

# **Secretary's Advisory Committee on Infant Mortality**

**Meeting Minutes of April 8-9, 2019**

**Webinar**

**Monday, April 8, 2019**

## **WELCOME AND INTRODUCTIONS**

*David S. de la Cruz, Ph.D., M.P.H.*

Principal Staff and Designated Federal Official, SACIM

Acting Director, Maternal and Child Health Bureau (MCHB)/Division of Healthy Start and Perinatal Services

*Edward P. Ehlinger, M.D., M.S.P.H.*

Acting Chairperson, SACIM

Dr. de la Cruz called the webinar meeting to order and thanked everyone for joining the meeting, which was conducted via webcast. Dr. de la Cruz then turned the meeting over to Dr. Ehlinger, who

welcomed the webinar participants. He explained that the meeting was intended to determine the group's focus and direction based on current science and also on the observations of the people who are affected most by infant deaths: Mothers, fathers, babies, and families. He also discussed the committee's need to organize the many facets of SACIM's work so that participants in the next in-person meeting can focus on making recommendations, leading to actions to move initiatives forward. He stressed that it will be important to match the committee members to their tasks based on their experience and skills.

## **INTRODUCTION OF COMMITTEE MEMBERS, EX- OFFICIOS AND OTHER ATTENDEES**

### Committee Members

Dr. Ehlinger invited the committee members, ex-officio members and others to introduce themselves:

**Jeanne A. Conry, M.D., Ph.D.**, President of the Environment Health Leadership Foundation has worked with the American College of Obstetricians and Gynecologists (ACOG) in two main respects: Counseling on patient safety with Dr. Barb Levy, and as Chair of the Women's Preventative Services Initiative. Her focus is on highlighting the maternal aspects of optimizing the health of women.

**Vijaya K. Hogan, Dr.P.H., M.P.H.**, was previously Program Officer at the W.K. Kellogg Foundation and is now an employment consultant. She has passed on the basic information about SACIM to their program officers and encouraged their future participation. Her specific interest is in equity in the field.

**Paul E. Jarris, M.D., M.B.A.**, Senior Principle Health Policy Adviser of The Mitre Corporation, described interests in research projects and maternal mortality, population and public health.

**Colleen A. Malloy, M.D.**, Assistant Professor of Pediatrics (Neonatology) at the Ann and Robert H. Lurie Children's Hospital of Chicago, is a neonatologist at Northwestern University and is also interested in maternal health and opioid addiction.

**Janelle F. Palacios, Ph.D., C.N.M., R.N.**, Nurse Mid-Wife, Kaiser Permanente Oakland Medical Center Labor and Delivery

**Magda G. Peck, Sc.D.**, Founder/Principal at MP3 Health Group and University of Nebraska Medical Center Department of Pediatrics in Public Health, is making others aware of SACIM and the opportunities that it presents to the field.

**Belinda D. Pettiford, M.P.H., B.S., B.A.**, is Women's Health Branch Head of the North Carolina Division of Public Health Women's and Children's Health Section, part of Title V and Healthy Start. She is working on improving birth outcomes with a focus on equity and the disparity gap.

**Paul H. Wise, M.D., M.P.H.**, is Professor of Pediatrics Health Policy and International Relations at Stanford University. He focuses on the impact of technical and clinical innovation on social disparities in perinatal, maternal and child health outcomes. He is also Co-Director of the Stanford March of Dimes Prematurity Research Center and participates in the March of Dimes Research Centers. He is involved in an emerging network that focuses on maternal and perinatal child health outcomes in migrant communities whose members are emerging from government detention on the southern U.S. border. He is also focused on a global consortium of global child health programs focusing on improving perinatal and maternal outcomes.

Others who introduced themselves briefly at this point were:

**RADM Wanda Barfield, M.D., MP.H.**, Assistant Surgeon General Director, Division of Reproductive Health, Centers for Disease Control and Prevention

**Wendy DeCourcey, Ph.D.**, of Social Science Research Analyst Office of Planning Research and Evaluation Administration for Children and Families

**Dianne Rucinski** speaking for Captain Felicia Collins, Deputy Assistant Secretary for Minority Health Director, Office of Minority Health U.S. Department of Health and Human Services

**Dorothy Fink, M.D.**, Deputy Assistant Secretary, Women's Health Director, Office of Women's Health, U.S. Department of Health and Human Services

**Karen Matsouka, Ph.D.**, Chief Quality Officer & CHIP Director, Centers for Medicare and Medicaid, Division of Quality & Health Outcomes

**Kristen Zycherman**, Coordinator for the CMS Maternal and Infant Health Initiatives Center for Medicaid and CHIP Services

**Richard E. Behrman**, Professor of Child Health Policy and Society CDDR

**Encina Heall**, Stanford University Center for Health and Policy

**Ronald T. Ashford**, Office of the Secretary, U.S. Department of Housing and Urban Development

**Paul Kesner**, Director of the Office of Safe and Healthy Students, U.S. Department of Education

**Iris R. Mabry-Hernandez, M.D., M.P.H.**, Medical Officer Senior Advisor for Obesity Initiatives, Center for Primary Care Prevention and Clinical Partnerships, Agency for Healthcare Research and Quality

**Danielle Ely, Ph.D.**, Division of Vital Statistics, National Center for Health Statistics, Centers for Disease Control and Prevention

**Cheryl S. Broussard, Ph.D.**, Associate Director for Science, Division of Congenital and Developmental Disorders, National Center of Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention

**Elizabeth Schumacher, J.D.**, Health Law Specialist, Employee Benefit Security Administration, U.S. Department of Labor

**Diane Bianchi, M.D.**, Director, Eunice Kennedy Shriver National Institute of Child Health and Human Development, National Institutes of Health

**Suzanne England, D.N.P., A.P.R.N.** Great Plains Area Women's Health Service, Indian Health Service and Clinical and Preventative Services

**Brandon Lipps**, Food and Nutrition Service, U.S. Department of Agriculture

Dr. Ehlinger listed the requests he has received from maternal and child health organizations for the committee to address, such as hospitals not being baby-friendly and supportive of breastfeeding and the suggestion that doula services be funded to allow them to help to improve infant health and reduce disparities in access to health care.

Dr. Ehlinger then mentioned the minutes from December 2018 meeting; the group had read the minutes and a motion for their approval was issued, seconded and, by vote, the minutes were approved.

## **WELCOME AND UPDATE FROM HRSA AND MCHB**

*Michael D. Warren, M.D., M.P.H., F.A.A.P.*

Associate Administrator for MCH, HRSA

Dr. Warren spoke about new division directors in the MCHB, including Dr. Sara Kinsman, who will serve in the Division of Child and Adolescent Health. She is an adolescent-medicine-trained physician from the Philadelphia Health Department; Dr. Tiffany McNair, Division Director for Healthy Start and Perinatal Services, trained as an obstetrician-gynecologist and joined MCHB from the Centers for Medicaid and Medicare Services; Cindy Phillips, Division Director for Home Visiting Early Childhood Services, who has been with the Health Resources and Services Administration (HRSA); and Joan Scott Division Director for the Division of Services for Children with Special Health Care Needs for HRSA. The Healthy Start awards totaling \$107 million are being applied to approximately 100 project sites with funding for maternal mortality. Findings show that the rate of maternal mortality and severe maternal morbidity are higher in the United States than in other Western countries. The goal is to address health disparities in the populations affected by societal issues such as opioid addiction.

The HRSA Maternal Mortality Summit was hosted at the HRSA headquarters in Rockville, Md., with representatives from the United States and six other countries. The event provided opportunities to share lessons learned and to think collectively about potential solutions. The Alliance for Innovation in Maternal Health (AIM) initiative, which MCHB has been supporting, involves provision of funding for the implementation of “safety bundles” a collection of practices—a sort of toolkit deployed in birthing hospitals and other facilities. It has been used to support about 2 million births. There was funding in the new budget to expand this initiative to all 50 states soon to cover all four million births in this country.

Dr. Warren said the FY '19 budget has \$38 million in new funding to address maternal mortality. Of this, \$12 million will go to Healthy Start and some of the remaining \$26 million will be used to expand AIM and the rest will be used to support state maternal health innovation awards.

He also discussed block grants from which 86 percent of all pregnant women and 99 percent of all infants have benefited. He noted that states will be conducting updated needs assessments, which must be done every five years and are due in July 2020. He explained that there are about 36 different national outcome measures, many of which are related to women’s or infants’ health and 15 national performance measures; about a third of those are related to the committee’s work. These measures are important to the committee from an accountability standpoint. The rate of infant mortality is one such measure. The Bureau’s mission is to improve the health of America’s mothers, children and families; it is the only federal agency that is specifically designated to do so. Since its inception in 1912, the Bureau has cut this country’s infant mortality rate in half. But how does the group elevate that conversation around what does a rate of 5.9—22,000 deaths per year—mean?

