

**Secretary's Advisory Committee on  
INFANT MORTALITY**

**Meeting Minutes of**

**March 30–31, 2004**

**Bethesda Marriott Hotel  
Bethesda, Maryland**

## GENERAL SESSION

TUESDAY, MARCH 30, 2004

### CALL TO ORDER

*James W. Collins, Jr., M.D., M.P.H., Chair, SACIM; Associate Professor of Pediatrics, Northwestern University Medical School, Chicago, IL*

### Welcome and Introductions

Dr. James W. Collins, Jr., welcomed participants to the Secretary's Advisory Committee on Infant Mortality (SACIM) meeting. He circulated some pertinent articles, and, after a round of introductions, called for approval of the minutes of the November 12–13, 2003, meeting. Dr. Collins called participants' attention to tab 8 in the meeting binder, which contains a report initiated by SACIM on early hospital discharge. The study used population-based data and confirmed that the vast majority of infants nationwide are discharged early from the hospital and that 51 to 83 percent of infants in the 19 States that use data from the Pregnancy Risk Assessment Monitoring System (PRAMS) were seen by health care providers in the first week after discharge. The majority of the infants seen were in the low-risk category (higher income, higher education, white, nonteenage mothers). Dr. Collins encouraged the meeting participants to read the report.

### HRSA Welcome and Update

*Stephen R. Smith, Senior Advisor to the Administrator, Health Resources and Services Administration, U.S. Department of Health and Human Services*

Mr. Stephen R. Smith welcomed participants and expressed the gratitude of Secretary of Health and Human Services Mr. Tommy G. Thompson and Health Resources and Services Administration (HRSA) Administrator Dr. Betty Duke for the Committee's work. In particular, Mr. Smith thanked and recognized the retiring Committee members: Mr. Bruce B. Bragg, Dr. Charles S. Mahan, Dr. Linda A. Randolph, Dr. E. Albert Reece, and Dr. Kenneth D. Wells.

Mr. Smith gave an overview of HRSA activities that address infant mortality, and he highlighted programs that affect mental health, border health activity, and international health activity. He referred to the rising infant mortality rate and HRSA's multipronged approach to attack the problem:

- The HHS Interagency Coordinating Council on Low Birth Weight and Preterm Birth (LBWCC) addresses the problem of infant mortality.
- The Closing the Health Gap Initiative on Infant Mortality has several goals, including decreasing racial and ethnic disparities in infant mortality, decreasing the low birth weight (LBW) rate for African Americans, and decreasing sudden infant death syndrome (SIDS) for African Americans and American Indians and Alaska Natives.

HRSA's Maternal and Child Health Bureau (MCHB) will take the lead role in developing the African American risk reduction pilot projects.

- The Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children, staffed by MCHB, includes physicians, geneticists, parents, and health care consultants. The Committee will make recommendations to Secretary Thompson on grants and projects to help States and local public health agencies improve screening, counseling, and health care services to newborns and children who have or are at risk for heritable disorders.
- MCHB and the Bureau of Primary Health Care have begun work on a collaborative effort on perinatal care and patient safety. The Community Health Center care model will focus on issues pertaining to pregnancy, delivery, and/or infancy. The goals are to develop comprehensive interventions to generate major improvements in outcome measures for perinatal care, including decreasing health disparities for infant mortality rates among high-risk populations, reducing maternal and infant HIV transmission, and reducing the incidence of LBW and SIDS.
- HRSA supports a set of ongoing programs, including Healthy Start, an initiative to decrease maternal transmission of HIV, training for providers of perinatal care, and care provision to mothers and infants in rural areas.

HRSA also supports a number of activities in mental health, border health, and international health:

- The purpose of the national bullying campaign is to educate Americans on ways to prevent bullying and youth violence. MCHB is leading HRSA's efforts in the campaign, the complete title of which is *Take a Stand. Lend a Hand. Stop Bullying Now*. The campaign was developed in partnership with more than 70 health, safety, education, and faith-based organizations. The campaign Web site ([www.stopbullyingnow.hrsa.gov](http://www.stopbullyingnow.hrsa.gov)) includes a resource kit on bullying prevention programs and activities that can be implemented at the school or community level. The resource kit can help in handling bullying problems and creating bullying prevention programs. Parents, educators, and community leaders should be encouraged to use these materials. The Web site also includes "webisodes" targeted to 9- to 13-year-olds.
- HRSA is working with the U.S.-Mexico Border Health Commission, Mexican health officials, and officials in the four border States and counties to plan a binational Border Health Week, scheduled for October 11–17, 2004. The week will be used to promote lasting health improvements on both sides of the border (60 kilometers north and 60 kilometers south of the border), where health conditions are poor and the rates of disease and death are high. During Border Health Week, 13 pairs of cities along the border will carry out information-sharing activities on immunization, diabetes, and accessing services and programs and perform health care outreach to the communities.

- Through the President’s Emergency Plan for AIDS Relief, HRSA is working to provide substantial new aid to 12 African countries and 2 Caribbean nations that are deeply affected by the AIDS epidemic. HRSA will fund two grantees to work with two Centers for Disease Control and Prevention (CDC) grantees to provide medical care and antiretroviral therapy to about 50,000 people in 12 of the 14 targeted countries. HRSA also will work with the U.S. Agency for International Development to develop partnerships between U.S.-based organizations and organizations in the 14 countries. These partnerships will work to prevent the transmission of HIV from mothers to their children. In addition, HRSA has funded a training and education center to train medical providers in the 14 countries to improve their capacity to care for people with AIDS.

## **Discussion**

Issues raised by Mr. Smith’s presentation included the following:

- In response to a question by Dr. Ann Miller, Mr. Smith stated that HRSA has not yet definitely identified the pairs of cities to be targeted during Border Health Week. When it is available, the information will be posted on the U.S.-Mexico Border Health Commission Web site.
- Mr. Bragg asked about the timing of the announcement of the grant awards for federally qualified health centers (FQHCs). Mr. Smith replied that the FQHC awards will be announced in the next 2 weeks.

## **MCHB Update**

*Peter C. van Dyck, M.D., M.P.H., Associate Administrator, MCHB, HRSA; Executive Secretary, SACIM*

Dr. van Dyck described four MCHB activities:

1. The national bullying campaign defines bullying as aggressive behavior that is intentional, involves an imbalance of power or strength, and is typically repeated over time. It can be hitting or punching (physical bullying), teasing or name-calling (verbal bullying), intimidation through gestures or social exclusion, and sending insulting images or messages by e-mail (cyber bullying). Studies show that between 15 and 25 percent of students in the 9- to 13-year-old category (“tweens”) are bullied with some frequency, and 15 to 20 percent report that they bully others with some frequency. Dr. van Dyck described the purpose of the bullying campaign—to help schools create an antibullying milieu. A youth panel of 9- to 13-year-olds formed a Federal advisory committee and met four times over a period of 2 years to give advice that resulted in the campaign materials, including the children’s part of the Web site, which highlights 2-minute cartoon movies about bullying, called “webisodes.” The campaign also includes a toll-free number, public service announcements, and posters. Dr. van Dyck passed around the campaign resource kit and the communications kit and asked for the Committee’s feedback.

2. The purpose of the Closing the Health Gap Initiative on Infant Mortality is to decrease the rates of African American infant mortality and SIDS in Michigan, South Carolina, Illinois, and Mississippi. Each State will receive a grant of \$500,000 to \$600,000 to select one or two communities with the highest rates of African American infant mortality, SIDS, LBW, or preterm birth, with the idea of reducing racial disparities over the 3-year period of the grant. At the same time, there is an effort to lower the Native American SIDS rate in two areas—Aberdeen, South Dakota, and Billings, Montana. Dr. Judith K. Thierry, of the Indian Health Service, spoke about the disproportionate nature of SIDS in the Native American population, especially in North Dakota, South Dakota, and Montana. The focus of the initiative in these States will be to develop surveillance and community capacity-building among tribes in the Aberdeen and Billings areas. Dr. van Dyck described a national, culturally competent media campaign, to be released this summer, to decrease African American and Native American infant mortality, LBW, and SIDS. In addition to the grants and media program, evidence-based programs to decrease disparities must be implemented by the sites, as elaborated by LBWCC.
3. An MCHB all-grantee meeting will be held in October to leverage ways to implement the Bureau's strategic planning and long-term goals.
4. The National Survey of Children's Health, developed by MCHB and the National Center for Health Statistics (NCHS), will result in uniform national and State data on the health and well-being of children as well as characteristics of their families and their neighborhoods. The purpose of the survey is to produce representative, reliable data for Healthy People 2010, for the national prevention objectives, for Title V planning and program evaluation, and for research. The survey addresses a variety of physical, emotional, and behavioral health indicators and measures of children's experiences in the health care system. It also incorporates an extensive set of questions for families, including questions about parental health status, parental ability for stress and coping behaviors, family activities, parental concerns about children, and parental perception of the child's neighborhood. The survey will inquire about eight domains: demographics, physical and mental health, health insurance, health care utilization and access to health care, the existence of a medical home, family functioning, parents' health, and neighborhood characteristics. In addition, the survey includes child age-specific modules. Data from the survey will be released in mid- or late 2005 and will be posted on the NCHS Web site.

## **Discussion**

Issues raised by Dr. van Dyck's presentation included the following:

- Dr. Mary Lou de Leon Siantz asked about the sampling for the national survey. Dr. van Dyck explained that the National Immunization Survey involved telephone calls to families to identify children aged 19 to 35 months old. These families are included in the sample for the National Survey of Children's Health.

- Dr. Miller asked how the survey will account for the poorest of the poor, who are not likely to have telephones. Dr. van Dyck replied that NCHS uses statistical methods to correct for undersampling, including comparison with the National Interview Survey, which is a household survey.
- In response to a question from Dr. Joyce E. Roberts about the language used in the survey, Dr. van Dyck stated that the survey will be conducted in English and Spanish and the questionnaire will be translated into 13 other languages for followup calls.
- In response to a question from Ms. Cheryl Austein Casnoff, Dr. van Dyck asserted that the survey will include some indepth questions about insurance.
- Mr. Bragg asked for more details about the infant mortality/SIDS initiative focused on the African American community and the way the grants will be administered in the States. Dr. van Dyck reiterated that four States are eligible to apply for the grants. Those States will identify one or two communities in their States with high rates of African American infant mortality, SIDS, LBW, and preterm birth. The States will each receive between \$500,000 and \$600,000 per year for 3 years.
- Dr. Robert E. Hannemann asked about the age range included in the National Survey of Children's Health and inquired about the amount of emphasis placed on emotional and behavioral problems in terms of both prevention and treatment. Dr. van Dyck replied that the survey will cover children to age 18 and that parents will report their perceptions in response to significant questions about behavioral and mental conditions regarding their children. It is expected that the appropriate age-specific questions for each module will show precursors of conditions and problems that begin before adolescence.
- Dr. Collins asked whether the SIDS rate among Native Americans is different for those who reside on reservations versus those who live off reservations. Dr. Thierry referred to an article in *Pediatrics* by David Grossman of the University of Washington about urban statistics on infant mortality. Clustering of SIDS cases exists outside of reservations. The Indian health care system provides care, but many patients are referred outside the system. Issues to be addressed include the postmortem differential diagnosis of SIDS.

