NFIMR

BULLETIN

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Fetal and Infant Mortality Review (FIMR): A Tool Communities Can Use To Identify and Address Issues Related to Health Disparity in Infant Outcomes

INTRODUCTION

The U.S. infant mortality rate decreased to 7.2 in 1998 approaching the year 2000 goal of 7 deaths per 1,000 live births. However, infant mortality data demonstrate that rates for African Americans, American Indians, and some Hispanic subgroups are higher than this national average. Surgeon General Satcher has targeted elimination of this disparity by the year 2010. While vital statistics data document this problem, they may not always suggest strategies to address it. Community-based fetal and infant mortality review (FIMR) is an action-oriented, continuous quality-improvement process that can play a significant role in better understanding community issues associated with racial disparity and developing racially and culturally sensitive interventions. This document reviews the population-based data about disparity in infant health outcomes, defines the FIMR process, describes the potential role of this method in addressing disparities in outcome, and provides specific examples of successful, new community actions developed by culturally diverse FIMR programs.

BACKGROUND

Unique among all health outcomes, infant mortality has always been viewed as a sentinel event that serves as a measure of a community's social and economic well-being as well as its health. It is also a measure of the organization and abilities of its health and human services resources. Infant mortality is associated with a variety of factors including quality and access to prenatal and pediatric health care, socioeconomic conditions, family stressors, strength of local service systems and community resources, and the soundness of the community's infrastructure.

Today, in the United States, about two-thirds of infant deaths occur during the first 28 days of life, the neonatal period. The most frequent causes of death during this period are birth defects, low birth weight/preterm birth, and respiratory distress syndrome. The remaining one-third of infant deaths occur during the postneonatal period between 29 and 364 days of age. The most frequent cause of death during this period is sudden infant death syndrome (SIDS), followed by birth defects and unintentional injuries. (1)

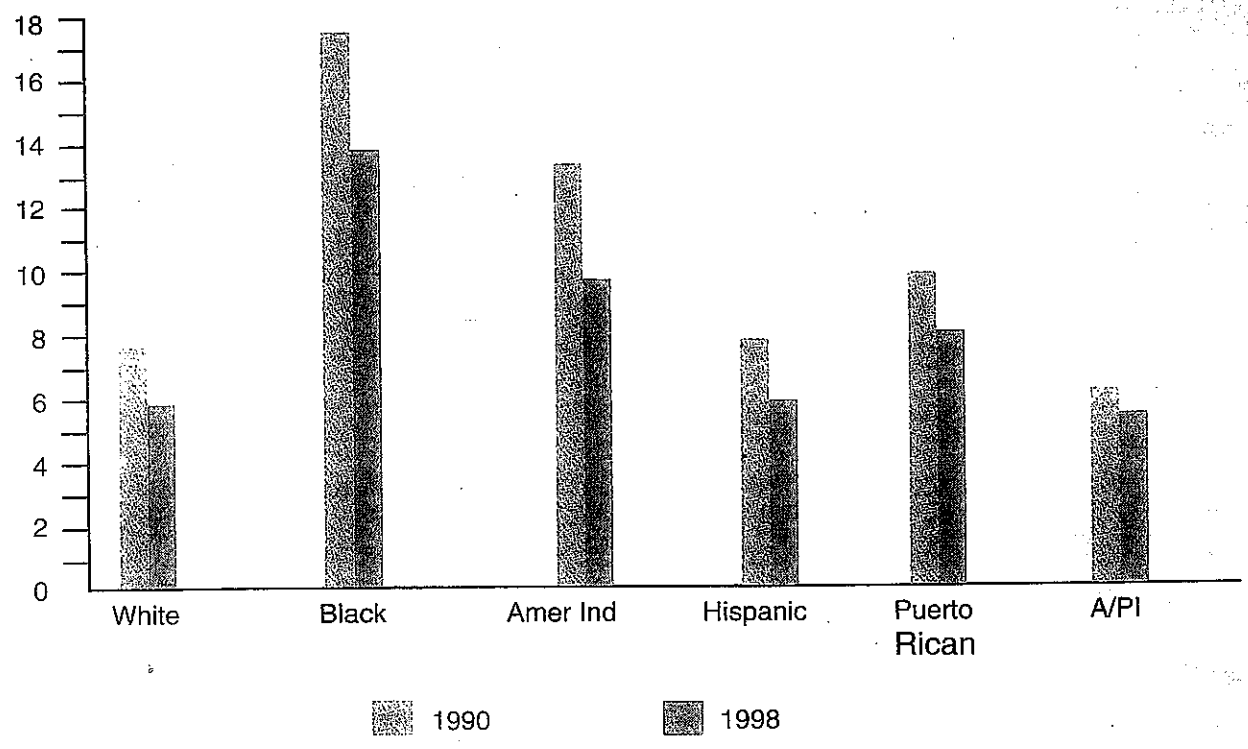
The U.S. infant mortality rate decreased from 9.2 in 1990 to 7.2 in 1998, approaching the year 2000 goal of 7 deaths per 1,000 live births. The decrease is believed to be attributable to many factors including use of new

