems—systems that are both addressed by the Minnesota Doula Project. The Minnesota Correctional Facility in Shakopee is the state's only women's prison. At this facility, 20 percent of the incarcerated women identify as AI/AN. Among the pregnant people at the facility, 35 percent are American Indian. The Minnesota Prison Doula Project has a mission to transform systems by reimaging justice, advancing health, and reclaiming dignity for all pregnant and parenting people. Their ultimate goal is to end prison birth in the US.

### Jocelyn Brieschke, Leech Lake Band of Ojibwe, Doula

Ms. Jocelyn Brieschke talked about being a doula within the Minnesota Department of Corrections and what the doula program needed going forward. She stressed that consistent, attainable funding was necessary to provide doulas with fair compensation for their work. The correctional system tends to misuse funds, while funding for doula services tends to be sporadic and inadequate. Doulas are underpaid and overworked, sometimes working for free if there is no alternative. The institutionalized racism and mistreatment of women is prevalent in hospitals, but is exponentially higher in the correctional system that feels it can justify mistreatment of incarcerated individuals and their children. She recommended the development of a doula project for Indigenous women in the Department of Corrections and efforts to ensure that the department values the importance of doula services in the context of reducing infant mortality.

### Autumn Mason, Former Client and Incarceration Survivor Lenice Antel-White, Former Client

Ms. Autumn Mason introduced herself as a doula, parenting peer support professional, program facilitator for the Minnesota Prison Doula Project, and former incarceration survivor. She was incarcerated at the correctional facility in Shakopee while seven-and-a-half months pregnant. She was able to study the system from the inside, observing how it disrupted many different cultures) and resulted in persistent repercussions from trauma.

Ms. Lenice Antel-White endured two pregnancies while incarcerated. She discovered she was pregnant when she had taken a required pregnancy test at the beginning of her three-year sentence at the correctional facility in Shakopee. She had her daughter while incarcerated and was released when her daughter was two years of age. She met Ms. Mason while at Shakopee and recognized that they shared the same fears and challenges about their pregnancies. Ms. Mason talked about the shared values of collectiveness, respect for elders, and mentorship from their African American and Indigenous cultures. The "no touch" policy at the correctional facility was particularly devastating to their need for emotional and physical support. Although they were both able to connect with the Prison Doula Project, they had the sense that more was taken away than was given to them as support.

Ms. Mason said highlighted some of the ways that being pregnant while incarcerated is very different than being pregnant while in the community. For instance, they were not able to choose a medical provider, set their own medical appointments, or have autonomy over their medical care. They were not able to share their experience with their partner, seek emotional support, or access adequate nutrition. Ms. Antel-White added that she was not given the opportunity to have an abortion, but that the medical care that she received while incarcerated may have been better than what she would have received in her community. Her community had high rates of addiction and overdose-related deaths, even among young children. She was afraid of having children in this environment and may not have been able to make medical appointments for herself. While in prison, she was able to go to all of the required medical appointments and have a healthy infant. Ms. Mason emphasized that it is important not to make assumptions about pregnancy while incarcerated. There are very few resources in urban communities. It is not easy to make and attend a medical appointment, and many lack adequate health insurance and are unable to pay for medical care. Conversely, many people in the correctional system may have medical issues that are not seed as valid or important.

Ms. Mason said that the lack of resources for urban communities impacts every part of life. There is more exposure to physical violence, substance use, and incarceration. A parent may be faced with a decision to sell illegal drugs or not feed their children. Ms. Antel-White talked about her experience as an Indigenous woman who does not have a voice. When she had her baby while incarcerated, she was not able to experience her Indigenous traditions, such as saving the placenta or smudging her baby. She was only able to have eight hours with her newborn before having to return to the prison. Her mother raised her daughter for two years, disrupting the important bonding time between mother an infant.

Ms. Mason shared her experience as a doula, describing how she has witnessed the stripping away of cultural and spiritual practices in the prisons. During the pandemic, religious groups were not able to access the prison, taking away the connection to spiritual and cultural practices that, for many people, was what was most needed during a traumatic experience. The system seemed to have been created to deteriorate your culture. Ms. Antel-White added that Wiccan followers had been allowed to meet regularly and even had access to prison-funded food and books, but native people could not maintain their cultural practices.

Ms. Mason said that these raw experiences were important to share to understand the trauma and to identify what can be done to counter it. Many women do not see their children or families for years. Doulas struggle to provide supportive visitation and witness the lasting devastation that the trauma has on families. Ms. Antel-White talked about how native women have to return to their reservation after release from prison. When she returned, her priority was to get to know her daughter. But when she experienced difficulty bonding with her daughter, she turned to drugs and was soon sent back into prison, where she experienced another pregnancy. Although she was able to have her son overnight this time, she also had to give birth while handcuffed to the bed with three male guards in the room. When she was sent back to the prison, she was barely able to walk due to stitches and pain, but was immediately sent back to prison work. Ms. Mason conveyed how the community had come together for Ms. Antel-White's first pregnancy. They could not touch or hug her, even though she was in pain and crying. They gathered necessities, such as pads and bras, extra photo tickets, and phone time so that she should check on her infant.

Ms. Mason and Ms. Antel-White talked about some of the foundational issues that drive disparities in incarceration. One of the reasons that the prison system does not represent the distribution of race and ethnicity in the US is because people of color are less likely to have the means to obtain proper representation. Most of the incarcerated women of color are incarcerated for either drug-related or domestic violence-related offenses. When they are released, they return to the community that put them at high risk for drug use and domestic violence, but without the resources and tools needed to succeed. Ms. Antel-White talked about losing her 16-year-old brother to gun violence two years ago. What needs to change in their community is the support available for youth. They are angry and need guidance. They need a place to go, such as a community center or sports. Money is being spent on casinos when it could be directed to solutions for the children and youth.

## Gwendolyn Packard, Ihanktonwan Dakota, Senior Housing Specialist, STTARS Indigenous Safe Housing Center, National Indigenous Women's Resource Center, (Virtual)

Ms. Gwendolyn Packard talked about the <u>STTARS Indigenous Safe Housing Center</u>, which is a new resource center funded by the Family Violence Prevention Services Administration to respond to housing insecurity and homelessness among AI/AN and native Hawaiian survivors of domestic violence. STTARS stands for safety, training, technical assistance, resources, and support. Their mission is to advocate for safe housing for all their relatives through centering Indigeneity, acknowledging their relationship to Earth Mother, recognizing and challenging the impacts of climate change on housing and violence, building on each other's gifts, understanding and resisting oppression and erasure, and acting upon the prayers of their ancestors to honor diversity and create belongingness. One the most critical factors for an Indigenous person weighing the risk of leaving or staying in a domestic violence environment is the lack of safe, accessible, and affordable housing. STTARS centers on creating more comprehensive housing solutions for all survivors of domestic and sexual abuse.

Ms. Packard said that housing is a public health imperative and is often a precursor to the removal of children from their families, domestic and sexual violence, mental health and substance use, trafficking, and missing and murdered Indigenous women and relatives. The

COVID-19 pandemic had profound impact on tribal communities, in which housing was a critical mitigating factor. Funding from the <u>Family Violence Prevention & Services Act</u> (FVPSA) program has been instrumental in their ability to provide hotel vouchers, application feeds, emergency rental assistance, transportation, test kits, preventive supplies, and transportation to testing and vaccination sites during the pandemic.

The scope of missing and murdered Indigenous relatives is vast and has been a centuries long crisis that has only recently begun to receive attention. There have been significant changes to funding, programs and services, public awareness, prevention strategies, judicial systems, and public attitudes. The <u>Urban Indian Health Institute</u> indicated that 53 percent of native women that they surveyed lacked permanent housing. The center is working to encourage all states to include housing as a mitigating factor to address missing and murdered Indigenous relatives. Indigenous people live within complex jurisdictional issues, experience inadequate resources for services, live in substandard and crowded housing, experience high rates of poverty and unemployment, and lack resources for mental health and substance use programs.

Violence against native women is rooted in colonization and the statistics are dire. Indian women are murdered at a 10 times higher rate than the national average. Homicide is the third leading cause of death in native women and 75 percent of these homicides were by an intimate partner. Although many tribes have domestic violence programs, they continue to be woefully inadequate to address the needs of their people. Housing needs for AI/AN in particular have not been adequately addressed. The Violence Against Women Act that was enacted in 1994 has been reauthorized in 2000, 2005, 2013, and 2022 and expanded tribal provisions in the 2005 reauthorization. The addition of the Oliphant fix expanded the jurisdiction for tribes to prosecute non-natives for certain crimes committee in tribal communities. But there is much more to be done to protect women and children.

Ms. Packard stressed that firearms and domestic violence are a deadly combination. Women in abusive relationships are five times more likely to be killed by their partner if the partner owns a firearm. The presence of a firearm in an intimate partner violence environment increases the risk of homicide by at least 500 percent. There are legitimate reasons for a firearm in Indian country, such as subsistence and hunting. But firearm laws have the potential to protect women and children.

Ms. Packard talked about the lack of housing and shelter among AI/AN. Some tribal communities are located hours away from the nearest shelter. There is virtually no housing inventory and spaces that are available tend to be unsafe, not trauma informed, not culturally rooted, and not supported by sustainable resources and funding. There are also problematic mindsets about who should and should not have access to housing and shelter. It is important to know that there are over 2,000 domestic violence shelters in the US, but fewer than 50 for tribes. There are 260 FVPSA-funded tribal domestic violence programs and there is a hope that FVPSA will increase the number of tribes that receive funding to build capacity for Indigenous people experiencing housing insecurity. The US is experiencing a housing crisis that was exacerbated by the pandemic when investment companies purchased housing and doubled or tripled prices. In remote tribal communities, there are people living in cars, caves, or in underground shelters that

people dug for themselves. Many tribes are seeking to create homeless shelters, which was unheard of only ten years ago. There are also infrastructure deficiencies with overcrowding and a lack of heating, plumbing, or even roofs or windows.

Ms. Packard emphasized that homeless shelters are not safe for survivors of domestic violence and their children. Homelessness is not the problem, but the result of the problem. STTARS seeks to change the factors that put people at risk of homelessness and to create safe, affordable, and accessible housing options for survivors of domestic violence.

### **Public Comment and Discussion**

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

### **Ingrid Skop**

Dr. Ingrid Skop is an obstetrician/gynecologist who has been practiced in Texas for 30 years. She talked about the deficiencies in data collection for maternal mortality. There is currently no requirement to report miscarriages and induced abortions or their complications and deaths. The National Vital Statistics System requires an ICD-O code to document a maternal death, but Ocodes only exists for abortion-related deaths from infection, hemorrhage, and embolism. Record linkage data indicate that a woman is two to four times as likely to die in the year following an abortion than following childbirth. Many of these deaths are not documented. It has been alleged that abortion restriction will increase maternal mortality, yet restricting later abortion will protect women because abortion-related maternal mortality increases by 38 percent weekly, exceeding the risk of death from childbirth. Restrictions will also prevent mental health disorders such as anxiety, substance use, self-harm, and suicide in vulnerable women. Dr. Skop reiterated that it is essential to improve maternal mortality detection and data analysis by recording and investigating deaths related to all pregnancy outcomes.

#### Candi Cornelius

Ms. Candi Cornelius is from the Menominee and Oneida Nations and is a prenatal care coordinator and certified childbirth educator. She spoke about her concerns about trends in delivery methods that she has seen in her county near Green Bay Wisconsin. Since 2011, she has seen a stable rate of Cesarean section birth across all races. Vaginal birth after Cesarean section (VBAC) is a delivery method that is associated with lower maternal morbidity and risk of complications. While there has been an overall increase in VBAC, there has not been an increase among Native American women. Nation women were seven times more likely to have repeat Cesarean section than any other race. Ms. Cornelius said that she will be looking at the data in her community to identify the root cause. She asked the Committee for additional support and promotion of both VBAC as a method of delivery for native women and Cesarean section as a potential risk factor for maternal mortality and morbidity in native women. She has personally witnessed her sister being persuaded away from VBAC as part of her birth plan. She also asked the Committee to advocate for doula care in tribal health facilities. As they are currently categorized as non-health providers, they experience barriers to being present during birth. Many American Indian women have little to no support and would benefit from a doula who is present

during delivery. More support and advocacy for doulas would help increase and improve maternal and child health among native people.

#### **Discussion**

Dr. Charlan Kroelinger expressed appreciation for raising awareness about the connection of increased mortality to delivery method. It is known that racism can affect VBAC because race is embedded in the VBAC calculator. People have to be told that VBAC is an option and research early on if their hospital supports it. This highlights the need for embedding cultural practices, Indigenous birth workers, advocates, and doulas, as well as increased awareness of the racial disparities.

Dr. Palacios said that even though there are national standards and definitions, women of color enter the hospital with barriers stacked against them. Clinicians and protocols do not always work in their favor. There is much yet to discover in hospital protocols and much to unlearn at the provider level.

Dr. Peck talked about the public testimony from Nickolaus Lewis from the Northwest Portland Area Indian Health Board as it relates to the need for meaningful involvement from tribal nations in research. Community-driven research that comes from lived experience and observations in the field should be given more support and is something that she will bring the Committee's Data and Research to Action Workgroup. Ms. Cornelius said that there was a recent study using the Pregnancy Risk Assessment Monitoring System (PRAMS) to oversample native women in 2020. They found that there were negative experiences in the hospital system and with not feeling involved with decision-making. Unfortunately, the funding was limited to one year.

### **Closing Drum/Flag Ceremony**

### Imnizska Drum Group with American Indian Veterans

### **Committee Reflections**

#### **ACIMM Members**

Dr. Ehlinger invited the panelists and the Committee to continue their discussion. He asked Dr. Shlafer if there were other doula prison programs in other states or programs that offer remote sites for labor and delivery outside of the prison. Dr. Shlafer answered that they are looking at states that offer pregnancy and/or postpartum support services. Some states have robust lactation programs, in which mothers can pump, store, and ship their breastmilk to caregivers in the community. The only alternative to separating mothers from their newborns is a prison nursery program. Minnesota passed the <a href="Healthy Start Act">Healthy Start Act</a> last year as an effort to prevent the separation of mothers and their newborns through community-based alternatives to incarceration. Implementation has been slow and there much to be learned about eligibility criteria and resources in the community. There is a long way to go in terms of innovative programs across the country.

Dr. Ehlinger asked Ms. Packard if there were best practices in data collection protocols for murdered and missing Indigenous women that she could recommend. Ms. Packard said that data

collection is at the discretion of states. It is currently jumbled and very challenging in terms of understanding the scope of the problem.

Dr. Charlene Collier echoed one of the panelist's statements about someone else benefiting from these crises and that they should not have the privilege of ignorance. At minimum, those who benefit should be held accountable by knowing the same information that the Committee has received. There needs to be an understanding of what happens to families when addiction is criminalized or when an investor is buying housing from reservations. Delivering recommendations to the Secretary is only part of the battle. She asked the panelists to consider who else would need to hear the Committee's recommendations.

Ms. Miakonda suggested that there should be a policy for funding that is outside of the IHS model. Their traditional birth workers and midwives do not need to be clinically trained but provide women with the traditional practices that gives them a sense of identity, self-esteem, and self-love. These practices were taken away by patriarchal federal policies. It is time to dismantle and deconstruct those policies and provide funding to those who know how to do the work needed for the community to prosper.

Dr. Palacios said that one of the lessons learned from the past few years is the importance of the home visiting program. Home visiting is a way to repair what has been taken away from native families. It includes more than that, but it is a social program at its core. It is not a novel program, but it does fill a gap.

Dr. Ramas hoped that the passion, pain, and generational trauma could be captured in the Committee's recommendations to the Secretary. It is also important to have adequate definitions to be able to translate different cultural perspectives into the systems in which the Committee works within. She also said that it is important that the Committee recognize that all of the disparities in this population can be reversed. She asked the panelists to describe what they meant by the term "system," which was repeated several times. She also asked the panelists to identify any strategies or resources that the Committee could use as a demonstrated return on investment. Policymakers want to do the right thing, but they also need to understand the bottom line.

Ms. Miakonda said that this system is white supremacy, whether it is judicial, law enforcement, health care, or education. Native people had their own systems of traditional governance, social structures, and food systems that were intentionally and systematically dismantled and replaced. The Māori are one example of creating a social return on investment. A social return on investment should be one that is intersectional, holistic, and touches every part of a woman's life. Right now, what they do is piecemealed between funding mechanisms. There is a need for a more stable, intentional wraparound approach for creating support systems for women. There is a need for people to listen and stop telling native people what is best for them.

Ms. Woodrich said that people who have the power will do whatever they can to keep it, which by and large is white men. The systems are schools, hospitals, health departments, police departments—all run by, designed by, and operated for someone else. Healthy

Start is a national program run by HHS that began in 1999 as a clinically-based program. Year after year they would listen to Black and American Indian people who would tell them that they did not need a clinical system, but something focused on social issues. But Healthy Start would not evolve out of a clinical care model into one that was more holistic, despite the feedback that they were hearing. There is a hospital system in Minnesota where there are a lot of native women being treated poorly during pregnancy, labor, and delivery. They need to get prenatal care, but they do not trust the system. The people in power are the ones who need to listen. They may not, but the message nonetheless needs to be repeated.

Dr. Buffalohead said that she is concerned about their sovereignty. They are losing their minerals, their land, their language, and their culture. The government does not acknowledge what was done to Indigenous people. Systems are set up without knowing who is at the receiving end. Within the systems is an interfacing of technology, such as the amount of funding that is thrown at electronic health records. The treaties that were made 200 years ago to provide health care and education forever are not something that the government wants to uphold. They would rather the native people go away. A panelist added that policymakers should be reminded that Indigenous people prepaid the return on investment by giving up their land.

Dr. Palacios reminded the Committee that Native American people were the only group in the country to consistently have to document who they are to provide their degree of bloodline. It was a long game for the government to require every federally recognized tribe decide what they would use to determine their membership. It was an intentional act by the government so that native people would cease to be here, and the government would no longer have to provide.

Dr. Ehlinger closed the day by reiterating Secretary Becerra's words to "never do mild." He asked Committee members to consider how to take the mild out of their recommendations.

### DAY TWO: Wednesday, September 14, 2022

### Welcome, Approval of Minutes, and Committee Reflections

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

The Committee unanimously passed a motion to approve the Minutes of the June 2022 meeting.

Dr. Ehlinger asked the Committee to reflect on their takeaways and unanswered questions from the previous day's presentations.

Dr. Joy Neyhart questioned why incarcerated mothers were being separated from their newborns when it is known to have negative consequences.

Ms. Pettiford considered whether the Committee had gone deep enough with their recommendations. She was struck by the different levels of trust in IHS. A recommendation for more IHS resources may not be enough. The issues are deeply ingrained, and the Committee should be looking for systemic change within their recommendations.

Ms. Thompson felt that the disrespect and stripping away of AI/AN women's beliefs and traditions is horrific and needs to be rectified.

Dr. Menard noted that there has been an effort to change the people to fit the systems instead of changing the system to fit the people. She hoped that the Committee's recommendations could highlight the need for systemic change. She emphasized the importance of respecting tradition and that much of the issue comes from a lack of in depth knowledge. More knowledge is needed across the clinical and public health fields.

Dr. Phyllis Sharps said that while it is important to be bold with recommendations, it is also important to build in accountability. The Committee should think about a mechanism for pushing the recommendations both inside and outside federal agencies to ensure that the right people hear the recommendations.

Dr. Sherri Alderman said that a spotlight had been placed on the need to shift the power from the dominant culture to the AI/AN people so that they can create their own systems and supports of choice. It is also important to recognize that there is diversity and disparities within the Indigenous population. She suggested that the Committee's recommendation should also address the diversity and disparities among AI/AN so that there is empowerment across all communities and families.

Dr. Ramas added two suggestions for the Committee's deliberations. First, there should be consideration for the current systems in place that advance and promote health equity that can be modeled and translated to the Indigenous community. Second, there should be creative solutions to address and promote the workforce among Indigenous people.

Dr. Peck made several points for the Committee to consider. First, she emphasized the power of story, and that people are clearly interested in sharing their stories if they can trust that they would be heard. Second, there is a need to learn and unlearn how urban Indian health issues are unique and often invisible. Third, passion and anger at this time are useful and expected. This is not a time to be polite but rather a time to stoke the fire, honor the anger, and act. Fourth, this is a moment of political will. The Committee has the attention of Secretary Becerra, HRSA Administrator Ms. Johnson, MCHB, and CDC. To create systemic change requires not only change in the community but also change where the power resides. There is a need to be bold while the Committee has this attention. Finally, Dr. Peck acknowledged the remarkable individuals who spoke and recommended that ACIMM look within in terms of recruitment to the Committee. While Dr. Palacios has provided extraordinary leadership, there should be greater voice and visibility within the Committee. If the Committee does not change within, it is unreasonable to expect change elsewhere.

Dr. Palacios expressed gratitude for the stories that had been shared and the Committee's reflections. She suggested that the Committee reframe their recommendations to boldly rename them as amends and restitution for what is owed to Indigenous people.

Dr. Ehlinger invited ex-officio members to share their reflections.

Dr. Kroelinger expressed appreciation for being at the table and having the opportunity to listen. The native voices and lived experiences were very impactful.

Dr. Amanda Cohn added that there were many more voices and lived experienced that need to be heard. She agreed that changes enacted to benefit the Indigenous population will benefit the whole population.

Dr. Michael Warren reflected on his own implicit role as a public health professional in a state that did not have large, federally recognized tribal communities. It did not cross his mind that there was work to do for urban Indian communities in the state. He expressed frustration for the missed opportunity but is grateful for this time of learning and unlearning. He added that the COVID-19 pandemic took away the in-person connections that could not be replicated virtually. The ability to feel the palpable pain, sorrow, and anger in the room is powerful and important.

Mr. Wilson said that there is a tendency to look at data, observe a problem, and view that problem through a lens of judgment about the people. It is too easy to ask what the people can do to change their own circumstance. It is the Committee's responsibility to address needs without judgment. He also said that if there is an inconsistency in the data, it does not make sense to do something different in another environment. If their efforts are focused on saving mothers and infants within the clinical system, it should be recognized that these families may be released into an environment that was just as destructive as before they entered the clinical system. It is important that the Committee make recommendations that are focused on the whole person and not just one experience they may have.

Dr. Ehlinger highlighted two birthdays. One was Ivan Pavlov, Nobel Prize winner for physiology, who said, "While you are experimenting, do not remain content with the surface of things. Do not become a mere recorder of facts, but try to penetrate the mystery of their origins." Dr. Ehlinger suggested that this quote is relevant to the idea of not only looking at data, but recognizing the mystery, substance, and pain within it. The other was Sydney Harris, a journalist, who said, "An idealist believes the short run doesn't count. A cynic believes the long run doesn't matter. A realist believes that what is done or left undone in the short run determines the long run." Dr. Ehlinger said that the Committee's charge to be a realist and to determine what is needed to improve the situation in the long run.

### **Shakopee Mdewakanton Sioux Community Programs and Activities**

# Joanna Bryant, Shakopee Dakota, Tribal Public Health Administrator at Shakopee Mdewakanton Sioux Community

Ms. Bryant talked about how the activities within the <u>Shakopee Mdewakanton Sioux Community</u> (SMSC) relate to the Committee's draft recommendations. The SMSC has its own health care system operated under their self-governance as a sovereign nation through federal funding that is passed through IHS. Although not every community or tribe is able to implement this model, it is the self-governance that is crucial to success. SMSC has very stable leadership with a mission

that is focused on the community. Their health care system is inclusive of all types of care (i.e., primary, urgent, vision, dental, and behavioral health) and uses a whole person care model. There is collaboration between departments through a unified medical record system that enables providers to connect care. For instance, a diabetes educator can see the last time their patient had a dental cleaning and can make the appointment for them. Their minimum appointment length is 30 minutes, giving providers time to observe and treat other family members, if needed. This flexibility is not realistic in other health care systems, which focus on revenue generation.

Ms. Bryant said that empowerment of individuals is the lowest hanging fruit that the Committee can focus on to impact AI/AN women and children. The Committee should look at the policies, recommendations, and funding guidance to enable federally recognized tribes to have the ability to take and receive funds to implement their own programs for community health; provide recommendations that enable tribes to take care of their own people and determine their own policies; and carefully consider the language that requires evidence-based care because there may not be the numbers needed to support a beneficial program or service. There should be no requirement to prove need or outcomes in order for an individual to receive care. There should not be a requirement of data that proves that the service is an appropriate use of funds.

There will always be the need for services outside of the community. To help maintain continuity of care in this situation, the SMSC provides the patient with their medical records and a clinical provider to travel with them to help navigate care and challenging diagnoses. This approach also ensures that there is no duplication of services. SMSC also practices a blending of services in which the community has child care facilities, social and emotional support programs for youth, and staff training on emotional needs and coping skills. This training is then extended to parents so that there is consistency and integration across the community. They address challenges with a full scale approach that touches every piece of the community.

Ms. Bryant encouraged the Committee to look carefully at the systems that they rely on to deliver their recommendations. For instance, there are a lot of references to Medicaid in the draft recommendations. The Committee should understand the challenges of understanding and managing primary and secondary insurance policies and the wait for services or supports that often occur because of limitations in Medicaid and complications about who will pay. These are the system barriers that should be considered as the Committee seeks to refine its recommendations.

### Discussion

Ms. Thompson asked for clarification about the ability of federally recognized tribes to self-govern. Her understanding is that if there is an increase in funds to tribes that are able to self-govern, they could extend their health care to urban tribes that do not have the ability to self-govern. Ms. Bryant said that to impact the health of the Indigenous population, it is important to recognize that they have the ability, will, and knowledge to improve the health of their own people. Instead of running funds through a gatekeeper, the tribes should be provided the funding directly. When they add or create a service on tribal land, it can also benefit urban Indians enrolled in a federally recognized tribe or who live within the community. But there are barriers to funding because it is normally provided only for care within the reservation. The ability for

displaced individuals to work or travel to receive care is a challenge and may benefit from a direct allotment for urban populations.

Dr. Ehlinger asked how they might use community outreach to influence the broader Minnesota population with their culture. Ms. Bryant said that she has heard presentations on the challenge of overcoming the lack of respect. To overcome this, the team provides cultural training and education to surrounding clinics and hospitals. They talk about traditions and what is needed to embed them into policy. For instance, one hospital has embedded a smudging policy that simply requires smoke detector covers while the individual is using that tradition. It requires substantial outreach to partner and create relationships. For instance, when they were focusing on nutrition, they partnered with the University of Minnesota to promote the Seeds of Native Health campaign. Relationships between Indian country and external government structures have not historically been positive, and it is hard work for both parties to come to the table and find ways to interface with those systems.

Dr. Menard said that as important as it is for the Committee to think bold, it is also important for them to think practical. She asked for clarification about the pass through statute with IHS, how it is negotiated, if it is practical for most tribes, and if it would be constructed at the state level. Ms. Bryant said that 60 percent of tribes in Minnesota use a self-governance contract. It is a choice that not every tribe may want to make. It involves an agreement, proof of ability to maintain financial components, proof of stability, and other red tape. There have been tribes that visit SMSC and learn about self-governance. It is difficult to blend bold with practical.

Dr. Warren said that HRSA has been looking for ways to expand their eligibility for grant programs that are directed to tribal communities. However, the way in which some laws are written directs those grants to the states. He asked if there were ways to better support interactions with tribal communities and states. Ms. Bryant said that the simple, but likely difficult, solution would be to change the language so that grants were not required to go through states. Outside of that, there could be solutions in terms of how states deliver funds so that there are no inherent barriers in the system. The most impact, though, would be to give the funds directly to a federally recognized tribe. It is a burden on the state to administer grant programs. If there was a tribal community in the state that has sovereign status and is able to facilitate their own health care, there should be no reason not to end the burden on the state and provide the funds to the tribe.

## Policy and Program Consideration to Improve Indigenous Birth Outcomes Maradith Raimondi, Vice President of Public Policy, National Council of Urban Ind.

# *Meredith Raimondi*, Vice President of Public Policy, National Council of Urban Indian Health

Ms. Meredith Raimondi introduced the National Council of Urban Indian Health (NCUIH), which is a nonprofit dedicated to the support and development of quality, accessible, and culturally-competent health and public health services for AI/AN. NCUIH has provided comments to the Committee in March 2022 and to HRSA in July 2022 on the critical importance of including urban native populations in HRSA's overall efforts for improving health outcomes for native people. Urban Indians are defined in statute to include descendants and state-

recognized tribal members. An urban Indian organization is a technical term used in the Indian Health Care Improvement Act to convey the health clinics that are run by urban Indians to provide health care to urban Indians. Minnesota is a historic site for hosting this meeting because it established some of the first official urban Indian organizations in the country.

In 1971, Representative Julia Butler Hansen, who ran the Appropriations Committee for IHS, stated that improving the health of mothers and children was of the highest priority in IHS and that the problem arises when Indians leave a reservation on their own and cluster in cities such as Minneapolis. Ms. Raimondi said that though this was stated 51 years ago, they continue to struggle with the same issues today. Urban Indian organizations were first established in 1976 when only 40 percent of native people were residing in cities. Today, the IHS budget for urban Indian health clinics is only one percent of the entire Indian health care budget. There are 41 urban Indian health clinics with 77 facilities that are growing at a rapid pace, but are unable to keep up the growth due to a lack of funding. She noted that the Oklahoma City Indian Clinic will be opening the first urban Indian maternal health clinic in the next year. Although at least 23 of the 41 clinics provide maternal and infant health care, there is no dedicated funding for urban Indian maternal and infant health.