### **HEALTHY START PROGRAM AND EVALUATION**

*Beverly Wright, M.S.N., M.P.H., C.N.M., Acting Chief, Healthy Start Branch, Division of Perinatal Systems and Women's Health, MCHB, HRSA*

*Susanna Ginsburg, M.S.W., Managing Vice President, Abt Associates*

*David de la Cruz, Ph.D., M.P.H., Senior Program Management Officer, Division of Perinatal Systems and Women's Health, MCHB, HRSA*

Ms. Beverly Wright presented an update on the Healthy Start program. In fiscal year (FY) 2004, an open competition will occur for two programs: (1) Eliminating Disparities in Perinatal Health: General Population and (2) Eliminating Disparities in Perinatal

Health: Border Health (Alaska, Hawaii, and the U.S.-Mexico Border States). Healthy Start anticipates awarding five to seven grants of up to \$1 million each in turnover funding. In FY 2005, those two grants as well as grants in interconception and perinatal depression will be up for renewal. A total of \$74 million in turnover funds will be awarded. The maximum size of these awards has not yet been determined. A total of 75 projects in this group will be up for renewal. In FY 2006, another competition will focus on eliminating disparities in perinatal health, with \$9.1 million in turnover funds and the number of awards to be determined. The objective review committee will meet May 11–14, 2004, in Silver Spring, Maryland, to review 40 to 50 grants.

Dr. David de la Cruz spoke briefly about the evaluation of Healthy Start. The national evaluation comprises two 2-year contracts. The first phase of the evaluation ends in September 2004; the next phase begins immediately thereafter. The evaluation incorporates advice and suggestions from SACIM, and Dr. de Leon Siantz is the SACIM representative to the Technical Expert Panel for the Evaluation of Healthy Start (TEPEHS).

Ms. Susanna Ginsberg provided information about the national evaluation of Healthy Start. Her presentation included background information and an update on evaluation activities, the overall evaluation approach, a review of the phase 1 evaluation design, and next steps.

### **Background Information and Update on Evaluation Activities**

The evaluation is a 4-year effort, with phase 1 focused on the full universe of grantees and phase 2 giving a more indepth evaluation of a subset of grantees. Key principles of the evaluation include the following:

- The evaluation assesses the national program, not individual grantee performance.
- The initial phase 1 evaluation focused on implementation of the program linked to the results.
- Key stakeholder inputs are critical to the evaluation effort.

The evaluation is currently in the process of data collection—fielding the survey, receiving and abstracting some of the information provided by the grantees, and beginning to look at the performance measurement data reported on for the first time this year. After data analysis, the final report will be completed and planning will continue for phase 2. Delays in the survey process will lead to delays in the final results and report, but data and information from the evaluation will be presented at the grantees' meeting.

From July 2003 to the present, the evaluators completed the survey development, conducted a grantee workshop in September, submitted an annual report and executive summary, prepared for data collection activities, and drafted an analysis plan.

## Overall Evaluation Approach

The evaluation focuses on engaging stakeholders in a participatory process. A key goal was to involve grantees in the evaluation design and the data collection instruments. Two workshops revealed that a wide diversity of opinion exists among the grantees regarding how they think about the Healthy Start program. To get a broader picture, the evaluators used a mapping process to determine the gestalt of the grantees' programs. Abt Associates is analyzing that information to determine what the data say about Healthy Start models. It will be incorporated into the final report for phase 1. The grantees also were involved in cognitive testing of the survey questions. The guidance from SACIM and TEPEHS was helpful in linking the information to results. The participatory approach also has helped in expanding the conceptual framework, refining the evaluation questions, and developing the content for and refining data collection tools.

The key evaluation questions are as follows:

- What are the features of Healthy Start programs?
- What results have Healthy Start programs achieved?
- What is the link between program features and program results?
- What types of Healthy Start programs (or program features) are associated with improved perinatal outcomes?

To answer those questions, a logic model has evolved. It will explain how the program is expected to affect results and outcomes. Two additional diagrams (the Hypothesized Link Between Healthy Start Services and Results and the Hypothesized Link Between Healthy Start Systems Activities and Results) support a more detailed examination of implementation and results. The diagrams provide a conceptual framework for the evaluation to help identify key features of the program and the types of results to be achieved as well as to develop appropriate data collection tools. Ms. Ginsburg explained in detail how the logic model helped to define what was important to look at in the evaluation. Her explanation covered the core services of Healthy Start programs, program infrastructure, and program implementation; intermediate outcomes, including service results and health systems changes; and long-term outcomes, including reduced disparities in access to and utilization of health care and reduced disparities in health status in the target community.

Examination of Healthy Start services and results focused on identifying a list of evidence-based services that clients should be receiving, including services for pregnant and postpartum clients as well as services for infants and toddlers. The three available Healthy Start mechanisms are the local action plan, the consortium, and the work with Title V and other organizations. The process involved in these mechanisms involves assessing needs and assets and setting priorities, which result in systems activities and systems outcomes, including changes in direct impact on participants and larger system changes.

## **Review of the Phase 1 Evaluation Design**

The data collection strategy emphasizes the primary data collected by the survey and supplemented by grantee reports and grantee performance measurement data for calendar year 2003. The use of data contained in the grantee program reporting requirements will be limited by their consistency and quality. The survey, which involved an intense development process and is now awaiting approval by the Office of Management and Budget (OMB), will be used in an electronic format to increase the ease of responding. The mail survey includes a number of components: staffing and organizational structure, Healthy Start service components, system components, and reflections on the program and results. The grantee reports will be revised to improve consistency across the grantees. Some data elements will be abstracted from grantee reports to reduce the reporting burden on grantees. Data from grantee applications, which are anticipated in April 2004, may provide more detailed descriptions of Healthy Start activities. The survey is expected to receive OMB clearance in April. The performance measurement data also are expected in April. The phase 1 report will include measures of program features and results, where data permit.

The analysis plan consists of three components:

1. A descriptive analysis of the program features, including a national profile of the Healthy Start program features, the range and variation across programs and the national program, and the range and variation of approaches
2. A descriptive analysis of the results achieved by Healthy Start programs during the current grant cycle, which is based on data collected through the survey and performance measures, relying on the mail survey for quantitative data and using performance measures selectively to support evidence on results
3. Linking program features with program results to determine whether certain features or approaches are associated with particular results, using descriptive and multivariate analyses, and controlling for certain basic characteristics of the programs.

## **Next Steps**

The implementation of data collection efforts includes fielding the survey, abstracting grantee guidance information, and reviewing performance measurement data. The analysis will be completed from May through August, with draft and final reports to follow. Phase 2 planning is limited at the present time.

## **Discussion**

Issues raised by Ms. Ginsburg's presentation included the following:

- Dr. Joyce Roberts asked three questions about the Healthy Start logic model, the performance measurement data, and the survey methodology:

- Regarding the Healthy Start logic model, Dr. Roberts asked what behavior changes are referred to in the Service Results box. Ms. Ginsburg responded that a component of Healthy Start involves health education, and the evaluation will determine what behavior changes occur as a result of Healthy Start interventions. The survey will supply more detailed information about health education activities of the grantees. Ms. Wright added that the program requires grantees to link pregnant women into certain health education programs (e.g., smoking, substance abuse, HIV/AIDS, prevention of preterm labor).
- Dr. Roberts asked about the potential measures listed on the “Using Performance Measurement Data” slide, specifically, how the adequacy of prenatal care is being rated. Ms. Wright responded that Healthy Start grantees are asked to use either the Kotelchuck or the Kessner Index to designate the number and timing of visits.
- Dr. Robert’s third question addressed the possibility of a low response rate when using electronic means to distribute a survey. Ms. Ginsburg responded that the grantees will be given a choice—to use a disk or to use hardcopy. She mentioned that the evaluation team is expecting close to a 100-percent response rate because the grantees were involved in the development of the survey. Dr. de la Cruz added that the national evaluation team and the project officers will encourage the grantees to respond.
- Referring to the slide that listed potential performance measurement data, Dr. Mahan remarked that he would like to know the percentage of pregnant clients who had late or no prenatal care, which the indexes will not be able to ascertain. He also asked what “facilitation” means in “Facilitation of provider screening for risk factors.” Ms. Ginsburg explained that MCHB developed the performance measures, which are available for use by multiple programs. The evaluators chose the measures on which the Healthy Start grantees will be reporting on the basis of what the Bureau and the program developed. Ms. Wright explained that the information to which Dr. Mahan referred is collected in another data source, but it is not one of the performance measures. Ms. Wright also explained that some grantees do not provide services themselves; they work with their contractors to ensure that women are screened for particular risk factors. They also teach Healthy Start clients about what they should be screened for. Dr. de la Cruz added that the performance measures will capture information about screening and completed referral (e.g., for spousal abuse).
- Mr. Bragg congratulated MCHB on its work over the past several years in the development of the evaluation. The logic model and the forthcoming information will

## **EXPLANATION OF COMMITTEE BREAKOUT SESSIONS ON THE LBWCC RESEARCH INVENTORY**

*Ann M. Koontz, C.N.M., Dr.P.H., Associate Director for Perinatal Policy, Division of Perinatal Systems and Women's Health, MCHB, HRSA*

Dr. Ann M. Koontz explained the background of the LBWCC research inventory and reiterated the task for the committee small-group work to be completed during the second day of the SACIM meeting. She explained that the committee members will be divided into three groups. Each group will examine the assigned sections of the research inventory to identify gaps in the Department's current research and to prioritize future research. In addition, each group will review two areas of the inventory—a section on research infrastructure and a listing of existing databases—and offer feedback regarding the need to fortify the research infrastructure and the need for particular databases. After the small-group sessions, the three groups will report their findings and recommendations to the full Committee for discussion.