INFANT MORTALITY RATES BY RACE, 1998

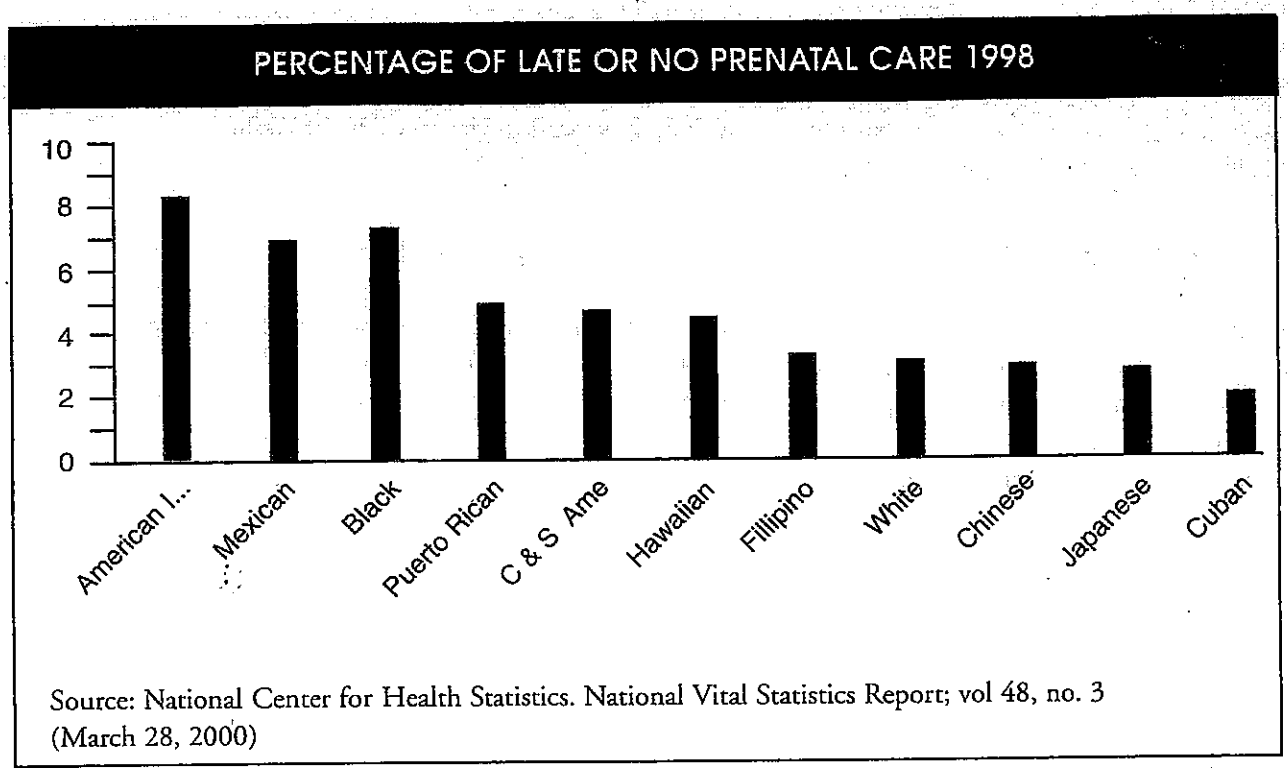
Race of mother	Infant	Neonatal	Postneonatal
All races	7.2	4.8	2.4
White	6.0	4.0	2.0
Black	13.8	9.4	4.4
American Indian	9.3	5.0	4.3
Asian or Pacific Islander	5.5	3.9	1.7
Chinese	4.0	2.7	1.3
Japanese	3.5	2.5	*
Hawaiian	10.0	7.3	*
Filipino	6.2	4.6	1.6

