Advisory Committee on Infant and Maternal Mortality

Meeting Minutes of December 7, 2022

Virtual Meeting

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DAY ONE: Wednesday, December 7, 2022

Welcome

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

Ms. Vanessa Lee called the Advisory Committee on Infant and Maternal Mortality (ACIMM) to order and welcomed attendees. Dr. Edward Ehlinger welcomed the Committee and members of the public, and briefly shared historical events such as the actions of President Andrew Jackson who moved American Indians from the southeast United States (US) to west of the Mississippi between 1829 and 1831. He expressed hope that the Committee's report on recommendations for American Indian and Alaska Native (AI/AN) mothers and infants would be a step toward addressing the infamy of these events.

The Committee unanimously passed a motion to approve the minutes of the September 2022 meeting.

Committee members viewed a <u>video</u> from the Centers for Disease Control and Prevention (CDC) <u>Hear Her Campaign</u>, which now highlights stories from AI/AN mothers about their experiences with pregnancy-related complications.

Finalize Report to the Secretary

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

Dr. Ehlinger reminded Committee members that their August 2021 report of recommendations touched on issues related to AI/AN mothers and infants, but could not adequately address the scope of challenges. The Committee therefore decided to focus more time and attention in the coming year on maternal and infant mortality among the AI/AN population. They invited a number of experts, stakeholders, and AI/AN people with lived experience to Committee meetings between September 2021 and June 2022, culminating in the September 2022 meeting on tribal land . Dr. Ehlinger acknowledged Committee member Dr. Janelle Palacios for her leadership and work to make that meeting a success. Dr. Ehlinger also expressed continued frustration that the Committee's requests for additional data from the Indian Health Service (IHS) had been unsuccessful.

Dr. Ehlinger gave an overview of the resulting report of recommendations for the Department of Health and Human Services (HHS) Secretary, "Making Amends: Recommended Strategies and Actions to Improve the Health and Safety of American Indian and Alaska Native Mothers and Infants". It includes a preface of important language, the history and context of challenges faced by AI/AN people, recommended strategies and actions, a number of quotes from AI/AN individuals who testified at Committee meetings, a full list of contributors, and a list of referenced documents (e.g., <u>Broken Promises</u>). The recommendations had been reviewed by a number of AI/AN individuals, including Two Spirit people who expressed gratitude for the inclusion of non-binary individuals in the report.

Dr. Ehlinger provided a general overview of the three recommended areas for strategic action, which were: 1) make the health and safety of AI/AN mothers and infants a priority for action; 2) improve the living conditions of AI/AN mothers and infants and assure universal access to high quality health care; and 3) address urgent and immediate challenges that disproportionately affect AI/AN women before, during, and after pregnancy. Cultural strength and resilience—both collective and intergenerational—were cross-cutting themes built into all three areas for strategic action. Under the three areas for strategic action were 58 specific recommendations addressing key issues such as data sovereignty, access to health care, social determinates of health, workforce diversity, missing and murdered Indigenous women and girls, incarcerated women, violence, substance use, and mental health. The report also included a standalone recommendation for federal advisory committee meetings to be held in the communities of focus in order to assure greater engagement, understanding, representation, and accountability with the population of interest.

Discussion

Dr. Ehlinger asked for final feedback on the report and recommendations, and the process of getting here. A Committee member suggested that the recommendations include references to qualitative data because stories provided a rich resource of information that could not adequately be captured by quantitative data alone.

Another Committee member added that the standalone recommendation #59 was especially important because it conveyed the importance of "nothing about us without us." It was suggested that there were other critically impacted populations that the Committee should address going forward. Dr. Ehlinger agreed and said that the report indicated that a focus on this population will benefit every other critically impacted population.

A Committee member expressed appreciation for the historical context included in the report and suggested that the report was the beginning of action and would provide guidance to federal agencies to dig deeper into the work. Dr. Ehlinger noted the importance of Dr. Palacios' input into the report, which highlighted the need for advisory committees to be more inclusive in their membership.

One member said that interweaving stories and data created a very compelling story. She expressed appreciation that the Committee was able to go to the community to hear their stories and suggested that community engagement will continue to be important going forward to identify other issues and ensure that recommendations are truly relevant.

A member noted that Dr. Palacios carried a heavy burden by being the only Indigenous member on the Committee and suggested that this should not be the model going forward. The Committee member also noted it was important that the report reflected that those who receive funding and take action are representative of the Indigenous community. Dr. Ehlinger agreed that Dr. Palacios carried a heavy burden and added that her work also created opportunities for others from the AI/AN communities to come forward and help.

Dr. Palacios acknowledged Dr. Ehlinger and Dr. Magda Peck for their mentorship and support for sharing her voice and historical context. As her membership term is ending, she emphasized the importance of not burdening an individual or having only one representative on the Committee. Dr. Ehlinger noted that the report of recommendations to the Secretary will include Dr. Palacios' signature, along with his, as a way to elevate representative leaders.

A Committee member noted the report of recommendations was not just a list of recommendations, but rather a resource for people who will be doing the work. The member talked about how this work had been a learning experience, which was both uncomfortable in the recognition of how much she did not know, and energizing in terms of what could be done.

Another Committee member said that the in-person meeting on native land in September provided a connection to the community and highlighted similarities across other communities affected by white supremacy, whose stories are often unspoken or silenced. She emphasized how difficult it was for a person to understand the impact of something if they are not experiencing it and the in-person ACIMM meeting experience provided that connection. Dr. Ehlinger added that there were multiple community partnerships that were formed during that meeting that would otherwise not have existed.

Mr. Lee Wilson of the Maternal and Child Health Bureau (MCHB) at the Health Resources and Services Administration (HRSA) said that he had two major takeaways from the in-person meeting in September. The first was the degree to which Committee members converged to hear and absorb the messages from the community. The second was the amount of work yet to be done. He emphasized the need to further uncover the circumstances surrounding the AI/AN population to really understand the extent of work needed. Dr. Ehlinger acknowledged that the Shakopee Mdewakanton Sioux Community was one of the richest tribes in the country and not representative of other tribes. He agreed that there is a need to expand understanding across other living conditions.