Dr. Warren pointed out that there is still a lot of work to be done to improve infant, child and maternal health. For example, many families put their babies in unsafe sleeping positions despite the Back to Sleep campaign that began in the early 90s. Many adolescents still do not get well child visits each year. Fewer than half of children with special needs receive care in a medical home. There continue to be high rates of maternal morbidity and mortality. In short, it is important to acknowledge the work that has been completed—the fact that the infant mortality rate has declined from about 11.8 to 5.9 over 30 years, but there is no room for complacency; how does the group accelerate the pace of change?

He also pointed out that positive changes have not occurred uniformly across the entire country. There are marked disparities in infant mortalities between white and black populations, for example. He cited the Bureau’s epidemiologist as predicting that recent rates of change in infant mortality rates shows that we can expect the black infant mortality rate to catch up to the 2017 mortality rate for white infants in 2069 or as late as 2093. He stressed that it is important to think of upstream solutions to these challenges; this means primary prevention of disease; not merely treatment—the ability to screen for and detect disease early. This involves vaccination, breastfeeding and promoting a healthy built environment as well as secondary prevention services that can be provided through home visits, for example. There are also tertiary prevention measures such as care coordination, early intervention, specialty care for children, sexual health care and

high-risk care for some mothers and children. Another way to think of this is as a life course model, which is well known to the committee. It involves an awareness of intergenerational influences; thinking about, not just our or our children's lives but our parents' lives as well and how their health and well being affected their descendants.

He also pointed out that clinical care accounts for only 10 to 20 percent of overall health; social, economic, community environmental and health behaviors are important to consider as well. All of these aspects can influence obesity rates for example—what is the child surrounded by, what counseling has (s)he received, are they physically active? Do they have access to healthy, nutritious food and to role models in this area?

Dr. Warren said that the Bureau doesn't do its work in isolation. It relies on partners in the field, like those on this committee, to improve maternal and child health and families as well as state needs assessments to accelerate upstream together.

### **Committee Questions and Discussion**

- Dr. Ehlinger asked whether anyone has looked into the effects Title V has had since its dramatic change in 1981 and whether that block granting is still the model that should be used for Title V.
- Dr. Jeanne Conry commented that contraception and family planning are critical and environmental toxins, such as exposure to air pollution, mercury and lead, as well as issues linked to obesity should be considered when discussing maternal and infant health.
- Dr. Magda Peck asked for clarification about the reorganization that is being proposed at the Secretary's level, outside the Bureau. She mentioned that the Association of Schools and Programs of Public Health reported on a proposed reorganization that would move family planning and teen pregnancy prevention into the Office of the Assistant Secretary for Health.
  - Dr. Warren said that he has not seen the plan but knows that collaborations will be a very important aspect in that development.
- Dr. Paul Jarris wondered whether states in their assessments would cover substance use such as opioids, methamphetamines and marijuana which women of reproductive age are increasingly exposed to mentioned vaccine hesitancy as well; these are areas in which MCHB may get involved.
  - Dr. Warren said that the Bureau has long supported administration of vaccines at the local health department level and that the issue came up during listening sessions with all of the states and territories at an Association of Maternal and Child Health Programs (AMCHP) meeting recently. Multiple players, such as the Centers for Disease Control and Prevention have a role in addressing environmental factors, substance use and vaccine hesitancy as well. This is why states do needs assessments every five years; to identify changing needs and priorities.
  - However, Dr. Warren also said it is important to think upstream—about trauma and other factors that may be implicated in these trends.
  - Dr. Jarris expressed surprise, however, that pregnancy and the flu vaccine were not raised during a recent HHS-sponsored meeting on the flu vaccine.
  - Dr. Wanda Barfield mentioned that patients' refusal of vitamin K shots during birth, a deficiency of which can cause bleeding in infants and suggested partnering with the American Academy of Pediatrics (AAP) to address such issues.
- Ms. Belinda Pettiford asked whether state Title V directors are on board with focusing on equity. Dr. Warren said that the extent to which equity is discussed depends on the state's composition and political environment, but the terms disparity reduction or elimination are used more often similarly to the way "equity" is framed.
  - Dr. Wanda Barfield brought up the question of vitamin K refusal and said this should be a priority area to also consider.

## **REPORT ON THE WORK OF THE PREVIOUS SACIM**

*Kay Johnson, M.Ed., M.P.H.*

Previous SACIM Chairperson

Ms. Johnson harked back to 1991, when she began attending advisory committee meetings and helped to develop its strategy. SACIM started by focusing on preconception, reproductive lifetime, family planning, women's immunizations and folic acid, and on achieving better infant and child health and maternal outcomes. On the child side, the focus was on the neonatal intensive care unit, immunizations, SIDS prevention and newborn screening — emphasizing health starting with birth.

In the wave of the Affordable Care Act the group set out six strategic directions that were within HHS' purview. The group zeroed in on the life course perspective, the engagement and empowerment of consumers, equity and disparities, negative social determinants of health, the MCH safety net, systems of care, service integration and the need for multi-sectoral public/private collaboration. They were concerned with finding actionable strategies and said that changes were needed at both the level of individual patients and at the provider level as well. SACIM was firm about the need for federal investments in the MCH safety net but was encountering directional changes between the Bush and Obama administrations. The Affordable Care Act opened up many opportunities although some thought that its passage meant that the Title V Block Grant program was no longer necessary. However, having insurance doesn't guarantee access or equitable access; safety net programs remain vital. The group wrote to then-HHS Secretary Sebelius calling for the first national strategy to address infant mortality.

The concept of advancing a national strategy was already going on with the National Prevention Strategy and the Action Plan to Reduce Racial and Ethnic Health Disparities. They drafted letters and the 2013 recommendations, and in 2014 and 2015, sent letters to the Secretary about multiple strategic directions. They also listened to groups like AMCHP, City Match, ACOG, March of Dimes and others as well as key federal agency staff. They formed working groups to focus on the national agenda, equity, health care reform, health care systems and then on Healthy Start. They were looking closely at the American AAP's Bright Futures, perinatal guidelines, ACOG and maternal safety and as it came on, the Women's Preventative Service Initiative along with many others. The offices of Minority Health, Adolescent Health and Population Affairs played roles as well.

However, between 2010 and 2014, with the roll out of the Affordable Care Act, the administration did not focus on many of the group's priorities although administrative agencies did respond to the ideas the group was disseminating. But, coordination on the release of infant mortality annual data did not happen in a timely way or during a reliable time frame. The Premie Act report, authorized through the Premie Reauthorization Act, which directed SACIM to produce a plan for conducting and supporting research, education, and programs on preterm birth through the Department of Health and Human Services also was not submitted because SACIM could not recruit a quorum of participating agencies to form a viable panel and it was not possible to hold a subsequent meeting. Dr. Johnson said that there is an opportunity for SACIM to pursue this initiative and to include the issue of equity.

She then discussed SACIM's recommendations, which reflected what the group was and was not able to accomplish: 1. Reflect a life course perspective; 2. engage and empower consumers; 3. reduce inequality and disparities and ameliorate the negative effects of social determinants; 3. protect existing maternal and child health safety programs; 4. advance system coordination and service integration; 5. leverage change through multi-sector, public and private collaboration and; 6. define actionable strategies that emphasize prevention and are continually informed by evidence and measurement.

Ms. Johnson pointed out that progress had been achieved in connection with the first two recommendations; SACIM was calling for Bright Futures for Women, a challenge that ACOG seems to have taken up. However the Medicaid Innovation and Demonstration projects the group hoped to see have not materialized. There also has not been progress in ensuring mental or behavioral health support services for women. Trying to achieve a continuum of faith and high-quality patient-centered care has been a major challenge as well although a lot has been done through the introduction of collaboration improvement and innovation (COIIN) projects. More also needs to be done using Medicaid to drive quality. The Agency for Healthcare Research & Quality and CDC's efforts around quality improvement and states' efforts to

improve perinatal quality are important. There is also more work to be done to determine how the Affordable Care Act community centers and workforce capacity relates to mother, child and family health.

The group picked specific topics and rated and evaluated what it decided were five key demonstrated preventative interventions, in connection with which progress was made although, since then ground has been lost. 1. Practice improvement by providers; 2. Changes in knowledge, attitudes and behaviors of men and women of childbearing age; 3. Empowered communities; 4. Health equity and; a serious commitment to prevention by all. SACIM did not convene an inter-agency expert panel to set goals for closing infant mortality gaps, a goal that those in SACIM might be able to work on in connection with addressing equity issues. Dr. Johnson noted that the group was able to support the transformation of Healthy Start but didn't offer new recommendations. Healthy Start is also implicated in influencing social determinants of health and current COIIN and AMCHP efforts would be relevant to that. Other areas of emphasis are reducing poverty, particularly through income support and the American Academy of Sciences published a report that endorses what SACIM said in its report and the need to invest in adequate data and surveillance. More attention should also be paid than has been in the past to unleashing the potential for inter-agency public/private and multidisciplinary collaboration.

Ms. Johnson suggested several "quick wins" that SACIM could now pursue: preparing and submitting the Premie Act report; investigating and reporting on the importance of the Affordable Care Act and Medicaid to women's and babies' health could be a subgroup activity, such as making a case for postpartum, fourth trimester and inter-conception care for those at risk. She said that it is important to listen to women and invite consumer voices but also to push for childhood immunizations, NICU and preventative care or Medicaid enrollment. She also urged SACIM to pursue goals that are within HHS' purview.

