

Secretary's Advisory Committee on Infant Mortality

**Meeting Minutes of
August 2–3, 2011**

**Hyatt Regency Bethesda
Bethesda, MD**

GENERAL SESSION

TUESDAY, AUGUST 2, 2011

CALL TO ORDER AND WELCOME

INTRODUCTION OF COMMITTEE MEMBERS

Michael C. Lu, M.D., M.P.H., Chairperson, SACIM

After the members of the Secretary's Advisory Committee on Infant Mortality (SACIM) were sworn in, Dr. Lu introduced himself, welcomed the attendees, and thanked the new members for their participation. He referred to the opportunities that SACIM would have to affect infant mortality in this era of health care reform and the challenges it would face in doing so.

The 21 SACIM members introduced themselves, and Dr. Lu recognized the efforts of the Maternal and Child Health Bureau (MCHB) staff lead by Dr. David de la Cruz.

MCHB UPDATE

Christopher DeGraw, M.D., M.P.H., Senior Medical Advisor, Maternal and Child Health Bureau, Health Resources and Services Administration (HRSA)

Dr. DeGraw welcomed the SACIM members on behalf of HRSA's MCHB. He presented a brief overview of HRSA and MCHB, followed by comments about maternal and child health (MCH) and the Affordable Care Act (ACA).

Overview of HRSA's Maternal and Child Health Bureau

HRSA, which is one of 11 agencies in the U.S. Department of Health & Human Services (HHS), is headed by Dr. Mary Wakefield and comprises six bureaus and two offices. Dr. DeGraw explained the structure, functions, and leadership of MCHB and stated its mission: to provide national leadership, in partnership with key stakeholders, to improve the physical and mental health, safety, and well-being of the MCH population, which includes all of the Nation's women, infants, children, adolescents, and their families, including fathers and children with special health care needs. MCHB's values statement upholds the importance of comprehensive care in medical homes that includes direct and enabling services; consumer-oriented, family-centered, and culturally competent care linked to community services; and continually improving health care based on research, evaluation, training and education, technical assistance, and the dissemination of up-to-date information. The central program in MCHB is the Title V Maternal and Child Health Block Grant, which was passed as part of the Social Security Act in 1935. The Title V legislation was the first time that the Federal Government pledged its support of State efforts to extend health and welfare services for mothers and children.

After explaining that authorizing legislation drives MCHB programs, Dr. DeGraw mentioned the formula grants to each State for MCH and services for children with special health care needs and the competitive grants, including Special Projects of Regional and National Significance (SPRANS) and Community Integrated Service Systems (CISS). Other legislated programs include Healthy Start,

Emergency Medical Services for Children, Universal Newborn Hearing Screening, the Traumatic Brain Injury Program, Family-to-Family Health Information Centers, Combating Autism Act Initiatives, Sickle Cell Service Demonstration Program, and Maternal, Infant, and Early Childhood Home Visiting Program. Annual appropriations provide the funding to carry out these programs. Dr. DeGraw explained the core public health services delivered by State MCH agencies, including direct health care services, enabling services, population-based services, and infrastructure-building services.

Defining areas for the work of the Bureau over several decades include children with special health care needs, family-centered care, and the medical home. MCHB has a strong focus on improving MCH data for policy, planning, and accountability. The Title V Information System (TVIS) electronically captures data from annual Title V Block Grant applications and reports, and this information is accessible by the general public. MCHB also partners with the National Center for Health Statistics (NCHS) of the Centers for Disease Control and Prevention (CDC) in sponsoring the National Survey of Child Health and the National Survey on Children with Special Health Care Needs. In addition, MCHB issues a number of publications regarding MCH and is actively engaged in MCH training and research programs.

MCHB and the Affordable Care Act

Dr. DeGraw explained that the Affordable Care Act (ACA) reauthorized the Emergency Medical Services for Children (EMSC) program, which was established in 1984 and is the only Federal program specifically focused on improving pediatric emergency care. ACA also established the new Maternal, Infant, and Early Childhood Home Visiting Program to fund States to provide evidence-based home visitation services to improve outcomes for children and families who reside in at-risk communities. The program is significant in its scope and its funding; ACA created both the authorization and the funding for the program. ACA also gives patients access, without cost-sharing, to preventive services recommended by the U.S. Preventive Services Task Force and the Advisory Committee on Immunization Practices. Comprehensive guidelines for health promotion and preventive services for all infants, children, and adolescents include children and youth with special health care needs. These HRSA-supported guidelines have been adopted as the national standard for well-child care by the American Academy of Pediatrics (AAP) and ACA. On August 1, 2011, the Secretary of HHS announced the Women's Preventive Services Required Health Plan Coverage Guidelines.

UPDATE FROM THE OFFICE OF MINORITY HEALTH

Garth Graham, M.D., M.P.H., Deputy Assistant Secretary for Minority Health, U.S. Department of Health & Human Services

Dr. Graham presented a broad overview of HHS activities involving health disparities, and he discussed the leveraging possibilities that SACIM should be informed about as it confronts this problem.

The goal of the Office of Minority Health (OMH) is to advise the Secretary on issues related to health disparities across HHS, which includes an array of programs involving health disparities. OMH coordinates programs across agencies, and several activities are being implemented as part of ACA. The Office of Adolescent Health is involved in a number of grant programs related to teen pregnancy and teen pregnancy prevention. These programs affect the risk factors involved in infant mortality in the African American, Hispanic, and Native American communities.

HHS released a strategic plan regarding health disparities on April 8, 2011. The key components of the plan are access to care, quality of care, cultural competence, workforce diversity, and data and research for subpopulations. Dr. Graham pointed out the great potential to change the statistics regarding the disparities in infant mortality. As ACA is implemented, the Federal Government will undertake more analysis of the social determinants of health across agencies, including education and housing. Dr. Graham encouraged SACIM to weigh in on all of the upstream factors that affect disparities in infant mortality.

A campaign to raise awareness about infant mortality in minority communities is underway. Launched in 2007, an infant mortality awareness campaign titled A Healthy Baby Begins With You targets the African American community to combat its disproportionately high rates of infant deaths. In 2011, OMH began a 3-year Native Baby Project to address the high infant mortality rates in American Indian communities, with a focus on urban populations. OMH also created the Preconception Peer Educators (PPE) program, which is based on research that shows preconception health as a significant predictor of birth outcomes and infant health. PPE uses the concept of the life-course perspective as its guiding principle. Dr. Graham urged SACIM to help raise awareness about the PPE program.

Discussion

Dr. Graham's presentation prompted the following questions and comments:

- In response to an inquiry from Dr. Miriam Labbok about next steps in the PPE program, Dr. Graham stated that OMH will perform an evaluation of the program to obtain feedback about moving forward and ways in which to work with program partners.
- Ms. Sharon Chesna asked how colleges are identified for the PPE program, what sort of training the peers receive, and what mechanisms are in place to ensure that the integrity of the curriculum and message is maintained. Dr. Graham stated that colleges were initially identified based on their interest, and information about the program was spread by word of mouth. He also stated that OMH provides training and offers technical assistance to program participants. In regard to ensuring the integrity of the program, Ms. Kay Johnson stated that health professionals' lack of fidelity to evidence-based practice is a much greater problem than the problem of possible misinformation from peer educators.

REVIEW OF RECOMMENDATIONS FROM THREE PREVIOUS SACIM COMMITTEE REPORTS

Yvonne Bronner, Sc.D., RD, LD, Professor, Morgan State University, Immediate Past Member, SACIM

Dr. Yvonne Bronner explained that the previous SACIM committee used a group process to eventually select three domains as the focus of their work. The committee formed three work groups and generated three reports with recommendations.

Report 1: Opportunities in Clinical Public Health Practice to Improve Birth Outcomes

The first report, Opportunities in Clinical Public Health Practice to Improve Birth Outcomes, had as its rationale the fact that improvements in birth outcomes have slowed and disparities persist. The focus of the report was to present strategies that promote the well-being of women across the lifespan. The report included four recommendations:

- The first recommendation was to promote the lifespan paradigm for infant mortality prevention, with an emphasis on preconception care for women of childbearing age. The strategies must address community-based and culturally competent social and economic determinants. This recommendation was supported by the CDC Summit of 2005.
- The second recommendation was to convene a state-of-the-evidence conference to identify interventions for which clear evidence exists of their effectiveness to reduce infant mortality. The identified strategies should be supported by HHS in its strategic planning process and resource allocation.
- The third recommendation called for the appointment of an interagency group to identify and prioritize a research agenda to effectively reduce infant mortality. The research agenda should include the causes of preterm birth, the impact of stress on birth outcomes, birth outcome disparities, and intergenerational impacts on birth outcomes.
- The fourth recommendation was to appoint an interagency group to identify, from existing sources, indicators that can be monitored to increase accountability for improving infant mortality rates.

The first report also stressed four opportunities to improve birth outcomes and reduce infant mortality:

1. In the area of pre-reproductive/preconception care, educate all women of reproductive age about healthy lifestyles (diet, physical activity, smoking/drug and alcohol use); address existing chronic disease; develop a reproductive plan for life; and integrate preconception counseling into routine “well-woman” care.
2. Pregnancy-related opportunities involve ensuring risk-appropriate prenatal and intrapartum care that includes evidence-based strategies such as back to sleep, smoking cessation, and hydroxyprogesterone to reduce preterm births; promote oral health; and promote continual quality improvement in prenatal care.
3. In the area of improving public health practice, advance the science of data sharing and utilization for program planning and monitoring birth outcomes; translate data into knowledge and practice; educate and advocate for evidence-based MCH policies; and commission the

Institute of Medicine (IOM) to do a 21st-century study regarding the lifespan approach to improving pregnancy outcomes.

4. Opportunities in clinical service delivery involve promoting systemwide use of evidence-based practices; recognizing and appropriately compensating good clinical practice; and increasing culturally appropriate health education to improve patient acceptance of new evidence-based obstetric practices.

Report 2: Effects of the Deficit Reduction Act on Maternal and Child Health Services

The second report, Effects of the Deficit Reduction Act on Maternal and Child Health Services, had as its rationale the recent decline in funding for MCH services. It was feared that the 2006 Deficit Reduction Act could affect Medicaid by increasing premiums and cost sharing and decreasing benefits and under the Maternal and Child Health Block Grant program. The report included five recommendations:

- The Centers for Medicare & Medicaid Services (CMS) should develop consistent policies for approval of State Medicaid services ensuring adequate and quality health care for women and children.
- There should be no reduction in match for targeted case management services.
- The Maternal and Child Health Block Grant funding should be restored to the 2005 level of \$724 million.
- MCHB should collaborate with other Federal agencies to eliminate health disparities and reach Healthy People 2020 objectives.
- Priorities, funding, and services should be focused on evidence-based practices and proven strategies to improve birth outcomes and reduce infant mortality. These practices should be the standards set for clinical practice and public health care.

In regard to the last recommendation, Dr. Bonner pointed out that HHS released guidelines for women's health care on August 1, 2011.

Report 3: Eliminating Health Disparities in Infant Mortality

The third report, Eliminating Health Disparities in Infant Mortality, focused on the fact that the dramatic downward trend in infant mortality over the past 100 years is not reflected in the rate among African Americans. The infant mortality rate among African Americans is at least twice that for whites and 40 percent above the rate for American Indians. This report contains a number of recommendations:

- Sponsor a state-of-the-science conference to determine what is known about the determinants of African American disparity in infant mortality.
- Use this knowledge to develop a strategic action plan to implement evidence-based strategies and fund gap-filling research and demonstration projects.
- Increase funding for research initiatives designed to specifically eliminate the African American disparity in infant mortality, such as investigation of biological, behavioral, psychosocial, environmental, and contextual factors that affect the African American disparity

in infant mortality, and development of effective translational research and monitoring results until the African American disparities in infant mortality are eliminated.

- Promote and adequately fund evidence-based projects like Healthy Start and other community-based models, and monitor outcomes and use competent evaluations to quickly identify and eliminate elements that are not working to lower African American infant mortality disparities.
- Add evidence-based effective strategies as they emerge from new research.

Summary of Recommendations

To summarize, Dr. Bronner listed six main focuses of the report recommendations:

1. Promote use of the lifespan paradigm for infant mortality remediation and prevention.
2. Convene state-of-the-evidence or science conferences to identify strategies and interventions that work.
3. Encourage HHS to use identified strategies and interventions to fund and solve the infant mortality problem, and encourage CMS to promote standardized procedures related to birth outcomes.
4. Focus on factors that affect specifically the African American infant mortality disparity.
5. Develop indicators that increase monitoring and accountability of efforts to improve infant outcomes.
6. Promote interagency collaboration to address the social, environmental, and contextual issues associated with infant outcomes, such as education, housing, and employment.

Dr. Bronner reported that there was some concern among committee members regarding the timely implementation of SACIM recommendations. She applauded OMH for implementing several SACIM recommendations in its project titled A Healthy Baby Begins With You. The PPE project is now nationwide.

Dr. Bronner ended her presentation by explaining the concept of biomimicry, which is the science of using designs in nature to create a new product or solution. She stated her hope that biomimicry will be helpful in finding a way to eliminate disparities in infant mortality.

Discussion

Dr. Bronner's presentation prompted the following questions and comments:

- Dr. Arden Handler asked Dr. Bronner to explain the process and structure that the previous SACIM group used to arrive at the three reports. Dr. Bronner replied that before the three subcommittees were formed, the members convened in general session to discuss the primary focus of the committee. Once the committee formed its three groups, those subcommittees worked between the general meetings to move the agenda forward and reported back to the full committee on their work.
- Dr. Adewale Troutman stated that Healthy People 2020 refers to health equity and includes a focus on the social determinants of health. He asked about SACIM's ability to effectively

move the agenda forward regarding social determinants through the Federal Government and down to the street level to make an ultimate difference. Dr. Bronner replied that the composition of the current SACIM embraces the community-based participatory model, whereas the former committee worked primarily in the medical model. As a result, current members will excel at policy, which is an important component of the committee's work. The life-course model is another important piece. Dr. Bronner encouraged the current committee to move with haste to determine its agenda.