One Committee member talked about how hearing multiple stories from multiple people in person allowed her to change her narrative about urban AI/AN individuals. She now recognized that the 70 percent of AI/AN people who live off the reservation were not necessarily "urban". As a result, she thought CityMatCH (an organization she had founded) would change the way they approached the urban perspective and would build relationships that had never before existed. The member also noted the serendipity of having Indigenous women singers in another part of the September meeting venue that provided the Committee with an unexpected opportunity to hear native voices.

A member added that the women singers also brought their young daughters, which highlighted the urgency of protecting children. She talked about the importance of the recommendation outlined in the report to support federal advisory committees traveling to communities and neighborhoods so that they are exposed to the populations that they develop recommendations for and/or on behalf of. She expressed hope that this requirement would be carried through HRSA/MCHB.

Committee members that could not attend the September meeting in person were asked to reflect on what they might need to make the in-person stories more tangible. All agreed that the reflections of others who shared how their in-person experiences shaped their thinking were very helpful.

Vote to Approve Report

ACIMM Appointed Members

The Committee unanimously passed a motion to approve the report *Making Amends:*Recommended Strategies and Actions to Improve the Health and Safety of American Indian and Alaska Native Mothers and Infants and send it forward to the HHS Secretary.

Discussion: Use and Dissemination of Report

Strategic Storytelling
Magda Peck, ScD, ACIMM Member
Janelle Palacios, Ph.D. CMN, RN, ACIMM Member

Dr. Peck introduced the concept of strategic storytelling as an evidence-based practice that honors the sacred stories that are integral to the Committee's work for equity and justice towards healthier women, fathers, children, families, and communities.

Dr. Palacios quoted Harvard lecturer Marshal Ganz, who said that the power of story is that "a story communicates fear, hope, and anxiety, and because we can feel it, we get the moral not just as a concept, but as a teaching of our hearts." Dr. Palacios retold the birth story of Rhonda Clairmont Swaney, former Tribal Council Chair for the Salish and Kootenai Tribes, which had also been shared with the Committee at the September 2022 meeting. Ms. Swaney's birth story from over 45 years ago highlighted persistent challenges still common among pregnant AI/AN individuals today, including limited access to health care, inadequate patient education about high risk conditions and risk factors, unmet mental health needs, subjugation, and systemic racism.

Dr. Palacios talked about how there were dominant stories that created and reinforced inaccurate stereotypes of historically marginalized people, such as being drug-seeking or having a higher tolerance for pain. She explained the importance of understanding the history behind the dominant perspectives and that the only way to change these perceptions was to replace them with powerful stories that connected the receiver to the storyteller. Neuroscientists have shown that human brains are wired to make sense of the world through stories.

Dr. Peck said that one of the reasons the *Making Amends* report was powerful was that it contextualized data with stories and history. She stated there was a need to shift business practices towards ensuring that data was humanized with stories as an integral part of developing valid and reliable practices and policies. Dr. Peck expressed hope that this report would set a standard for advisory committees and public health professionals to use stories not just as community engagement, but toward shaping sustainable solutions. She then reviewed several examples of evidence-based and practice-informed storytelling initiatives currently being used to

effectively transmit important narratives strategically and intentionally. Examples included the CDC <u>Hear Her Campaign</u>, the Alliance for Innovation on Maternal Health (AIM) Community Care Initiative (CCI) <u>Maternal Monologues Toolkit</u>, and the University of Massachusetts Amherst <u>Hear Our Stories</u> initiative. She emphasized how stories could impact policy, highlighting the stories collected by National Public Radio (NPR) and ProPublica in <u>Lost Mothers: Maternal Mortality in the US</u> and the <u>Kira Johnson Act</u> to address racial equity that resulted from the story of Kira Johnson's preventable death after childbirth. Other grassroots storytelling efforts mentioned were the podcasts <u>Birthright</u> and <u>Birth Stories in Color</u>, and Dasha Kelly-Hamilton's show <u>Makin' Cake</u>, which all promote community conversations and change.

Dr. Peck invited Committee members to share other examples of strategic storytelling to help the Committee build an inventory of practices. She encouraged them to use best practices in "storifying" ACIMM's work such as intentionality, ethical consideration, and science- and experience-based knowledge. Dr. Palacios provided an overview of how "storifying" shaped the *Making Amends* report. It was understood that data alone were insufficient as context and that history and lived experience were needed to frame the narrative embedded in the recommendations. She said that Dr. Ehlinger had contacted each person who was quoted or whose story was included in the report to ensure that the information was accurate. This effort to engage people with lived experience catalyzed new partnerships and reinforced the Committee's commitment to improving the lives of AI/AN women, infants, and families.

Hear Her Campaign Charlan D. Kroelinger, Ph.D., CDC-Division of Reproductive Health Sarah David Carrigan, M.P.H., CDC-Division of Reproductive Health

Ms. Sarah Carrigan provided an overview of work that CDC was conducting to serve AI/AN women and communities. She shared that AI/AN women were two times more likely to die from complications related to pregnancy than White women. This disparity resulted from historical trauma and systemic barriers rooted in racism, colonization, genocide, forced migration, reproductive coercion, and cultural erasure. Ms. Carrigan stated that CDC was dedicated to reaching AI/AN communities with resources, to better understand pregnancy-related deaths, and applying these data into action. She described the Hear Her Campaign, which CDC launched in August of 2020, to raise awareness of potentially life-threatening warning signs during pregnancy and to improve communication between health care providers and patients. In 2021, the HHS Office of Minority Health provided funding to develop a segment of Hear Her that dedicated to AI/AN women and communities. Storytelling was at the center of the Hear Her Campaign, she explained. CDC engaged with AI/AN people to include their voices and perspectives throughout the development of the AI/AN-dedicated segment. She additionally shared that CDC engaged an American Indian photographer to capture images for the campaign.