Source: National Center for Health Statistics. National Vital Statistics Report; vol 48, no. 12 (July 20, 2000)

INFANT MORTALITY RATES BY RACE AND ETHNICITY 1998



Source: National Center for Health Statistics. National Vital Statistics Report; vol 48, no. 12 (July 20, 2000)



Source: National Center for Health Statistics. National Vital Statistics Report; vol 48, no. 3 (March 28, 2000)

Disparity in infant outcome may also reflect underlying American societal problems such as racial and class discrimination. (12) Surgeon General Satcher targeted elimination of racial disparities in infant outcome by the year 2010 as one of his priority areas. (13)

A Vision of a Healthy Community Infrastructure

A resilient economy provides ample jobs that pay a family wage; a wage that ensures a decent standard of living. Police and law enforcement services work with residents to keep neighborhoods safe. An affordable and nondiscriminatory housing market makes it possible for everyone to enjoy decent housing and for many to own their homes. An efficient transportation system connects all sectors of the community and enables residents to reach jobs and services. The physical environment benefits from clean air, safe drinking water, carefully planned growth, and parks where neighborhood families can gather and children can play. Health care services and community resources for childbearing and child-rearing families are available, easily accessible, and culturally competent. Young fathers have training and employment opportunities that, in turn, foster pride and family solidarity. A policy- and decision-making group with culturally representative, active citizen participation works closely with local, state, and federal government to keep child and family issues top priorities and promote community cultural requirements.

Adapted from: Melaville AI, Blank MJ. Together we can: a guide for crafting a profamily system of education and human service. Washington, DC: U.S. Government Printing Office, 1993. p. 6–8

the service system and community resources. Teams may also develop other ways to stay informed about the progress of interventions.

As problems are resolved and the health care, physical, and social environment for families improves, communities that implement FIMR change for the better. The FIMR process not only improves services and resources for women, infants, and families, but also can generate a sense of energy and hope in a community because the community is, indeed, successfully addressing local issues.

FIMR CAN ADDRESS ISSUES ASSOCIATED WITH DISPARITIES

Community-based FIMR is an action-oriented, continuous quality-improvement process that plays a significant role in building community partnerships, understanding community issues associated with heath disparity, and developing culturally sensitive interventions. Three components of the FIMR process and information from FIMRs are particularly valuable in assisting local communities to understand and work toward eliminating health disparities:

- the diverse coalition/community partnership-building component of the process itself
- inclusion of the voice of local families who have lost their babies–through the information obtained from maternal interviews
- the outcome interventions–based on the decisions of the whole community and the families who live there

The Coalition/Community Partnership-Building Component of the Process Itself

As a first step, each community must develop a greater understanding and appreciation of its diversity. FIMR is a community coalition/partnership-building strategy that can bring together all ethnic and cultural views in the community and become a model of respect and understanding. In turn, this sharing of diverse community values provides a platform for factions within the community to grow in understanding of cultural information and community cultural requirements.

Successful FIMR projects include a wide variety of culturally diverse partners in their activities. Typically FIMR engages 30 to 50 active community members including policymakers, representatives of organizations, families, and consumer advocacy groups. Team membership should reflect both the community at large and the community most affected by high infant mortality rates.

"During the past three years, the FIMR teams have grappled with many difficult issues. Racial and ethnic sensitivity of all team members has increased. We believe the CRTs have worked well together and have all grown in understanding of others who are not of their sex, race, ethnicity, or profession."

Mary Hibbard, MD, Former Commissioner of Health, Suffolk County, New York

Inclusion of the Voice of Local Families Who Have Lost Their Babies Through the Maternal Interview

The FIMR process includes a home interview, if she agrees, with the mother who has experienced a loss. Very few other maternal and child health initiatives include this comprehensive type of family perspective. The mother is asked about the health and human services and resources that were available, barriers to care, services she received or wished for, her cultural worldview of the experiences during pregnancy and the birth and death of her child, background information about her neighborhood's resources and infrastructure, her relationship with the father and other support people, physical/emotional stressors, economic hardships, and grief reaction to the loss.

