



A community approach to improving health care for Indiana's Mothers & Babies

Too many babies are dying in Indiana! Indiana continues to have one of the highest infant mortality rates in the United States. As a response, the Indiana Perinatal Advisory Board has developed "Lessons Learned From The Indiana Fetal – Infant Mortality Review (FIMR) Projects." This report contains summaries of the findings of the Indiana Projects, and recommendations for reducing the number of infant deaths and low birthweight babies in our state.

Just as the infant mortality rate is viewed as an important measure of a state's health, individual infant and fetal deaths can be viewed as sentinel events to identify and understand failures in the health care system. Sadly, the infant mortality rate in our state increased in 1996 because too many babies are born too small, and too soon.

FIMR Projects are descriptive, community-based reviews of fetal and infant deaths, designed to examine factors in a community's health and social service delivery system that may have contributed to the deaths. A team of providers reviews information from medical records, autopsies and extensive family interviews, and then makes recommendations on ways to improve the community's health system for mothers and infants. Another intent of FIMR Projects is to improve communication and collaboration between local public and private agencies, and to foster coordination among all providers in the community's perinatal care delivery system.

Since a FIMR Project can be an effective mechanism to monitor how well a community's existing systems work, it is a valuable process when incorporated into the ongoing, overall community effort to improve the health of pregnant women and infants.

We would like to personally acknowledge the special efforts of health providers, community agencies, professional associations, and public and private institutions who participated in these Projects. The hard work and commitment of these individuals to improve both pregnancy outcomes and the quality of health in Indiana communities should be greatly admired. And finally, we are most grateful to the families who willingly shared about their own loss in order to help other infants stay alive.

Please do all that you can to help every pregnant woman and her family to learn about and follow the important lessons contained in this report.

A handwritten signature in black ink, appearing to read "Paula Parker-Sawyers".

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Indiana Perinatal Advisory Board
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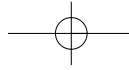
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Judy O'Bannon
First Lady of Indiana



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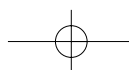
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LESSONS LEARNED FROM THE INDIANA FETAL AND INFANT MORTALITY REVIEW PROJECTS 1993 – 1997

The following findings and recommendations are the result of an extensive review of over 500 cases of fetal and infant deaths conducted in Allen, Elkhart/St. Joseph, Lake, and Marion counties. This handout is designed to enhance and reinforce our educational efforts with pregnant women.

PRETERM LABOR

Findings

Preterm labor was a contributing factor in 50% of the deaths. Often, the woman failed to recognize the signs and symptoms of preterm labor in time for appropriate intervention. Recent research has shown that untreated vaginal infections may be a significant contributor to preterm labor.

Recommendation

At the beginning of the 2nd trimester, all pregnant women should be routinely educated and reminded at each visit about the signs and symptoms of preterm labor and what to do if this occurs. A suggested description of preterm labor for patients could include:

- Contractions every 10 minutes or more than 5 times in 1 hour
- Backache that does not go away after resting
- Changes in vaginal discharge
- Pelvic pressure that feels like the baby is pushing down inside
- Menstrual-like cramps
- Abdominal cramps and diarrhea

SMOKING DURING PREGNANCY

Finding

Exposure to tobacco smoke was seen in 40% of all infant deaths. Smoking during pregnancy has long been associated with prematurity, low birthweight and infant mortality.

Recommendation

Repeatedly encourage all women to quit or reduce cigarette smoking and maintain a smoke-free environment during and after their pregnancy. Contact the Indiana Family Helpline at 1-800-433-0746 for a list of smoking cessation programs in your area.

LATE ENTRY INTO PRENATAL CARE

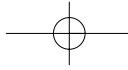
Findings

Care beginning after the 1st trimester was seen in 25% of deaths. Inadequate or no prenatal care has long been associated with increased infant mortality and morbidity. In the Indiana Pregnancy Risk Assessment Monitoring Survey, women cited the following barriers to 1st trimester care:

- difficulty in getting appointments
- difficulty affording care
- not recognizing they were pregnant.

Recommendations

The content of prenatal care should include the recommendations of the 4th Edition of the "Guidelines for Prenatal Care" (GPC) from AAP and ACOG. A copy can be obtained by calling 1-800-762-2264. All providers should schedule women for their initial visit within the first 12 weeks of their pregnancy.