Ms. Carrigan then shared a video from the Hear Her campaign that emphasized the importance of culturally appropriate care and self-advocacy. Ms. Carrigan invited Committee members to view other <u>AI/AN Hear Her stories</u>. In addition to the Hear Her Campaign, she said CDC developed educational materials such as the <u>Urgent Warning Signs</u> poster, <u>conversation guides</u>, and <u>materials for health care providers</u>. Ms. Carrigan noted that CDC had also recently developed campaign materials such as <u>media resources</u> and <u>shareable graphics</u> that were

developed in collaboration with the National Indian Health Board. Additionally, she said CDC would be hosting a Tribal Learning Collaborative in January 2023 to help build tribal capacity for implementing these campaign materials.

Dr. Charlan Kroelinger then presented maternal mortality data from state maternal mortality review committees from 2017 to 2019. She said that the methodology for collecting these data were based on best practices outlined by organizations such as the Urban Indian Health Institute, which classified AI/AN persons through the inclusion of free text responses and regardless of Hispanic origin or multiple race classification. Across this time period, she said 17 pregnancy-related deaths were classified as AI/AN. Of these, 16 had a known underlying cause of death and 15 were determined to be preventable. The most frequent cause of death was mental health conditions, followed by hemorrhage. Dr. Kroelinger said that these data can be found on the CDC website.

Discussion

A Committee member expressed appreciation for the CDC's inclusion of AI/AN people and businesses to develop the Hear Her Campaign. She suggested that AI/AN people might also use free text to indicate their specific tribal affiliation rather than just "Native American" and encouraged CDC and other federal partners to consider identifying and counting these tribal affiliations to capture more of the population.

National MCH Organizations from September 2022 Meeting Scott Berns, MD, MPH, Chief Executive Officer, NICHQ LaToshia Rouse, CD/PCD(DONA), Board Member, NICHQ Terrance Moore, MA, Chief Executive Officer, AMCHP Magda Peck, ScD, Senior Advisor, CityMatCH

Dr. Scott Berns and Ms. LaToshia Rouse provided a brief update on the activities that the National Institute for Children's Health Quality (NICHQ) had engaged in since the September 2022 meeting. Dr. Berns shared that he plans to follow up with IHS to learn more about what is underlying the negative impressions that were discussed at the meeting. He had also shared the "Broken Promises" report during NICHQ meetings and said he has taken on a perspective of "giving up power" rather than "sharing power." He further shared that NICHQ had continued to build in antiracism and equity work throughout the organization and with more intentionality toward AI/AN communities. Specifically, he shared that NICHQ was meeting with the National Indian Health Board and addressing AI/AN populations in their grant proposals. And as the technical assistance and support center for Healthy Start communities, Dr. Berns shared that they had engaged with Dr. Palacios to conduct outreach with AI/AN communities.

Dr. Berns suggested that it was important for maternal and child health organizations to be ambassadors for the Committee's report. He stated that he had already shared some of the draft recommendations, which had started conversations specifically on what could be done to improve AI/AN data.

Mr. Terrance Moore noted that it was unusual to be asked back after presenting to a Committee panel to talk about the activities that partner organizations were moving forward, and suggested

that it should be a common business practice. He talked about the Committee's recommendations that the Association of Maternal & Child Health Programs (AMCHP) could immediately move forward. For instance, AMCHP had recently finalized their new strategic plan, which was centered on advancing health equity and reducing racism. They had also been meeting bimonthly with other organizations, such as NICHQ, the National Healthy Start Association, and CityMatCH, to discuss collective efforts in health equity, particularly as it related to the AI/AN population. He noted the recommendation to end data erasure and said that AMCHP hoped to work in partnership with CDC and HRSA to ensure that they were collecting accurate data, as well as qualitative data from storytelling. Part of AMCHP's strategic framework was to speak truth about the history and infrastructure that has caused great harm to the AI/AN population. Finally, he shared that AMCHP planned to engage the community, such as at their next conference where they hoped to hold a number of sessions dedicated to the Committee's recommendations and opportunities for partnerships. He invited Committee members to consider how to effectively shape and convene such sessions.

Dr. Ehlinger acknowledged Dr. Tina Pattara-Lau, Maternal and Child Health Consultant at IHS, and requested that she provide comments on what had been shared by the national organizations. Dr. Pattara-Lau stated that the Committee's recommendations would be helpful in guiding maternal and child health priorities at IHS and affirmed her ongoing commitment to the Committee. She talked about the sustainability of the health care workforce and her efforts to engage with youth as they considered their choices in education and training. She said she encouraged youth to physically visit IHS facilities, engage with practitioners and patients, and consider what skills were needed and where. She said that IHS was working on initiatives to address mental health and substance use disorders, which are common underlying causes of maternal mortality.

Dr. Peck spoke on behalf of Ms. Denise Pecha, Deputy Executive Director of CityMatCH, on the activities that CityMatCH had engaged in since the September meeting. The meeting, she said, was an impetus for every CityMatCH health department member to strengthen their ties with Urban Indian Health Centers. CityMatCH's next meeting would be held in September 2023 in New Orleans and Dr. Peck shared the organization planned to engage directly with tribal communities in that area. Finally, she noted that CityMatCH had connected with the Urban Indian Health Board to coordinate a strategy for urban Indian health.

Discussion

Dr. Ehlinger encouraged Committee members to work with their state maternal and child health directors to address AI/AN issues, such as data collection at the local and state levels. Collectively, he believed these efforts would help improve AI/AN health across the U.S.

A Committee member said that it was important that the report be shared verbally and face-to-face to ensure that the stories were not lost. Although it was a government document, there was a need to not lose the emotion and power that it was built from. She stated there was a need to provide a warm handoff of the recommendations to partners and communities rather than letting it sit on a shelf. She said that the Committee should continue to be intentional about bringing people and their stories into the work and expressed hope that this was not the end of an effort to

embed storytelling into the Committee's recommendations. Dr. Ehlinger said that a component of the Committee is partnership with and accountability to each other in order to move action forward.