Dr. Koontz passed out brief descriptors defining the inventory categories and a list of evidence-based interventions identified by LBWCC for inclusion in the Closing the Health Gap Initiative. Although they are not specific to the inventory, the interventions were offered as background for illuminating the work of the groups.

### **Discussion**

Issues raised by Dr. Koontz's presentation included the following:

- Dr. Hannemann asked for clarification of the purpose of the planned breakout activity. He referred to a report compiled by SACIM for the Secretary of Health and Human Services that contained a very exhaustive, comprehensive list of potential areas of significant research in the area of LBW infants. The LBWCC members were to review the current and planned research efforts of their agencies to compile a prioritized list of research areas. Dr. Hannemann expressed his concern about whether the experts on LBWCC matched their list with that of SACIM to arrive at a list of prioritized research activities. Dr. van Dyck responded that the process entails LBWCC's assessment of the agencies' current and planned research activities, followed by input from SACIM, as the parent committee with broad knowledge and skill levels. The analysis will continue after LBWCC receives SACIM's recommendations. After that, SACIM will conduct a final review. Dr. van Dyck reiterated that the breakout groups will examine the research inventory to identify gaps and describe deficiencies. The review process is valuable for collecting the input, tapping into the synergy of the larger group, and encouraging fresh thinking among the participants.
- Dr. Miller commented that this point in the process is like taking the next step in a conversation.

- Dr. Koontz stated that the inventory represents current and planned activities for FY 2004; however, some of those activities have been ongoing for quite a while. Therefore, not everything on the grid can be interpreted as being responsive to SACIM's original recommendations.

### **EXPLAINING RECENT TRENDS IN INFANT MORTALITY**

*Charles J. Rothwell, M.S., M.B.A., Director, Division of Vital Statistics, National Center for Health Statistics, CDC*

Mr. Charles J. Rothwell described a report he received in October 2003 that provided preliminary data on all causes of mortality for the United States. The preliminary data showed that the infant mortality rate increased by about 3 percent between 2001 and 2002. The question was whether this increase was an aberration, and the challenge was to explain the increase for public release. More detailed preliminary data were needed, along with more current preliminary data, fetal death data, and 2003 counts of infant deaths from the States. Supplemental analysis of the data also was necessary.

The infant mortality rate was split between neonates (early neonates and late neonates) and postneonates. The problem seemed to be in the early neonate period, that is, infant deaths at less than 7 days. The rate went from the lowest it has ever been nationwide (6.8) to 7.0 per 1,000 live births. The recent trend lines show that the postneonatal rate is fairly flat, the late neonatal rate has been fairly flat for the past 2 years, and the early neonatal rate has gone up in the past year. In general, looking at the longer term trends, some improvements had been seen in the early neonatal period and the postneonatal period, but not in the late neonatal period.

Major changes in the causes of infant mortality occurred in relation to LBW, congenital malformations, and maternal hypertension. Perinatal, late fetal, and early neonatal mortality rates from 1990 to 2002 reveal a general decrease in the late fetal mortality rate, an increase in the early neonatal mortality rate, and a gradual but consistent decrease in the perinatal mortality rate until this point in time. In fact, the perinatal mortality rate in 2002 was the same as the 2001 rate. From January to September 2003, the rates were lower than they were for 2002. The 2002 uptick may be a 1-year spike that will go back down but not to the 2001 level.

Mr. Rothwell offered a point of reference to view the status of the United States regarding infant mortality rates. The United States ranks 27 internationally. For whites, the rate is 5.8 per 1,000 live births; for blacks, it is 14.3 per 1,000 live births. The increase in infant mortality seemed to take place in both racial groups.

Mr. Rothwell stated that a look at potential explanatory factors failed to pinpoint the problems that caused the uptick in infant mortality. The factors include birth weight-specific mortality, high-risk mothers, and delivery procedures. The statistics reveal the following information:

- The percentage of LBW and preterm births continues to increase.
- The twin birth rate in the United States also has increased, whereas the skyrocketing triplet rate has dropped off in the past several years.
- Preterm and LBW rates among singleton births also have been on the rise.
- The preponderance of the increase is in the moderately preterm and moderately LBW groups.
- The distribution of singleton births by gestational age shifted between 1990 and 2002.
- Multiple births following assisted reproductive therapy (ART) do not seem to be any more high risk than non-ART births; data on singleton ART births may suggest the opposite.
- The rates of induction of labor by length of gestation in the United States between 1989 and 2002 increased, as did the rates of cesarean delivery by length of gestation.

All of this information points to areas of possibility for explaining the uptick in infant mortality in 2002.

The NCHS research agenda will examine whether the increased infant mortality rate is the result of changes in risk before birth, including maternal characteristics (age, race, education, medical risk factors, prenatal care, and tobacco use), infant characteristics (plurality, birth weight, gestational age, and congenital anomalies), or characteristics of labor and delivery (premature rupture of membranes, induction of labor, and cesarean delivery). If the increase in the infant mortality rate is found to be the result of changes in risk before birth, then how are these factors associated with age and cause of death? Were there overall changes in birth weight-specific, gestation-specific mortality rates in the Nation? Were there changes in obstetric and neonatal care? Did these events happen in specific areas of the country?

The vital statistics system used to be the bedrock of public health reporting, but data quality issues must be addressed. Reengineering the vital statistics system entails looking at the process by which vital statistics are collected from a registration, not a statistical, system. NCHS is attempting to improve the data items, establish configurable electronic systems, and integrate electronic systems. Higher quality data will result from data edited and queried at the source and from standardized systems across the Nation. More standardized data will result from standardized collection instruments, instructions, and definitions. More timely data will result when data are released within months of the event. When births and infant deaths are linked automatically, data will be available simultaneously.

In summary, Mr. Rothwell noted that the 2002 rise in the infant mortality rate was the first increase in more than four decades. The rise seems to be among neonatal deaths

only. The causes of infant death appear to be pregnancy related. Fetal mortality is down, and perinatal mortality is unchanged. The infant mortality rate no doubt decreased in 2003, but it may not reach the 2001 level. NCHS will examine the linked infant birth and death data set to arrive at a fuller explanation of the troubling change. The infant mortality rate must be studied closely regardless of whether the rate increases or decreases.

## **Discussion**

Issues raised by Mr. Rothwell's presentation included the following:

- Dr. Mahan asked whether the vital statistics data will sort out the normal from the accidental rates of cesarean delivery and induction of labor. Mr. Rothwell replied that such differentiation will not occur. Dr. Mahan expressed concern about the quality of birth certificate data and the need for better training of the data collectors. He made the point that the investment of information technology in U.S. health is abysmal. Mr. Rothwell agreed and called for reengineering the vital statistics process.
- Dr. Roberts asked about other data related to the rise in the rates of cesarean delivery by length of gestation at less than 32 weeks and at 32 to 36 weeks. If there are no additional data, then perhaps the existing data should be added to the research agenda on LBW. Mr. Rothwell replied that those data will be included in the research agenda, but causal links cannot be determined. Vital statistics do not reveal why physicians make the decisions they do. When Dr. Roberts asked if the statistics differentiate between elective and indicated cesarean section, Mr. Rothwell said no. He pointed out that if automated systems existed and were fairly responsive, events could be queried and followup studies could be conducted.
- Dr. Collins commented that certain questions cannot be asked of vital records because of the way the system is set up now. The system addresses population-based trends, not clinical questions. More linkage and interaction with hospitals and physician-related information would give a more complete picture of individuals and populations. Dr. Collins asked whether death records are linked on the national level or the State level and, if the latter, how much variability exists from State to State. Mr. Rothwell responded that the linkages are very effective. The issue involves the quality of the information within the linked file.
- Dr. Mahan commented that some nurse-midwives make the birth certificate a dynamic part of the prenatal chart. It might be a good idea to merge the prenatal chart with the birth certificate electronically. He also remarked on the Healthy Start sites in Tampa and St. Petersburg, Florida, where stress and drugs surface as causal factors in infant mortality.
- Mr. Rothwell commented that electronic interchanges (local, State, Federal, and interstate) would make it possible to collect information about mothers before delivery and to track for birth outcomes.

- Dr. Miller asked about privacy and consent issues regarding data collected about women and their babies. Mr. Rothwell stated that the medical information on a birth certificate is not released in an identifiable form at the State or Federal level.
- Dr. Hannemann asked about a correlation between the medical/legal climate, either State-specific or nationwide, and the infant mortality rate. If the cesarean section rate rises to 50 percent, as is predicted, could we predict that the infant mortality rate would likewise rise for medical/legal reasons? Mr. Rothwell responded that he does not believe that any statement can be made relative to that situation. Dr. Hannemann asked whether any States have been singled out as being responsible for the rise in the infant mortality rate and, if so, whether there is a relationship with the socioeconomic status of the population. Mr. Rothwell responded that demographics have an impact, but that a State with a higher infant mortality rate might have a better rate for high-risk groups and low-risk groups. A higher preponderance of high-risk mothers delivering in such a State might raise its overall infant mortality rate.
- Dr. van Dyck asked which States contributed most to the rise in infant mortality. Mr. Rothwell responded that the information will be released in a couple of months, after the high-risk rates are examined and compared with those of other States.
- Dr. Michael Kogan asked whether changes in obstetric practices in the country have been examined in terms of other factors, such as plurality, race/ethnicity, and repeat or first-time cesarean sections. Mr. Rothwell responded that the changes will be examined. Dr. Kogan asked Mr. Rothwell to speculate on the anomalous situation with the increase in the infant mortality rate, that is, the increase is related to short gestation or LBW, yet extremely LBW or extremely preterm births have not increased. The increase has been only in the moderate range, which is relatively low risk. Mr. Rothwell responded that a very small movement in very LBW events can cause a problem. He is not ready to respond completely to this question.
- Dr. Mahan commented that “putting a human face” on the problem means that 474 babies have died over this time period. It is possible to extrapolate from the literature that roughly, for every baby who died, five would survive with lifelong disabilities. Mr. Rothwell was unable to confirm this assertion. Dr. Mahan remarked that the linked tracking system in Florida between education and health reveals that 20 percent of Florida’s children cannot enter kindergarten on time.