Communities should provide free pregnancy testing and educate consumers on the value of early prenatal care and the availability of Medicaid coverage for uninsured pregnant women. Women on Medicaid should be referred for prenatal care coordination services. Contact the Indiana Family Helpline at 1-800-433-0746 for a list of prenatal care coordinators in your area.

DECREASED FETAL MOVEMENT

Findings

Decreased fetal movement was associated with more than 20% of deaths. In many cases, either the mother or the medical staff did not recognize the urgency, or respond in time with appropriate interventions.

Recommendations

All providers should be aware of the clinical conditions that contribute to fetal deaths and provide early screenings and treatment as recommended in GPC. All women should be educated about normal fetal activity. Beginning in the 7th month of pregnancy, all women at risk for antepartum fetal demise should be educated on counting fetal movements.

The following is one example of a suggested method for patients:

- At a regular time each day lie down on your left side
- Keep track of how much time it takes you to feel the baby move 10 times
- If you count less than 10 movements in 2 hours contact your healthcare provider

All staff from health care providers offices and clinics should be trained on how to respond to these calls.

INADEQUATE WEIGHT GAIN

Findings

Weight gain of less than 25 lbs. was noted in over 50% of infant deaths reviewed by one project. Inadequate weight gain is associated with increased infant mortality and low birthweight.

Recommendation

Women within normal body size before pregnancy should gain 25 - 35 lbs. All eligible women should be referred to the WIC Program early in their pregnancy. Contact the Indiana Family Helpline at 1-800-433-0746 for the nearest WIC Program in your area.

INFANT SLEEP POSITION

Findings

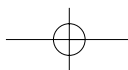
In a significant number of the deaths due to Sudden Infant Death Syndrome, it appears that parents were unaware of, or did not follow the Back to Sleep guidelines.

Recommendations

All full-term, healthy infants should be placed to sleep on their back on a firm mattress. Parents should maintain a smoke-free environment during and after pregnancy. The 30% decline in SIDS deaths recently reported in the media appears to be associated with a change to back or side sleep position.

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INDIANA
COMMUNITIES
PARTNERING
TO
SAVE
BABIES



Healthier Beginnings Project
Allen County

Healthy Babies Project
Elkhart and St. Joseph Counties

Northwest Indiana FIMR Project
Lake County

Indianapolis Healthy Babies
FIMR Project
Marion County

HEALTHIER BEGINNINGS PROJECT

ALLEN COUNTY

*“My baby was a
funny purple color
and his fingernails
were blue, even
after he came home.
Why did they let
him go home?
I feel mothers and
babies should be
kept in the hospital
longer. I agreed
to talk to you
because I hope this
will stop this from
happening to
someone else.
I’d do anything
to help.”*

From a teen mother
whose baby died from a
congenital heart anomaly

The Healthier Beginnings FIMR Project, sponsored by St. Joseph Medical Center in Ft. Wayne and supported by St. Joe Angels Children’s Fund and the Indiana State Department of Health, began in January 1995 as a prospective study of all fetal and infant deaths in Allen County. The program is under the medical direction of Dr. Scott Wagner, a forensic pathologist at St. Joseph Medical Center and Dr. William Lewis, Medical Director, Neonatal Intensive Care Unit at Parkview Memorial Hospital.

The objectives of the study are to:

- Identify and examine the significant social, economic, cultural, and health system factors associated with fetal and infant mortality through review of individual cases;
- Plan and implement interventions and educational programs that address these factors with special emphasis on prenatal providers and expectant parents.

Infant deaths are identified via vital statistics from the county health department. The medical and socioeconomic histories of the mothers and infants are abstracted and reviewed and recommendations are developed as to how the community may redirect resources to reduce fetal and infant mortality.

A consortium consisting of key prenatal and infant care professionals has been assembled to assist in the review process. Other key community organizations involved in this collaborative effort include the local SIDS Chapter, Neighborhood Health Services Clinic, Allen County Health Department, Lutheran Hospital, Catholic Charities, the Allen County Coroners Office and the March of Dimes.

To date, 82 individual infant and fetal deaths have been reviewed and 83% of these families have actively participated in the review process by consenting to a family interview.

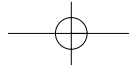
The consortium found that while women generally sought early and continuous prenatal care, many still experienced a fetal or infant death as a result of not recognizing the warning signs of preterm labor or decreased fetal movement. The consortium recommended that project staff continue reviewing individual deaths and also develop educational plans directed at providers and consumers addressing the following issues:

- Signs and Symptoms of Preterm Labor
- Fetal Movement/Kick Counts
- Smoking During Pregnancy
- Back to Sleep
- Folic Acid

As a result of the Healthier Beginnings Project, an innovative program, Healthier Moms and Babies was implemented. This program employs prenatal care coordinators to guide high risk women through their pregnancy.