### **Committee Questions and Discussion**

- A member observed that the Innovation Center at CMS actually led the development of the Maternal Opioid Misuse Model. There are valuable lessons learned in the Strong Start Initiative, which published its final report last year. It focused on the Innovative Models of Prenatal Care for women and the Integrated Care for Kids (INK) Model, which examines the intersection between physical and behavioral health in children and similar pathways are being created in connection with maternal health.
- Dr. Ehlinger wondered about how SACIM has worked in the past during a transition from one administration to another.
  - Ms. Johnson said that the best approach is to ensure that the outgoing administration signs a nomination package to avoid the necessary waiting until the incoming administration addresses this. She added that greater continuity in membership is helpful.
- Dr. Ehlinger asked how SACIM could increase its visibility within HHS to also increase its influence.
  - Ms. Johnson suggested finding ways to publish reports more frequently and produce those that are not scientific but make recommendations, such as the Premie report, which spurs investigation into areas where other agencies already have a presence. Her participation on the National Vaccine Advisory Committee, for example, brought her in proximity with the HHS Secretary or the assistant secretary. Using networks and focusing on inter-agency collaboration builds visibility.
- Dr. Jarris asked whether SACIM has access to public information only after release, or to pre-released information or administrative deliberations.
  - Ms. Johnson said that this is an administration-driven decision. She recalled that, she and others on the National Vaccine Advisory Committee had access to confidential data but much of what she saw as chair of SACIM was publicly released data.

## **REPORT FROM THE HISTORY WORKING GROUP**

*Magda G. Peck, Sc.M., Sc.D., M.C.H.*

Member of SACIM

Dr. Peck provided a look back at SACIM's activities and on longer-term issues in maternal and child health. She explained that the report reflects conversations she and her team held with people over the past three months and was a charge that was agreed to during a meeting in December. It is intended to examine what SACIM did in the past and would complement a report from Ms. Johnson

(<https://www.hrsa.gov/sites/default/files/hrsa/advisory-committees/infant-mortality/correspondence/recinfantmortality-2013.pdf>).

Dr. Peck explained that all of the people now serving on the Secretary's Advisory Committee on Infant Mortality are new so it is important to review its work over a 30-year period to determine what is relevant and feasible for the committee to accomplish going forward. The current committee has pledged to build on the strong foundations of the group. Great progress was noted by Dr. Michael Warren earlier but persistent gaps have remained. They and previous members of SACIM recognize that it is important to follow outcomes for women, children, families, and fathers and that infant mortality is an important indicator and proxy. The committee wants to recognize the long arc of history as it addresses social determinants and life course across generations. The methods her team used over the last three months were a series of key informant interviews conducted by e-mail communications which would be synthesized and presented in the aggregate accompanied by a very limited amount of literature review. They framed their work around four guiding questions.

First, If we do this third-generation of SACIM work, what is it most important to do? How does the current membership build on what has been done before? The SACIM has gravitas and bases the work on science but should not be shutting advocacy to the side. The committee needs to find a strategic balance and should be able to fairly identify what the clear endpoints are through which they can influence outcomes. It is also important to remember that data alone are not enough; it takes political will as well to muster and sustain desired changes.

Another guiding question was: how to ensure that SACIM's work will be productive and have substantial impact. Dr. Peck noted that there was a call for strategic pragmatism; it is important to be clear about the early wins that are accomplished, such the Premie Act. There also needs to be, not just timely release of data, as Ms. Johnson pointed out, but innovation surrounding that data. It is important to keep the focus on health care that is sustained and maintained for all of the highest quality. It is important to build and stabilize on what works, and if the focus is on maternal mortality, go beyond the quality bundles in clinical care to take the upstream work around equity and integrate that into maternal mortality work. It is important to also take into account social determinants as well; the focus has to be on fathers, fatherhood and families as well as mothers and children. The issue of equity is important as well and that is tied up with the fact that housing access, quality and security affects infant outcomes. And specific recommendations, not just ideology, that are evidence based are key as well.

As for how to do the work, it involves recruiting members who are strong and engaged and motivating them to get the job done. It is also essential to convey an understanding of equity and making it a priority because this may not come up in the clinical or other settings. Another priority should be to involve, not just organizations that are run by women but those that are started and managed by people of color. Other advice: structure the work, be well-intentioned and consider having an ethics officer in the room but also be prepared to take the work right up to the edge of what can be done. SACIM should contain the brain power of a think tank; it needs to be a go-to place for ideas and innovation.

Another guiding question Dr. Peck addressed was what lessons from history should be accounted for as the committee takes on upstream forces and factors that drive maternal and infant health outcomes. SACIM must have the courage "to go back to go forward" and acknowledge the cumulative traumas that have been visited on American Indians and the legacy of slavery. It must also realize that maternity issues drove many of the policy decisions that were made 100 years ago. Granting women the right to vote and the Sheppard Towner Act, which was enacted to reduce maternal and infant mortality paved the way toward a better



understanding of the need for universal access to care.

She concluded by saying that past SACIM members would be glad to help; they want to participate in this group, which they hold in high esteem and want to sustain the work to improve the health of mothers, infants, children, fathers and families.

## **DISCUSSION OF THE VISION AND SCOPE OF WORK OF SACIM**

*Edward P. Ehlinger, M.D., M.S.P.H.*

Acting Chairperson

Dr. Vijaya Hogan and Dr. Ehlinger noted that points that were likely to be raised in the committee questions and discussion that would normally follow Dr. Peck's presentation would also suitable to cover in this discussion topic so the decision was made to cover them here.

In the context of the SACIM Charter and in light of previous SACIM work and the History Working Group report the following questions were included in the agenda:

- How is the current SACIM potentially different than previous groups?
- What do we want the current SACIM to achieve?
- How can SACIM be successful its work?
- Who do we want to influence and why?

Dr. Hogan said that, in addition to acknowledging past traumas, some things may need to be reversed in the present based on what happened in the past to ensure a level playing field, because many disparities flow from past events and their outcomes. It is important to distinguish social determinants and equity, which are related but not synonymous. Social determinants need to be dealt with in a way that achieves equity and this is a distinction that the committee can clarify for the field and for the child and maternal health community. She also mentioned that, although the need to focus on providers, improvement and practice and on changing knowledge, attitudes and behavior toward women and families, MCH agencies in the context of equity was not included. Organizations, agencies and people who work with and make decisions about policy, programs and clinical care are not being included in this discussion but they contribute to inequity by perpetuating a system that is entrenched in it.

In addition to the organizations and the agencies and people who work with mothers and children, who make decisions about policy and programs and clinical care, SACIM must also think about the Title V agencies, national organizations and even community-based organizations, which should be structured to promote equity in their work, policies, practices and procedures and the way they think. If equity issues don't permeate what is done, societal change will never happen which means addressing social determinants at the level that will achieve equity will never happen. Dr. Ehlinger also pointed out that other agencies should be considered as well, such as the U.S. Department of Agriculture, the U.S. Department of Labor, economic development agencies and the Department of Transportation, all of which deal with social issues that affect health (e.g. transportation challenges and lack of paid maternity leave can have adverse effects on mothers, families and potentially, infant health). In short, providing health and quality of life benefits only to the wealthy increase health disparities. Thus, getting other federal government agencies involved is important.

The constitution of the committee is also very important. People select priorities based on their world view, and where they stand, the context that they understand and have developed their own sense of priorities, that's why diverse membership on the committee is important. This is why it is also important to include young professionals in the field in this work, to ensure a pipeline of future members is established. Dr. Jarris agreed with the latter point but stressed that it is also important to stress to those who follow in SACIM members' footsteps where the committee has succeeded but also where, how and why it has failed.

Dr. Palacios stressed that local leaders of Native American and other communities should be informed about what SACIM is doing in this area. Dr. Jarris added that the African-American community needs to be included as well. Dr. Hogan said that this could be done currently through public service announcements.

Dr. Ehlinger warned that creating an office of equity in a state health department, rather than building it into everything the department does might be ineffective because, once you place responsibility for equity issues in a separate entity, it becomes someone else's responsibility and collective focus on this priority could be lost.

In the discussion of who should be influenced early on in this discussion, Dr. Ehlinger asked, should the focus only be on the Secretary of HHS or the Health Resources and Services (HRSA) administrator? Dr. Peck reminded the committee that it has a charter and is obliged to work within HHS channels, which does report to the Secretary. She added however, that it is appropriate to consider how to influence the larger maternal and child health community and shape practice; it is possible to influence policies and practices beyond HHS. Dr. Ehlinger agreed, saying that SACIM's charter calls for the committee to provide advice on how to best coordinate federal, state and local government programs and private resources and activities and that one way to do this is to gather input from people at meetings and other gatherings and explain SACIM's goals, initiatives and priorities.