### **MATERNAL OBESITY AND ITS EFFECT ON PREGNANCY OUTCOMES AND IMPLICATIONS FOR THE POSTPARTUM PERIOD**

*Anna Maria Siega-Riz, Ph.D., R.D., Associate Professor, Department of Maternal and Child Health and Department of Nutrition, School of Public Health, University of North Carolina at Chapel Hill*

Dr. Anna Maria Siega-Riz presented an overview of the prevalence of maternal obesity in the United States and its implications during pregnancy and the postpartum period. The

proportion of the U.S. population that is classified as obese has increased steadily over the past 30 years; it does not necessarily differ by gender. The national nutritional monitoring data sets classify overweight as a body mass index (BMI) of 25.0 to 29.9, type 1 obesity as BMI 30.0 to 34.9, and type 2 obesity as 35.0 to 39.9. The most recent evidence shows that the prevalence of obesity among women of childbearing age is as high as 28 percent. Obesity rates differ by ethnic groups: minority women have higher rates of obesity.

The general health burden of the trend in obesity, independent of pregnancy, has been well described in the literature and has been associated with cardiovascular disease, type 2 diabetes, gallbladder disease, osteoarthritis, and reduced fecundity and fertility. Overweight and obese women are 3 times more likely to experience ovulatory infertility, 25 percent of which can be attributed to obesity. During pregnancy, the implications of obesity include gestational diabetes, gestational hypertension, preeclampsia, cesarean delivery, fetal macrosomia, late fetal death, early neonatal death, thromboembolic diseases, and birth defects. In the postpartum period, the implications of obesity include postpartum weight retention and anemia.

Dr. Siega-Riz described the Pregnancy, Infection, and Nutrition (PIN) study funded by the National Institute of Child Health and Human Development (NICHD) at the University of North Carolina. The study collects birth outcome information from delivery logs and performs extensive abstraction of medical records. In terms of weight gain, a delicate balance must be struck between the benefits of weight gain for the infant and the consequences of weight retention for the mother. The recommendations for weight gain during pregnancy have become more liberal over time. In addition, PIN data show that a majority of women, regardless of their prepregnancy weight, are gaining weight excessively during pregnancy. Women who diet habitually before becoming pregnant gain more weight during pregnancy and retain more weight postpartum. A 1999 study showed that, compared with unrestrained eaters, fewer restrained eaters experienced weight gains within the recommended range for their prepregnancy BMI.

Liberal weight gains might not necessarily be associated with the high gestational weight gains seen during pregnancy. A 1997 study measured fat gain during pregnancy and found that underweight women who gained within the Institute of Medicine (IOM) recommendations put on 6.0 kilograms of fat, whereas normal and overweight women put on 3.5 kilograms and obese women actually had a net loss of 0.6 kilograms. During the postpartum period, overweight women retain more weight than do normal-weight women.

With regard to physical activity during the postpartum period, women who retain more weight (at least 5 kilograms at 1 year postpartum) tend to be less physically active than women who gained less. Among women who gained 10 kilograms postpartum, 23 percent were not active during their leisure time, compared with 4 percent of the women who retained less weight.

Another interesting finding related to maternal obesity is the link between obesity and birth defects, which cannot be explained by prenatal supplement use, dietary folate intake, use of diet pills, or previous history of neural tube defects (NTDs). Seventeen studies reported in the literature since 1969 show a twofold increased risk in NTDs and a two- to sixfold increased risk for congenital heart defects for obese women compared with normal-weight women.

Gestational diabetes mellitus (GDM), a carbohydrate intolerance first recognized in pregnancy, is an established risk factor for adverse birth outcomes. Its prevalence is 3 to 5 percent in the United States, but this figure may be rising because of the increased number of obese women in their childbearing years. Women with GDM have a 30-percent chance of developing type 2 diabetes later in life, and there are implications for the fetus. Data from the PIN clinics—which practice universal glucose screening and classify women into mutually exclusive groups (normal glucose tolerance, impaired glucose tolerance [IGT], and GDM)—show a higher percentage of obesity associated with women classified as having IGT or GDM. Prevalence of GDM in the PIN clinic population is about 5.5 percent, and prevalence of IGT is 2.7 percent. When studying the relationship between weight gain and prepregnancy weight on the risk of developing both GDM and IGT, the findings show that both overweight and obese women, independently of weight gain, have a higher risk of GDM. White women who were overweight tended to be more sensitive than black women to becoming IGT as the amount of weight gain during pregnancy above the IOM recommendation increased.

Gestational hypertension is elevated among overweight and obese women at a risk factor of about 1.7 and 2.2, respectively, compared with women with normal range BMIs. The risk of preeclampsia is twofold for overweight and obese women compared with underweight women.

An overview of the literature (seven observational studies) on the relationship between prepregnancy obesity and cesarean delivery reveals an adjusted odds ratio of 1.7 to 4.0 for prepregnancy obesity. Dr. Siega-Riz pointed out that odds ratios should not be used because they overestimate the risk. In one study, the sample was restricted to low-risk, term pregnancies with a spontaneous onset of labor. Obese women had a higher prevalence (57 percent) of use of oxytocin to augment labor than did normal-weight women (40 percent). In addition, the study showed an increase in cesarean delivery rates in obese women (11 percent) compared with normal-weight women (6 percent).

We know that the prevalence of overweight and obesity is increasing among women of childbearing age; that generally women gain weight outside of their prepregnancy-specific, IOM-recommended range; that a higher cesarean delivery rate is reported along with an increased risk of perinatal mortality, and that weight gain can contribute to postpartum weight retention and childhood obesity. What we need to know is whether the association between maternal prepregnancy weight status and cesarean delivery is accurate. If so, why are overweight and obese women more likely to have a cesarean delivery? The only way to answer these questions is to conduct an extensive medical

chart review. Another question is whether the intrapartum experience of overweight and obese women is different from that of normal-weight women.

A recent study restricted multivariable analyses to women who underwent a trial of labor and excluded 29 women with an elective cesarean delivery. The study computed unadjusted and adjusted risk ratios and 95-percent confidence intervals for the risk of an emergent cesarean delivery. The final sample for the multivariable analysis was 612 women (297 normal weight, 115 overweight, and 200 obese). Obese women had a 50-percent increased relative risk of cesarean delivery. The difference between overweight and obese occurs in cesarean sections due to shoulder dystocia. Therefore, overweight and obese women may have an increased risk for an emergent cesarean delivery compared with normal-weight women. The risk is not as high as those reported in previous studies that used odds ratios instead of relative risk due to the prevalence of cesarean sections. The risk is highest in obese women when the cesarean is based on an indication of dystocia. Providers waited longer than the 2-hour minimum for arrest of dilation for first-stage cesareans due to dystocia.

Labor progression is another interesting topic. Current definitions of labor protraction and arrest are based on Friedman's work in the 1950s. Despite dramatic changes in the management of labor and delivery as well as the patient population over the past 50 years, clinicians continue to refer to Friedman's work. Changes in obstetric practice include obstetric interventions such as induction of labor, which increased from 9 percent in 1989 to 20.6 percent in 2002, and augmentation of labor, which increased from 10.9 percent in 1989 to 17.3 percent in 2002. Other changes occurred in obstetric procedures, such as fetal monitoring and ultrasound, and in birth outcomes, such as cesarean delivery, which increased from 20.7 percent in 1996 to 26.1 percent in 2002. Changes in the patient population include increases in both maternal prepregnancy weight and gestational weight gain, which correspond to increases in fetal size and infant birth weight. A 1999 study shows that labor appears to proceed more slowly than originally suspected, especially during the active phase.

The PIN study (1995 to 2002) examined the median duration of time elapsed in labor for each centimeter of cervical dilation for term, nulliparous women, according to their prepregnancy BMI. The study found that, compared with normal-weight women, overweight and obese women have a significantly longer median duration of labor from 4 to 10 centimeters. The prolonged labor of overweight women was concentrated around 4 to 6 centimeters, whereas the prolonged labor of obese women was due to a slower labor progression before 7 centimeters.

The PIN study data show that, compared with normal-weight women, obese women have a moderately increased risk for an emergent cesarean delivery, overweight women have a weak increased risk for an emergent cesarean delivery, both overweight and obese women have a slower labor progression before 6 centimeters, and maternal weight gain and fetal size do not appear to explain this association.

The literature provides possible explanations for these occurrences. One explanation is that dystocia due to an increased deposition of soft tissue in the maternal pelvis might be a factor. The size of the infant might be a reason for concern, and inadequate uterine contractions and nonclinical factors might offer other explanations. A large patient dropout due to a first-stage cesarean delivery may have influenced some of the PIN study results. To assess whether the trends persisted among vaginal deliveries, the study fitted the same models but excluded women who delivered by cesarean section. Normal-weight and overweight women had a similar median duration of labor from 4 to 10 centimeters, but all other trends persisted in the data.

In 1980, the attributable risk factor associated with obesity for cesarean section was 3.9 percent; by 1999, it increased to 11.6 percent. The risk for cesarean section associated with GDM changed significantly from 12.8 percent in 1980 to 29.6 percent in 1999. During the same time period, the risk for cesarean section increased from 6.5 to 19.1 percent for large gestational age infants, and from 16.2 to 25.7 percent for macrosomia. Therefore, we can predict that these problems will become more prevalent if obesity and overweight trends continue.

The period of postpartum health has not been well studied. Overweight and obese women tend to retain and even gain weight in the postpartum period. Overweight and obese women also are less likely than normal-weight women to breastfeed. In addition, they are at increased risk for postpartum anemia. One study found that women with a BMI of 28 had about 1.8 times the postpartum risk of anemia and women with a BMI of 36 had approximately 2.8 times the risk as that of women with a BMI of 20.

Maternal obesity and the nutritional status of women should be approached from a life cycle perspective. By the time a woman becomes pregnant, her weight status already has implications for the pregnancy, and what goes on during the pregnancy (e.g., GDM, hypertension) can cause some long-term implications for infant health status. If maternal obesity affects lactation, that situation also could affect the infant's health status.

Because obesity is a multifactorial disease, it calls for a multidisciplinary approach. A full understanding of obesity is needed if it is to be treated. Given the lack of success in the treatment of obesity among adults, it is important to learn about ways to prevent obesity as early in life as possible. Women, infants, and young children are most vulnerable to nutritional influences and, therefore, are the most important targets for preventive efforts. Multidisciplinary teams must be created to handle this problem. The field of maternal nutrition and obesity should have the highest priority.