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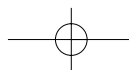
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HEALTHY BABIES PROJECT

ELKHART and ST. JOSEPH COUNTIES

“Try to put yourself in the parents’ position and have some compassion, whether you are an EMT or a detective sent into the home. Don’t reprimand someone for their disbelief at the death of their child. It’s not appropriate and most of all it’s terribly unkind.”

From parents whose child died of SIDS

To increase the community’s understanding of the causes and contributing factors associated with infant mortality in Elkhart and St. Joseph counties, the Healthy Babies Infant Mortality Case Review (IMCR) Project started in 1993. The IMCR Project is supported by the Indiana State Department of Health and Memorial Hospital of South Bend. Dr. Bob White, Medical Director of the Regional Newborn Program at Memorial Hospital serves as the project’s Medical Director. The IMCR Project utilizes a community-based, multi-disciplinary team of key individuals to review medical and autopsy records and information from family interviews. The goal is to identify common trends and system problems and make recommendations that could reduce infant and fetal mortality.

A review to date of 220 deaths revealed the following significant information:

- 48% were fetal deaths,
- Exposure to cigarette smoke was seen in 44% of deaths,
- Many women did not recognize the early warning signs of preterm labor,
- Many women did not know the significance of decreased fetal movement.

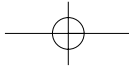
Educational presentations on local findings were made over a two-year period to health professionals, clinical office staff, service providers, nursing staff of emergency, pediatric and obstetrical units, paramedics and law enforcement officers throughout the community.

The IMCR Project is administered in conjunction with the Healthy Babies Project, well-known locally for operating an information and referral helpline for pregnant women in the community. It is in a unique position to impact infant and fetal mortality because of its emphasis on adequate prenatal care, public awareness and advocacy on maternal and child health issues. Healthy Babies staff members have developed close working relationships with health care and social service providers, schools, universities, the media and youth organizations, including young pregnant and parenting women.

Based on IMCR findings, the Healthy Babies Helpline has revised its intake form to assess smoking behaviors and automatically send callers information on smoking reduction programs. Patient reminder cards describing the symptoms of preterm labor, how to monitor fetal movement, and what to do in response to these warning signs, have been widely distributed to health care and human service providers, public health clinics and pregnant women throughout the community.

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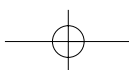
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NORTHWEST INDIANA FIMR PROJECT

LAKE COUNTY

“The review project has helped us, as professionals, to see where we sometimes fall short in our counseling of these parents. This program has helped all the hospitals improve their handling of fetal, neonatal and infant deaths.”

From a physician participating in the review process

The Northwest Indiana FIMR Project in Lake County, initiated in May 1995, is a required component of Healthy Start, a federally funded infant mortality reduction program implemented in this area in 1994. The project involves identifying infant deaths via vital records, summarizing medical records and information obtained from family interviews and presenting the cases to the Technical Review Committee. The findings and recommendations are then reviewed by a Community Review team for possible implementation.

Key partners in the project include local health officers, hospitals, voluntary agencies such as the March of Dimes and Project LINK and representatives from managed care organizations. The Indiana State Department of Health, Maternal and Child Health Services, the federal Maternal and Child Health Bureau and the Chicago Healthy Start Project also provided extensive technical assistance during the development of the project. Dr. Janice Zunich, Genetics Director of the Northwest Center for Medical Education, serves as chairman of the technical review committee.

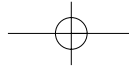
During 1995, there were 112 infant and fetal deaths in Lake County, 47 of which were reviewed by the FIMR Project. The review project found that a high percentage of women experiencing an infant loss received inadequate or no prenatal care. It was further determined that medical system issues, such as not being able to get an appointment, contributed to over 40% of the cases of inadequate care. There was also a high incidence of substance use, especially tobacco, among women experiencing a death. Preterm labor was noted in nearly half of all cases reviewed. Most surprising, only 36% of the mothers who experienced a death were enrolled in the Healthy Start Care Coordination Project.