- Ms. Chesna asked Dr. Bronner about her greatest frustration as a member of SACIM. Dr. Bronner explained that her personal frustration involved her prior and ongoing experience in the community and therefore her interest in conversations regarding education, housing, jobs, etc. She called for developing data and metrics for monitoring translational research and developing the ability to recognize when that activity is going in the wrong direction. The three reports reflect the important issues that are now on the table.
- Ms. Susan Sheridan asked whether the previous SACIM had any mechanisms or pathways to reach mothers for their input. Dr. Bronner replied that SACIM did not directly solicit information or input from mothers. Such input is very welcome on the current committee.
- Dr. Sara Shields noted that the three reports are from May 2007 and asked about Dr. Bronner's impression of what has happened in the 4 ensuing years regarding the recommendations. Dr. Bronner responded that the composition of the current committee is in itself progress. ACA understands where funding is needed. What is also needed is knowledge about how to make things happen. This committee seems to be ready to move forward in this regard.
- Dr. Labbok referred to recent literature on the contribution of stress and lack of social networks to the incidence of prematurity and infant mortality. The health care system must not be discounted; however, other factors outside the medical model must be considered when dealing with infant mortality. Dr. Phyllis Dennery pointed out that stress is biological and has many impacts on many systems; therefore, we should not dissociate what seem like peripheral, unrelated elements from medical considerations. An integrated team of medical and social scientists should work together to achieve desired outcomes. Dr. Labbok agreed and pointed out that, for example, paid maternity leave is relevant to a discussion of infant mortality.
- Dr. Troutman referred to the importance of language in this discussion and cited the definition of health by the World Health Organization (WHO) as the presence of physical, psychological, social, economic, and spiritual well-being and not merely the absence of disease and infirmity. Stress, neighborhoods, and urban blight are all part of the health system. He pointed out that the Surgeon General's National Prevention Council includes representatives from Cabinet Departments (Labor, Education, Housing, etc.), which are part of the solution of providing good health.

Dr. Robert Corwin pointed out the importance of weaving in the concepts of health literacy and public relations, especially related to vaccinations. Dr. Joanne Martin called for a broader conceptualization of functional health literacy and the importance of capacity-building within the population to really understand and apply it. She also harked back to a classic definition of infant mortality as a social problem with health consequences, saying that infant mortality is the most sensitive indicator of the well-being of a community. In addition, Dr. Martin cited the concept of microinequities and microaffirmations and their cumulative effect in relation to chronic stress.

INFANT AND MATERNAL MORTALITY IN THE UNITED STATES: DATA FROM THE NATIONAL VITAL STATISTICS SYSTEM

Marian F. MacDorman, Ph.D., Statistician and Senior Social Scientist, Division of Vital Statistics, National Center for Health Statistics, Centers for Disease Control and Prevention

Dr. MacDorman explained that her presentation would cover four topics: (1) the data, (2) fetal mortality, (3) infant mortality, and (4) maternal mortality.

Explanation of the Data

Most of the data in Dr. MacDorman's presentation came from vital statistics. The National Vital Statistics System (NVSS) is a voluntary, decentralized system in which States compile data from birth certificates, death certificates, and reports of fetal death and transmit these data to the National Center for Health Statistics (NCHS), where they are made into national data files. NCHS produces a natality dataset, a mortality data file, a linked birth/infant death dataset, and a fetal death dataset. Fetal deaths are reported by all U.S. States, with some variability in data completeness and quality.

The use of vital statistics data presents several analytical challenges. For example, the U.S. standard certificates of birth, death, and fetal birth were revised in 2003, but not all States have adopted the new certificates. Some items are not comparable between old and new versions of the certificates. Therefore, we currently do not have national data on some important data items that are either new or changed between the old and new certificates—for example, maternal smoking, prenatal care, and maternal education. NVSS is also challenged by concerns about timeliness. Currently, preliminary birth and death certificate data are available through 2009. However, the linked birth/infant death data file is available through 2007, and fetal death data through 2005. NCHS is working to catch up on data production in a limited resource climate.

Fetal Mortality

Dr. MacDorman stated that fetal mortality is a major but often overlooked public health problem. In 2005, there were an estimated 6.4 million pregnancies in the United States, including 4.1 million live births, 1.2 million induced abortions, and 1.1 million fetal deaths. There are nearly as many fetal deaths as infant deaths nationwide each year. Fetal deaths are evenly divided into those at 20–27 weeks of gestation and those at 28 weeks or more. In 2005, the U.S. fetal mortality rate was 6.22 at 20 weeks of gestation or more per 1,000 live births. In 2009, the preliminary infant mortality rate was 6.42 infant deaths per 1,000 live births, which was quite similar to the fetal mortality rate. Fetal mortality declined more slowly than infant mortality during the 1990s and, as with infant mortality, has shown signs of a plateau in the past few years, with no appreciable decline from 2003 to 2005.

When fetal deaths are examined by gestational age, all of the decline since 1990 has been among late fetal deaths (28 weeks of gestation or more). There has been little or no change in the fetal mortality rate at 20–27 weeks. As with infant mortality, fetal mortality rates vary considerably by race and Hispanic origin of mother. In 2005, the fetal mortality rate for non-Hispanic black women was 11.1, which was 2.3 times the rate for non-Hispanic white women at 4.8. The fetal mortality rate for American Indian women was 29 percent higher, and the rate for Hispanic women was 14 percent higher than for non-Hispanic white women.

Infant Mortality

After significant declines in the 1990s, the U.S. infant mortality rate did not decline between 2000 and 2005, although it has declined slightly since then. The U.S. infant mortality rate in 2009 was 6.42 infant deaths per 1,000 live births, based on preliminary data.

There are large differences in infant mortality rates by race and ethnicity. In 2007, the infant mortality rate for non-Hispanic black women was 2.4 times the rate for non-Hispanic white women. The rate for American Indian women was about 1.5 times that for non-Hispanic white women. Generally, infant mortality rates for most Hispanic-origin groups were lower than for non-Hispanic white women, with the exception of Puerto Ricans, whose infant mortality rate was 44 percent higher than for non-Hispanic white women.

About two-thirds of all infant deaths occurred within the first 28 days of life, the neonatal period, and one-third occurred during the postneonatal period from 1 to 11 months of age. In 2007, the infant mortality rate for mothers born in the United States was 40 percent higher than the rate for mothers born outside the United States. Infant mortality rates for non-Hispanic white, non-Hispanic black, and Asian/Pacific Islander women were significantly higher for mothers born in the United States than for those born outside the United States. Among Hispanic groups, only U.S.-born Mexican mothers had significantly higher rates than those born elsewhere. Several hypotheses have been mentioned to explain these variations, including possible differences in migration selectivity, diet and nutrition, social support, and risk behaviors.

Infant mortality rates were substantially higher for teen and for older mothers, with rates 2 to 3 times those for mothers in the lowest-risk age group of 30–34 years. Infant mortality also increases sharply with the increasing number of infants in the pregnancy. In 2007, the infant mortality rate for twins was nearly five times the rate for single births. The rate for triplets was 11 times; for quadruplets 24 times, and for quintuplets and higher-order births 50 times the rate for single births. Infant mortality rates are also high for mothers without timely prenatal care, for those who smoke, and for those with less education.

The leading causes of infant death in 2007 were congenital malformations, disorders related to short gestation and low birth weight, sudden infant death syndrome (SIDS), maternal complications of pregnancy, and unintentional injuries. Both short gestation/low birth weight and maternal complications are closely linked to the continuing problem with preterm births in the United States. After explaining the changes related to sudden unexpected infant death (SUID) versus SIDS, Dr. MacDorman discussed CDC's grouping of preterm-related causes of death. In 2000, 34.6 percent of all infant deaths were preterm related; by 2007, this figure had increased to 36.0 percent. The

impact of preterm-related infant mortality was also considerably higher for non-Hispanic black and Puerto Rican infants, with 45 percent and 39 percent of deaths being preterm related. For non-Hispanic black women, preterm-related infant mortality rates were more than three times those for non-Hispanic white women. Rates for Puerto Rican women were almost twice those for non-Hispanic white women. Prematurity is the leading cause of infant death in the United States.

After presenting detailed information about preterm birth by gestational age, induction of labor, and method of delivery, Dr. McDorman stated that while the overall percentage of preterm births increased from 1991 to 2006, the number and percentage of preterm births that were spontaneous vaginal deliveries declined sharply.

Dr. MacDorman continued her presentation with a preview of a forthcoming NCHS data brief that analyzes the reasons for the elevated infant mortality rates for non-Hispanic black, American Indian, and Puerto Rican women. The overall infant mortality rate can be divided into two key components: (1) gestational age-specific infant mortality rates (i.e., the mortality rate for infants at a given gestational age) and (2) distribution of births by gestational age. After displaying gestational age-specific infant mortality rates for the three race and ethnic groups with high infant mortality compared with non-Hispanic white women, Dr. MacDorman stated that at less than 32 weeks of gestation, infant mortality rates were 26 percent higher for non-Hispanic black than for non-Hispanic white infants and the other differences were not statistically significant. At 32–33 weeks of gestation, differences among groups were not statistically significant. However, mortality differences were larger for infants at 34 weeks of gestation or more. Infant mortality rates for American Indian women, those with the highest mortality rates at 34 weeks or more, were double those for non-Hispanic white women. For non-Hispanic black women, infant mortality rates were 32–70 percent higher for each gestational grouping at 34 weeks or more. In contrast, for Puerto Rican women, the rates were not significantly different from those for non-Hispanic white women.

The percentage of preterm births by race and ethnicity also varied widely. After reviewing the percentage contribution of gestational-age specific infant mortality rates and the distribution of births by gestational age to race/ethnic differences in infant mortality rates, as well as the contribution of causes of death to the gap between infant mortality rates between the three groups and non-Hispanic white women, Dr. MacDorman presented international comparisons of infant mortality. Over the past few decades, the United States ranking for infant mortality has fallen from 12th in 1960 to 29th in 2004. In 2005, the United States ranked 30th in the world in infant mortality, behind most European countries, Canada, Australia, New Zealand, Hong Kong, Singapore, Japan, and Israel. In addition, the percentage of preterm births is much higher in the United States than in Europe.

Dr. MacDorman summarized this part of her presentation by stating that, although reporting differences exist between countries, they are not the primary explanation for the relatively poor international ranking of the United States. In 2005, 22 countries had infant mortality rates under five. One would have to assume that these countries did not report more than one-third of their infant deaths for their infant mortality rates to equal or exceed the U. S. rate. This level of underreporting appears unlikely for most developed countries. The main cause of the high U.S. infant mortality rate when compared with Europe is the very high percentage of preterm births in the United States, the period when infant mortality is greatest.

Maternal Mortality

A maternal death is the death of a woman while pregnant or within 42 days of the end of pregnancy from any cause related to or aggravated by the pregnancy. A late maternal death is the death of a woman from direct or indirect obstetric causes more than 42 days but less than 1 year after the end of the pregnancy. The maternal mortality rate is the number of maternal deaths divided by the number of live births times 100,000.

Two main data-collection systems provide data on maternal mortality in the United States: (1) the National Vital Statistics System (NVSS) and (2) the Pregnancy Mortality Surveillance System (PMSS). NVSS is based on death-certificate data and is coded according to WHO rules. PMSS is a complementary activity to NVSS that collects data on pregnancy-related deaths and pregnancy-associated deaths through the use of death certificates and other sources of information.

After rapid declines in maternal deaths early in the 20th century, the U.S. maternal mortality rate plateaued in the 1980s and 1990s. Beginning with data for 2003, States have been adopting a separate question on their death certificates on whether a woman was pregnant at the time of death or within 42 days of death. Information from the question is used to supplement what is reported on the cause-of-death statement to improve ascertainment of maternal deaths. The new question increases ascertainment of maternal deaths, leading to higher maternal mortality rates. However, it has been difficult to measure the exact effects of the new question because only four States added it in 2003 and each year more States added it. By 2007, 24 States had added the new question, and by 2011, 38 States had added it. To complicate matters even further, some States included a pregnancy question that was different from the recommended question. NCHS is working with States to encourage them to adopt the standard question, and the number of States with comparable data is increasing.

The reported U.S. maternal mortality rate was 9 per 100,000 live births in 2002, 12 in 2003, 15 in 2005, and 12.7 in 2007. This change has alarmed many people. However, research has shown that most of this increase is due to improvements in ascertainment of maternal deaths, although a small, real increase in maternal mortality risk cannot be ruled out.

Maternal mortality is a major public health problem and deserves urgent attention from policy makers. Despite measurement issues, maternal mortality rates in the United States are high compared with other industrialized countries, and there has been no improvement in maternal mortality rates in the United States since 1982. The 500–600 maternal deaths each year in the United States are generally unexpected deaths of otherwise healthy young women, many in their 20s and 30s, with families and other children. The impact of these deaths on families and communities is large. There are also huge race and ethnic disparities in maternal mortality—some of the widest disparities found in public health, which raises questions of equity and access to quality health care. In addition, at least 40 percent of pregnancy-related deaths are preventable; many are due to common problems such as hemorrhage or complications of maternal chronic diseases (e.g., diabetes, hypertension).

International data show that maternal mortality rates in Germany, Canada, France, and England and Wales are about 40–50 percent lower than in the United States. The data on race and ethnic disparities show that the maternal mortality rate for non-Hispanic black women is 28.4 percent per

100,000 live births, almost three times the rate of 10.5 for non-Hispanic white women and more than three times the rate of 8.9 for Hispanic women. Such large race and ethnic disparities are fairly rare in health care data and raise questions about equal access of African American women to quality health care. There are also large differences in maternal mortality rate by maternal age. Rates for women older than 35 are about four times those for mothers in their early 20s.