### **REPORTS FROM BREAKOUT GROUPS ON VISION AND SCOPE OF SACIM**

Dr. Ehlinger assigned three groups of committee members to address the following three questions—assigning one group to each question—which was followed by general discussion of SACIM's vision and scope.

- What are the unique opportunities that SACIM has right now?
- Who are the partners with whom we want/need to work?
- How do we best build and leverage the “stature” of SACIM?

Ms. Pettiford, Dr. Ehlinger and Dr. Malloy addressed the first question. They said that SACIM has unique opportunities in connection with some states' participation in Medicaid expansion to address maternal and infant mortality and the disparities that play a role in these outcomes. There are also opportunities afforded by the \$26 million in funding the Bureau has received, which could address issues of equity and could enhance efforts to provide women with earlier access to prenatal care. SACIM should also focus on stressing the importance of vaccination and ensuring that the clinical care and public health sectors work together as a team. Other opportunities or trends for SACIM to focus on include: 1. focusing on Title X and family planning in connect with pregnancy intendedness; 2. the potential impact of marijuana use on birth outcomes; 3. incarceration and its effect on equity; 4. efforts to reach out to organizations that are working on observing the 400 year anniversary of slavery and to address discrimination generally; 5. Advocacy for a livable wage and parental leave and; 6. Increasing use of telemedicine, which can help address access issues in rural and urban communities.

Dr. Jarris, speaking for his group, which included Dr. Conry and Dr. Hogan; addressed which groups SACIM should work with. He said that the Council on Patient Safety and its complementary organization, the Women's Preventative Services Initiative and, specifically within that group, Diana Ramos. ACOG's Barb Levy, who staffs those groups would be a valuable resource as well. The Alliance for Community Health Plans is also a possible partner. In terms of philanthropy, the California Endowment, Tony Iton and Robert Wood Johnson could both inform the Secretary of HHS but also in terms of funding. Dan Frane, a family physician, who is working in the area of preconception health, could also be a useful resource. In the environmental field, Ken Cook examines exposures that affect work outcomes. An unidentified participant commented that finding a leader from the International Society for Developmental Origins of Health and Disease.

Dr. Peck reminded the committee of the importance of hearing directly from the communities being served or who need services and to bring the next generation of leaders into these discussions. She suggested that ways be found to involve younger staff, schools of public health students and other non-MCH trainees in

SACIM's areas of focus. Dr. Ehlinger said he hopes to recruit an intern to work with the committee to both learn from and inform it. Another commenter said that perhaps it would be more effective to choose someone who is early in his/her career to serve as a young committee member. Dr. Warren said that it might be possible to find funding to bring young staff members or trainees to SACIM meetings.

Dr. Barfield said that the Treasury Department is providing \$75 million in awards through the Social Impact Partnership to Pay for Results Act to state and local governments to scale evidence-based innovation in the areas of pregnancy, improving birth outcomes, early child health, reduction of preventable diseases and health improvement among those with mental, emotional and behavioral needs. Dr. Peck also asked whether SACIM could pursue private sector (foundation) funding to attract partners by participating in meetings since currently funding for travel is limited. Dr. Warren said he would check into the committee's ability to seek such support and suggested that the funding could be used to underwrite the cost of events more globally.

Dr. Wise spoke for the third group, which included Dr. Broussard, Dr. Peck and Dr. Palacios, and addressed how best to build and leverage SACIM's status. He said that the committee's stature will depend on the strategic choices it makes. The committee could work to elevate the broader issue of infant mortality and maternal well-being—make it a more compelling issue. Another approach would be to hold various groups accountable for including infant mortality and associated issues in initiatives being pursued through Medicaid and within or outside HHS. He mentioned a paper written by Angus Deaton and his colleagues at Princeton that reported on falling life expectancy and said that the status quo processes used to address this are inadequate. The committee could look for leverage points within HHS' active initiatives to ensure that infant mortality is included, and that nontraditional voices have a say. The committee could also serve as a communicative clearinghouse of information to support engagement that cuts across silos.

## **REPORT FROM THE NARRATIVE WORKING GROUP**

*Edward P. Ehlinger, M.D., M.S.P.H.*

Acting Chairperson

Dr. Ehlinger said that when focusing on advancing health equity and the concept of national health for all, and narrative is very important because you have to capture public sentiment to succeed. It is important to craft messages that will reflect and resound with people of different ages and backgrounds. Infant mortality is not shrinking as rapidly here as it is in other highly-resourced countries and disparities are not being addressed adequately. This is more of a social justice issue than a math issue. He noted that disparities dropped during World War II because there was a strong sense of belonging; of everyone working toward a common goal; but at that time, government provided national maternity care—a type of maternity insurance, provided because women were a vital part of the work force. Neighborhood health centers came out of the Office of Economic Opportunity, reflecting back to 1913 when the Children's Bureau was in the Department of Labor, as a reflection of economic development. And then, when the country started moving away from some of those policies, infant mortality rates started to increase, and the disparities started to increase, especially in the late 1970 and we are now one of the few countries in which infant and maternal mortality rates, particularly among African-American women, are rising. This is not due to a lack of resources. In OECD countries, for every dollar that is spent on health care, \$2 are spent on social services. In the United States 55 cents are spent for every dollar of health care. The general narrative is that if everyone works hard, makes good lifestyle choices, they will be healthy and, thereafter, if they get sick, the health care system kicks in. The emphasis is on individual responsibility and over-investment in the bio-medical model of health care. However, health behaviors are often influenced by the social and economic conditions in which people live. For many people, it is not easy to make healthy choices.

Today, the mission is to really advance health equity and improve the health overall but it requires the ability to actually change living conditions, which is where narrative comes in; the narrative has to be aligned to build public understanding and the will to organize the necessary resources. Resources need to be shifted and people organized to affect decision makers, develop relationships and align interests. It involves getting people to the table who have power to make change by influencing policy with the goal of achieving social cohesion and social justice.

Dr. Ehlinger said that, while working with the Association of State and Territorial Health Officials in Minnesota he helped to develop the Triple Aim of Health Equity, which involves creating equity as a goal, include health in all policies that are established and then strengthen the capacity of communities to create healthy futures. However, we're in an era where many people focus on smaller government, which has led to less investment in initiatives that will advance the public good. But we need to evolve a narrative that conveys health as a community responsibility.

In looking to see how to advance this narrative, ASHTO came across the World Health Organization's Framework for Advancing Health Equity, which can be used as a primer for expanding and advancing the narrative Dr. Ehlinger described.

## **WHO SOCIAL DETERMINANTS OF HEALTH FRAMEWORK**

*Marilyn Metzler, R.N., M.P.H.*

Senior Analyst, Health Equity, CDC

*Joanne Klevens, M.D., Ph.D., M.P.H.*

Epidemiologist, Division of Violence Prevention, CDC

Ms. Metzler said that, she is focusing on living and working conditions, because when people's basic needs are met, which can improve the effectiveness of behavioral and clinical interventions. She said that key resources come from the 2016 WHO Commission on Social Determinants of Health, which was convened from 2005 to 2008 and one from the National Academy of Science, Engineering and Medicine, which provides guidance on educating health professionals on the social determinants of health. The Division of Violence Prevention at CDC is always working on social determinants and health equity uses the WHO Framework for Advancing Health Equity. The first step is an examination of the data to see where there are gaps that cause inequities. Then intermediary determinants of health to see which might be contributing to the outcome gaps the data have revealed. These include living and working conditions, behavior, biology, psychosocial conditions and the health system and which groups do and do not have access to conditions that contribute to health. Hierarchy of advantage and disadvantage are also examined by groupings, such as social class, race/ethnicity, gender and others. Many of these hierarchies are created through access to education, which affects access to occupation and income.

The next step is to see what policy and cultural concepts contribute to the hierarchy of advantage and disadvantage; these are the structural determinants of health inequities. She pointed out that the more advantaged groups are more likely to set relevant policy. The framework also has a cross-cutting box that shows the types of capacity that exist and what would need to be developed to change outcomes across the framework. Use of the framework showed that poverty, residential instability and high-violence neighborhoods contributed to inequities, specifically, since this is the area the division is studying, in risk of child abuse and neglect. These factors, along with race and ethnicity also negatively affected educational outcomes and were associated with inequities in spending on public education, mortgage lending rates and hiring practices. This also followed through in the areas of housing, food and security.

Dr. Klevens said that the division stopped trying to raise awareness about child abuse because many people discussed it as being a problem that did not affect or involve them. Instead, the emphasis switched to child development and stressing the need for stable, nurturing relationships for all children. The division wrote a document, the Essentials for Childhood Framework in 2012 to suggest how states, cities and communities could foster nurturing relationships and environments for children. They were trying to track whether intermediary determinants were followed by a reduction of inequities in child abuse and neglect. They also asked experts what policy changes were needed to address the social determinants of child mistreatment. The recommendations were to reduce and deconcentrate poverty, increase residential stability, increase access and continuity to affordable high-quality child care, access and continuity to high-quality pre-kindergarten education, and facilitate children's access to health care and parent's access to health care, including mental health care. A literature review showed that a \$1 dollar increase in the minimum wage is associated with a 2 percent decrease in teen births, preterm births, in low birth weight, and a 4 percent decrease in infant mortality. Policies such as tax credits, housing vouchers and family-friendly work policies were found to reduce risk of child mistreatment.

