

# THE FETAL AND INFANT MORTALITY REVIEW (FIMR) IN DELAWARE:

FINDINGS FROM THE PILOT STUDY AND LESSONS LEARNED ABOUT IMPLEMENTING A STATEWIDE FIMR

August 2005





**The Fetal and Infant Mortality Review (FIMR) in Delaware:  
Findings from the Pilot Study and Lessons Learned about Implementing a Statewide FIMR**

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## EXECUTIVE SUMMARY

Beginning in the mid 1990's the infant mortality rate in Delaware was increasing while the national rate was decreasing annually until 2002. This trend in Delaware's infant mortality rate prompted Governor Minner's convening an Infant Mortality Task Force (IMTF) in June 2004. The Fetal and Infant Mortality Review (FIMR) pilot study was born out of an interest to help inform the IMTF on the potential benefits of locally applying the national FIMR model, a process of reviewing fetal and infant deaths to address gaps in the systems of care that serve women, children and their families. Infant births that resulted in a death at Christiana Care Health System during 2003 were selected for the pilot study. The study was limited to one hospital for logistical ease and to facilitate medical record availability. Fifty-six potential infant death cases that met the inclusion criteria were identified. Eight cases were excluded as being inappropriate for FIMR, and hence the final pilot study sample was comprised of 48 infant deaths occurring to 43 mothers.

Maternal and infant medical records were abstracted on each of the 48 cases, and medical social workers from the Division of Public Health (DPH) attempted to contact all 43 mothers to obtain a maternal interview. In 18 cases (38% of the pilot sample), maternal interviews were completed. In 21 cases (44%) the mothers refused the interview, and in 9 cases (19%) the mothers could not be located. Information from the medical record, the state service database and the maternal interview, if available, were used to prepare an anonymous summary of each case. One of two multidisciplinary Case Review Team (CRT) panels reviewed each case summary. The CRT panels identified pertinent risk factors for poor pregnancy outcomes in each case, community resources that were available but not used by the mother, and community resources that are not currently available but that may have benefited the mother or infant. From their discussion, the CRT panels derived recommendations to address issues of concern and gaps in systems of care for pregnant women, infants and their families. Five priority issues that were recurring themes upon case review and the resulting recommendations include:

**The Issue:** There were many women who presented late to medical attention with advanced preterm labor. Some of these women did not correctly identify earlier signs of preterm labor or chorioamnionitis.

**The Recommendation:** There is a need for a more comprehensive approach to preterm labor education.

- Education on the signs and symptoms of preterm labor should begin with the first prenatal visit and be reinforced throughout pregnancy.
- Prenatal classes for mothers with risk factors for preterm labor should be expanded and cover the risks to the infant of being born premature. This would help women become informed decision-makers if an emergency arises. Videos that educate on preterm labor and the risks of prematurity should also be disseminated for use in clinic waiting areas, thus reaching a wider audience of pregnant women.

**The Issue:** Many women with risk factors for poor pregnancy outcome, including significant psychosocial needs, experienced a delay in follow-up or inadequate referrals made for public assistance or public health services.

**The Recommendation:** Facilitate the screening and referral of high-risk pregnant women to increase access to case management, mental healthcare and public assistance programs as appropriate.

- Develop and distribute a community resource list to obstetric and family practice clinics that can be given to all pregnant women regardless of their insurance status. This resource list should include information on preterm labor and Medicaid application and eligibility.
- A toll-free phone number and website should be developed to allow women to get help in accessing needed services.
- Develop and disseminate a mini psychosocial screening tool for obstetric providers, office staff, emergency room staff and hospitals to screen all pregnant women for mental health and social assistance needs.
- Work towards a single point-of-entry system.
  - Promote a toll-free number and a website that women can use to access care.

- o Develop and promote an easy to use access number for DPH so that providers can refer any woman identified at risk by the mini psychosocial screen.

**The Issue:** Many women with infant losses are not accessing bereavement support services.

**The Recommendation:** There is a need for more culturally appropriate and community-based bereavement support services.

- There should be a standardized packet of information distributed to families in the hospital that contains grief counseling resources in the community.
- All mothers with a fetal or infant loss should receive a phone call from a bereavement counselor after discharge from the hospital to provide them with another opportunity to ask questions, receive counseling and be referred for services.
- Community resources for bereavement support should be culturally appropriate. There is a particular need for more peer support and community-based services for Black women in Wilmington.
- More home visiting services are needed to provide one-on-one support for women and men who do not feel comfortable in a group setting.

**The Issue:** A notable proportion of the FIMR pilot sample included women who had sub optimal health such as significant medical conditions, significant past obstetric history of a poor pregnancy outcome or poor lifestyle choices at the time of pregnancy.

**The Recommendation:** There should be a comprehensive strategy to expand the vision and the provision of preconception and interconception—between pregnancy--care to encompass all women and not only those who want to become pregnant. This may involve developing a public education campaign to promote women’s health especially among groups at risk for poor health and pregnancy outcomes.

- A consistent message on healthy lifestyle should be repeated in many venues where women access the healthcare system. All points of contact are potential opportunities for identifying risk factors and counseling women on risk modification.
- For women with a history of poor pregnancy outcomes or significant risk factors, provide wrap-around services such as case management to prolong inter-pregnancy intervals and modify risk factors. Such

services should include nutrition counseling, family planning, genetic counseling, general health checks, psychosocial screening and bereavement support as appropriate and based on level of risk.

**The Issue:** Some women in the pilot sample with multiple gestation and/or obesity had inadequate or excessive weight gain during pregnancy.

**The Recommendation:** Nutrition counseling services should be more widely available and reimbursable as a standard of care in pregnancy, especially among high-risk women.

- All high-risk women, such as those with multiple gestation, diabetes, obesity or chronic diseases, should be referred for nutrition counseling.

The cases included in the FIMR pilot study sample are not representative of all infant deaths in Delaware. The infant deaths included in the FIMR pilot differed from those deaths excluded in some notable ways, and these differences should be kept in mind when considering the recommendations made. The pilot sample included a higher proportion of cases from suburban New Castle County and fewer cases from Kent and Sussex Counties. A greater proportion of mothers included in the pilot sample had early prenatal care and private health insurance compared to those mothers excluded from the pilot. The infants in the pilot were of younger gestational age and lower birthweight as a group compared to those infants not included in the pilot. Eighty-five percent of infants in the pilot died of complications of prematurity. There were three infants in the pilot who were born at term, after 37 weeks gestation.

There were some limitations faced in conducting the FIMR pilot study such as the lack of generalizability of the FIMR pilot sample, the 38% acceptance rate of the maternal interview and gaps in the medical record information available for case review. These limitations help the planning for the long-term implementation of FIMR in Delaware. Recommendations for the major next steps of FIMR implementation include:

- Institutionalize the coordination of FIMR with child death review under the statutory authority of the Child Death, Near Death and Stillbirth Commission.

- Fund staff to implement FIMR including: a FIMR Coordinator, maternal interviewer, an administrative assistant and, for start up, a physician consultant. The maternal interviewer should be integrated into DPH's functions through a close working relationship with and a referral process to DPH case management and outreach staff.
- Expand the network of community partners working with FIMR to serve on Case Review Teams in Kent and Sussex Counties as well as a team for New Castle County and, if deemed appropriate, the City of Wilmington.
- Set up a community action team to begin reviewing and implementing the recommendations from the pilot study with subcommittees in each of the counties.

**The proposed plan for FIMR is a starting point for discussion among the partners and stakeholders in Delaware committed to improving maternal and infant health outcomes. FIMR is a process that is adaptable to local needs and should be reviewed on a regular basis to best serve Delaware's communities.**

## ACKNOWLEDGEMENTS

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**Virginia Phillips, MSW**

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Finally, this report is dedicated to all the women and families whose lives have been marked by the loss of an infant. Their stories are our call to action to move forward and keep working to ensure that infants are born healthy in our communities.

- Meena Ramakrishnan

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## LIST OF ABBREVIATIONS

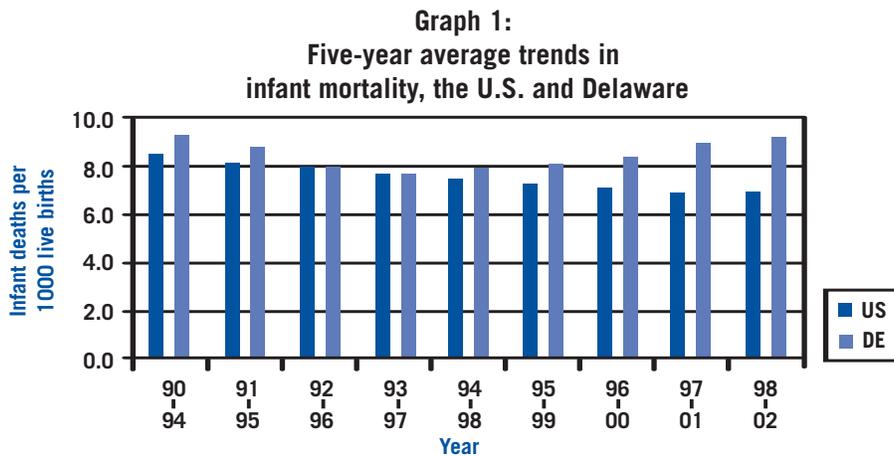
ART.....	Assisted Reproductive Technology
CAT.....	Community Action Team
CCHS.....	Christiana Care Health System
CDNDSC.....	Child Death, Near Death and Stillbirth Commission
CRT.....	Case Review Team
DPH.....	Division of Public Health
FIMR.....	Fetal and Infant Mortality Review
IMR.....	Infant Mortality Rate
IMTF.....	Infant Mortality Task Force
LBW.....	Low Birthweight
NHPS.....	Nemours Health and Prevention Services
NICU.....	Neonatal Intensive Care Unit
OB/GYN.....	Obstetrics and gynecology
PNC.....	Prenatal Care
PRAMS.....	Pregnancy Risk Assessment Monitoring System
STD.....	Sexually Transmitted Disease
VLBW.....	Very Low Birthweight
WIC.....	Special Supplemental Nutrition Program for Women, Infants, and Children

# INTRODUCTION

## Infant Mortality Trends in Delaware

Beginning in the mid 1990's the infant mortality rate (IMR) in Delaware has been increasing. (See Graph 1.) This is in contrast to the national trend in IMR, which had been decreasing annually until 2002. In the five-year period from 1998-2002, Delaware had the sixth worst IMR in the country.

The largest increase in IMR has been among very low birthweight infants, specifically those infants born weighing 1,000 to 1,499 grams in Delaware. Analysis of vital statistics has also revealed that the IMR increased significantly for infants of mothers in a historically low-risk group: those over 30 years who were married, covered by private insurance, entering prenatal care in the first trimester and residing in suburban New Castle County.<sup>1</sup>

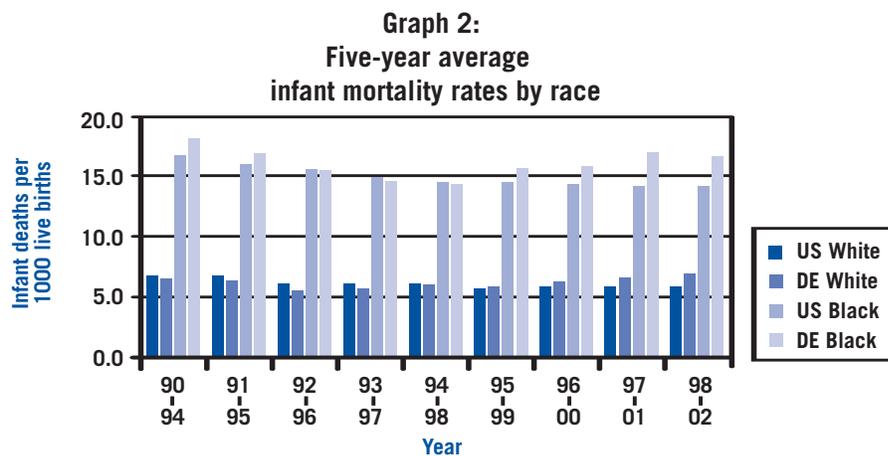


Source: Delaware Vital Statistics, <http://www.dhss.delaware.gov/dhss/dph/hp/files/infantmortality02.pdf>

<sup>1</sup> Centers for Disease Control and Prevention. *Increasing Infant Mortality Among Very Low Birthweight Infants—Delaware, 1994-2000*. MMWR 2003; 52: 862-866.

The racial disparity in IMR is as striking in Delaware as in the rest of the country. The IMR for whites in Delaware is significantly higher than for whites nationwide, with rates of 6.9 and 5.8 per 1000 live births, respectively, in 1998-2002 (Graph 2). Over that same time period, the black IMR in Delaware was also statistically significantly higher than the national rate at 16.7 and 14.2, respectively.<sup>2</sup>

This concerning trend in Delaware’s IMR prompted Governor Minner’s convening an Infant Mortality Task Force (IMTF) in June 2004. In the Task Force’s Report of May 2005, implementation of “a comprehensive review of every fetal and infant death in Delaware” was the first recommendation.<sup>3</sup> The Fetal and Infant Mortality Review (FIMR) pilot study was born out of an interest to help inform the IMTF on the potential benefits of locally applying the national FIMR model, a process of reviewing fetal and infant deaths to address gaps in the systems of care that serve women, children and their families.



<sup>2</sup> Delaware Vital Statistics Annual Report 2002, Infant Mortality Highlights, <http://www.dhss.delaware.gov/dhss/dph/hp/files/infantmortality02.pdf> accessed 6/5/05.

<sup>3</sup> Infant Mortality Task Force. Reducing Infant Mortality in Delaware: The Task Force Report. May 2005.

## The Fetal and Infant Mortality Review (FIMR) Model

**“The FIMR process brings together key members of the community to review information from individual cases of fetal and infant death in order to identify the factors associated with those deaths, determine if they represent system problems that require change, develop recommendations for change and assist in the implementation of change.”<sup>4</sup>**

Currently FIMR programs have expanded since the model’s inception in the mid 1980’s to include over 200 communities in 37 states. Local variations in the model allow for flexibility to match available resources. The key components of the FIMR process are depicted in Figure 1 and are as follows:

- **Data Gathering:** FIMR uses data from a variety of sources including birth and death certificates, records from hospitals and physicians, WIC, Healthy Start and other social service and public health programs. Important and unique to the FIMR process is information gathered from maternal interviews.
- **Case Review:** A multidisciplinary team discusses the case based on all the information gathered and seeks to identify gaps in the systems of care. The case review team considers such questions as: Did the family receive the services or community resources that they needed? What does this case reveal about trends in service delivery and program effectiveness?<sup>5</sup>
- **Community Action:** The case review team generates recommendations for systems change that are then taken up by a community action team. The community action team translates the recommendations to the local, community context and seeks to build networks for community cooperation to meet the identified goals. The team develops action steps and participates in their implementation.
- **Changes in Community Systems:** Tracking and evaluation of the effects, if any, of implementing FIMR recommendations is a key component of the FIMR model. As the action steps are implemented and changes are made to the community-level provision of services, the FIMR model allows for a continuous feedback mechanism. Examination of new fetal and infant death cases will provide feedback on the changes made based on previous community action efforts and in this way help to evaluate their effectiveness.

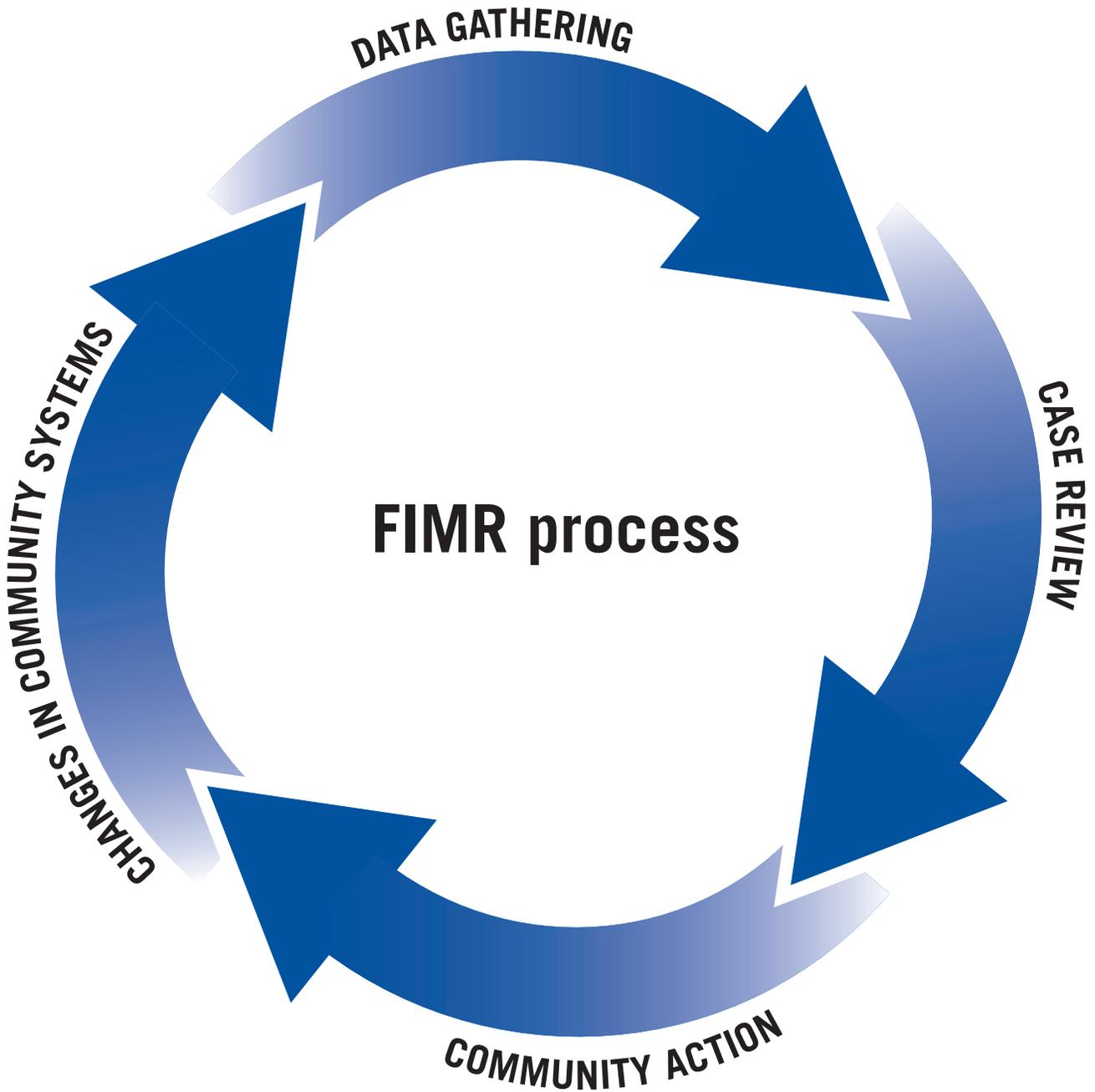
### **The FIMR model has some noteworthy strengths:**

- **It considers a broad range of factors that may contribute to poor pregnancy outcomes, including medical care, socioeconomic factors and emotional stress.**
- **It includes the voice of the mother and shares her perspectives on accessing care, interacting with service providers and facing the grief of a loss. This allows for unique insights into systems of care from the “consumers” point of view.**
- **It brings together members of the medical, public health and local community to work cooperatively to meet identified needs.**

<sup>4</sup> NFIMR Program. Fetal and Infant Mortality Review Manual: A Guide for Communities. June 1998.

<sup>5</sup> NFIMR Program. Fetal and Infant Mortality Review Manual: A Guide for Communities. June 1998.

**Figure 1: A Cycle of Systems Improvement**



# PART I: THE FIMR PILOT STUDY

## OBJECTIVES

The objectives of the FIMR pilot study are as follows:

- Conduct a FIMR review of 50 infant deaths that occurred during 2003 in Delaware.
- Introduce the FIMR process to stakeholders in Delaware by soliciting their input on the design of the pilot study, including interested persons in the case review process and reporting the results in a forum for dissemination of recommendations and lessons learned.
- Inform the Delaware Infant Mortality Task Force during the FIMR process and present the interim report on the pilot study to the Task Force for its consideration.
- Explore some of the hypotheses for the increase in Delaware's infant mortality rate.
- Provide in-depth information—including mothers' narratives—to generate recommendations for the improvement of services geared towards pregnant women and infants in Delaware.
- Train stakeholders and staff at the Division of Public Health (DPH) and other institutions who will be implementing the FIMR pilot study data collection, interview and case review activities.
- Plan for the implementation of a statewide FIMR in Delaware in conjunction with the Child Death, Near Death and Stillbirth Commission (CDND-SC), DPH and other interested stakeholders.

## STUDY METHODOLOGY

The FIMR pilot study was undertaken under the authority of the CDNDSC, the body with the statutory mandate to review such fetal and infant deaths in Delaware Code. The Commission approved the pilot study proposal and appointed Commissioners to chair the FIMR pilot study planning group. Infant death cases from calendar year 2003 were identified through vital statistics reporting. 2003 was the year chosen for review because that was the most recent year with complete reporting on linked birth-death certificates. The linked birth and death certificate file was used to identify births and deaths that occurred at Christiana Care Health System (CCHS) in that year. Fifty-six infant births resulted in a death that occurred at CCHS. Identifying information on these 56 cases was provided to CDNDSC staff in order to copy the pertinent medical records on the mother and infant previously obtained by the CDNDSC through their subpoena powers. All 56 cases had already undergone a panel or physician review as part of the current child death review protocol.

These medical records were transferred to Nemours Health and Prevention Services (NHPS) as an agent of DPH with the authority to conduct the FIMR pilot study. Information on the 56 cases was also released to collaborators at DPH in order to search the DPH database on services provided to the mothers and infants by state programs. Once the medical records and state service data were assembled, steps were taken to protect the security of the identifying information. All hard copies of the medical records were stored at NHPS in a locked file cabinet. The only identifying electronic file--the linked birth and death certificate file--was stored on the network drive, which is password protected and accessible only by the FIMR abstractor. All other electronic files are de-identified and also stored on the password-protected network drive. No identifying electronic information was stored on the hard drive of any computer at NHPS.

The medical records and state service data were quickly reviewed to determine each case's appropriateness for inclusion in the pilot study. Of the 56 possible cases, eight cases were excluded from

the FIMR pilot sample for the following reasons:

- Five cases involved an elective abortion.
- One case involved a family member in the infant's accidental death.
- One case had substantial gaps in the medical records available for review.
- One case was a misclassification, and the infant involved did not die.

Review of cases resulting from elective abortions is not permissible under the current CDNDSC legislation, nor are such cases deemed appropriate by the national FIMR model for review. Brief summaries of the remaining 48 cases were released to the DPH supervisor overseeing the maternal interviewers. The supervisor distributed cases to the maternal interviewers, who attempted to contact all mothers for an interview. As interviews were completed, the corresponding medical and state agency records for the case were abstracted at NHPS. A case summary was prepared putting together the information from the interview, if available, and medical and state service records. (See Appendix 2 for sample forms used in the FIMR pilot study.)

This case summary served as the basis for the Case Review Team's (CRT) discussion. There were two CRT panels that met over the course of three months--February to April 2005--to consider each of the 48 cases in the pilot. The CRT panels included:

- Public health nurses, supervisors and medical social workers from DPH
- Obstetricians and pediatricians
- Representatives from Children and Families First, Delaware Early Children's Center and the Delaware Chapter of the March of Dimes
- Representatives from CCHS' Women & Children's Health Services and the Alliance for Adolescent Pregnancy Prevention
- Members of the NHPS staff
- Bereavement counselors
- School health nurses and educational consultants

- Nutritionists
- Social workers
- An epidemiologist
- Community members

Please see Appendix 1 for a list of the members of the CRT panels. About 10 to 15 members attended each meeting.

The CRTs discussed three to five cases per meeting. First, CRT members identified pertinent risk factors in each case and then discussed community resources that did benefit or could have benefited this mother and family. The CRTs made recommendations based on the identified systems gaps or issues of concern. These recommendations were compiled and sorted by topic for inclusion in this report. The maternal and infant characteristics of the 48 pilot sample cases were also summarized to help discern whether the pilot sample is representative of all infant deaths in Delaware, and thus whether the recommendations arising from the pilot study are generalizable to all infant deaths. The Z-test of difference in proportions was used to compare mothers and infants in the pilot sample to a comparison group.

## RESULTS

### Summary of the 48 Infant Death Cases in the Pilot Study

The FIMR pilot sample is a subset of the total Delaware infant death cohort of 2003 and is comprised of those infants who were born and died at CCHS. About sixty percent of all births in Delaware occur at CCHS in any given year. The pilot study sample includes a total of 48 cases of infant deaths—out of a possible 56 cases—born to 43 mothers. The reasons for excluding 8 cases from the pilot study were: the mother had an elective abortion (5 cases), a family member was involved in the death of the infant (1 case), insufficient medical records (1 case) and an error in reporting (1 case). Maternal interviews were obtained for 18 cases, 38% of the FIMR pilot sample. In 21 cases (44%) the mothers refused the interview, and in 9 cases (19%) the mothers could not be located. A higher proportion of mothers who agreed to an interview were black and in their late 20's compared to those mothers who were not interviewed, a group among whom teens and Wilmington residents were overrepresented. Mothers interviewed were similar to those not interviewed in terms of educational background, health insurance status and entry into prenatal care. (Data not shown.)

For comparison purposes, mothers in the pilot study—both those interviewed and not interviewed—were compared to mothers not included in the pilot study and who had an infant death in 2003. There were 46 mothers who had infants born or die at a hospital other than CCHS in 2003. As these were mothers who also experienced an infant loss in the same year, it was felt that they form an appropriate comparison group for the pilot study sample. Data on these mothers who were not part of the FIMR pilot sample was available only from vital statistics and linked birth-death certificates.

Table 1 compares the racial background of mothers in the pilot study sample, mothers with infant deaths not included in the pilot, these two groups of mothers combined (all mothers with an infant death in 2003) and all Delaware women with live births in 2002. Forty percent of the mothers in

the pilot study are white, 56% are black and 5% are Hispanic, and these proportions are similar in the group of mothers not included in the pilot. Black women are overrepresented in the group of women with an infant loss: they account for over half of all the mothers with an infant death in 2003, but they comprise only about one-quarter of all women giving birth in the State.<sup>6</sup>

**Table 1: Maternal Race**

Maternal Race	Mothers in Pilot Sample (%)	Mothers not in Pilot (%)	All Mothers with an Infant Death (%)	DE Births (%)*
White	17 (40)	19 (41)	36 (40)	7,772 (70)
Black	24 (56)	23 (50)	47 (53)	2,706 (24)
Hispanic	2 (5)	4 (9)	6 (7)	1,313 (12)
Total	43	46	89	11,083

<http://www.dhss.delaware.gov/dhss/dph/hp/files/births02.pdf>

Maternal age is another point of comparison between the mothers in the FIMR pilot sample and those mothers not in the sample (Table 2). Both groups have a similar proportion of teen mothers. There is a higher proportion of mothers in their young 20's in the group not included in the pilot study, while the pilot sample has a higher proportion of mothers in their late 20's. About one-third of mothers in both groups are over the age of 30 years. Overall, the age distribution of the mothers included and not included in the pilot sample is not unlike that of all women giving birth in Delaware in 2002, of whom 11% were teens, 51% were in their 20's and 38% were over 30 years.

**Table 2: Maternal Age**

Maternal Age (years)	Mothers in Pilot Sample (%)	Mothers not in Pilot (%)	All Mothers with an Infant Death (%)	DE Births (%)
<20	7 (16)	6 (13)	13 (35)	1,233 (11)
20-24	8 (19)	13 (28)	21 (24)	2,799 (25)
25-29	15 (35)	11 (24)	26 (29)	2,858 (26)
30+	13 (30)	16 (35)	29 (33)	4,193 (38)
Total	43	46	89	11,083

<sup>6</sup> Delaware Vital Statistics <http://www.dhss.delaware.gov/dhss/dph/hp/files/births02.pdf> accessed 6/5/05.

Information on maternal education is presented in Table 3 for the pilot sample and the comparison groups. Compared to mothers excluded from the pilot, there were fewer mothers with less than a high school education and more mothers with some post-high school education in the pilot study sample. There were more high school graduates in the pilot sample compared to all women giving birth in Delaware in 2002.

**Table 3: Maternal Education**

Maternal Education	Mothers in Pilot Sample (%)	Mothers not in Pilot (%)	All Mothers with an Infant Death (%)	DE Births (%)
<12 yrs	6 (14)	14 (30)	20 (22)	2,224 (20)
High school	22 (51)	19 (41)	41 (46)	3,715 (34)
13-15 yrs	5 (12)	2 (4)	7 (8)	1,981 (18)
16+ yrs	10 (23)	10 (22)	20 (22)	3,057 (28)
Unknown	0	1 (2)	1 (1)	106 (1)
<b>Total</b>	<b>43</b>	<b>46</b>	<b>89</b>	<b>11,083</b>

Kent and Sussex Counties are underrepresented in the FIMR pilot sample compared to the overall proportion of infant births and deaths occurring in these two counties, but this difference was not statistically significant (Table 4). The FIMR pilot sample includes 35 mothers from New Castle County (81%)—including 12 residents of Wilmington—five mothers from Kent County (12%) and three mothers from Sussex County (7%). There is a higher proportion of mothers from suburban New Castle County included in the pilot sample (53%) than compared to the group of mothers not included in the pilot study (28%), and this difference was statistically significant ( $p < 0.001$ ). Wilmington residents are overrepresented in both the pilot and non-pilot groups, making up 30% of mothers with an infant loss, while they make up only 11% of all women delivering in Delaware.

**Table 4: Maternal Residence**

Maternal Residence	Mothers in Pilot Sample (%)	Mothers not in Pilot (%)	All Mothers with an Infant Death (%)	DE Births (%)
Suburban New Castle	23 (53)	13 (28)	36 (40)	5,909 (53)
Wilmington	12 (28)	15 (33)	27 (30)	1,254 (11)
Kent	5 (12)	10 (22)	15 (17)	1,902 (17)
Sussex	3 (7)	8 (17)	11 (12)	2,018 (17)
<b>Total</b>	<b>43</b>	<b>46</b>	<b>89</b>	<b>11,083</b>

Entry into prenatal care occurred earlier for pilot sample mothers compared to mothers not included in the pilot, and this difference was statistically significant ( $p < 0.001$ ) (Table 5). About eighty-six percent of mothers in the pilot sample and among all women giving birth in Delaware began prenatal care in the first trimester as compared to only 65% of those mothers not in the pilot sample. Non-pilot mothers tended to receive later prenatal care—15% in the second trimester and 7% in the third trimester—and a higher proportion received no prenatal care (11%) compared to any other group. Thus the group of mothers not included in the pilot study appears to have later access to prenatal care and possibly more barriers to care than mothers included in the FIMR pilot sample and all women with live births in Delaware. Of the non-pilot mothers, 55% delivered at Christiana Hospital, a proportion similar to that among all Delaware mothers giving birth in 2002. Forty-one percent of non-pilot mothers delivered at other hospitals.

**Table 5: Entry into Prenatal Care (PNC)**

Entry into PNC	Mothers in Pilot Sample (%)	Mothers not in Pilot (%)	All Mothers with an Infant Death (%)	DE Births (%)
1st trimester	37 (86)	30 (65)	67 (75)	9,619 (87)
2nd trimester	3 (7)	7 (15)	10 (11)	1,035 (9)
3rd trimester	0	3 (7)	3 (3)	259 (2)
No PNC	2 (5)	5 (11)	7 (8)	125 (1)
Unknown	1 (2)	1 (2)	2 (2)	45 (0.4)
<b>Total</b>	<b>43</b>	<b>46</b>	<b>89</b>	<b>11,083</b>

Method of payment for prenatal and obstetric care was similar between mothers in the pilot study and all women delivering in Delaware: over one-third of pregnant women were covered by Medicaid, and 58% were covered by private insurance. In contrast, mothers with infant deaths who were not included in the FIMR pilot had a higher proportion of Medicaid recipients (46%) and uninsured women (15%) (Table 6). There was a significantly higher proportion of mothers in the pilot sample with private insurance compared to the non-pilot mothers ( $p < 0.05$ ).

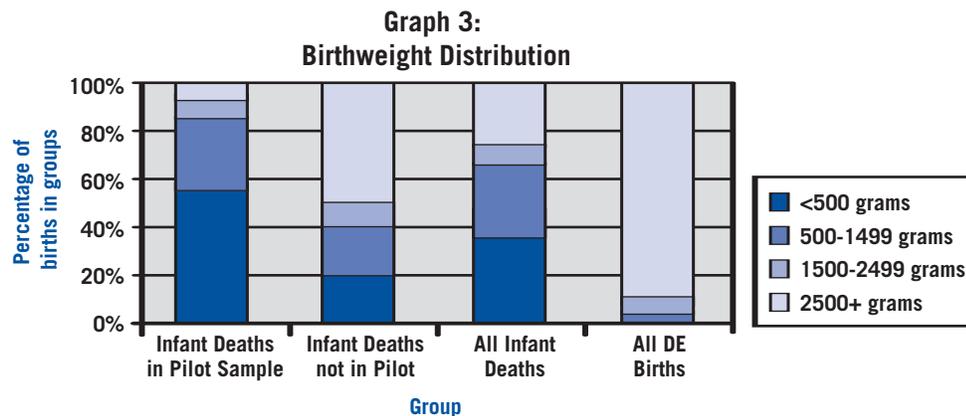
Method of Payment	Mothers in Pilot Sample (%)	Mothers not in Pilot (%)	All Mothers with an Infant Death (%)	DE Births (%)*
Medicaid	15 (35)	21 (46)	36 (40)	4,312 (39)
Private	25 (58)	18 (39)	43 (48)	6,430 (58)
Uninsured	3 (7)	7 (15)	10 (11)	307 (3)
<b>Total</b>	<b>43</b>	<b>46</b>	<b>89</b>	<b>11,083</b>

The birthweight and gestational ages of the 48 infants in the pilot sample were heavily skewed to the lower end in both categories. There were many pre-viable infants included in the pilot study as defined by being born weighing less than 500 grams (56% of the pilot sample) and/or before 22 weeks gestation (23%). Eighty-eight percent of the infants in the pilot sample were very low birthweight (VLBW) or less than 1500 grams. (See Table 7 and Graph 3.) In comparison, of those infant deaths not included in the pilot sample, only 39% were VLBW. Half of those infants not included in the FIMR pilot

sample and who died had normal birthweight (over 2500 grams), whereas only 6% or 3 infants in the pilot sample were of normal birthweight. There was a significantly higher proportion of mothers in the pilot sample with infants weighing less than 1500 grams ( $p < 0.001$ ) and less than 2500 grams ( $p < 0.01$ ) compared to the non-pilot sample. