

Secretary's Advisory Committee on Infant Mortality

Meeting Minutes of December 4, 2018

**Parklawn Building
Room 5W11
Department of Health and Human Services
Rockville, MD 20857**

Tuesday, December 4, 2018

SWEARING IN OF NEW COMMITTEE MEMBERS

Newly appointed SACIM members were sworn in shortly before the meeting officially commenced.

CALL TO ORDER AND WELCOME

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

Dr. De La Cruz called the meeting to order and thanked everyone for attending. He explained that the December meeting, which was originally scheduled to be held over two days, would instead conclude on Dec. 4 because President Trump had designated Dec. 5 as a national day of mourning to mark the passing of former President George H.W. Bush; as a result, all federal government offices would be closed. He noted that Dr. Louis Sullivan issued a call to action in 1991 to address a steeply rising rate of disparity in health outcomes among African-American women compared to white women. This led to the formation of the Healthy Start program, to which SACIM provides guidance and support. He explained that he, Michelle Loh, a management analyst in the Health Resources and Services Administration (HRSA) and Dr. Michael Warren, HRSA's new associate administrator for maternal and child health serve as the committee's staff with the assistance of contracting officer Juliann DeStefano. He then turned the meeting over to Dr. Ehlinger.

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

Acting Chairman, SACIM

Dr. Ehlinger pointed out that the meeting was being held on land that was once occupied by members of Native American tribes—specifically, the Ojibway and Dakota tribes—and, in acknowledgement of this fact, he called the Tribal Health Directors from 11 of these tribes in Minnesota and asked them whether they had a message he could convey to the committee. They told him that they, who are often forgotten in discussions, should not be left out of the committee's deliberations and to remember that they were the first to occupy the land on which this meeting is taking place.

Dr. Ehlinger recalled having testified in several congressional hearings on infant mortality. In his third appearance in 1988, he noted that infant mortality is not primarily a medical problem but a social problem that is embedded in all social sectors. He also identified it as a social justice issue and added that reducing it is a social responsibility. Efforts to address this challenge must include a variety of approaches, including providing paid parental leave, child subsidies and subsidized day care to ensure child and family health. He called on the nation as a whole to be committed to the wellbeing of children but added that policies have not changed much since he delivered this testimony. Although the infant mortality rate has been dropping, disparities in infant and child health among various populations persist.

He then asked all committee members to identify themselves and explain what they hope to achieve through their participation in SACIM.

INTRODUCTION OF COMMITTEE MEMBERS, EX- OFFICIOS AND OTHER ATTENDEES

Committee Members

Vijaya Hogan, Dr.P.H., M.P.H., Program Officer, W.K. Kellogg Foundation said she is interested in addressing health inequities. She plans to share the work she does on the committee with maternal and child health stakeholders at the local, state and national levels and with the Kellogg Foundation as well as other funder collaboratives of which she is a member.

Paul Jarris, M.D., M.B.A., Principle, PE Jarris Health and Recreation, LLC wants to address health inequity and would like to focus public health and health care generally on population health; he is also interested in the effects of nature, the natural environment and green space on health. He plans to share what he does on the committee with Georgetown University where he teaches health policy with its students, fellows and residents.

Magda Peck, Sc.D., founder and principal of MP3 Health Group, said that, as a founder of two schools of public health and advisor to CityMatCH, she wants to bring academic partners to this discussion and to change the narrative on who lives and dies and why. She will take what she does with the committee to CityMatCH, in and around Milwaukee and in schools of public health.

Jeanne Conry, M.D., Ph.D., President, Environment Health Leadership Foundation and President-Elect of the International Federation of Obstetricians and Gynecologists, wants to ensure healthy pregnancies to improve infant health, in part by reducing exposure to chemicals, including lead and mercury and toxic herbicides such as glyphosate. She will share what she does on the committee with the American College of Obstetrics and Gynecology (ACOG).

Janelle Palacios, Ph.D., C.N.M., R.N., Nurse Mid-Wife, Kaiser Permanente; a Native-American, she has worked with Native American communities in the areas of maternal and child health on and off reservations, including teen parents and in the hospital setting. She is interested in approaches that reach the individual through the community. She will take what she does on the committee to the Native Research Network, the largest national network of American Indian document researchers and the Academy of Certified Nurse Midwives.

Paul Wise, M.D., M.P.H., Richard E. Behrman Professor of Child Health and Society, Stanford University, has worked with the Committee since the early 1980s and has been involved in infant mortality reduction efforts throughout the United States and in parts of the world affected by war and other violent conflicts. He has focused on clinical innovation and its effects on maternal and child health and is interested in reducing health disparities. He will share what he does on the Committee with the March of Dimes Prematurity Research Centers and the March of Dimes Policy Committee.

Colleen Malloy, M.D., Assistant Professor of Pediatrics (Neonatology), Ann & Robert H. Lurie Children's Hospital of Chicago, Northwestern University hopes to improve infant health from a national standpoint and policy perspective, beginning with efforts to ensure healthy pregnancies; she is also interested in telemedicine as a key way to reach hard-to-reach communities. She will take what she does with the Committee back to her colleagues at Northwestern.

Belinda Pettiford, M.P.H., B.S., B.A., Women's Health Branch, Head of North Carolina Division of Public Health, Women's and Children's Health Section has been working to improve birth outcomes, especially among African-American and American Indian women and seeks to address health disparities; she has worked with Healthy Start through North Carolina's Title V program. She will share what she does on the Committee with the Association of Maternal & Child Health Programs (AMCHP and the National Healthy Start Association as well as stakeholders in North Carolina such as the March of Dimes and a legislative study commission, the Child Fatality Taskforce.

Dr. Ehlinger urged Committee members to report SACIM's activities and conclusions to their various constituencies and bring feedback from them back to the Committee.

Dr. Ehlinger then asked the ex-officio members of SACIM who were present to introduce themselves. Dr. de la Cruz explained that they are federal partners who can, through their participation, provide relevant information from their organizations while also taking what they learn back to their offices; they do not have voting status. He also asked other attendees to identify themselves.

Ex-Officio Members

Danielle Ely, Division of Vital Statistics, National Center for Health Statistics, Centers for Disease Control and Prevention (CDC)

Suzanne England, DNP, APRN, Great Plains Area Women's Health Consultant, Great Plains Area Indian Health Service is a nurse midwife and a family and psychiatric nurse practitioner.

Wendy DeCoursey, Ph.D., Social Science Research Analyst, Office of Planning and Evaluation, Administration for Children and Families, Department of Health and Human Services (HHS), which is involved with Head Start, Temporary Assistance for Needy Families (TANF) and other initiatives, and hopes she can provide information from them to inform the committee's work and vice versa.

Kristen Zycherman, Centers for Medicare and Medicaid Services (CMS)

Karen Matsuoka, Ph.D., Chief Quality Officer for Medicaid and CHIP, Director, Division of Quality and Health Outcomes, CMS

Other Attendees, Including Presenters

Lee Warner, Ph.D., M.P.H., Chief, Women's Health Fertility Branch, Division of Reproductive Health, Centers for Disease Control and Prevention (CDC)

Cheryl Broussard, Ph.D., Associate Director for Science, CDC's Division of Congenital and Developmental Disorders (substituting for Cynthia Moore, National Center of Birth Defects and Developmental Disabilities, CDC.) Her division focuses on saving infants through birth defects prevention and research.

Juliann DeStefano, Senior Program Analyst, Division of Healthy Start and Perinatal Services, Maternal and Child Health Bureau (MCHB)

Vanessa Lee, M.P.H., Infant Mortality CoIIN Coordinator, Division of Healthy Start and Perinatal Services, Maternal and Child Health Bureau (MCHB)

Arthur James, M.D., Consultant, First Year Cleveland, Interim Medical Director, Care Alliance Health Center. He explained that he is an obstetrician, gynecologist and pediatrician and was a member of SACIM during the previous term; this will be his last meeting.

Sharyn Parks Brown, Ph.D., M.P.H., Senior Epidemiologist, Division of Reproductive Health, National Center for Chronic Disease Prevention and Health Promotion, CDC, is on the Infant Health Team within CDC's Maternal and Infant Health Branch and works with the center's Sudden Unexpected Infant Death Case Registry.