Dr. MacDorman summarized her presentation by citing stagnation in the rate of decline of both infant and fetal mortality rates. There has been no detectible decline in maternal mortality rate since 1982 and a recent modest decline in preterm birth and infant mortality. Still, preterm birth rates and infant mortality rates are much higher in the United States than in most developed countries. Large race and ethnic disparities in fetal, infant, and maternal mortality suggest that not all race/ethnic groups have benefited equally from social and medical advances. Preterm birth is a primary cause of high infant mortality in the United States and contributes substantially to both race and ethnic disparities and this country's poor international ranking. Interventions to address the Nation's high preterm birth rate must address prevention of both spontaneous preterm labor and iatrogenic preterm birth.

Discussion

Dr. MacDorman's presentation prompted the following questions and comments:

- Judy Wilson asked whether, when the maternal mortality rate is examined by year, the rates for blacks are stable, increasing, or declining. Dr. MacDorman stated that the maternal mortality rate for African American women follows a similar trend to the overall maternal mortality rate.
- Dr. Raymond Cox stated his concern that, although the United States has the best race-based data in the world, the questions we ask (i.e., the "how" and "when") might not be the right ones; the question "why" remains unasked. Dr. Cox asked how the committee can reformulate the data to answer the question "why." Dr. MacDorman stated that more detailed research and analysis are needed.
- Dr. Wanda Barfield stated that consideration must be given to the sort of questions posed in the surveillance system. More questions must be directed to women regarding their experiences with health care. We need richer data, and we need to work better with the data we have. Dr. Lobbok noted that the United States must prevent prematurity and do better with our full-term babies to have an effect on disparities. Surveillance data may not be entirely helpful in getting to the "why." Dr. Cox pointed out that we must drill down in the data to get, for example, to provider disparities in very low birth weight rates, which are still too high. Using these data to come up with solutions is the concern. Dr. Barfield stated that we must be much more strategic regarding solutions to the Native American problem of infant mortality.
- Dr. Lu asked Dr. MacDorman what the committee can recommend to the Secretary to help enable NCHS to better analyze the data or improve population surveillance in terms of maternal and infant mortality. Dr. MacDorman responded that the biggest problem involves the nonstandardized use of the new birth certificate.
- Dr. Handler commented on the devastation of the statistics system in this country. SACIM should form a data subcommittee to address the question of a national birth certificate in order to compile uniform data. Dr. Joann Petrini asked whether it would be helpful if requirements

instead of recommendations were in place for State-level systems. Dr. MacDorman stated that a Federal mandate about collection of vital statistics data would facilitate the process of collecting uniform data, but funding for support to the States is a problem.

- Dr. Petrini mentioned the public's feeling of futility regarding the obvious disparities in infant mortality, and Dr. Shepherd remarked on the usefulness of geocoding. Dr. MacDorman stated that geocoding would improve NCHS data, but because of concerns about timeliness of data most States do not geocode their data before they send them to NCHS.
- Dr. Lu noted the recommendation for data standardization and geocoding and asked what the barriers are to implementing these recommendations. Dr. MacDorman responded that lack of funding is the major barrier.
- Ms. Chesna asked whether longitudinal analysis of the data would reveal the same disparities; whether a correlation exists between a mother's education and her access to health insurance; and whether there is a correlation between the health of mothers and infant mortality. Dr. MacDorman explained that the infant mortality gap between blacks and whites narrowed in the 1960s and then widened in the late 1970s and 1980s. These changes in the gap cannot be explained from vital statistics, although some reports relate the changes to social programs. The same patterns exist in the data for many years. NCHS does not have direct data on income or poverty based on vital statistics, but maternal education is a rough proxy for those elements. Women who have not completed high school, for example, have much higher infant mortality rates than women who have. Dr. Dominguez stated that the racial gap increases as we go up the socioeconomic scale. Higher socioeconomic status (SES) is not as protective of African American women's health as one would expect it to be. Dr. Cox pointed out that the rate of decrease in infant mortality rates in high-income whites is much faster than the rate of decrease among high-income African Americans.
- Ms. Johnson noted that the former chair of SACIM, Dr. James Collins, has written extensively on this subject; she suggested that SACIM ask him to respond to this question. ACTION ITEM: Dr. Lu will ask Dr. Collins to respond to the question about the association between SES and infant mortality rates in African American women.
- Dr. Lu confirmed that data show that SES affords less protection for African American women than it does for white women. On the point regarding maternal morbidity, Dr. Lu mentioned an increasing concern that maternal morbidity might be on the rise. He asked about the feasibility of using national data for tracking population surveillance of maternal morbidity in terms of preexisting chronic conditions as well as obstetric complications. Dr. Dominguez stated that the data suggest that the African American maternal mortality rate in early pregnancy is linked to maternal morbidity issues. Dr. Barfield stated that maternal morbidity is an important issue that is analyzed through hospital discharge data but that practice fails to reveal the burden of morbidity over time for women individually.
- Dr. Fleeta Jackson asked how life course is measured, especially in terms of family history, and what data would be valuable to gather life course information for the purposes of intervention. Her concern involves ways to rapidly translate data into intervention. Dr. Dominguez mentioned a research project that saw a trend in young women who were not aware of their preexisting hypertension until they became pregnant. In terms of life course, better primary care is needed through adolescence.
- Dr. Bronner remarked on the issue of education relative to the data. Looking at African American education and infant mortality, we find that African Americans who are poorly

educated have a much higher level of infant mortality than African Americans who are highly educated, which means that education is protective. We must realize that education and income are protective, and we must use the data we have to address the social, contextual, and environmental factors involved in policy decision making.

- An audience member, Carolyn Aoyama, a senior consultant for women's health for the Indian Health Service (IHS), stated that violence against women should be taken into consideration. Screening and surveillance systems must be built to compile the dataset on violence against women, including geocoding and communities in which violence has been normalized. Women must be able to control their sexuality, contraception, access to care, and nutrition.
- Dr. Dennery stated that despite the protective quality of education and income, without equity the gap still exists. If the African American population does not gain the same benefits from higher education and income as the non-African American population, then there is still a gap that needs to be addressed.
- Dr. Jackson stated that if the destination is intervention, then cultural aspects that are not easily measured within groups must be discovered to ascertain the driver that will inform the change.
- Dr. Troutman pointed out that there are data within the data within the data. The gap in health outcomes between African Americans and whites exists at every socioeconomic level. Furthermore, the definition of middle class is not the same for everyone. All middle class people are not a homogeneous group.
- Ms. Sheridan stated that surveys and focus groups have revealed that mothers care very much about the health of their newborns regardless of their educational attainment. The question involves how health care advocates can learn to motivate, activate, and engage these women in a way that they can respond to.
- Dr. Shields mentioned her surprise at the fact that being born in the United States is a risk factor for preterm birth.
- Dr. Lu stated that one of the tools we have in terms of getting at the why is the Pregnancy Risk Assessment Monitoring System (PRAMS). He asked what recommendations SACIM can make to enhance/improve/strengthen the effectiveness of PRAMS. Dr. Barfield explained that PRAMS surveys women who recently delivered a live birth and includes information from before, during, and after pregnancy. Much of PRAMS data are underutilized, including data about stressful life events, delays and/or obstacles to receiving prenatal care, and nutrition. States can select questions for their surveys, including a Reactions to Racism module. An opportunity to analyze the data also exists; any investigator who wants to use PRAMS data has more access to it and the turnaround time is much quicker. An inquiry system called CPONDER on the PRAMS Web site allows a user to look at variables in preset categories. In addition, innovative approaches can be used with the data. Dr. Barfield mentioned that the military community has made great strides in terms of improving racial disparities. Differences are by rank, not by race, and all individuals have equal access to care. Minority groups report a much better experience in their work and less racism than in other environments. Reductions in disparities are apparent, especially in early preterm birth for African Americans. Dr. Barfield pointed out the opportunity to over-sample PRAMS in communities for community-based research and the opportunity to overlay other data, such as birth certificate-based questions.
- Ms. Johnson remarked that every State does not have PRAMS. She suggested a way to get

HHS and CDC to think about creative incentives in the Federal-State partnership. Dr. Barfield noted that 39 sites now exist and a few more might be added within the next few months. Dr. Handler stated that PRAMS could have been used as a sampling frame for the National Children's Study and called attention to the fact that people do not think outside their silos.

- Dr. Lu remarked that the group discussion has resulted in some important considerations regarding data collection and population surveillance that could affect infant mortality. He challenged the committee members to start thinking about SACIM recommendations to the Secretary that are actionable and that would make a difference.

AFFORDABLE CARE ACT AND INFANT MORTALITY

Kay Johnson, M.Ed., M.P.H., President, Johnson Group Consulting, Inc.; Member, SACIM

Ms. Johnson presented information about opportunities in health reform to reduce infant mortality. She presented a brief history of MCH policy efforts to improve birth outcomes, highlighted lessons learned from an emphasis on prenatal and neonatal care, and described current efforts to improve preconception health and health care. She also discussed strategies and opportunities related to health reform.

History of MCH Policy

Ms. Johnson stated that Julia Lathrop produced the Children's Bureau report series on infant mortality, focusing on living conditions in cities, association with family earnings and unemployed fathers, and opportunities to provide care and interventions. Jo Baker was a physician and public health advocate who, in 1912, pointed to prematurity as a problem with social, economic, medical, and hygienic dimensions. Virginia Apgar was a surgeon, anesthesiologist, and public health-trained scientist who was interested in the risk factors involved in infant mortality.

In 1976, *Toward Improving the Outcome of Pregnancy (TIOP I)* covered regional systems of neonatal care, and in 1993, *TIOP II* emphasized neonatal and prenatal care. A national study of the impact of Medicaid expansions on prenatal care and birth outcomes found that Medicaid expansions were associated with an increase in early initiation of prenatal care without any evidence of significant, large-scale improvements in birth outcomes. Regionalization was effective, and technology worked to save babies but not necessarily turn the curve. The focus was not on root causes, and the cost of intensive care was high. Prenatal care has a demonstrated impact on maternal risks, but recommendations for changes in the content of care were never fully implemented. The interventions were often too little or too late to modify health conditions and other risks. One randomized controlled trial showed no impact on low birth weight or prematurity rates.

On the policy front, Medicaid block grants expanded maternity care coverage. The goal of Medicaid expansions for pregnancy was to reduce financial barriers to prenatal care for low-income women, thus improving pregnancy outcomes and reducing spending for high-risk newborn care. States with a multifaceted strategy to Medicaid prenatal expansions, such as Rhode Island, were more successful in improving access to care and outcomes than other States.

Ms. Johnson stated that evaluations of Medicaid prenatal care expansions neglected to ask the right

questions. Leaping from eligibility to outcomes made it impossible to understand the effect of intervening variables.

Focus on Preconception Health and Health Care

Areas of recommendation for preconception health and health care include individual responsibility across the life span, consumer awareness, preventive visits, interventions for identified risks, interconception care, prepregnancy checkups, coverage for low-income women, public health programs and strategies, research, and monitoring improvements. The first principle is to improve coverage. Four of 10 low-income women of childbearing age have no health insurance.

Regarding interconception/interpregnancy care, Georgia and Louisiana have CMS approval for interpregnancy care Medicaid waivers. Interconception care has been one of the nine core components of Healthy Start since 2001. In 2007, the consensus of the Policy Finance Work Group was that an annual well-woman health exam be a covered benefit in public and private plans, including preconception and family planning. In 2008, a health reform report titled Trust for America's Health called for health reform to provide coverage for all. Under existing Medicaid law, States can increase reimbursement levels and maximize family planning and other waivers.

Health Reform Opportunities: The Affordable Care Act

Ms. Johnson stated that the promise of the Affordable Care Act is enormous, but it must be fulfilled through action. ACA gives access to health care coverage for millions of Americans, and it gives access to affordable coverage by 2014. It sets a national Medicaid floor for people with income of 133 percent of poverty. Plans in Health Insurance Exchanges and all new plans will have a cap on what insurance companies can require in out-of-pocket expenses, such as copays and deductibles. Preventive-services protections are in place for adults. Health Insurance Exchanges will be the key functional mechanism. States are planning those now, with requirements for simplified processes, uniform consumer information, and qualified health plans.

Consumer protections include prohibiting denial of coverage to children due to preexisting conditions; permitting young adults to age 26 to stay on their parents' plans; banning lifetime dollar limits on benefits; restricting annual dollar limits on coverage; covering recommended preventive services with no deductible, copayments, or coinsurance; ensuring choice of any available primary care provider in a plan's network; access to out-of-network emergency care without prior authorization or higher cost sharing than would otherwise be charged; improving appeals processes; and prohibiting rescissions of coverage based on a mistake on an application.

ACA also addresses disparities by increasing the investment in primary care for the medically underserved, ensuring funding to increase workforce diversity, using community health workers, and investing in research about disparities. In terms of quality and efficiency, ACA sets out mechanisms at the Federal level, such as a national quality strategy and measures, a patient-centered outcomes research institute, and the CMS Center for Innovation. State and local action is required for patient-centered medical home pilots, community-based collaborative care networks, and community health teams to support the patient-centered medical home.

The national prevention strategy, the prevention and public health fund, and community transformation grants provide integration with public health. Ms. Johnson pointed out that many MCH advocates are not engaging in the conversation about community transformation grants. The question is whether the emphasis will be on prevention or chronic disease in older people. New program investments involve, among others, home visiting, pregnant teens, personal responsibility, school-based health clinics, community health centers, breastfeeding, and nursing training.

HHS priorities for action include coordinating interagency activity; permitting additional States to use interconception care Medicaid waivers; investing in innovation in primary care designed to apply what is known about the well-woman visit and preconception; monitoring implementation of the well-woman benefit; participating in Exchange design; funding demonstrations and pilots; maximizing community strategies, care coordination, and navigators; and supporting the development of messages.