## **Discussion**

The issues raised by Dr. Siega-Riz's presentation included the following:

- Dr. van Dyck remarked on the increasing rate of obesity and its possible contributions to infant mortality. Is there a way to tie these two things together as analysis is performed to determine contributing or causal factors? Mr. Rothwell responded that

BMI information is not currently on birth certificates, but when it is, the quality of the data will be a concern. PRAMS has much more detailed information. Dr. Eve M. Lackritz from CDC reported on a recent analysis of the contribution of obesity to cesarean section. She mentioned that PRAMS data are useful because they cover a large number of States. The attributable risk is about 26 percent of cesarean sections. Dr. Siega-Riz added that one-half of preterm births at the North Carolina health centers are medically induced and that obese women are more likely to have medically induced cesarean sections. This trend should be examined nationwide.

- Dr. Roberts asked whether any data suggest the sequelae of obesity extending from one pregnancy to another. Dr. Siega-Riz responded that she has not seen any data that have followed women progressively over time, but an ongoing study shows that the incidence of overweight and obesity due to postpartum weight retention is substantial. Because women cannot lose weight in the postpartum period, they start the next pregnancy at a higher risk because they are at a higher weight. The problem is exacerbated over time.
- In response to a question from Dr. Mahan, Dr. Siega-Riz responded that the women who were studied did not have higher rates of prenatal anemia. Dr. Mahan pointed out that, regarding drug doses, perhaps the standard recommended iron dose for an obese person is different from that for an overweight person. He also referred to a recent article that proposes that something in the baby's brain triggers labor and that a weight differential might be of importance in that regard. Dr. Siega-Riz added that the drugs used to augment labor are not necessarily based on body weight.
- Dr. Roberts expressed surprise at the shorter second stage of labor for obese women. Dr. Mahan mentioned that more cesarean sections are performed in the first stage of labor. Even with modern ultrasound, judging baby size can be difficult in an obese woman.
- Dr. Randolph asked about MCHB's response as it relates to the need for a more comprehensive approach to women's health, especially regarding prevention and effective interventions for obesity. Dr. Collins mentioned that Dr. Randolph's concern would be addressed at the next morning's session. Dr. Koontz introduced Ms. Lisa King from the Bureau, who explained a small demonstration grant (April 16 deadline) on decreasing the risk of overweight and obesity in women. MCHB will fund up to three or four grants up to \$150,000 per year for up to 3 years.
- Dr. de Leon Siantz mentioned the need for a family approach to the issue of obesity in the Hispanic population.
- In response to a question from Dr. Robert E. Sapien about postpartum depression, Dr. Siega-Riz noted that some data seem to indicate that overweight women have more perinatal and postpartum depression.

- Dr. Moore noted that in her patient population, once overweight or obese women are diagnosed with GDM, given nutritional counseling, and started on a diet, their weights begin to fall. She asked whether any studies call for putting all pregnant patients on a low-carbohydrate diet. Dr. Siega-Riz said no but stated that the larger issue involves counseling pregnant and postpartum women about nutrition and physical activity. A multidisciplinary team should provide prenatal care.
- Dr. Koontz referred to the slide on BMI and cesarean section and the significant difference related to dystocia. She asked how much of the dystocia was related to fetal size rather than maternal soft tissue. Dr. Siega-Riz responded that the risk assessment did not change when the models were run with both total gestational weight gain and separating out net weight gain and size of the infant.
- Dr. Collins pointed out that the data show that obese women are more likely to have macrosomic or large-for-gestational-age (LGA) infants. Are there data related to LGA infants that show they are more likely to become obese children, obese young adults, and obese adults? Dr. Siega-Riz responded that pieces of those data show that both ends of the weight spectrum can lead to adult obesity.
- Dr. Moore asked about the increased incidence of birth defects as related to fertility or ovulation issues. Dr. Siega-Riz responded that she is not sure whether the subject is under study.

## **FETAL AND INFANT FATAL AND NONFATAL INJURIES—PANEL**

### **U.S. Infant Injury Mortality**

*Mary D. Overpeck, Dr.P.H., Epidemiologist, Office of Data and Information Management, MCHB, HRSA*

Dr. Mary D. Overpeck’s presentation focused on what we know about infant injury deaths, how the information is obtained, and what we need to know to support effective prevention. The experts use two definitions of injury: (1) injury caused by acute exposure to energy (e.g., heat, electricity) or the kinetic energy of a crash, fall, or bullet, and (2) injury caused by the sudden absence of essentials (e.g., heat or oxygen) as in the case of drowning. The rate of infant injuries over the past 10 years shows an increase during the past 3 years. The conversion between International Classification of Disease (ICD)-9 and ICD-10 occurred in 1999; however, the conversion did not make a difference in the injury rate. Dr. Overpeck pointed out that the studies included in the meeting binder are all based on the ICD-9 nomenclature and classifications.

The terms “natural” and “traumatic” are used on death certificates. Natural deaths are caused by congenital conditions; conditions related to short or complicated gestation, labor, and delivery; and SIDS. A separate section on the death certificate concerns traumatic (due to injury) deaths. From 1999 to 2001, 95 percent of deaths among infants were due to natural causes, and only 5 percent resulted from injury, representing approximately 1,300 deaths of infants in any single year. In contrast, 44 percent of deaths

among children aged 1 to 4 years resulted from trauma, representing slightly more than 500 deaths per year. Therefore, the injury burden is greater for infants than for older children.

The only national source of injury information for fatalities is the death certificate. For nonfatal injuries, the sources are medical treatment records from national surveys on hospitalizations, emergency departments, and physicians' office surveys. All of this information can be viewed on the CDC Web site, including data from the Consumer Product Safety Commission. NCHS conducts personal surveys on the national level through either in-person visits or telephone surveys.

Injury classifications from death certificates include the underlying cause of death, the manner of death, and injury events coded to the external cause of death classification system, historically called "e-codes." For infants, the leading cause of death based on the nature of death information from death certificates is suffocation, whereas very few suffocation deaths occur among children aged 1 to 4 years. Transport-related deaths are fairly comparable between the two groups. Infants are far more likely than children aged 1 to 4 years to be killed by what is termed assault, NOS (not otherwise specified), meaning that no other information is available about the means of assault. Likewise, abuse and neglect are more likely to occur in infants than in older children, with very little available information about the mechanism of abuse or neglect. If combined, the rates for assault and abuse and neglect are higher than the rates for transport-related deaths. Finally, the higher rate of drowning among older children probably reflects their increasing mobility.

Information about nonfatal injuries comes primarily from emergency department sources. About 1,000 emergency department visits occur for each fatality for infants. The rate of nonfatal injuries for infants in transport-related accidents is extremely high (70 per 1,000), probably because of better ascertainment in this category of injuries. Rates of nonfatal injuries for older children due to falls or being struck by or running into something are relatively high, probably because of the mobility factor. Rates of fire and burn injuries are comparable for infants and older children, and rates of ingestion of foreign bodies (either food or small objects) are higher in older children, probably because of access.

Almost all injury data are presented as either intentional or unintentional. Examples of underlying cause of death are drowning, suffocation, blunt force, motor vehicle crashes, poisoning, firearms, and exposures to cold or heat. Mixing of information occurs in the underlying cause categories. At the same time, any of the causes may be classified as intentional, unintentional, or of undetermined intent. A determination of cause and intent is based on State requirements for the examination of unexpected deaths, and it varies from State to State. If there is no attending physician at the time of death, then a medical examiner or coroner system is used, which results in a great deal of variability. NCHS has produced a *Handbook for Completion of Death Certificates*, which is available at the CDC Web site. In addition, the National Association of Medical Examiners has issued a handbook on recommended methods for completion of death certificates.

Cause and intent in injury deaths differ from noninjury or natural deaths in that the nature of the death may not be included in the e-codes; the biological issues surrounding the cause of death are not known. However, knowledge of both nature and cause are needed. Besides that issue, intent is determined separately from underlying cause. Determining injury intent on death certificates includes a number of possibilities: unintentional (accidental), intentional (homicide or suicide), undetermined manner or intent, and pending investigation.

The leading causes of infant injury deaths by intent can be divided into unintentional and intentional/suspicious. From 1999 to 2001, more than twice as many unintentional injury deaths (an annual average of 901) occurred as did intentional/suspicious deaths (an annual average of 405). Suffocation/strangulation in bed represents about 30 percent of unintentional deaths, but it is unknown whether such deaths occurred in the infant's crib or the parent's bed; the death certificate does not include this information. Twelve percent of all unintentional injury deaths result from suffocation, NOS; 8 percent are due to obstructive inhalation/suffocation; and 6 percent are from other suffocation. Nearly 20 percent of intentional or suspicious deaths are classified as suffocation. Transportation represents about 20 percent of unintentional deaths, and drowning, fire/burn, and poisoning represent about 15 percent of unintentional deaths. Among intentional or suspicious deaths, about one-third are from child abuse or neglect. In some cases, the mechanism that might have led to the death is known, but specific information is lacking on the death certificate. Nearly one-third of intentional or suspicious deaths are classified as assaults, NOS. Shaken baby syndrome is a classic example of the problem with intent and, therefore, a problem with prevention.

The majority of infant injury deaths occur by the end of the fourth month of life; therefore, prevention efforts must be undertaken early. Examination of homicide cases for which a birth certificate was attached in the linked birth/death files showed that 95 percent of the deaths classified as homicides did not have a clinician present at the delivery. A similar investigation has not been undertaken for unintentional deaths. Sources for the risk factors for infant injury deaths are linked birth and death certificates. The risk factors identified from the birth certificates include maternal education of fewer than 12 years, maternal age of less than 20 years, no prenatal care, Native American ethnicity, and at least two previous pregnancies. Risk factors for unintentional injury deaths vary by cause:

- Mechanical suffocation (found in bed or cradle, young maternal age, and at least two prior pregnancies)
- Choking (birth weight below 1,500 grams or birth weight between 1,500 and 2,400 grams)
- Motor vehicle crashes (being Native American)

The factors for homicide and undetermined or suspicious intent are very similar. Half of the deaths occur by the fourth month of life, and two-thirds occur by the sixth month.

Five percent occur by the end of the first week of life. Another risk factor is being the second or later child of a mother younger than age 17; such a child is 10 times more likely to be killed than a child of a mother aged 24 or older. A second-born or later child of a mother who delivered between age 17 and 19 has a sixfold elevated risk. Other homicide risk factors include no prenatal care and a maternal education of fewer than 12 years.

No information on birth or death certificates describes the circumstances of death. There is no way to determine the nature of deaths for many classified as child abuse or neglect or intentional assaults. In addition, birth and death certificates supply no information on the circumstances to target specific interventions. Other circumstances shown by State record reviews include the following:

- Native American motor vehicle deaths are often due to the use of pickup trucks as the primary family vehicle.
- Males are more likely to be perpetrators in homicides after the infant's first week of life.
- U.S. child abuse deaths are underestimated by more than 60 percent.
- Many deaths classified as SIDS or accidental suffocation are probably child abuse or homicides.

Over the years, the classification of SIDS occurred after a thorough investigation revealed no cause of death. A more specific diagnosis has been applied recently. A diagnostic shift has occurred from SIDS to a nonspecific ICD called "other sudden death, cause unknown." More cases that were previously assigned to SIDS are being reassigned to trauma. "Sudden unexpected deaths" is the underlying definition for both SIDS and trauma. SIDS has shown a continued decrease since the beginning of the *Back to Sleep* campaign. The increase in infant deaths may be due to a diagnostic shift.

Conclusions drawn from the presented data are that (1) infant and early childhood injury deaths are related to developmental stages, (2) risk factors guiding prevention should be specific to the cause and the circumstances, (3) additional review of the circumstances surrounding infant and child deaths is needed, and (4) a better classification alternative is needed for infant and early childhood deaths.

### **Injuries During Pregnancy: Understanding and Tracking the Hidden Epidemic**

*Hank Weiss, Ph.D., M.P.H., Director and Associate Professor, Center for Injury Research and Control, University of Pittsburgh*

Dr. Hank Weiss presented information about injuries during pregnancy, which he referred to as a hidden, overlooked, and misunderstood part of the child injury problem. The intersection of the study of injuries with maternal and fetal health has received very little attention. Other health sciences that study maternal and fetal exposure to toxic substances, radiologic agents, and infectious agents pay a great deal of attention to that

critical period of human development during pregnancy, but the injury field has not. Consequently, the injury field lags far behind the other prenatal exposures in research, surveillance, and prevention. Inattentiveness by professionals in both injury prevention and child health continues even as injuries have become the leading cause of maternal death during pregnancy; estimates suggest that as many as 6 to 8 percent of all pregnancies involve an emergency department visit for an injury.

Dr. Weiss presented an introduction to the epidemiology of maternal injury, the nature and importance of fetal and infant injuries, the deficiencies and barriers of existing data, and ways to improve surveillance of pregnancy-related injury and outcomes.

The injury severity pyramid addresses maternal injury as the basis of the threat to fetuses. At the top of the pyramid are maternal injury deaths, followed by maternal injury hospitalizations, and maternal injury emergency department visits. The leading causes of death in the United States for women of childbearing age (ages 15 to 34) are unintentional injury, malignant neoplasms, homicide, heart disease, and suicide. In the United States, more pregnant women die from intentional and unintentional injury than from all maternal mortality-related conditions combined. Data for the middle level of the injury severity pyramid are obtained from hospital discharges following pregnancy-associated injury. Two studies that linked hospitalizations with birth certificates demonstrated pregnancy-related information. Motor vehicle crashes are the leading cause of maternal hospitalization for injury, followed by falls and then poisoning. The leading cause of emergency department visits is motor vehicle crashes.

Birth-related threats include fetal death, prematurity, LBW, and obstetric complications, including placental injury, uterine rupture, amniotic rupture, and trauma-related elective and therapeutic abortion. Threats to infants that happen *in utero* but have their effect later include neonatal death and direct and indirect neural and other organ damage. None of these conditions is an injury in the classic sense; they are the result of injury.

What can vital statistics tell us about fetal injury deaths? The information is hidden because of the ICD. In ICD-9, for a fetus or newborn affected by maternal conditions classifiable to injury-related diagnoses, the classification was 760.5. However, the e-code, which describes mechanism and intent, is to be used as the primary code if and only if the morbid condition is classifiable to chapter 17, or an injury diagnosis. Unfortunately, this code is not in chapter 17. Because these codes are not in the range of diagnosis codes used to define injuries, none of the injury reports compiled by CDC, the National Institute for Occupational Safety and Health, or State health departments includes these conditions in injury reports. These conditions are hidden and sometimes ignored. In ICD-10, fetuses do not seem to be accounted for. The result of the coding and classification issues is that none of the important national injury data sources and publications mentions maternal fetal injury. Because the numbers are not available, the public health agendas at the national and State levels do not address the issue. The data remain hidden, and little preventive action has been taken.

Most, but not all, States collect data on fetal deaths occurring after 20 weeks of gestation. The fetal death registries include a merger of a death certificate and some birth certificate-related information about the pregnancy and pregnancy-related complications. Because the deaths are coded by ICD, there are limitations, but there is a space for narratives. A study of 256 fetal death certificates with written cause narratives showed that the leading cause of traumatic fetal deaths in selected States for 1995 to 1997 was motor vehicle crashes (82 percent). When the data are extrapolated to the country as a whole, making adjustments for missing data, motor vehicle fetal deaths far outnumber many other causes of fatal childhood injury that receive much more attention in the media and from public health practitioners.

Because of the unique situation of the developing fetus, there are many more fetal threats and adverse outcomes to be concerned about other than mortality. Limited studies have pursued this research. Fetuses are at unique risk for a variety of adverse outcomes from maternal injury, but research is needed to quantify these outcomes and the long-term risks.

The leading cause of maternal fetal death is motor vehicle injuries, as is the leading cause of hospitalizations and emergency department visits. A motor vehicle crash with a pregnant woman can be simulated using computer software. Only two population-based studies have examined motor vehicle crashes and birth outcomes. The Utah study showed that 3 percent of births were linked to a police-reported motor vehicle crash during pregnancy in which a pregnant woman was driving. This number extrapolates to about 160,000 exposures per year in the United States, which is 7 times the number of infants reported in crashes by the National Highway Traffic Safety Administration. Fetuses take on the risk of their mothers who are driving. Pregnant women not wearing seatbelts during a crash were 1.3 times more likely to have LBW babies and nearly 3 times more likely to experience fetal death compared with pregnant women who used seatbelts. Furthermore, the total miles driven by women of reproductive age show a major increase in exposure over the past 30 years.

Dr. Weiss summarized his presentation by saying that motor vehicle injury is a surprisingly common occurrence during pregnancy. Motor vehicle trauma to pregnant women has probably increased substantially over the past 20 years. Major critical gaps in the reporting and surveillance of pregnancy-related injury hide the problem. Fetal injury mortality represents a large proportion of childhood injury mortality. We are just beginning to understand and measure the adverse birth outcomes due to trauma. No one has measured the long-term impact of nonfatal fetal injury among children.

Dr. Weiss made the following recommendations:

- Incorporate maternal/fetal injury in national health prevention and research objectives.
- Change ICD coding guidelines to encourage the coding of the external cause of maternal injury in vital records.

- Include maternal injuries in an expanded definition of maternal mortality.
- Incorporate pregnancy status and fetal outcomes in crash and other injury surveillance systems.

Other recommendations include the following:

- States should continuously link birth data to hospital discharge data to create a maternal injury surveillance system.
- CDC should incorporate injury experience in pregnancy risk assessment research (PRAMS).
- CDC should improve maternal injury details in its birth defects surveillance system.
- NICHD should examine ways to study development outcomes in children exposed to *in utero* trauma.

Dr. Weiss offered the following recommendations regarding motor vehicles:

- All States should continuously link birth and crash data.
- The Federal Highway Administration should add pregnancy status to its driver behavior surveys so that maternal behaviors regarding driving can be better understood.
- NHTSA should mandate pregnant crash dummy tests to understand crash dynamics on women and fetuses.
- States should enhance education and primary belt laws to improve the use and proper use of seatbelts by pregnant women.
- International seatbelt exemptions for pregnant women should be removed.
- Research should explore ways to enhance occupant protection and reduce the risks of maternal driving, motor vehicle travel, and crashes.

Fetal injury should be added to the list of public health concerns, and fetal injury prevention should be added to the list of palliative programs. Injury, trauma, and their sequelae should be considered as important preventable causes of fetal and neonatal loss, a potential teratogen, and an important cause of acquired birth defects that unfortunately remains hidden. If we do not count fetal injuries, we cannot measure them. If we do not measure them, the problem will continue to be hidden and ignored.

## **Preventing Injuries and Violence: Infants and Young Children**

*Stephanie Bryn, M.P.H., Director of Injury and Violence Prevention Programs, Division of Child, Adolescent, and Family Health, MCHB, HRSA*

Ms. Stephanie Bryn began her presentation by referring to a chart that depicts the top seven leading causes of death for Americans. Unintentional injury is the seventh leading cause of death for infants and the leading cause of death for children aged 1 through 4. The Healthy People 2010 objectives include reducing deaths caused by motor vehicle injury to children aged 14 and younger, reducing residential fire deaths for children aged 4 and younger, and reducing drownings for children aged 4 and younger. Healthy People also is working on reducing homicides for children younger than 1 year of age and for children aged 1 through 4 years, as well as reducing maltreatment of children aged 18 and younger. Reducing maltreatment fatalities for children aged 18 and younger is another Healthy People objective, as is increasing the percentage of healthy full-term infants who are put on their backs to sleep.

MCHB requires its agencies and programs to report on the rate of deaths of children aged 14 and younger caused by motor vehicle crashes per 100,000 children. Pedestrian-related and bicycle-related deaths that involve motor vehicles are included in this national performance measure. Each maternal and child health (MCH) program writes between 7 and 11 State performance measures based on its individual needs assessment and priority needs. The State-written objectives reveal that 7 States address child deaths due to injuries, 13 States address child abuse, and 10 States address morbidity due to injuries.

The “three Es approach” to injury prevention includes (1) educating and persuading to promote behavior changes, (2) making environmental and engineering modifications to create safer surroundings, and (3) enforcing legal requirements and prohibitions to reduce risk. Ms. Bryn gave specific information about the three Es approach:

- **Education**—Supervision of children and infants is crucial to preventing suffocation (food, objects, cribs, layovers during co-sleeping), drowning (toilets, buckets, bathtub seats, pool covers, personal flotation devices, cardiopulmonary resuscitation), motor vehicle crashes (safety seat use and placement), fire/burn (smoke alarms, flame-retardant clothing), child abuse (home visiting services, shaken baby syndrome, firearm storage), falls (infant and child development, railings, gates, window bars), and poisoning (storage, child-resistant packaging).
- **Environment/Engineering**—Actions to be taken are related to suffocation (drawstrings on clothing, blind cords without loop ends, cribs, railings, toys), drowning (pool fencing, gates, pool alarms, and pool covers), fire/burn (smoke alarms, water temperature, child-resistant lights), falls (playground surfaces, baby walkers, window guards, safety gates, handrails), and poisoning (infant and child-resistant packaging, safe storage).
- **Enforcement**—Areas of concern include motor vehicle crashes (infant and child safety seats and placement, tricycle and bicycle helmet use), suffocation (4-inch

width between crib slats), drowning (perimeter fencing), fire/burn (smoke alarm and sprinkler systems, Flammable Fabrics Act), child abuse (reporting laws), and poisoning (Poison Prevention Packaging Act).