This information was reflected in narratives used in strategic messaging that explains why problems occur and who is responsible for solving them. Current guidance is geared toward training people to ask, not “what’s wrong with you” but “what happened to you” and to ensuring that the people who ask those questions be trauma informed. Reactive narratives need to be more prevention driven. Science indicates the importance of starting with shared values and choosing language carefully to account for the fact that most people react initially through instinct and only later with rationale thought. This led to the development of messages stressing that the positive development of future generations is key to the state’s future prosperity and that early experiences build the architecture of the developing brain. Another message is that we, collectively, not individually, can solve difficult problems. It can also be helpful to cite research that supports these findings. Finally, messaging should include an “ask” in messaging; explain what the audience can do to be part of the solution, such as sharing this information with others and educating their leaders on preventative strategies. These approaches were incorporated into messaging that promoted the benefits of an earned income tax credit and instituting livable wages.

The division has started tracking five states in which this approach is being used and has seen changes in policies that strengthen support for families, such as California’s increasing the minimum wage and affordable housing and eliminating the family cap on Temporary Assistance for Needy Families. North Carolina and Colorado increased their child care subsidy and number of pre-K slots. States who received this messaging had 27 times more policies that were in line with this CDC guidance than those that were not exposed to it.

This messaging approach has been built into technical packages designed to reduce sexual, youth and intimate partner violence and suicide. They discuss policy approaches and include comprehensive strategies covering clinical and behavioral interventions and reflect available evidence. The division is also doing more policy analysis to see which ones result in desired outcomes and is developing new narratives and trainings on how to devise them.

### **Committee Questions and Discussion**

- Dr. Hogan said that she does not see the WHO framework as an equity framework but as one dimension of it. For example, Brazil has nationalized health care but impoverished workers there cannot access it because of the way it is structured. This shows that policy alone will not ensure equity. How they are implemented and other social conditions need to be taken into account. Policies need to positively influence people at all socio-economic levels. The cultural/historical influence of ongoing trauma needs to be factored in as well.
  - Ms. Metzler agreed and noted that the effects of racism would be reflected across the framework.
  - Dr. Palacios said that it is also important to make certain difficult subjects, such as child abuse, easier to discuss.
- Ms. Dianne Rucinski of the Office of Minority Health reiterated the need to focus on shared values when discussing problems that need to be addressed rather than on individual problems, which may seem irrelevant or unimportant to those who have not been exposed to or affected by them.
  - An unidentified caller said that the California Department of Child Protective Services now sees addressing poverty as being within its purview; it is starting to focus more on primary prevention than it had in the past.
- Dr. Wise cautioned against elevating the impact of social causation by diminishing that of clinical capability. It would be a mistake to suggest that most health problems are social in origin and that the medical system has little in the way of solutions to offer, especially when the country is struggling to provide high quality health care to all who need it. Social forces can be relevant in neonatal intensive care units and in the lives of women. Failure to provide adequate access to neonatal intensive care to the poor will increase rates of infant mortality.
  - Dr. Jarris said that structural and social determinants affect every aspect, including clinical care. Where a person lives can affect health care quality and access. He also noted that the best way to eliminate disparities is to eliminate a universal threat as soon as you can—for

example, through vaccinations. But variations in the extent and timing of implementation need to be addressed as well.

### **SETTING AN EQUITY FRAME FOR THE WORK OF SACIM**

*Edward P. Ehlinger, M.D., M.S.P.H.*

Acting Chairperson

Dr. Ehlinger said that the trajectory of infant mortality in the United States for the last century has demonstrated that overall improvement in infant mortality rates have not been equitably shared by all populations within the country. However, a reduction in and the ultimate elimination of disparities in infant mortality rates would benefit every infant born in this country. As a result, every project, activity or policy recommendation SACIM makes will be crafted through an equity framework and evaluated according to its effect on reducing health disparities among infants and mothers.

He also defined equity as every person having the opportunity to attain his or her full potential; this also applies in a health context, of course, because health equity is part of overall equity. This is why equity must be part of everything that SACIM does and everything must be evaluated.

Dr. Hogan said that a way should be developed to implement this ideal. Dr. Ehlinger agreed and suggested that a group be convened to determine how to do that. Dr. Jarris said that the WHO focus on how a strategy affects maternal and infant mortality but also how it affects fairness is also important. Improving infant mortality across the board is important but that may not address the equity imbalance. Another participant said that it is important to both have an evidence base of what improves infant mortality rates but also focus on ways to implement these strategies in ways that affect all populations.

Ms. Rucinski said that it is important to tailor the intervention to the community you are trying to serve—culturally, linguistically and socioeconomically. Dr. Jarris pointed out that communities that are trying to do prevention work often get grants because they're successful in writing them and stick to a specific, proven model which may not work in rural environments or low-population reservations. He called on funders and policy leaders to allow programs to be implemented in the best way for communities that aren't addressed by academe and that those who can't hire grant writers be able to compete for them. Ms. Rucinski said that the Substance Abuse and Mental Health Services Administration has a disparities impact statement that asks programs it funds to indicate how the work they are doing will affect disparities in the community being served. Dr. Peck said that SACIM may be structured in a way to focus on low expectations that have been met and that this structure needs to be examined to ensure that its work is not rhetorical but grounded and that it strives for equity in terms of its capacity, composition and hearing voices of those outside the committee as it figures out how to achieve this.

### **EVALUATION OF THE DAY AND CLOSING COMMENTS**

*Edward P. Ehlinger, M.D., M.S.P.H.*

Acting Chairperson

Dr. Ed Ehlinger thanked everyone for participating in the webinar and adjourned for the day at 5:00 p.m.

**Tuesday, April 9, 2019**

**RECAP AND OBSERVATIONS FROM DAY ONE**

*David S. de la Cruz, Ph.D., M.P.H.*

Principal Staff and Designated Federal Official, SACIM

*Edward P. Ehlinger, M.D., M.S.P.H.*

Acting Chairperson, SACIM

Dr. de la Cruz called the webinar to order and he and Dr. Ehlinger welcomed the webinar participants back for the second day of the meeting. Dr. Ehlinger noted that Dr. Johnson and Dr. Peck had shared a wealth of background information on the first day that helps to set the historical framework for the committee's work and future direction, and also poses a number of challenges the group will examine. The conversation with Ms. Metzler and Dr. Klevens highlighted the need for narrative to message effectively and hands-on approaches in advancing optimal health for all. The need to focus on equity provides an opportunity to move forward in a unique and powerful way, and not only for the committee but in MCHB, HRSA and across the federal government. At issue is that those who are privileged get to ask the questions and deal with them forthrightly; they also have access to a lot of resources. Those who do not have those opportunities often have limited options. Thus, equity is about giving everyone the option to thrive and to give everyone options among which to choose to move themselves forward. The question is, how to transition from the theory and philosophy of equity to real action.

Participants shared their impressions and take-aways from the previous day. Ms. Pettiford echoed the issue of equity as a major focus and that the issue will need to be approached strategically in devising a framework that all agree on to advance the work. Dr. Peck stressed the need to change the language used from clinical to equity and to widen the scope to consider all determinants and dimensions that affect mothers, children, fathers and families. Dr. Jarris expressed an appreciation of the comprehensive nature of the agenda and establishing a framework as a guide to handle the multitude of issues as they arise. He also stressed the importance of spending time on implementation and to break down barriers to doing this. Dr. Palacios noted that larger communities are becoming ready to tackle equity. The public consciousness is ripe for talking about these things, and this committee should take advantage of that while acknowledging that some approaches are going to be more effective than others.

Dr. Conry appreciated the historical perspective and the information from Dr. Peck and Dr. Johnson which gives the group a great launch pad because they indicated how much has already been accomplished. Looking at the next step has more to do with systematic approaches in areas where acceleration is occurring and building on existing knowledge from those health systems, those stakes, those health plans, and the positions where they're already accomplishing a great deal and use that to leverage more action on a state by state basis.

Dr. Hogan believed that the previous day's discussion highlighted the importance of addressing both the high rates of infant mortality as well as the inequities. The group needs to develop a better narrative to convey to everyone the importance of both, and how addressing equity benefits the whole population and disadvantages no one. Dr. Wendy DeCoursey expressed the wish to have protocols and approaches that will allow the work to be continued in the future by others without having to relearn the basics that have been covered, thus setting the stage for years to come.

**THE INTER-CONNECTION OF MATERNAL HEALTH/MORTALITY WITH INFANT HEALTH/MORTALITY**

*Wanda Barfield, M.D., M.P.H., F.A.A.P.*

Director, Division of Reproductive Health, CDC

Dr. Wanda Barfield discussed the connection of maternal and infant health and morbidity and mortality, on infant health and mortality along with some policy issues for consideration. She explained that former CDC director Tom Frieden proposed a framework for public health impact that was published in the American Journal of Public Health, which places at its base socio-economic factors, such as poverty, which, if

addressed would, he said, have a huge impact on improving health. Moving up the pyramid, there are policy areas in which decision makers can influence the health of large populations without their direct involvement such as through enacting smoke-free laws or introducing water fluoridation. Long-term interventions include effective therapies such as immunization. Clinical interventions include treatment of diabetes and counseling and education, including conveying the importance of healthy diet and exercise. Moving up the pyramid the interventions can be more individual and may require reaching a broader audience but with less population impact.