Ms. Johnson presented her vision of the future:

- All Americans would have health coverage and access.
- All men and women of childbearing age would have high reproductive awareness.
- All women would engage in reproductive life planning, with 90 percent of pregnancies planned and intended.
- Women with a prior pregnancy loss would have access to intensive and comprehensive interconception risk-reduction programs.
- Infant mortality and morbidity would be reduced equitably, with disparities eliminated.

Discussion

Ms. Johnson's presentation prompted the following questions and comments:

- Dr. Handler commented that the reason the benefits of prenatal care coverage and delivery were not apparent involves the logic model and the fact that the evaluation covered only women's prenatal care at delivery, not Medicaid coverage during pregnancy. Because of the lack of messaging, many women did not know that they were eligible for prenatal care. Hospitals claimed Medicaid coverage for the deliveries, which was evaluated as if the women received prenatal care before that point. What is needed is universal access to prenatal care and well-woman health visits beginning at age 12.
- Dr. Jackson followed up with a comment regarding messaging and the difficulty in enrolling women for interpregnancy care. She also asked about "the best evidence for evidence-based programs" and posed a question about whether SACIM should consider expanded criteria for the evidence base. Ms. Johnson stated that not every good program can afford to do the research to show effectiveness. Furthermore, no study shows the effectiveness of well-child visits or prenatal care overall because these elements involve a process, not an intervention. Evidence-based interventions are applied through the process based on risk and identified need for individuals. An Early and Periodic Screening, Diagnosis, and Treatment Program (EPSDT) gold standard was linked to the American Academy of Pediatrics guidelines for several years, but it is in no way uniformly implemented by pediatricians.

- Dr. Handler stated that a book on the evidence base for reproductive and perinatal health interventions to reduce racial and ethnic disparities was produced last year. Some of the information might be useful for this committee at some point.
- Dr. Petrini noted that the challenges faced by SACIM in the past most likely involved timing, but now the timing is right for action on ACA and health care reform.
- Ms. Sheridan asked whether patient protection in ACA has been examined from the neonate point of view. SACIM's subcommittee process should look at post-discharge for mothers and babies and standardization regarding patient safety and quality improvement for the maternity and infant population.
- Dr. Lu referred to the eight components of the IOM recommendations for clinical preventive services for women (gestational diabetes, HPV testing, counseling for sexually transmitted infections, counseling and screening for HIV, counseling on contraceptive methods, breastfeeding support, screening and counseling for interpersonal and domestic violence, and well-women visits) and asked the committee whether it should endorse this list of comprehensive women's health services or whether other components should be added to the list. Ms. Johnson pointed out that the list is comprehensive for preventive services. The question is whether those services would be included in the essential benefits package without cost-sharing (i.e., without copays and deductibles). Ms. Johnson would urge the Secretary to set up the structures for monitoring the implementation of the components.
- Dr. Handler stated that the list omits a physical exam and that the well-woman visit package should include the other components.
- Ms. Sheridan would recommend standardized preventive services and procedures for newborns, including safe childbirth procedures, and education of both mothers and practitioners.
- Dr. Cox stated that SACIM should endorse the IOM recommendations but broaden its own work to include an examination of the system or platform from which care that reduces infant mortality is delivered. The "bundle" of prenatal care in a patient-centered medical home model includes continuity of care; appropriate newborn screening; and activation of patients, the medical community, and health-professional community to reduce infant mortality. He noted that the elements of prenatal care do not matter as much as the caring itself. Implementing care in a culturally and linguistically competent manner for the patient population is what is important. Appropriate and standardized discharge planning returns a patient to the outpatient or preventive community for a continuum of care.
- Dr. Lu stated that SACIM must look at the timing, content, and delivery of these services. The essential services for women's health should include nutritional counseling.
- Dr. Troutman called for a way to activate thought processes regarding other services that might be needed based on certain social-determinant criteria: SES, neighborhood, education, etc. He also pointed out that an important theory in social determinism involves social gradient.
- Ms. Johnson mentioned that pilots have been created in Vermont to determine the role of community health teams.

MEDICAID AND INFANT MORTALITY

Marsha Lillie-Blanton, Dr.P.H., Director, Division of Quality, Evaluation & Health Outcomes, Center for Medicaid, CHIP and Survey & Certification, Centers for Medicare & Medicaid Services

Dr. Lillie-Blanton presented information about Medicaid initiatives to improve maternal and infant health. She began with background information about CMS, which operates three programs: Medicare, Medicaid, and the Children's Health Insurance Program (CHIP). In the past, CMS was a payer, but it evolved from payer to purchaser as CMS moved into the era of managed care. The agency's three-part aim is better health, better care, and lower cost. To achieve the three-part aim, Medicaid and CHIP are the source of health insurance coverage for low-income children and low-income adults. These programs provide assistance to elderly and disabled Medicare beneficiaries, long-term care services and supports, revenue for health care system and safety-net providers, and revenue to support States in providing coverage to residents.

Medicaid is critically important to mothers and children. It covers at least 2 of 3 adult women in their reproductive years, 4 of 10 births, and approximately 2 of 3 publicly funded family planning services, including prenatal and postpartum care, gynecologic services, and testing and treatment of sexually transmitted diseases. Medicaid and CHIP cover about 37 percent of all children under age 18 and 60 percent of children in families with income below 200 percent of poverty.

The Challenge and Opportunity

The challenge is that, although the programs offer coverage, the quality of care delivered to beneficiaries is not what the health care system has the capacity to provide. As a payer and purchaser, CMS has the opportunity to help to reduce the number of low birth weight infants. When infant mortality is stratified by level of education, there is still a disparity by racial group within the strata. Using the data to answer the question why helps us to see how large a problem we are addressing. A gap exists for higher-educated African American women versus lower-educated white woman. Therefore, the gap exists by race and income, using education as a marker of income.

Broadening Understanding of Factors Contributing to Poor Maternal and Infant Health Outcome: The People, Places, and Services

Income, race/ethnicity, and neighborhoods shape patterns of health. Income and race are very much interconnected and are linked to neighborhood conditions. Lower-income people across races tend to live in neighborhoods with less access to resources that help keep people healthy. Education resources, recreation facilities, and safe neighborhoods reduce stress and allow people to live a healthier life and have a healthier child. In addition, place of residence shapes patterns of health. Factors cluster together in low-income communities. The question becomes what CMS can do as a payer and purchaser to affect health outcomes. In terms of standardization, in the Federal-State partnership, CMS gives guidance, but it is up to States to accept the guidance. The only universal package of benefits from CMS is for children through the EPSDT program. Through ACA, CMS can ensure comparability between what happens in the Exchanges and what happens in Medicaid.

CMS Efforts Underway To Improve Maternal and Infant Health: CMCS and CMMI

Dr. Lillie-Blanton presented information about the Center for Medicaid, CHIP and Survey & Certification (CMCS) and the Center for Medicare and Medicaid Innovation (CMMI). The Neonatal Outcomes Improvement Project is a result of Medicaid transformation grants in three pilot States—Arkansas, North Carolina, and Ohio. In Arkansas, a telemedicine outreach program resulted in savings and improvements. North Carolina worked successfully on an effort to reduce the rate of elective preterm deliveries, neonatal intensive care unit (NICU) admissions, and newborn complications. Ohio reduced the number of statewide preterm births and decreased NICU admissions.

A symposium held in June 2011 titled *Perinatal Outcomes: Where Are We? Where Can We Go?* profiled interventions to improve perinatal outcomes and outlined key components of an agenda to advance perinatal outcomes, including primary preventive strategies, preconception and interconception care, linkage of datasets across systems, women and children’s accountable care homes, and engagement of communities. In addition, CMCS has produced webinars on patient safety in the NICU and improving birth outcomes in Medicaid.

Through CMMI, new ideas and promising practices will be tested, including interventions and new models of care that address medical and social factors contributing to prematurity-related poor birth outcomes such as new or not widely used approaches to maternity care, support systems, and payment strategies. CMS is seeking to align payment with evidence-based maternity care.

Medicaid and CHIP’s partners in improving maternal and infant health include the States and other HHS agencies as well as partners within CMS and outside Government, such as providers, advocacy groups, and professional associations. Dr. Lillie-Blanton welcomed ideas and suggestions from SACIM.

Discussion

Dr. Lillie-Blanton’s presentation prompted the following questions and comments:

- Dr. Lu asked for suggestions about how SACIM can partner with CMS. Dr. Lillie-Blanton responded that feedback on the adult performance measures would be very helpful, as would the package of services and the evidence base for it. CMMI is required by Congress to document return-on-investment (ROI), which requires a prior evidence base to ascertain likely impact. SACIM’s expertise would be welcome. She also encourages partnership with Medicaid agencies.
- Dr. Lobbok underscored the Plan, Do, Study, Act (PDSA) approach in North Carolina, which enjoyed extraordinary results in reducing prematurity. The question is whether SACIM can encourage use of this effective methodology.
- Dr. Jackson referred to the term “promising practices” in relation to the idea of evidence base. She noted that the standard for evidence base is what is published in the journals. Promising practices might not meet the standards for the journals, but they might be very effective. What are the opportunities to elevate community-based projects, programs, or models that work?

Dr. Lillie-Blanton responded that CMS now uses the term “evidence-informed,” meaning that the evidence might not have gone through peer review. CMS is aware of the results of successful interventions that have not been peer reviewed. She pointed out that foundations have much more latitude than Government in this regard; they can take risks that Government cannot take because public dollars are involved.

- Dr. Dennery noted the significantly different outcomes regarding infant mortality between African American and Hispanic women of similar SES. Perhaps other elements involving biology and/or environment are being ignored. To make a change, we should consider elements in combination. Dr. Lillie-Blanton concurred and noted that poverty rates among Mexican American women are comparable to those among African American women, but their outcomes are better. She also pointed out that the data point for Hispanics includes a broad assortment of Hispanics and that the longer Latina/Hispanic women are in this country, the poorer their outcomes become. Being in this country is a risk factor for poor outcomes. Dr. Lillie-Blanton called for unpacking the combination of factors, for example, to discover the cumulative impact of stress or poor nutrition.
- Dr. Cox described a program through the Ascension Healthcare System that involves perinatal patient safety elements. This program has seen significant reductions in preterm delivery and birth injury.
- Dr. Shields stated that in terms of promising practices, some evidence has been published about prenatal group visits and the centering approach to pregnancy care. Dr. Lillie-Blanton noted that CMS is interested in the centering approach and documenting its impact. Dr. Dominguez mentioned the Neonatal Outcomes Improvement Project, nurse midwives, and freestanding birth centers as interventions with a comprehensive, empowerment-based, community-based approach. The midwifery model might be very appealing in communities of color with low-income women and poor access to care. Perhaps a recommendation could involve issues around Medicaid reimbursement for these services to access populations at higher risk for infant mortality.
- Dr. Barfield commented on the issue of Medicaid programs working with State and other MCH programs particularly in the context of innovation activities. Dr. Lillie-Blanton noted that Medicaid encourages learning collaboratives, communication, and cooperation with State public health departments.
- Dr. Troutman stated that an episode of a PBS documentary series called Unnatural Causes contains an excellent discussion of the so-called Hispanic/Latina paradox. Another episode discusses the Pima people and a social policy decision that caused a high incidence of diabetes in one segment of this population.
- Ms. Johnson listed six topics that SACIM should address in CMS: (1) quality measures, (2) improving perinatal outcomes, (3) CMMI work on innovations, (4) the need for consumer-friendly Exchanges, (5) opportunities for learning collaboratives, and (6) variation in Medicaid coverage among the States. Dr. Lillie-Blanton stated that input on the evidence base on the CMMI topic is needed in the next 2 weeks.
- Dr. Handler asked about creative opportunities to implement promising models for intervention. Dr. Lillie-Blanton mentioned the need to incentivize linkages and stated that the best model for which evidence exists is the Nurse-Family Partnership. An example of forward thinking is using Medicaid to fund employment-based services for people with mental health problems. In the maternity care package, we are closer to incentivizing the more direct

linkages of social determinants (e.g., nutrition, identifying risk, mental health/social service needs). Perhaps SACIM can provide the evidence base. Dr. Lillis-Blanton mentioned the possibility of using information from “the gray literature.”

A COMMUNITY AND PUBLIC HEALTH APPROACH TO INFANT MORTALITY

Wanda Barfield, M.D., M.P.H., Director, Division of Reproductive Health, Centers for Disease Control and Prevention

Dr. Barfield presented information about infant mortality prevention from a community and public health point of view. A discussion of infant mortality must include social determinants and maternal health. CDC’s public health approach is through community-based prevention efforts.

Infant mortality is a significant indicator of the health of the Nation. Dr. Barfield noted that we have failed to meet the goals for reduction of infant mortality, although we have made some advances through obstetric and neonatal care. Preterm birth (less than 37 weeks of gestation) is the most frequent cause of infant death, and there is a persistent racial disparity in the United States infant mortality rate.

The Social Determinants of Health

An increasing body of evidence points to factors beyond the infant and immediate pregnancy. The social determinants of health are the conditions under which individuals are born, grow, live, work, and age. Economics, social policies, and politics affect health inequity. WHO defines social determinants and makes three recommendations for improvement: (1) improve daily life, (2) address the inequity in quality of life, and (3) measure and assess the impact of policies and programs and how they motivate change.

To make a change, we must assess the true impact of policy change and evaluate focused interventions and the use of evidence-based interventions to inform States, localities, and agencies. It is possible to examine individual-level data linked to surveillance data. The life-course perspective is integral to this concept.

Dr. Barfield presented Kaplan’s multilevel framework for health to show the circle of influences. In terms of infant mortality, the health of the fetus ultimately is influenced by other factors, including the health of the mother and the complex physiology between them even before conception. The social relationships of the mother, the father, the family; organizational structures, support within families, neighborhoods and communities, policies and the interactions between them—this environment will influence the life course of the fetus.