The purpose of the FIMR home interview is:

- to learn about the mother's experiences before and during pregnancy
- to learn about the events during the infant's life and around the time of death
- to identify community infrastructure assets and deficits that affected her life during her pregnancy, birth, and the death of her infant
- to assess the family's needs and provide appropriate culturally appropriate referrals
- to facilitate bereavement and suggest appropriate interventions
- to accurately convey the mother's story of her encounters with the local systems and resources and her loss to the larger community

> "Maternal interviews give a voice to the disenfranchised in my community, those without clout or power. FIMR provides a rare opportunity for the "providers" in a community to hear from the "consumers."
>
> Patt Young, FIMR Interviewer, Alameda/Contra Costa Counties, California

The home interviewer then conveys the mother's de-identified story to the FIMR members. Thus, the home interview lets the voice of each bereaved parent speak to the community at large. The community finds that this home interview provides some of the most valuable information in the review. It is extremely important to their understanding of whether or not services and community resources are available, accessible, and culturally appropriate. FIMR teams can also more readily identify issues of racism and other forms of discrimination in service delivery systems through the interview and begin to address them.

MAKING A DIFFERENCE:
A SAMPLER OF FIMR ACTIONS TO ADDRESS HEALTH DISPARITIES

As a nation, we may not yet understand all the larger societal issues, local infrastructure dynamics, or individual physiologic mechanisms that contribute to disparities in outcomes. FIMR programs across the country, however, have come to the conclusion that there is much that can and ought to be done now to ensure a high standard of service for communities at highest risk for poor infant outcomes. Some common FIMR action agendas related to reducing health disparities that emerge from this sampler include:

- increasing respect and understanding among community agencies, providers, and citizens
- raising community awareness about issues related to health disparities—especially among those at highest risk
- fostering broad-based community involvement in problem solving
- developing culturally and linguistically appropriate health education messages and materials
- ensuring culturally competent health and human services
- creating new, culturally appropriate health services targeted to communities most at risk
- reducing barriers and gaps in services for all families, but especially those at high risk for poor outcomes
- raising awareness about community infrastructure issues that affect disparities, such as cultural and racial discrimination, neighborhood safety, adequate housing, transportation, and the community's economic status

Today there are more than 200 local FIMR programs in 40 states. The information from the many FIMR case reviews of these programs provides a good view into the problem of health disparities. The reviews also suggest unique, locally significant solutions. While it is not possible to document every intervention from each FIMR program, the following sampler demonstrates that the FIMR methodology is being used to address issues related to health disparities in infant outcomes:

Alaska

Issue: In past decades, Alaska has had a high incidence of infant mortality, especially within Alaska Native peoples. In the early 1970s, the Public Health Service (IHS)—with its highly developed system of health care to both urban and Alaska bush communities—began Native infant death reviews. After several years, the Alaska Department of Health and Social Services expanded the mortality reviews to all infant deaths (Native and non-Native). This mortality review process has become known as the statewide Alaska Maternal Infant Mortality Review (AMIMR) Project. The AMIMR Project also includes interviews with mothers who have experienced an infant loss. Each year, a medical epidemiologist conducts an annual aggregate analysis of case information. The findings are presented at an annual meeting in December to the deputy commissioner of Health and Social Services, the Division of Public Health director, and the members of the Maternal-Infant Mortality Review Committee. As a result of this presentation, formal recommendations are made and then finalized with the deputy commissioner and the public health director. These recommendations become the basis for proposing timely actions to the Alaska state legislature, which convenes in January each year.

In 1977, the Public Health Service's mortality review of Native infants documented the need for a program to provide intensive services to medically/socially high-risk pregnant Native women.

For more information, contact: Kelly Sanders, Women and Children's Health Network, c/o Hartford Primary Care Consortium, 30 Arbor Street North, Hartford, CT 06106.

Florida

Issue: In Sarasota County, the community was unaware of the magnitude of the disparity in infant outcomes between the African-American population and the total county population.