Another member talked about how the Committee had not been very visible four years ago and that the new members were committed to raising its visibility and viability. This report and discussion were demonstrative of the restoration and growth of the Committee and had opened doors for the next iteration of Committee members to become ambassadors "for word to deed".

Public Comment

Vanessa Lee, MPH, Designated Federal Official, ACIMM

One request to provide oral comments had been received. Ms. Joy Burkhard, MBA, Founder and Executive Director of the nonprofit organization 2020 Mom (soon to be called the Policy Center for Maternal Mental Health) shared the mission of 2020 Mom was to close the gap in maternal mental health care by centering on the stories of mothers to develop critical and creative policy solutions. She described data such as one in five women suffer from maternal mental health disorders, and Black and Indigenous women suffer at nearly twice the rate as White women. She reiterated that the CDC shared previously during the meeting that suicide and drug overdose were the leading causes of maternal death, disproportionately affecting Indigenous and White women. Ms. Burkhard said they were particularly interested in reducing birth trauma and ensuring that all women were screened, accurately diagnosed, and offered a range of evidence-based treatment options. She thought there was an opportunity to further interagency and committee work in maternal mental health, given that it did not fall neatly under any one agency. She further shared that Healthcare Effectiveness Data and Information Set (HEDIS) data had recently included screening for maternal mental health disorders, and showed that less than 20 percent of all women in the U.S. were being screened. Ms. Burkhard invited Committee members to join the 2020 Mom 13th annual Maternal Mental Health forum in March 2023, which would include a presentation on Indigenous maternal mental health and maternal mortality.

Discussion

Committee members were interested in more information on the HEDIS measures and dates of the forum. Ms. Burkhard shared a link to the <u>HEDIS data</u> on maternal mental health screening and the <u>2020 Moms forum</u> on March 22-24, 2022.

Committee members expressed appreciation for the work that 2020 Mom was doing to increase awareness in maternal mental health and one member talked about the compounding factor of historical and intergenerational trauma that affected perinatal mental health in historically marginalized communities.

A member suggested that there should be Committee discussion about the storytelling tools that Committee members need to present the recommendations as one clear story and how they can best serve as ambassadors in the field.

Another Committee member noted that many birthing facilities require depression screening, but the challenge was what to do with a positive screen. A disproportionate number of Black, Indigenous, and people of color (BIPOC) do not have access to quality behavioral health services. She asked if there was an opportunity to incorporate and align efforts with primary care providers to support a continuum of care for birthing parents. Ms. Burkhard said that the bifurcation of mental health care delivery is a significant challenge. There were major workforce shortages across the U.S. particularly post-pandemic, she said. 2020 Mom developed 50 "levers" to pull toward addressing this challenge, 20 of which had been pulled (e.g., including maternal mental health screening data as a HEDIS measure), with much still left to do. She added that there had been an effort to identify obstetric providers as the medical home in the perinatal period and as an appropriate place for screening. Not all obstetricians agreed she said, and there had been some work looking into the use of peer support specialists to augment obstetric capacity for mental health screening, brief intervention, and care coordination.

Mr. Wilson said that HRSA MCHB had a number of programs focused on maternal mental health. For instance, their <u>Maternal Depression and Related Behavioral Disorders Program</u> was a "doc-to-doc" service currently in seven states and there was a plan to award a larger number of state grants, depending on 2023 funding. MCHB also hosted the <u>National Maternal Mental Health Hotline</u> that linked individuals to available services in their community. Ms. Burkhard expressed hope for a national doc-to-doc program that would reach all states.

Federal Update: Healthy Start Initiative

Benita Baker, MS, Healthy Start Branch Chief, Division of Healthy Start and Perinatal Services, MCHB, HRSA

Lee Wilson, Director, Division of Healthy Start and Perinatal Services, MCHB, HRSA

Ms. Benita Baker provided a brief overview of the Healthy Start Initiative, which was established in 1991 as a community-driven demonstration project across 15 sites to reduce infant mortality by 50 percent. After multiple rounds of funding and a replication phase, Healthy Start was now focused on four core elements that aimed to decrease infant mortality and emphasized women's health, family health, and community/population health. There were currently 101 Healthy Start sites across 35 states, Washington DC, and Puerto Rico. The average funding at each site was \$980,000, totaling approximately \$125 million in grants. Healthy Start aimed to decrease infant mortality through improved health outcomes before, during, and after pregnancy and through a reduction in racial and ethnic disparities. Healthy Start programs were in communities with infant mortality rates of at least 1.5 times the national average.

She described Healthy Start's base services such as screening and referral, breastfeeding support, parent education/skill building, housing assistance, and job placement. Additionally, Healthy Start grantees established a Community Action Network of organizations not directly related to maternal and child health (e.g., the Department of Transportation) and people with lived experience. Ms. Baker explained that the Healthy Start Initiative also added clinician funding to provide grantees with additional funding to increase clinical services in their project. She also noted recent funding for some Healthy Start grantees to hire, train, and certify doulas.

Ms. Baker described MCHB's goal of reaching infant health equity by 2030. Towards that aim, she shared that some Healthy Start grantees were provided supplemental funds to develop action plans for systems level changes and to address social determinants of health that were impacting disparities in infant mortality in their communities. She shared that MCHB Healthy Start staff had also conducted listening sessions with grantees, doula organizations, and other maternal and child health organizations to better understand what was needed to reduce disparities. Some key themes from the listening sessions included the need for workforce development among people from all populations, strengthened community relationships, increased funding for activities, a greater focus on fathers, and changes in data collection tools and benchmarks.

Finally, Ms. Baker asked the Committee to consider design and implementation factors to increase the focus on equity in the Healthy Start Initiative. She said that MCHB would soon release a Federal Register Notice to obtain public feedback on their Healthy Start program activities to reduce racial and ethnic disparities. Mr. Wilson added that Healthy Start has had a number of efforts to seek input for the program to better address the perinatal health outcomes of underserved individuals who have the greatest needs. Some of the priorities had shifted over the years and the program sought to obtain input from as many sources as possible. Ms. Baker said the Committee had an opportunity to provide input now, as well as through the Federal Register Notice when it was released.