The outcome of the fetus, infant mortality, and health disparities are explained by individual characteristics of the fetus and mother, the family, and the community, and the outcome is a consequence of the determinants existing on all of these levels. These determinants can create disparate outcomes.

CDC's Work

CDC focuses on safe motherhood to address reproductive, maternal, and infant health outcomes. The rationale of CDC's safe motherhood emphasis is on safeguarding the health of mothers by improving women's health before, during, and after pregnancy and identifying strategies that could reduce maternal and infant deaths in the United States.

The emphasis of CDC's Division of Reproductive Health, which is in the National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP), is on social determinants and the life course approach. The action areas within NCCDPHP include the public health infrastructure, healthy communities, and health care environments. The public health infrastructure includes surveillance, applied research, and capacity building and workforce development. Healthy communities involve looking at tobacco control, nutrition and physical activity, child and adolescent health, oral health, and sexual health. Work on health care environments includes promoting delivery of clinical preventive services, chronic disease management, and healthy schools and work environments. The social determinants perspective approach is an opportunity to focus on the biggest impacts, namely, socioeconomic factors. Other factors involve policy, long-term interventions, clinical interventions, and counseling and education. CDC works with communities in many ways, including through community transformation grants and chronic disease consolidation grants.

Examples of Improving Social Determinants in Maternal Health

CDC is reaching communities to improve maternal social determinants. In eastern North Carolina, a project seeks to reduce cardiovascular disease (CVD) risk among women accessing reproductive health services. CVD risks include diabetes, high cholesterol, high blood pressure, obesity, and smoking. The program screens for these five risk factors and evaluates a lifestyle and weight loss intervention. In Los Angeles, Healthy African American Families (HAAF) is a community participatory project with targeted interventions to support women during pregnancy. Based on feedback, the community developed the 100 Acts of Kindness to care for pregnant women.

CDC also is evaluating interventions such as the approach to weight loss and smoking cessation among American Indian women of reproductive age. Using PRAMS data, CDC is evaluating State tobacco control policies, spending, and taxes on smoking before, during, and after pregnancy, and on birth outcomes and assessing Medicaid coverage of smoking-cessation services.

Looking at the body of evidence to improve clinical practice, CDC has worked in collaboration with the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD), March of Dimes, and many others to demonstrate the risks including increased mortality and morbidity associated with late preterm birth. This collaboration provided the evidence for professional organizations such as the American Congress of Obstetricians and Gynecologists (ACOG), the Association of Women's Health, Obstetric and Neonatal Nurses (AWHONN), and American Academy of Pediatrics (AAP) to change the practice on the care of late preterm infants and to look at non-indicated induction of C-section delivery for less than 39 weeks gestation.

Data from CDC in a meta-analysis showed that the risk of death is greater for very low birth weight infants born at non-level III facilities. CDC, in collaboration with AAP, ACOG, HRSA, March of Dimes, and CMS and States, tried to address the issue of perinatal regionalization and the data in order to think about regulating services and facilities.

On the issue of contraception and teen pregnancy, CDC works with providers regarding the options they provide. CDC's PRAMS is associated with many success stories, including "The Stork Reality" project in Louisiana and an evaluation measuring the effect of military affiliation on preterm birth. Dr. Barfield also mentioned that in Massachusetts a CDC-funded pregnancy-to-early-life longitudinal system was used to link birth certificate data, hospital discharge data, PRAMS, early intervention program data, WIC data, assisted reproductive technology data, area resource data, Healthy Start data, and birth defect surveillance data. CDC is planning to fund some additional linkage projects to focus on community-based quality improvement. It has been found that quality improvement collaboratives are very effective in reducing the rate of preterm birth.

Another area of infant mortality prevention is the prevention of SIDS. CDC is working with NICHD and HRSA with the National Child Death Review to improve the classification of SUID, which includes SIDS and accidental suffocation in bed.

CDC also is working with MCHB to build capacity in communities through the Maternal and Child Health Epidemiology Program (MCHEP). CDC wants to provide more technical assistance in States through MCHEP.

To summarize, Dr. Barfield emphasized that social determinants and maternal health matter in reducing infant deaths and disparities. Integrative prevention research in communities is needed to assess social determinants. We cannot lose ground on things that we know are effective interventions. We must think broadly about data systems used to measure impacts, and we must increase and diversify the public health workforce.

Discussion

Dr. Barfield's presentation prompted the following questions and comments:

- Dr. Cox acknowledged the critical nature of CDC's work on social determinants and asked about CDC's geomapping capability at the ZIP Code level. Dr. Barfield replied that CDC uses geomapping as well as some health information systems technology for disease outbreaks, but because of funding limitations, geocoding and mapping used for other purposes are not as robust as they should be. The Division of Reproductive Health uses some mapping to examine perinatal services such as obstetric and neonatal care.
- Dr. Labbok also acknowledged CDC's work in this area. She explained that her group at the University of North Carolina concentrates on the three Bs: birth spacing and birth delay, birth practices, and breastfeeding. Dr. Barfield mentioned community transformation grants and baby-friendly hospitals.
- Dr. Shields asked about the rising C-section rate and CDC's interest in it as a public health issue in terms of its impact on maternal morbidity and breastfeeding rates. Dr. Barfield replied

that the available data suggest that the decision involving C-section presents a complex interaction between the woman and the family during the time of labor. We need better understanding of the many components of that decision.

- Dr. Lu asked for specific recommendations that SACIM could make to the Secretary to improve reproductive health and reduce infant mortality. Dr. Barfield replied that we must ensure an emphasis on mothers, families, and communities. We also must sustain the gains, focus on the disparities, and seize the opportunities regarding preventive services for women in areas such as gestational diabetes and smoking cessation. In addition, we should encourage development and training of the public workforce in the States and consider how to help clinical providers adopt a more public health perspective, particularly obstetrics providers.

SECRETARY'S ADVISORY COMMITTEE ON INFANT MORTALITY

WEDNESDAY, AUGUST 3, 2011

UPDATE ON THE HEALTHY START PROGRAM

Beverly Wright, CNM, M.S.N., M.P.H., Team Leader, Healthy Start Program, Division of Healthy Start and Perinatal Services, Maternal and Child Health Bureau, HRSA

Ms. Wright's presentation covered the history of the Healthy Start program, its legislative base, its core systems and services, and other Division of Healthy Start and Perinatal Services (DHSPS) programs and initiatives.

History of the Healthy Start Initiative

Healthy Start began in 1991 with the first President Bush. The U.S. infant mortality rate was rising, and the United States was ranked 22 among developed countries. Traditional strategies to combat infant mortality were not as successful as expected, and there was an increased focus on racial and ethnic disparities in health and health care. Healthy Start was established as a Presidential initiative to improve health care access and outcomes for women and infants, promote healthy behaviors, and combat the causes of infant mortality. The goal was to have a 50 percent reduction in infant mortality in 5 years.

Fifteen Healthy Start sites were funded from 1991 to 1998. Later, seven sites were funded, for a total of 22 initial sites. Fiscal year (FY) 1998 congressional language called for replicating best models and lessons learned from the demonstration phase, with existing sites serving as resource centers. Twenty of the 22 original sites became mentoring sites, and 50 to 76 new communities were added between 1998 and 2001. Healthy Start's lessons learned from these projects were evaluated, an internal assessment was carried out by national consultants, and SACIM made recommendations about how to proceed with Healthy Start.

The overarching conclusions and lessons learned were elements necessary for success, including strong neighborhood-based outreach and a case management model, a focus on service integration and a close link to the clinical care system, implementation of evidence-based practices, and consistency in program implementation over time and across program sites. It was determined that services should begin in the prenatal period and extend from beyond the postpartum period to throughout the entire interconceptional period (i.e., from the end of one pregnancy to either the next pregnancy or to 2 years after delivery).

The Legislative Base for the Healthy Start Initiative

Healthy Start was authorized under Title III of the Public Health Service Act as an initiative to reduce the rate of infant mortality and improve perinatal outcomes. The legislation directs the Secretary to make grants for project areas with high annual rates of infant mortality. The legislation also calls for community consortia of individuals and organizations, including agencies responsible for administering block grant programs under Title V of the Social Security Act, consumers of project services, public health departments, hospitals, health centers, and other significant sources of health

care services.

The Healthy Start Initiative Today: Core Systems and Services

The goals of Healthy Start are to improve health care access and outcomes for high-risk women and infants and to promote healthy behaviors and reduce the causes of infant mortality. In 2007, the overall rate for infant mortality was 6.75 deaths per 1,000 live births. For whites, the rate was 5.64, for African Americans 13.24, for Hispanics 5.71, and for non-white Hispanics 5.63.

Healthy Start's role in reducing disparities includes reducing the rate of infant mortality, eliminating disparities in perinatal health, implementing innovative community-based interventions to support and improve perinatal delivery systems in project communities, ensuring that every participating woman and infant gains access to the health delivery system and is followed through the continuum of care, and providing strong linkages with local and State perinatal systems.

Currently, there are 97 Healthy Start communities; 78 projects are funded to 2014, 13 are funded to 2015, and 6 are funded to 2012. Next year, 6 grantees will be funded. The border, Alaska, and Native Hawaiian projects include eight communities. Healthy Start is now in 39 States, the District of Columbia, and Puerto Rico. The program serves indigenous populations, border communities, and new immigrants.

Core services include outreach and client recruitment, case management, health education, interconception care, and depression screening and referral. In addition to the core services, Healthy Start requires each project to work on activities to ensure that Healthy Start operates collaboratively with others in the community and State and that it provides evidence of being sustainable beyond the time when Federal funding is available. Healthy Start projects also must work within the community to establish and maintain a system of care that makes comprehensive perinatal care understood and available. The projects also must provide sound management of resources and ensure that they are capable of obtaining and using data to improve care and evaluate impact. These activities can be grouped as follows: local health systems action plan for comprehensive perinatal care, consortium, sustainability, and collaboration and coordination linkages with Title V and others.

To date, Healthy Start has been successful in reducing infant mortality in the Nation's populations at highest risk for adverse outcomes. In contrast to the total national infant mortality rate of 6.42 per 1,000 live births in 2009, the infant mortality rate for Healthy Start participants was 6.0. Thirteen Healthy Start projects reported no infant deaths for the 3-year period from 2007 to 2009. Eight Healthy Start projects reported no infant deaths for the period from 2008 to 2009.

Other Division of Healthy Start and Perinatal Services Programs and Initiatives

DHSPS risk reduction and risk prevention activities include multiple risks screening, intimate-partner violence and postpartum depression, and perinatal depression screening. Infrastructure-building activities include the National Fetal Infant Mortality Review Resource Center, the Healthy Start Leadership Training Institute, the Community-Based Doula Program Leadership Institute, and the Interconception Care Learning Collaborative. Health promotion activities include innovative approaches to promoting a healthy weight in women, breastfeeding education, a folic acid campaign,

and the Bright Futures for Women's Health and Wellness perinatal focus on adaptation and emotional wellness. Leadership activities include the Advisory Committee on Infant Mortality, the National Hispanic Prenatal Hotline, and the Steering Committee for the Select Panel on Preconception Care.

The purpose of the First-Time Motherhood/New Parents Initiative is to develop and evaluate social marketing approaches that concurrently increase awareness of existing preconception and interconception care, prenatal care, and parenting services and programs, and to address the relationship between such services and health/birth outcomes and a healthy first year of life. The key objectives of this initiative are to: (1) reexamine pregnancy risk factors in the context of women's health development by integrating the life-course perspective into current MCH awareness campaigns; (2) increase the public's and provider's knowledge of the importance of integrating the life-course perspective into preconception/interconception care to reduce adverse pregnancy outcomes and improve reproductive health; (3) increase the pregnant women's and expectant parent's awareness of and access to economic and social resources that will assist them before, during, and after pregnancy; (4) provide linkages to preconception/interconception care, prenatal care, family support, and social services for men and women contemplating becoming parents to reduce the occurrence of risky behaviors and increase the likelihood of a healthy pregnancy; (5) increase public awareness of the importance of preparing couples for transitioning into their roles as new parents; and (6) increase public awareness of family support and parenting education programs available to expectant/new parents.

The First-Time Motherhood/New Parents Initiative was funded at \$4.5 million per year. Only State Title V programs were eligible to receive these funds. Demonstration projects from the first cycle of grantees ended in 2010. The second-cycle grantees are involved in a 3-year demonstration project that funded 11 new projects in September 2010.

The community-based doula program identifies and trains indigenous community leaders to mentor pregnant women during the months of pregnancy, birth, and the immediate postpartum period. Doulas provide culturally sensitive pregnancy and childbirth education, early linkage to health care and social services, labor coaching, breastfeeding education, and counseling and parenting skills while fostering parental attachment. In 2008, the program was funded at \$1.4 million. The program included three urban projects, three rural projects, and the Community-Based Doula Leadership Training Institute. In 2009, an additional \$1.4 million funded the continuation of activities along with three additional urban projects, three additional rural projects, and the leadership institute.

The Business Case for Breastfeeding is a HRSA resource kit developed to improve lactation support in the workplace. A train-the-trainer model was used from 2008 to 2010. Healthy Start also created the Bright Futures Taking Care of Mom booklet and a pamphlet on perinatal depression.

Discussion

Ms. Wright's presentation prompted the following questions and comments:

- Dr. Cox asked how many deliveries the Healthy Start program covered and how it achieved

its reduction in infant mortality. Ms. Wright responded that Healthy Start has about 161,000 participants and 40,000 deliveries and that the program uses case management, outreach, screening for depression, and systems building.