Each year 24,000 infants die and their deaths are often linked to poor maternal health or environment. During her previous presentation to SACIM, Dr. Barfield discussed various strategies for preventing infant mortality, ranging from educating women about good health practices (e.g., reducing obesity and smoking cessation) to reducing typical causes of infant mortality (e.g., sudden infant death syndrome). She also stressed that minority groups may not seek information about good parenting practices from physicians and that culturally appropriate messages may need to be delivered by community leaders. She also discussed new models of care that empower and offer social support, such as father involvement and recognizing the importance of child and adolescent health and provision of care through the life course.

In a scenario of infant mortality prevention, the pyramid would include efforts to address poverty, education, racism, inequity, and the provision of health insurance. Other policies would have impacts in several areas, such as improving women's overall health, which would also benefit children's health. Through this changed context, high-risk mothers would be identified and referred, tobacco control policies would reduce the risk of smoking in pregnancy. Effective long-term interventions such as contraception to reduce unwanted pregnancies and counseling on healthy behaviors for both mothers and infants (e.g., safe sleeping and smoking reduction). These are things that can be done but there is much we need to learn how to prevent and predict such as idiopathic preterm birth, preterm labor, premature rupture of membranes and pre-eclampsia, that contribute to mother and infant morbidity.

Dr. Barfield pointed out that there has been a lot of media attention on maternal mortality and racial disparities in the United States. At least half of the approximately 700 women who die due to pregnancy or delivery complications are preventable. There are 13 deaths per 100,000 live births for white women; that ratio is 44: 100,000 among African-American women and black women are three to four times more likely to die of pregnancy-related causes than are white women. In addition, black college-educated women who gave birth in local hospitals were more likely to suffer pregnancy or childbirth complications than were white women who never graduated from high school.

The overall maternal mortality rate in the United States has been rising for several years; chronic—specifically cardiovascular—disease is considered to be the most likely cause and CDC statistics bear this out. The proportion of pregnancy-related deaths due to hemorrhage and hypertension has decreased since 1987 while the proportion of deaths due to heart disease and other chronic medical conditions has increased, according to data collected by Maternal Mortality Review Committees (MMRC) in nine states from 2008 to 2017; this was a collaboration between the CDC Foundation, Merck for Mothers and AMCHP.

These committees conduct a multi-disciplinary process through which they identify and review maternal deaths that occur within one year of pregnancy regardless of the pregnancy outcome. Once a death is deemed to be pregnancy related, they identify the underlying cause of death and determine where the areas of vulnerability are, which become the basis for the committees' specific recommendations. A 2018 report from these nine committees indicated that the largest proportion of factors that contributed to pregnancy-related deaths were patient family factors, followed by provider and system-of-care factors. Patient factors were often linked to providers and consistency of care. In any case, multiple, simultaneous factors are identified. MMRCs have probably not felt empowered to make recommendations about social determinants of health or disparities even though they contribute to morbidity and mortality and efforts will be made to have review committees and non-MMRC committees to focus on these in such areas as the availability of general health services, behavioral health, transportation and the social and economic environment. The rate of severe maternal morbidity, which includes unexpected outcomes of labor and delivery that result in significant short- or long-term consequences to women's health is on the rise and affected more than 50,000



women in the United States in 2014. This could be driven by a combination of factors including increase in maternal age, pre-pregnancy obesity, pre-existing chronic conditions and complications during delivery.

In terms of infant mortality, in 2016, the rate was 5.9 deaths per 1,000 live births. The 10 leading causes accounted for 67.5 percent of all infant deaths in the United States. Some causes, such as cord and placental complications, can be related to maternal health. Birth defects accounted for 20 percent of all infant deaths and some are associated with preterm birth. Prevention has been effective in some cases, such as the use of pulse oximetry to detect and address critical congenital heart defects, which can save 120 babies per year according to one study. Preterm birth and low birth weight accounted for about 17 percent of infant deaths in 2017; contributors include age, race, socioeconomic status and behaviors such as tobacco and substance abuse. Maternal health may play a role as well. Racial and ethnic differences exist as well, the rate of preterm birth was 50 percent higher in African-American women than in white women. There were 3,607 sudden unexpected infant deaths (SUID) in the United States in 2016, which includes unknown causes and accidental suffocation and strangulation in bed, many of which can be prevented with safe sleep practices. SUID rates among African-American infants were more than twice those for white infants.

Women's health care is often focused on only during pregnancy and, even then, the emphasis has typically been on the baby, which needs to change. Women in crisis need to be heard; postpartum health for mother and baby are important as well but these health needs may not be covered by insurance. More research is needed on factors that drive adverse maternal health and infant outcomes, including social, biologic, environmental and policy. SACIM can influence the larger federal research agenda on maternal, infant and fetal health.

The prevention strategies highlighted were:

- Improving women's health prior to conception;
- Treatment of chronic conditions in pregnancy; long acting, reversible contraception (birth spacing); safe infant sleep/injury prevention;
- New models of care (e.g. Centering); improving quality of perinatal care (e.g. reducing non-indicated C-sections);
- Perinatal regionalization; health insurance and employment.

Opportunities for collaboration (noted from the 2013 SACIM meeting) included:

- COIIN;
- The Maternal Mortality Initiative;
- Surveillance of Preventive Services;
- Tips from Former Smokers Campaign; and
- CDC's National ART Surveillance System.

New models of care could include:

- Group care that offers empowerment and social support;
- Father involvement;
- Life course perspective, recognizing the importance of childhood and adolescent health, and seeing opportunities of home visitation in a life course and;
- How fostering and protecting the maternal infant bond has economic benefits and life course trajectory and school performance and beyond.

### **Committee Questions and Discussion**

Dr. Hogan asked whether anyone has developed a diagram or other illustration that shows the connections between all of the issues that were discussed and others, which can help providers apply broader solutions to address several issues at once. Dr. Jarris noted that there is a tendency to separate the issues of the babies and mothers in obstetrics and pediatrics and the hospital settings for each can differ. This can lead to separate attention being paid to a prenatal patient or a postnatal patient. The mother and infant need to be followed throughout the whole experience.

Dr. Barfield said there are about 36 MMRCs but there are various versions. The data are not being collated but the Maternal Mortality Review Information and Analysis (MMRIA) database may be used to do this. She added that it may be possible for less densely populated states to gather data by regions. However, more needs to be done outside hospitals and in the later postpartum period, particularly to gather more information on social determinants.

Dr. Conry noted that California has developed a systematic approach to driving down maternal and infant mortality to rates that are the lowest in the nation, bolstered by a strong partnership with the Department of Public Health. Kaiser Permanente has a large database with a systematic approach that can analyze how tobacco, alcohol and substance abuse programs can drive down infant deaths and pregnancy/delivery/neonatal complications. This could apply to other organizations with large databases such as the Geisingers and the Mayo Clinics. This could prove to be a better approach than randomized trials, which take a long time to conduct. Dr. Barfield agreed, saying that this would be a great way of engaging with health organizations. She also said that clinical care operates in a social context and that it is important to show disparities in terms of the type of care that is provided for different groups. She said that her division has developed a logged model to create a MMRC that includes process and outcome measures, which is on the website that refers to MMRIA.

Dr. Peck said that she can provide a link to everyone to access a panel at Harvard University School of Public Health that addresses maternal mortality. She brought up the importance of hearing the women when they talk about their health issues and the narrative that is developed. Dr. Barfield noted that information on the nine MMRCs that are currently working on the MMRC will be available.

She said that MMRCs could consider a number of questions in conducting maternal mortality reviews: 1. Was the death pregnancy related? 2. What is the underlying cause of death? 3. Was the death preventable? 4. What factors contributed to the death? 5. What were the social and environmental factors? 6. What actions could be taken and what impact would their implementation have? Making decisions on these questions would help MMRCs to address, not just clinical factors but broader issue with regard to health equity.

Dr. Palacios talked about safe sleeping practices and breastfeeding practices and cultural differences that encourage co-sleeping which, she suggested, could incorporate safe sleeping practices. She suggested that these cultural considerations need to be addressed. Many women will not share this fact with their doctors. Dr. Barfield discussed the Pregnancy Risk Monitoring System (PRAMS), which acknowledges these different cultural views toward co-sleeping, infant sleeping positions, placing soft objects in the bed, etc. She said housing conditions can also influence these decisions, citing the example of mothers who slept with their infants to prevent them from being bitten by rats. In some places, mothers may co-sleep with their infants in the winter just to keep them warm. Thus, although women need to be educated about safe practices, it is also important to understand the circumstances that may drive their behavior.