Joyce Martin, M.P.H., Division of Vital Statistics, National Center for Health Statistics, CDC; she leads the Perinatal Vital Statistics Data Group.

Quinney Harris, M.P.H., Director of Health Equity and Community Partnerships at the National WIC Association.

HRSA UPDATE

George Sigounas, M.S., Ph.D.

Administrator, Health Resources & Services Administration (HRSA)

Dr. Sigounas began by explaining that HRSA's mission is to improve the health of the populations it serves by providing access to quality services and through 90 innovative programs. He pointed out that this meeting is the first time SACIM has convened since 2015. The committee advises Dr. Sigounas and the HHS Secretary on HHS programs and activities to reduce infant mortality, including the innovation of

the Healthy Start program and achieving infant mortality objectives stated in HHS's Healthy People 2020 program. The committee also represents a public-private partnership, which allows stakeholders throughout the country to provide guidance and focus attention on the policies and resources needed to reduce infant mortality. HRSA is playing a key role in helping HHS Secretary Alex Azar's priorities, which are to:

- Transform the health care system into one that pays for value.
- Reduce the cost of prescription drugs.
- Address the high cost of health insurance.
- Combat the opioid epidemic.

Dr. Sigounas pointed out that HRSA's Maternal and Child Health Bureau awarded \$360 million to states, territories and nonprofit organizations through its Maternal, Infant and Early Childhood Home Visiting Program. In 2018, HRSA had the biggest budget in its history and will have an even larger one to work with in 2019. He thanked the committee for its help in reducing infant mortality.

MCHB UPDATE & HISTORY OF SACIM

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

Executive Secretary, SACIM

Associate Administrator for MCH, HRSA

Dr. Warren reminded attendees that the committee is expected to advise the Secretary of HHS and the HRSA Administrator on issues affecting infant mortality and to offer recommendations on how to approach this mandate as a nation.

He provided a history of how the United States has dealt with public health challenges beginning with the formation of the Marine Health Service in the late 1700s, which was founded to provide health care to merchant seamen but also to respond to epidemics and the need for quarantines. It was the precursor to the U.S. Public Health Service, which focused on improving hygiene and preventing the spread of infectious disease, by, for example, introducing the smallpox vaccine in the 1800s and creating local and state health departments. However social concerns, such as the effects of child abuse, including child labor, also arose. Because an organized child welfare system did not exist, members of the Society for the Prevention of Cruelty to Animals were consulted, which led to the formation of the Society for the Prevention of Child Abuse, leading in 1912 to the establishment of the Children's Bureau, the first federally funded effort to improve maternal and child health. The Bureau published educational materials but also advocated for cooperation between federal partners to gather statistics and the development of a national birth registry. In the 1920s, the Sheppard-Towner Act, also known as the Maternity and Infancy Care Act and established grants given to states and served as the precursor to the 1935 Title V of the Social Security Act, which resulted in 1989, the Title V Maternal and Child Health Services Block Grant Program. This program gave the states the ability to design maternal and child interventions to meet their populations' needs, a process they will repeat in 2020 through submission of needs assessments that they will use to outline needs and priorities over the next five years. Title V also ushered in Services for Crippled Children, reflecting an awareness of the need to support children with special needs. During this period, infant mortality rates were reduced through the introduction of medical intervention such as antibiotics, improved neonatal care, newborn screening, family planning, the establishment of Medicaid, the Maternal, Infant and Early Childhood Home Visiting Program and Healthy Start. When SACIM was established in 1991, it was followed by an initial decline in infant mortality, followed, however, by static results which prevail to this day due to disparities in care.

Dr. Warren went on to discuss MCHB, which uses its approximately \$1.3 billion budget to support 90 programs, the most well-known of which are the above-mentioned block grant program, the Maternal,

Infant and Early Childhood Home Visiting Program and Healthy Start. MCHB uses national performance measures to gauge the health system's performance such as the number of well-women visits, low-risk caesarean deliveries and risk-appropriate prenatal care. Outcome measures include timing of prenatal care, birth weight, gestational age and mortality rates at various intervals. This set of assessments includes a focus on the life course model; an examination of risk factors that may diminish optimal health trajectories but also protective factors that can mitigate these risks.

Dr. Warren stressed that a social-ecological model must be applied as well; clinical interventions alone will not guarantee good maternal and child health; in fact, only up to 20 percent of health outcomes are ultimately determined by health care. Other, broader factors, such as community conditions, health behaviors and genetics play roles as well, he pointed out. Thus, the health not only of individuals but also of families and communities play a part in healthy development. He argued that fostering practices and environments that are protective, rather than relying on clinical responses after a health problem has developed is more likely to improve maternal and child health. He used as an analogy a poem, "A Fence or an Ambulance" to make his point; the poem points out that erecting a fence to prevent falls from a steep cliff is a more effective health intervention than ensuring that an ambulance is nearby to respond once a person has already fallen.

He suggested that opportunities to further improve maternal and child health include recognizing that infants grow up in families and communities and ensuring that all of these stakeholders are "at the table" and focusing, not only on health improvement of society as a whole but of sub-populations (i.e., reducing health disparities). Instituting primary and secondary health risk prevention measures—the fence vs the ambulance—should be considered as well.

He noted that SACIM has been effective in making key recommendations to the HHS Secretary and HRSA, especially in the area of programming. He cited as examples, advocating for improvements in funding priorities, such as increasing investment in Healthy Start in rural areas and with the American Indian population. He also praised revisions that were made to the Maternal and Child Health Block Grant Program several years ago, which included maintaining key measurements of infant mortality, birth weight, age, prenatal care and prenatal smoking rates.

Committee Questions and Discussion

- Dr. Ehlinger asked Dr. Warren why he joined MCHB, what he hopes to contribute and who he sees as his partners.
 - Dr. Warren said his background is in pediatric primary care but felt he did not have time in the clinical care sector to improve the health care trajectory and public health generally. He was exposed to special funding to address infant mortality and women's health while doing a practicum in the state governor's office and, thereafter, started connecting with the state public health department. He also wants to move from mitigating the effects of existing risk factors to anticipating and preventing others, in part through data collection and analysis and working with a broad range of stakeholders, including nonprofits and advocacy organizations, as well as funders (i.e., Congress) and using their combined feedback and influence as legislators' constituents to achieve this.
- Dr. Ehlinger asked what type of information MCHB needs that is lacking.
 - Dr. Warren said that although vital statistics collection is good, it could be improved through collection of death data from hospitals, funeral homes and medical examiners. Health data collected, not just at the national or state level but from subpopulations, would be useful as well, including those related to social determinants.

- Dr. Peck asked whether it is appropriate to pursue a recommendation that the committee include as a priority, not just a focus on pregnant women's health but women's health generally as well as maternal mortality.
 - Dr. Warren said that the broader perspective is warranted and that preconception care can affect and should be considered in the context of maternal and infant health.
- Dr. James pointed out that, although politics sometimes takes priority over SACIM's recommendations in the decision-making process, the recommendations should still be made because they may empower local communities to respond, even if the nation as a whole does not. He also pointed out that preventive measures (a fence vs. an ambulance) are sometimes adopted more readily for affluent than for low-income communities.

UPDATE FROM CENTERS FOR DISEASE CONTROL & PREVENTION

Data on Infant Mortality

Danielle M. Ely, Ph.D.

Fetal, Perinatal, and Infant Mortality

Division of Vital Statistics

National Center for Health Statistics, CDC

Dr. Ehlinger prefaced Dr. Ely's presentation by presenting statistics showing improvements in the infant mortality rate from about 1915 or 1920 until the 1950s and 1970s when they worsened. He attributed the declines in progress to a lack of positive health outcomes among African-Americans, Native Americans and Hispanics positive health outcomes that whites were enjoying, disparities that were reflected in their reading comprehension levels and other factors as well.

Dr. Ely presented fetal, perinatal and infant mortality statistics from the Linked Birth/Infant Death Pilot, which she recently began managing. She explained that the 2017 birth file is available, as is the rapid release for visual estimates through the first quarter of 2018. The fetal death data file and fetal cause of death files are available as well. Only demographic data are available for 2015 and 2016; the cause of death data for these years are likely to be made available in 2019. As of 2017, both demographic and cause of death data will be released simultaneously and their release is also expected in early 2019. The linked birth and infant death file for 2016 and the cohort file for 2012 are available. The 2017 period file and 2013 cohort files will be released in early 2019. The rapid release provisional estimates are available through the end of 2017. The period file includes two years of birth and one year of death; the cohort file contains one year of birth and two years of death. Beginning in 2017, files from the previous year can be re-released so that users can create their own cohort files from two years of the period file. Total fetal deaths are those within 20-plus weeks of gestation; late fetal deaths are 28 weeks or more. The perinatal mortality rates include fetal mortality rates along with infant mortality that occurs at less than seven days of age.

The linked birth and infant death data file links births and death certificates for infant deaths that occurred within a year of birth, which provides more information from the birth certificates, including maternal characteristics such as pregnancy risk factors and others that affect infant health and mortality. The data also include maternal race and ethnicity data supplied by the mother.

There have been declines in fetal and perinatal mortality rates but they have slowed in recent years. Dr. Ely showed total infant, neonatal (deaths that occur before one month—28 days) and post-neonatal (28-364 days) rates; they have declined over time as well; however, there has been a general stalling of these mortality rates from 2011 to 2016. In particular, non-Hispanic black, Hispanic and non-Hispanic white rates did not decline from 2014 to 2016. Dr. Ely confirmed that it is possible to pull data that indicate

whether a mother is a U.S. resident or foreign born. Hispanics and non-Hispanic whites and Asian or Pacific Islanders have the lowest infant mortality rates compared to non-Hispanic blacks and American Indians or Alaska natives. In fact, non-Hispanic blacks' infant mortality rates are more than twice as high than those of non-Hispanic whites or Hispanics and nearly two-and-a-half times as high or more than those of Asians or Pacific Islanders.

The CDC's Division of Vital Statistics also recently released a report on infant mortality rates by state (excluding U.S. territories) using 2013 through 2015 data combined to create more stable rates, especially for smaller states, which Dr. Ely updated with 2016 data. The rates vary widely throughout the country and range from fewer than four infant deaths per 1,000 live births to more than nine. For example, there were 3.47 infant deaths per 1,000 in Vermont to 9.03 in Alabama. The U.S. rate was 5.87. The data cover race but not the mother's socioeconomic status; however, other 2017 data will contain information on the mother's educational status and whether the mother received WIC assistance or was a Medicaid recipient upon delivery. Dr. Ehlinger said that the committee could recommend that Medicaid files be linked to vital records. Dr. Corny said that it would be interesting to see an overlay of data comparing infant and maternal mortality.

Dr. Ely reported that, essentially, fetal mortality rates remained largely unchanged between 2011 and 2016. The same could be said about total infant mortality, and, because there have been no improvements in fetal mortality or infant or overall perinatal mortality. Only four states significantly improved their infant mortality rates between 2011 and 2016, and those were: California, New Jersey, New York, and Virginia.

She noted that non-Hispanic black infants continue to have infant mortality rates that are higher than other race and Hispanic-origin groups, and that Native American or Alaska Native infants have the second-highest infant mortality rates. Compared to 2011, the mortality rates for non-Hispanic white and Asian or Pacific Islander infants were lower in 2016. However, the rates for the other three race and Hispanic-origin groups were essentially unchanged.

The leading causes of total infant death were: congenital malformations, low birth weight, maternal complications, sudden infant death syndrome (SIDS), and unintentional injuries. These have been, consistently, the leading five causes of infant mortality since 2006.

The leading causes of death for neonatals included low birth weight; congenital malformations; maternal complications; placenta, cord, and membrane complications; and bacterial sepsis. These have been the leading causes of neonatal mortality since 2007, with the exception of 2011, when bacterial sepsis was ranked sixth. These were the same five leading causes of neonatal mortality for each of the race and Hispanic-origin groups.

The leading causes of post-neonatal death were congenital malformation, SIDS, unintentional injuries, diseases of the circulatory system, and homicide. These have also been the leading causes of post-neonatal mortality for several years, specifically, since 2010. Previously, however, homicide or assault was ranked sixth or seventh for several years. These were the same five leading causes of post-neonatal mortality across races and origin groups.

Since 2007, SIDS rates have declined by 33 percent and sudden unexpected infant death (SUID) rates have declined by 7 percent. However, researchers believe SIDS had a sharper decline due to changes in how these cases are being identified. Preterm-related causes of death accounted for more than 1/3 of infant deaths in 2016, and there were substantial differences by race and Hispanic origin: nearly a 15 percent difference when looking between non-Hispanic white and non-Hispanic black.

Total infant, neonatal, and post-neonatal mortality rates are higher in rural counties than urban counties.

This has been consistent over time, and we know that these differences are actually getting wider over time. Dr. Jarris noted that many women in rural areas have trouble accessing obstetric care.

Looking ahead, the 2017 linked data file will be based fully on the 2003 birth certificate revision, which will include the items discussed earlier: being participation and education and moving to a more encompassing file of the variables that are on the birth certificate. Users will be able to make their own cohort file, starting with the re-release of the 2017 data, which are expected to occur a few months after the first round is released. Dr. Ely predicted efforts would continue to improve the type and delivery time of data with more resources to work with.

Committee Questions and Discussion

- Dr. Jarris suggested that future requests for data should include those for American Indians and Alaska Natives.

PRAMS, SIDS/SUID, Maternal Mortality & Opioids

Lee Warner, Ph.D., M.P.H.

Chief, Women's Health & Fertility Branch

Division of Reproductive Health

National Center for Chronic Disease Prevention and Health Promotion, CDC

Sharyn Parks-Brown, Ph.D., M.P.H.

Senior Epidemiologist

Division of Reproductive Health

National Center for Chronic Disease Prevention and Health Promotion, CDC

Dr. Warner discussed the Division of Reproductive Health, information on maternal mortality and opioid use and the Pregnancy Risk Assessment Monitor System (PRAMS). The division focuses on improving women's reproductive health through pregnancy and infant health, with a related focus on chronic disease prevention. She reported that about 700 women die each year from post-pregnancy complications.

She credited media attention, including medical journal coverage, for leading to \$12 million in funding for 2019 to establish Maternal Mortality Review Committees in up to 30 states to help standardize reporting. Another division priority is the documentation and impact reduction of maternal opioid use disorder. She referred to a summer 2018 issue of *Mortality and Morbidity Weekly Report (MMWR)* in which the division reported that opioid abuse is increasing among both the general public and women upon delivery in a hospital setting. Statistics reveal a more than four-fold increase in opioid disorder in this group from 1999 to 2014.

The CDC provided the division with \$9 million to

- Improve and standardize data on pregnancy-related overdose deaths by working with the Maternal Mortality Review Committees.
- Establish a learning community in partnership with the Division of Congenital and Developmental Disorders to support state teams that are addressing opioid use through the implementation of programs and policies.
- Improve collection of state-based data on non-fatal opioid use through PRAMS.

Dr. Warner explained that PRAMS was established a little more than 30 years ago as part of the Infant Health Initiative to collect self-reported maternal behaviors from participating states, before, during and

shortly after pregnancy. The extent of coverage—47 states, excluding Ohio, Idaho or California, each of which has their own PRAMS-like assessment—provides nearly national estimates. State samples, which range from 1,500 to 3,000 per year, are taken from birth certificate records of infants from two to six months old. The division has partnered with the three non-participating states on measures and in projects such as Healthy People 2020 objectives.

PRAMS has a number of indicators, including

- Preconception health
- Maternal weight
- Tobacco and alcohol use
- Receipt of services such as timing of prenatal care
- Health insurance status
- Postpartum use of contraception
- Drug use
- Effects from hurricane conditions
- Breastfeeding practices
- Infant sleep practices

Other areas for data collection, involving the Food and Drug Administration (FDA) include e-cigarette and hookah use, data on the Zika virus and counseling, testing and correction practices pregnant women have received.

The division also:

- Conducted a PRAMS-like survey among women undergoing hospital delivery two to six weeks postpartum.
- Will partner in 2019 with NIH to collect data on maternal disability status.
- Will add a module on opioid use during pregnancy.
- Is conducting a project in Utah to survey women whose infants are stillborn.
- Is conducting a survey, “PRAMS for Dads” to examine fathers’ roles and behaviors during pregnancy.
- Is using PRAMS in 11 states to evaluate Healthy Start programs’ effects and outcomes.

PRAMS data for 2016 were released this past summer and 2017 data are being released now. They can be requested from <https://www.cdc.gov/prams/researchers.htm>.

Dr. Parks Brown focused her presentation on infant safe sleep. She explained that about 3,500 SIUD cases occur among children younger than 1-year-old annually. These include accidental suffocation/strangulation in bed and unexplained causes. The division saw a steep decline in sleep-related infant deaths in the early 1990s when the American Academy of Pediatrics (AAP) recommended that infants sleep on their backs, followed soon thereafter by the NIH’s Back to Sleep campaign. But this decline in cases began to decrease in the late 1990s and has remained largely unchanged since about 2000. AAP’s most recent policy statement has 19 recommendations to address prenatal, post-natal and environmental factors that increase the risk of sleep-related infant death. They include guidance for health care providers, such as calling for them to endorse the recommendations and counsel families on the importance of safe sleep.

Using 2009 to 2015 PRAMS data, the division used Vital Signs, a high-profile CDC suite of products for the public and the media using clear language and graphics, along with social media approaches and calls to action along with an *MMWR* article on the subject. The article presents case statistics and suggestions

for what can be done at the state, local and federal levels to address infant safe sleep for caregivers and providers; the materials are also available on the division website.

In 2015, the overall prevalence in the PRAMS sample of sleep data was 22 percent. Sixty-one percent reported bed sharing with infants and 39 percent reported using at least one type of soft bedding in the sleep environment. There was a great deal of variation by race-ethnicity and maternal age.

The core PRAMS questionnaire has five safe-sleep questions that are asked of all participants and the questions align more closely to AAP recommendations than they had. CDC has also had an SIUD Registry since 2009, funded in part by NIH, which is built on the National Center for Child Fatality Review and the Child Death Review programs. The registry makes it possible to increase surveillance of sudden death up to the age of 18. This funding has also allowed additional postmortem clinical review and genetic testing on a subset of cases. Surveillance through 2023, involving 17 states and five jurisdictions is being done to cover 32 percent of all SUID in the United States. The registry shows a higher-than expected rate of deaths among African-American, American Indians/Alaska Natives and younger mothers with a median age of 25; 99 percent of these cases had unsafe sleep environments. Most of the infants were four months old or younger and a slight majority were males.

States have responded by changing childcare licensing laws to require adherence to safe-sleep recommendations and several states introduced safe-sleep training curricula for child welfare professionals. One requires parent-safe sleep education in hospitals. Another developed a data dashboard, to provide anyone with local-level SUID data in real time, without submitting a data request from the state health department. Another developed a health care provider notification system so that a notification about the SUID death is sent to the pediatrician, the OBGYN, as well as the birthing hospital. Finally, the division hosted an Infants' Safe Sleep CDC Public Health Grand Rounds last month, which consisted of an overview of epidemiology and trends of SUID. It included a review of the role of the medical examiner in the death certification and investigation process and discussion of behavior-change theory along with some promising new interventions in safe-sleep promotion. A SUID parent advocate also talked about his foundation's work to promote infants' safe sleep through a children's board book.

Committee Questions and Discussion

- Dr. Palacios asked whether the research presented covers types of parental sleep-with-baby patterns such as co-sleeping, breastfeeding as the mother sleeps or bottle feeding in bed. She said that co-sleeping is not necessarily dangerous if the mother is not using substances inappropriately and may even be beneficial in terms of thermal regulation and to establish hormonal and neural reactivities.
 - Dr. Parks-Brown said that she's not aware of any research indicating that co-sleeping is recommended and the CDC calls for the infant to sleep separately on a non-soft surface. She noted that the AAP calls for precautions in connection with co-sleeping, such as ensuring it takes place in an adult bed and on a hard surface and that breastfeeding in bed be supervised by a third person after which the infant should be returned to its own bed.
- Dr. Ehlinger asked who is on the mortality review committees.
 - Dr. Parks-Brown said she was not in a position to speak about the national centers' processes but most have community members participating as well as public health officials and health care providers. Much of the discussion focuses on how to translate recommendations into action.
- Dr. De La Cruz said that because a planned presentation on the mortality review committees had to be cancelled due to the abbreviated nature of the meeting, this information will be sent to attendees as soon as possible.

- Ms. Pettiford asked Dr. Warner to discuss survey response rates and whether responses could be submitted by cell phone.
 - Dr. Warner reported a 61 percent response rate, which she thought was quite acceptable and asked for suggestions from SACIM about how the questions asked could be improved. She noted that responses can be transmitted by phone and mail and a web module is envisioned as well. She would also like to see it programmable in a cell phone. Phone completion rates are at 20 percent and may improve with use of a call center. Responses can be stratified by types of groups (e.g., high-risk), birth weight and race.

Congenital & Developmental Disorders

Cheryl S. Broussard, Ph.D.

Associate Director for Science

Division of Congenital and Developmental Disorders

National Center on Birth Defects and Developmental Disorders, CDC

Dr. Broussard discussed her division's efforts to reduce infant mortality. Its four thematic areas are:

- Saving infants through birth defects prevention and research.
- Understanding developmental disabilities.
- Reducing complications related to blood disorders.
- Improving the health of people with disabilities across the lifespan.

She noted that one in 33 infants are born with birth defects in the United States, which cause one in five deaths during the first year of life. About 11 infant deaths related to birth defects occurred in the United States from 2011 to 2013, according to a 2017 *MMWR* article. The rates differ by race/ethnicity, gestational age and age group at death. She noted that post-neonatal infant mortality due to birth defects for pre-term infants and both neonatal and post-neonatal infant mortality due to birth defects for term infants were approximately 45 percent higher for deliveries covered by Medicaid, than those that were covered by private insurance.

Forty-three states have birth defect tracking programs but not all gather consistent or usable data. The CDC funds 14 population-based state programs. Information from birth defects tracking systems is used by public health officials, policymakers, and scientists to:

- Determine whether the number of birth defects is increasing or decreasing over time.
- Plan and evaluate activities in death-preventing birth defects.
- Refer babies and families affected by birth defects to appropriate services.
- Help allocate resources and services for affected babies and their families.

There are several research-based Centers for Birth Defects Research and Prevention across the nation funded by the CDC, which have been conducting one of the largest studies of birth defects ever undertaken in the United States: the National Birth Defects Prevention Study. The centers built on the study to further examine promising findings and evaluate pregnancy exposures. Findings from this research are used to inform clinical practice and are available on the division's website.

Dr. Broussard highlighted progress towards survival among infants with spina bifida and heart defects. Between 1979 and 2003, survival of infants born with spina bifida improved but the rate of survival among African-American and Hispanic infants remained lower than that among white infants. She noted that CDC promotes the use of folic acid among all women who can get pregnant to prevent spina bifida and other neural tube defects, and conducts public health research to decrease mortality and improve the health of those with spina bifida.

In connection with congenital heart defects, which are the most common, nearly one in 100 births in the United States, one-year survival for infants with critical congenital heart defects improved between 1979 and 1993 and 1994 to 2005 but mortality remains high.

Newborn screening for these critical heart defects (CHD) using pulse oximetry can identify the defects before infants leave the hospital, reducing infant mortality. In a *JAMA* article published last year, the CDC and collaborators showed that mandated critical CHD screening using pulse oximetry reduced early infant deaths from critical CHD by 33 percent, or 120 early infant deaths from critical CHD averted per year. The CDC has worked with the division's partners to track state implementation of screening for critical CHDs, which has now been implemented nationwide, and conducts public health research to improve health and reduce mortality of those living with heart defects.

The division is also reducing use of alcohol and other substances and teratogenic medications during pregnancy. CDC promotes the implementation of alcohol screening and brief intervention (SBI) in health systems providing women's health services to reduce risky alcohol use among women by collaborating with the Substance Abuse and Mental Health Services Administration and the National Committee for Quality Assurance on the quality improvement learning collaborative to promote a Healthcare Effectiveness Data and Information Set measure on Unhealthy Alcohol Use Screening and Follow-Up and by targeting five health care disciplines to engage providers in alcohol SBI and message delivery to patients. The division is also taking the lessons learned from our many years of studying fetal alcohol syndrome and fetal alcohol spectrum disorders to see how these can be applied to other substances of concern, including opioids and marijuana use.

Treating for Two is CDC's national initiative to promote health for moms and babies through safer medication use in pregnancy. Because research has shown that a majority of content available via online sources, even from seemingly reputable sources, does not adequately reflect what is known about medication safety in pregnancy, the division is proposing a concept through the Small Business Innovation Research Grant program to develop an evidence-based, gold-standard information source for providers to consult regarding treatment decisions in pregnancy. The division asked a company called Right Answer, Inc., to develop this platform as a mobile app. It's now in phase two of the Small Business Innovation Research process, and the goal is for the app to be launched, sustained, and updated as new information becomes available. The grantee is partnering with the University of Washington and the Teratogen Information Service, or TERIS Database, to populate the app content, and once launched, the goal is: reduce use of teratogenic medications, as well as better counseling for women during pregnancy.

The division is also monitoring emerging threats, such as the Zika virus and their impact on infants. Preliminary work from Brazil suggests that about 10 percent of infants affected by congenital Zika may die during infancy. The division has also led a cross-CDC working group on longitudinal surveillance of pregnant-women-and-infant dyads, and the CDC has developed a core variable list for surveillance efforts, which will improve opportunities to monitor other health threats that contribute to infant mortality and identify interventions that could reduce mortality. The division also led a CDC Public Health Grand Rounds, which was held on September 18 to highlight the opportunities for public health surveillance to address health threats that can impact infant mortality.

Another CDC cross-center workgroup that both this and the Division of Reproductive Health are conducting is the Maternal Immunization Workgroup, which promotes maternal immunization for infant benefits. The Advisory Committee on Immunization Practices recommends influenza vaccine before or any time during pregnancy and a Tetanus-Diphtheria-Pertussis vaccine during each pregnancy, preferably from 27 to 36 weeks' gestation, but coverage among pregnant women is low. Maternal immunization will also be considered for other current and emerging vaccines, including for the Ebola and Zika viruses.

The division is also working to monitor and understand risk factors for fetal deaths, which is roughly

equivalent to the number of infant deaths each year in the United States. The CDC is working to monitor, better understand the causes of, and prevent fetal deaths but it is important to note that different countries might have variations in the way that they consider live births and still births; therefore the definitions of fetal and infant deaths must be considered.

Committee Questions and Discussion

- Dr. Peck asked whether there was any interest in combining fetal and infant mortality statistics.
 - Dr. Broussard said that perinatal mortality rates that combine fetal and infant deaths are published as are two other types of perinatal rates.
- Dr. Ehlinger referred to data indicating that increasing the price of alcohol could decrease deaths caused by alcohol, car crashes, sexually transmitted diseases and violence but did not indicate alcohol's effect on pregnancy outcomes.
 - Dr. Broussard agreed that such research would be of interest and said there are efforts under way to encourage health care providers to discuss alcohol use with women and adults generally.

UPDATE ON DIVISION OF HEALTHY START & PERINATAL SERVICES HEALTHY START/MATERNAL AND CHILD HEALTH BUREAU

Healthy Start

Juliann DeStefano, R.N., M.P.H. (substituting for Johannie Escarne, M.P.H)

Senior Program Analyst

Division of Healthy Start and Perinatal Services

Maternal and Child Health Bureau, HRSA

Ms. DeStefano provided a history of the Healthy Start Program and described some of its accomplishments and future plans. Healthy Start was launched in 1991 as a demonstration project, designed to support and provide services to communities with high infant mortality rates—higher than one-and-a-half times the U.S. average—and other adverse perinatal outcomes as well as to reduce racial and ethnic disparities. Grants issued in 2014 indicate the program's transformation that year; there were three levels of funding: Level one was community based while level two focused enhanced services and level three focused on leadership and mentoring.

There was also a focus on quality involving requirements for core competencies and standardized interventions. Healthy Start CoIIN was very involved in this development. Areas of emphasis included engaging parents and families, examining the aspects of stress and resilience that underlie disparities in birth outcomes and Community Action Networks and using the collective impact framework to drive system change. The program also used performance measures and rigorous evaluation to ensure accountability and drive improvement.

Ms. DeStefano then recounted notable program accomplishments, which include:

- The EPIC Center, Healthy Start's technical assistance resource center, which provided website support, increased the knowledge base, provided peer-learning teams and individualized teaching assistance, including mentoring, trainings and more than 80 monthly webinars.
- A community health worker course, which all programs are required to access.
- Success in connecting more than 60,500 participants to health insurance and almost that many to a medical home. This led to encouraging or helping to arrange reproductive life plans, postpartum visits, well-woman visits and screening for intimate partner violence.

- In 2016, Healthy Start screened more than 31,000 women for perinatal depression and provided connections to more than 4,000 follow-up services. In addition, more than 16,200 fathers and male partners were involved in Healthy Start participants' pregnancies and more than half that number remained involved with the child until age 2.
- Also in 2016, more than 11,900 children up to two years old were read to daily.

The program's purpose in FY 2019 is unchanged: to improve health outcomes before, during and after pregnancy and reduce racial and ethnic differences in rates of infant death and adverse perinatal outcomes. Healthy Start reflects a single, enhanced model in which all of its programs will have one funding level and a single set of program requirements, which are designed to improve women's and family health and wellness and bring about system change while ensuring positive impact and effectiveness. Every Healthy Start-funded project funded under this notice will serve at least 700 participants each calendar year and focus on children from zero to 18 months of age. Applications were due November 27, 2018 with a plan to issue notice of award by April 1, 2019 ; funding will be made available for up to 100 applications.

Committee Questions and Discussion

- Dr. Ehlinger asked how much the program would have to expand to go to scale.
 - Dr. De La Cruz said that efforts have been made to ensure that the technical assistance center has all of the curricula and lessons learned that were used, which are available for anyone to use on the website. This TA center is also encouraged to serve non-Healthy Start communities. And Healthy Start has received increased funding for its activities.
- Dr. De La Cruz noted that the level 2, which focused on providing enhanced services, was the most successful in implementing Healthy Start and received about \$1 million per year with an added \$120,000 annually devoted to reducing maternal mortality. He acknowledged that it can be hard to administer the program in some parts of the country—such as in rural areas, where people face transportation and other challenges and the program works with grantees to contribute as much as possible to their success.
- Dr. DeCoursey asked where she could obtain information about Healthy Start's evaluation and quality improvement activities.
 - Dr. De La Cruz explained that this is the first time the program has been allowed to collect participant-level data, which grantees must submit monthly. Data on almost 2,000 performance measures are submitted annually. And, in response to concerns about whether Healthy Start is serving the highest number of at-risk women and families in communities, linkages to PRAMS are also being established to gauge whether there are differences between participants and non-participants in the same community. Efforts are also underway to try to determine outcomes among those who are lost to follow up by linking birth to death records and following those infants.
- Dr. Peck asked whether there's a pathway from community health worker credentialing into the new bachelor's degree in public health planning.
 - Dr. De La Cruz said that no pathway exists but this could be explored.
 - Dr. DeCoursey said that the Administration for Children and Families (ACF) are doing an evaluation of health professional development, data for which will be available for secondary analysis within a few months. Dr. Peck suggested that there might be an opportunity for ACF, HRSA and MCHB to connect on this to do cross-development.
 - Dr. Jarris said that efforts have been made to create a bridge between local communities and community and bachelor's and master's degree programs, which could be an entry point for community health workers.
 - Dr. De La Cruz said that several grantees have taken a certification course for lactation consultants.

- Dr. Hogan said that some states are working on obtaining Medicaid reimbursement for establishing state credentials to certify community health workers, which would remove the need for Healthy Start to pay for it. for it.
- Dr. Peck reported that southern San Francisco, which is not eligible for Healthy Start, has started a “Solid Start” program with investment from San Francisco General Hospital, the health department and the California Health Care Foundation. Meanwhile, Alameda County is conducting a Best Babies Zone program, Healthy Start and Solid Starts, a zero-to-three program. She suggested that it could be helpful to see what overlapping zonal strategies are happening between some of these programs. She also asked whether, if Healthy Start is focusing on level two, enhanced services, at the possible expense of level three, leadership and mentoring, and if so, who will focus on leadership, system change and capacity building.
 - Dr. De La Cruz said that, rather than 18 level three grantees receiving extra money for leadership capacity building, baseline funding for the TA center has been increased to allow it to fund level three activity through Healthy Start. He also noted that Healthy Start and Title V have a history of working together but, in some instances, may be serving the same communities and better coordination may be needed. There are also efforts to ensure that Healthy Start funding goes farther through leveraging the Bureau of Primary Health Care rather than duplicating services offered by the two.
 - Ms. Pettiford stressed the importance ensuring that people who are experienced in working with Healthy Start are providing ongoing technical assistance, which involves a process that may be unfamiliar to those who know the program well.
- Dr. James said that the most recent set of cumulative Healthy Start data on infant mortality he knows of dates back to 2015 and whether it needs to be updated, particularly for African-American infants.
 - Dr. De La Cruz said that there are 2016 data with 2017 data finalized and ready for release but these are self-reported grantee data, which can be problematic in some respects, but he said the 2016 and 2017 data could be sent out with the notes.

Infant Mortality CoIIN

Vanessa Lee, M.P.H.

Infant Mortality CoIIN (Collaborative Improvement and Innovations Network) Coordinator
 Division of Healthy Start and Perinatal Services
 Maternal and Child Health Bureau, HRSA

Ms. Lee provided an update on the Infant Mortality CoIIN, an initiative in the Division of Healthy Start and Perinatal Services, which has 10 or more, varied MCHB-sponsored CoIINs currently. CoIINs are a methodology (collaborative learning, innovation and quality improvement) that focuses on collective impacts and a platform that allow participants to engage in collaborative learning to achieve a common goal. CoIINs use quality improvement methods, techniques and innovation to spread and scale policy and program innovations to improve strategies that contribute to desired health outcomes. They are also rapid learning, cycle change and innovation initiatives that can last anywhere from 12 months to four years; most of the work is team-based and conducted virtually.

The Infant Mortality CoIIN’s purpose is to reduce infant mortality and disparities and support collaborative improvement, innovation and the spread and scale of best practices. It was the first, starting in 2012, and involved HRSA Regions IV and VI—the 13 southern states, which participated in an infant mortality summit where they formed state teams and devised state action plans. After the summit, state health officials approached HRSA seeking a way to continue collaborating to address infant mortality. A subsequent study of these efforts indicated reductions in pre-term births and early elective deliveries and in smoking during pregnancy rates. In 2014, the remaining HRSA regions came on board, spawning a national effort involving 51 states and jurisdictions in the most recent phase, the national expansion of the

CoIIN, was led by the National Institute for Children’s Health Quality (NICHQ) and ended last summer. The NICHQ produced a two-page summary document, which was distributed to the meeting participants. The topic areas focused on during this phase were smoking cessation, social determinants of health, safe sleep, pre-conception and inter-conception care, risk-appropriate perinatal care and preventing pre- and early-term birth.

The current “2.0” phase retains helpful elements of past phases but addresses identified challenges and barriers. Its purpose remains unchanged but CoIIN teams that are funded in this round will show measurable improvements in what they seek to accomplish by discovering and developing new evidence, innovations to reduce infant mortality and disparities while supporting dissemination, spread and scale of the practices they identify. This CoIIN negotiated four three-year, \$500,000 cooperative agreements for projects that began in September 2017. The recipients are expected to provide subject matter content, technical support and expertise to their state-based CoIIN teams and, for the first time, will provide a small amount of financial support as well through sub-awards.

ACT Associates has been contracted to provide data and technical assistance to the grantees—both CoIIN teams and the state teams they support. TA focuses primarily on a quality improvement innovation, assistance with data collection and measurement and evaluation. ACT also provides CoIIN teams with a web-based shared workspace or online platform where the data are housed and a data dashboard to track shared measures.

Committee Questions and Discussion

- Ms. Pettiford confirmed that all of the CoIIN teams are strongly encouraged to partner with local Healthy Start programs and that Title V programs need to be involved as well otherwise are free to select their own state and local partners.
- Dr. Peck asked in connection with CoIIN activities in the border states how pregnancy is being handled in those who are in detention or incarcerated.
 - Ms. Lee said that the Healthy Start border programs that are taking the lead in four states haven’t raised this issue. The innovation prototypes the team has developed focus on education and the use of mobile technology to encourage women to take pregnancy tests and enter care earlier. In California, where teams want to work more closely with prenatal care providers in Mexico who may be serving women in the first trimester of their pregnancies but because of data quality issues, this information may not be documented but these data are not being transferred to the California medical record.
 - Dr. De La Cruz said that those who need such services are not asked about their citizenship or residency status; support is provided to anyone who needs it both at the clinic and the community levels.
 - Dr. James pointed out that Dr. Ehlinger has challenged attendees to determine who they need to seek information from and take it to in their communities—to identify the appropriate organizations to press for necessary change in areas where the committee or Healthy Start cannot; this could be one of those issues.
- Dr. Ehlinger said that he would be interested to see what the Social Determinants of Health CoIIN does. He pointed out that, unlike the other areas, which are more program/service-oriented and focused on rapid-cycle change, social determinants of change are dealing with multiple sectors and policy change that may not lend themselves to rapid-cycle development.

Maternal Mortality & Morbidity
Kimberly Sherman, M.P.H., M.P.P.

Women's Health Lead
Division of Healthy Start and Perinatal Services
Maternal and Child Health Bureau, HRSA

Ms. Sherman described HRSA's Maternal Mortality Summit that was held this past June, the division's women's health activities, the Alliance for Innovation on Maternal Health and the Women's Preventive Services Initiative as well as its special reports to Congress, such as a recent one containing recommendations to address child mortality and morbidity. The division also led a federal partners workgroup to improve maternal health, which permits alignment of funding activities in these areas across operational divisions. She also pointed out that the 2019 fiscal year appropriations includes a \$40 million increase in HRSA's budget to improve national health outcomes.

The summit attracted domestic and international maternal health experts to share ways to address maternal mortality and severe maternal morbidity with an emphasis on policy programming and data surveillance. Participating countries included Brazil, Canada, Finland, India, Rwanda and the United Kingdom, along with representatives from the World Health Organization and the U.S. Surgeon General. Other partners included people doing research in women's health, data and clinical practices. Brazilian representatives discussed their efforts to reduce C-section rates, those from India and Rwanda discussed community health worker models to spearhead change. The UK representatives highlighted the roles midwives play in care provision; Canada and Finland described their national surveillance programs to verify where deaths are occurring and target those areas. Participants then discussed preconception care and its link to maternal mortality, moving through pregnancy, labor and delivery and closed with a postpartum session. Substance abuse, mental health challenges, emergency preparedness and the obesity epidemic were discussed as well.

Key findings included:

- The need to provide comprehensive care to women before, during and after pregnancy.
- A request to increase types and distribution of health care providers, with a focus on training pipelines in the United States and integrating a team-based approach involving physicians, nurses, doulas and behavioral health specialists.
- An acknowledgement that disparities cannot be addressed without better data; there was also a call for national definitions and measures for maternal mortality and severe maternal morbidity.
- There was also a request to improve state level Maternal Mortality Review Committees' availability to analyze data, take action at the state level and to improve maternity care services through the Alliance for Innovation on Maternal Health (AIM) program and other safety protocols.

Ms. Sherman said that the division is finalizing a technical report about the meeting in addition to other already available resources from it. Much of the additional funding HRSA will receive will be used to highlight state innovation on these activities and will be used to support states and address disparity with an emphasis on high-risk populations. The division is working with the CDC to coordinate efforts and avoid duplication.

She then described AIM and the Women's Preventive Services Initiative, both of which are funded through the American College of Obstetrics and Gynecology (ACOG) through a cooperative agreement with HRSA to improve maternity care services in the United States. Through AIM, the division has developed maternity safety bundles (evidence-based practices) and technical assistance that are being used to train hospital staff in U.S. birthing facilities—currently in 19 states and more than 900 hospitals—on the causes of and treatment for obstetric emergencies. These efforts, which will run through 2024, will

be expanded to cover all states and territories. The bundles are available to any birthing facility and are on the division's website. Data are being collected on implementation on these short quality improvement projects and once a hospital or state reports success in implementing one bundle, it can select another.

ACOG gets \$1 million per year to convene a multidisciplinary expert panel to review the evidence, develop updated recommendations and disseminate them for incorporation into standard practice. She showed a chart that helps women and clinicians know what to screen for by age. There are materials for patients as well as information on appropriate screening tools. This information is available at <https://www.womenspreventivehealth.org>.

Committee Questions and Discussion

- Dr. Hogan asked what references to states addressing disparities means—does it involve a specific approach or framework and are approaches consistent and science based?
 - Ms. Sherman says the approach can differ from one state to another to reflect the types of disparities that exist. California, for example, has a large tribal population and overdoses are the leading cause of death. The approach is to look at maternal outcomes, find where disparities exist and identify high-risk populations.
- An unidentified female speaker who attended the Maternal Mortality Summit noted the UK representative said the country's goal is to have one midwife for every 27 and said that would be a laudable goal for the United States to adopt.

Behavioral Health

Dawn Levinson, M.S.W.

Behavioral Health Lead

Division of Healthy Start and Perinatal Services

Maternal and Child Health Bureau, HRSA

Ms. Levinson provided an update on how MCHB addresses mental health and substance abuse issues and some examples of the bureau's services. She explained that HRSA serves everyone from infants to the elderly to ensure access to a broad range of primary care and public health services, especially for vulnerable, underserved, and isolated populations in the United States; it supports many activities, including direct patient health care, clinician training, research, and more. More than 27 million people in the United States receive primary care through a HRSA-supported health center and nearly 90 percent of these centers provide mental health services; about 70 percent of them provide substance abuse services. More than 60 million mothers and children rely on MCHB-program-provided services across the life span. These programs promote, prevent, screen, intervene, refer, treat, train, and address behavioral health issues on multiple levels.

At the provider level, grantees in MCHB programs like Healthy Start and Home Visiting use evidence-based approaches to screen perinatal women and parents of young children and refer them to treatment and support for mental and substance use disorders. They also provide health education and guidance for parents of young children, including caring for babies born with neonatal abstinence syndrome.

MCHB also funds the development and dissemination of clinical guidelines, including those for the obstetric management of women with opioid dependence.

At the systems level, states and can use the Title V Maternal and Child Block Grant funds to address their unique needs through backfilling, direct services, and enabling public health services and systems. States are using the block grant funds that relate to opioids and neonatal withdrawal syndrome to conduct:

- Provider training on best practices.
- Use of screening tools for early detection of high-risk women.
- Teleconsultation services for health providers who are treating perinatal women with psychiatric and substance-use disorders.
- Address the needs of pregnant women and their babies, including care coordination, standardizing care for infants with neonatal withdrawal syndrome.
- Use a maternal mortality review panel to explore the relationship between maternal mortality and mental health, and more.

MCHB has two new tele-behavioral health programs that improve the mental health and wellbeing of mothers and children. Another grant to states supports building early childhood systems of care at the state, county, and community levels, and improving children's developmental health and family wellbeing outcomes.

Another new grant is the Rural Health IMPACT Grant. The Rural Health Integration Models for Parents and Children to Thrive program—the IMPACT program—will provide tailored technical assistance to communities to implement evidence-based, two-generational strategies that promote the health and wellbeing of children, prenatally to age three, and create economic opportunities for their families. Target rural communities include those especially at risk for or who have experienced adverse childhood experiences, including dealing with opioid use and natal withdrawal syndrome.

At the workforce training level, MCHB supports interdisciplinary graduate training, such as its Developmental Behavioral Pediatrics Training program, and supports education for the practicing workforce around pediatric mental and behavioral health through its Collaborative Office Rounds program and others. At the patient and family level, grantees such as the state-based Family to Family Health Information Centers provide training and education to families with children with special health care needs, including behavioral health needs, to help families navigate the health care system and to connect to services.

Finally, at the policy level, the Supporting State MCH Policy Innovation Program, (MCH PIP), supports innovative policy initiatives at the state level that improve access to quality health care for MCH populations, which includes a focus on behavioral health. Related to the MCH PIP, HRSA is funding four national policy associations to engage and support state-team cohorts who are identifying the topic areas now, in year one, several of which also address mental health and/or substance use.

Committee Questions and Discussion

- Dr. Jarris said that, according to an article reporting on an ACT survey in 2015, only 15 percent of federally qualified health centers (FQHCs) said they have information on sobriety; he called for them to be pressured to treat substance abuse.
 - Dr. James said that clinicians who work at FQHCs care for some of the states' sickest patients, many of whom abuse substances; these patients require much more care and attention than the general population and FQHC clinicians are paid less than providers elsewhere to care for them; he believes this is an issue that needs to be addressed at the federal level. Dr. Ehlinger agreed, saying that, of the \$11,000 per person that is spent on health care, only \$450 goes toward primary care.
- Ms. Levinson said that MCHB collaborates with SAMHSA on mental health in school activities.

HEALTH EQUITY AND INFANT MORTALITY

Arthur R. James, M.D., F.A.C.O.G.

Consultant, First Year Cleveland
Interim Medical Director, Care Alliance Health Center

Dr. James said that he believes racial disparity and its effects on birth outcomes is the most problematic maternal-child health challenge the nation faces and that physiological differences attributable to race do not adequately account for higher maternal and infant mortality and morbidity. He also said that historical and contemporary racism are the root causes of these disparities and that government agencies, white people and white organizations must lead the charge to end racism.

He pointed out that, in 1980, African-American babies were dying at two times the rate of white babies; over time, this rate increased to almost 2.5, a reflection of the fact that the white infant mortality rate was decreasing more rapidly than that of black infants. He noted that, in 2016, the black infant mortality rate was 11.76 deaths per 1,000 live births; a rate comparable to white infant deaths in 1978—a 38 year gap. In other words, it could take until 2054 before black infant survival rates match those for white infants in 2016. Although some have attributed this to a larger number of preterm births among African-Americans and other clinical factors, he pointed out that this disparity in white and black infant mortality actually decreased from the 1960s to the 1970s. Dr. James attributes this to the Civil Rights Act's effect on Medicare and Medicaid, which allowed black women in southern states to deliver their babies in hospitals for the first time.

He also noted that goals for reductions in rates of infant mortality among white infants set for Health People 1990 and Healthy People 2000 were reached ahead of schedule; those for black infants were less ambitious. For Healthy People 2010, a single goal of 4.5 deaths per 1,000 live births was set across the board. It was not achieved but the black infant mortality rate for that year was 12—the goal that had been set for this group for Healthy People 1990. Although it has been suggested that it is not possible to improve the black infant mortality rate at a faster pace than for white infants, according to the CDC, the black infant rate *had* improved by 16 percent compared with 12 percent for white infants from 2005 to 2011. Meanwhile, the goal for Healthy People 2020 was to have an overall mortality rate of 6 deaths per live births, a milestone that was reached for white infants in 2007. In short, Healthy People goals have been reached three times out of four times for white infants but only once for black infants. He also noted that the number of black infant deaths over a three-year period varied widely from state to state, with a rate of 6.9 deaths per 1,000 live births in Massachusetts, compared with a rate twice as high in Kansas and similarly high rates in Ohio and Wisconsin, an indication of variations in the extent to which black families receive the support they need to improve birth rates.

Dr. James argued that it is not enough to view birth rates in strictly clinical terms; social determinants—the provision of food, housing, income, education and employment—are just as influential; in fact, they can exacerbate or lead to adverse clinical conditions.

He acknowledged that many of HRSA's policies and programs help families surmount obstacles through managed care, Healthy Start and through centering and nurse/family partnerships but said that efforts should not end there, noting that, despite these interventions, families continue to live in conditions that required agencies to provide assistance in the first place. When asked which social determinants agencies should focus on, at a community level, the focus should be on where you can get the most buy-in, where there's the most will for change and the most people are willing to engage; however, ultimately all must be addressed. These include socioeconomic policies, our institutions and living conditions. So, it's the same situation where this social determinant stuff is concerned. He invoked a quote from Alexander den Heijer, "When a flower doesn't bloom, you fix the environment in which it grows, not the flower." Applied in this context, it means that socioeconomic position, race, ethnicity, and gender all structure the likelihood of multiple exposures at multiple points in time over the entire life course. This life-long cascade of interacting, multiple exposures, balanced against available resources, are important

determinants of how social inequalities leave their imprint as health disparities. Social determinants, such as poverty and constructs such as race are intertwined; each can make the other worse. Racism represents a particularly damaging and pervasive exposure, and for the poor; it is intricately woven into every domain in American life and has cumulative damaging effects throughout an individual's lifetime, across all domains and across generations. He also invoked Michael Marmot, a co-author of a World Health Organization document on social determinants, who suggested that addressing social determinants is a moral obligation and a social justice issue.

Dr. James argued that social determinants are influenced by structural determinants—by the policies, systems and practices that determine the conditions in which people live. For example, high stress levels can adversely affect a woman's pregnancy and her fetus; and this can have multi-generational effects. African-Americans have lived under extraordinary stress throughout their presence in this country. They arrived in the United States in 1619, endured 246 years of slavery, followed by 99 years of Jim Crow. These two periods of time, to this day, account for 87 percent of the African-American's experience and this was followed by what Douglas Blackmon refers to as neo-slavery, in which, despite being legally free and no longer considered a slave African-Americans were not close to being fully autonomous. For example, if a black person, particularly a black man, was walking on the wrong side of the street or deciding to leave a job to go to another job but didn't ask permission from the owner of the company that he was leaving to be able to do so, he was arrested had had to pay for the cost of his trial and, if not able to afford it had to work it off. Under this system, prisoners were then loaned out to companies throughout this country—effectively a form of slavery.

He also referenced the Tuskegee Experiments, in which African-Americans were infected with and then denied treatment for syphilis to determine the disease's effects on them. Other examples of unfair treatment include discrimination in housing and efforts to stymie their right to vote as well as mass incarceration as a response to the War on Drugs, which has left many black families without fathers. He noted that the opioid epidemic has triggered a medical approach to a solution, while the crack epidemic triggered a far more different response that punished victims rather than treating them.

Dr. James explained that, in short, from the time slave ships landed in Jamestown in 1619 until now, African American history has consistently provided substantial advantage to whites but disadvantages to African-Americans. The disparities that exist in this country are not natural; they were created and they can be fixed. But this is a matter, not merely of health equity, but equity across the board, influencing every aspect of life and society. However, it also requires working within communities to determine how to address inequities rather than trying to prescribe from without what they need. "No more about us without us." Human and financial resources need to be applied across all policy objectives and all social settings with a scale and intensity that reflects and addresses each level of disadvantage. He also suggested that the disparities that are built, not only into racism but capitalism need to be addressed.

Committee Questions and Discussion

- Dr. Malloy said that many African-American women choose not to breastfeed and believes that hearing about its benefits from within their communities rather than from a clinician outside the community could increase acceptance rates. She asked how the community could be engaged to deliver such messages.
 - Dr. James said that community-based efforts to effect positive change have historically been discouraged; that black communities have been disempowered and that part of any efforts on the part of those outside the black community to encourage change that decreases infant mortality must include acknowledgement of the history of discrimination it has endured.

- Dr. Hogan pointed out that the logistical and procedural difficulties of accessing programs or meeting their requirements can be a major deterrent to pursuing services, as can the many day-to-day obstacles that women face. She cited as an example, low-income women who have to return to work within four weeks of delivery but do not have the option to breastfeed on the job. She stressed that those structural barriers need to be addressed.
- Dr. Ehlinger urged attendees to distinguish between disparities and equity; that it is important to eliminate the factors that prevent improvements in the black infant mortality rates. However, it is equally important to ensure that everyone has the opportunity to thrive, regardless of where they end up in terms of outcomes.
 - Ms. Pettiford said that this should involve, not only the traditional health care community but others who can contribute—and they should be identified.
- Dr. Peck listed the points she believed she heard Dr. James articulate:
 - Addressing social determinants of health and efforts to achieve health equity are not ideals; they are achievable; this has been accomplished in terms of reducing white infant mortality and, although to a far lesser extent, black infant mortality.
 - We all need to be aware of history and its impact on those who have borne its effects.
 - Addressing social determinants is a moral necessity.
 - Achieving health equity will not be possible without achieving equity across the board; a partial solution will not work.
 - It is not enough to have health providers and policy makers in the room; other actors who affect the quality and types of challenges people of color face must participate as well: criminal justice, housing, transportation, education, economics, etc. The lens through which infant and maternal health is viewed must be expanded.
 - There can be no excuses for not pursuing all avenues to reducing disparities, ensuring equity and reducing infant mortality and planning for the long term in doing so.
 - Dr. Jarris said that a parent or family that has suffered an infant mortality should be in the room as well “to keep us a little more honest.”
- Dr. Peck asked, given all of the above, where the clinical piece would now fit in to this approach. She said it is important to build on progress that has been made while focusing on these other considerations as well—clinical considerations must be expanded along with other efforts to achieve equity.
 - Dr. Peck suggested that examining Healthy Start, Best Babies Zones and what California has done through its California Fed and Building Healthy Places Initiative as well as other models, for guidance.
- Dr. Ehlinger suggested that thought be given to who could serve on workgroups representing various sectors to start changing the narrative on how to advance equity for mothers and infants.
 - Dr. James suggested that people who have participated on the committee previously should also be tapped to participate.
- Dr. Ehlinger asked all of those present to indicate what type of data they would like to see presented to help guide future avenues for exploration—which follow-up paths need to be pursued (i.e., history, which former SACIM members and representatives from other agencies should be invited to participate, the story telling/narrative path, etc.)
- Dr. De La Cruz suggested that members of various agencies outside the health community who could contribute to this discussion—from education, transportation, etc.—could be invited to participate as ex-officio members rather than taking up a SACIM slot or votes. This would also prevent conflicts of interest (because they would not influence how far in any one area the committee could push for change).
 - Ms. Pettiford offered to work with Dr. De La Cruz on possible former SACIM members and representatives from other agencies to serve as ex officio members on this effort to broaden the discussion beyond strictly health care issues that affect infant mortality

- Dr. Peck offered to work with Dr. James on the history component.
- Dr. Ehlinger offered to take on discussing narrative to move the needle off of a narrow focus on infant mortality and on to everything else that influences and could contribute to health equity.
- There was general agreement that all involved should come together in some fashion in March or April to report progress and make long-term plans.

COMMITTEE BUSINESS, WRAP-UP AND ADJOURN FOR THE DAY

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

Principal Staff and Designated Federal Official, SACIM

Acting Director, MCHB/Division of Healthy Start and Perinatal Services

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

Acting Chairperson, SACIM

Dr. De La Cruz said that the committee's charter expires on September 27, 2019 but is typically renewed every two years unless the HHS Secretary decides not to do so.

Dr. Ehlinger equated the progress the committee made in this meeting—and hopes to make—to the Granger Movement, which caused farmers to organize and change how they interacted with railroads, land owners and banks to improve their livelihoods. He thanked all of those present for participating in the meeting.

Dr. De La Cruz adjourned the meeting.