Discussion

Dr. Ehlinger asked if the request for input came from HRSA MCHB alone as a federal entity or with the Healthy Start projects because where the request came from would shift the strategy for community engagement. Mr. Wilson answered that the request was from all of the above. Input that was received would be shared with existing and future grantees, as well as HRSA MCHB. He shared one of the issues that had been identified by several sources was a call for maximum flexibility to reflect culture and community.

A Committee member said that his community recently had outreach from a Federally Qualified Health Center (FQHC) about providing comprehensive, midwife-directed care. He asked if there had been any merging of FQHC work with Healthy Start because doula and midwifery care seemed to be done in piecemeal. Ms. Baker said that FQHCs were eligible to apply for Healthy Start grants and there were a number of current Healthy Start grantees who were FQHCs. Mr. Wilson added that there were a number of dual grant recipients that were funded by both Healthy Start and an FQHC. Mr. Wilson suggested that MCHB may want to engage with Committee members as they consider proposed funding for a doula grant program. He said there was a priority to make doula services more institutionalized, professionally sustainable, recognized, and reimbursable.

A Committee member asked if there was any likelihood of reaching the 2030 goal of eliminating disparities in infant mortality or if the goal was aspirational. She also asked if Healthy Start had plans to be involved in the movement to make amends to the AI/AN communities by making allowances for their small numbers to qualify to become a Healthy Start site. Ms. Baker answered that they were looking for strategies to ease the requirement burden on those populations. Mr. Wilson added that HRSA used the Committee's recommendations as direction

that comes from a cross-section of experts and key informants rather than one agency. Similar to HRSA's response to the Committee's recommendation to support a doula initiative, he said he expects HRSA to also consider the current recommendations for AI/AN mothers and infants, including the challenge of including communities with small numbers in Healthy Start funding.

A Committee member talked about how communities are required to meet a list of focus areas for a Healthy Start grant. She thought if instead there was a menu of areas that communities could choose from, the conversation about what their specific needs are would be more authentic.

Another Committee member asked if there were efforts to ensure that doula training was affordable to people of color who represent their communities. In her area, Medicaid could be used to pay for doula services, but the doula training was unaffordable. As a result, there were not enough doulas who would represent the people needing services. Ms. Baker said that the proposed Healthy Start budget for 2023 is \$20 million and that the grants would be open to all entities, not just Healthy Start sites. HRSA could not direct funds to a specific population, but they were looking to write the Notices of Funding Opportunities to encourage communities with higher need/higher adverse outcomes to apply for grants. If the proposed budget was approved, these particular grants would cover doula training and certification costs.

Review the Work and Accomplishments of ACIMM

Edward Ehlinger, M.D., M.S.P.H., ACIMM Acting Chair Arthur James, M.D., FACOG, Former ACIMM Member

Dr. Ehlinger provided a brief overview of ACIMM's history and then highlighted key pieces of work. In December 2001, the Committee submitted three reports to the Secretary: the <u>Low Birth Weight Report and Recommendations to the Secretary</u>, the <u>Promoting the Health of Newborns and Mothers through Postpartum Services</u>, and the <u>Recommendations on the Future of the Healthy Start Initiative</u>. In January 2013, the Committee submitted to the Secretary a report of Recommendations for HHS Action and Framework for a National Strategy.

In December 2018, Dr. Ehlinger said he and members of the current iteration of the Committee held their first meeting. Between this and the subsequent Committee meeting in April 2019, Committee members established a path forward to build on the strong research base created by previous iterations of the Committee and agreed to center their future efforts on programs and policies that addressed social and economic determinants such as structural racism and poverty. He shared the Committee also adopted an approach for addressing the complex factors involved in maternal and infant health, ensuring that their work was centered on equity, guided by community voices, focused on connections, and progressed by asking powerful questions and seizing opportunities. This focus and approach were maintained over the subsequent four years, he stated, as the Committee accomplished a number of actions to advance equity.

Dr. Ehlinger then highlighted a few significant Committee accomplishments over the last four years. He said notably, the Committee endured despite an Executive Order to reduce the number of federal advisory committees. The Committee also renewed and expanded its Charter to include maternal mortality and severe maternal morbidity in recognition of the importance of the

mother-infant dyad. He thought the status of the Committee in its leadership and advisory capacity was bolstered by the attendance of the HRSA Administrator, the Assistant Secretary of Health, and the HHS Secretary during a number of Committee meetings throughout his tenure as Acting Chair.

Dr. Ehlinger described the letters submitted to the HHS Secretary between 2018 and 2022. In March 2020, the Committee rapidly responded to the COVID-19 pandemic with an <u>initial set of recommendations</u> addressing the needs of mothers and infants. In June 2020, the Committee <u>refined and expanded these recommendations</u> in a follow-up letter to the Secretary. In August 2021, the Committee submitted a <u>letter of recommendations</u> addressing migrant and border health, the physical environment, safe systems of care, and workforce issues. Finally, during this December 2022 meeting, the Committee voted in approval a set of recommendations addressing AI/AN maternal and infant health.

Dr. Ehlinger noted that the Committee had broken ground with its elevation of community voices, and the implementation of their recommendations by organizations such as the Association of State and Territorial Health Officials, and the facilitation of a Committee meeting outside of the Washington, DC area held on tribal land. He also recalled how the number of Committee meetings had expanded from two to four times a year, necessitating a greater level of resources and support from HRSA MCHB. He encouraged Committee members to continue this bold path on their way forward. He then introduced Dr. Arthur James, a former ACIMM member who led the Committee to focus on structural racism and inequities in December 2018.

Dr. James gave an updated version of a presentation he had given to the Committee in 2018, sharing that the greatest challenge in maternal and child health is racial disparities in birth outcomes. He noted that maternal and infant mortality is highest among Black and AI/AN individuals, despite the lack of physiological differences across race and ethnicity. Although advances in health care had reduced overall infant mortality, these advances had benefited White infants more than Black or AI/AN infants. Dr. James reviewed the "survival time lag" between Black and White infants in Ohio, which indicated that the current infant mortality rate in Black infants was comparable to the White infant mortality rate 44 years ago. For Black infants to reach the White infant mortality rate of today, the nation would have to wait until the year 2063. Further, the survival time lag between Black and White infants had been increasing since 1935. Although Ohio had consistently met or exceeded Healthy People infant mortality goals among White infants, it had never reached the goal among Black infants. Although Dr. James used Ohio as an example, he emphasized that the same trend occurred across several states.