Dr. Jarris cited a couple of studies that have found causes of death among pregnant and postpartum women, aged 10 to 29, in Illinois. The major causes of death were motor vehicle accidents, suicide, substance use, and then pregnancy- and delivery-related causes. In Texas, drug overdoses were the major cause of death. This shows the need to not limit the data to medical causes. Dr. Barfield said that this underlines the importance of look at the causes of maternal mortality outside the hospital setting. But trying to include issues of equity will be a challenge. It's important to include data from the American Community Survey and census data; sources outside the usual suspects that can better inform health equity. Dr. Conry pointed out that domestic violence is more common than diabetes but because the latter is screened for, that is what is detected. Dr. Jarris noted that data on domestic violence is not collected because no one knows what to do with the results.

Dr. Ehlinger pointed out that poverty is now listed as an ICD-10 code as it relates to inadequate housing. He asked what interventions other than clinical can be applied to those societal factors and whether they are they preventable. Dr. Barfield said that some factors are and should be considered. One example would be a woman with mental issues who was never seen after her six-week visit. This leads to the narrative issue, Dr. Ehlinger pointed out that focusing on clinical issues can cause other equity issues to be missed. There are factors outside the hospital that, even if not preventable, can be addressed in various ways. Ms. Pettiford

suggested that ex officio members of SACIM who are dealing with housing, labor, urban development, agriculture and Indian health services might be collecting potentially useful data.

Dr. Jarris wondered if the charge of the committee being focused on infant mortality limits the ability to look into some of the maternal issues on a very deep level or if it needed to be spelled out. Dr. Warren and Dr. de la Cruz said that the committee is addressing it already in many ways and that the charter was purposefully written broadly to allow the committee to address a wide range of activities that are related. Dr. de la Cruz said that a proposal to broaden the committee's charge could be submitted to the government.

Dr. Ehlinger steered the conversation to the working group breakouts and the direction they should take, to strategically determine the areas where they can see some immediate action and wins. He also hoped they would lay the framework for future projects, and use what is unique to the SACIM to make a difference in outcomes. Three issues to discuss are: 1. The Preemie Act — working on that with the MCHB and using questions that past SACIMs have posed; 2. Equity and maternal health — making a transition from theory to practice; 3. the need to collect data that can be used for decision making, and policy and program development; 4. The need to identify environmental issues that affect maternal and child health. He instructed the groups to think about these issues in terms of upstream and downstream focus and the continuum.

Dr. Peck mentioned the infrastructure of SACIM and how the work can be organized and continued in an effective way. She urged the committee to think about where it could be the leading edge or primary driver of an issue, particularly in terms of informing federal policy and spilling over to external organizations. It might also take on issues that are already being pursued by other advisory committees, such as vaccines, Vitamin K, pollution and its link to pre-term birth, etc. – where SACIM could be a secondary partner but she also warned about the risk of duplicating other efforts unnecessarily. She also urged the committee to consider who to ask for input.

Dr. Ehlinger mentioned that the Health Resources and Services Administration within HHS funded a COIN focusing on foundational practices for health equity, focusing on local health departments but could be used by any agency, that he helped to put together. It focused on how to use data and work with communities.

Dr. Warren asked whether there are key issues or developments that the committee should be measuring or reporting on that would give it visibility if the committee acted on it; he wondered whether it needs to be stratified. This could be another topic to discuss. Dr. Ehlinger said that this speaks to the type of data that may need to be collected—such as data on housing, transportation and agriculture that could affect maternal health. Dr. Barfield said that relevant data collection is important. She alluded to an example described earlier that showed surfactant is an effective medical intervention but the timing of its administration is important. Its level of efficacy depends on how soon after birth it is given to an infant. This example shows how poor infrastructure or lack of quality can make a difference in outcomes.

Ms. Pettiford mentioned the need to collect qualitative data, in part by talking to people with lived experience but also to determine which programs or services are already available.

Dr. Ehlinger asked whether there are any burning issues for people—any issue in particular that they'd like to focus on. Dr. Jarris said that an emerging issue is the fact that in rural areas, where 20 percent of the population lives, hospitals and maternity wards are closing, forcing people to travel long distances for care. Part of this is driven by Medicare, which funds critical access hospitals, meaning the funding does not go into their cost basis. Meanwhile, rural maternity mortality rates are almost 30 per 100,000 compared with 18 per 100,000 in urban areas. He also referred to the significant racial and ethnic disparities in rural states such as Georgia, the Dakotas and Montana.

Dr. Ehlinger asked Dr. Peck or anyone else whether she could identify any cross-cutting issues for the committee to focus on. She said that one way to look at this is to ask what it will take for transformational change to happen. The committee should be looking for a way to reset the social DNA around infant mortality and maternal health. It could involve data and research, around innovation in policies and

programs? Developing the political will for change could also be a factor. This all could be applied to the challenges rural hospitals are facing.

Ms. Pettiford asked whether the ex-officio members should be more involved in the workgroup discussions and Dr. Ehlinger said that this was the plan so that the groups can support each other and the committee can better leverage their efforts and various backgrounds. Dr. Peck stressed that showing the committee has strong priorities to which it is committed and that they are sustainable and showing that it can deliver something new is important to getting ex-officios more involved. SACIM itself needs to tell a compelling story that will encourage people to engage. He also pointed out that, focusing on policy also means focusing on how entities are organized—on what silos exist and how they are created. How does MCHB relate to SAMHSA, the Department of Housing and Urban Development and the CDC? The cross-cutting areas could be data, equity and policy/organizational capacity. The discussion could be how to address maternal, infant, rural health, environmental issues and clinical services from the three lenses of data, equity and policy.

Dr. Barfield suggested focusing on maternal health issues that drive infant outcomes, mortality and morbidity and the committee can inform the Secretary of HHS about social determinants of health. Dr. de la Cruz suggested that a department's or administration's stated priorities can be a springboard or link to what the committee is doing. For example, departmental priorities are value-based care, health reform and opioids; all of these have clear links to maternal and infant health. SACIM should also continue to elevate the notion of the life course; focusing on maternal morbidity and mortality is probably not enough. That's what's meant by moving upstream. He is also worried that the current emphasis on maternal mortality may be pushing infant mortality off the radar screen. Losing 22,000 babies a year is not acceptable. Dr. Jarris noted that the opioid crisis, health insurance reform, drug pricing and value-based care are "transactional" whereas infant mortality is a more systemic issue.

Dr. Ehlinger asked the committee members to email Dr. De la Cruz the three things each of them believes SACIM should focus on by the end of lunch time.

## **REPORT FROM THE MEMBERSHIP WORKING GROUP**

*Belinda Pettiford, M.P.H*

Member of SACIM

Dr. Ehlinger said that the committee can have up to 21 members; it currently has nine. The Membership Working Group included Ms. Belinda Pettiford, Dr. Vijaya Hogan and Dr. Arthur James who was on the previous SACIM. Ms. Pettiford spoke about health equity as being the frame for the work group and listed the following considerations: Inclusivity, which covers race, ethnicity, gender, geography, rural/urban areas and age, plus, perhaps, the urban mix. Younger peers need to be brought to the table because they will be moving the work forward. In looking at potential additional representatives they tried to think a bit outside of maternal and child health, and have fatherhood represented as well. They considered recruiting a member from:

- the rural health community
- the Urban League
- the National Panhellenic Council, which consists of nine African-American sororities and fraternities
- the Association of Women's Health, Obstetrics and Neonatal Nurses
- the American Academy of Pediatrics
- the American College of Obstetrics and Gynecology.

For ex-officio members, someone from:

- the USDA, which administers the Women, Infants and Children program
- Barbara Ferrara, with the Los Angeles Health Department
- Dr. Rene Anthony at the University of Nebraska Medical Center
- David Williams with Harvard University
- Elizabeth Howell out of New York
- Brian Smedley with the National Collaborative for Health Equity

- Ken Harris with Healthy Start who is also doing a lot of work on fatherhood training and technical assistance
- Dr. Don Warren at the University of North Dakota who is an American Indian
- Elliot Maine with the California Quality Collaborative
- Dr. Heyward Brown, president of ACOG, in Florida.

(the U.S Department of Labor and HUD are already represented even if they are not particularly active; perhaps they need some orientation or data.) She invited other suggestions as well.

Dr. Hogan said that she believed it would be important to include someone from the southern states, which tend to have the worst outcomes and unique political, economic and social contexts and power structures. Midwives should be represented and the National Medical Association, which represents African-American physicians and has done work in the areas of breastfeeding and maternal/infant outcomes. She also thought that orientation sessions are important both to learn what new members can bring to the committee's work but also how the committee can promote the issues and policies that matter to them. Dr. Peck thought perhaps some organizations that are upstream and have an effect on the downstream issues should be included such as the National Academy of Science and the Federal Reserve Bank, perhaps not as committee members, but participating in some way. She also mentioned Healthy Places and Doug Jukes. She also called for some representation and the Latino and immigrants' perspective, particularly given what's happening on the border. Dr. Jarris suggested Diana Ramos from LA County, Charlene Collier in Mississippi with the Perinatal Quality Collaborative and the Department of Health and MMRC. Dr. Palacios suggested Patricia Nez Henderson of Navajo domain and her husband, Jeff Henderson. Another suggestion was Dr. Neil Shaw an OB/GYN. Some community organizers could come from Black Mothers Matter and Sister Song, such as Monica Simpson. Dr. de la Cruz suggested representation from the religious community as well as family organizations like First Candle.