Action: FIMR conducted a well-attended community forum in the county's largest African-American neighborhood, with speakers from the local African-American community, including a perinatologist, an obstetrician, a minister, and the former mayor of Sarasota. Local data about the disparity in outcomes were presented. A local college group provided theatrical vignettes to illustrate locally significant barriers to receiving comprehensive prenatal care. Community residents in attendance pledged to help educate their families, neighbors, and friends about risks. Local business owners have agreed to distribute literature about the importance of early prenatal care. A local television station also featured the topic on a talk show directed to African-American viewers.

For more information, contact: Sarah Gorman, Healthy Start Coalition of Sarasota County, Inc., 2477 Stickney Point Road, Suite 311B, Sarasota, FL 34231.

Issue: The Polk County FIMR team found that not every prenatal care provider had Spanish-speaking staff. Therefore, important health education messages about signs and symptoms of preterm labor and danger signs of pregnancy were not being communicated to all Hispanic prenatal patients. Additionally, few Hispanic women would attend Prepared Childbirth Education classes because they were primarily taught in English. Another barrier is that the classes were for couples. Because of their traditions, most Hispanic men did not attend. Typically, childbirth education offers special in-depth information that improves knowledge about important health matters, increases compliance with treatment regimens, and promotes healthy lifestyle habits, thereby helping to reduce the risks for preterm and low-birth-weight babies.

Action: The Healthy Start Coalition collaborated with the East Coast Migrant Association to train two Hispanic family support workers in prepared childbirth education. The standardized Florida Outreach Childbirth Education Project curriculum was used for the training. These workers, who are fluent in Spanish, now conduct home visits to bring the benefits of childbirth education to every Hispanic prenatal patient. The workers teach patients to recognize symptoms of preterm labor, danger signs, and what to do if they occur, as well as many other important health education messages. The home visit also provides an opportunity to conduct a family needs assessment and provide culturally appropriate referrals.

For more information, contact: Holly Boyer, Healthy Start Coalition of Hardee/Highlands/Polk Counties, Inc., Old Town Square, 357 Third Street, NW, Winter Haven, FL 33881.

Issue: Between 1996 and 1999, the nonwhite infant mortality in Jacksonville, Florida, increased from 10.8 to 15.3 deaths per 1,000 live births. White infant deaths rose from 6.4 to 7.0 deaths per 1,000 live births during the same period.

Action: The Northeast Florida Healthy Start Coalition examined fetal and infant deaths by race using the Perinatal Periods of Risk Approach (PPOR). This method divides poor birth outcomes into groups based on age at death and birth weight. Use of these FIMR findings enabled the coalition to develop prevention and intervention strategies tailored to the actual experience in Jacksonville. For example, one important finding that emerged from this analysis was the need for preconceptional care

priate messages in the African-American neighborhoods identified as high risk. Additionally, many more posters will be strategically placed in schools, churches, clinics, grocery stores, Laundromats, etc. The intent is to blanket the community with messages that promote awareness of the need for prenatal care and a healthy lifestyle. All PSAs and print materials also include the toll-free Indiana Family Helpline for assistance and information, including a free video.

For more information, contact: Marsha Wetzel, Indiana Perinatal Network, 1716 White Water Court, Fort Wayne, IN 46824.

Issue: The Indiana State Department of Health Maternal and Child Health Services wanted to develop a statewide campaign to improve birth outcomes. However, it needed more information to be able to fully develop a program that would be effective and reach the culturally diverse communities throughout the state.

Action: The Indiana State Department of Health, Maternal and Child Health Services worked with the Indiana Perinatal Network and Minority Health Coalition to develop the plan. The Indiana Perinatal Network and Minority Health Coalition has a culturally diverse membership with representatives from African-American and Latino communities. The coalition input helped ensure a culturally competent approach to the state's activities. Based on FIMR findings, it developed the Baby First Campaign. The campaign comprises the following six consumer health education messages suggested by FIMR reviews: 1) Start prenatal care as soon as you find out you are pregnant; 2) Know the signs of preterm labor and what to do about it; 3) Don't smoke while you are pregnant; 4) Pay attention to when the baby moves inside your body; if you count less than 10 movements in two hours, call your health care provider; 5) Eat well and gain 25–35 pounds during pregnancy; and 6) Put your baby on its back to sleep. The Department of Health makes a special effort to ensure that all its educational materials are culturally appropriate. Next, the Department of Health developed GIS maps to identify areas throughout the state at risk for poor outcomes. The maps located neighborhoods with high infant mortality, late prenatal care, low birth weight, maternal smoking, and teen pregnancy. This information helps local cities and counties target services to those most in need.