Dr. James said that these data demonstrated an urgent need to act immediately to reduce disparities in infant mortality. He talked about the relationship of historical genocide, marginalization, and forced migration and high infant mortality rates in AI/AN communities. Likewise, there was a relationship between the 246-year history of slavery and the 99-year Jim Crow Era and high infant mortality rates in Black communities. Racial disparities persisted despite the passage of the Civil Rights Act in 1964 he noted, and the implications of these historical traumas were often not mentioned in terms of health disparities. The chronic stress that resulted from years of racism and inequality could create physiological changes that affected not

only the individual, but also the fetus, and those changes could be passed to subsequent generations.

Dr. James said that current efforts to address these disparities involved "helping" programs that help an individual navigate around obstacles. Instead, he said there should be a focus on permanently removing these obstacles so that everyone has the same opportunities for success. The goal should not be health equity, but overall equity. Dr. James reviewed Dr. Camara Jones's three key requirements to achieve equity: 1) valuing all individuals and populations equally, 2) recognizing and rectifying historical injustice, and 3) providing resources according to need. Dr. James ended by quoting Nelson Mandela in that, "it always seems impossible until it is done."

Discussion

A Committee member asked what key mitigation strategies Dr. James had observed that Committee members might use within their own spheres of influence. Dr. James referenced Dr. Michael Warren's article "Accelerating Upstream Together: Achieving Infant Health Equity in the United States by 2030," which was published in the Journal of Pediatrics in January 2022. The article addressed what it would take to achieve equity—not Healthy People 2030 goals, but the same degree of successful birth outcomes as White infants. He said the Healthy People 2030 goals could serve as a benchmark for measuring the degree to which efforts needed to increase. One potential action he thought would be to hold Healthy Start sites accountable for achieving equity, or at least to serve as a model of success for the rest of the nation. Dr. James encouraged Committee members to use their pulpit aggressively. The biggest contributors to disparities are the non-clinical issues that adversely affect populations of color and it will take more funding and resources than HRSA has available. But making equity a priority will shift actions into the right direction, he said. He cited the successful reduction of infant mortality among Black infants in Kalamazoo County in 2000, despite having the highest Black infant mortality rate in the state as an example.

Dr. Ehlinger referenced Dr. James's slide on infant mortality between 1915 and 2017. He noted that there were three time periods in which infant mortality was reduced, all of which were related to a policy approach: 1) in the early 1900s when a social model was used to address poverty and women's and children's rights, 2) during the Great Depression when people came together to fight a war and the Social Security Act addressed child health, and 3) during the War on Poverty when policy was used to reduce poverty and disparities. He expressed hope that the Committee could take the same approach of using policy to address maternal and infant mortality.

A Committee member talked about the wisdom of Native American cultures in their acknowledgement that stressful environments could negatively impact the mother-infant dyad and their practices to prevent exposure to death or war. She noted how Western culture considers this a relatively new scientific discovery. She asked Dr. James what the Committee could do immediately to fast-track action toward equity, aside from the need for more funding.

Another member echoed Dr. Palacios' question and added that there is often willful resistance to attempts to apply practices that specifically support communities that need it most. Accelerating improvement for all will not be enough for those who need more.

Dr. James spoke about HRSA's readiness to do more and the Committee's responsibility to help them. He said that addressing the social determinants of health is the track that the Committee should focus on, but that it is not a fast track. It is important to start with the social determinant that garners the most support from a community. Once that determinant is chosen, there should be an organized effort to also address the other determinants because they act as dominoes. Progress can then be measured for each determinant. Although clinical approaches are still important, he said the priority should be on social determinants.

ACIMM Workgroup Review of Accomplishments

Belinda Pettiford, M.P.H., BS, BA Health Equity Co-Lead

Janelle Palacios, Ph.D., CNM, RN, Health Equity Co-Lead

Steve Calvin, M.S., Quality and Access Workgroup Lead

Magda Peck, ScD., Data and Research to Action Workgroup Lead

Dr. Ehlinger invited Workgroup Leads to provide a brief review of lessons and accomplishments from the three ACIMM Workgroups over the last four years.

Dr. Calvin summarized the key areas of need identified by the Quality and Access Workgroup. The workforce shortage of clinicians, midwives, and other practitioners would continue to be a significant challenge going forward. It would be important to consider how the shortage would impact access to care and there would also be a need to develop a workforce that represents the communities they care for.

Ms. Pettiford said that the standing up of the Health Equity Workgroup was itself an important accomplishment. They discussed inequities related to the COVID-19 pandemic at a time when there was little attention on the specific needs of mothers and infants. The Workgroup also addressed workforce diversification and the need to ensure race concordant care and cultural sensitivity. They also elevated the roles of doulas, nurse midwives, and community health workers. Under the leadership of Dr. Palacios, the Workgroup kicked off the focus on AI/AN mothers and infants across the Committee. Dr. Palacios added that the diversity of the Workgroup itself brought multiple perspectives and supported rich discussions. She acknowledged Ms. Pettiford for her mentorship and community partnerships, and Ms. Pat Loftman for bringing forward the voice of diverse care experiences.

Dr. Peck said that the Data and Research to Action Workgroup was initiated to assure that the Committee's ongoing deliberations were based on evidence and science that was credible, reliable, timely, and relevant. The Workgroup acknowledged the low capacity and understaffing that was contributing to the lack of uniform, critical data on racism and small populations and the lack of data interoperability that limited the ability to measure social determinants of health. She acknowledged Dr. Paul Wise, former ACIMM member, who led discussions on a redesign of data architecture. The Workgroup also focused on the knowledge base needed to support COVID-19 prevention and racial equity. They talked about the need to expand mortality reviews

and to build capacity and workforce to strengthen data systems. Finally, the Workgroup brought to the Committee the power of storytelling and lived experience that is now integrated in the Committee's recommendations. Dr. Peck thanked the two other Workgroups for their collaboration and the members of the Workgroup for their leadership.