Dr. de la Cruz also said that SAIM's charter expires in September and that he will be writing a new one; he welcomed suggestions about what it should contain. Dr. Peck suggested that a small ad hoc work group be formed to work with Dr. de la Cruz on this and Dr. Ehlinger agreed. He explained that SACIM would submit a nomination package, which must be approved by the Bureau, MCHB, HRSA and HHS. It then goes to the Office of the White House Liaison and it is subject to being halted or adjusted at any point during the review process. The current term of each charter is two years but that could be changed.

Dr. de la Cruz issued a call for public comments for the record. None were submitted in writing and no one asked to deliver oral comments.

Dr. Ehlinger asked the committee to break into two groups of four members each to discuss equity and data and how they can be used to address cross-cutting issues that were mentioned earlier.

## **BREAKOUT GROUP DISCUSSIONS: MAXIMIZING THE EFFECTIVENESS OF SACIM**

### *Report from the Equity Group*

Dr. Vijaya Hogan reported for the equity group, which included Dr. Jarris, Dr. Palacios and Ms. Pettiford. The first step is to develop a framing of equity that all people can buy into so that they can see how it affects the whole population. It should incorporate data and stories because people do not always respond to data and may interpret it according to their values or beliefs. It is also important to distinguish between an epidemiologic-population-based point of view and a clinical point of view, which are different.

The group also focused on narratives as a way to frame SACIM's work and thought it might be helpful to examine Robert Wood Johnson's work on narratives, and those of other groups to assess what type of narrative approach might be best to adopt. Next, they noted the need to document the unique exposures that create and sustain inequity—for example the opioid issue and the fact that it is defined as either a health issue or a criminal justice issue and examples of other substances used by populations of color that are criminalized to see the unique exposures and pathways that different populations face. The third point is the need to articulate the distinction between social determinant approaches and health equity approaches, convey that they are not the same and show how they are related. Fourth was the need to emphasize the role

that racism and history play in creating inequity and translate the action to undo the impacts those things have had. The group noted that some people do not understand or accept how history affects current circumstances and conditions. As a result, it may be necessary to find examples of how history has affected populations that are not people of color and show how history has affected their health or socioeconomic status. The fifth point was the need to identify operational- and science-based models of how people are approaching an equity frame, compile examples and try to come to a consensus about what works best for maternal and child health. This also has to make sense in the context of science, applicability and potential impact. The challenge is that there is no model approach to achieving equity; there are some models but they have not been compared and assessed. A more systematic approach to looking at, not causality but implementation models need to be developed. In terms of individual potential partners in the equity realm, the group mentioned Freida Mac Jackson, who has done a lot of work on racism, Brian Smedley, who just completed an analysis of equity approaches in the public health and Indian health settings and Ray Perry from Black Mothers Matter. People who might be able to participate in a panel on equity include Art James, Don Wame and Carl who had done something powerful and useful with March of Dimes. There may not be enough funding to hold an in-person meeting but perhaps it could be done by webinar. It might also be useful for the committee to compile all of the webinars related to equity that it can identify to come up with a resource that it could use and share with others.

#### *Report from the Data Group*

Dr. Magda Peck reported for the group (Dr. Ehlinger, Dr. Conry, Dr. Malloy and Dr. Barfield). They discussed cross cutting issues and where there are overlaps and focused on four dimensions of trying to manage the data piece. First, it might help with both the equity and data pieces to agree and define the set of principles through which they will do the work to use data strategically. First steps may be to identify and define the set of principles by which the work will be done to utilize data strategically to ensure their effects are measurable and intentional. The data have to be responsive to questions and stories, qualitative data and community voice must be captured. The group agreed that the work has to be science driven and the work should model transparency and accountability. They talked about data quality, access, effective use, capacity, the equity lens and innovation in data. Third, the work should be anchored around data and should focus on preventing maternal and infant mortality from whatever causes are identified as the most important, whether it be premature births or toxic stress and cross-vector it with other data—for example, examining how housing security affects pregnant women's stress levels, which would lead to a search for the housing data. SACIM needs to look at equity questions from upstream and downstream perspectives, finding ways to integrate specific, applicable data, not just data for everyone.

Finally, the basic principles will frame across the different dimensions of data and be anchored around maternal health, are we leading new work or amplifying the work that is already being done? How does the group work with urban institutions that are working with usable data and other data hubs for transformation, weaving together the public and private sectors?

The group also decided that it may also be useful to have a short-term data activation working group to inform the committee's work and that of other organizations with the goal of showing results by this fall.

Dr. Peck elaborated on the need for support systems in communities, and the notion of food security and housing security that women need before, during, after and beyond the childbirth experience. Other issues factor large, such as criminal justice and incarceration over substance abuse or mental illness rather than providing support systems for those affected. Housing and nutrition also figure into this.

Dr. Hogan raised the issue of over-reliance on evidence- based data because what we sometimes diverge in what we consider to be evidence, which is very value-laden. Something that could be added to the data group is discussion of the types of evidence that fall outside clinical trials. What are some other types and how will it lead to the implementation of improvements? This could also lead to an examination of the types of science that are used to develop evidence and implementation science, which is a different process. You can have the best evidence in the world but if it's not being implemented correctly, it will not work. It's important to look at some of those process issues. Dr. Conry said that some of that is being addressed with the Women's Preventative Services Initiative, which is evidence based or evidence informed, which consists of getting clinicians together and looking at what the holes are and how the committee could provide

guidance to physicians. The committee does not have the expertise to make those decisions but can get guidance from the American Academy of Pediatricians, American College of Obstetricians and Gynecologists, and Society for Maternal-Fetal Medicine, which can pull together physicians and scientists, evaluate research and make recommendations. Dr. Peck also noted that who determines what is science and what is evidence has historically been influenced by implicit bias that causes anecdotal or qualitative stories of the lived experience to be discounted. It is worth thinking about how the data group can reinforce the value these voices add and using data to shape the narrative because it is the voices that move people so it would be unwise to separate the story piece from the data piece. The data need to be translated into stories that can be heard.

Dr. Ehlinger noted that there were overlapping references and priorities between the two groups; both mentioned the need for science, stories, principles, framing, evidence based/informed information and narrative. Dr. Peck said that she picked up on the need to do things now and not get bogged down and, therefore, slowed down especially with regard to the equity issue. Another priority is to engage other strategic partners and investors.

### **NEXT STEPS AND ASSIGNMENTS**

Dr. Jarris asked about staff availability to help with some of the tasks and work, such as interns. Dr. Hogan suggested schools of public health where students are required to do practicums and Dr. Peck noted MCHB funded training programs and MCHFB SIE programs could be helpful. Dr. Warren noted that George Washington and Georgetown have programs that would fit the bill.

Dr. Ehlinger asked if some of committee members, specifically, Dr. Hogan and Dr. Peck would participate in a follow-up call, to talk through how the committee to find the commonalities between the data and equity groups. They agreed but Dr. Hogan said she would like to see their work vetted by the entire committee. Dr. Ehlinger and he said he would work up some notes based on the meeting to help with that conversation. They will also approach Paul Wise.

Dr. Ehlinger said that he would like to get someone from the March of Dimes to attend the next SACIM meeting to talk about the Premie Act.

### **EVALUATION OF THE DAY AND CLOSING COMMENTS**

*David S. de la Cruz, Ph.D., M.P.H.*

Principal Staff and Designated Federal Official, SACIM

*Edward P. Ehlinger, M.D., M.S.P.H.*

Acting Chairperson, SACIM

Dr. Ehlinger said that what he took from this meeting is that the committee reached a consensus on the importance of focusing on equity in all activities that relate to mothers, infants, families and communities and will look at ways to implement actions to advance equity in these communities. This will be done through services, policies, data and by finding ways to implement, to go from theory to practice. He also said that maternal outcomes are disparate and affected, not only by clinical activities but by the social environment in which people live.

Dr. Hogan said that it is important to focus on the narrative, to be able to communicate the issues SACIM is focusing on to different populations.

Dr. Peck noted the committee's interest in expanding membership and getting the ex-officio members more involved.

Dr. Malloy said she found it worthwhile to acknowledge all of the federal partners who are working actively to achieve the committee's goals or similar ones.

Dr. Palacios said that there are many long-term goals and activities that the committee can help to shape but it can be difficult to identify the short-term ones, also those that will be most effective or easy to reach in trying to improve infant mortality.

Dr. Peck said she appreciated Dr. de la Cruz mentioning that a religious perspective is not necessarily represented.

Dr. Ehlinger and Dr. de la Cruz thanked everyone for participating and working so hard on the committee and Dr. de la Cruz adjourned the meeting at 3:00 p.m. on April 9.