- Dr. Troutman stated that the Healthy Start approach in Louisville offered early identification of pregnancy, home visits by nurses, incentives for prenatal care, follow-up through delivery, and a 2-year follow-up with the child with regular home visits and assessments. Over a 4-year period, the infant mortality rate was zero. The evaluation compared women in the same neighborhood with the same risks who were not in the program with women in the program. A dramatic difference in the infant mortality rate existed between the two groups of women.
- Dr. Cox noted that the programs he is familiar with are very successful and support the data presented. He asked why, given the significant success of many of the projects, they have not been replicated on a larger scale. Many of these programs focus on stress reduction in particular. It appears obvious that the bundle of elements contribute to the program's success. Dr. DeGraw posed the question of when Healthy Start should be taken to scale after 30 years of demonstration.
- Dr. de la Cruz, the project officer for the national evaluation, presented information about the third national evaluation of Healthy Start, which is underway now. The earlier evaluation attempted to determine which of the nine components were the most effective at making intermediate and long-term changes in perinatal health. The current evaluation is building on the earlier evaluation. Health education, client outreach, and early recruitment are very important as well as having a strong consortium at the systems level. However, "If you've seen one Healthy Start site, you've seen one Healthy Start site." The problem is the need to evaluate the program across 105 projects that are implemented completely differently. The very first evaluation, which was performed by Mathematica in the early 1990s, used comparison communities and a minimum dataset and was designed to determine which projects were successful in reducing infant mortality by 50 percent in 5 years. The current evaluation is attempting to determine which subcomponents of the nine core components are in play, including public information and public education (e.g., health fairs, bulletin boards, billboards). Future SACIM meetings will feature reports on the national evaluation. A survey, which has been sent to all 105 project directors to determine how their programs are implemented, will look at the performance measurement data. The question involves what makes Healthy Start unique.
- Dr. Cox asked whether we are over drilling by looking at a specific component. It appears that Healthy Start has identified a bundle of components that works on a standardized level and then each community has the option of adding the components necessary to make that bundle work in that community. The problem might be that we are over focusing. Dr. de la Cruz noted that this is a legitimate fear. The evaluation team is very careful not to say that certain components work and others do not seem to be as effective. The components are intertwined; a variety of different activities seems to result in the most success.
- Dr. Labbok noted that the goal is to scale up by determining the lessons learned. Dr. de la Cruz stated that all three of the national evaluations of Healthy Start have been guided by the work of SACIM. Healthy Start reports out to SACIM so that it can receive SACIM's guidance.
- Ms. Johnson agreed about the caution against over drilling. She pointed out that the home visit can include case management, health promotion, risk screening, and cognitive behavioral

therapy. She also stated that the Healthy Start program has been plagued by inadequate reporting by grantees that are not skilled at collecting data. Data are necessary to describe success, and MCHB has worked hard to remedy the situation. The grantees resist undertaking a quality improvement project, but they are adopting and adapting the tools of quality improvement.

- Dr. Dennery asked about sustainability. Ms. Wright stated that Healthy Start encourages its grantees to seek grants from private organizations to improve parts of their programs (e.g., smoking cessation), and that strategy has been successful for several grantees. By working with public and private partners, the grantees ensure their sustainability. Dr. de la Cruz stated that the projects run for 4–5 years and many have gone through multiple grant cycles over the 20 years of the program, with the vast majority in existence for a decade or longer. However, none of the projects has received an increase in funding in years. Instead, new money goes to new communities, not to increasing the funding levels of the existing communities, which is a decision that was made years ago. In the current fiscal climate, sustainability has been stressed. Ms. Wright added that the current preference requires that grantees be funded above new sites. Old sites get funded first; any additional dollars go to fund new sites.
- Dr. Lu asked what recommendations SACIM could make to the Secretary to strengthen the impact of Healthy Start projects. Ms. Wright responded that additional funding to current grantees that are not at the base level of \$750,000 would help to expand the program and guarantee the same level of services across projects to implement the program as recommended. Dr. de la Cruz would like to see a recommendation from SACIM regarding whether new money should go to new communities versus increasing the base funding of the current communities. Many of the projects are at capacity, serving as many high-risk families as possible and focusing efforts on the highest of the high risk—those families that would be more likely to have a negative pregnancy outcome. As a result, we might begin to see some of the data “go in the wrong direction.” Can SACIM answer the question of how to continue asking for support for successful programs that might be so overtaxed that the data will begin to show a drop-off in success? Are we doing the right thing by keeping level funding and expanding it across the country or should that practice be rethought?
- Dr. Lu introduced Stacey Cunningham, director of the National Healthy Start Association, and asked her about possible SACIM recommendations for the Secretary. Ms. Cunningham noted that when her association goes to Congress to request increased funding, it is uncertain whether to ask for funds for existing programs or for new programs.
- In response to a question from Dr. Cox regarding the impact of ACA, Ms. Johnson mentioned the discussion of provisions regarding community health workers and whether Healthy Start fit into the home visiting program. On the latter point, publications and data were not sufficient in the Mathematica review to make a decision to include Healthy Start as a home visiting program despite its impact on infant mortality. Discussion is also ongoing about the role of Medicaid in funding case management services and prenatal care for eligible women and an ongoing concern continues regarding spending cuts. Rev. Mark Bartel asked whether ACA might jeopardize funding for Healthy Start because some might see Healthy Start as duplicative of home visiting programs. Ms. Johnson replied that such a concern does exist. Dr. de la Cruz cited the disappointment of many Healthy Start projects that they “did not make the cut” for home visiting. He pointed out that Healthy Start is a comprehensive program that includes home visiting. Ms. Wright stated that some of the grantees have the

money for home visiting through the States.

- Dr. Troutman spoke about sustainability at the local level and the possibility of reaching out to local hospital systems for money to expand the reach of the projects.
- Dr. Handler suggested that SACIM recommend that all Healthy Start projects be allowed to eventually draw down home visiting dollars if they adopt one of the models and that every State's Healthy Start home visiting program be allowed to get the Medicaid match for case management. She pointed out that Healthy Start has been an incubator for many models.

UPDATE ON THE FETAL AND INFANT MORTALITY REVIEW PROGRAM

Kathleen Buckley, M.S.N., CNM, Director, National Fetal-Infant Mortality Review Program, American College of Obstetricians and Gynecologists

Ms. Buckley presented information about the National Fetal and Infant Mortality Review (NFIMR). NFIMR is a cooperative agreement between ACOG and MCHB. Since 1990, NFIMR has been the designated resource center working with States and communities to develop fetal and infant mortality review (FIMR) programs.

Conceptual Threads and Unique Elements

The FIMR process was developed by MCHB in the 1980s, and since then it has become a model of continuous quality improvement. The idea is that review of cases of infant mortality serves as a springboard to create community change and improve services and resources for women, infants, and families. Certain conceptual threads run throughout FIMR. Confidentiality is key; the cases under review are de-identified. FIMR is an inclusive community coalition that focuses on systems of care and is a gap finder. FIMR is action-oriented.

FIMR gathers extensive and comprehensive medical and related information about the health of the mother to include in the review. It also includes maternal interviews and highly values input from mothers who have lost infants. In addition, the review team includes comprehensive representation of women's providers, agencies, and institutions as well as infant health. As the health care system for women and infants changes, expands, and contracts, FIMR is a timely early warning system about quality-of-care issues. Ms. Buckley quoted Julia Lathrop on infant mortality as an issue that concerns not only medical factors but also economic, social, civic, and family conditions.

Milestones

Today FIMR has programs in 42 States, the Virgin Islands, and Puerto Rico. A major milestone was the very positive Johns Hopkins evaluation of FIMR in 2002. The study concluded that FIMR is an evidence-based perinatal systems initiative. Another milestone, the Cultural and Linguistic Competence Organizational Assessment Instrument for FIMR Programs, is a tool developed by the National Center for Cultural Competence (NCCC) in collaboration with NFIMR. NCCC stated that FIMR developed an instrument to address the unique issues of local programs. The tool is on the NFIMR Web site (<http://www.nfimr.org>), which is user-friendly and visually pleasing.

As a resource center, FIMR provides technical assistance, and one of NFIMR's main objectives is to

adapt FIMR to other types of MCH morbidity and mortality sentinel events. Examples of modifications of FIMR include Florida's pregnancy-related mortality review, Baltimore's congenital syphilis review, and Louisiana's Katrina aftermath.

CDC stated that interventions exist to eliminate perinatal HIV transmission in the United States, but many infants still become HIV positive due to missed prevention opportunities. Like infant mortality, perinatal HIV transmission is an MCH sentinel event warranting investigation and action through the continuous quality improvement process of FIMR. Highly effective service systems, robust community resources, and comprehensive interventions must be put in place to prevent perinatal HIV transmission.

From 2005 to the present, national partners—CDC, ACOG, MCHB, NFIMR, and CityMatCH—have worked together to adapt FIMR to review cases in which HIV transmission is possible. CDC funded a pilot from 2006 to 2008, and a second funding cycle has run from 2009 to 2011. In July 2011, CDC required that all 60 perinatal programs do some type of FIMR HIV review.

A new 5-year cooperative agreement began in 2010, and an NFIMR conference will be held in 2012.

NFIMR Special Objectives

NFIMR adopted some special objectives for the current 5-year grant cycle: (1) describe, expand, and clarify FIMR's role in reducing racial disparities, (2) partner more closely with Healthy Start, and (3) describe and clarify how FIMR can incorporate Dr. Lu's life-course model into its framework. Ms. Buckley presented an excerpted version of Dr. Lu's 2010 article and noted that FIMR is involved in work that fulfills numbers 2 and 6 in the 12-point plan to close the black-white gap in birth outcomes by improving the quality of care for African American women and enhancing systems coordination and integration for family support services.

In terms of care to mothers with prior adverse pregnancy outcomes (point 1), a cornerstone of the FIMR process is a home interview with the bereaved family, most often the mother. The FIMR program routinely comes in contact with high-risk women who have had a poor pregnancy outcome, and referrals are made for services. If the mother agrees, the FIMR home visitor can directly facilitate referrals to address interconceptional risk factors that affect the mother's health and may affect a future pregnancy.

Other ways that FIMR institutionalizes an interconceptional referral process are by developing labor and delivery protocols for referrals for women who have had poor pregnancy outcomes. These protocols are meant to counteract the possibility that "If the mom loses the baby, the system loses the mom." FIMR also develops comprehensive outreach and services for women who have poor pregnancy outcomes, for example, Project Magnolia in Jacksonville, FL.

Ms. Buckley stated that FIMR can contribute to undoing racism (point 12) by listening to mothers who accessed the system and are underserved, ensuring that the FIMR team interactions and deliberations are culturally competent by using the NCCC tool, and being more aware of issues related to institutional racism and taking action to correct any that are identified.

Discussion

Ms. Buckley's presentation prompted the following questions and comments:

- Ms. Melinda Sanders stated that Missouri has two FIMR sites, both of which are Healthy Start grantees. Information gained through the FIMR process helps to guide the Healthy Start projects in identifying unique community characteristics, which in turn results in communication with Title V on the State level. Information is enriched at every step thanks to FIMR.
- Ms. Sheridan asked how to ensure that all States have a FIMR, and she asked whether mothers can report poor outcomes directly to FIMR, including reports of morbidity. Ms. Buckley replied that in some cases mothers have, but they do not usually report morbidity unless FIMR has a special concern, for example, cases of congenital syphilis in Baltimore that involved gaps in services. Ms. Sheridan noted that FIMR might become a mechanism to identify areas to improve infant mortality.
- Dr. Jackson noted that SACIM should examine how systems respond to families who are mourning the loss of babies to ascertain the mental and emotional needs related to that loss.
- Dr. Shields noted Healthy Start's involvement in postpartum care and interconception care and asked what happens in a case of infant mortality when no well-child visits are scheduled. Ms. Johnson mentioned her study of interconception care, which found a greater emphasis on the child than on the woman (i.e., a well-child visit was scheduled; a developmental screening tool was in place). Most of the time, the child had health coverage and the mother had lost hers. Grantees are now trying to determine how to retool their activity to include appropriate screening assessment for the mother in the 60 days before she loses coverage.
- Dr. Labbok mentioned the dyad—the infant and the mother—and the need to support it. FIMR is a strong model based on continuous change that is driven by the data. Ms. Buckley noted that vital statistics can contribute to our knowledge about what is happening but cannot tell us why. FIMR gives us that information.
- Ms. Sheridan asked whether each State funds its own FIMR project or whether the projects are funded through different mechanisms. Ms. Buckley replied that the majority of funding for FIMR comes from State Title V; 24 States have a State FIMR coordinator who oversees local projects. On the other hand, in places like Reno, the health department funds FIMR.
- Dr. Petrini asked whether States without FIMRs lack awareness or funding or both. Ms. Buckley replied that it is both, but there has to be the will to confront infant mortality as a major issue.
- Dr. Dominguez referred to the ability to adapt FIMR to different situations and noted that California, with a Maternal Mortality Review Committee similar to a FIMR model, has three times the disparity in maternal mortality for African American women as for non-Hispanic white women. She suggested that the FIMR model could be adapted to maternal mortality. Dr. Labbok stated that the model was originally developed for maternal mortality decades ago.
- Ms. Chesna stated that New York State lost its coordinated FIMR program when it was on the cusp of making important systemic changes in the health care system and in the way in which families in the community were served. She noted that FIMR was not a costly program; rather, it is a cost-effective mechanism to address infant mortality.

TITLE V BLOCK GRANT TO STATES AND INFANT MORTALITY

Michele Lawler, M.S., RD, Deputy Director, Division of State and Community Health, Maternal and Child Health Bureau, HRSA

Ms. Lawler presented information about Title V of the Social Security Act and MCH infant mortality efforts. Title V authorizes appropriations to States to improve the health of all mothers and children, to enable the States to provide access to quality MCH services, and to reduce infant mortality and morbidity. Title V also authorizes appropriations to States to increase immunizations, health assessments, and health services for children; to provide prenatal, delivery, and postpartum care for low-income, at-risk pregnant women; and to provide preventive and primary care services for children. In addition, Title V authorizes appropriations to States to provide rehabilitation services for blind and disabled individuals under the age of 16 and to provide and promote family-centered, community-based, coordinated care for children with special health care needs.

To receive Title V Maternal and Child Health Block Grant funding, States must submit an application and an annual report each year as well as a comprehensive statewide needs assessment every 5 years. The assessment must identify the need for preventive and primary care services for pregnant women, mothers, and infants up to age 1; preventive and primary care services for children; and services for children with special health care needs.

Highlights of the Title V Maternal and Child Health Block Grant Program

The block grant program operates as a partnership between Federal and State programs involving MCH and children with special health care needs. The block grant program is implemented in collaboration with a wide range of Federal, State, local, and private-sector partners. The program emphasizes accountability through annual reporting while providing appropriate flexibility for each State to respond to the particular needs of its MCH population. It helps States to support capacity and infrastructure-building, population-based and enabling services, and direct health care services where no services are available. States use their Title V dollars to implement a wide range of MCH activities. Decreasing the national rate of infant deaths has been and continues to be one of the primary focuses of the Maternal and Child Health Block Grant.

Title V and Infant Mortality

Infant mortality is a HRSA priority. MCHB is collaborating with the Association of State and Territorial Health Officials (ASTHO) on the potential development of a national strategy to reduce infant mortality across the United States. In 2010, ASTHO convened a meeting of State health officials, MCH directors, and HHS regional health administrators to discuss infant mortality and identify a strategic direction for addressing the issue. MCHB plans to lend collaborative and logistical support and technical assistance to the multi-State effort initiated by ASTHO in Regions IV and VI.

Under the proposed implementation, the Bureau will organize a series of summits on infant mortality. Working with ASTHO and the Association of Maternal and Child Health Programs (AMCHP), MCHB will plan and implement follow-up activities based on the recommendations from the summits. The Bureau also will provide technical assistance to States to address identified needs.

Ms. Lawler delineated the objectives of the summits and follow-up activities; described the national outcome measures, national performance measures, and health status indicators; and reviewed the State priority needs, State performance measures, and State outcome measures regarding birth outcomes. State Title V MCH infant mortality activities focus on prevention or reduction of low birth weight and very low birth weight, late preterm birth, prematurity, birth defects, SIDS, infant injury, maternal complications and infections, teenage pregnancy, and unintended pregnancy. The activities also focus on promotion of preconception and interconception care, newborn screening, safe sleep, early and regular prenatal care, smoking cessation during pregnancy, improved maternal nutritional status and reduction of obesity, substance-abuse programs, and depression screening.

Identified State infant mortality strategies range from the reduction of racial/ethnic disparities, to reduction in barriers to Medicaid or other types of coverage, to improving preconception wellness, to utilization of the Centering Pregnancy Model. States use key data sources such as PRAMS and FIMR and partner or collaborate with Healthy Start projects, State and local WIC agencies, the March of Dimes, and injury prevention programs. Ms. Lawler presented several examples of State Title V activities, including programs in Arizona, California, Delaware, Florida, Illinois, Kentucky, Louisiana, and Michigan.

Discussion

Ms. Lawler's presentation prompted the following questions and comments:

- Dr. Shepherd described Kentucky's FIMR needs assessment, which used community forums and consumer surveys, and she commented that illicit substance abuse and smoking in pregnancy are topics that SACIM should discuss. Ms. Sanders added that 30 percent of Title V funds must be spent on children with special health care needs, but otherwise the States can tweak their programs according to their unique needs. Missouri uses a rigorous system to determine funding and maximizes its funds through a strong collaboration process.
- Dr. Troutman asked about the summits and the part played by the National Association of County and City Health Officials (NACCHO) and the American Public Health Association in the planning. Ms. Lawler stated that it is early in the process and that the summits will involve a wide range of partners. Ms. Johnson expressed her concern that the summits will merely recycle strategies. She hopes for a deliberate effort to focus through the lens of ACA, the inclusion of Medicaid, recognizing partners, and the role of Healthy Start and community health centers. Ms. Lawler confirmed that the summits will represent a broad effort. Ms. Sheridan urged Title V to seek out the perspective of mothers.
- Dr. Lu asked about recommendations from SACIM to the Secretary. Ms. Lawler stated that the States know their populations and their priorities. A collective look at the State programs presents a wide range of efforts and activities and can lead to a national strategy. Dr. Shepherd noted that the Title V block grant is the infrastructure by which States address infant mortality and other child health issues locally. SACIM could weigh in on the need to fully fund the block grant.
- Dr. Lu asked Dr. Michael Fraser, the CEO of AMCHP, to address the question about SACIM recommendations to improve the impact of the Title V block grant. Dr. Fraser urged SACIM

to think strategically about a recommendation to the Secretary regarding the role of Title V in addressing infant mortality across the country. He also reminded the committee that the Secretary spends what Congress appropriates; therefore, conversations about funding must be strategic regarding work with congressional liaisons and representatives who make these decisions. He noted that the core infrastructure to address infant mortality has been eroded because of constrained resources and that SACIM should look carefully across HHS for collaboration and coordination on this issue. He also stated that the committee should examine the presented data and the Title V needs assessments and play a leadership role in efforts to enhance the work at hand. Dr. Fraser also urged SACIM to look at policy interventions related to preterm birth, breastfeeding, smoking cessation, and the inclusion of families in policy developments. He stated that all SACIM recommendations should be tempered by the reality that there are 59 States and jurisdictions.

- Dr. Labbok asked how Title V regions coordinate with Food and Nutrition Services regions. Ms. Lawler answered that Title V collaborates with USDA's child nutrition programs, but the regions do not align.
- Ms. Sheridan asked whether States determine their programs and priorities with patient engagement. Ms. Lawler responded that States develop their own program plans and how they address the needs, but they also involve stakeholders and families. Ms. Johnson added that Federal law requires that families have public input into the plans. Title V endorses family-centeredness.

WELCOME AND REMARKS FROM THE HRSA ADMINISTRATOR

Mary Wakefield, Ph.D., RN, Administrator, Health Resources and Services Administration

Dr. Wakefield thanked the SACIM members for their participation and willingness to add their expertise to the topic of infant mortality. She urged the members to review recommendations from the previous committees; presented information about CHIP, ACA, and other activities at HRSA that affect infant mortality; and encouraged SACIM to offer its advice about the HRSA activities.

Dr. Wakefield referred to the HHS guidelines for preventive health services for women, CDC's work in targeting areas with a high incidence of infant mortality, and the home visiting program lead by HRSA with cooperation from the Administration for Children and Families (ACF). ACA also expands the primary care safety net, and federally supported school-based health center programs will serve children in high school, thereby having an impact on the reproductive health of teenagers.

ACA affects the issue of infant mortality through investments in community health centers. In terms of women's health managed through those centers, 11 million patients are women and girls. The centers focus on training residents who serve underserved populations in ambulatory sites. Another area of HRSA investment is textforbaby.org, an initiative conducted in partnership with CDC whereby pregnant women sign up to receive evidence-based health text messages three times a week. HRSA also supports Healthy Start, family-to-family health information centers, a healthy weight initiative, and activities with a special emphasis on breastfeeding.

Dr. Wakefield ended her presentation by urging SACIM to lend its significant expertise to driving down the numbers regarding infant mortality.

Discussion

Dr. Wakefield's presentation prompted the following questions and comments:

- Dr. Lu thanked Dr. Wakefield and stated that SACIM has an opportunity to affect infant mortality. The committee has identified five priorities to guide its work: (1) implementation of ACA, (2) quality of care and safety, (3) strengthening Title V programs, (4) research data and health information technology, and (5) health disparities. SACIM will heed Dr. Wakefield's call to review recommendations from the previous committees and to look for opportunities for collaborations and synergy both within and outside HRSA.
- Dr. Shields thanked Dr. Wakefield for pointing out ways that ACA can promote both teaching community health centers and the expansion of primary care physicians in underserved areas. On the same topic, Dr. Petrini commented on the importance of residency training in primary care grants and the need for monitoring and incentivization.
- Dr. Troutman commented on the training of public health professionals and the need for grants and scholarships. He also mentioned the importance of addressing the social determinants of health and the gap in creating health equity. In regard to the public health workforce, Dr. Wakefield noted the concern about the loss of expertise resulting from retirements. She also stated that the importance of the social determinants of health is a given, but the question involves how to move that agenda forward.
- Ms. Sheridan mentioned her involvement in consumer advocacy groups involving quality and patient safety. The vision, experience, and wisdom of mothers must be sought to drive a reduction in infant mortality and morbidity. She asked how to reach out to mothers in this country and bring them into what is truly patient-centered care. Dr. Wakefield called for operationalizing strategies to bring mothers into the conversation because empowered consumers result in more informed discussion.

THE MATERNAL, INFANT, AND EARLY CHILDHOOD HOME VISITING PROGRAM

Audrey M. Yowell, Ph.D., M.S.S.S., Chief, Policy, Program Planning and Coordination Branch, Home Visiting and Early Childhood Systems Division, Maternal and Child Health Bureau, HRSA

Dr. Yowell presented information about ACA and the Maternal, Infant, and Early Childhood Home Visiting Program. Her presentation covered legislative authority and program goals and priorities, evidence-based home visiting models, and the status of program implementation.

Legislative Authority and Program Goals and Priorities

The home visiting program came about as an amendment to Title V. The appropriation is for \$1.5 billion over 5 years. Grants are made to States, with a 3 percent set-aside for grants to tribes, tribal organizations, or urban Indian organizations and a 3 percent set-aside for research, evaluation, and technical assistance. HRSA collaborates with ACF as well as other Federal agencies. The purposes as stated in the legislation are to (1) strengthen and improve the MCH programs and activities carried out under Title V of the Social Security Act, (2) improve coordination of services for at-risk communities, and (3) identify and provide comprehensive services to improve outcomes

for families who reside in at-risk communities.

The home visiting program goals involve improvements in (1) prenatal, maternal, and newborn health; (2) child health and development; (3) parenting skills; (4) school readiness and child academic achievement; (5) family economic self-sufficiency; and (6) referrals for and provision of other community resources and supports. Another goal involves reductions in crime or domestic violence.

The States must report on six benchmarks, and the first benchmark involves improved maternal and newborn health. Additional program goals involve (1) supporting the development of statewide systems to ensure effective implementation of evidence-based home visiting programs grounded in empirical knowledge, (2) established home visits as a key early childhood service delivery strategy in high-quality, comprehensive statewide early childhood systems, (3) fostering collaboration among MCH, early learning, and child abuse prevention, and (4) promoting collaboration and partnerships among States, the Federal Government, local communities, home visiting model developers, families, and other stakeholders.

The priority populations to be addressed include families in at-risk communities, low-income families, pregnant women younger than age 21, families with a history of child abuse or neglect, families with a history of substance abuse, families that have users of tobacco in the home, families with children with low student achievement, families with children with developmental delays or disabilities, and families with individuals who are serving or have served in the armed forces, including those with multiple deployments.

Evidence-Based Home Visiting Models

The home visiting program relies on evidence-based policy. The legislation requires grantees to implement evidence-based home visiting models and allows for implementation of promising strategies. The home visiting program recognizes eight models that meet the criteria of evidence base: (1) Early Head Start, (2) Family Check-Up, (3) Healthy Families America, (4) Healthy Steps, (5) Home Instruction for Parents of Preschool Youngsters, (6) Nurse-Family Partnership, (7) Parents as Teachers, and (8) the Public Health Nursing Early Intervention Program for Adolescent Mothers. Dr. Yowell stated that the programs are reviewed on an ongoing basis, and she reviewed the favorable outcomes that are expected to be achieved through use of the particular home visiting models.

The States may select a model that meets criteria for evidence of effectiveness, propose another model not reviewed by the HomVEE study, request reconsideration of an already reviewed model, or propose use of up to 25 percent of funds for a promising approach.

Status of Program Implementation

Dr. Yowell described the three-tiered method for awarding the FY 2010 dollars for the home visiting program. The plans, which were due June 8, 2011, will be approved in the next several weeks. Dr. Yowell explained that the States must show that they have met at least four benchmarks by the third year of the grant. States also must provide a plan for data collection for each of the six benchmark areas.

For FY 2011, \$224 million will be awarded to States. Of that amount, \$125 will be awarded by formula, and \$99 million will be awarded on a competitive basis.

Discussion

Dr. Yowell's presentation prompted the following questions and comments:

- Ms. Chesna referred to Dr. Yowell's statement that some States identified the entire State as a priority area and asked if that is acceptable. Dr. Yowell replied that no State can address the problem across the whole State. The home visiting program asks the States to target their at-risk communities. Competitive grants are available this year for innovative programs. It is hoped that a review of the benchmarks and the Secretary's national evaluation will establish that home visiting works.
- Dr. Shepherd noted that Kentucky identified the entire State as a priority area. Kentucky has a 10-year track record of home visiting with Healthy Start in all of its counties. The program can demonstrate reduced rates of preterm birth and infant mortality in the population, but it serves only first-time mothers and seeks to expand. The current funding allows it to reach only nine counties.
- Dr. Labbok mentioned that postpartum visits occur between 4 and 6 weeks and asked whether any programs have an earlier visit. Dr. Yowell replied that home visits can occur weekly for the first 2 months postpartum and continue until the child turns 2. The visit schedule depends entirely on the model. Dr. Yowell explained that the program asks States for a detailed justification for why they picked a certain community and model, and she noted that home visiting programs are already in place in the majority of States.

PRECONCEPTION HEALTH

Samuel F. Posner, Ph.D., Editor in Chief, *Preventing Chronic Disease*; Deputy Associate Director for Science, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention

Dr. Posner presented information about preconception health and health care. He pointed out that there is no funding authorization for preconception care. Infant death is the catastrophic end event of at least one generation or a lifetime or multiple lifetimes of challenges. Prenatal care is not enough; it is episodic and event-centered care and does not reduce maternal risks before fetal exposure. Nor does it address the health of the woman and her partner as the primary patient or support informed reproductive decision-making and family planning. Prenatal care is often reactive rather than proactive.