The state encourages high-risk areas to apply for assistance to develop free pregnancy test sites, prenatal care services, prenatal care coordination, and other needed services. A statewide Indiana family telephone Helpline was implemented. Staff are multicultural and include African-American, Latina, disabled, and white operators. They are chosen because they are sensitive to community issues and are well versed in the FIMR recommendations and health education messages. Each woman who calls the line is screened regarding pregnancy and assisted with needed services and sent a Baby First education packet, which also contains a consumer video based on FIMR findings. Grants have been successfully written to assist communities of color to implement the FIMR recommendations.

For more information, contact: Maureen McLean, Indiana State Department, Maternal and Child Health Services, 2 North Meridian, Suite 700, Indianapolis, IN 46204.

Iowa

Issue: The Siouxland District Health Department serves residents of Woodbury County. This community is culturally, ethnically, and racially diverse. Woodbury County is also located in a tristate region with Nebraska and South Dakota and serves many Native American families. The department needed to understand knowledge, attitudes, and beliefs about SIDS risk-reduction messages in order to promote changes in behaviors. FIMR case reviews also found that many families did not have a crib at home for the newborn.

Action: In a collaborative process, the two local hospitals and the agencies providing home visitation services worked together to develop a postpartum

culturally appropriate protocol built upon existing resources. Each organization formally approved the protocol and trained its staff to implement the organization's component. Soon substance abuse counselors will provide home visits and, if possible, meet with women before they are discharged from the hospital. Outreach workers, with additional bereavement sensitivity training, also follow up at home.

For more information, contact: Barbara May, Southern New Jersey Perinatal Consortium, Kevin Office Center, 2500 McClellen Avenue, Suite 110, Pennsauken, NJ 08100-4613.

South Carolina

Issue: Aiken's FIMR case reviews found excess infant mortality and low-birth-weight babies in the city's African-American communities. The FIMR also identified a need to increase early and continuous prenatal care in these same neighborhoods.

Action: Aiken's FIMR developed a unique outreach program that capitalized on the preexisting positive relationship between its community-oriented policing program and citizens, MOMS and COPS (Managing Our Maternity Services with Community-Oriented Policing Systems). Trained by public health nurses, community-oriented police officers provide prenatal and postpartum outreach, education, and referrals to women living in their assigned high-risk neighborhoods. With a MOMS and COPS referral, women can avoid waiting in line to obtain health and human services. COPS officers take gifts to newborns and show parents how to avoid SIDS through proper bedding and infant positioning. They also check for smoke alarms. Nurses have found that officers can often find their clients who have missed appointments.

For more information, contact: Karen Papouchado, 7 Burgundy Lane, Aiken, SC 29801.

Virginia

Issue: Several years ago, after reviewing a number of African-American infant deaths due to SIDS, the Richmond FIMR identified the need for culturally appropriate SIDS risk-reduction education materials. The FIMR team was unable to locate materials that depicted an African-American infant sleeping on his back. The team also found that many new mothers as well as other family members and some community day-care providers did not know about SIDS risk-reduction practices.

Action: The Richmond FIMR director worked with the Richmond City Department of Health to design culturally appropriate education materials. They took a photo of an African-American infant and developed a door hanger with the "back to sleep" recommendation. The Richmond Healthy Start Consortium and the regional perinatal council distributed the door hangers throughout the community. This campaign is being continued today. This health education approach has been adapted by several other states.

For more information, contact: Cheryl Nunnally Bodamer, Virginia Commonwealth University Health Systems, MVCH, P.O. Box 980034, Richmond, VA 23298.

Issue: The Northern Virginia Perinatal Council FIMR serves a diverse population including Latino, Asian, Russian, African, African-American, and Arabic families. As a first step in addressing issues related to disparity, the council has recognized the need to provide prenatal and well-child health education messages in all these languages.

Action: The FIMR program has been able to find written health education materials with appropriate reading levels in all these languages, including Russian, Farsi, and Spanish. However, over time, the team discovered another approach that has been even more effective. The Northern Virginia FIMR finds that while not everyone will read printed materials, families who have a Resource Mother or Healthy Families support worker respond to health education messages that these persons teach them. The Northern Virginia Perinatal Council now con-

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