The review project also identified problems with continuity of care and has recommended that prenatal records be routinely available at hospitals prior to delivery. The review project also identified deficiencies in primary care capacity in several areas within Lake County and is working with key individuals to open a community health center. A need for inpatient substance use treatment programs for pregnant women and grief counseling and support services for bereaved families was also identified.

As a result of the project, increased outreach efforts directed towards hard-to-reach women have been initiated, including intensive door-to-door campaigns in high risk neighborhoods. Efforts have also been made to increase educational activities regarding preterm labor. Recommendations were also made to increase access to pregnancy testing and develop an educational campaign regarding the importance of prenatal care, good nutrition and the risks associated with substance use during pregnancy.

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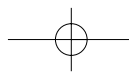
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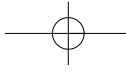
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INDIANAPOLIS HEALTHY BABIES FIMR PROJECT

MARION COUNTY

“A 15-year-old girl who began prenatal care in the 1st trimester was admitted to the hospital at 27 weeks gestation complaining of abdominal pain and bleeding. Fetal movements were absent for the past 3 days. She smoked cigarettes throughout the pregnancy and also used marijuana before becoming pregnant. Her mother had died shortly before she became pregnant and no other immediate family lived nearby. She delivered a stillborn male infant with congenital anomalies.”

To better understand the specific factors which cause poor birth outcomes in Marion County, The Health and Hospital Corporation, in partnership with all hospitals providing obstetrical services, implemented a formal review of all fetal and infant deaths of Marion County residents. The review project began in October 1995 and utilized much of the information from an earlier review project sponsored by the I.U. School of Medicine and the Indiana State Department of Health from 1989 – 1991.

The specific objectives of the project are to:

- Clearly identify local risk factors associated with fetal and infant deaths,
- Provide information and education to perinatal care providers,
- Provide better information and services to families who have experienced a loss.

The Health and Hospital Corporation, through its Indianapolis Healthy Babies Project, utilized the FIMR model developed by ACOG and other professional associations which emphasizes a community-based approach and the importance of a positive working relationship between clinical, public health and social service providers. Dr. Virginia Caine, Marion County Health Officer and Dr. Haywood Brown, Maternal/Fetal Medicine Specialist, Wishard Memorial Hospital, serve as Medical Directors of the project.

A technical review panel, which has been organized into three working sub-panels meets on a regular basis to review case summaries. The summaries usually include the death and birth certificate, medical records, family interview summary, autopsy reports and other appropriate public health or social service reports. The panel uses a consensus process to identify the cause of death and determine whether the death may have been prevented. The panel then develops findings and recommendations regarding public health, clinical or social service policy changes that may contribute to reductions in infant mortality and improvements in the overall health of women and infants.

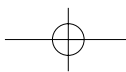
A review of 200 cases of fetal and infant death occurring between July 1995 and June 1996 revealed the following information:

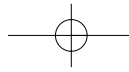
- There were several instances of inconsistent information between the birth/death certificate and medical records;
- Many medical records lacked documentation of prenatal risk scoring, prenatal education and important information such as lab work or discharge plans;
- High risk women were not referred for prenatal care coordination services;
- Postpartum follow-up for interconceptual care to decrease the chances of a future death was lacking for high risk women; and
- Substance use and not recognizing signs of preterm labor and decreased fetal movement were also noted.

A summary of the complete findings will be presented to a Community Panel of the Indianapolis Healthy Babies Consortium so that specific recommendations and improvements in the perinatal care systems can be identified and implemented.

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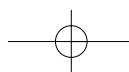
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INDIANA PERINATAL NETWORK

A community approach to improving health care for Indiana's Mothers & Babies

The following table illustrates the rate of infant deaths in Indiana from 1987 – 1996. The Indiana Perinatal Network board and staff are in the process of strengthening both policy and practice on a statewide level. The Indiana Perinatal Systems Strategic Plan, a community-based blueprint for action, has as its priorities to:

1. Develop regional multi-county advisory boards to look at perinatal care and outcomes;
2. Promote early identification of at-risk mothers and babies to ensure timely, appropriate, and effective care;
3. Support proactive interventions to improve perinatal outcomes and avoid expensive neonatal care;
4. Adopt a consensus-building approach to changes in guidelines, recommendations, and standards of care;
5. Increase the visibility and awareness of resources to improve connections among providers, agencies and communities, and,
6. Foster accessible information and efficient communication.

INDIANA INFANT MORTALITY RATE PER 1,000 LIVE BIRTHS