Injury and violence prevention is interdisciplinary. This endeavor involves the following people: MCH and safety professionals, mental health professionals, safety engineers, psychologists, educators, law enforcement and criminal justice professionals, epidemiologists, biostatisticians, policy analysts, community officials, and families. Education of health and safety professionals includes instruction in methods to incorporate injury and violence prevention into patient assessment, education, treatment, and disposition as well as use of case studies of injury and violence prevention intervention to demonstrate what works. In the home and community settings, it is important to identify potential injury hazards through the use of environmental assessments; to develop safety and awareness resources and tools to educate individual, families, caregivers, and professionals; and to instruct parents and caregivers on home hazards and protective behaviors and devices.

Ms. Bryn concluded by reiterating the importance of beginning early with primary prevention messages. Combining the three Es is the most effective way to prevent injuries and violence toward infants and children; education alone is not effective. A variety of players should be involved in the effort. Findings must be evaluated and disseminated. Much more information on the circumstances of death is needed from fetal and infant mortality review teams and child death review teams in States and communities.

Resources to be used in the prevention effort include the Children's Safety Network, the MCH National Child Death Review Resource Center, the MCH National Fetal and Infant Mortality Review Resource Center, the CDC National Center for Injury Prevention and Control, the Consumer Product Safety Commission, and the American Academy of Pediatrics.

## **Discussion**

The following issues were raised during a discussion of the panel's presentation:

- Dr. Miller asked for clarification regarding Dr. Weiss' motor vehicle recommendations regarding pregnant women riding in and driving cars. Dr. Weiss reiterated that reducing travel by car should be considered. He noted that women are not restricted from smoking or drinking during pregnancy, but they are given information about reducing exposure.
- Dr. Moore asked Dr. Weiss to comment on air bags in motor vehicle crashes with pregnant women. Dr. Weiss pointed to fairly good biomechanical evidence that pregnant women are better off with air bags than without them. Additional design constraints should be considered regarding pregnant occupants interacting with air bags.

- Dr. Collins asked Dr. Overpeck about racial disparities in infant deaths due to injuries. Dr. Overpeck referred to the paper on homicide, which noted that more African American women have earlier teen pregnancies; therefore, a greater preponderance of homicide is related to early maternal age. However, when controlled for marital status and other factors, the racial disparity was reduced, and differences for racial disparity disappeared when controlled for age. White women who married early were at higher risk for homicide, possibly because of the lack of a social support system.
- Dr. Sapien asked Dr. Overpeck to comment on infant homicides when the male in the home is not the biological father. Dr. Overpeck referred to information from the child fatality review teams, not birth certificates, because information on the father was missing in 60 percent of homicide cases. The State review teams found that the male caretakers were fathers, uncles, brothers, grandfathers, and boyfriends—all of whom did not know how to stop babies from crying. Home nurse visitation programs follow high-risk families and have been shown to reduce child abuse, protect the mother, and delay the period between conceptions. A community-based study in New York City found that children living in a home in which the male is not the biological father are four times more likely to die from homicide, but this study may not be generalizable.

**WEDNESDAY, MARCH 31, 2004**

**COMMITTEE DISCUSSION—LBWCC RESEARCH INVENTORY: GAPS AND RECOMMENDATIONS**

Dr. van Dyck introduced Dr. Duane Alexander, Director of NICHD and co-chair of LBWCC. The workgroup leaders reported on the gaps and recommendations identified by their groups during the small-group breakout sessions on the LBWCC research inventory.

**Preterm Birth Prevention**

*Workgroup Leader: James W. Collins, Jr., M.D., M.P.H.*

Dr. Collins indicated that the workgroup did not prioritize the topics it submitted. He then presented the workgroup's suggestions for additions to the research agenda:

- Emphasize the entire life course perspective when looking at risk factors for preterm birth, including the disparity in occurrence.
- Study birth interval or interpregnancy interval, with population-based information.
- Study stress in general and specifically chronic stress from exposure to racism as risk factors for poor pregnancy outcome (i.e., preterm delivery), particularly among African Americans.
- Study the racial disparity in middle-risk and low-risk groups instead of just high-risk groups; try to better control for confounders, and look at the effect of race in the group of women who are low risk by definition.
- Perform a cost-benefit analysis to determine the cost of racial disparity and the cost-effectiveness of prevention.
- Study protective factors for pregnancy outcome among immigrants, especially among first-generation immigrants.
- Study the effect of resiliency among high-risk women or women who live in high-risk areas; look at the impact of protective factors.
- Study preterm delivery, specifically spontaneous preterm delivery versus medically indicated preterm delivery.
- Conduct research on depression, particularly as it relates to obesity and its negative impacts on pregnancy outcome.

- Study other behavioral changes, including their effects during the postpartum period.
- Examine the role of the team (including use of community health workers) in relation to prevention of depression.

Interventions that merit further investigation are as follows:

- Observe international experiences, in particular those of Canada and France, to determine positive interventions.
- Study strategies that focus on depression and behavioral changes. For instance, examine cultural practices and health beliefs, especially regarding prevention of depression and promotion of healthy weight patterns.
- Focus on women and making better use of community members who have a commitment to and expertise in empowering women during and after pregnancy, using a life course model.
- Examine practices of primary care providers that pertain to screening for violence and establishing a mechanism to put people in contact with appropriate services when risk factors are identified.
- Dovetail pregnancy outcome into the obesity campaign, including attention to subsequent pregnancies.

## **Discussion**

Dr. Collins's presentation elicited the following comments and suggestions:

- Dr. Alexander asked if the workgroup discussed the National Children's Study (NCS) and its targeting of issues related to infant mortality, LBW, and preterm delivery. Dr. Roberts commented that NCS should consider subsequent pregnancies, with an emphasis on the postpartum and interconceptional periods. Dr. Alexander stated that NCS will study subsequent pregnancies and pregnancy intervals. Part of the cohort might be enrolled prepregnancy to include information about planned pregnancies, unplanned pregnancies, difficulty in conceiving, and assisted reproductive therapy.
- Dr. Hannemann remarked that as NCS results become available or show some relation to LBW or preterm birth, information should be released as quickly as possible to the agencies conducting research on the topic. Dr. Alexander stated that once the full cohort is assembled, the data will be analyzed quickly and the results of the analysis will be released to investigators and the public.
- Dr. Susan F. Meikle added that information about the design of the study should be made available and knowledge should be compiled in one place before recruitment occurs. Dr. Alexander stated that the draft version of the protocol will be

disseminated for public comment and suggestions as the draft goes through various iterations of development.

- Dr. Collins pointed out that the NCS data set might help determine the relation of early-life factors, experiences, and exposures to pregnancy outcome. Dr. de Leon Siantz pointed out that the workgroup emphasized the pregnancy period as just one period in the overall health of the woman. Dr. Alexander added that one advantage of NCS, because of the intent and design, is its ability to gather information about the health history and environmental exposure history of mothers.

### **Low Birth Weight Prevention**

*Workgroup Leader: Robert E. Hannemann, M.D.*

Dr. Hannemann explained that the workgroup on LBW prevention looked at the critical gaps in the research agenda, then prioritized them as follows:

- Concentrate on substance abuse research, including prescribed medications, illegal drugs, tobacco, and alcohol. Study the relationship between substance abuse and LBW, the availability and effectiveness of substance abuse cessation programs, and dissemination of the messages to the public, in particular, the high-risk group.
- Consider the role of the Food and Drug Administration in LBW prevention and in relation to nutrition in general, nutritional additives, and obesity. The National Institutes of Health (NIH), CDC, and the Agency for Healthcare Research and Quality might study the role of obesity in congenital anomalies. How well is obesity research being translated into practice? What is the relationship of obesity and infertility? Do surgical treatments for obesity affect LBW?
- Study the relationship of stress to LBW, with respect to work environment, neighborhood, minority status, and policies regarding disability and coverage during and after pregnancy.
- Study the relationship of procedures for cervical dysplasia in teens to pregnancy outcome. Other obstetrical practice topics to be studied include induction of labor, cesarean delivery, effect of the medical malpractice liability climate, and public dissemination of information about particular procedures.
- Research the topic of initiation of labor, especially emotional and behavioral factors. Build bridges between new areas of cellular science and obstetrics.
- Examine the etiology of preeclampsia and its relationship to LBW.
- Study the relationship of adolescent pregnancy to LBW, including strategies for prevention and reduction, and the education of teen mothers on infant safety.

- Study the effect of environmental issues on LBW. Report up-to-date information from NCS as soon as it becomes available.

The workgroup also made the following general suggestions:

- Investigate the programs and practices of those countries that have been successful in reducing LBW rates.
- Improve the rapid transfer of research findings to the public and to health care providers.
- Solicit outside experts to review and make recommendations about the research inventory and the use of newer analytic models, including organizations such as IOM, the American College of Obstetricians and Gynecologists (ACOG), the American Academy of Pediatrics, and the Academy of Engineering.

### **Preterm or LBW Infants and Their Sequelae SIDS Prevention**

*Workgroup Leader: Linda A. Randolph, M.D., M.P.H.*

Dr. Randolph praised the Department for the amount of research it oversees and its attempts to interrelate the research across agencies. This workgroup did not prioritize the topics it submitted. Its recommendations for additions to the research agenda for preterm or LBW infants and their sequelae are as follows:

- Focus research on ethics and on making difficult decisions. Should we be doing all that we know how to do? At what cost (both dollar cost and human cost)? What about patient/family satisfaction?
- Conduct research on the methodologies of hospital ethics committees, their decision-making processes, and the role of families in those processes.
- Closely observe international comparisons in terms of positive outcomes both on a population and a systems basis. Include State comparisons. Identify the factors and interventions that produce the better outcomes.
- Study public information and cross-cultural messages, in particular when the evidence points to positive outcomes. How are the messages defined in a cultural context, how are they communicated, and how are they interpreted when they are received?
- Study the interconceptional period and interventions for followup of women at high risk for a subsequent LBW infant. How can we maintain these women in the system?
- Study the impact of early intervention systems that blend the health (medical home) and education (ready to learn) infrastructures. Examine influences on the access that

newborn intensive care unit graduates have to early intervention programs (e.g., States' policies).