Preconception care can improve health for women, infants, and families. Health is intergenerational, and pregnancy outcomes reflect in part the cumulative health experience of the woman and her partner. A model of preconception care can improve the health of women before pregnancy and has benefits beyond reproduction. It is a potential model for care that provides continuity across the lifespan.

Overview of Preconception Care Since 2004

Much has happened in the field starting in the 1980s. In 2004, an internal work group at CDC formed a Select Panel on Preconception Care made up of Federal partners and private-sector entities. Preconception care is a model of care that identifies and modifies biomedical, behavioral, and social risks to a woman's health or pregnancy outcome through prevention and management, emphasizing those factors that must be acted on before conception or early in pregnancy to have maximal impact.

Summary of Work Group Activities

The CDC Preconception Care Initiative involves work groups in the following areas: clinical, public health, consumer, policy and finance, and research. The clinical work group reviews and evaluates the significant evidence for preconception care that is published in the literature and endorses clinical provider training. The public health work group has been involved in urban and rural public health practice collaboratives and identified a State preconception health data indicators set among other activities. In the policy and finance arena, the work group issued a call to action to bring about change. The Trust for America's Health 2011 brief, which came out in June at the Preconception Care Summit, called for increasing delivery of preconception care to high-risk women, expanding Title X, expanding Medicaid eligibility and coverage, increasing Medicaid waiver use, and ensuring adequate funding for CDC, HRSA, and the National Institutes of Health focused on preconception care. The consumer work group has looked at the social determinants of health and eliminating disparities in interconceptional care. The Preconception Care Message Bundling Study involved preconception health awareness, how women of reproductive age conceptualize preconception health, and if or how they group preconception care health behaviors.

Selected State and Local Initiatives

In 2005, a paper was published on State Title V priority needs related to preconception health and health care, with 25 States participating. Now 45 States have issued narratives reporting on activities, measures, or priorities related to preconception health. People understand this model of improving health. Every Woman South East, a regional collaborative to share best practices, is supported by the March of Dimes, University of North Carolina, and State health departments. In addition, a number of States have instituted projects involving preconception care.

Priority Areas

Dr. Posner named several priority areas: (1) support and encourage coordination of related activities across HHS, (2) capitalize on the IOM recommendation to integrate preconception care into HHS benefit design for first-dollar well-women visits, (3) permit States to expand use of Medicaid waivers for more interconception care, (4) encourage Federal agencies to invest resources to focus on improving preconception care and maternal and infant health, (5) support the development of positive messaging about preconception health to all audiences, and (6) support evaluation of existing preconception activities.

Discussion

Dr. Posner's presentation prompted the following questions and comments:

- Dr. Dominguez asked Dr. Posner about the arguments against preconception care. Dr. Posner reported that some of the negative emails he got involved sexism, class, and race.
- Dr. Handler thanked Dr. Posner for mentioning the subject of family planning, contraception, abortion, and reproductive decision making. Dr. Jackson asked whether there is a "safe space" in which to talk about pregnancy, family planning, and abortion. Dr. Shields mentioned "accidental pregnancies" and "accidental children" and called for language to be used in this committee to discuss these issues. Dr. Cox asserted that the IOM recommendations include family planning and leave space for recognizing the fact that religious health care organizations can and should be exempted from some of the recommendations based on their own ethical and religious directives. Dr. Posner stated that the reproductive life plan should mirror that at the individual level, making the space safe for individuals' personal beliefs, whatever they are.
- Dr. de la Cruz asked members of the public to send him any comments directly so that they can be included in the meeting summary.

COMMITTEE BUSINESS: DISCUSSION AND NEXT STEPS

Michael C. Lu, M.D., M.P.H., Chairperson, SACIM

Dr. Lu outlined the objectives of the committee business section of the meeting: (1) to review the SACIM charge, (2) to discuss the meeting with Secretary Sebelius, (3) to propose a framework for organizing SACIM's subcommittees, and (4) to discuss next steps.

Review of the Committee Charge

At the previous day's meeting, Dr. Lu had read from the Objectives and Scope of Activities section of the SACIM charter, which states that (1) the committee will advise the HHS Secretary regarding programs directed at reducing infant mortality and improving the health status of pregnant women and infants, (2) provide guidance and focus attention on the policies and resources required to address the reduction of infant mortality, and (3) provide advice on coordinating Federal, State, local, and private programs concerned with the health and social problems affecting infant mortality. Dr. Lu also referred to the Description of Duties section of the charter. Because the charter is scheduled to expire in September, SACIM is called on to update the charter for the next 2 years.

During the committee business section of the day's meeting, Dr. Lu asked Dr. de la Cruz for some background information about the charter. Dr. de la Cruz explained that the charter must be approved at the HRSA level by September 30. The charter is generic and broad in comparison with other advisory committee charters; it is not prescriptive and covers a wide variety of topics. He directed the members to look at the Membership and Designation section of the charter, in particular the designation of ex officio members. He asked if the members would like anyone else included and explained that all of the people listed are invited to the meetings but are not required to attend. The ex officio members receive the final meeting notebook with all of the updated slides, and they are

offered the written summary of the meeting.

Discussion

- Members noted that representatives from CDC and the Agency for Healthcare Research and Quality should be included formally as ex officio members, as well as representatives from the Department of Housing and Urban Development and the Department of Labor. Dr. de la Cruz mentioned that a particular person can be invited to serve as an ex officio member, can be formally invited to attend meetings, or can be informally invited to attend meetings. The members agreed that an official representative of the Surgeon General's National Prevention Council should be formally invited to be a part of this group. Representatives from all other departments that have a role in social determinants also would be welcome. Dr. de la Cruz reported that there is no corporate representative and no elected official at present but that Virginia Pressler is a business member from Hawaii Pacific Health.
- In response to a question about operating costs, Dr. de la Cruz stated that he is required to update that information every year.
- In response to a question about terms of office of the members, Dr. de la Cruz explained that one-third of the current members will serve a 2-year term, one-third will serve a 3-year term, and one-third will serve a 4-year term, as designated in the invitation letters. This system ensures continuity, fresh ideas, and varied expertise. Individual members' terms began on the date of the letter from the Secretary.
- Dr. Lu asked that other comments be sent to him regarding this topic.

Meeting With the Secretary to Discuss SACIM Priorities

Dr. Lu will meet with Secretary Kathleen Sebelius. He asked the members to review his list of priorities for 2011 and 2012, which include (1) health care reform and financing, (2) Medicaid innovations, (3) Title V and MCH programs, (4) health disparities, and (5) data and research.

Discussion

- Dr. Corwin provided information about vaccines and asked Dr. Lu to urge the Secretary to address the need for a universal program of vaccination and an ongoing campaign regarding vaccine safety.
- Dr. Handler would emphasize the social determinants of health and health care to women and families, and Dr. Labbok would emphasize the provider role in disparity issues.
- Members discussed the somewhat confusing overlap between the priorities as stated and the list of subcommittees and the possibility that it might be too soon to name specific MCH programs in the list of priorities. Instead, recommendations for priorities should flow from the committee's future discussion of the issues. Furthermore, it would be helpful for the committee to get the Secretary's "read" on infant mortality and SACIM's role in advising her about it. Dr. Cox suggested that the Secretary be informed that the committee is impatient, expects action to be taken on its recommendations, and supports the comments made by Dr. Wakefield regarding quality and safety, disease prevention and health promotion, preventive services coverage, prioritizing "hot ZIP Codes," home visiting, addressing

disparities, breastfeeding, and consumer input.

- Ms. Sheridan noted HRSA’s involvement in newborn screening initiatives and asked about SACIM’s responsibility in this regard. Because screening prevents newborn deaths, it must be “kept on the radar.” The Secretary should be reminded that every infant death matters, regardless of SES level, and that every mother will benefit from SACIM’s recommendations.
- Dr. Lu stated that some of what he emphasizes regarding quality and safety will mean a quick ROI.
- Dr. Martin asked when the information is needed, and Dr. Labbok noted that “breastfeeding promotion” should be changed to “breastfeeding support.”
- Dr. Troutman raised the question of evolving language and stated that Healthy People 2020 refers to “health equity” instead of “health disparities.”

Proposed Subcommittees

Dr. Lu proposed the following subcommittee structure for discussion: (1) health care reform and financing, (2) MCH and Title V programs, (3) quality and safety, (4) data, research, and health information technology, and (5) maternal and infant health disparities.

Discussion

- Dr. Handler stated that she definitely sees health disparities as its own task. Dr. Lu mentioned the possibility of inviting Assistant Secretary Howard Koh to the next meeting to discuss this topic.
- Dr. de la Cruz reminded the members that the charter specifically mentions, under Description of Duties, Healthy Start and Healthy People 2020 as areas on which the committee will advise the Secretary.
- Dr. Shepherd asked which subcommittee would cover evidence-based practices. Another cross-cutting theme involves leveraging and integration across agencies. Dr. Lu mentioned that evidence-based practices might fall under data and quality and suggested expanding the charge of the second proposed subcommittee to include synergies and collaborations within HRSA.
- Dr. Labbok noted that the first two subcommittees involve funding and the rest are cross-cutting. She suggested thinking more in terms of areas such as prevention, clinical quality, safety, environment, disparities, data, and research.
- Dr. Cox stated his confusion about the committee’s framework, how it fits into the larger discussion on infant mortality, and what SACIM wants to contribute to that discussion. Health care reform and financing are clearly cross-cutting issues. The topic of Healthy People could be addressed under quality and safety. Disparities or achieving health equity should be its own subcommittee, but achieving health equity is the capstone to quality and safety. Dr. Cox stated that quality cannot be achieved unless it is equitably distributed.
- Ms. Chesna stated that the proposed breakdown of the subcommittees needs more discussion. She asked Dr. Lu how he envisions the work of the five subcommittees, after a 4-year term, affecting infant mortality. Dr. Lu replied that in terms of an overall impact, the subcommittees will make recommendations to the Secretary. The overlap among the subcommittees might not allow for a clear division of responsibilities, but the work must be undertaken. He noted

that the list captures most of the interests of the members, and he proposed monthly subcommittee calls to get the work started.

- Ms. Chesna cited the need to pose a national research agenda specific to perinatal health or reducing infant mortality instead of establishing a data and research subcommittee. Another concern is how to take what we know are solid successes and spread those programs across all communities. Also, ACA focuses on prevention and wellness, and social marketing must be used to spread the message and engage consumers. These concerns could cross every subcommittee.
- Dr. Martin raised a question regarding the audience for each subcommittee message. Dr. de la Cruz stated that the committee needs to decide the answer to that question guided by the charter. The question involves who would be implementing the committee's recommendations. He emphasized that he finds the current conversation very refreshing, and he urged the members not to be frustrated by uncertainty or the lack of answers.
- Dr. Shepherd stated that the focus must be on policy, environmental, and systems change regardless of what the subcommittees are.
- Dr. Dennery asked how the committee gives and gets clear communication and direction about the various programs. Dr. Lu stated that part of the charge of SACIM is to identify opportunities for collaboration and systems integration across all of the various agencies doing work on infant mortality.
- Dr. Handler noted that the group has not had enough time to talk through the issues or work together. Dr. Lu stated that they would try to convene another meeting quickly to continue this conversation.

Next Steps

- Dr. Lu asked for suggestions for the next 2-day face-to-face meeting date.
- Dr. Martin suggested that the members submit information about their interests to Dr. Lu as a way of describing what they wish to contribute to SACIM. Dr. Lu will send out a request for that information to all of the committee members to determine the subcommittee structure.
- Ms. Chesna stated her interest in the policy implications and advocacy component of SACIM's work. Dr. DeGraw noted that SACIM advocates to the Secretary, who represents the authority within the administration for health. Dr. de la Cruz stated that whatever SACIM submits to the Secretary, once she officially acknowledges receipt of it, then it can be disseminated.
- Dr. Lu reminded the members of Medicaid's requests for SACIM's feedback on its performance measures. Dr. Lu will send the list of performance measures to the members along with information about evidence-based practices, best practices, and promising practices. Members will send Ms. Michelle Loh information to be shared with Medicaid, and then Dr. de la Cruz and Ms. Loh will compile the information and send it to Medicaid.
- Dr. de la Cruz stated that a draft summary of the meeting will be sent to the members.

The meeting adjourned at 3 p.m.

PARTICIPANT LIST

Advisory Committee Members

Michael C. Lu, M.D., M.S., M.P.H., Chairperson
Mark Bartel, M.Div., BCC
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Robert Mande Corwin, M.D., FAAP
Raymond L. Cox, Jr., M.D., M.B.A.
Phyllis Armelle Dennery, M.D.
Tyan A. Parker Dominguez, Ph.D., M.P.H., M.S.W.
Carolyn L. Gegor, CNM, M.S., FACNM
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Kay A. Johnson, M.P.H., Ed.M.
Miriam Harriet Labbok, M.D., M.P.H.
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Monica Mayer, M.D.
Joann R. Petrini, Ph.D., M.P.H.
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Susan E. Sheridan, M.I.M., M.B.A.
Sara G. Shields, M.D., M.S.
Adewale Troutman, M.D., M.P.H., M.A., CPH

Ex Officio Members

Members' Appointments are Pending

Advisory Committee Staff

Executive Secretary (Acting)

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Maternal and Child Health Bureau
Health Resources and Services Administration

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Staff Assistant

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Other Attendees

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IHS

Grace Berg
Zero to Three

J.M. Cooper
MCHB

Stacey Cunningham
National Healthy Start Association

Kim Deavers
MCHB

Juliann DeStefano
DHSPS

Elizabeth Edgerton
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Johannie Escarne
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Maaden Eshete
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Kathleen Kiltrare
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Ellen Pliska
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