MCHB Review of the Committee Vanessa Lee, MPH, Designated Federal Official, ACIMM Lee Wilson, Director, Division of Healthy Start and Perinatal Services, MCHB, HRSA

Ms. Lee thanked the Committee for drawing attention to social and structural determinants of health, which helped lead MCHB to develop funding opportunities outside of clinical care. She talked about how the Committee increased knowledge and capacity of not only MCHB staff, but also HRSA grantees and public health professionals who attended Committee meetings. She expressed appreciation for the diversity of speakers that were brought in to share their insights and lived experiences. Finally, she thanked the Committee for highlighting the need to include all perspectives on the Committee. Ms. Lee reminded Committee members of a Federal Register Notice calling for new member nominations and asked them to consider what perspectives were needed to maintain the work on disparities.

Mr. Wilson recognized the Committee as an anchor during a time in which MCHB was experiencing reorganization and challenges related to the pandemic. He had found it helpful to lean into the expertise of Committee members as an objective source of information and guidance. He also acknowledged the role of the Committee in guiding the direction of MCHB and in justifying many of the agency's advances, such as the doula program, that were drawn directly from Committee recommendations and feedback.

Next Steps for ACIMM

Vanessa Lee, MPH., Designated Federal Official, ACIMM ACIMM Members

Ms. Lee provided a brief overview of projected Committee activities for 2023. HRSA hoped to have the next Committee Chair in place before the next meeting in March 2023. There would then be another meeting in June 2023, after which the logistics contract would need to be recompeted before planning the last two meetings of 2023. The exact dates of the March and June meetings were to be determined and Ms. Lee would provide them as soon as possible. She shared that HRSA was also reviewing a new member nomination package, and hoped to bring on up to seven new Committee members in 2023. She added that the current call for nomination packages would close on January 23, 2023 and those nominations would be reviewed for openings in 2024. Ms. Lee shared that HRSA was engaging with Historically Black Colleges and Universities (HBCUs) and with the Office of Tribal Affairs to reach Black and AI/AN communities with the solicitation. She said they were also looking into how to reach more early career professionals, which current ACIMM members had said was missing from the Committee.

Dr. Ehlinger asked if there was a plan for enhanced support for the Committee. Ms. Lee answered that HRSA is committed to continuing the logistics contract and can build into the scope of work additional support for any unmet Committee needs. She added that she will

remain the Designated Federal Official and may have more time to support the Committee in 2023. Additionally, there will be a new part-time staff member who can support the Committee with program content and background. Dr. Ehlinger suggested that student internships would be a helpful resource for the Committee. He also suggested that it would be helpful for the Committee to have more insight into federal activities, such as the Tribal Summit that recently took place.

A Committee member suggested that there was a missed opportunity to engage with students in maternal and child health programs or in midwifery programs to serve with ACIMM for educational credit and networking opportunities. It would help build a pathway she said, both toward Committee membership, but also toward policy work.

Way Forward with the Report on AI/AN Recommendations

Dr. Ehlinger invited Committee members to discuss how they might use and disseminate the *Making Amends* report on AI/AN. He noted that he plans to send the report with a letter to his state's governor and senator, as well as schools of public health, state agencies, and students that he has mentored.

A Committee Member said that she had multiple connections that she could share the report with, such as the Maternal Health Learning and Innovation Center; the executive leadership at the AIM Initiative; and the Society for Maternal-Fetal Medicine, Quality and Safety Committee. However, to do so effectively, she said she would need a slide deck or an executive summary to help her get on an agenda to introduce the report. She suggested that their story should be consistently told and that there could be a slide deck for all Committee members to use. Dr. Ehlinger agreed that there should be a slide deck and that he planned to continue working with Dr. Palacios and Dr. Peck to develop a synthesis of the storytelling.

Another member suggested that a press release would help reach audiences such as scholarship programs and health centers. If HRSA was unable to launch a press release, then another agency, such as the American Academy of Family Physicians, might be able to. She said that she planned to share the report with her state governor, as well as state organizations, medical associations, and community health associations. She stated that she also planned to submit a proposal to present at the National Association of Community Health Centers annual meeting. She also suggested that the release of information should be consistent, and frequent to keep the information at the forefront. She agreed that a consistent presentation would increase the impact of the message. It would also be important to share stories, possibly engaging with local media outlets to bring the stories to the public.

Dr. Ehlinger said that he was not sure if HRSA had a mechanism for press releases and agreed that other organizations such as CityMatCH, AMCHP, and March of Dimes could be asked to release it. He asked Mr. Wilson if there was anything that Committee members should be aware of as they share the report. Mr. Wilson said that Committee members can speak as Committee members but not from a position of the federal government, which is the role of the Secretary. HRSA would not be able to disseminate the report to entities such as the press because that would imply that the Secretary had adopted the recommendations, which had not yet happened.

Another Committee member said that once she was no longer on the Committee, she would be initiating a local NPR KQED podcast interview about the report.

A member said that she had already shared the report with AMCHP and planned to share it with the National Healthy Start Association, with hopes that it becomes an agenda item for their March 2023 conference. She had engaged with the North Carolina Commission on Indian Affairs to obtain feedback and had scheduled a meeting with their Executive Director. She also planned to share the report with the North Carolina Maternal Mortality Review Committee and Perinatal Health Equity Collective. She hoped to partner with their Commission on Indian Affairs and state Title V program to ensure that the recommendations were broadly shared across the state. She said North Carolina had 8 recognized tribes, with several opportunities to connect with them.

Another member echoed that she would similarly share the report with her network and added that it would be an important exercise to somehow track the impact of dissemination. There could be a strategic approach to sending it out in intervals and a system for tracking where it is being sent, she said. For instance, there could be a blind copy for every email communication that is sent out. There could also be a repository of communication tools so that a new letter would not have to be written each time. Strategic communication would help ensure that the information did not go stale.

A Committee member suggested that Dr. Ehlinger, Dr. Palacios, and Dr. Peck write an opinion editorial to a major newspaper so that it could be picked up by multiple media sources.

Dr. Ehlinger suggested that Ms. Lee could be an appropriate blind copy on communications until a new Committee Chair was on board. He asked ex-officio members to add their thoughts on dissemination.

Dr. Kroelinger said that CDC would highlight the report across the Division of Reproductive Health programs upon its release.

Dr. Alison Cernich said that she had distributed the report to the Maternal Health Task Force across the National Institutes of Health and shared an early draft with a group that recently conducted a tribal consultation within their Maternal Health Research Centers of Excellence. The recommendations had already been incorporated into the design of funding opportunities and there was a plan to conduct another tribal consultation after awards.

An acting ex-officio member from the Office of Minority Health said that they were currently reviewing the report to understand how it aligned with their work with the Center for Indigenous Health Equity so that they could strategically leverage and operationalize the recommendations.

Mr. Wilson said that MCHB would be responsible for working with the Office of the Secretary to generate any specific responses to the recommendations. In addition, he shared they were looking at ways to incorporate the recommendations into the design of new programs and redesign of some existing programs.

Dr. Danielle Ely said that she had disseminated the report to the CDC National Center for Health Statistics leadership in an effort to address the challenge of collecting data on small populations so that there could be more information on AI/AN outcomes.

Way Forward as a Committee

Dr. Ehlinger invited Committee members, particularly the continuing ones, to share the issues that they considered a priority for the coming years.

One member said that it would be important to prioritize the impact of toxic stress on maternal health as a pathway to risk factors for infant mortality, such as preeclampsia or hypertension. She said stress was often not acknowledged or taken seriously.

Another Committee member said that there should be a continued focus on health equity because there is still so much left to do. She added that there should be a focus on ensuring safe women's health and reproductive care—not only for patients but also their providers. She said it would be important to consider how current legislation and state decision-making will potentially increase disparities.

Dr. Ehlinger said that there should be continued dialogue with IHS to obtain the data that the Committee has requested and more information on their evaluation contract with the American College of Obstetricians and Gynecologists.

Another Committee member concurred with continued engagement with IHS and obtaining their available data to fully understand the scope of disparities. She added that IHS has been challenged by a lack of funding and accountability that is not a reflection of IHS staff. She also said that another priority area is to track the rate of C-sections alongside new diagnostic criteria for chronic hypertension.

A Committee member suggested continuing to focus on data issues, such as lack of data congruence from federal to state and even from institution to institution. She also suggested being consistent about measuring demographics and outcomes so that there could be a better understanding of disparities. Also, she suggested looking at return on investment in social determinants of health as an intervention. Concrete information could further support the work and might be drawn from the Committee's AI/AN work as a fiscal model, she noted.

Another Committee member reiterated the importance of tracking the dissemination of their report going forward. She added that there should be a blend of short- and long-term goals. In the short-term, she thought there could be a focus on access to culturally congruent and respectful, risk-appropriate care. She said this priority area could be an umbrella for other key challenges such as rural health and access to specialty and mental health care. She commented that it was important that the social determinants of health work not be separated from clinical work because understanding those barriers was the long-term goal.

Another member said that the Committee should include midwives and other community members, who would be an asset in addition to the perspectives that Ms. Thompson brings.

One Committee member reminded the new and continuing Committee members that there were now three letters of recommendations submitted to the HHS Secretary, and proposed that those recommendations be reviewed and not put on the "backburner". For instance, she said the recommendations related to the COVID-19 pandemic would continue to be relevant and should be at least reviewed in preparation for future events. She further said the recommendations for environmental health, climate change, border and global migration—particularly during a time of war, and housing insecurity, were all issues that might require a deeper dive. She added that Committee members should also hold those they advise accountable for putting recommendations into action.

A Committee member reminded the Committee of the Secretary's message to be bold, which she said was needed to create any type of change.

Wrap Up and Transition

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

Dr. Ehlinger asked retiring Committee members to share their parting thoughts.

One Committee member conveyed her appreciation for the opportunity to work with the Committee and felt that she was leaving the Committee in a good place. She emphasized the importance of the health equity work going forward.

Another departing member shared three insights. She first encouraged Committee members to create accountability. For instance, ex-officio members could report back on their progress on the recommendations that were relevant to their agency. She also expressed gratitude for the storytelling work that had been integrated into the Committee and urged Committee members to continue to bring data to life and fuel their recommendations with stories. Finally, she recommended that the Committee make space for disagreement and doubt. She asked Committee members to not avoid conflict but rather mine it for the best and boldest results.

A member talked about the importance of relationships—both as colleagues and friends—within the Committee. She asked the Committee to be a model for relationships and mentorship.

Dr. Ehlinger asked Ms. Lee and Mr. Wilson for their thoughts on the retiring Committee members. Mr. Wilson thanked Dr. Peck and Dr. Ehlinger for their leadership and for modeling their extraordinary commitment and dedication to the Committee. He acknowledged Dr. Ehlinger's tireless efforts to evolve the Committee into something that is reckoned with and now has a reputation for creating change in the community and across the nation. He thanked Ms. Pettiford for her grace, intellect, expertise and influence on the Committee and Dr. Palacios for modeling to the next generation to not rest until something is resolved. He expressed appreciation for all that he learned from the four Committee members, both personally and professionally. Ms. Lee thanked the retiring members for helping her become a better public health and maternal and child health professional.

Dr. Ehlinger conveyed that his experience on the Committee had been gratifying, but also sad because there was so much yet to be done. He concluded the meeting by referencing Dr. Martin Luther King Jr.'s Nobel Peace Prize speech of 1964.

"There is no deficit in human resources; the deficit is in human will."

Dr. Martin Luther King Jr.

Adjourn

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

Dr. Ehlinger adjourned the meeting at 6:00 PM ET.