- Consider the research infrastructures of the U.S. Department of Education and the U.S. Department of Agriculture and the idea of collaboration with HHS. Obtain data across jurisdictions and agencies.
- Look at privately funded research (e.g., the Robert Wood Johnson Infant Health and Development Study) that has served as a springboard for HHS-supported research.
- Study the systems issues and action research regarding proven or highly potential interventions for preterm and LBW infants in the foster care population.

Dr. Randolph commented that the workgroup wondered about the impact of HIV relative to the research agenda.

In regard to SIDS, the workgroup made the following suggestions, observations, and comments:

- Address the need for clarity of definition regarding SIDS.
- Sleep research is very important and should include a participatory research focus in which families are involved in the process. (The workgroup observed that the magnitude of the research on topics such as sleep cannot be determined from examining the inventory.)
- Some neonatologists have questioned whether sleeping on the back shows a cause-and-effect relationship or an association or proxy. Certain communities (e.g., African American communities) show resistance to implementing recommendations. The underlying relationships, as well as cultural messages, should be identified.
- Study the effectiveness of child fatality review teams. Consider the extreme variability of the medical examiner/coroner system across the country and the implications of that variability related to attempts to intervene regarding child fatality reviews.
- Examine the extent to which childcare providers receive the Back to Sleep message and then implement it.

## **Discussion**

Dr. Randolph's presentation prompted the following comments:

- Dr. Alexander commented on a recent NICHD conference on "research at the boundaries of viability," that is, research on extremely LBW infants, the advisability of salvaging these infants, the implications of the salvage efforts for families, and the

potential impact that salvaging these infants has on the statistics. The increased rates of LBW and infant mortality could be attributable to more aggressive efforts to resuscitate basically stillborn, very tiny infants and a shift in classification from stillbirths to live births. Has our zeal to save progressively tinier babies caused a rise in infant mortality and LBW and a larger cadre of babies with extreme disabilities? Dr. Alexander asked whether the workgroup or the NCHS presentation addressed this question.

- Dr. Miller responded that the workgroup addressed this question in relation to families and care providers and considered the agonizing deliberations that result. Dr. Randolph reiterated that the workgroup would like a better understanding of the decision-making process of ethics committees as they address these issues. Dr. Alexander stated that he is less concerned about the ethics committees than he is about the decision-making that takes place in delivery rooms on the part of attending physicians. Dr. Miller mentioned the lack of clarity on this issue among direct care physician providers and their fear of lawsuits. Dr. Collins pointed out that ethics committees in most hospitals handle problems after they occur, and the trend has been to err on the side of over-resuscitation. Dr. Miller mentioned the benefit of a national-level consent form on this topic.
- Dr. Hannemann referred to the medical and legal aspects of the issue. Being “a victim of one’s own success” is reflected in the public’s lack of understanding, including the issue of prematurity versus LBW. Dr. Alexander referred to raised public expectations because of enhanced resuscitation techniques and aggressive efforts that lead to negative outcomes.
- Dr. Collins added that he would like to see more parental education on the *in vitro* fertilization phenomenon.
- Dr. Roberts referred to a document produced by the ACOG committee on obstetrics in the late 1980s, which addresses infant care at the cusp of viability. The committee recommended the development of prospective policies, including the family’s input. The directives, which exist at ACOG, should be revisited.
- Dr. Mahan remarked that the ACOG ethics committee did a huge disservice recently when it announced its decision regarding elective cesarean delivery. We do not know how much cesarean sections contribute to the LBW rate because of errors in detection of gestational age. Dr. Alexander announced that plans are under way for a consensus development conference on cesarean section on demand or on request. The conference would pull together the available data on the risks of cesarean section, the likelihood of repeat cesarean delivery, the relation of cesarean section to premature or LBW delivery, and the validity of the reasons for elective cesarean.
- Dr. Mahan referred to the development of an evidence-based informed consent for cesarean section. When a mother dies after an elective repeat cesarean section, the

consent form most often shows that she was not informed about the increased risk of death.

- Dr. Moore pointed out that the primary elective cesarean section has been a rare occurrence; therefore, cesarean sections performed after labor or in other situations are different from primary elective cesarean sections and should not be compared with them.

Dr. Alexander thanked the SACIM members for their intensive effort in making the recommendations for the research agenda. The recommendations will be presented at the May 6 meeting of LBWCC, which will revise the recommendations in terms of supplemental material, increased emphasis, or prioritization. A revised document will be submitted to SACIM in July at its next meeting. Dr. van Dyck thanked Dr. Koontz, MCHB staff, and other LBWCC members (Drs. Meikle and Thierry) for their work on the inventory.

### **ACKNOWLEDGMENT OF RETIRING MEMBERS**

*James W. Collins, Jr., M.D., M.P.H., Chair, SACIM*

*Peter C. van Dyck, M.D., M.P.H., Associate Administrator, MCHB, HRSA; Executive Secretary, SACIM*

Drs. Collins and van Dyck presented a certificate and letter from Secretary Thompson to retiring SACIM members:

- Mr. Bruce B. Bragg (2000–2004)
- Dr. Charles S. Mahan (1995–2004)
- Dr. Linda A. Randolph (1996–2004)
- Dr. Kenneth D. Wells (2000–2004)
- Dr. E. Albert Reece (1996-2004)—in absentia

Drs. Collins and van Dyck thanked the retiring members for their years of service to SACIM.

### **COMMITTEE BUSINESS**

Dr. Collins announced that the next SACIM meeting is scheduled for July 13–14, 2004. New committee members will be present at that meeting.

Participants offered the following ideas for speakers and topics at the next meeting:

- Dr. Sapien suggested a presentation on patient safety, particularly as it involves dosing for newborns and infants.
- Dr. de Leon Siantz suggested inviting Dr. Craig Ramey of Georgetown University to speak about longitudinal methods for followup of preterm infants.

- Dr. Collins suggested inviting Dr. Michael Kramer to provide input about Canadian vital statistics and trends.
- Dr. Miller called for SACIM to stay abreast of the impact of State economic challenges on the Children's Health Insurance Program and insurance access for babies.
- Dr. Hannemann would like to hear an update on LBWCC.
- Dr. Sapien suggested a review of private foundation projects, such as those of the Robert Wood Johnson Foundation and the Rand Corporation. Dr. Roberts mentioned the March of Dimes project for women with substance abuse problems. Dr. Hannemann added that an update on the March of Dimes LBW program would be helpful.
- Dr. de Leon Siantz called for an update from the NIH Office of Minority Health on innovative projects on LBW and infant mortality.
- Dr. Sapien suggested a presentation on domestic violence.
- Dr. Moore mentioned the topic of ethical decision-making and informed consent for mothers of LBW infants.
- Dr. Collins called for a presentation on depression and its association with obesity, pregnancy, and reproductive outcome. Dr. Moore added that the focus could be on the postpartum period and risks to the infant resulting from maternal depression.
- Dr. Miller asked about a presentation on the effect of welfare reform on mothers and infants. Dr. van Dyck stated that he would check on that possibility in terms of time limits. He also called on the new members to focus on their special interest areas. The presentations are meant to pique the interest of SACIM members on issues that deserve exploration and investigation that can lead to recommendations for HHS.
- Dr. Roberts mentioned the impact of the medical malpractice crisis on decision-making in the provision of care and the ability of providers to continue to practice. Followup on that topic would be of interest to committee members.
- Dr. Moore mentioned the topic of routine followup care for new mothers related to both postpartum depression and breastfeeding support. Dr. de Leon Siantz recommended Dr. JoAnne Solchaney of the University of Washington to speak on the topic of prenatal depression.

Dr. Collins asked participants to e-mail him with other ideas in the next week or so.

The meeting was adjourned.

## PARTICIPANT LIST

### Advisory Committee Members

James W. Collins, Jr., M.D., M.P.H.,  
Chair  
Robyn J. Arrington, Jr., M.D.  
Bruce B. Bragg, M.P.H.  
Mary Lou de Leon Siantz, Ph.D., R.N.,  
FAAN  
Robert E. Hannemann, M.D.  
C. Renee Elmen Hollan, R.N.  
Charles S. Mahan, M.D.  
Ann Miller, Ph.D.  
Yvonne F. Moore, M.D.  
Linda A. Randolph, M.D., M.P.H.  
Joyce E. Roberts, C.N.M., Ph.D.  
Robert E. Sapien, M.D.  
Kenneth D. Wells, M.D., M.P.H.

### Ex-Officio Member

Cheryl Austein Casnoff, M.P.H.  
Director, State Children's Health  
Insurance Program  
Centers for Medicare & Medicaid  
Services

### Advisory Committee Staff

Peter C. van Dyck, M.D., M.P.H.  
Associate Administrator, MCHB, HRSA  
Executive Secretary, SACIM

Ann M. Koontz, C.N.M., Dr.P.H.  
Associate Director for Perinatal Policy  
Division of Perinatal Systems and  
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### Presenters

Duane Alexander, M.D.  
Director, NICHD  
Co-chair, LBWCC

Stephanie Bryn, M.P.H.  
Director of Injury and Violence  
Prevention Programs  
Division of Child, Adolescent, and  
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Associate Professor  
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Health and Department of Nutrition  
School of Public Health  
University of North Carolina at  
Chapel Hill

Stephen R. Smith  
Senior Advisor to the Administrator,  
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Peter C. van Dyck, M.D., M.P.H.  
Associate Administrator, MCHB, HRSA  
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Hank Weiss, Ph.D., M.P.H.  
Director and Associate Professor  
Center for Injury Research and Control  
University of Pittsburgh

Beverly Wright, M.S.N., M.P.H.,  
C.N.M.  
Acting Chief, Healthy Start Branch  
Division of Perinatal Systems and  
Women's Health, MCHB, HRSA

**Other Attendees**

Nancy Barnes  
Office of the Assistant Secretary for  
Planning and Evaluation

Kathy Beckley  
National Fetal and Infant Mortality  
Review

R. Lorraine Brown  
MCHB, HRSA

Amy Chanlongbutra  
HRSA Scholar

Lori Cooper  
National SIDS and Infant Death Project  
IMPACT

Nancy Davis  
Substance Abuse and Mental Health  
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Julie Gage  
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Ellen Hutchins  
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National SIDS/Infant Death Resource  
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Eve Lackritz  
Centers for Disease Control and  
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Michele Lawler  
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Henry Maingi  
Association of Maternal and Child  
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Susan F. Meikle  
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