Ms. Raimondi reviewed some of the common barriers to care experienced by urban AI/AN. For instance, 41 percent of AI/AN women cite cost as a barrier to prenatal visits, 21 percent are uninsured, 23 percent report experiencing discrimination in clinical settings, and 15 percent avoid medical care due to fear of discrimination. The federal trust responsibility is a sacred promise that the US made to AI/AN to provide health care. Ms. Raimondi emphasized that this is a prepaid health care plan and that it is the US government's responsibility to ensure the highest possible health status among Indians and urban Indians. But the system cannot be successful without the necessary resources. Urban Indian organizations do fulfill the trust responsibility to provide health care to native people in native areas but does so with inadequate funding. Over half of urban Indian organizations provide maternal care but underfunding limits their capacity to provide services and expand to meet the needs of the community. As a result, expecting mothers who wish to visit an urban health clinic must be referred to hospitals and non-urban Indian clinics for care.

Ms. Raimondi reviewed NCUIH recommendations to the Committee. NCUIH supports the Committee's recommendation to reauthorize the HRSA MIECHV. Earlier this year, they signed a letter to support doubling the tribal set-aside in this program. Ms. Raimondi stressed that set-aside funding is a way to provide non-grant-based funds directly to the people who need it. NCUIH supports tribal data sovereignty and recommends that the Committee and other stakeholder collaborate with urban Indian organizations to obtain critical and accurate information on urban AI/AN. Data on AI/AN maternal and infant mortality is extremely limited and is challenged by identity misclassification.

NCUIH also recommends that the Committee advise the Secretary to lead the establishment of an urban confer policy across HHS agencies. Urban confer is an established mechanism for dialogue between federal agencies and urban Indian organizations that would support the coordination of efforts to improve maternal and infant health, adverse outcomes, and mortality.

They also support elevating the IHS Director to an Assistant Secretary role so that the agency can better work with HHS as a collaborator. NCUIH recommends that there be an appointed urban Indian provider and a tribal provider on the Committee and an ACIMM subcommittee dedicated to addressing AI/AN maternal and infant health disparities. Ms. Raimondi said that if native representatives are at the table, then conversations about health equity will not do justice to native people. She encouraged Committee members who work with an equity project that does not include a native voice to urgently change that. She expressed hope that the stories that have been presented will resonate with the administration and begin to create lasting policy changes.

## Stacy Bohlen, Sault Ste. Marie Tribe of Chippewa, Chief Executive Officer, National Indian Health Board, (Virtual)

Ms. Stacy Bohlen talked about the National Indian Health Board (NIHB), which represents and serves all 574 recognized AI/AN tribal governments. They provide a consolidated unified voice for Indian country from a federally recognized tribal perspective and seek to reinforce tribal sovereignty, strengthen tribal health systems, secure resources, and build capacity to achieve the highest level of health and wellbeing for AI/AN people. Ms. Bohlen said that when referring to any policymaking environment, the correct term to use is "American Indian and Alaska Native" because this legal term portends their legal status, is written into the US Constitution and US treaties, is codified in Supreme Court cases, and promotes respect for their political status. The term" Indigenous" oversteps this legal and political status and is not the correct term when discussing federal policy. She pointed out that the lack of reference to native Hawaiian people is not due to a lack of respect or recognition of their histories, but rather a reference to their different legal status.

Ms. Bohlen talked about issues related to structural policy, practices, and funding priorities that contribute to the congoing harm of AI/AN. The CDC Life Expectancy Report of August 2022 showed a drop in life expectancy in the US for the second year in a row. This drop was less than one year across all Americans in aggregate, but 6.6 years among AI/AN. This is an unacceptable statistic that should capture the attention of policymakers. It serves as a bellwether for the years of structural racism that has saturated American policymaking and left AI/AN with the worst health status, systems, and outcomes in the nation. Historical trauma from genocide, forced migration, cultural erasure, forced sterilization, and a severe lack of funding and resources for health care among AI/AN is not adequately represented in the limited diagnosis of post-traumatic stress disorder. Similarly, social determinants of health are not adequate to describe the experience of AI/AN. AI/AN health is defined by the full health of mind, body, and spirit, which lends itself to the cultural integrity of traditional values, healing, and knowing. Therefore, the NIHB is developing a native social determinants of health wheel. The National Indian Health Board also initiated an annual AI/AN Maternal Mortality Prevention Institute, partnered with CDC to form a tribally-led Maternal Mortality Review Committee, and participated in the Hear Her campaign.

On January 26, 2021, President Biden <u>reaffirmed the Executive Order 13175</u> that requires that all executive departments and agencies engage in regular, meaningful, and robust consultation with tribal officials in development of federal policies that have tribal implications. Tribal consultation is a specific activity that is conducted between the federal government and

sovereign tribal nations and the NIHB therefore encourages the Committee to engage with tribes on any public recommendations they seek to advance.

NIHB also recommends Committee support for the expansion of Medicaid to eliminate the coverage gap for AI/AN women who reside in states that have refused to expand Medicaid or to extend postpartum coverage. Although AI/AN people have a relationship with the federal government to obtain health care as payment for the land, soil, oil, trees, and water that were taken from them, the states do not have such an agreement. States control Medicaid, which means that there are many AI/AN who do not have access to the Medicaid expansion that is critical for expectant mothers and their children. NIHB has a committee called the Medicare, Medicaid, and Health Care Reform Committee that advises and provides technical support to the Tribal Technical Advisory Group to CMS. Ms. Bohlen invited the Committee to attend the NIHB 50th anniversary celebration at the end of September. NIHB will also be launching a library containing a compendium of the work they have done over the last 50 years.

Ms. Bohlen talked about the President's 2023 HRSA budget request, which included funding for 48 students to receive loans to become certified nurse midwives. This is not even one person per state, let alone the number needed to address the urgent needs of AI/AN mothers. The tribes are requesting that the President's 2024 budget include \$15 million for scholarships to train 200 nurse midwives to practice specifically in Indian country. The Committee has an opportunity to bolster this request with their recommendations.

NIHB also supports tribal data sovereignty and research capacity. The Indian Health Care Improvement Act of 2010 states that <u>Tribal Epidemiological Centers</u> must be treated as public health authorities for the purpose of the Health Insurance Portability and Accountability Act (HIPAA). For years, tribal data has been held by CDC, NIH, and other agencies within HHS. Tribal nations and Tribal Epidemiological Centers have experienced uneven data access, which was affirmed by the GAO through a <u>report</u> issued earlier this year. GAO developed five recommendations that the NIHB supports. NIHB also supports two pieces of legislation that would ensure tribal data sovereignty—<u>H.R. 2841</u> and <u>S.1397</u>. NIHM requests that the Committee promote the passage of these two bills in their recommendations to the Secretary.

Ms. Bohlen talked about the work of Michael Chandler with <u>First Nations in Canada</u>. He showed that a strong cultural presence in a community would lower that community's suicide rates. In the 1820s, the federal government had invested in religious institutions to scrub AI/AN of their identity. This was scrubbing of identity was furthered in 1860 when the federal government established boarding schools. The Truth and Healing Commission on Indian Boarding School Policies, <u>S.2907</u> and <u>H.R. 5444</u>, would provide healing for these traumas that are at the root of outcomes such as maternal mortality and health disparities. NIHB also requests that the Committee promote these pieces of legislation in their recommendations.

NIHB recommends increased funding for IHS, housing for doctors and health care providers so that they would not have to commute long distances, prenatal care capacity investments, culturally- and linguistically-appropriate care, the Tribal MIECHV, and food and nutrition for peri- and postnatal mothers. NIHB is currently developing a tribal-led Maternal Mortality

Review Committee and suggests working with the Committee to request adequate funding to enhance and launch the program. Ms. Bohlen concluded by saying that NIHB is also very engaged in health equity work, although there is a lack of investment for NIHB and tribal entities to conduct the key informant interviews and outreach needed to develop health equity policies. She invited the Committee to if they would like to engage with NIHB on the tribal side of health equity.

# Patrice H. Kunesh, Standing Rock Lakota, Founder and Director, Pehín Haha Consulting, Major Gifts Officer, The Native American Rights Fund

Earlier in the day, Ms. Patrice Kunesh had provided <u>commentary</u> for NPR's Marketplace on the swearing in of Chief Lynn Malerba as the new US Treasurer. She began her presentation by describing her personal experience as a young mother who was receiving a number of social services and attempting to juggle the navigation of those services, work, school, and parenthood. She had struggled to maintain the important family tradition of breastfeeding her infant. A public health nurse visited Ms. Kunesh's apartment and threatened to take her daughter if she was not fed. The nurse did not ask about Ms. Kunesh's life circumstances, but was judgmental and hurtful. Poor health care and outcomes in AI/AN mothers is interconnected with poor health outcomes in their infants.

Ms. Kunesh talked about the importance of inclusive prosperity and building community. The poor health outcomes and disparities among AI/AN are rooted in displacement, relocation, and termination. Policies are needed to allow families to remain collectively in place and to invest in those communities so that they can prosper. She talked about the supplemental income distribution that occurred during the pandemic. In just two years, supplemental poverty rate measures significantly decreased from 12.5 percent to 9.7 percent in 2020 and to 5.2 percent in 2021. An additional 3.4 million children were pulled out of poverty because of social safety nets, such as the earned income tax credit and the child tax credit. It is essential to enact a permanent earned income tax credit to maintain these low poverty rates.

Ms. Kunesh reiterated that the care of native mothers promotes the care of native children. One significant concern is the separation of the infant from their mother. This can occur at birth, when the mother is subject to a urinalysis that, if positive, triggers removal of the infant into Child Protective Services. A simple and inexpensive intervention for this situation is providing a parent mentor who has been through the system and can guide the mother through the birthing process to ensure that the infant can remain with the mother. Another concern has been the impact of COVID-19 on native caregivers. Native women are often primary income earners for their household and therefore much more vulnerable to COVID-19. In the past two years, there has been a significant increase in mortality among native women, leaving a number of native children orphaned. One in 168 AI/AN children became a "COVID orphan" as compared to one in 753 White children.

Ms. Kunesh reflected on the White House Conference on Hunger, Nutrition, and Health later this month and the importance of nutrition in AI/AN mothers and infants. She also talked about Raj Chetty's Opportunity Atlas, which overlays social mobility demographics and outcomes over the map of the US. These data indicated two important findings related to Indian country: 1) native

women had the largest disparities for intergenerational mobility and 2) native children who grow up in or near their reservation had greater mobility potential, suggesting that the community-interconnectedness of tribal lands can promote intergenerational mobility and growth. These findings further support the need to invest in community wellbeing. She quoted Lakota Chief Sitting Bull, who said, "Let us put our minds together and see what kind of life we can make for our children."

#### **Discussion**

Dr. Palacios said that the sometimes difficult relationship between states and tribal communities can be rooted in jealousy over not having the special relationship that sovereign nations have, as well as a lack of understanding for AI/AN history. She also clarified that "urban" in the data includes towns with populations over 2,500. There are very rural communities with populations over 2,500 people, which is important to remember when considering the statistic that 76 percent AI/AN are urban. She added that all native communities are underfunded.

Mr. Wilson said that Committee discussion has not yet referenced native men, with the exception of conversations about violence. Given that the panel presentations have veered toward societal and community wellbeing, he asked the panel how they would advise the Committee to address the whole family and if any of their recommendations should be directed specifically at the needs of men.

Ms. Kunesh said that native men are integral to maternal and infant health and wellbeing. Statistically, native women are heads of household as the primary income provider. This suggests that native men are absent and that whatever community support exists for job training, employment, housing stability, or income support should apply to both women and men. Ms. Raimondi added that young native men aged 18 to 34 have the highest rates of suicide of any other population. Their work with urban Indian youth councils and mental health awareness campaigns has been a critical part of their program. This year, for instance, the NCUIH Rivers of RejuveNation Youth Council hosted a series of events in support of mental health. They found that the young men in this program are extremely dedicated and willing to make a change for future generations. But there can be no change without continued investment to support these programs. Ms. Elisha Sneddy of the NIHB said that she will relay back to Ms. Bohlen the interest in including men into the conversation. She has seen the effects of intergenerational trauma in her community. Although there have been great programs and resources at the national level, there are communities, such as certain Navajo reservations, that do not have the resources or funding mechanisms to create councils or programs. She has also heard discussion about the need for supportive community figures, such as Big Brother and Big Sister.

Dr. Colleen Malloy talked about her experience as a neonatologist in a hospital in which people are categorized by their race and ethnicity. There can be a lot of judgment related to these categorizations, as well as a lot of assumptions. There are many times in which native women were not correctly categorized as American Indian when admitted to the hospital for delivery. She asked the panel to address how to improve data collection so that it more accurately reflects a person's true history. Ms. Raimondi said that she noticed that the questionnaire for the COVID-19 vaccine allowed for only one selection for race. Native American populations are

most often combined with other populations and forcing people to select one box results in not collecting data properly. She has also heard experiences from her colleagues of being repeatedly reclassified as White when they go to a clinic. The US Census is also an undercounting of AI/AN. There needs to be improvement to data collection for accuracy and nondiscrimination. Dr. Malloy added that the race and ethnicity of fathers who are not involved at birth is unknown and can also contribute to misclassification of infants of American Indian descent.

## **Indigenous Workforce and Training Issues**

# Mary Owen, M.D., Tlingit, Associate Dean of Native Health, University of Minnesota Medical School

Dr. Mary Owen started by acknowledging the swearing in of Alaska Native Mary Peltola to the US House of Representatives on September 13. She talked about her experience working in a tribal clinic, where she would see patients several times and recognize that she could not address their social circumstances. When she began working at the University of Minnesota, she researched social determinants of health and found Dr. Ehlinger's report on the impact social determinants have on the health of all communities. She echoed that inclusion and representation is important when making policy decisions about AI/AN in order to recognize their traditions and beliefs. For instance, Native Americans believe that all living things are related, whether it is animals, trees, or one another. This is an important belief because people are less likely to do harm upon each other if they are related. Yet, AI/AN are too often considered "other" and not connected to the rest of the country.

Dr. Owen said that representation is also important because autonomy is connected to health outcomes. A lack of control over one's life can lead to chronic stress, which in turn leads to negative health outcomes. For generations, the lack of autonomy has negatively impacted native communities across every system. There is also a need to address bias and stereotypes of native people. A <u>study</u> of 154 care providers across five hospitals showed that 84 percent implicitly preferred non-Hispanic White adults and children. Notably, American Indian children were seen as more challenging and less compliant as the proportion of American Indian children in the emergency departments increased. Representation is important, yet <u>2018 data</u> of the physician workforce indicated that AI/AN make up only 0.3 percent of all active physicians. In 2022, only 26 of the approximately 20,000 physician graduates were AI/AN. <u>HRSA data</u> show that AI/AN are underrepresented in all health occupations.

Dr. Owen said that the disparity is becoming increasingly worse. One challenge is helping AI/AN youth get across the barriers to medical school. In Dr. Owen's town of Duluth, Minnesota, the high school graduation rate for American Indian students is 41 percent post-pandemic. Dr. Owen noted that Duluth prides itself on its education outcomes. The Doctrine of Trust Responsibility that requires the US government to provide for AI/AN health and wellbeing not only applies to health care, but also to education.

The <u>Human Development Index</u>, developed by economist Mahbub ul Haq, measures the status of a country by the health of its people. According to 2010 statistics, AI/AN rank at the bottom of the index. Between 2005 and 2016, measures of the Human Development Index show that all

races and ethnicities but Native Americans improved in the education index. In terms of economic outcomes, median incomes among Native American men dropped by more than \$3,300 from 2005 to 2016. These negative economic outcomes are a result of being relocated off of good land; the US government not upholding promises of education, jobs, and housing; and termination of trust relationships with some of the reservations. At least half of Native Americans are currently under the poverty rate. In terms of health outcomes, life expectancy of all races but Native Americans increased between 2005 and 2016. The average life expectancy of Native American men is only 62 years of age.

One of the outcomes of overfunding IHS is high physician vacancy rates, which is nearly 50 percent in Dr. Owen's community. Racism persists in health care systems and can discourage AI/AN from obtaining the care they need. Historical trauma, particularly from colonization and oppression, contribute to health disparities among AI/AN and the repercussions are tremendous. AI/AN children are nearly three times as likely to die from unintentional injuries and more than three times as likely to die by homicide than White children.

Dr. Owen said that despite these statistics, there is good news. A 2008 study showed that when AI/AN culture is preserved and AI/AN people have autonomy over their destinies, there is a dramatic reduction of suicide risk. When clinics work together to provide collaborative, whole person care, negative outcomes related to chronic diseases are reduced. There is a recent movement for decolonization through the Land Back movement. Legislation has been introduced to address the cultural genocide of Native Americans through boarding schools. The Office of the Assistant Secretary for Planning and Evaluation (ASPE) released a document earlier in the year indicating that social determinants of health strategies, such as providing housing and nutrition, results in improved outcomes.

Dr. Owen provided several recommendations for consideration by the Committee. She suggested that the health of AI/AN mothers and infants be prioritized through prenatal care supports such as transportation, daycare, and (ideally) payments to attend visits. She offered several suggestions to improve the living conditions of AI/AN mothers and infants through universal health care, expanded treatment availability, whole community intervention approaches, investment in mental health services, collaboration with the Department of Education to include AI/AN history in schools, trauma informed care training, increased capacity and decreased reliance on grants, and transparency from IHS. She referenced an article she wrote on the lack of collaborations with IHS to increase the workforce. She also asked the Committee to support the Indian Child Welfare Act to reduce the separation of children from their families.

The <u>Indigenous Health Education & Resources Task Force (IHEART)</u> is an association of physicians, IHS, and professional associations that Dr. Owen created to address AI/AN health care professional shortages. The scope of IHEART is vast and creates the capacity, programs, and collaborations needed to promote an educational pathway to health professions from kindergarten to postdoctoral students.

#### **Discussion**

Dr. Ehlinger asked how much of the total IHS budget goes to health care. Dr. Owen said that it recently increased to \$9.1 billion, but that \$48 billion is what was needed to adequately care for AI/AN people.

Ms. Thompson asked if there were more data on the cause of low rates of high school graduation. She also asked if the recommendation to increase the number of mental health counselors was specific to AI/AN counselors or counselors who had received cultural sensitivity training. Dr. Owen answered that the low rates of graduation was related to social determinants. It is related to poverty, inadequate housing, inadequate nutrition, and the fact that their history is not taught in schools. She said that they need both types of counselors because there will never be enough mental health professionals to fill the need.

Dr. Ehlinger asked where tribal colleges fit as a potential solution to the health practitioner shortage. Dr. Owen answered that tribal colleges are part of the IHEART program. Students generally want to go to school and work in their communities, so tribal schools are a critical part of the solution.

Dr. Peck asked what is different at this moment in the 50 year history of efforts to improve outcomes that might influence a more transformational, urgent, and strategic change. Dr. Owen said that she has more hope now than she has had in a long time because of the decolonization movement. That ACIMM hosted this meeting on tribal land is also critically important. The Committee can support the Shakopee effort to include Native American history in textbooks. They could promote a collaboration with the Department of Education to support programs like IHEART. They could advocate for IHS to be fully funded and have more power so that they can be more transparent without fear or repercussion.

Dr. Malloy asked if the school closures during the pandemic affected graduation rates and if there might be worse outcomes as a result. Dr. Owen said that there was a decrease in the high school graduation rate from 51 percent to 41 percent during the pandemic. There are structural issues that affect the children whether they are in school or not. They need access to food and good broadband coverage.

Dr. Ramas talked about how AI/AN youth often have to prioritize work over education because of the need to contribute to their multigenerational or single family homes. She asked what kind of programs or services could be leveraged to help these youths prioritize education and to encourage families to value the pathway to health care professions. Dr. Owen answered that there are programs that specifically recognize the impact of the family on the path that students take. For instance, they recently received a grant to work with a tribal college to support students through a successful matriculation into the university's science school and then to research or medical school. There are components of that program that educate families about what it means to have a family member go through education pathways. There is also support for transportation, books, and computers. They provide a traditionalist to work with the students and families. It is critical that programs such as these continue to receive funding.

## **Learning from Our History to Create New Birthing Stories**

# Rhonda Clairmont Swaney, J.D., Salish & Kootenai, Past Managing Attorney and Former Tribal Council Chair for Confederated Salish & Kootenai Tribes, (Virtual)

Ms. Rhonda Clairmont Swaney shared her birth story from 45 years ago. She lives on the Flathead Reservation in Montana, which is rural and has limited access to health care. When she was 25 years old, she had attended college, was married, and worked for the tribe. When she became pregnant, she attended all of her prenatal appointments through her family doctor. On her six-month appointment, she was told that she had protein in her urine. She was sent home without any education or warning for what might occur. She developed pre-eclampsia the next night and drove herself to the local emergency department. She was transferred to a bigger hospital 60 miles away because the rural hospital did not have her blood type available. She never met with the on-call doctor. When she began the transfer, her baby's heart was still beating, but by the time she reached the hospital, the heartbeat could not be detected. She hemorrhaged and was hospitalized for several days. When she was released, she was not given instruction for care nor for when she could safely become pregnant again.

She was pregnant shortly after her experience and was designated as high-risk because of the stillbirth. She had to travel 120 miles round trip for a 15 minute appointment. She never received special care or testing. She began spotting one night and was told that she was in preterm labor and that her son would probably not live through the night. He did live but was transferred to a neonatal unit 500 miles away. She was told that his chances of survival were one in 100 and was asked to sign a liability waiver. Her son is now a 44 year old man with severe cerebral palsy and profound deafness.

Despite these events occurring 45 years ago, nothing has changed. Native women are still at high risk of complicated pregnancy. She learned that pre-eclampsia could be caused by extreme stress, which most AI/AN experience daily. AI/AN infants die at the higher rates than any other population. There is a scarcity of funds for health care, not enough providers, low health literacy, inadequate housing and transportation, and unmet mental health needs stemming from intergenerational trauma and endless encounters with racism. She challenged each Committee member to help just one Native American woman.

### Nicolle Gonzales, Dine', Nurse-Midwife Navajo Nation (Virtual)

Ms. Nicolle Gonzales is a nurse midwife practicing in a rural area of Albuquerque. She is one of 20 Native American nurse midwives in the US. Like many other Native American nurse midwives, she does not work for IHS because of the racism and lateral violence they experience when trying to serve their own communities. She created a nonprofit organization called Changing Woman Initiative, which provides home birth services to Native American women, using traditional medicine, medicine people, and trained doulas. They provide food from local farmers every two weeks for up to six weeks postpartum. They also provide traditional medicine, body work with healers, plant medicines, tinctures, and teas. A paid doula attends their birth, and a lactation specialist provides consultation and support through their pregnancy and postpartum. The fee for all of these services is \$4,000 per client. Currently, Medicaid reimbursement for midwifery care is \$1,500.

As in other areas, New Mexico has experienced closures of medical centers that provide obstetrics care. Native women are now required to navigate complex health care systems, often having to travel, or be transferred to another facility at some point during their pregnancy. Many women have not received any care at 20 weeks postpartum because they cannot access a provider, have to travel a long distance to access care, or have to wait more than six weeks for an appointment. Not receiving care in the first trimester is associated with increased maternal mortality and IHS is not fulfilling their treaty obligation to provide maternal and women's health care.

Recently, Ms. Gonzales spoke at the <u>Committee on the Elimination of Racial Discrimination</u> in Geneva to present on the crisis of maternal mortality in native women and the need for cultural respectful maternal health care. Despite President Biden increasing the IHS budget to \$9.1 billion, those funds are not going to the grassroots organizations that are filling care gaps. Native women are not being honored in their birthing experience. They are receiving unnecessary episiotomies. There has been no apology from IHS for the forced sterilizations that native women underwent in the 1970s. Ms. Gonzales wondered at what point in the telling of these stories will people start to listen.

She provided several recommendations for the Committee's consideration. First, she suggested a federal mandate within IHS to work with grassroots midwifery, doula, and birth assistants to improve maternal health care. Specifically, these organizations need funding to train people to work in rural communities. She also recommended anti-racism training and oversight within IHS for all providers and nurses. There should be funding for nonprofits and grassroot organizations that are addressing health care gaps in maternal health care. It takes more than \$100,000 for her nonprofit to provide care to just 30 families and their budget of \$1 million falls far short of what is needed to take care of all the families who need their support. She said that there also should be funding for health impact research for areas that have lost their obstetrics services. Although there has been research focused on maternal health in native populations, the focus on indigenous culture and traditions is seen through a white lens. There needs to be research to understand whether native women feel honored or respected. There should also be tax incentives from the state or federal government for midwives to conduct home birth service.

Ms. Gonzales said that she would like a statement of support for Indigenous midwifery in collaboration with grassroots organizations serving their community. Her organization has been trying to meet with Fort Defiance Hospital in Navajo Nation. Rather than granting a meeting, the hospital has conducted meetings on the safety of meeting with a community organization. She reminded the Committee that not everyone in the community has the capacity to obtain education to be a doctor or other clinical health care professional. Many do not have adequate transportation, technology, or even electricity. There should not be an expectation that these individuals go to school and come back to their community as health care providers. There is a need for creativity and innovation, opportunities for birthing in hogans or teepees, and more native midwives and doulas. She concluded by referencing reports on maternal mortality in native women and President Biden's recommendations for reproductive health care and asked the Committee to address how to move these efforts into the communities.

### Abra Patkotak, Inupiaq, Alaska Native Birth Workers

Ms. Abra Patkotak is an Alaska Native and an Indigenous birth worker. Alaska is the largest state in the US with 586,412 square miles, but a population of only 700,000 with several very rural areas. Most of the births are conducted at the <u>Alaska Native Medical Center</u> in Anchorage. Alaska Native people have ownership in their health care system and births are generally very cultural affirming and special. However, the pregnancy-associated mortality rate for Alaska Native women is 17.9 per 100,000 live births as compared to 4.1 per 10,000 in White women.

Ms. Patkotak shared three overarching concerns specific to pregnancy and birth in Alaska Native women. The first concern is language. Alaska Natives do not use the word doula. They also use their eyebrows, nose, and other body language to communicate. If a non-Alaska Native provider is not aware of these language differences, the Alaska Native women may feel like they are not being listened to and frustrated at the need to repeat their answers.

The second concern is the need for women to fly to Anchorage to give birth and the complications and risks that involves. Medical providers generally do not want women to fly at 40 weeks pregnant and therefore require women to leave their families and support systems at 35 weeks pregnant to give birth alone, hundreds of miles away from home. It is very stressful situation that may leave families struggling to find childcare, flights, or places to stay in Anchorage. Ms. Patkotak told a story about a mother who was overdue and put on a commercial flight. She gave birth only two hours after landing. She told another story of a women who had a difficult time finding a flight due to weather and could not find a place to stay because all of the hotels were booked. She was alone and very close to not having shelter. Ms. Patkotak found one Medicaid-approved hotel that required a \$100 deposit, which Ms. Patkotak put on her credit card. In addition, mothers must fly home with their newborn and there is little, if any, research on the effects of a flight on a newborn.

Her third concern was the need for an advocate to accompany women during the birthing process. There may be stressful news to navigate. There could be threats of violence to the health care workers from male partners. Having a community member who knows the family and the language, traditions, and culture is critical to maternal health.

She concluded with recommendations for the Committee. There should be Indigenous birth workers at all births and consideration for language barriers. There is a need for Alaska Native people conducting home visiting programs in the community so that they can watch for risk factors in pregnancy, such as domestic violence or overdoses. There should be AI/AN maternal and child death review committees led by AI/AN so that they can honor those lives. Finally, the Committee should consider expanding their membership to include expertise in law enforcement, suicide prevention, and rural emergency services.

#### Discussion

Dr. Malloy commented that there have been substantial advances in neonatal medicine that have improved treatment and outcomes for premature births. She understands that the problem is making these advances available to every community so that an infant born prematurely in a rural area has the same outcome as an infant born prematurely in a city with access to university

hospitals. Ms. Patkotak responded that what happened to Ms. Clairmont Swaney 45 years ago is happening today in Alaska. She reflected on a case in which an infant needed to be medevacked to Anchorage and there was no room for the mother, who was separated from her child with no resources for her to travel.

Dr. Neyhart talked about serving on the Alaska maternal and child death review committee and her fight to include tribal representation at the table. Only those who represent the communities in which these deaths occur can contribute the insights needed to create change.

Dr. Ramas said that the idea of access to health care in the US is biased toward a person going somewhere to receive care and does not generally include home services and support. It is becoming increasingly evident that a multidisciplinary team of practitioners, such as family physicians and nurse midwives, can create a comprehensive and safe place for birthing families. She asked the panelists to comment on what the ideal birthing setting would be for their communities. Ms. Patkotak said that the health care in Anchorage is excellent. Alaska Native people can receive primary care at South Central Foundation, which practices the <a href="Nuka System of Care">Nuka System of Care</a>. A pregnant person can receive primary care, behavioral health care, and midwifery care all in the same room. However, this does not exist anywhere outside of Anchorage, and she would like to see all native people have access to the same level of care.

Ms. Gonzales answered that the colonization model has made native people dependent on a system that is not serving them. This results in having to navigate a complex health system, not being able to practice their traditional ways of life, and being separated from their support systems. Decolonization would allow tribal people to incorporate their practices, taking the burden off of families to access care by providing home care, and reversing policies that criminalizes traditional medicine healers and other community providers who choose not to license or be regulated. Currently, native women's bodies are highly regulated and decisions about access to care is tied to funding and government decisions that they are not a part of. Ideally, she would like to see a think tank of doctors, midwives, doulas, and medicine people who can talk about the problems and develop innovative solutions to present to the Committee. Native people tend to be invited on the back end of recommendation development and are often not in the room when these recommendations are translated into policy changes.

Dr. Ehlinger said that he was a pediatric resident at the University of Utah 45 years ago and was part of the team that fly newborns to intensive care units. One of the things that drew him into health disparities work was the inequities he witnessed throughout the Intermountain Wiest during this time.

## **Maternal and Child Health Focused Policy Organizations**

Facilitator: Magda Peck, ScD, SCM, PA, ACIMM Member

Denise Pecha, LCSW, Deputy Executive Director, CityMatCH

Stephanie Graves, BSN, PHN, Red Lake Ojibwe, Board Chair, CityMatCH

Terrance Moore, MA, Chief Executive Officer, Association of Maternal & Child Health Programs (Virtual)

Scott Berns, MD, MPH, Chief Executive Officer, National Institute for Children's Health Quality (NICHQ)

LaToshia Rouse, CD/PCD(DONA), Board Member NICHQ

**Deborah Frazier**, Chief Executive Officer, National Healthy Start Association, (Virtual) Dr. Ehlinger said that the objective of this panel session was for the Committee to learn about the organizations that support maternal and child health and that could leverage the implementation of the Committee's recommendations. Dr. Peck began the session by inviting the panelists to brief descriptions of each organization.

Mr. Terrance Moore said that the <u>Association of Maternal & Child Health Programs</u> (AMCHP) is a membership organization that represents governmental public health, particularly among state leaders, communities, families, and people with lived experience. They are deeply committed to anti-racism and recognize the need to acknowledge past harm and interrogate the ways in they interact with each other and the community.

Ms. Deborah Frazier said that the <u>National Healthy Start Association</u> is a community-driven and community-based program to address disparities and inequities in birth outcomes for mothers, fathers, and families.

Ms. Stephanie Graves said that <u>CityMatch</u> is a national maternal and child health organization with membership consisting of local and urban public health and community members that work to improve the lives of women and children and to enhance birth outcomes. Ms. Denise Pecha added that CityMatch also focuses on health equity and is committed to anti-racism.

Dr. Scott Berns said that the <u>National Institute for Children's Health Quality</u> (NICHQ) is a nonprofit organization with a mission to improve child health and a vision that every child achieves their optimal health. They achieve this by boldly leading improvements in children's health by addressing inequities and other complex issues that families face. Ms. LaToshia Rouse is a birth and postpartum doula and NICHQ board member.

Dr. Peck asked panelists to address what has been learned and what strengths their organization brings to this moment of explicit and intentional focus on AI/AN health, equity, and policy change.

Ms. Graves said that she has observed a shift from an idea that one group matters to the recognition that all people matter. She has seen the dynamic change to include more people of color, including AI/AN, at the table. CityMatch is listening and taking action. As an anti-racist organization, they first had to look internally before trying to change the rest of the world. Ms. Pecha said that they had received feedback from the Tribal Epidemiological Centers that they

were not doing enough. They took this feedback seriously and their next conference will include Abigail Echo-Hawk as a keynote speaker and a session on data sovereignty. They are intentionally looking for all of the opportunities to continue building this engagement.

Mr. Moore first acknowledged ACIMM member Ms. Pettiford as the <u>newly-elected</u> AMCHP President. He said that one of the lessons that AMCHP has learned is that there is not often acknowledgement about the harms that have occurred. Step one of their journeys to racial equity has been reconciliation. They have examined and are deeply regretful of the times that the organization has used language that characterized racial groups as "at risk" or "vulnerable," as if the race of a person was a predetermined factor as opposed to racism as the factor. They acknowledge that they have contributed to the invisibility of Indigenous populations of women, children, tribes, and birth caregivers by existing for decades without few longstanding relationships with them. AMCHP has also looked internally at their membership structure, events, and annual conference, recognizing that these are not always easily accessible for community-based organizations. They have also not always prioritized engagement of Indigenous wisdom. Mr. Moore said that clarity about these failures is the first step toward improving and challenging others to do the same.

Ms. Frazier also acknowledged Ms. Pettiford as a founding member of National Healthy Start Association. She said that National Healthy Start is the membership organization for MCHB's Healthy Start grantees. Healthy Start began as a demonstration project in 1991 and expanded in 1999 to address health disparities. At the end of that funding period, the Healthy Start program had several tribal nation members, and National Healthy Start Association developed a report of recommendations during this time. But they began losing tribal nations over the next two funding periods and, today, the organization has only two tribal nation members. The organization's tribal partners have asked them to provide an update on those recommendations, but there was not much to update because very few recommendations had been implemented. One of the challenges is that the Healthy Start program has eligibility criteria that tribal nations cannot meet. When the tribes do receive Healthy Start funds, the funds improve maternal and infant mortality and morbidity, but they are often automatically eliminated because their population numbers cannot meet eligibility. The Healthy Start Notices of Funding Opportunities are generally written for the general public. Tribal leaders know what is best for their communities, but their decisions may not be what works for researchers.

Ms. Pettiford said that the report of recommendations was developed in 2005 but is still aligned with the recommendations that the Committee is drafting today. There has been no movement. The tribes provided feedback that the Healthy Start screening tool is too much of a burden for AN/AI families to complete. Ms. Pettiford agreed with the challenge of meeting data eligibility requirements. There must be a way to change the way data is release and the qualification requirements so that a whole population does not get eliminated.

Ms. Rouse said that if she, as a Black woman, closed her eyes during this meeting, she would hear the same issues that the Black community is struggling with. She added that her voice as a NICHQ Board Member is important because it adds lived experience to organizational conversations that too often focus on data and strategy. Dr. Burns acknowledged ACIMM

member Dr. Collier as a NCHQ Board Member. He said that his key takeaway from the presentations is that the organization has much more work to be done. They have worked with tribes in Alaska and Oklahoma. They have been purposeful in their anti-racism efforts by looking internally to diversify staff, board members, and vendors. But they acknowledge that there is clearly more work needed.

Dr. Peck asked the panelists to address how the Committee can make their recommendations stronger and what their organizations can do to move the recommendations into action for change.

Ms. Rouse said that there is often no way to know how recommendations are meant to be interpreted and implemented. For instance, a community-based doula program may mean different things to different people. She suggested that the Committee include clear detail about how they intend their recommendations to be implemented. Dr. Burns emphasized the importance of continued community engagement. He also talked about NCHQ's <a href="Equity Systems Auditing Tool">Equity Systems Auditing Tool</a>, which they are developing to enable an organization to evaluate <a href="where they stand">where they stand</a> on the equity continuum. An organization can be, for instance, a savior design system (i.e., to rescue but not consider root cause), an ally design system (i.e., to partner but not necessarily to inform decisions), or an equity-empowered system (i.e., to share power toward identifying root case and informing decision-making).

Ms. Frazier said that the crisis is beyond urgent. It is important to see a person in every piece of data and number and to stop expecting people to be resilient. Instead, organizations, structures, and funding need to become resilient to serve the population.

Ms. Pecha pointed out that work at the systems-level also includes running for office and understanding who one is voting for. Ms. Graves added that the Committee has been in existence for approximately 30 years, yet nothing has changed for AI/AN. She urged Committee members to change their narrative and do something different. AI/AN are in a constant state of emergency and they do not want to be a mythical creature that is only sometimes thought about. There is a need to undo biases and do better for AI/AN people.

Mr. Moore said that it is clear that there is no solution to the crisis that AI/AN do not already have. As a membership organization, AMCHP can continue to listen to, invest in, and actualize these solutions. They can also strive to remove the fundamental health barriers, such as the loss of health care coverage and the loss of access to abortion care.

Ms. Rouse added that organizations can offer platforms that help educate the public and clinical and social service professionals about the solutions that AI/AN use, such as smudging and cradleboards. They can bring their stories to the forefront so that other people of color can connect similar experiences and demonstrate that these experiences are not anomalies.

Dr. Peck asserted that those at the frontlines of tribal perspectives and those at the frontlines of maternal and child health perspectives should nevermore be in separate places, but rather

integrated going forward. Dr. Ehlinger said that these organizations should also be partnered with the Committee to amplify their recommendations.

# Moving Forward in Improving the Health of First Nations and Indigenous Populations

# Donald Warne, MD, Oglala Lakota, Co-Director, Center for Indigenous Health, Johns Hopkins University

Dr. Donald Warne addressed how to contextualize what has been learned into next steps. "American Indian/Alaska Native" is the legal term for this population set forth by the US government. Not all Alaska Natives are America Indian—for instance, the Inuit people live in Alaska but also Siberia, Canada, and Greenland. According to the 2020 US Census, there are 9.7 million AI/AN in the country. Anyone can self-identify as AI/AN in the US Census, but to be eligible for services such as IHS, one must be enrolled in their tribe, a descendent, or closely connected to the community. Of the 9.7 million self-identified AI/AN, only 2.6 million are enrolled with IHS. "Native American" is a term that includes AI/AN, but also native Hawaiians and Indigenous people of Pacific Islands. "Indigenous" is a term that encompasses all first inhabitants of various parts of the globe, including Native Americans. Dr. Warne said that it was important to understand these terms so that they are used specifically and appropriately in the recommendations.

Dr. Warne reviewed how tribal communities and colonization determined certain state names. For instance, North and South Dakota could have been called North and South Lakota had colonization come from west to east instead of east to west, but the Dakota war in the 1860s pushed the Dakota people west of the Red River. Dr. Warne shared that the name "Minnesota" is Dakota for "the land where clouds rise off of the water." The 13 American colonies of the northeast were particularly devasting to the tribes whose land they settled on. For instance, Jeffrey Amherst was a colonial governor in Massachusetts who ordered blankets from a smallpox hospital to be distributed to regional tribes with the direct purpose of killing them. Jeffrey Amherst killed thousands of Indigenous people but is today honored in name by Amherst the city, Amherst College, and University of Amherst. In 1830, the Indian Removal Act removed tribes from their homelands in the southeast into what is now Oklahoma. Some tribal members refused to move, creating a dichotomy of tribes in Oklahoma and in the southeast. Additionally, the discovery of gold devastated tribes in California.

Dr. Warne said that it is important to understand this historical trauma in the context of chronic disease disparities. AI/AN is a small population today because the US government removed or killed them. The history of boarding schools in the US was also forced removal. Tribal families were given the choice to give their children up to boarding schools or lose their food sovereignty. The purpose of the boarding schools was to strip children of their culture and there were significant mortality rates among the thousands of children who had been removed. It was not until 2022 that the Department of Interior release a report on the federal boarding school policies, which was only made possible by the 2021 appointment of Deb Haaland, a Native American, as Secretary of Interior.

Dr. Warne talked about an epigenetic study of boarding school survivors and their adult children to evaluate intergenerational epigenetic changes to DNA. There is some evidence that there is an epigenetic basis for historical trauma that has yet to be fully elucidated. He reviewed gestational and childhood stressors such as teenage pregnancy and federal food distribution programs. He talked about efforts to prevent teenage pregnancy that failed until a nurse started a program of paying teens \$5 a week to not get pregnant. Federal food policies such as the Women, Infants and Children (WIC) program distributed infant formula and unhealthy commodity foods, such as shortening, flour, and corn syrup. These programs led to high rates of diabetes, heart disease, and obesity. AI/AN also have higher rates of adverse childhood experiences (ACEs) as a result of historical trauma, which can contribute to the risk of health conditions. Adults can also experience adversity from living with marginalization and racism. These factors put the population at tremendous risk of poor health outcomes. In the decade before the pandemic, the average age of death for White people in North Dakota was 79. The average age of death for American Indians in North Dakota was 58—a 21 year difference.

Dr. Warne shared his recommendations for strengthening the Committee's draft recommendations to address disparities in AI/AN maternal and infant mortality. In the framing and introduction of the recommendations, there should be a reference to the strength, resilience, and wisdom of Indigenous communities for ensuring healthy birth outcomes. There should also be a shift from including Indigenous people as active participants to an inclusion of Indigenous people as *key leaders* and *decision makers*. The boarding school era should also be mentioned in the framing of historical context. There should be a call to understand the root causes of inequities, such as structural racism and social determinants, and a commitment to ongoing exploration of full partnerships with Indigenous communities. The Committee should encourage the expansion of prenatal and postpartum caregiver programs, including funding for home visiting programs and access to doulas and midwives. These programs should be highlighted as essential, with a need to ensure access across all tribal communities.

Dr. Warne added that Indigenous people have inherently protective teaching embedded in their culture—much of which are not considered best practices, such as breastfeeding, proximate cosleeping, SIDS prevention, and birth support workers. The Committee's recommendations should frame Indigenous practices as knowledge that modern science has finally caught up with. Although telemedicine is a great approach, it is often not culturally congruent. The Committee should consider alternative solutions such as investments for the development of AI/AN medical and paraprofessionals, as well as alternative care models that extend in person care into communities. Dr. Warne emphasized that state legislatures can stand in the way of American Indians' access to federal funds. For instance, there can be a call for Medicaid expansion, but it is a state-to-state decision. State doula accreditation standard restrict Medicaid coverage to nationally accredited doulas. This can be cost prohibitive for many people. Therefore, the Committee should recommend for the recognition of tribal certification of doulas.

He agreed with the challenge of meeting reporting requirements for Healthy Start grants. AI/AN live in rural areas and there cannot be a one size fits all approach. There are only two tribal programs in Healthy Start, which is unacceptable because they are the communities in most need of funds. MIECHV is an effective program, but currently tribes must compete for a three percent

carve out. The distribution of MCHB Title V State Block Grants to AI/AN depends on how friendly a state is to AI/AN. In addition, IHS should not be viewed as a failed system, but rather a *starved* system. It is not known how effective IHS could be if it were fully funded. Dr. Warne suggested that Tribal PRAMS programs be expanded in addition to supporting tribal data sovereignty. Family Spirit is an evidence-based home visiting program that was designed by and for American Indian families, but the program is dependent on grant funding. Three randomized controlled trials have shown that Family Spirit significantly improves parenting efficacy; reduces drug use and depression; and improves social, emotional, and behavioral development in children through three years postpartum. A program with such an evidence base should be reimbursable.

Dr. Warne concluded by saying that a one size fits all approach does not work in equality. There needs to be some flexibility and unique programming for certain populations. AI/AN face systemic barriers that must be addressed broadly. The Committee has an opportunity to be part of the broad solution by facing these challenges directly.

### **Public Comment**

## Lee Wilson, Acting Designated Federal Official, ACIMM

## **April Phillips**

Ms. April Phillips is the Clinical Director of the Psychiatric Mental Health Nurse Practitioner Program at Frontier Nursing University. According to the most recent MMRC report, it was found that 11 percent of maternal deaths was related to a mental health condition. A recent study found that American Indian women have a 62 percent increased risk of developing a mental health diagnosis during pregnancy. Approximately 72 percent of women with perinatal mental health conditions bever receive treatment. There is a dire need to increase access to mental health services during the prenatal and postpartum periods.

### **Candy Hadsell**

Ms. Candy Hadsell is a nurse specialist for the Minnesota Department of Health. She said that there has been an increase in syphilis cases, not only in Minnesota but across the country. Approximately half the cases are females of childbearing age and there is also an increase in congenital syphilis. Sexually transmitted diseases are often overlooked; therefore, it is important that the Committee was aware of the rates of syphilis in pregnant native women.

### **Discussion**

Dr. Ehlinger said that when he was Commissioner of the Minnesota Department of Health, he was shocked to learn that congenital syphilis had become an issue because he thought it had been eliminated. It is particularly prevalent in AI/AN for multiple social conditions.

Ms. Pettiford and Dr. Neyhart stated that there had also been an increase of congenital syphilis in North Carolina and Alaska and thanked Ms. Hadsell for raising awareness.

Dr. Peck said that it could be helpful to look to CDC and HRSA to determine if there were investments currently directed to address this situation. asked if the Committee should incorporate this topic in their recommendations for AI/AN or if they should consider it more broadly in future reports. Dr. Kroelinger said that they were aware of the issues in many different states and has a center specifically focused on it. She will get back to the Committee about the level of investment.

Ms. Hadsell said that it was critical to understand that syphilis is preventable and the medical system, whether IHS or tribal health, does not generally understand that it was not eradicated and that the test for syphilis needs to be administered three times, not just once.

Dr. Ehlinger suggested that their recommendations may not address the issue directly, but they do address the issues that contribute to risk. Mr. Lee said that they will pull together information about the issue for future discussion.

### **Discussion with Previous Presenters and Discussion of Recommendations**

### **ACIMM Members**

Dr. Ehlinger invited Dr. Tina Pattara-Lau, Maternal and Child Health Consultant at IHS, to share her thoughts on the presentations and discussions. Dr. Pattara-Lau said that her role is to serve as a subject matter expert to advise IHS and maintain the spotlight on maternal and child health in AI/AN. She spoke about her engagement with other agencies, such as with CDC to evaluate their data processes and with HRSA to review their cervical cancer screening processes. She conveyed to the Committee and the panelists that although she could not be in the room with them, she had been actively listening. She has heard the loss, pain, and call for more work to be done. She has heard the need for more patient navigator and advocate roles and the solutions needed to expand access to care. She invited the panelists to reach out to her to for further conversation and collaboration.

Dr. Ehlinger asked Dr. Pattara-Lau to review the most recent draft of their recommendations for additional comment. As the Committee moves forward with the recommendations, there will be an ongoing need for additional information, and he hoped that the Committee's relationship with IHS going forward will be conducive of dialogue and collaboration.

Mr. Wilson conveyed to the Committee that Dr. Pattara-Lau has not been in this new role at IHS for very long, but that she has been continuously engaged. He expressed appreciation for the opportunity to bridge the gap with IHS and looks forward to the continued relationship and information sharing.

Dr. Peck expressed gratitude to Dr. Warne for his mentorship and asked him to clarify what he meant by "positionality." Dr. Warne answered that positionality can be the physical, cultural, and/or historical space that they currently are in. Work in AI/AN maternal and child health today is very different than it was ten years ago. It is important to formally recognize positionality as part of the framework for discussion.

Dr. Peck asked about the idea of adult ACEs, including birth and parenting trauma, and asked how the Committee might build on the cumulative, toxic effect of acute childhood events and adult trauma. Dr. Warne said that their population experiences stressors at all times and across all age groups. Many self-medicate their childhood trauma with various substances and this setting often leads to adverse outcomes such as unplanned pregnancy and incarceration. Children who experience abuse and neglect eventually become parents, creating an intergenerational cycle and challenge. The cumulative effect of toxic stress can begin as early as prenatally, when the mother experiences toxic stress, and continues across the lifespan.

Dr. Peck thanked Dr. Warne for his framing the intergenerational trauma from the perspective of weaponization through disease-carrying blankets, threats of starvation, education that strips culture away, and commoditized foods. Dr. Warne agreed that seemingly innocuous provisions such as blankets, food, and education have been intentionally implemented to harm.

Dr. Palacios commented that self-medication not only affects adults, but also young children. She also talked about the power that the states have on health outcomes. It was not long ago that maternal mortality rates were blinded, and it was unknown which state had the highest rates. She urged the Committee to consider the action needed at the federal level to compel the states to take action. She reiterated that IHS is starving for funds and has been given a large number of seemingly unsurmountable tasks. The problem lies largely with the larger federal government. She asked Dr. Warne if universal health care might be a possible solution. Dr. Warne said that universal health care would benefit many populations. The US health care model spends much more money and has much worse outcomes than other countries. It has not been an intelligent, strategic design of a system, but rather the result of multiple stakeholders with different priorities. He is always surprised when Congress criticizes IHS because they are responsible for funding IHS. If a full tank of gas is needed to go from point A to B, but one only puts in half a tank of gas, then it is not the fault of the driver, the car, or the road. It is the fault of the one who put in just a half a tank of gas.

Dr. Ehlinger asked Dr. Warne if there were recommendations that the Committee should prioritize. Dr. Warne said that the Committee should characterize recommendations by what can be implemented within HHS, what needs to be done across other agencies, what requires Congress or the administration, and what requires advocacy.

Dr. Neyhart was struck by the lack of Dr. Warne's bitterness in conveying the horrifying history of American Indians that should be known to all Americans. It was also important for the Committee to recognize the chronic and crippling underfunding at the root of the problem.

Dr. Menard commented on the idea of making AI/AN a 51<sup>st</sup> state and asked Dr. Warne what that might look like across the hundreds of tribes. Dr. Warne said that American Indians are unique in the US because the tribes have a relationship with the federal government as a separate political entity. This nation-within-a-nation relationship could be amended through the Social Security Act and Title 19 to move state legislature out of the way of federal funds to American Indians. The US <u>Constitution Article 1</u>, <u>Section 8</u> is the Commerce clause, which states that Congress

shall regulate commerce with foreign nations and Indian tribes. The current framework of state authority and regulation is technically legal, but unconstitutional.

Dr. Warren commented on Dr. Warne's concrete suggestions on changes within MCHB. He told the Committee that MCHB Title V Block Grant guidance is updated every three years, which is in process now and an request for information (RFI) will be released soon. MCHB has also been conducting listening sessions with Healthy Start grantees. There will be two more listening sessions in October and November and there will also be a public RFI. These are all opportunities to submit input on the way the MCHB programs are structured.

Dr. Ehlinger asked the Committee to review the draft recommendations in the context of what they have heard over the last two days. He asked Committee members to consider how to strengthen the recommendations and potential the timelines, partnerships, and evaluation metrics that could be included. He also asked them to consider how to reframe the recommendations as more of a given, obligation, or responsibility of the US government to AI/AN. Mr. Wilson added that the Committee should be mindful of language and how it represents the needs of AI/AN, considering that not all members are AI/AN.

Dr. Ramas suggested referencing the law that obligated the US government to provide optimal care. Dr. Peck said that this information is in the <u>Broken Promises</u> report. She suggested that the Broken Promises report and the Committee charter are both important references as they frame their recommendations. Dr. Palacios said that the briefing book from this and the June 2022 meeting both have important resources.

# DAY THREE: Thursday, September 15, 2022 Review, Reflections, and Learnings of Previous Days

#### **ACIMM Members**

Dr. Ehlinger set the expectations for the Committee's discussion on revising their recommendations. First, he asked the Committee to aim for consensus on the context by which to frame the recommendations. Second, he asked the Committee to be bold within the charge and scope of ACIMM. Finally, he asked the Committee to consider what the Secretary could put into action.

#### **Framing**

The Committee first addressed the framing of the recommendation document. Dr. Ehlinger said that one given frame was the treaty obligations that the US government had committed to, but not always honored. Dr. Palacios suggested that they could use language from the Broken Promises report, which used wording that was more about repairing promises rather than words such as "demand" or "owed." Dr. Sharps said that the language could also focus on a call to action to restore trust and enhance relationships. Dr. Menard suggested using a framework of deliberate actions that highlight equity. Dr. Neyhart said that a request or a stated expectation for a response within a certain timeline should also be included. Dr. Ramas said that the framing should elucidate efficiency, effectiveness, and responsive targeted actions. She suggested that there should also be an architecture of short, medium, and long-term timelines to set a level of

urgency. This could help the Secretary focus on short-term goals and plant seeds for longer term goals after his service. It would be useful to consider who exactly might read and/or summarize the document for others. Dr. Ehlinger reminded the Committee that their North Star is equity and racial justice, which should be used to center recommendations.

Dr. Peck provided several suggestions for framing the document. She said that previous Committee reports of recommendations were unlikely to be read. Therefore, they should ensure that this is a standalone document with reference to the previous work that it builds from. She also encouraged Committee members to model strategic, appropriate, and respectful language such as legal and cultural definitions. She agreed with Dr. Ramas about the need to build a framework of urgency. She also suggested that the cover letter reference their consultation with tribal and urban AI/AN representatives and their commitment to upholding the principle of consultation as a component of the government obligation. Critically, it is important the document should convey the urgency of maternal and infant health in AI/AN. As maternal mortality is a proxy for the health of the country, it should be stated that a focus on maternal and infant health will cause a ripple effect toward the health of others. Dr. Ehlinger agreed on the need to highlight their consultation with AI/AN and that their recommendations were developed after hearing lived experiences as well as the data and research.

Ms. Pettiford added that their language should not limit actions to the federally recognized tribal entities because there are so many that are not recognized. Dr. Ehlinger said that there could be documentation of these numbers in an appendix. It will be important to including supporting documents to uphold their recommendations. Ms. Pettiford said that there should be a call for continued conversations with organizations and people with lived experience.

Dr. Tara Sander Lee said that there should be urgency for the issues that women in rural areas are facing, not only to access basic care that they are not currently receiving but also advanced care for special cases. Dr. Palacios highlighted the discussion on looking outside academic education to build the community health workforce. Dr. Ehlinger appreciated the thought that science was catching up to tribal tradition and suggested that this idea be built into the document. Dr. Steve Calvin added that programs such as Dr. Love-Thurman's program to draw youth into the field are important and should be highlighted. Dr. Sharps agreed and said that there were other models, such as doula programs with nursing students or recruitment programs that go to high schools and tribal colleges.

Dr. Ehlinger said that Dr. Warne's presentation on historical context should be built in. Dr. Ramas suggested that the preamble of the document should include the understanding that holistic, multidisciplinary preventive care reduced poor health outcomes; the concept that community resiliency built on agency is necessary; and the idea that Indigenous practices should be elevated.

## Prioritize the Health of Indigenous Mothers and Infants

*Include Indigenous Individuals as Active Participants* 

Dr. Ehlinger recommended that this language be changed to American Indian and Alaska Native. He asked the Committee to comment on whether there should be a focus on individuals or

communities. Dr. Menard suggested using "lead" rather than "engage," referencing the need to transfer power to the community. Dr. Ramas suggested that a change to "key decision maker" would help ensure that "leadership position" was not translated as tokensim. Ms. Pettiford added that the recommendation to "include at least one Indigenous member" could also be tokenism and that too often "at least one" means only one. She suggested that the wording should include that the Committee should reflect the diversity of the population. Dr. Neyhart suggested that it could be even bolder and recommend that it reflect the population with the largest disparities in maternal and infant health. Dr. Palacios said that the panelists had recommended at least two representatives—one from an Indigenous national organization and one from a tribal organization. Dr. Ehlinger agreed that both tribal and urban representation should be included. Dr. Peck said there was a distinct difference in Alaska Native communities and suggested inviting both an American Indian and an Alaska Native instead of combining the populations. It should be about voice and representation rather than numbers. Dr. Ehlinger reminded the Committee that Indigenous refers to a broad population of AI/AN, as well as native Hawaiians and people from Pacific Islands. The representation should include all perspectives rather than limiting it to one or two populations.

Dr. Neyhart wondered if it was possible to have a standing sub-committee of people external to ACIMM to fully represent the diversity of the population. They could be charged with monitoring the Committee's progress. Dr. Ehlinger said that the ACIMM charter does not currently state that there are standing committees but that it could be created and included in the charter renewal. Mr. Wilson said that the charter allows for ad hoc workgroups. There are rules for standing committees to ensure that they are not making decisions separate from the will of the Committee. He added that the Committee is not a decider of membership because there are other considerations such as geography, gender, and professional diversity, as well as other factors. Since the Committee and its members are constantly evolving, they may want to consider broad recommendations that outline intentions rather than a prescription for the future. Dr. Menard asked if they could include a recommendation that would be aimed internally to create a structure for continuing and diverse community input. Dr. Ehlinger suggested that this could be framed as a recommendation that the Secretary ensure that the diverse voices within the Indigenous community are represented within Committee membership.

Dr. Peck asked Dr. Warren to clarify the role and structure of ex-officio members. She wondered if ex-officio members had any accountability to leverage the Committee's recommendations. Dr. Warren said that the last iteration of the charter aimed to broaden ex-officio membership to other agencies such as the Office on Women's Health, the Office on Minority Health, specific divisions within CDC, CMS, NIH, ACF, and the Substance Abuse and Mental Health Services Administration (SAMHSA). The charter also enumerates agencies outside of HHS such as the Departments of Agriculture, Education, Housing and Urban Development (HUD), and Labor. Dr. Peck suggested that this could also include the Department of Interior. She added that the Secretary has several advisory committees that may have alignment with Indigenous communities. National organizations have also been working on this for a long time. It might be helpful to do some homework on other entities to ensure that Indigenous leaders already in leadership roles are not being tapped multiple times. Dr. Warren said that there is an advisory committee called the Secretary's Tribal Advisory Committee. He said that the ACIMM charter

indicates that the Committee can, "[...] facilitate any other interaction related to intergovernmental responsibilities or administration programs, including those that arise explicitly or implicitly under statute regulation or Executive Order."

Mobilize Federal Agencies, State Agencies, and Funding to Accurately Identify Indigenous People

Dr. Ehlinger said that there was a recommendation to add "to end data erasure by accurately identifying and including Indigenous people in policy and development processes." Dr. Palacios agreed with the term "data erasure." Dr. Peck said that there was a lens by which to consider data that should go into the preamble of this section. This lens includes data erasure, data as a weapon of oppression, data sovereignty and ownership within treaty obligations, data methods with regard to small numbers, racial classification in mixed race individuals, data partnership, data leadership, the need for qualitative data, data interoperability across systems, and data that lead to research and discovery. She said that the two categories of these lenses are cultural systems and methods. She added that there was language to "reinstate funding," which she suggested was a mild recommendation. There is nothing missing from the recommendations, but they could be bundled differently. She would add language to assure that the focus is on maternal and infant mortality and that there may be national, state, and local standard practices.

Ms. Thompson felt that the recommendation for training on identifying race and ethnicity would increase the risk for racism. Dr. Palacios said that the recommendation was meant to be training on the self-identification of data and was glad that Ms. Thompson pointed out the ambiguity. Dr. Peck suggested that the idea of national statewide training may create red flags. She asked Ms. Thompson to help her word the recommendation so that it was less likely to be misconstrued.

Dr. Menard said that she reviewed the section on interpreting violence and wondered if it might more appropriate under this recommendation. The challenge with maternal mortality reviews is the small numbers. Adding morbidity would provide a much broader view. Dr. Peck agreed and suggested using either "pregnancy associated" or "pregnancy related" to be more inclusive. Dr. Ehlinger said that the same language was used in the recommendation for murdered and missing Indigenous women and girls.

# Improving the Living Condition of Indigenous Mothers and Infants and Assure Universal Access to High Quality Healthcare

Address Social Determinants of Health

Dr. Neyhart suggested that in number 14, "dedicate funding" should be "adequately fund." In number 15, "mothers, fathers, and same sex couples" should be "all parents" and the phrase "promote the health of Indigenous parents" seems paternalistic. In number 16, there should be an added recommendation to make the Medicaid application process less onerous and more streamlined and to continue Medicaid coverage to at least 12 months postpartum and to 12 months of age for the infant without the need to reapply.

Dr. Palacios added Dr. Peck's suggestion to build on a cross-agency relationship with HUD. She removed "members" in number 16 for consistency. She reiterated that Indigenous should be replaced with AI/AN. Ms. Thompson suggested change the word "essential" the preamble to

"promised." Dr. Ehlinger suggested using both terms. Dr. Peck suggested that number 14 address access to broadband. Dr. Palacios agreed and added that it should include support for home visiting.

Dr. Peck talked about adding language for research on the fiscal impacts of payment innovation models, such as payments to attend prenatal care, not just paid maternity leave. Dr. Ehlinger agreed that both could be included. Dr. Neyhart suggested that the preamble for this section include stronger language and that "Indigenous mothers and infants" should be "Indigenous people." Dr. Ramas said that a solution is needed for transportation as a social determinant. She suggested using language such as safe, available, and affordable transportation. Having access is not enough. There was also the notion of bringing services to remote communities that might be included. Dr. Palacios said that this could be framed as enhancing access.

Dr. Menard suggested incorporating the discussion about removing state legislators and public health and allowing tribes to have direct access through their own process into number 16. Dr. Neyhart said that part of the recommendation should be about making Medicaid enrollment less onerous. Her experience is AI/AN often have no legal documentation available to meet documentation requirements as proof of status. Mr. Wilson asked Ms. Kristen Zycherman if CMS had a recommendation for the Committee to address AI/AN direct access to Medicaid that is separate from the state-based process and if there were any categories of individuals under the Affordable Care Act that were brought into Medicaid directly. Dr. Zycherman said that she would take the questions back to her colleagues who work in eligibility. Ms. Thompson said that Dr. Warne talked about the this being a solution for federally recognized tribes. She asked what might be possible for those that are not federally recognized.

Evaluate, Sufficiently Fund, and Improve the Indian Health Service

Dr. Neyhart asked how include the US government's historical obligation to AI/AN to the section, including the title. This could be a reference to IHS's mandated responsibility. Dr. Palacios suggested language about fulfilling treaty obligations to improve AI/AN health, with IHS as one approach. Dr. Ehlinger added that the idea of prepaid health care should also be included.

Dr. Neyhart suggested that number 17 not include "provide adequate mandated funding." Number 18 should reference that the assessment is to be reformed by Indigenous recipients. Number 20 should say "involve tribal members before changes in IHS are made." Number 21 should use stronger language such as "must."

Ms. Thompson asked who would conduct the audit in number 19 and 21. Dr. Ehlinger suggested that this should be "AI/AN-led assessment". Dr. Menard asked what is meant by "improve Indigenous maternal and infant health." Dr. Ehlinger said that it included not only quality of service, but also budgets and other components of service delivery.

Dr. Menard talked about number 22 from the perspective of an ACOG member. The ACOG contract with IHS is meant to provide a quality review upon hospital request. They bring in a team, conduct a structured process, and provide a brief report. Some of the report includes

confidential patient information, but other parts of the report, such as lists of training courses, could be shared with the Committee. Dr. Palacios said that these reports could be useful in terms of understanding the foundation of care that IHS provides that needs improvement. Mr. Wilson said that they reached out to ACOG to see if they could provide information. They reminded him that they have a contractual obligation to IHS and are not at liberty to share information. This is important in terms of directing recommendations to the appropriate entity.

Dr. Collier said that it should be made clear that not meeting mandates has been the source of inequity and poor health outcomes. It is the source of the problem that needs to be corrected. Dr. Palacios said that there should be a measure for "adequate funding." There is a division in the Tribal Budget Workgroup that has expertise in how much funding should be allotted to IHS. It might be worth citing their report so that "adequate" is not interpreted as a small increase.

Dr. Peck encouraged the inclusion of language in numbers 19 and 22 that references making reports publicly available because it is not sufficient to shine a light on a recommendation without understanding what happened to initiate the recommendation. Dr. Ehlinger suggested that auditors can only report what is going on. Decision makers, such as CMS or IHS, could use the audits to determine next steps. Dr. Ramas asked what incentive could help get the work done. She asked this was under ACIMM's purview. Dr. Ehlinger suggested that this was a staged activity, taking the first step now to conduct the evaluation and then developing next steps later. Dr. Ramas suggested that there could be strong encouragement for partners to actively work towards the workflows and processes to reduce disparities.

Ms. Thompson asked if there was AI/AN representation on ACOG. Dr. Ehlinger said that the recommendation that AI/AN be represented in all committees speaks to that, if not directly.

### Expand and Diversity the Workforce

Dr. Calvin suggested that number 27 was broad and asked Dr. Menard and Dr. Palacios to provide their input. Dr. Menard agreed that the term, "midwifery education programs" could be more specific. She added that the panelists had called for training Indigenous and traditional birth workers, which the recommendation does not currently speak to. Dr. Ehlinger agreed that the definition or scope should expanded to include traditional birth workers. Dr. Neyhart said that they should be careful with this recommendation because each state licenses midwives differently. Some states allow direct-entry midwives to practice independently and there should not be a sense that the Committee supports one model over another. Dr. Sharps suggested expanded the recommendation to include other advanced practice nurses who would care for children beyond infancy. Dr. Palacios said that the feedback from the panelists was intended to expand the scope of birth workers without the barrier of licensing or accreditation.

Ms. Thompson asked how the panelists' recommendation for tribal birth practices should be included. Dr. Ehlinger said that it should be an additional recommendation that specifies the need for traditional birth workers, cultural practices, and training on tribal practices for all providers. Dr. Ramas suggested including the concept of respecting and valuing a team-based approach. Dr. Ehlinger said that the focus of the recommendations is currently on what states and territories can do. He asked the Committee how to focus on facilitating tribal decisions. Dr. Collier added

that "trained midwives" is a broad term that would be in accordance with tribal-approved guidelines. Anything more specific might be perceived as an intentional exclusion. Dr. Ramas reminded the Committee that the issues was the lack of acknowledgment about the validity of traditional birthing practices. Dr. Ehlinger asked Ms. Pettiford to help blend recommendations 27 with the new recommendation that she was working on. Dr. Menard added that the urgent need to inform the workforce on historical influences and cultural practices belongs in these recommendations. Ms. Pettiford suggested that the language from the Committee's previous recommendations on implicit bias training could be used.

Strengthen the Relationship Among Title V and Tribal Communities

Ms. Pettiford asked if there were data available to determine whether Title V sites were already doing this work or not. Mr. Wilson said the Title V Information System can provide data on those sites that provided information, although it may not be comprehensive. He will follow up with the Committee with these data. Ms. Thompson added that there should be some accountability for ensuring that tribes can access the increase in Title V funds. Ms. Pettiford said that there were MCHB reporting requirements but not specifically for distribution to tribes. Dr. Peck asked if the recommendations were specific to Title V Block Grants only or if it included Special Projects of Regional and National Significance (SPRANS). Dr. Ehlinger suggested that language be added to this section to demonstrate that the goal is to increase AI/AN involvement through Title V Block Grants and SPRANS and that a third recommendation be added specifically for SPRANS. Ms. Pettiford said that the language should specify an increase to both Title Five Block Grants and SPRANS so that money is not simply shifted. Dr. Peck and Ms. Pettiford will work on context language and the third recommendation.

# Give Special Attention to the Issues of Incarceration, Substance Use, Intimate Partner Violence, Murdered and Missing Indigenous Women and Girls, and SIDS/SUID

Expand Efforts to Identify Murdered and Missing Indigenous Women and Girls and Prevent Its Occurrence

Dr. Ramas said that the term "historic devaluing" should be included in the preamble. She wondered whether number 30 should reference a federal office to support the sense of urgency that was expressed by the panelists. Dr. Ehlinger said that both previous Committee meeting presentations and Secretary Becerra recommended action at the state-level. Dr. Ramas said that the need was to encourage standardization to address the discrepancies across states. Dr. Peck suggested that including regional, state, and local jurisdiction would support the regionality of tribes and provide the Secretary with more flexibility at the federal level. Dr. Ramas suggested that numbers 30 and 31 could be combined. She wondered if number 32 should include a review board that is reflective of priority populations to help identify root causes. Dr. Ehlinger suggested including adequate resources for data in number 31. Dr. Peck suggested including investments for strengthening systems standardization and interoperability.

Dr. Ramas wondered if word "support" in number 34 should be backed up with specific examples. Dr. Ehlinger said that this recommendation was general as a way to raise visibility of a serious issue. Dr. Ramas recommended using the word "promote" and combining 34 and 35. Dr. Peck said that 31 could also be combined with 36 with inclusion of the urban Indian experience. Dr. Ramas reiterated the need for repeated references to historic trauma and the need for

continued training for state and tribal communities. Dr. Ehlinger said there should be an early statement that historical trauma affects every single issue addressed in the recommendations.

Expand Violence Surveillance and Universal Screening

Dr. Menard suggested putting numbers 44 and 39 before the others. She wondered whether numbers 41 and 42 belonged in the data section. Dr. Kroelinger said that her team reviewed the CDC Maternal Mortality Review Committee reports, and the majority are already examining pregnancy-associated deaths. They have also taken some action based on panelist feedback, including a release next week of the first ever brief on pregnancy-related deaths among AI/AN and the preventability and the leading causes of these deaths. Ms. Pettiford added that reporting these deaths at the federal level is helpful. North Carolina has not released AI/AN pregnancy-related deaths because it may only be one person and therefore identifiable.

Dr. Kroelinger said that they have employed a new methodology to examine multiracial and Hispanic individuals who identify as American Indian. Dr. Peck suggested that Dr. Kroelinger submit a letter to Dr. Ehlinger to demonstrate to new Committee members how their recommendations become actions. She added that it would be helpful to include the denominator when reporting small numbers and suggested aggregating data at the regional level because HRSA's regional designations do not align well with tribal areas. Dr. Neyhart asked Dr. Kroelinger if there had been retroactive work to more accurately identify women who were misidentified as White. Dr. Kroelinger answered that there have been some retroactive reviews. The NIHB's mention of the GAO report that recommended releasing data to the Tribal Epidemiological Centers was helpful and CDC is actively working on that recommendation.

Mr. Wilson added that HRSA is meeting quarterly to address grant development and design and will be reviewing the Committee's recommendations.

Dr. Sharps suggested that number 40 be more specific to differentiate homicide of women and femicide. The dynamics between the two are very different and it would be helpful to have that distinction in the mortality reviews so that more can be learned about the perpetrators of pregnancy-related homicides. Dr. Palacios asked if there was a way to formalize the inclusion of key informants in mortality reviews. Dr. Kroelinger said that was an excellent suggestion and a Committee recommendation would be an impetus for CDC to identify funds to support it. There is often not much information about femicide in records and key informant interviews would provide essential context. Ms. Pettiford said that state legislation may not allow this data collection, but there could be language to strongly encourage it. Dr. Kroelinger pointed out that states may have limitations, but the tribes have the ability to interview their members and bring that information to the review committee. Ms. Thompson suggested including the maternal mortality reviews in the recommendation to prioritize the health of Indigenous mothers and infants.

Improve Care of Incarcerated Pregnant and Postpartum Women

Dr. Ramas suggested that number 45 include "identify standard for care and practices required in the provision of maternity care for incarcerated, pregnant, and postpartum people" and that number 46 include "that support evidence-based interventions surrounding physical, emotional,

mental, and cultural health that improve birth outcomes." She also suggested striking some of number 47 because it had been made clear that evaluating and expanding programs is important and adding a requirement of training and documentation of prison staff on the humane treatment of pregnant and postpartum women.

Dr. Ramas suggested four new recommendations: 1) encouraging breastfeeding, pumping, and lactation services for postpartum people; 2) reviewing and creating guidelines on accommodations for group support for pregnant and postpartum people on cultural resiliency within incarcerated settings; 3) creating a care management program to prepare incarcerated pregnant persons mentally and emotionally for intrapartum and postpartum transitions, both internally and externally; and 4) promoting mother-infant bonding delivery to prevent adverse outcomes. Dr Ehlinger suggested that some of these could be included as sub-recommendations under number 47. He also suggested including "as appropriate" in number 47 because there is not a lot of data for the programs.

Dr. Palacios said universal screening for substance use or domestic violence has repercussions to the community because children will be taken by Child Protective Services. This is a barrier to reporting and creates a perpetuating cycle that puts people back into at-risk situations that will involve self-medication and incarceration. There needs to be consideration for this in the recommendation for universal screening and mandated reporting. Dr. Ehlinger said that there are different ramifications for universal screening inside and outside of a prison environment. He suggested including text be sensitive to the challenges, such as specifying "where there is an active treatment program available" so that screening does not occur for the sake of screening but to identify something that can be treated. Dr. Palacios said that the implication is also about the taking away of the child's identity when they are removed from their family. Dr. Neyhart added that Alaska has returned the control to Alaska Natives so that they are not required to call protective services. This has resulted in better outcomes. She asked if there were mechanisms in the lower 48 states to avoid state interventions and give control to tribal courts. She added that number 47 should encourage the ceasing of automatic removal of a newborn from their mother's immediate care.

Dr. Peck said that jails tend to be under local jurisdiction and that the recommendations should be inclusive of all incarceration. She added her concern for conjugal visits and the potential for rape and suggested that there should be ongoing universal pregnancy tests beyond admission. Ms. Thompson suggested that including the term "sizable" might eliminate states with small AI/AN populations. The recommendation could be that each state has one or more facility with these programs. Dr. Menard agreed and said that the intent is to achieve access to these programs for everyone.

### Improve Treatment of Substance Use and Mental Health Problems

Dr. Ehlinger said that this issue is so expansive that it could not be adequately addressed in this set of recommendations. He suggested removing the section altogether and referencing the issue in the preamble as one that is essential and will be addressed in another set of recommendations. Dr. Peck agreed that it was important to address it as a critical issue that was receiving federal attention, some of which should be directed to AI/AN. Dr. Ehlinger sad that it could be a

recommendation for ACIMM to address it in more detail. Dr. Sharps said that what this section was missing models of trauma-informed care. If it was left out, then the preamble should reference models of trauma-informed care as culturally informed by key AI/AN stakeholders. It is also important in recommendations for universal screening and the potential for unintended consequences. Dr. Sander Lee suggested that this could be an opportunity to request data or information from HHS. Dr. Ehlinger said that it might be best to keep this section in but to add a recommendation that ACIMM or another agency look at the issue in more depth. There could be an explanation that more data, information, and expertise is needed to adequately address it.

Address Sudden Infant Death Syndrome and Sudden Unexpected Infant Death
Ms. Sharps suggested adding "key stakeholders and decision makers" as part of meaningful
consultation in number 53. Number 56 should include "support Indigenous practices." Numbers
58 and 59 might be best under the preamble with a reference to the Indigenous practices that
reduce risk.

## Finalize Recommendations and Next Steps

### **ACIMM Members**

Ms. Pettiford expressed concern over the number of recommendations and wondered if there was a way to consolidate some of them. Dr. Peck agreed and suggested that there be an executive summary as guidance for how to address the larger document with urgency. Dr. Ehlinger countered that it was not very overwhelming. There were five recommendation areas that could be highlighted in the transmittal letter and preamble. It would be difficult to leave anything out. Dr. Menard agreed that it is a lot of recommendations and that one important concept that is missing in the five recommendation areas is the need to transfer power and remove barriers that have been put in place by the dominant culture. Dr. Neyhart agreed and said that the framing should emphasize that the government has not fulfilled its promise, resulting in negative outcomes. A shift in power to tribes and appropriate funding will reduce these poor outcomes.

Dr Peck said that the concern is a trade-off between providing comprehensive recommendations and providing recommendations that will be read. The Committee should possibly seek consultation about how to ensure that the recommendations will be read and acted upon with accountability so that the effort is different than other reports that have been submitted. Dr. Palacios said that Dr. Warne had novel approaches for helping tribal entities access more funding. She suggested that these be expanded on within the recommendations.

Dr. Ehlinger concluded that no new recommendations will be added but there may be some paring down or repackaging. The key takeaways about historical trauma, intergenerational issues, racism, and power differentials will be highlighted. He will send the revision to the Committee with a plan to submit a final document to the Secretary before the November 2022 election.

## **Planning for December Virtual Meeting**

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

Ms. Vanessa Lee said that the next Committee meeting will be two consecutive days sometime between December 6-8, 2022 and will be virtual. She will send out a Doodle Poll to identify the best two consecutive days.

Dr. Peck stated that the three Committee Workgroups are still active and augmentable. There may be overlap with the Workgroups' discussions and these recommendations. Dr. Ehlinger invited Committee members to send their input to Workgroup Chairs or to himself.

## Adjourn

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

Dr. Ehlinger adjourned the meeting on September 15 at 12:30 ET.

### **Public Comments:**

#### **Nickolaus Lewis**

## Written Testimony of Nickolaus Lewis The Northwest Portland Area Indian Health Board September 12, 2022

My name is Nickolaus Lewis, and I serve as Secretary on the Lummi Indian Business Council, and as Chair of the Northwest Portland Area Indian Health Board (NPAIHB or Board). I thank the Committee for the opportunity to provide written testimony on infant and maternal mortality among American Indian and Alaska Native (AI/AN) people in the Northwest.

NPAIHB was established in 1972 and is a tribal organization under the Indian Self-Determination and Education Assistance Act (ISDEAA), P.L. 93-638, that advocates on behalf of the 43 federally-recognized Indian Tribes in Idaho, Oregon, and Washington on specific health care issues. The Board's mission is to eliminate health disparities and improve the quality of life of American Indians and Alaska Natives (AI/AN) by supporting Northwest Tribes in the delivery of culturally appropriate, high quality health care. "Wellness for the seventh generation" is the Board's vision.

## Maternal and Infant Mortality Rates Among AI/AN People

Nationally, AI/AN people had the second highest rate of pregnancy-related deaths of all race and ethnic groups from 2016 to 2018. Studies have found that the three leading causes of pregnancy related mortality among AI/AN people were: hemorrhage, cardiomyopathies, and hypertensive disorders of pregnancies. In Washington, AI/AN women had the highest maternal mortality ratios of all race and ethnicity groups. In Idaho, one of the five pregnancy associated deaths in 2019 was an AI/AN person.

Maternal morbidity is also alarming in the Northwest. Based on Washington CHARS data and race-corrected Oregon hospital discharge data, the rate of severe maternal morbidity at time of delivery among AI/AN women was 191 per 10,000 delivery hospitalizations in comparison to 120 per 10,00 among non-Hispanic white women. Factors that increased risk of severe maternal morbidity include: pre-eclampsia, hypertension, high risk age (under 20 or over 40), living in a completely or mostly rural county, and insufficient prenatal care.

Lastly, infant mortality rates in the Northwest is a growing public health concern. During 2017- 2019, AI/AN people in the U.S. had the second highest infant mortality rate compared to

<sup>&</sup>lt;sup>1</sup> https://www.cdc.gov/reproductivehealth/maternal-mortality/pregnancy-mortality-surveillance-system.htm

<sup>&</sup>lt;sup>2</sup> https://www.liebertpub.com/doi/10.1089/jwh.2020.8890

<sup>&</sup>lt;sup>3</sup> https://doh.wa.gov/sites/default/files/legacy/Documents/Pubs//141-010-MMRPMaternalDeathReport2014-2016.pdf

<sup>&</sup>lt;sup>4</sup> https://publicdocuments.dhw.idaho.gov/WebLink/DocView.aspx?id=20799&dbid=0&repo=PUBLIC-DOCUMENTS&cr=1

other race and ethnicity groups.<sup>5</sup> In Washington State, AI/AN people experience a significantly higher infant mortality rate compared to the state average.<sup>6</sup> During 2016-2020, the infant mortality rate among AI/AN people was 60% higher compared to the state average.<sup>7</sup> The leading causes of infant death among AI/AN people in Washington were: complications during labor and delivery (20%), infections (20%), Sudden Infant Death Syndrome (17%), Prematurity/Low Birth Weight (17%), and birth defects (13%).<sup>8</sup> In Idaho, the infant mortality rate among AI/AN people during 2017-2019 was 11.3 deaths per 1,000 live births, which was 2.5 times higher than the rate for White people in the state.<sup>9</sup>

### Recommendations to Address Maternal and Infant Mortality and Morbidity

Based on this alarming data of AI/AN maternal and infant mortality and morbidity, we make the following recommendations. The Committee must ensure that actions taken to address maternal and infant morbidity and mortality are holistic and culturally relevant, and include individual, family, community, and systems-level strategies. There must be early and equitable access to health care, including comprehensive reproductive health, prenatal, postnatal care services, and mental and behavioral health services.

In order to achieve early and equitable access to health care, the Indian health system must be fully funded. Tribal leaders estimate that full funding of the Indian Health Service (IHS) is around \$51 billion. Yet, in Fiscal Year 2022, the IHS was only funded at \$6.6 billion which is significantly below full funding. Additionally, in the Portland Area, we do not have an IHS or Tribal hospital and many of our outpatient programs have to refer out OBGYN and prenatal care. This means that Purchased/Referred Care (PRC) funding is crucial to addressing access to reproductive health, prenatal, and postnatal care services. In FY 2022, PRC received less than a 1% increase. When there is little increase and no consideration of population growth, Northwest Tribes are forced to cut essential health services.

Additionally, we recommend that Tribally-led Maternal Mortality Review Committees are funded and supported to understand local-level causes of maternal mortality, and/or ensure representation of Tribal and urban Indian communities in state-level Review Committees.

Maternal and Child Health (MCH) positions are crucial to addressing the infant and maternal mortality crisis facing Indian Country. An MCH position must be funded at each of the 12 Tribal Epidemiology Centers to assist with the development of MCH initiatives and to fund data scientists to perform ongoing linkage and analysis of MCH data to track efforts intended to improve pregnancy outcomes.

Lastly, we recommend that any additional research studies examining maternal and infant

<sup>&</sup>lt;sup>5</sup> https://www.marchofdimes.org/peristats/data?reg=99&top=6&stop=92&lev=1&slev=1&obj=1

<sup>&</sup>lt;sup>6</sup> Washington Community Health Assessment Tool

<sup>&</sup>lt;sup>7</sup> Id.

<sup>&</sup>lt;sup>8</sup> Id.

<sup>&</sup>lt;sup>9</sup> https://www.marchofdimes.org/peristats/data?reg=99&top=6&stop=94&lev=1&slev=4&obj=1&sreg=16

morbidity and mortality in AI/AN communities consider the following:

- Respect Tribal sovereignty and seek appropriate Tribal permission before conducting any research of Tribal communities;
- Meaningfully involve Tribal Nations as partners in research and
- Assess and address root causes of any disparities observed, including historical trauma, colonization, systemic racism, and the persistent underfunding of the Indian healthcare and public health systems; and
- Address issues related to data collection, analysis, and reporting that may result in the underreporting or misclassification of AI/AN people in administrative and surveillance systems, including those that measure maternal and infant morbidity and mortality.

### **Conclusion**

We thank you for the opportunity to provide testimony to the Committee. If you have any questions, please contact Elizabeth J. Coronado, Senior Policy Advisor, Northwest Portland Area Indian Health Board (NPAIHB) at <a href="mailto:ecoronado@npaihb.org">ecoronado@npaihb.org</a> or (5559) 289-9964.

## Ingrid Skop, MD

## Addressing the U.S. maternal mortality crisis: Looking beyond ideology Ingrid Skop, M.D.

### **Introduction:**

After years of failure to obtain accurate statistics on maternal mortality, researchers recently noted a sharp increase in the United States' maternal mortality with widening racial disparities. <sup>10</sup> Much discussion has followed about possible etiologies of the rise, but severe deficiencies in data collection and analysis are agreed upon by all. <sup>11</sup> Identification, review and prevention of maternal deaths remain critical but elusive goals despite seventy years of attention and effort. <sup>12</sup> Additionally, in the wake of the U.S. Supreme Court's recent *Dobbs vs Jackson Women's Health* decision to return induced abortion regulation back to the states' legislatures, resulting in implementation of legal induced abortion restrictions in many states, a common narrative has formed that these restrictions will worsen the problem of maternal mortality. <sup>13</sup> In order to discover effective strategies to improve the health of women surrounding pregnancy, it is imperative that we follow the science surrounding maternal mortality, even if it leads to uncomfortable conclusions.

As a practicing obstetrician/gynecologist in Texas for thirty years, I hope to convey what the maternal mortality crisis looks like from the perspective of a physician in the trenches. I have seen how this issue affects patients and their caregivers, and for years I have been digging deeper into the issue to uncover details that others may miss. As an advocate for both of my patients, a woman and her unborn child, I have become aware that there is much unreported maternal mortality and morbidity associated with legal induced abortion, often obscured due to the political nature of the issue.

While an observer might assume all maternal deaths occur due to catastrophic events at delivery, the reality is that there are many different causes, temporal relationships and pregnancy outcomes associated with maternal mortality. Maternal Mortality Review Committees (MMRCs) in the U.S. document that 25-38% of maternal deaths occur during pregnancy, 15-18% on the day of delivery, 18% in the week following, 18-21% one to six weeks after delivery, and 11-25% occurring more than six weeks but less than one year after the end of the pregnancy, demonstrating that only 1/3 of maternal deaths are due to complications at or shortly after

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<sup>&</sup>lt;sup>10</sup> MacDorman M, Declercq E, Cabral H, and Morton C. Recent Increases in the U.S. Maternal Mortality Rate: Disentangling Trends from Measurement Issues. Obstetrics & Gynecology 2016;128:447–55.

<sup>&</sup>lt;sup>11</sup> Joseph K, Lisonkova S, Muraca G, Razaz N, et al. Factors Underlying the Temporal Increase in Maternal Mortality in the U.S. Obstetrics & Gynecology 2017;129(1):91–100.

<sup>&</sup>lt;sup>12</sup> St. Pierre A, et al. Challenges and Opportunities in Identifying, Reviewing, and Preventing Maternal Deaths. Obstet Gynecol 2018;131:138–42.

<sup>&</sup>lt;sup>13</sup> Verma N, Shainker SA. Maternal mortality, abortion access and optimizing care in an increasingly restrictive United States: A review of the current climate. Seminars in Perinatology. 2020;151269:1-7; Morrison C. "End of Roe v. Wade expected to increase maternal mortality" Washington Examiner. July 6, 2022. Available at <a href="https://www.washingtonexaminer.com/most-recent-articles/2">https://www.washingtonexaminer.com/most-recent-articles/2</a>, accessed August 7, 2022.

delivery. 14 Only 60-66% of maternal deaths are associated with childbirth, implicating early pregnancy events in approximately 1/3 of maternal deaths. 15

I have personally cared for two women who died in proximity to pregnancy, and the reasons were surprising. One died from overwhelming sepsis after a legal second trimester prostaglandin infusion abortion. I held her hand in the ICU as she pleaded with me not to let her die, with fear in her eyes. The other patient was shot by her boyfriend in a murder suicide six weeks after a normal term delivery. It is likely that neither of these women's deaths came to the attention of the U.S. Centers for Disease Control and Prevention (CDC) or entered U.S. maternal mortality statistics. Like most physicians, at the time I was unaware that unless I alerted the CDC personally, they were unlikely to become aware of these deaths.

### **Definitions:**

Data on maternal mortality are compromised by the lack of uniform definitions among organizations responsible for collecting and analyzing maternal mortality data. Deaths are categorized based on their causation and proximity to the end of the pregnancy with lack of consistency in these determinations.

The broadest category is a "pregnancy-associated death": the death of a woman while pregnant or within 365 days (one year) of the end of pregnancy from any cause. Examples include both deaths due to complications of the pregnancy or its management, and deaths due to seemingly unrelated events, such as a car accident, cancer death or homicide, within a year of the pregnancy outcome. When these deaths come to the attention of organizations tasked with data collection and analysis, they are usually analyzed to determine if they should be categorized as pregnancy-related or merely pregnancy-associated.

Upon analysis, a death may be subcategorized a "pregnancy-related death": the death of a woman while pregnant or within 365 days (one year) of the end of pregnancy, irrespective of the duration or site of the pregnancy, from any cause related to or aggravated by the pregnancy or its management, excluding accidental or incidental causes. This category excludes deaths felt not to be caused by the pregnancy or its sequelae. An example would include a death from sepsis after premature rupture of membranes or cardiac decompensation in a woman with a pre-existing congenital cardiac malformation.

https://www.cdcfoundation.org/sites/default/files/files/ReportfromNineMMRCs.pdf, accessed August 7, 2022; Davis NL, Smoots AN, Goodman DA. Pregnancy-related deaths: Data from 14 U.S. Maternal Mortality Review Committees, 2008-2017. Atlanta GA: Centers for Disease Control and Prevention, U.S. Department of Health and Human Services; 2019. Available at https://www.cdc.gov/reproductivehealth/maternal-mortality/erase-mm/mmrdata-brief\_2019-h.pdf, accessed August 7, 2022.

<sup>&</sup>lt;sup>14</sup> Petersen, EE, Davis NL, Goodman D, et al. Pregnancy-related Deaths, United States, 2011-2015, and Strategies for Prevention, 13 States, 2013–2017. Morbidity and Mortality Weekly Report 2019;68:423–29. Available at www.cdc.gov/mmwr/volumes/68/wr/mm6818e1.htm?s\_cid½mm6818e1\_w, accessed August 7, 2022; Brantley MD, Callaghan W, Cornell A, et al. 2018. Building U.S. Capacity to Review and Prevent Maternal Deaths: Report from Nine Maternal Mortality Review Committees. MMRIA. Atlanta, GA: Centers for Disease Control and Prevention, US Department of Health and Human Services. Available at

<sup>&</sup>lt;sup>15</sup> Curtin SC, Abma JC, Ventura SC. NCHS Data Brief No. 136, December 2013. Centers for Disease Control and Prevention, National Center for Health Statistics, Atlanta. Available at https://www.cdc.gov/nchs/data/databriefs/db136.pdf, accessed August 7, 2022; Burgess AP, Dongarwar D, Spigel Z, et al. Pregnancy-related mortality in the United States,2003-2016: age, race, and place of death. Am J Obstet Gynecol. 2020;222:489.e8.

Pregnancy-related deaths may be "direct"-resulting from obstetric complications (as in the first example), or "indirect"-resulting from preexisting disease or disease that developed during pregnancy; not due to direct obstetric causes but aggravated by the physiologic effects of pregnancy (as in the second example).

Pregnancy-related deaths are further divided into a "maternal death": the death of a woman while pregnant or within forty-two days (six weeks) of the end of her pregnancy, in which pregnancy or its management may have contributed to the cause of death. This could include a new disease caused by the pregnancy such as preeclampsia, ectopic pregnancy or pulmonary embolus, a chronic disease worsened by the physiologic effects of the pregnancy such as decompensation of cardiac disease, or hemorrhage due to a surgical mishap during a cesarean section, as long as the death occurred during pregnancy or within six weeks of the end of pregnancy.

A "late maternal death" is the death of a woman from direct or indirect obstetric causes more than 42 days (six weeks) but within 365 days (one year) of the end of pregnancy. An example would include a death due to heart failure from postpartum cardiomyopathy two months after delivery or a woman who died after a prolonged course in the ICU resulting from complications at delivery.

The World Health Organization (WHO) and the CDC's National Vital Statistics System (NVSS) define maternal mortality as a pregnancy-related death occurring **within six weeks** of a pregnancy (maternal deaths only). <sup>16</sup> The CDC's Pregnancy Mortality Surveillance System PMSS defines maternal mortality as a pregnancy-related death occurring until **one year** after the pregnancy ends (maternal deaths plus late maternal deaths). <sup>17</sup> Neither system counts pregnancy-associated but not pregnancy-related deaths in their data collection. Additional categories may include "not pregnancy associated or related" (false positives) or "unable to determine if pregnancy related or associated".

Different pregnancy outcomes can also be subcategorized. Of particular interest is an "abortion-related death": any death from a direct complication of an induced abortion (legal or illegal), an indirect complication caused by a chain of events initiated by an abortion, or an aggravation of a pre-existing medical condition by the physiologic or psychologic effects of abortion without any time limit, reflecting the fact that there is no clear temporal limit on physiological and psychological effects after abortion that may contribute to subsequent death. <sup>18</sup> Best practices for identifying maternal deaths:

World Health Organization. (2004) ICD-10: International Statistical Classification Disease and Related Health Problems: Tenth Revision. WHO, Geneva; WHO Working Group on Maternal Mortality and Morbidity Classification. 2012. "The WHO Application of ICD-10 to Deaths during Pregnancy, Childbirth and the Puerperium." 25–27. Available at https://apps.who.int/iris/bitstream/handle/10665/70929/9789241548458\_eng.pdf, accessed August 7, 2022; Hoyert DL. National Center for Health Statistics. Maternal mortality rates in the United States, 2020. Available at https://www.cdc.gov/nchs/data/hestat/maternal-mortality/2020/E-stat-Maternal-Mortality-Rates-2022.pdf, accessed August 8, 2022.

<sup>&</sup>lt;sup>17</sup> Petersen, EE, Davis NL, Goodman D, et al. Pregnancy-related Deaths, United States, 2011-2015, and Strategies for Prevention, 13 States, 2013–2017. Morbidity and Mortality Weekly Report 2019;68:423–29. Available at www.cdc.gov/mmwr/volumes/68/wr/mm6818e1.htm?s\_cid<sup>1</sup>/4mm6818e1\_w, accessed August 7, 2022 <sup>18</sup> Kortsmit K, Mandel MG, Reeves JA, et al. Abortion Surveillance-United States, 2019. MMWR Surveill Summ 2021;70(No. SS-9):1-29. Available at <a href="https://www.cdc.gov/mmwr/volumes/70/ss/ss7009a1.htm">https://www.cdc.gov/mmwr/volumes/70/ss/ss7009a1.htm</a>, accessed August 8, 2022; Cates W, et al. Mortality from abortion and childbirth: are the statistics biased? Journal of the American Medical Association. 1982;248:192-196.

The most comprehensive way to detect all maternal mortality would be to link all death certificates from women of reproductive age with all pregnancy outcomes (as documented on infant birth certificates and fetal loss certificates), to determine the total number of deaths for each pregnancy outcome within a defined time period of a deceased woman's most recent pregnancy. This methodology has been utilized in Scandinavian countries which have single payer healthcare and meticulous record-keeping, so that all pregnancy events are detected and all complications and deaths from those events are known. <sup>19</sup> Once all pregnancy-associated deaths have been detected, then investigation of causality can determine the subset that is pregnancy-related.

Comprehensive records-linkage studies from Finland demonstrate a fact that will implicate the accuracy of the U.S. CDC data drawn primarily from death certificates. In Finland, death certificate documentation alone detects only 26% of deaths after a live birth or stillbirth, 12% of deaths following miscarriage or ectopic pregnancy, and just 1% of deaths following induced abortion. Records-linkage determination of maternal mortality is far superior to death certificate identification.

### Process of maternal mortality determination in the U.S.:

In the U.S., the maternal mortality data collection process is initiated by attending physicians, funeral directors, coroners and medical examiners at a local level with completion of maternal death certificates. Some states are divided geographically into local registration districts which collect and then submit data to state agencies, whereas others require submission directly to the state vital statistics office.<sup>21</sup>

These death certificates are then provided by the state's vital statistics office to the CDC's National Center for Health Statistics (NCHS) which compiles national data and assigns WHO International Classification of Diseases (ICD) codes to create a "maternal mortality ratio", defined as maternal deaths while pregnant or within 42 days postpartum compared to 100,000 live births. It then publishes a National Vital Statistics System (NVSS) Report titled, "Deaths: Final Data". This provides data which can be compared internationally with other countries utilizing ICD coding but is limited for purposes of analysis due to the paucity of data provided on a death certificate. <sup>23</sup>

The CDC also receives maternal mortality data from its National Center for Chronic Disease Prevention and Health Promotion's Pregnancy Mortality Surveillance System (PMSS) which was developed in 1988. The PMSS uses a pregnancy checkbox on death certificates (asking whether the woman was pregnant at the time of death or had been pregnant within the past year), or occasionally uses linked maternal death and infant birth certificates in order to identify deaths.

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<sup>&</sup>lt;sup>19</sup> Gissler M, Berg C, Bouvier-Colle M, et al, Methods for identifying pregnancy-associated deaths: population-based data from Finland 1987-2000. Paediatr Perinat Epidemiol 2004;18(6):448-455.

<sup>&</sup>lt;sup>20</sup> Gissler M, Berg C, et al, Pregnancy Associated Mortality After Birth, Spontaneous Abortion or Induced Abortion in Finland. 1987-2000. American Journal of Obstet Gynecol. 2004;190:422-427.

<sup>&</sup>lt;sup>21</sup> Physicians Handbook on Medical Certification of Death. Available at https://www.cdc.gov/nchs/data/misc/hb\_cod.pdf, assessed July 20, 2022.

<sup>&</sup>lt;sup>22</sup> Brantley, MD, Callaghan W, Cornell A, et al. 2018. Building U.S. Capacity to Review and Prevent Maternal Deaths: Report from Nine Maternal Mortality Review Committees. MMRIA. Atlanta, GA: Centers for Disease Control and Prevention, US Department of Health and Human Services. Available at https://www.cdcfoundation.org/sites/default/files/files/ReportfromNineMMRCs.pdf, accessed August 7, 2022.

<sup>&</sup>lt;sup>23</sup> St. Pierre A, et al. Challenges and Opportunities in Identifying, Reviewing, and Preventing Maternal Deaths. Obstet Gynecol 2018;131:138–42.

Epidemiologists then analyze the death records to determine pregnancy-relatedness, producing a national "pregnancy-related mortality ratio". 24

In order to develop more detailed recommendations for action, multi-disciplinary Maternal Mortality Review Committees (MMRCs) have convened at local, state, regional and federal levels to comprehensively review reported maternal deaths, utilizing data from multiple sources, including medical records, social records, autopsy reports, and informant interviews. The MMRCs submit their conclusions to state level Perinatal Quality Collaboratives (PQC) to support the implementation of their recommendations of best clinical practice in hospitals, which often include additional screening, communication, training, access to care, and management of mental health conditions.<sup>25</sup>

Organizations such as the Alliance for Innovation on Maternal Health, the American College of Obstetricians and Gynecologists (ACOG) and the California Maternal Quality Care Collaborative have developed toolkits to assess risk and provide preventative treatment of hypertensive disorders, hemorrhage, sepsis, and thromboembolism, and these have been enacted in many hospitals. Additionally, the Levels on Care Assessment Tool evaluates appropriateness of care depending on resources available in individual hospitals to give guidance on when maternal transfer may be indicated depending on hospital resources.<sup>26</sup> In order to address increasing late maternal mortality, ACOG's Optimizing Postpartum Care Recommendations advise contact with a care team within three weeks postpartum and extending insurance coverage for a full year postpartum, with mental health screening and referrals as appropriate.<sup>27</sup> The CDC's Division of Reproductive Health has initiated the "Building U.S. Capacity to Review and Prevent Maternal Deaths" initiative to provide tools and training for data review and sharing and development of best practices to assist MMRCs. 28 The Maternal Mortality Review Information Application (MMRIA) has been created as a repository for standardized data generated by these committees, reported as local or state "pregnancy-related mortality ratios". 29 Because relatively few deaths occur in individual states and not all states have active MMRCs,

Petersen, EE, Davis NL, Goodman D, et al. Pregnancy-related Deaths, United States, 2011-2015, and Strategies for Prevention, 13 States, 2013–2017. Morbidity and Mortality Weekly Report 2019;68:423–29. Available at www.cdc.gov/mmwr/volumes/68/wr/mm6818e1.htm?s\_cid½mm6818e1\_w, accessed August 7, 2022
 Report from maternal mortality review committees: A view into their critical role. Available at <a href="https://www.cdcfoundation.org/sites/default/files/upload/pdf/MMRIAReport.pdf">https://www.cdcfoundation.org/sites/default/files/upload/pdf/MMRIAReport.pdf</a>, accessed September 6, 2022.
 Improving diagnosis and treatment of maternal sepsis. Available at <a href="https://www.cmqcc.org/sites/default/files/Sepsis%20Toolkit\_FINAL.2\_Errata\_7.1.22.pdf">https://www.cmqcc.org/sites/default/files/Sepsis%20Toolkit\_FINAL.2\_Errata\_7.1.22.pdf</a>, accessed August 7, 2022;

Improving health care response to maternal venous thromboembolism. Available at https://www.cmqcc.org/resources-toolkits/toolkits/improving-health-care-response-maternal-venous-thromboembolism, accessed August 7, 2022; Obstetric hemorrhage toolkit. Available at https://www.cmqcc.org/resources-tool-kits/toolkits/ob-hemorrhage-toolkit, accessed August 7, 2022; Hypertensive disorders of pregnancy toolkit. Available at https://www.cmqcc.org/resources-tool-kits/toolkits/HDP, accessed August 7, 2022.

<sup>&</sup>lt;sup>27</sup> Minnesota maternal mortality report 2017-2018. Available at <a href="https://www.health.state.mn.us/docs/people/womeninfants/maternalmort/maternalmortreport.pdf">https://www.health.state.mn.us/docs/people/womeninfants/maternalmort/maternalmortreport.pdf</a>, accessed September 6, 2022.

<sup>&</sup>lt;sup>28</sup> Building U.S. capacity to review and prevent maternal deaths. Available at <a href="https://www.cdcfoundation.org/building-us-capacity-review-and-prevent-maternal-deaths">https://www.cdcfoundation.org/building-us-capacity-review-and-prevent-maternal-deaths</a>, accessed September 6, 2022

<sup>&</sup>lt;sup>29</sup> Maternal mortality review information application-MMRIA. Available at <a href="https://reviewtoaction.org/tools/mmria">https://reviewtoaction.org/tools/mmria</a>, accessed September 6, 2022.

regional committees have been able to collate greater amounts of data to produce recommendations for action.

Yet not all states are active participants, and published recommendations come from relatively small groups of MMRCs. A nine-state committee composed of Colorado, Delaware, Georgia, Hawaii, Illinois, North Carolina, Ohio, South Carolina, Utah and Virginia released a report in 2018 analyzing data from 2008-2017, although not all states contributed data for each year. They were joined by Arizona, Florida, Louisiana, Mississippi, Tennessee and Utah (minus Virginia) to release a fourteen-state report in 2019 analyzing data from 2008-2017. Additionally, a thirteen-state coalition of the same states (minus Virginia, including DC and NYC) also released a collaborative report in 2019 of data from 2011-2015. 32

### U.S. data deficiencies: Unknown numerator of maternal deaths:

The CDC relies primarily upon the individual states' vital statistics death certificate documentation (via ICD death codes or pregnancy checkboxes), or deaths that happen to come to its attention from other sources, in order to calculate maternal mortality statistics. The CDC states it also searches for additional deaths through hospital discharge data, media reports and obituary searches, but it is not documented how systematically, proactively and vigorously they seek to find additional maternal deaths.<sup>33</sup> Concerns about the inadequacy of the CDC's ad hoc system for identifying abortion-related deaths is underscored by the fact that in a given ten-year time span, a single journalist identified 39% more abortion-related deaths from court records and autopsies alone than were identified by CDC.<sup>34</sup>

Differentiating pregnancy-related from pregnancy-associated deaths can be difficult and prone to interpretation or bias. There are not nationwide comprehensive protocols for making such

https://www.cdc.gov/nchs/data/misc/hb\_cod.pdf, assessed July 20, 2022; Brantley, MD, Callaghan W, Cornell A, et al. 2018. Building U.S. Capacity to Review and Prevent Maternal Deaths: Report from Nine Maternal Mortality Review Committees. MMRIA. Atlanta, GA: Centers for Disease Control and Prevention, US Department of Health and Human Services. Available at

https://www.cdcfoundation.org/sites/default/files/files/ReportfromNineMMRCs.pdf, accessed August 7, 2022; Hoyert DL. National Center for Health Statistics (US-NCHS-CDC). Maternal Mortality and Related Concepts. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics, Hyattsville. Vital Health Stat 3. 2007;33:1-13; Hoyert DL. National Center for Health Statistics. Maternal mortality rates in the United States, 2020. Available at https://www.cdc.gov/nchs/data/hestat/maternal-mortality/2020/E-stat-Maternal-Mortality-Rates-2022.pdf, accessed August 8, 2022

<sup>34</sup> Reardon D, Strahan T, and Thorp J. Deaths Associated with Abortion Compared to Childbirth-A Review of New and Old Data and the Medical and Legal Implications. J. Contemp. Health Law & Policy. 2004;20(2):1-51; Mark Crutcher. Lime 5: Exploited by Choice. Life Dynamics, Inc. Denton, TX. 1996.

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<sup>&</sup>lt;sup>30</sup> Brantley, MD, Callaghan W, Cornell A, et al. 2018. Building U.S. Capacity to Review and Prevent Maternal Deaths: Report from Nine Maternal Mortality Review Committees. MMRIA. Atlanta, GA: Centers for Disease Control and Prevention, US Department of Health and Human Services. Available at <a href="https://www.cdcfoundation.org/sites/default/files/files/ReportfromNineMMRCs.pdf">https://www.cdcfoundation.org/sites/default/files/files/ReportfromNineMMRCs.pdf</a>, accessed August 7, 2022.
<sup>31</sup> Davis NL, Smoots AN, Goodman DA. Pregnancy-related deaths: Data from 14 U.S. Maternal Mortality Review Committees, 2008-2017. Atlanta GA: Centers for Disease Control and Prevention, U.S. Department of Health and Human Services; 2019. Available at <a href="https://www.cdc.gov/reproductivehealth/maternal-mortality/erase-mm/mmr-data-brief">https://www.cdc.gov/reproductivehealth/maternal-mortality/erase-mm/mmr-data-brief</a> 2019-h.pdf, accessed August 7, 2022.

Petersen, EE, Davis NL, Goodman D, et al. Pregnancy-related Deaths, United States, 2011-2015, and Strategies for Prevention, 13 States, 2013–2017. Morbidity and Mortality Weekly Report 2019;68:423–29. Available at www.cdc.gov/mmwr/volumes/68/wr/mm6818e1.htm?s\_cid<sup>1</sup>/<sub>4</sub>mm6818e1\_w, accessed August 7, 2022. Physicians Handbook on Medical Certification of Death. Available at

determinations, leaving the process susceptible to reviewer preferences. Determining pregnancy relatedness is particularly difficult in the case of mental health or accidental deaths. Even cancer-related deaths can be problematic, as treatment options may have been limited or modified based on pregnancy status, resulting in potentially different outcomes. In such cases, the MMRC may simply note that it was unable to determine pregnancy-relatedness. Likewise, determinations about the effect of pregnancy on chronic health conditions may be difficult to delineate, especially as time progresses from the end of a pregnancy.<sup>35</sup>

For example, those who believe that mental health complications often follow abortion might conclude that a suicide following an induced abortion is related to that event, whereas those who believe mental health complications cannot be caused by abortion would reject this interpretation. Even regarding term births, researchers often will not consider mental health deaths to be pregnancy-related unless there is clear documentation in the obstetric record that the woman was distressed by her pregnancy.<sup>36</sup>

The numbers of deaths reported by the CDC's two different systems-National Vital Statistics System and Pregnancy Mortality Surveillance System-have differed dramatically. A 2005 article documented that only half of maternal deaths were reported in both systems. For the years 1995-1997, the NVSS reported 898 maternal deaths, because they did not classify a death as maternal if it was coded outside a specific ICD-9 range (630-676), while the more inclusive PMSS reported 1387 pregnancy-related deaths. The authors concluded that changes in guidelines for coding maternal deaths under ICD-10 might improve data collection. Additional codes became available with implementation of ICD-10 in 2015, resulting in additional deaths being reported, but there is no evidence that this has resulted in better correlation between PMSS and NVSS numbers since that time.<sup>37</sup>

Studies estimate 39-93% of all U.S. maternal deaths are not reported as pregnancy-associated on death certificates, and the secrecy associated with induced abortion reporting makes it likely that the problem is even worse with abortion-related deaths.<sup>38</sup> While MMRCs have concluded that more thorough data collection could be obtained by linking death certificates of reproductive aged women with infant birth or death certificates, this is rarely performed. Additionally, the lack of any mandatory documentation of induced or spontaneous pregnancy losses prior to twenty weeks gestation leaves deaths associated with early pregnancy events unobtainable through records-linkage.<sup>39</sup>

<sup>&</sup>lt;sup>35</sup> St. Pierre A, et al. Challenges and Opportunities in Identifying, Reviewing, and Preventing Maternal Deaths. Obstet Gynecol 2018;131:138–42.

Hoyert DL. National Center for Health Statistics. Maternal mortality rates in the United States, 2020. Available at https://www.cdc.gov/nchs/data/hestat/maternal-mortality/2020/E-stat-Maternal-Mortality-Rates-2022.pdf, accessed August 8, 2022; Hoyert DL. National Center for Health Statistics. Maternal Mortality and Related Concepts. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics, Hyattsville. Vital Health Stat 3. 2007;33:1-13. (determining pregnancy relatedness)
 MacKay A, Berg CJ, Duran C, et al. An assessment of pregnancy-related mortality in the U.S. Pediatric & Perinatal Epidemiology 2005;19:206–214; Hoyert. Maternal Mortality and Related Concepts. Vital & Health Statistics. Series 3, Analytical and Epidemiological Studies. 2007;33:1-13. Available at https://europepmc.org/article/med/17460868, accessed August 9, 2022.

<sup>&</sup>lt;sup>38</sup> Horon IL, Cheng D, Chang J, et al. Underreporting of Maternal Deaths on Death Certificates and the Magnitude of the Problem of Maternal Mortality. AJ of Public Health. 2005;95:478-82; Dye TD, Gordon H. Retrospective maternal mortality case ascertainment in West Virginia, 1985 to 1989. Am J Obstet Gynecol. 1992;167(1)72-6.

<sup>39</sup> Report from maternal mortality review committees: A view into their critical role. Available at https://www.cdcfoundation.org/sites/default/files/upload/pdf/MMRIAReport.pdf, accessed September 6, 2022.

To address maternal mortality data deficiencies, 40 a pregnancy checkbox was added to death certificates in 2003, but was unevenly implemented by the states, resulting in no official published U.S. maternal mortality ratio from 2007 to 2016.<sup>41</sup> Even after addition of the pregnancy checkbox, its inappropriate use has been documented. Investigators discovered that the pregnancy checkbox was often falsely marked when no evidence of a related pregnancy could be documented. A study group of nine MMRCs found a death certificate false positive rate of thirteen percent. In 119 of 850 potential pregnancy-associated deaths they were unable to document a preceding pregnancy.<sup>42</sup> In Texas, where the greatest increase in maternal mortality among the states was identified, The Texas Maternal Mortality Task Force discovered through records review that more than fifty percent of the "maternal deaths" identified by pregnancy checkbox showed no evidence of a preceding pregnancy, and another ten percent had insufficient information to determine whether a pregnancy had occurred.<sup>43</sup> In fact, nationally in 2018, 147 death certificates of women > 85 years old had a positive checkbox indicating a pregnancy within the past year!<sup>44</sup> It is undocumented whether any of these MMRCs attempted to obtain abortion clinic records and whether lack of this information may have contributed to the difficulty in documenting preceding pregnancies.<sup>45</sup> Conversely, however, the pregnancy checkbox did improve detection of some maternal deaths on death certificates. Without the checkbox, 50% of pregnancy-related deaths during pregnancy, 11% of deaths within six weeks of pregnancy and 8% of deaths occurring six weeks to one year after the end of pregnancy would have been missed.<sup>46</sup>

Following are additional reasons that maternal deaths, particularly those following induced abortion, may not be documented on death certificates and fail to come to the attention of the CDC:

- 1. **Preceding pregnancy not known:** Often, maternal deaths are separated from the end of pregnancy by weeks or even months. Unless the woman is pregnant at the time of death, the death certifier may not have knowledge of any preceding spontaneous or induced abortions. In many cases, even a live birth within the prior year may be unknown.
- 2. **Initiating pregnancy event known but not documented:** It is recommended that the cause of death section of a death certificate include the immediate cause of death and

MacDorman M, Declercq E, Cabral H, and Morton C. Recent Increases in the U.S. Maternal Mortality Rate: Disentangling Trends from Measurement Issues. Obstetrics & Gynecology 2016;128:447–55.

<sup>&</sup>lt;sup>41</sup> Horon IL, Cheng D. Effectiveness of pregnancy checkboxes on death certificates in identifying pregnancy-associated mortality. Public Health Rep. 2011;126(2):195-200.

<sup>&</sup>lt;sup>42</sup> Brantley MD, Callaghan W, Cornell A, et al. 2018. Building U.S. Capacity to Review and Prevent Maternal Deaths: Report from Nine Maternal Mortality Review Committees. MMRIA. Atlanta, GA: Centers for Disease Control and Prevention, US Department of Health and Human Services. Available at https://www.cdcfoundation.org/sites/default/files/files/ReportfromNineMMRCs.pdf, accessed August 7, 2022.

<sup>43</sup> Baeva S, Saxton D, Ruggiero K, et al. Identifying Maternal Deaths in Texas Using an Enhanced Method

<sup>&</sup>lt;sup>43</sup> Baeva S, Saxton D, Ruggiero K, et al. Identifying Maternal Deaths in Texas Using an Enhanced Method. Obstetrics & Gynecology 2018;131:762–769.

<sup>&</sup>lt;sup>44</sup> Hoyert DL. National Center for Health Statistics. Maternal mortality rates in the United States, 2020. Available at https://www.cdc.gov/nchs/data/hestat/maternal-mortality/2020/E-stat-Maternal-Mortality-Rates-2022.pdf, accessed August 8, 2022.

<sup>&</sup>lt;sup>45</sup> Baeva S, Saxton D, Ruggiero K, et al. Identifying Maternal Deaths in Texas Using an Enhanced Method. Obstetrics & Gynecology 2018;131:762–769.

<sup>&</sup>lt;sup>46</sup> Report from Maternal Mortality Review Committees: A view into their critical role. Available at <a href="https://www.cdcfoundation.org/sites/default/files/upload/pdf/MMRIAReport.pdf">https://www.cdcfoundation.org/sites/default/files/upload/pdf/MMRIAReport.pdf</a>, accessed September 6, 2022.

underlying causes in Part One, and reporting of all other significant diseases, conditions or injuries that may have contributed to death in Part Two. 47 In many deaths due to catastrophic events at delivery, a cascade of events may result in death, but only the most proximate events may be listed on the death certificate. For example, arrest of dilation in labor > C-section delivery > injury of uterine vessels > hemorrhage > hypotension from blood loss > cerebral vascular event (stroke) from hypoperfusion. Dysfunctions in multiple organ systems may cumulatively lead to death: hemorrhage > disseminated intravascular coagulation (DIC) > thromboembolism (clots) > pulmonary embolus. Hypoperfusion from hemorrhage could also lead to cardiac damage > cardiac dysfunction > myocardial infarction (heart attack). The same woman could experience all the adverse outcomes noted above after a hemorrhage. With so many events occurring, it is easy to see how the initiating events might be omitted due to space limitations on the death certificate or provider time constraints. It is not unusual for documentation of a maternal death to record the immediate cause of death (for example, embolism, sepsis or hemorrhage) without mention of initiating event (for example, legal induced abortion). Thus, depending on how a death certificate is completed, the cause of death might be listed as "hemorrhage", when it should more accurately be reported as "legal induced abortion", without which the hemorrhage would never have occurred. A well-publicized case from New Mexico documents that Keisha Atkins died while undergoing an abortion at 24 weeks gestation. She developed a uterine infection and rapidly decompensated. She was taken to the operating room for completion of the abortion where she died of a cardiac arrest. Her death certificate lists her cause of death as "pulmonary embolism due to pregnancy". 48 Based on this diagnosis, her death would be recorded by the CDC as a pregnancy-related death, not an abortion-related death.

- 3. **Technologic limitations:** Physicians may have difficulty operating the complex electronic death registries, particularly if they use the systems infrequently or have technologic limitations, which may lead to incomplete documentation. The electronic medical record search engine may fail to discover the limited O-codes that document obstetric death. For example, the Texas "TxEVER" death registration system requires the funeral home to initiate the death record process, then notify the medical certifier to complete the medical data entry. Often the certifier is given only a short period of time to complete the document, and the physician may complete the certificate with incomplete recollection of the events or without access to autopsy results.<sup>49</sup>
- 4. **Incomplete or unavailable autopsy results:** It should be noted that autopsies are not mandated after a suspected maternal death, nor is there a standardized protocol for

<sup>&</sup>lt;sup>47</sup> Physicians Handbook on Medical Certification of Death. Available at https://www.cdc.gov/nchs/data/misc/hb cod.pdf, assessed July 20, 2022.

<sup>&</sup>lt;sup>48</sup> Keisha Adkins' autopsy report. Available at <a href="https://abortiondocs.org/wp-content/uploads/2017/08/Autopsy-Report-Keisha-Atkins.pdf">https://abortiondocs.org/wp-content/uploads/2017/08/Autopsy-Report-Keisha-Atkins.pdf</a>, accessed August 31, 2022.

<sup>&</sup>lt;sup>49</sup> TxEVER User Guides. Available at <a href="https://www.dshs.texas.gov/vs/partners/txever-guides/">https://www.dshs.texas.gov/vs/partners/txever-guides/</a>, accessed September 6, 2022.

- performing an autopsy. For example, toxicology testing is often not performed after an accidental or mental health maternal death.<sup>50</sup>
- 5. Mental health related deaths are often not considered to be pregnancy-related: Epidemiologists determining pregnancy-relatedness may not consider a mental health related death to be related to the pregnancy outcome, even though the way the pregnancy was resolved may have contributed to the death (such as a stillbirth or coerced abortion leading to suicide). A traumatic pregnancy outcome may worsen or initiate interpersonal or maladaptive behaviors, which can cause diminished mental or physical health, and eventually lead to death. Anxiety and depression may lead to self-harm and high-risk taking behavior, resulting in deaths from suicide, homicide, fatal accidents, substance abuse and overdoses.<sup>51</sup>
- 6. **Complete medical records are often unavailable:** State and local MMRCs are provided with maternal death certificates and can usually obtain hospital or obstetric clinic records for review, but records related to early pregnancy events such as a miscarriage occurring outside of a hospital or an induced abortion (often performed in an independent abortion clinic, or with pills obtained outside of the medical system) are usually not available to MMRCs. Since most induced abortions are paid for privately rather than through insurance, one cannot link insurance payment records to detect adverse events related to abortion. <sup>52</sup>
- 7. Coding deficiencies related to induced abortion are common: According to the National Center for Health Statistics, "the number of maternal deaths does not include all deaths occurring to pregnant or recently pregnant women, but only those deaths with the underlying cause of death assigned to International Statistical Classification of Diseases, 10th Revision code numbers A34, O00–O95, and O98–O99."<sup>53</sup> A perusal of the WHO ICD-10 coding book documents few codes related to complications or deaths from legal induced abortion: O03=spontaneous abortion, O04=medical abortion, O05=other abortion, O06=unspecified abortion, O07=failed attempted abortion. A code is lacking for surgical abortion, even though most abortion deaths from physical complications occur following surgical abortion, leaving the coder to choose between the imprecise categories of "other" or "unspecified" abortion. Each code can be made more precise by adding numbers after the decimal: 0.0-0.4=incomplete, that is the death occurred before

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<sup>&</sup>lt;sup>50</sup> Quesinberry D, Bunn TL, Hargrove S, Slavova S. Impact of a drug overdose toxicology testing legislative mandate on informing coroner death investigation and certification practices. Acad Forensic Pathology. 2019;9(1-2):66-80.

<sup>&</sup>lt;sup>51</sup> Karalis E, et al. Decreasing mortality during pregnancy and for a year after while mortality after termination of pregnancy remains high: a population-based register study of pregnancy associated deaths in Finland 2001-2012. BJOG. 2017;124:1115-1121; Gissler M. et al. Injury deaths, suicides and homicides associated with pregnancy, Finland 1987-2000. Eur J of Public Health. 2005;15(5):459-463.

<sup>&</sup>lt;sup>52</sup> State funding of abortion under Medicaid. Available at <a href="https://www.guttmacher.org/state-policy/explore/state-funding-abortion-under-medicaid">https://www.guttmacher.org/state-policy/explore/state-funding-abortion-under-medicaid</a>, accessed September 6, 2022.

<sup>53</sup> WHO Working Group on Maternal Mortality and Morbidity

Classification. 2012. "The WHO Application of ICD-10 to Deaths during Pregnancy, Childbirth and the Puerperium." 25–27. Available at https://apps.who.int/iris/bitstream/handle/10665/70929/9789241548458\_eng.pdf, accessed August 7, 2022.

the pregnancy tissue was completely removed or 0.5-0.9=complete or unspecified, that is the death occurred after completion of the procedure or timing not known. Specifically, adding 0.5=complete or unspecified abortion complicated by genital tract and pelvic infection, 0.6=complicated by delayed or excessive hemorrhage, 0.7=complicated by embolism, 0.8=with other or unspecified complications, and 0.9=without complication. Strangely, it seems intuitive that an "induced abortion without complication" would not result in a maternal death, which is undoubtedly the worst kind of complication, and this code would be unnecessary. Additional codes related to deaths following cardiac, anesthetic or mental health complications do not exist.<sup>54</sup>

- 8. Induced abortion complications may be miscoded as resulting from spontaneous abortion (miscarriage): If death occurs following a legal induced abortion, even if a preceding pregnancy is identified, the certifier may mistakenly believe a spontaneous and not induced abortion preceded death. Abortion providers often do not maintain hospital privileges, so when serious complications occur after induced abortion, frightened women often present to an emergency room rather than return to the abortion clinic.<sup>55</sup> Other physicians will then provide emergent care but may be unaware that the pregnancy loss was induced rather than spontaneous if the woman withholds that information, or the physician may be hesitant to ask a woman specifically if she had an abortion. There is also often a failure to distinguish between legal and illegal induced abortion complications as many states have imposed abortion restrictions and illegal medical abortion pills are widely available. A study of all Medicaid financed abortions in seventeen states documented that in 2015, 61% of women presenting for emergency care for complications following a legal induced medical abortion and 39% presenting following surgical abortion complications were miscoded as having had a spontaneous abortion. An analysis of the FDA's Adverse Event Reports (AERs) data for medical abortions revealed that only 40% of surgical procedures for failed medical abortions were provided by the abortion provider, demonstrating the frequency with which abortion providers are unavailable to care for their complications.<sup>56</sup>
- 9. **Induced abortion history may be intentionally concealed:** Abortion-related deaths may be concealed (if the abortion is known) by the family to protect the deceased family member and family from shame.
- 10. And finally, due to the political nature of abortion, ideologic commitments may cause the death certifier to omit notation of induced abortion as the precipitating event. This discussion makes it clear that reported abortion-related mortality data probably represents only the tip of the iceberg.

<sup>&</sup>lt;sup>54</sup> WHO ICD 10 Coding Manual. Available at https://www.icd10data.com/, accessed August 7, 2022.

<sup>55</sup> Studnicki J, Longbons T, Fisher J, et al. Doctors who perform abortions: Their characteristics and patterns of holding and using hospital admitting privileges. Health Serv Res Manag Epidemiol 2019;6:1-8.

<sup>&</sup>lt;sup>56</sup> Studnicki J, Harrison DJ, Longbons T, et al. A Longitudinal Cohort Study of Emergency Room Utilization Following Mifepristone Chemical and Surgical Abortions, 1999-2015. Health Services Research and Managerial Epidemiology. 2021;8:1-11; Aultman K, Cirucci CA, Harrison DJ, et al. Deaths and severe adverse events after the use of mifepristone as an abortifacient from September 2000 to February 2019. Issues Law Med 2021;36(1):3-26.

## US data deficiencies: Unknown denominator of all pregnancy events:

Ideally, the CDC would report a "maternal mortality rate" comparing all maternal deaths to the total number of pregnancies, for a true analysis of "at-risk" individuals. It could also compare risks for different pregnancy outcomes by calculating rates specific for childbirth, induced abortion, and natural losses. But in the U.S, these calculations are impossible to perform due to incomplete pregnancy outcome data. The reporting of the numbers of spontaneous pregnancy losses, including miscarriages, ectopic pregnancies, molar pregnancies and stillbirths (estimated 15-17% of pregnancies) and legal induced abortions (estimated 18-20% of pregnancies) are not mandated and thus unavailable.<sup>57</sup> Fetal death certificates are required only after twenty weeks gestation or if the birth weight is greater than 350 grams, and even then, fetuses who die of induced abortions after twenty weeks are excluded from reporting requirements.<sup>58</sup> No serious attempts have been made to document all spontaneous losses or to mandate legal induced abortion reporting.<sup>59</sup> Even pro-choice medical organizations have documented the deficiencies resulting from the interest only in pregnancy outcomes that occur in the second half of pregnancy. 60 Resistance has followed any recommendations for improving this data collection by mandating reporting of early pregnancy events based on the argument that this would breach a woman's right to privacy.<sup>61</sup>

Since only the number of live births can be accurately measured due to mandated reporting on birth certificates, the number of live births has become the default denominator. This data is collected in the CDC's Wide-ranging Online Data for Epidemiologic Research (WONDER) database. Thus, the CDC has chosen to report a "maternal mortality ratio," which is defined as the number of maternal deaths per 100,000 live births. Using a maternal mortality ratio instead of a maternal mortality rate introduces inaccuracies because the denominator (live births) is disconnected from the numerator (deaths related to any pregnancy outcome). Only two-thirds of maternal deaths occur in conjunction with a live birth, so many events occur in the numerator (deaths due to ectopic pregnancies, molar pregnancies, miscarriages, stillbirths and induced abortions) that are not represented in the denominator, resulting in an overly inflated maternal mortality ratio. 4

https://wonder.cdc.gov/wonder/help/main.html#What%20is%20WONDER, accessed August 8, 2022.

<sup>&</sup>lt;sup>57</sup> Studnicki, et al. Improving the Metrics and Data Reporting for Maternal Mortality: A Challenge to Public Health Surveillance and Effective Prevention. Online Journal of Public Health Informatics. 2019;11(2):e17.

<sup>&</sup>lt;sup>58</sup> National Center for Health Statistics. State definitions and reporting requirements for live births, fetal deaths, and induced terminations of pregnancy. Hyattsville (MD) NCHS; 1997. Available at <a href="https://www.cdc.gov/nchs/products/other/miscpub/statereq.htm">https://www.cdc.gov/nchs/products/other/miscpub/statereq.htm</a>, accessed August 7, 2022.

<sup>&</sup>lt;sup>59</sup> Kortsmit K, Mandel MG, Reeves JA, et al. Abortion Surveillance-United States, 2019. MMWR Surveill Summ 2021;70(No. SS-9):1-29. Available at https://www.cdc.gov/mmwr/volumes/70/ss/ss7009a1.htm, accessed August 8, 2022.

<sup>&</sup>lt;sup>60</sup> American College of Obstetricians and Gynecologists Committee Opinion 748. The importance of vital records and statistics for the obstetrician-gynecologist. Obstet Gynecol. 2018;132:78-81.

<sup>&</sup>lt;sup>61</sup> Search histories, location data, text messages: How personal data could be used to enforce anti-abortion laws. CNN Business. Available at <a href="https://www.cnn.com/2022/06/24/tech/abortion-laws-data-privacy/index.html">https://www.cnn.com/2022/06/24/tech/abortion-laws-data-privacy/index.html</a>, accessed August 26, 2022.

<sup>&</sup>lt;sup>62</sup> Model State Vital Statistics Act and Regulations, 1992 Revision, February 1994. Centers for Disease Control and Prevention/National Center for Health Statistics (CDC/NCHS). Available at <a href="https://www.cdc.gov/nchs/data/misc/mvsact92b.pdf">https://www.cdc.gov/nchs/data/misc/mvsact92b.pdf</a>, accessed August 7, 2022.

<sup>63</sup> What is CDC WONDER? Available at

<sup>&</sup>lt;sup>64</sup> Curtin SC, Abma JC, Ventura SC. NCHS Data Brief No. 136, December 2013. Centers for

Abortion-related deaths should be calculated based on the number of deaths per 100,000 legal induced abortions. As mentioned earlier, the numerator of abortion-related deaths is unreliable, but this is also true of the denominator. The estimated number of legal induced abortions is voluntarily provided by local and state health departments to the CDC, and independently estimated by abortion providers who report to the Guttmacher Institute, with a large disparity between the two sources. In 2017, the CDC documented 619,591 abortions<sup>65</sup> while the Guttmacher Institute documented 862,320.66 The CDC acknowledges that eight reporting areas do not consistently report abortion data (California, District of Columbia, Illinois, Maryland, New Hampshire, New Mexico, New York, Wisconsin), so they turn to the Guttmacher Institute's data to calculate the denominator for abortion-related deaths, basing their statistics on a hybrid data collection system. Even the states that do consistently report data do not use standardized forms, so the collected data may differ by state. It is documented that women report less than half of past abortions in interviews, so health complications related to previous abortions often remain undiscovered.<sup>67</sup> Regarding the numerator, abortion-related deaths should be determined by investigation of all deaths of women with a history of abortion, and should include comprehensive investigation of deaths from suicide, substance abuse, risk-taking, and other selfdestructive behaviors. But presently, there is no systematic collection of data regarding abortionassociated deaths as few are noted on maternal death certificates. The CDC's Abortion Surveillance System only identifies and counts deaths which are voluntarily reported or sporadically discovered.<sup>68</sup>

## What does the available U.S. data show?

In 2019, several state MMRCs reported that thirty-six percent of pregnancy-associated deaths documented by death certificates were indeed pregnancy-related. Sixty to sixty-five percent of these maternal deaths were considered preventable, defined as "a chance it could have been averted with one or more reasonable changes to patient, community, provider, facility and/or systems factors". Demonstrating the importance of patient responsibility and familial support, 38.2% of deaths might have been prevented if the patient or family's actions had changed, whereas 33.9% might have been prevented if the provider's actions had changed. About 1/3 of pregnancy-related maternal deaths occur outside medical facilities. Also, about a third of the

Disease Control and Prevention, National Center for Health Statistics, Atlanta. Available at https://www.cdc.gov/nchs/data/databriefs/db136.pdf, accessed August 7, 2022.

<sup>&</sup>lt;sup>65</sup>Kortsmit K, Mandel MG, Reeves JA, et al. Abortion Surveillance-United States, 2019. MMWR Surveill Summ 2021;70(No. SS-9):1-29. Available at https://www.cdc.gov/mmwr/volumes/70/ss/ss7009a1.htm, accessed August 8, 2022.

<sup>&</sup>lt;sup>66</sup> Induced Abortion in the U.S. Available at https://www.guttmacher.org/fact-sheet/induced-abortion-united-states, accessed July 22, 2022.

<sup>&</sup>lt;sup>67</sup> Jones RK, Kost K. Underreporting of induced and spontaneous abortion in the United States: An analysis of the 2002 National Survey of Family Growth. Studies in Family Planning 2007:38:187–197.

<sup>&</sup>lt;sup>68</sup> Skop, I. Abortion Safety: At Home and Abroad. Issues in Law & Medicine 2019;34:44.

<sup>&</sup>lt;sup>69</sup> Report from maternal mortality review committees: A view into their critical role. Available at https://www.cdcfoundation.org/sites/default/files/upload/pdf/MMRIAReport.pdf, accessed September 6, 2022.

<sup>&</sup>lt;sup>70</sup> Burgess AP, Dongarwar D, Spigel Z, et al. Pregnancy-related mortality in the United States,2003-2016: age, race, and place of death. Am J Obstet Gynecol. 2020;222:489.e8.

pregnancy-related deaths occur in women who either do not receive any prenatal care or initiate such care late in pregnancy. 71

The most recent U.S. maternal mortality statistics from NVSS document 861 women died of pregnancy-related causes in 2020 (23.8/100,000 live births) and 754 died in 2019 (20.1/100,000 live births).<sup>72</sup> Only two abortion-related deaths were documented by the CDC in 2019.<sup>73</sup>

### What does the best data show? U.S. comparison to international records-linkage studies:

A frequently referenced 2012 study misrepresented the poor-quality U.S. maternal and abortionrelated mortality data, reportedly showing legal induced abortion to be fourteen times safer than childbirth by comparing the maternal mortality ratio to the abortion mortality rate, a meaningless exercise. One of the authors, a vocal abortion advocate, previously headed the CDC's Abortion Surveillance Division, so he was aware of the deficiencies in the data. He even acknowledged this in the article, "weaknesses include the likely underreporting of deaths, possibly differential by pregnancy outcome (abortion or childbirth)". In addition to the non-comparable denominators and the reality that an abortion-related death is counted in both numerators, the authors also ignored the disparity in lengths of the pregnancy events: the average induced abortion is performed at 8 weeks gestation, whereas the average length of pregnancy resulting in childbirth is 37 weeks gestation, allowing a much longer period for untoward events to occur when a pregnancy is carried to term. <sup>74</sup> A former director of the CDC, Dr. Julie Gerberding, has clarified that maternal mortality ratios and abortion mortality rates "are conceptually different and are used by the CDC for different public health purposes". Additionally, although the authors reportedly performed a literature review, they ignored many high-quality records-linkage studies demonstrating far more deaths after induced abortion than after childbirth.<sup>76</sup> While this study was meaningless for science, it provided powerful disinformation to accomplish its purpose for abortion advocacy propaganda.

As mentioned previously, the best method of detecting maternal mortality would be to document, "how likely is a woman to remain alive after a pregnancy ends?", linking all death certificates from women of reproductive age with all infant birth certificates and all fetal loss certificates, to determine the total number of deaths for each pregnancy outcome within a certain time period of a deceased woman's most recent pregnancy. Studies that have employed this methodology have documented findings contrary to the common assumption that induced abortion is safer than pregnancy.

<sup>&</sup>lt;sup>71</sup> Creanga AA, Syverson C, Seed K, et al. Pregnancy- related mortality in the United States, 2011-2013. Obstet Gynecol. 2017;130:366–373.

<sup>&</sup>lt;sup>72</sup> Hoyert DL. National Center for Health Statistics. Maternal mortality rates in the United States, 2020. Available at https://www.cdc.gov/nchs/data/hestat/maternal-mortality/2020/E-stat-Maternal-Mortality-Rates-2022.pdf, accessed August 8, 2022.

<sup>&</sup>lt;sup>73</sup> Kortsmit K, Mandel MG, Reeves JA, et al. Abortion Surveillance-United States, 2019. MMWR Surveill Summ 2021;70(No. SS-9):1-29. Available at https://www.cdc.gov/mmwr/volumes/70/ss/ss7009a1.htm, accessed August 8, 2022.

<sup>&</sup>lt;sup>74</sup> Raymond EG, and Grimes DA. The Comparative Safety of Legal Induced Abortion and Childbirth in the US." Obstetrics & Gynecology 2012;119:215–19.

<sup>&</sup>lt;sup>75</sup> Letter from Julie Louise Gerberding to Walter Weber, July 20, 2004. Available at <a href="http://afterabortion.org/pdf/CDCResponsetoWeberReAbortionStats-Gerberding%20Reply.pdf">http://afterabortion.org/pdf/CDCResponsetoWeberReAbortionStats-Gerberding%20Reply.pdf</a>, accessed September 6, 2022.

<sup>&</sup>lt;sup>76</sup> Reardon D. Rebuttal of Raymond and Grimes. Linacre Quarterly. 2012;79(3): 259–260.

An 8-year records-linkage study of California Medicaid recipients found that a woman was 162% more likely to die from all causes in the year after an abortion than after childbirth, 182% more likely to die in an accident, and 254% more likely to commit suicide. The death rate two years after childbirth was 112/100,000 pregnancies and after abortion was 228.9/100,000. High quality records-linkage studies from Finland revealed that the risk of death in given year for a non-pregnant woman is 57/100,000 person-years, after term pregnancy is 28.2/100,000 pregnancies, after miscarriage is 51.9/100,000 and after induced abortion rises to 83.1/100,000. The risk of death from any violent cause was six times higher after abortion than childbirth, suicide six times higher, accidental death five times higher, and death by homicide ten times higher.

Similar records-linkage studies from Denmark revealed that after a first trimester induced abortion or miscarriage, a woman had an 244% increased risk of death within 180 days (19/100,000 pregnancies), and 615% increased risk of death within 180 days for second/third trimester abortion (55/100,000) compared to childbirth (7.8/100,000). The death rate within a year after childbirth is 17.9/100,000 pregnancies, after miscarriage is 31.2/100,000, after first trimester abortion is 33.8/100,000, and after second/third trimester abortion is 110/100,000. Additionally, a dose-response was noted, with mortality rates increasing the more abortions a woman had.<sup>79</sup>

Finally, a 2017 meta-analysis of all available records-linkage studies documented that the risk of death is twice as high within six months following abortion than childbirth and remains elevated for many years, with a documented dose-effect as each additional abortion increased a woman's risk of dying by 50%. The review documented a curious lack of interest in the issue of maternal mortality and pregnancy loss, as only eleven of 989 identified studies contained enough information to make a determination related to all types of pregnancy losses.<sup>80</sup>

<sup>&</sup>lt;sup>77</sup> Reardon D, Ney P, Scheuren F, et al. Deaths associated with pregnancy outcome: a records linkage study of low-income women. Southern Medical Journal. 2002;95(8):834-841.

<sup>&</sup>lt;sup>78</sup> Gissler M, Kauppila R, Merilainen J, et al. Pregnancy Associated Deaths in Finland 1987-1994. Acta Obstetricia et Gynecologica Scandinavica. 1997;76:651-657; Gissler M, Berg C, Bouvier-Colle MH, et al. Injury deaths, suicides and homicides associated with pregnancy, Finland 1987-2000. Eur J of Public Health. 2005;15(5):459-463; Gissler M, Berg C, Bouvier-Colle MH, et al. Pregnancy Associated Mortality After Birth, Spontaneous Abortion or Induced Abortion in Finland. 1987-2000. American Journal Obstetrics and Gynecology. 2004;190(2):422-427; Gissler M, Berg C, et al. Methods of Identifying Pregnancy Related Deaths: Population Based Data From Finland. 1987-2000. Pediatrics and Perinatology Epidemiology. 2004;18(6):448-55; Gissler M, et al. Suicides after pregnancy in Finland, 1987-94. Register linkage study. British Medical Journal. 1996;313:14311434; Karalis E, et al. Decreasing mortality during pregnancy and for a year after while mortality after termination of pregnancy remains high: a population based register study of pregnancy associated deaths in Finland 2001-2012. British Journal Obstet Gynecol. 2017;124:1115-1121; Reardon D, Thorp J. Pregnancy associated death in record linkage studies relative to delivery, termination of pregnancy, and natural losses: A systematic review with a narrative synthesis and meta-analysis. SAGE Open Medicine. 2017;5:1-17.

<sup>&</sup>lt;sup>79</sup> Reardon DC, Coleman PK. Short- and long-term mortality rates associated with first pregnancy outcome: Population register based study for Denmark 1980-2004. Med Sci Monit 2012;18(9):71-76; Coleman PK, Reardon DC, Calhoun B. 2013. Reproductive History Patterns and Long-term Mortality Rates: A Danish population-based record linkage study. Eur J of Public Health. 2013;23(4):569-574.

<sup>&</sup>lt;sup>80</sup> Reardon D, Thorp J, Pregnancy Associated Death in record linkage studies relative to delivery, termination of pregnancy, and natural losses: A systematic review with a narrative synthesis and meta-analysis. Sage Open Medicine. 2017;5:1-17; Reardon David C et al. Deaths Associated with Abortion Compared to Childbirth--a Review of New and Old Data and the Medical and Legal Implications. The Journal of Contemporary Health Law and Policy 20, no. 2, 2004, 279–327.

While it is probable that records-linkage studies will produce many pregnancy-associated, but not necessarily pregnancy-related deaths, wouldn't it be preferable to cast a broad net and have an extensive list of deaths for MMRCs to investigate to more completely detect pregnancy-related deaths, than to have a known incomplete system that does not detect all maternal deaths? It is both the starting point for all investigations, but also useful in and of itself, to identify differences in pregnancy-associated mortality that are not easily determined by a forensic examination. For example, unless there are suicide notes, it is difficult to identify all contributing factors to a mental health related death. But strong statistically significant differences in suicides and accidental deaths after abortion compared to childbirth, such as shown by the Finnish researchers, are certainly very telling. Therefore, pregnancy-associated mortality rates are useful for public health policy...and informed consent...even if causality cannot be definitively determined.

### The method of separating a woman from her child impacts her maternal mortality risk:

When a pregnancy progresses to childbirth, delivery may occur by several methods. Term spontaneous vaginal delivery (SVD) has the lowest risk of maternal death compared to other methods of term deliveries. <sup>81</sup> Operative vaginal delivery, assisted with vacuum or forceps, has a higher risk of hemorrhage and adjacent tissue damage than an SVD. <sup>82</sup> Cesarean section delivery has much higher risks of maternal death, both because pregnancy complications may necessitate the cesarean section, as well as increased risks of hemorrhage, infection, thrombotic complications, and direct organ damage from this major intraabdominal surgery. Studies indicate maternal mortality from cesarean section may be as much as one hundred times higher compared to vaginal birth. <sup>83</sup> One third of U.S. births occur by cesarean section, a relatively large percentage compared to many other developed nations, and this may also contribute to the U.S.' higher maternal mortality ratios. <sup>84</sup>

Preterm deliveries (< 37 weeks gestation) may occur by vaginal delivery, operative vaginal delivery or cesarean section, and are inherently riskier due to complications that lead to early delivery. For example, premature separation of the mother and fetus may be required due to a hypertensive crisis, bleeding emergency or other conditions. Preterm births also have an increased likelihood of cesarean section due to malpresentation, fetal intolerance of labor, failed induction or other factors. Medical interventions to delay preterm birth may also increase risks, such as toxicity from magnesium sulfate administration or increased risk of sepsis from expectant management of preterm, premature rupture of membranes.<sup>85</sup>

<sup>81</sup> Cunningham, et al. Williams Obstetrics. 23rd Edition. (McGraw Hill Medical. New York. 2010.) p 374-409.

<sup>82</sup> Cunningham, et al. Williams Obstetrics. 23rd Edition. (McGraw Hill Medical. New York. 2010.) p 511-526.

<sup>&</sup>lt;sup>83</sup> Caughey AB, Cahill AG, Guise J, and Rouse DJ. Safe Prevention of the Primary Cesarean Delivery. Obstetric Care Consensus No. 1. American College of Obstetricians and Gynecologists. Obstetrics & Gynecology 2014;123:693–711; Lanska M et al., Mortality From Abortion and Childbirth, (letter), Journal of the American Medical Association. 1983;250:361-362; Cunningham, et al. Williams Obstetrics. 23rd Edition. (McGraw Hill Medical. New York. 2010.) p 544-576.

<sup>&</sup>lt;sup>84</sup> Why is the U.S. Cesarean section rate so high? Childbirth Connection Fact Sheet. Available at <a href="https://www.nationalpartnership.org/our-work/resources/health-care/maternity/why-is-the-c-section-rate-so-high.pdf">https://www.nationalpartnership.org/our-work/resources/health-care/maternity/why-is-the-c-section-rate-so-high.pdf</a>, accessed August 31, 2022.

<sup>85</sup> Petersen, EE, Davis NL, Goodman D, et al. Pregnancy-related Deaths, United States, 2011-2015, and Strategies for Prevention, 13 States, 2013–2017. Morbidity and Mortality Weekly Report 2019;68:423–29. Available at www.cdc.gov/mmwr/volumes/68/wr/mm6818e1.htm?s\_cid<sup>1</sup>/<sub>4</sub>mm6818e1\_w, accessed August 7, 2022.

Natural losses: Spontaneous abortions (miscarriages) may resolve spontaneously without intervention, may require medications such as misoprostol or mifepristone, or may be treated with surgical dilatation and suction aspiration, with or without sharp curettage. Some may require a combination of these procedures. The gestational age at the time of the pregnancy loss impacts risk, as later miscarriages have higher risks of retained tissue leading to excessive hemorrhage or infection.<sup>86</sup> An ectopic pregnancy implants in a location outside of the uterus (or rarely within the cervix or cornual junction between the uterus and tube). Most commonly, it implants in the fallopian tube where continued growth can stretch the tube to the point of rupture, resulting in catastrophic internal bleeding. Once diagnosed, it must be treated surgically or with an injection of methotrexate unless there is clear evidence it is resolving through miscarriage.<sup>87</sup> Gestational trophoblastic disease, also called hydatidiform mole, is a rare abnormal pregnancy that has the potential for invasion and metastasis of the pregnancy tissue. When diagnosed, it is treated with surgical removal of the abnormal tissue. Close follow up is required to rule out systemic invasion, which is treated with chemotherapy or additional surgery if it occurs.<sup>88</sup> Induced abortion is the intentional ending of fetal life within the uterus. 89 The gestational age when the abortion is performed impacts risk, as maternal mortality increases as the gestational age increases. The CDC documents a 38% increase in mortality for each week that an abortion is performed beyond 8 weeks, with 14.7-fold increased mortality early in the second trimester, 29.5-fold increase in the mid-second trimester, and 76.6-fold increase in the risk of death to a woman from abortion after viability (second half of pregnancy). 90

Medical (chemical) abortion is usually performed with mifepristone to withdraw hormonal support and misoprostol to induce uterine contractions. It has been associated with excessive hemorrhage and atypical infections, accounting for at least 26 reported maternal deaths in the U.S. <sup>91</sup> It is also associated with pharmacologically induced anxiety and depression in the animal model. <sup>92</sup> Complications occur four times as often as with surgical abortions. Surgical completion due to retained pregnancy tissue is required in approximately three to eight percent of first trimester procedures. Abortion initiated medically but completed surgically compounds these risks. <sup>93</sup> Data regarding medical abortion complications are often unobtainable, especially since abortion advocates have begun advising women to withhold disclosure of a previous

<sup>&</sup>lt;sup>86</sup> Cunningham, et al. Williams Obstetrics. 23rd Edition. (McGraw Hill Medical. New York. 2010.) p 215-237.

<sup>&</sup>lt;sup>87</sup> Cunningham, et al. Williams Obstetrics. 23rd Edition. (McGraw Hill Medical. New York. 2010.) p 238-256.

<sup>&</sup>lt;sup>88</sup> Cunningham, et al. Williams Obstetrics. 23<sup>rd</sup> Edition. (McGraw Hill Medical. New York. 2010.) p 257-265.

<sup>&</sup>lt;sup>89</sup> Texas Health and Safety Code. Available at <a href="https://statutes.capitol.texas.gov/Docs/HS/htm/HS.245.htm">https://statutes.capitol.texas.gov/Docs/HS/htm/HS.245.htm</a>, accessed September 6, 2022.

<sup>&</sup>lt;sup>90</sup> Zane, Creanga, et al. Abortion Related Mortality in the U.S.:1998-2010. Obstet Gynecol. 2015;126:(2)258-265; Bartlett, Berg, et al, Risk Factors for Legal Induced Abortion Related Mortality in the U.S. Obstet Gynecol. 2004;103:(4)729-737.

<sup>&</sup>lt;sup>91</sup> Aronoff DM, Hao Y, Chung J, et al. Misoprostol Impairs Female Reproductive Tract Innate Immunity against Clostridium Sordellii." Journal of Immunology 2008:180:8222–8230.

<sup>&</sup>lt;sup>92</sup> Camilleri C, Beiter R, Puentes L, et al. Biologic, behavioral and physiologic consequences of drug-induced pregnancy termination at first-trimester human equivalent in an animal model. Front Neurosci 2019;13:544.
<sup>93</sup> Raymond E, Weaver S, Winikoff B. First trimester medical abortion with mifepristone 200 mg and misoprostol: a systematic review. Contraception 2013;87(1):36-37; Chen M, Creinin M. Mifepristone with buccal misoprostol for medical abortion: A systematic review. Obstet Gynecol 2015;126:12-21; Niinimaki M, Pouta A, Bloigu A, et al. Immediate complications of medical compared with surgical termination of pregnancy. Obstet Gynecol 2009;114(4):795-804; Mentula MJ, Niinimaki M, Suhonen S, et al. Immediate adverse events after second trimester termination of pregnancy. Hum Reprod 2011;26(4):927-932.

medical abortion if they should happen to seek emergency care for abortion-related complications. <sup>94</sup>

The FDA recently removed its in-person Risk Evaluation and Mitigation Strategy (REMS) restrictions, allowing medical abortion pill distribution outside of medical supervision through on-line ordering and mail-order delivery. These unsupervised medical abortions are being increasingly promoted to women, especially in states with abortion restrictions, but failed abortion from underestimation of gestational age (resulting in more tissue to be expelled), missed diagnosis of ectopic pregnancy due to failure to perform ultrasound (these medications do not treat an ectopic), and missed opportunity for RhoGAM immunoprophylaxis (which may produce complications in future pregnancies), all increase the risk of maternal mortality both in the current and future pregnancies. 96

Later medical abortions, performed after the first trimester, are usually induced by oral or vaginal prostaglandins (misoprostol), or mifepristone and misoprostol, but may require surgical suction or sharp curettage for retained pregnancy tissue in up to 39% of women. <sup>97</sup> Feticide (injecting medications to stop the fetal heart) is often performed prior to induction, but this may lead to maternal cardiac complications if digoxin or potassium chloride enters a woman's bloodstream; <sup>98</sup> and if feticide is not performed, a live birth may occur and the abortionist may perform active or passive infanticide. <sup>99</sup> Intraamniotic instillation procedures such as saline infusion, prostaglandin infusion or urea infusion are rarely performed due to deaths from electrolyte imbalances, infections and hemorrhage. <sup>100</sup>

Surgical abortions require opening the cervix by osmotic dilatation, prostaglandin dilatation or mechanical dilatation or a combination of the above. Cervical damage or creation of a false passage during dilatation and/or perforation of the uterus during surgical curettage may lead to catastrophic hemorrhage or infection requiring emergency surgical intervention or to complications in a subsequent pregnancy. First trimester dilatation and suction aspiration may occur with or without sharp curettage (D&C), and sharp curettage has been linked to uterine damage. Second/third trimester dilatation and evacuation/extraction (D&E) may deliver the fetus intact ("partial-birth" abortion) or non-intact ("dismemberment" abortion), although an intact D&E is illegal by federal law. A non-intact D&E requires many blind passes of surgical

<sup>&</sup>lt;sup>94</sup> Women help women. Will a doctor be able to tell if you've taken abortion pills? Available at <a href="https://womenhelp.org/en/page/1093/will-a-doctor-be-able-to-tell-if-you-ve-taken-abortion-pills">https://womenhelp.org/en/page/1093/will-a-doctor-be-able-to-tell-if-you-ve-taken-abortion-pills</a>, accessed September 6, 2022.

<sup>&</sup>lt;sup>95</sup> Mifepristone information. Available at <a href="https://www.fda.gov/drugs/postmarket-drug-safety-information-patients-and-providers/mifeprex-mifepristone-information">https://www.fda.gov/drugs/postmarket-drug-safety-information-patients-and-providers/mifeprex-mifepristone-information</a>, accessed September 6, 2022.

<sup>&</sup>lt;sup>96</sup> Skop I. Chemical abortion: Risks posed by changes in supervision. Journal of the American Association of Physicians and Surgeons. 2022;27(2):56-61.

<sup>&</sup>lt;sup>97</sup> Mentula, et al. Immediate adverse events after second trimester medical termination of pregnancy: results of a nationwide registry study. Human Reprod. 2011;26(4):927-932.

<sup>&</sup>lt;sup>98</sup> M Molaei Effectiveness and Safety of Digoxin to Induce Fetal Demise Prior to Second Trimester Abortion. Contraception. 2008;77(3):223; L Pasquini, et al. Intracardiac Injection of Potassium Chloride as a Method of Feticide. BJOG. 2008;115(4):528.

<sup>&</sup>lt;sup>99</sup> Springer S, Gorczyca ME, Arzt J, et al. Fetal Survival in Second-Trimester Termination of Pregnancy Without Feticide. Obstet Gynecol 2018;131:575–579.

<sup>&</sup>lt;sup>100</sup> Grimes D and Cates W. Second Trimester Abortion. 1980. (Berger, et al editors) Chapter 10.

<sup>&</sup>lt;sup>101</sup> Autry A, Hayes E, Jacobson G, and Kirby R. A Comparison of Medical Induction and Dilation and Evacuation for Second Trimester Abortion. American Journal of Obstetrics and Gynecology 2002:187:393–97.

instruments into the uterus, which can also lead to damage of the uterus or retained tissue. <sup>102</sup> Hysterotomy (cesarean section) or hysterectomy abortions are rarely performed, but if performed, are associated with high maternal mortality. <sup>103</sup> Later surgical abortions are associated with increased complications from uterine perforation or adjacent organ damage due to the relaxed uterine musculature, which may increase the risk of sepsis, hemorrhage, and thrombosis. <sup>104</sup> After 18 weeks gestation, the mortality rate from induced abortion (7.4 deaths/100,000) is more than twice that for vaginal childbirth (3.6 deaths/100,000). <sup>105</sup>

### **Direct causes of maternal deaths:**

The triad of infection, hemorrhage, and hypertensive disorders of pregnancy, which in the past accounted for >90% of all pregnancy-related deaths, now accounts for only about one-third of these deaths. New causes of death have emerged, and currently, about half of pregnancy-related deaths involve cardiovascular, cerebrovascular, and other medical conditions. "Deaths of despair" from mental health disorders are also increasingly common causes of maternal deaths. 106

Cardiovascular conditions are the most common physiologic category identified by MMRCs as causing maternal mortality (accounting for 13.8-14% of pregnancy-related deaths, although this number excludes deaths from cardiomyopathy and preeclampsia). 107 Many women who had complex cardiac repairs as infants due to congenital anomalies have now lived to reproductive age. While their repaired anatomy is sufficiently functional to allow them to mature to adulthood, it may decompensate when dramatic vascular changes occur during pregnancy. <sup>108</sup> The poor preconceptual health of many American women-obesity, advanced age, diabetes, hypertension or other cardiovascular diseases-may predispose them to extreme and difficult to control blood pressure fluctuations and other cardiovascular stress, which can lead to heart attacks, seizures, strokes, liver rupture and other catastrophic complications. Deaths due to accelerated hypertension from preeclampsia or eclampsia occur most commonly at delivery or within a week of delivery (accounting for an additional 7.4-8.3% of deaths). Cardiomyopathy (accounting for an additional 9.3-10.7% of deaths), a pregnancy related inflammation of the heart, is relatively rare, but has a 10% mortality rate, and is the most common cause of late maternal death. Although maternal mortality is measured (at most) until a year after the end of a pregnancy, it should be noted that a history of abortion or miscarriage is associated with an

<sup>&</sup>lt;sup>102</sup> Lerma. Current and potential methods for second trimester termination. Best practice and research clinical obstet and gynecol. 2020;63:24-36.

<sup>&</sup>lt;sup>103</sup> American College of Obstetricians and Gynecologists Practice Bulletin 135: Second Trimester Abortion: Obstetrics & Gynecology. 2013;121(6):1394-1406.

<sup>&</sup>lt;sup>104</sup> American College of Obstetricians and Gynecologists Practice Bulletin 135: Second Trimester Abortion: Obstetrics & Gynecology. 2013;121(6):1394-1406; CDC Abortion Surveillance-U.S. 2015. MMWR Surveillance Summary. 2015;61:1-44.

<sup>&</sup>lt;sup>105</sup> Marmion P, Skop I. Induced abortion and the increased risk of maternal mortality. The Linacre Quarterly. 2020;87(3):302-310.

<sup>&</sup>lt;sup>106</sup> Creanga AA, Berg /CJ, Ko JY, et al. Maternal mortality and morbidity in the U.S.: Where are we now? Journal of Women's Health. 2014;23(1):3-9.

<sup>&</sup>lt;sup>107</sup> See reference #5; Peterson, Brantley and Davis reports.

<sup>&</sup>lt;sup>108</sup> Kuklina E, Callaghan W. Chronic heart disease and severe obstetric morbidity among hospitalizations for pregnancy in the USA: 1995–2006. BJOG 2011;118:345–352.

increased risk of cardiovascular disease in subsequent pregnancies<sup>109</sup> and in increased risk of death from cardiovascular disease over many years.<sup>110</sup>

**Hemorrhage** accounts for 13.1-14% of maternal deaths. 111 This most commonly occurs due to atony, failure of the uterus to contract sufficiently to shut off the massive blood flow through the enlarged uterus. Safety toolkits and hemorrhage drills are utilized in most hospital systems, but sometimes, even in the best equipped and prepared hospital, death may be unavoidable. One increasingly common cause of hemorrhagic maternal death is an abnormally invasive placenta. "Placenta accreta spectrum disorder" occurs in 1:272 pregnancies and is associated with uterine damage from prior uterine surgery (cesarean section, myomectomy or sharp curettage for miscarriage or induced abortion). Catastrophic bleeding due to inability to separate the placenta from the uterus may require many blood products that can overwhelm a hospital's blood supply. If diagnosed before birth, these women should be electively delivered in a tertiary medical center with a specialized multidisciplinary program and the ability to perform mass transfusion protocols. Often a hysterectomy is required. 112 Placental abruption has also been associated with faulty placental attachment due to prior uterine damage and is also linked to excessive blood loss and poor maternal and neonatal outcomes. 113 Early in pregnancy, a ruptured ectopic pregnancy can also lead to catastrophic internal bleeding and death. Undiagnosed ectopic pregnancies that rupture in women undergoing unsupervised medical abortions are 30% more likely to result in death than if the woman had not sought an abortion, because she may interpret the pain and bleeding as a sign the medication is working rather than a sign her life is in danger. 114

**Infection** accounts for 10.7-11.4% of maternal deaths<sup>115</sup> but early diagnosis and treatment of sepsis has also been well addressed with safety toolkits in most hospital systems, increased awareness and use of broad-spectrum antibiotics. Maternal death due to sepsis may be associated with expectant management of extremely early premature rupture of membranes to optimize fetal outcomes. Cervical incompetence (painless dilation), associated with risk of extreme premature delivery, may be increased with prior cervical or uterine instrumentation (conization for dysplasia, or dilatation and curettage for spontaneous or induced abortion). We have poor ability to predict or prevent preterm delivery, which occur in 10% of U.S. deliveries, but it should be noted, there is a dose dependent increase in premature delivery after prior

<sup>&</sup>lt;sup>109</sup> Tsulukidze M, Reardon D, Craver C. Elevated cardiovascular disease risk in low-income women with a history of pregnancy loss. Open Hear. 2022;9(1):e002035. doi:10.1136/openhrt-2022-002035)

<sup>&</sup>lt;sup>110</sup> Reardon DC, Ney PG, Scheuren F, et al. Deaths associated with pregnancy outcome: A record linkage study of low-income women. South Med J. 2002;95(8):834-841

<sup>&</sup>lt;sup>111</sup> See reference #5; Peterson, Brantley and Davis reports.

<sup>112</sup> Baldwin HJ, Patterson JA, Nippita TA, et al. Antecedents of Abnormally Invasive Placenta in Primiparous Women: Risk Associated With Gynecologic Procedures. Obstet Gynecol 2018;131:227-233; Mogos MF, Salemi JL, Ashley M, et al. Recent Trends in Placenta Accreta in the United States and Its Impact on Maternal-fetal Morbidity and Healthcare-associated Costs, 1998-2011. Journal of Maternal-Fetal and Neonatal Medicine 2016;29:1077.

<sup>&</sup>lt;sup>113</sup> Klemetti, et al. Birth Outcomes after induced abortion: A nationwide register-based study of first births in Finland. Hum Reprod 2012.

<sup>&</sup>lt;sup>114</sup> Atrash HK, MacKay T, Hogue CJR. Ectopic pregnancy concurrent with induced abortion: Incidence and mortality. Am J Obstet Gynecol. 1990;162(3):726-730.

<sup>&</sup>lt;sup>115</sup> See reference #5; Peterson, Brantley and Davis reports.

induced abortions. Large meta-analyses have demonstrated 25-35% increase in preterm birth after one induced abortion, and 32-72% increase after more than one. 116

Embolism describes an occlusion of vascular flow with potentially deadly consequences (accounting for 8.4-9.5% of deaths). A woman may form an accentuated clotting response due to physiologic changes in pregnancy or complications from pregnancy management (venous thromboembolism), leading to obstructed vessels in the lungs (pulmonary embolus) or brain (cerebrovascular accident). Air or amniotic fluid can also enter the circulation and lead to a vascular obstruction. Fortunately, these events are rare, but are often deadly. Embolisms may occur spontaneously during labor but are also associated with vascular complications from surgical abortions or cesarean sections when instruments have lacerated vessels and introduced foreign matter. 118

Mental health conditions have been determined to be causative in 7-8.8% of maternal deaths, <sup>119</sup> even though researchers often do not attribute mental health conditions to the woman's death, labeling them "pregnancy-associated" rather than "pregnancy-related" deaths. While there are many ways in which an adverse pregnancy outcome could affect a woman's mental health, there is a high likelihood that these deaths are often missed and unaccounted for in U.S. maternal mortality statistics. No standardized protocols exist for determination of whether a mental health condition contributed to a woman's death, so researchers may use subjective criteria to determine causality.

**Anesthetic reactions, complications or overdose** are rare but sometimes occur, accounting for < 2% of maternal deaths. <sup>120</sup>

Demonstrating the difficulty in accurately determining causes of death, approximately 7.5% of maternal deaths have **undetermined causes.**<sup>121</sup>

### In addition to direct causes, maternal mortality is impacted by indirect causes:

Indirect contributions to maternal mortality, sometimes referred to as "upstream determinants of health", are highlighted by the known racial disparities in U.S. maternal mortality. Non-Hispanic Black women have 2.9 times the maternal mortality ratio of non-Hispanic white women, with conversation often limited to suggesting institutional factors of systemic racism. <sup>122</sup> Some researchers have even counterintuitively stated that race is not a biological variable, but a social construct and thus maternal mortality should be the same in all ethnic groups if society

<sup>&</sup>lt;sup>116</sup> Swingle, et al. Abortion and the Risk of Subsequent Preterm Birth: A Systematic Review and Meta-Analysis. Journal of Reproductive Medicine. 2009;54:95-108; Liao, et al. Repeated medical abortions and the risk of preterm birth in the subsequent pregnancy. Arch Gyn Ob 2011;284:579-586.

<sup>&</sup>lt;sup>117</sup> See reference #5; Peterson, Brantley and Davis reports.

<sup>&</sup>lt;sup>118</sup> Shirazi M, Sahebdel B, Torkzaban M, et al. Maternal mortality following thromboembolism; incidence and prophylaxis strategies. Thrombosis Journal. 2020;18(36):1-7.

<sup>&</sup>lt;sup>119</sup> See reference #5; Peterson, Brantley and Davis reports.

<sup>&</sup>lt;sup>120</sup> See reference #5; Peterson, Brantley and Davis reports.

<sup>&</sup>lt;sup>121</sup> Davis NL, Smoots AN, Goodman DA. Pregnancy-related deaths: Data from 14 U.S. Maternal Mortality Review Committees, 2008-2017. Atlanta GA: Centers for Disease Control and Prevention, U.S. Department of Health and Human Services; 2019. Available at https://www.cdc.gov/reproductivehealth/maternal-mortality/erase-mm/mmrdata-brief\_2019-h.pdf, accessed August 7, 2022.

<sup>&</sup>lt;sup>122</sup> Margerison CE, Roberts MH, Gemmill A, et al. Pregnancy-Associated Deaths Due to Drugs, Suicide, and Homicide in the United States, 2010–2019Obstet Gynecol 2022;139:172–180.

were equitable. 123 Yet, in a military study that controlled for economics and health care access, non-Hispanic Black women receiving the same health care as non-Hispanic white women were still 2.8 times as likely to be admitted to an intensive care unit and 1.7 times as likely to experience severe maternal morbidity compared to non-Hispanic white women. 124 There are many factors potentially contributing to maternal morbidity and mortality and these should be more fully explored as we strive to understand the racial disparities.

It is important to note that the outcomes of pregnancy differ among ethnic groups. Spontaneous abortion (miscarriage) rates are similar among all ethnicities, approximately 16%. The rates of legal induced abortion vary dramatically, however, affecting 34% of the pregnancies in non-Hispanic Black women but only 11% in white women. Abortions after the first trimester, which are more dangerous, are also more common in the non-Hispanic Black population, accounting for 13% of abortions among non-Hispanic Blacks compared to 9% among non-Hispanic whites. As a result of these factors only 48% of pregnancies among the non-Hispanic Black population result in childbirth as compared to 65% of pregnancies among the non-Hispanic white population. 125 It is worth investigating if there are risk factors associated with abortion that may contribute to the excessive maternal mortality documented in this population. **Preconceptual health risk factors** impact maternal mortality, and these differ by ethnicity. Obesity affects 47% of the non-Hispanic Black population and 47% of the Hispanic population, but only 38% of the non-Hispanic white population. 126 Hypertension affects 40% of the non-Hispanic Black population, but only 26% of the Hispanic population and 27% of the non-Hispanic white population. <sup>127</sup> Diabetes affects 13% of the non-Hispanic Black population and 12% of the Hispanic population, but only 7% of the non-Hispanic white population. <sup>128</sup> An inherited thrombophilia will increase the propensity to form blood clots that block blood vessels and this occurs more commonly in the non-Hispanic Black population. 129 These preconceptual factors may directly predispose to mortality due to disease related complications, and they are also associated with early delivery and increased C-section rates, which indirectly raise mortality risk. Chronic hypertension may lead to preeclampsia or eclampsia, which accounts for 11.4% of deaths in non-Hispanic Black women, but only 6.5% of deaths in non-Hispanic white women. 130

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<sup>&</sup>lt;sup>123</sup> Megan Gannon. Race is social construct, scientists argue. Scientific American February 5, 2016. Available at <a href="https://www.scientificamerican.com/article/race-is-a-social-construct-scientists-argue/">https://www.scientificamerican.com/article/race-is-a-social-construct-scientists-argue/</a>, accessed September 6, 2022. <sup>124</sup> Hamilton JL, Shumbusho D, Cooper D, et al. Race matters: Maternal morbidity in the Military Health System. American Journal of Obstet Gynecol.org. 2021;512e6.

<sup>&</sup>lt;sup>125</sup> Studnicki, et al. Improving the Metrics and Data Reporting for Maternal Mortality: A Challenge to Public Health Surveillance and Effective Prevention. Online Journal of Public Health Informatics. 2019;11(2):e17.

<sup>&</sup>lt;sup>126</sup> Hales CM, Carroll MD, Fryar CD, and Ogden CL. "Prevalence of Obesity among Adults and Youth: United States, 2015–2016." NCHS Data Brief 2017;188:1–8.

<sup>&</sup>lt;sup>127</sup> CDC (Centers for Disease Control and Prevention). "Racial/Ethnic Disparities in the Awareness, Treatment, and Control of Hypertension—United States, 2003–2010." Morbidity and Mortality Weekly Report 2013:62:351–55.

<sup>&</sup>lt;sup>128</sup> CDC (Centers for Disease Control and Prevention). National Diabetes Statistics Report, 2017. Atlanta, GA: Centers for Disease Control and Prevention, US Department of Health and Human Services. Available at <a href="https://www.cdc.gov/diabetes/data/statistics-report/index.html">https://www.cdc.gov/diabetes/data/statistics-report/index.html</a>, accessed August 7, 2022.

<sup>&</sup>lt;sup>129</sup> Phillip C. Differences in thrombotic risk factors in black and white women with adverse pregnancy outcome. Thromb. Res. 2014;133(1)108-111.

<sup>&</sup>lt;sup>130</sup> Davis NL, Smoots AN, Goodman DA. Pregnancy-related deaths: Data from 14 U.S. Maternal Mortality Review Committees, 2008-2017. Atlanta GA: Centers for Disease Control and Prevention, U.S. Department of Health and

**Poverty** is a risk factor for failure to obtain appropriate medical care and may contribute to the racial disparity noted in maternal mortality. Additionally, poverty is associated with the preconceptual health risk factors mentioned above: obesity, hypertension and diabetes. Twenty percent of non-Hispanic Black women live in poverty compared to 16 percent of Hispanic women and 8 percent of non-Hispanic white women. Only 5 percent of married couples live in poverty, so the high rates of unmarried childbirth in minority populations may also contribute to the likelihood of poverty. Unmarried birth occurs in 67% of non-Hispanic Black women, 39% of Hispanic women, and 27% of non-Hispanic white women. But independent of financial status, giving birth and caring for a child without a partner places a woman at an obvious disadvantage. If she should become ill, she may not seek timely emergency care due to lack of social support, childcare, or transportation.

**Location:** Where a woman lives in proximity to health care may affect her outcome in the event of a health care emergency. Many rural hospitals have closed or no longer offer obstetric services, so a woman dwelling in a "health care desert" may not find emergency care as readily as an urban woman. Protocols and partnerships for transport of critically ill women from low level to higher level hospitals are essential so life-saving care can be provided quickly in an emergency. So too, is incentivizing training and recruitment for reproductive specialists to locate to rural areas. <sup>133</sup>

Advanced maternal age: There are societal pressures for women to have children at older ages due to delayed marriage, education and career prioritization, access to birth control and abortion, infertility, and other factors. The average age at first birth has increased from 21 (1970) to 27 (1990) to 30 (2019). Advanced maternal age is associated with an increased risk of maternal death. The CDC documents that from 2003 to 2016, U.S. maternal mortality in the population 25-34 years old was 7/100,000 but this skyrocketed to 79/100,000 in the 45-54 years old group. Assisted reproductive technology has advanced dramatically. Physicians can perform miraculous interventions to help infertile women, but they may have difficulty saying "no" to the requests of those who have preexisting conditions that dramatically raise their risk of maternal mortality, such as morbid obesity or significantly advanced age. Reproductive specialists should seek to prioritize preconceptual counseling and optimize control of medical comorbidities prior

Human Services; 2019. Available at https://www.cdc.gov/reproductivehealth/maternal-mortality/erase-mm/mmrdata-brief 2019-h.pdf, accessed August 7, 2022.

<sup>&</sup>quot;Poverty in Black America," Black Demographics. Available at http://blackdemographics.com/households/poverty/, accessed August 7, 2022.

<sup>&</sup>lt;sup>132</sup> Dramatic increase in the outside of marriage in the United States from 1990 to 2016. Available at https://www.childtrends.org/publications/dramatic-increase-in-percentage-of-births-outside-marriage-among-whites-hispanics-and-women-with-higher-education-levels, accessed August 7, 2022.

<sup>&</sup>lt;sup>133</sup> Rural health. Available at <a href="https://www.cdc.gov/chronicdisease/resources/publications/factsheets/rural-health.htm">https://www.cdc.gov/chronicdisease/resources/publications/factsheets/rural-health.htm</a>, accessed September 6, 2022.

<sup>&</sup>lt;sup>134</sup> Morse A. Stable fertility rates 1990-2019 mask distinct variations by age. Available at https://www.census.gov/library/stories/2022/04/fertility-rates-declined-for-younger-women-increased-for-older-women.html?utm\_campaign=20220406msacos1ccstors&utm\_medium=email&utm\_source=govdelivery. Accessed July 11,2022.

Burgess AP, Dongarwar D, Spigel Z, et al. Pregnancy-related mortality in the United States, 2003-2016: age, race, and place of death. Am J Obstet Gynecol. 2020;222:489.e8.

to natural or assisted conception and should carefully consider the risks vs benefits of reproductive assistance at the upper extreme of maternal age. 136

Mental health factors may impact pregnancy outcomes. As noted above, 7-8.8% of maternal deaths have been attributed by MMRCs to mental health causes, but the lack of a standardized protocol to determine causality likely means that many deaths caused by mental illness are not identified as such. These identified deaths are usually related to childbirth, because as documented throughout this discussion, an abortion-related death due to mental health complications is almost impossible to detect due to inadequacies in the system.

The association between legal induced abortion and mental health consequences is controversial, but there is no longer any dispute over the fact that abortion is associated with higher rates of mental illness. The only dispute is over when, if ever, abortion is the sole cause of subsequent mental illness. <sup>137</sup> In either case, it is intuitive that the delivery of a desired baby and the lifestyle changes that accompany that should be protective of a mother's health, whereas a pregnancy loss might be expected to have a detrimental effect on her mental health.

A 2011 meta-analysis of 22 studies found an 81% overall increased risk of mental health problems after abortion. Specifically, it found 34% increased risk of anxiety, 37% increased depression, 110% increased alcohol abuse, 230% increased marijuana abuse, and 155% increased suicidal behavior. 138

A 2013 meta-analysis of all available studies, performed by a respected pro-choice researcher, concluded that there is "no credible evidence to support the research hypothesis that abortion reduces any mental health risks associated with unwanted/unplanned pregnancies that come to term". This researcher had previously documented a 30% increase in substance abuse and anxiety after abortion in a 30-year longitudinal study which controlled for confounding variables. <sup>140</sup>

A 2016 study examining data from the U.S. National Longitudinal Study of Adolescent to Adult Health revealed that abortion is linked to a 45% higher risk of subsequent mental health problems, after controlling for prior mental health and a host of other confounding factors. A dose effect was demonstrated, with each additional abortion associated with a 23% increased risk of subsequent mental health disorders. <sup>141</sup>

National public health action plan for the detection, prevention and management of infertility. Available at <a href="https://www.cdc.gov/reproductivehealth/infertility/pdf/drh\_nap\_final\_508.pdf">https://www.cdc.gov/reproductivehealth/infertility/pdf/drh\_nap\_final\_508.pdf</a>, accessed September 6, 2022.
 Reardon DC The Abortion and Mental Health Controversy: A Comprehensive Literature Review of Common Ground Agreements, Disagreements, Actionable Recommendations, and Research Opportunities. SAGE Open Medicine 6, 2018, 205031211880762.

<sup>&</sup>lt;sup>138</sup> Coleman PK Abortion and mental health: quantitative synthesis and analysis of research published 1995-2009. Br J Psychiatry, 2011;199:180-186.

<sup>&</sup>lt;sup>139</sup> Fergusson DM, Horwood LJ, and Boden JM Does abortion reduce the mental health risks of unwanted or unintended pregnancy? A re-appraisal of the evidence. Aus NZ J Psych, 2013;47(9):819-827; Fergusson DM, Horwood LJ, Boden JM. Abortion and mental health disorders: evidence from a 30-year longitudinal study. Br J Psychiatry. 2008;193(6):444-451.

Fergusson, DM, Horwood, LJ, and Boden, JM Abortion and mental health disorders: evidence from a 30-year longitudinal study. Br J Psychiatry, 2008;193:444-451; Fergusson DM, Horwood LJ, Boden JM. Abortion and mental health disorders: evidence from a 30-year longitudinal study. Br J Psychiatry. 2008;193(6):444-451.
 Sullins DP. Abortion, substance abuse and mental health in early adulthood: Thirteen-year longitudinal evidence from the U.S. Sage Open Medicine. 2016;4:1-11; Sullins DP. Affective and Substance Abuse Disorders Following Abortion by Pregnancy Intention in the United States: A Longitudinal Cohort Study. Medicina (B Aires) [Internet]. 2019;55(11):1-21.

Finally, a 2019 comprehensive review of the available literature revealed that two thirds (49 out of 75) of the available studies showed a positive correlation between abortion and adverse mental health outcomes.<sup>142</sup>

Additionally, the American Psychological Association has identified some sub-groups of women receiving abortion known to be at higher risk of adverse mental health outcomes, including those who experience pressure from others to terminate, those who end a pregnancy that is meaningful due to coercion or concern for maternal or fetal health, those who lack social support, those who are ambivalent about the decision, those with a history of mental health problems, those with previous abortions, and those who have an abortion later in pregnancy.<sup>143</sup>

"Deaths of despair" are an increasing but often underrecognized cause of maternal mortality. A review of 11,782 maternal deaths in 33 states from 2010-2019 documented 11.4% were attributed to drug-related causes, 5.4% due to suicide and 5.4% due to homicide (comprising over a quarter of all deaths). Family breakdown may predispose a woman to domestic violence leading to homicide. Suicide is a leading cause of maternal death in many countries. Numerous studies have documented that childbirth protects a woman from suicide, whereas induced or spontaneous pregnancy loss increases her risk. 147

Other high risk-taking behavior, including that associated with substance abuse, may result in death from motor vehicle accidents and or other accidents, and could be linked to a preceding pregnancy outcome, but these deaths are often excluded per protocol in the U.S. <sup>148</sup> It has been reported that 30% of Swedish maternal deaths were related to motor vehicle accidents and other

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<sup>&</sup>lt;sup>142</sup> American Association of Pro-Life Obstetricians & Gynecologists. Practice Bulletin 7. Abortion and Mental Health. Available at <a href="https://aaplog.org/wp-content/uploads/2019/12/FINAL-Abortion-Mental-Health-PB7.pdf">https://aaplog.org/wp-content/uploads/2019/12/FINAL-Abortion-Mental-Health-PB7.pdf</a>, accessed September 5, 2022.

<sup>&</sup>lt;sup>143</sup> Major B, Appelbaum M, Beckman L, et al. Report of the American Psychological Association Task Force on mental health and abortion. Washington, DC: American Psychological Association, 2008, 105 pp, available at <a href="https://www.apa.org/pi/women/programs/abortion/mental-health.pdf">https://www.apa.org/pi/women/programs/abortion/mental-health.pdf</a>, accessed September 5, 2022.

<sup>&</sup>lt;sup>144</sup> Margerison CE, Roberts MH, Gemmill A, et al. Pregnancy-Associated Deaths Due to Drugs, Suicide, and Homicide in the United States, 2010–2019Obstet Gynecol 2022;139:172–180.

<sup>&</sup>lt;sup>145</sup> Margerison CE, Roberts MH, Gemmill A, et al. Pregnancy-Associated Deaths Due to Drugs, Suicide, and Homicide in the United States, 2010–2019Obstet Gynecol 2022;139:172–180.

<sup>&</sup>lt;sup>146</sup> Oates M. Suicide: the leading cause of maternal death. Br J Psychiatry. 2003 Oct;183:279-81; Phillips MR et al., Suicide Rates in China, 1995–99, The Lancet. 2002;359:835-836; Hoyer G, Lund E. Suicide among women related to the number of children in marriage. Archives of General Psychiatry. 1993;50:134-137; Appleby L. Suicide after pregnancy and the first postnatal year. British Medical Journal. 1991;302:137-140.

<sup>&</sup>lt;sup>147</sup> Gissler M et al. Suicides after pregnancy in Finland, 1987-94. Register linkage study. BMJ. 1996;313:1431-1434; Karalis E, et al. Decreasing mortality during pregnancy and for a year after while mortality after termination of pregnancy remains high: a population based register study of pregnancy associated deaths in Finland 2001-2012. BJOG. 2017;124:1115-1121; Gissler M. et al. Injury deaths, suicides and homicides associated with pregnancy, Finland 1987-2000. Eur J of Public Health. 2005;15(5):459-463; Ney PG, et al. The effect of pregnancy loss on women's health. Soc Sci Med. 1994;38(9):1193-1200; Coleman PK. Post abortion mental health research: distilling quality evidence from a politicized professional literature. J of Am Phys and Surg. 2017;22(2):38-43; Giannandrea S, Cerulli C, Anson E, et al. Increased risk for postpartum psychiatric disorders among women with past pregnancy loss. J Women's Health. 2013;22(9):760-768; Gissler M, Karalis E and Ulander VM. Decreased suicide rate after induced abortion, after the Current Care Guidelines in Finland 1987–2012. Scand J Public Health 2014; 43(1):99–101.

<sup>&</sup>lt;sup>148</sup> Texas Maternal Morbidity and Mortality Task Force. 2016. Available at https://www.dshs.texas.gov/ConsumerandExternalAffairs/legislative/2016Reports/M3TFBiennialReport2016-7-15.pdf, accessed August 7, 2022; Coleman PK. Induced abortion and increased risk of substance abuse: a review of the evidence. Curr Womens Health Rev. 2005;1(1):21-34.

accidents. <sup>149</sup> Mental health professionals counseling women struggling with pregnancy loss have documented increased risk-taking and self-destructive behaviors, which may contribute to a higher risk of accidents. <sup>150</sup>

In determination of causation, Maternal Mortality Review Committees often neglect to attribute pregnancy contributions to mental health deaths unless they can document clear demonstration from a mental health profile form in the prenatal records, even though they concede this likely leads to under-attribution of pregnancy events and childbearing to mental health deaths. <sup>151</sup> Comprehensive analysis necessitates that MMRCs begin investigating accidental deaths within the framework of mental health conditions and pregnancy outcomes.

**Preterm birth:** There are several potential mechanisms by which an induced abortion may increase the risk of subsequent premature deliveries. Forced dilation of an unripe cervix may result in cervical trauma, and later cervical incompetence. Instrumental trauma of the uterus may result in faulty adherence of the placenta in subsequent pregnancies, resulting in abruption (premature separation) or placenta previa/acreta/increta (invasion of the placenta into the cervix, uterine wall, or other adjacent organs) which may require early delivery. In addition, the abortion procedure may alter the bacterial composition of the uterus, resulting in intra-amniotic infection in subsequent pregnancies. <sup>152</sup>

Obstetric interventions to delay delivery in the setting of premature labor or premature rupture of membranes can increase a woman's risk of medication toxicity and infection/sepsis which can lead to maternal death. Early deliveries are more frequently performed by cesarean section due to fetal malpresentation or other complications, which increase the risk of maternal mortality. Mothers who deliver preterm are also at a higher risk of medical complications later in life, including cardiovascular disease and stroke. Prematurity is the number one cause of infant deaths as well as the cause of substantial lifelong morbidity for many children. The overwhelming evidence from 168 studies over fifty years demonstrates a connection between abortion and preterm birth. One meta-analysis found that there was a 25% increased risk of premature birth in a subsequent pregnancy after one abortion, 32% after more than one, and 51% after more than two abortions. Likewise, another meta-analysis found a 35%

<sup>&</sup>lt;sup>149</sup> Kvarnstrand L, Milsom I, Lekander T, et al. Maternal fatalities, fetal and neonatal deaths related to motor vehicle crashes during pregnancy: A national population-based study. Acta Obstetrica et Gynecologica. 2008;87:946-952.

<sup>&</sup>lt;sup>150</sup> Burk T, Reardon D. Forbidden grief: the unspoken pain of abortion. Springfield, IL. Acorn Books. 2007, p. 334. <sup>151</sup> Report from maternal mortality review committees: A view into their critical role. Available at

https://www.cdcfoundation.org/sites/default/files/upload/pdf/MMRIAReport.pdf, accessed September 6, 2022. 
<sup>152</sup> Klemetti Birth Outcomes after induced abortion: A nationwide register-based study of first births in Finland. Hum Reprod 2012; Liao, et al. Repeated medical abortions and the risk of preterm birth in the subsequent pregnancy. Arch Gyn Ob 2011;284:579-586; Van Oppenraaij et al. Predicting Adverse Obstetric Outcome After Early Pregnancy Events and Complications: A Review. Human Reproduction Update Advance Access 2009;1(1):1-13.

<sup>&</sup>lt;sup>153</sup> CDC Premature Birth. Available at <a href="https://www.cdc.gov/features/prematurebirth/index.html">https://www.cdc.gov/features/prematurebirth/index.html</a>, Accessed September 5, 2022.

<sup>154</sup> American Association of Pro-Life Obstetricians & Gynecologists. Practice Bulletin 5. Abortion and Risks of Preterm Birth. Available at https://aaplog.org/wp-content/uploads/2021/11/PB-5-Overview-of-Abortion-and-PTB.pdf, accessed September 5, 2022; American Association of Pro-Life Obstetricians & Gynecologists. Practice Bulletin 11. A Detailed Examination of the Data on Surgical Abortion and Preterm Birth. Available at https://aaplog.org/wp-content/uploads/2021/11/PG-11-A-Detailed-Examination-of-the-Data-on-Surgical-Abortion-and-Preterm-Birth.pdf, accessed September 5, 2022.

<sup>155</sup> Swingle, et al. Abortion and the Risk of Subsequent Preterm Birth: A Systematic Review and Meta-

increased risk of delivery of a very low birthweight infant after one abortion, and 72% after two or more abortions. Despite the widespread knowledge of an abortion-preterm birth link in the academic literature, women are often not warned by their physicians that an induced abortion could increase the risk for premature birth of subsequent children. Abortion advocates downplay this link, as demonstrated by a 2018 National Academy of Sciences report, which considered only five of the 168 available studies, to falsely reassure the public that there was no link between induced abortion and preterm birth. 157

### Maternal mortality predictions as state-level abortion restrictions are enacted:

In the politically polarized climate following the Supreme Court's decision *in Dobbs vs Jackson Women's Health*, reversing *Roe vs Wade*, and allowing states to regulate abortion, allegations have arisen that this action will increase maternal mortality. One researcher even went so far as to predict that a total abortion ban in the U.S. would result in 7% increase in pregnancy-related deaths in the first year and 21% increases yearly thereafter. Fortunately, there are many reasons to expect abortion restrictions to decrease, rather than increase, maternal mortality.

**Abortion restrictions will not prohibit medical interventions for life-threatening emergencies** because all states have exemptions allowing abortion to save the life of the mother if her pregnancy poses a severe risk to her life. The necessity for an abortion in this situation is extremely rare, however, because usually these heart-breaking situations do not occur until the second half of pregnancy, when a woman's obstetrician can deliver her in a medically standard way, by induction or cesarean section, and often the baby's life can be saved also. An entire subspecialty of obstetrics-maternal fetal medicine-exists to help high risk women and their children make it safely through pregnancy and delivery. Health care providers ranging from the American Association of Pro-Life Obstetricians and Gynecologists to Planned Parenthood have all acknowledged that treatment of an ectopic pregnancy is not the same as abortion and all states will allow treatment of this life-threatening condition. <sup>160</sup>

Management of miscarriages is also not affected by legislation restricting elective abortion. Although the treatment of a deceased fetus can be similar to induced abortion, there is a clear difference in the intent of actively ending fetal life and caring for a woman once that life has ended. It is extraordinarily rare for a life-threatening miscarriage event to occur while a fetus is

Analysis. Journal of Reproductive Medicine. 2009;(54):95-108.

<sup>&</sup>lt;sup>156</sup> Shah, et al. Induced Termination of Pregnancy and Low Birth Weight and Preterm Birth: A Systematic Review and Meta-Analysis. BJOG. 2009;116(11):1425-1442.

<sup>&</sup>lt;sup>157</sup> National Academy of Sciences, Engineering and Medicine. The Safety and Quality of Abortion Care in the United States. March 16, 2018. Available at <a href="http://www.nationalacademies.org/hmd/Reports/2018/the-safety-and-quality-of-abortion-care-in-the-unitedstates.aspx">http://www.nationalacademies.org/hmd/Reports/2018/the-safety-and-quality-of-abortion-care-in-the-unitedstates.aspx</a>, accessed September 5, 2022.

<sup>158</sup> Stevenson AJ. The Pregnancy-Related Mortality Impact of a Total Abortion Ban in the United States: A Research Note on Increased Deaths Due to Remaining Pregnant. Demography 2021;58(6):2019–2028.

<sup>&</sup>lt;sup>159</sup> Harned M and Skop I. Pro-Life laws protect mom and baby: Pregnant women's lives are protected in all states. Available at <a href="https://lozierinstitute.org/pro-life-laws-protect-mom-and-baby-pregnant-womens-lives-are-protected-in-all-states/">https://lozierinstitute.org/pro-life-laws-protect-mom-and-baby-pregnant-womens-lives-are-protected-in-all-states/</a>, accessed September 6, 2022.

<sup>&</sup>lt;sup>160</sup> American Association of Pro-Life Obstetricians & Gynecologists. Practice Bulletin 9. Ectopic pregnancy. Available at https://aaplog.org

still alive, but if it does, the provider can provide the necessary treatment under the exemption for life-saving treatment.<sup>161</sup>

As previously noted, the population most impacted by maternal mortality, non-Hispanic Black women, has abortion rates that mirror their maternal mortality. Clearly abortion is not protecting them from maternal mortality and may be increasing their risk. The following are reasons that allowing fewer abortions will lower the risk of maternal mortality:

Abortion restrictions will limit dangerous, later abortions. Approximately 8-10% of U.S. abortions occur after the first trimester and 1% occur in the second half of pregnancy (after viability when the baby can survive separated from his mother). Non-Hispanic Black women have a higher percentage of later abortions (13%) than non-Hispanic white women (9%), raising their risk of death from the procedure. These abortions are usually performed by dilatation and evacuation (D&E), which is much more dangerous than earlier abortion procedures, as it requires forcibly dilating a strong muscular cervix and multiple blind passes of surgical instruments to disarticulate the fetus and remove the pregnancy tissue, with risks of hemorrhage, infection, retained tissue, damage to adjacent organs, anesthetic complications and stroke, heart attacks and deaths, if severe. Even though the CDC's data on maternal mortality is known to be incomplete, the available data documents that a woman's risk of death from abortion increases dramatically as the pregnancy progresses. The second strong and the pregnancy progresses.

**Abortion restrictions will reduce the incidence of repeat abortions.** As previously mentioned, abortion is associated with an increase in all-cause mortality rates, especially when women are exposed to multiple abortions. <sup>164</sup> To the degree abortion restrictions contribute to a reduction in exposure to multiple abortions, this should reduce the overall mortality rate of women of reproductive age.

Abortion restrictions will prevent some future pregnancy complications. Abortion can predispose to future pregnancy complications, although there is no way to document this causality with our current poor documentation systems. For example, surgical trauma to the uterine lining in a dilatation and suction, curettage or evacuation procedure, may cause an abnormal placental attachment in the next pregnancy. Placental abruption (premature separation) can occur if the attachment is not secure, and placental accreta syndrome (pathologic invasion) can occur if the attachment is too strong. Both of these abnormal placental attachments can lead to life-threatening bleeding at delivery. Also, abortion has been documented to increase the risk of a subsequent preterm birth which is associated with higher maternal mortality. Limiting

<sup>&</sup>lt;sup>161</sup> Skop I. Fact sheet: medical indications for separating a mother and her unborn child. Available at <a href="https://lozierinstitute.org/fact-sheet-medical-indications-for-separating-a-mother-and-her-unborn-child/">https://lozierinstitute.org/fact-sheet-medical-indications-for-separating-a-mother-and-her-unborn-child/</a>, accessed September 6, 2022.

<sup>&</sup>lt;sup>162</sup> "Abortion rates by race and ethnicity," Guttmacher Institute. Available at https://www.guttmacher.org/report/characteristics-us-abortion-patients-2014, accessed August 7, 2022; Jones R and Finer L. Who Has Second Trimester Abortions in the U.S.? Contraception 2012;85:544–51.

<sup>&</sup>lt;sup>163</sup> Bartlett LA, Berg CJ, Shulman HB, et al. Risk factors for legal induced-abortion-related mortality in the U.S. Obstet Gynecol. 2004;103(4):729-737.

<sup>&</sup>lt;sup>164</sup> Liao, et al. Repeated medical abortions and the risk of preterm birth in the subsequent pregnancy. Arch Gyn Ob 2011;284:579-586

Swingle, et al. Abortion and the Risk of Subsequent Preterm Birth: A Systematic Review and Meta-Analysis. Journal of Reproductive Medicine. 2009;(54):95-108; Shah, et al. Induced Termination of Pregnancy and Low Birth Weight and Preterm Birth: A Systematic Review and Meta-Analysis. BJOG. 2009;116(11):1425-1442.

abortion will decrease women's risk of maternal mortality in subsequent pregnancies for these reasons.

Abortion restrictions will prevent future mental health disorders in some women. Abortion is linked to mental health disorders such as anxiety, depression, substance abuse or overdose, excessive risk-taking behavior, self-harm and suicide, all of which can contribute to maternal mortality. 166 Unfortunately, our inadequate maternal mortality reporting system often does not detect these "deaths of despair" related to abortion. Conversely, delivery of a new baby often leads a woman to reduce her risk of accidents by staying at home to care for her new child. Abortion restrictions may lead to more fathers taking responsibility for their children and decrease the rates of single motherhood. Abortion has devastated the family structure and social relationships in our country. The narrative that reproduction is a "woman's choice" has led many men to be absent fathers if a woman chooses to give birth to her child. This increases the odds that she lives in poverty as a single mother, which is associated with medical conditions such as obesity, hypertension, diabetes, and lack of insurance. Without a supportive partner or other family support to encourage her to seek help in a medical emergency, access to transportation, or childcare for other children, she may delay life-saving medical care until it is too late. It is beyond the scope of this discussion, but absent fathers have also been documented to contribute to many other societal ills. 167

Abortion restrictions will encourage more women to give birth and are unlikely to result in illegal septic abortions. The frightening narrative that a woman denied abortion will seek it in an unsafe way, resulting in 5000-10,000 deaths yearly, drove its widespread legalization in 1973, and is being recycled today as states pose restrictions. Yet, in the years prior to Roe vs Wade, the CDC documented less than 100 deaths from both legal and illegal abortions. Abortion had been becoming safer long before it was legalized due to improved surgical techniques, safer anesthesia, and widespread antibiotic use. Even then, 90% of abortions were performed by physicians, albeit illegally. Today, abortion advocates are aggressively promoting unsupervised medical abortion to women in states with restrictions. Although more likely to result in complications than surgical abortion, only 26 deaths have been attributed to medical abortion in the U.S. since 2000, so it is unlikely that restrictions will contribute to excessive maternal deaths. Besides, the most likely outcome for a woman who encounters obstacles to abortion is that she will carry her pregnancy to term and grow to love her child.

Abortion restrictions will encourage both men and women to change their sexual behavior. Studies of changes in abortion laws, both in the U.S. and internationally, show that with moderate limitations on abortion, the abortion rate goes down, while the birth rate stays the same. With tighter restrictions, such as a complete ban, this may temporarily increase the birth rate by a small amount, but this stabilizes over time. As the "cost" of abortion rises, women

<sup>&</sup>lt;sup>166</sup> American Association of Pro-Life Obstetricians & Gynecologists. Practice Bulletin 7. Abortion and Mental Health. Available at https://aaplog.org/wp-content/uploads/2019/12/FINAL-Abortion-Mental-Health-PB7.pdf, accessed September 5, 2022.

<sup>&</sup>quot;Child Abuse Statistics & Facts," Childhelp, available at <a href="https://www.childhelp.org/child-abuse-statistics/#:~:text=More%20than%2070%25%20of%20the,least%20one%20parent%20as%20perpetrator,">https://www.childhelp.org/child-abuse-statistics/#:~:text=More%20than%2070%25%20of%20the,least%20one%20parent%20as%20perpetrator,</a> accessed September 6, 2022; Philip Ney, Relationship between Abortion and Child Abuse. The Canadian Journal of Psychiatry 24 (1979): 610-620; Richard Stith Her Choice, Her Problem: How Having a Choice Can Diminish Family Solidarity. International Journal of the Jurisprudence of the Family 2011;2: 179.

<sup>&</sup>lt;sup>168</sup> CDC Abortion Surveillance Summaries. Available at <u>www.stacks.cdc.gov</u>, accessed August 8, 2022

<sup>&</sup>lt;sup>169</sup> Calderone D. Illegal abortion as a public health problem. AJ of Public Health. 1960;50:949.

modify their behavior by decreasing promiscuous sexual activity and use of more effective contraception. <sup>170</sup>

Abortion restrictions may reduce the number of unwanted abortions. As many as 64% of women with a history of abortion report feeling pressured into their abortions by other people, such as their male partner or parents. Since "perceived pressure from others" to have an abortion is one of the risk factors for mental health problems after abortion that has been identified by the APA, it is reasonable to hope that abortion restrictions, especially those requiring abortion providers to screen for mental health risk factors, will reduce the rate of abortion in women at greatest risk of negative psychological reactions. This will reduce the rate of suicide and self-destructive behaviors that have been observed among women exposed to unwanted or coerced abortions.

**Abortion restrictions in other countries have not been shown to increase maternal mortality.** Examination of international trends demonstrates that maternal mortality does not increase after abortion restrictions are imposed. Chile, which had legal abortion from 1957-1988 and prohibited abortion from 1989-2007, found that maternal mortality declined despite the change in legal status of abortion as education and obstetrical care improved. Similarly, Mexican data showed the 32 states that permitted abortion had a 30% higher maternal mortality ratio and 89% higher abortion mortality rate than states with restrictive abortion laws. Likewise, demographically similar countries of the Republic of Ireland and the United Kingdom with disparate abortion laws, demonstrated a lower maternal mortality rate in restrictive Ireland, than in the permissive UK. Salvador, Poland, and Nicaragua, which all enacted abortion restrictions, have seen their maternal mortality improve afterwards. South Africa, on the other hand, has seen maternal mortality worsen after the legalization of abortion. Throwing more money at the problem is unlikely to be the solution. While the U.S. spends \$10,103 per person per year on health care, one of the poorest countries in Europe, Moldova, spends \$244.

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<sup>&</sup>lt;sup>170</sup> Levine P. Sex and Consequences: Abortion, Public Policy, and the Economics of Fertility. (Princeton University Press. 2004.) P 107-132.

<sup>&</sup>lt;sup>171</sup> Rue VM, Coleman PK, Rue JJ, et al. Induced abortion and traumatic stress: a preliminary comparison of American and Russian women. Med Sci Monit 2004; 10(10): SR5–SR16.

<sup>51.</sup> Major B, Mueller P and Hildebrandt K. Attributions, expectations

<sup>&</sup>lt;sup>172</sup> Koch E, Thorp J, Bravo M, et al. Women's educational level, maternal health facilities, abortion legislation and maternal deaths: A natural experiment in Chile from 1957-2007. PlosOne 2012;7(5):1-16.

<sup>&</sup>lt;sup>173</sup> Koch E, Chireau M, Pliego F,et al. Abortion legislation, maternal healthcare, fertility, female literacy, sanitation, violence against women and maternal deaths: a natural experiment in 32 Mexican states. British Medical Journal Open. 2015;5:e006013.

<sup>&</sup>lt;sup>174</sup>Confidential maternal death enquiry in Ireland. 2016-2018. Available at <a href="https://www.ucc.ie/en/media/research/maternaldeathenquiryireland/ConfidentialMaternalDeathEnquiryReport2016">https://www.ucc.ie/en/media/research/maternaldeathenquiryireland/ConfidentialMaternalDeathEnquiryReport2016</a> <a href="https://www.ucc.ie/en/media/research/maternaldeathenquiryireland/ConfidentialMaternalDeathEnquiryReport2016">https://www.ucc.ie/en/media/research/maternaldeathenquiryireland/ConfidentialMaternalDeathEnquiryReport2016</a> <a href="https://www.ucc.ie/en/media/research/maternaldeathenquiryireland/ConfidentialMaternalDeathEnquiryReport2016">https://www.ucc.ie/en/media/research/maternaldeathenquiryireland/ConfidentialMaternalDeathEnquiryReport2016</a> <a href="https://www.ucc.ie/en/media/research/maternaldeathenquiryireland/ConfidentialMaternalDeathEnquiryReport2016">https://www.ucc.ie/en/media/research/maternaldeathenquiryireland/ConfidentialMaternalDeathEnquiryReport2016</a> <a href="https://www.ucc.ie/en/media/research/maternaldeathenquiryireland/ConfidentialMaternalDeathEnquiryReport2016">https://www.ucc.ie/en/media/research/maternaldeathenquiryireland/ConfidentialMaternalDeathEnquiryReport2016</a> <a href="https://www.ucc.ie/en/media/research/maternaldeathenquiryReport2016">https://www.ucc.ie/en/media/research/maternaldeathenquiryReport2016</a> <a href="https://www.ucc.ie/en/media/research/maternaldeathenquiryReport2016">https://www.ucc.ie/en/media/research/maternaldeathenquiryReport2016</a> <a href="https://www.ucc.ie/en/media/research/maternaldeathenquiryReport2016">https://www.ucc.ie/en/media/research/maternaldeathenquiryReport2016</a> <a href="https://www.ucc.ie/en/media/research/maternaldeathenquiryReport2016">https://www.ucc.ie/en/media/research/maternaldeathenquiryReport2016</a> <a href="https://www.ucc.ie/en/media/research/maternaldeathenquiryReport2016">https://www.ucc.ie/en/media/research/maternaldeathenquiryReport2016</a> <a href="https://www.ucc.ie/en/media/research/maternaldeathenquiryRep

<sup>&</sup>lt;sup>175</sup> Notifications in accordance with section 20 of the protection of life during pregnancy act 2013. Available at <a href="https://assets.gov.ie/19420/c9bc493cb2274e098e28f3ba59067ba0.pdf">https://assets.gov.ie/19420/c9bc493cb2274e098e28f3ba59067ba0.pdf</a>, accessed August 29, 2022.

<sup>176</sup> Abortion statistics: England and Wales 2018. Available at <a href="https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\_data/file/808556/Abortion\_Statistics\_England\_and\_Wales\_2018\_1\_.pdf">https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\_data/file/808556/Abortion\_Statistics\_England\_and\_Wales\_2018\_1\_.pdf</a>, accessed August 29, 2022.

<sup>&</sup>lt;sup>177</sup> Hogan MC, Foreman KJ, Naghavi M,et al. Maternal mortality for 181 countries, 1980–2008: a systematic analysis of progress towards Millennium Development Goal 5. Lancet 2010; 375: 1609–23

<sup>&</sup>lt;sup>178</sup> Current health expenditures per capita-Moldova, United States. Available at <a href="https://data.worldbank.org/indicator/SH.XPD.CHEX.PC.CD?locations=MD-US">https://data.worldbank.org/indicator/SH.XPD.CHEX.PC.CD?locations=MD-US</a>, accessed August 29, 2022.

births. <sup>179</sup> In fact, the U.S. has the worst maternal mortality ratios compared to other developed countries. <sup>180</sup> The U.S. has also been noted to have a relative undersupply of maternity care providers, especially midwives, and lacks comprehensive postpartum support. <sup>181</sup> **Conclusion:** 

The politics of maternal mortality and legal induced abortion should not prevent us from following the data where it leads. Far too often, discussion of maternal mortality has branched into policy issues rather than true concern for discerning the factors that really underlie the disgraceful statistics of America's excessive mortality rate, the worst in the developed world. We need to all come together in the search for truth in order to care for our mothers. Documenting all pregnancy events, complications and maternal deaths is a necessary place to start. Pursuit of better maternal morbidity and mortality data should be a commonsense, bipartisan initiative. We can't truly answer a problem unless we know how widespread the problem is and what factors contribute to it.

For those who are hoping for quick fixes to our maternal mortality crisis, unfortunately we are likely only beginning to understand the extent of the need. Improved medical intervention for obstetric emergencies in hospitals would clearly be beneficial and is being addressed, but awareness is needed that any pregnancy outcome can result in maternal mortality, and these events often occur outside of the health care system, often temporally separated from the end of pregnancy. We must expand detection of adverse events in early pregnancy, particularly when related to legal induced abortion. Mental health disorders must be thoroughly investigated, and diligence applied to determining how a pregnancy event may have contributed to a "death of despair".

# <u>Policy recommendations to improve data accuracy and protect women from maternal deaths:</u>

### **United States Department of Health and Human Services:**

- Mandate reporting of all pregnancy outcomes (term and preterm live births and stillbirths, legal induced abortions, ectopic pregnancies, gestational trophoblastic disease and miscarriages) by local providers, collected by state health departments, and then relayed to the CDC. Do not permit a reporting exemption for induced abortion after 20 weeks as is currently allowed.
- Standardize reporting forms should be consistent in all reporting areas. Ideally this would be in the form of "fetal loss certificates" much as live and stillbirths after 20 weeks are documented on birth certificates. To allay privacy concerns, all the same privacy protection mechanisms used in other medical reports filed with state health officials (such

World Health Organization Trends in Maternal Mortality 2000-2071. Available at: <a href="https://apps.who.int/iris/bitstream/handle/10665/327596/WHO-RHR-19.23-eng.pdf">https://apps.who.int/iris/bitstream/handle/10665/327596/WHO-RHR-19.23-eng.pdf</a>, accessed August 29, 2022.
 What we see in the shameful trends in U.S. maternal health. New York Times. November 17, 2021. Available at <a href="https://www.nytimes.com/interactive/2021/11/17/opinion/maternal-pregnancy-health.html">https://www.nytimes.com/interactive/2021/11/17/opinion/maternal-pregnancy-health.html</a>, accessed August 29, 2022.

<sup>&</sup>lt;sup>181</sup> Maternal mortality and maternity care in the United States compared to 10 other developed countries. November 18, 2020. Commonwealth Fund. Available at <a href="https://www.commonwealthfund.org/publications/issue-briefs/2020/nov/maternal-mortality-maternity-care-us-compared-10-countries">https://www.commonwealthfund.org/publications/issue-briefs/2020/nov/maternal-mortality-maternity-care-us-compared-10-countries</a>, accessed August 31, 2022.

- as with cancer registries, venereal disease reports, birth defect registries) should apply to protect personal identifying information.
- Mandate reporting of all complications and deaths associated within a year of any pregnancy outcome to state health departments, with special emphasis on reporting of complications that occur outside of the standard medical system (hospitals usually have comprehensive reporting systems but abortion and private gynecologic clinics often do not). Be aware that severe maternal morbidity is closely related to maternal mortality and accurate reporting of "near-miss" events should also be prioritized and mandated. Enforce strict noncompliance penalties for failure to report or misrepresentation of events (for example, induced abortion complications intentionally misreported as resulting from a miscarriage).
- Enforce these mandatory reports by linking requirements to federal CMS reimbursement, with monetary penalties for withholding data. Do not allow states to refuse to report abortions or abortion-associated deaths for ideologic reasons as California, Maryland and New Hampshire do currently.

### **States' Departments of Health:**

- Link reproductive age women's death certificates, birth certificates and fetal loss certificates to publish a report each year tabulating the total number of deaths for each pregnancy outcome within 42 days and within one year of the deceased woman's most recent pregnancy.
- Streamline and standardize the death certification electronic medical records system.
- Create an easy-to-use electronic reporting form for pregnancy complications that do not result in death and ensure that doctors are aware that it is available and encouraged to report.
- Make tutorials readily available for physicians to ensure accurate use of death and complication reporting forms, engaging state medical societies to assist with promotion.
- Provide the reporting forms in a timely fashion and make submission as simple as possible through direct electronic transmission.

### Hospital Associations, Joint Commission AHO and State Medical and Pharmacy Boards:

- Educate physicians on accurate reporting of pregnancy outcomes and complications with specific recommendations on how this should be done through email blasts, required CME, residency training requirements, etc.
- Provide oversight on complication trends related to the various ends of pregnancy and require the same standards of care from abortion providers as from all other health care providers.
- When states implement new legal induced abortion restrictions, state medical boards should engage with legal counsel, and state attorneys general to provide interpretation of the new legislation to health care providers to minimize confusion and misinterpretation of the laws. Hospital systems should create medical oversite quality committees that can be convened rapidly to facilitate decisions on emergency care in situations where medical

- compliance with state law may be unclear. Similarly, state boards of pharmacy should give guidance regarding protocols and medical oversite of potentially teratogenic and embryocidal medications.
- All hospitals should utilize maternal safety toolkits to assess risk and provide
  preventative treatment for hypertensive disorders, sepsis, thromboembolism and
  hemorrhage and hospitals should require frequent emergency drills to train staff to more
  effectively manage emergent situations.
- Improve rural healthcare by creating algorithms for care and transfer from low level rural hospitals to higher level hospitals for complex cases. Provide community education notifying residents of facilities where obstetric care is available. Prioritize and incentivize recruiting and retention of rural physicians.
- Develop new primary care and ob/gyn community residency programs in rural areas. Currently, only 93% of allopathic medical students and 90% of osteopathic medical students obtain their desired residency opportunity after medical school graduation. While we bemoan a shortage of rural physicians, resulting in "health care deserts", Congress has failed to allocate additional residency funding in over thirty years. Prioritizing funding to train healthcare providers who desire to provide primary and obstetric care in underserved areas will improve outcomes in those areas and optimize the investment we have made in training physicians.

## **ICD-10 coding registry:**

• Expand induced abortion complication and death causes coding to account for all possible complications and optimize search engine discovery.

### **Reproductive Health Specialists:**

- Reproductive specialists should optimize health of women prior to assisting them in attaining pregnancy. Primary care physicians and ob/gyns should prioritize discussion of pregnancy intent, with effective contraception offered if pregnancy not desired; and if pregnancy is desired, pre-pregnancy optimization of high-risk medical conditions.
- Attention should be directed to improving obstetric management of high-risk pregnant
  women with advanced age, obesity, diabetes, hypertension, thrombophilia, cardiac
  disease, congenital cardiac disorders and/or prior poor pregnancy outcomes, as well as
  managing new onset pregnancy complications such as multiple gestation, gestational
  diabetes, pregnancy-induced hypertension and thromboembolism.
- Women should be counseled regarding the increased risks associated with induced abortion on reproductive and mental health and with childbirth at more advanced ages.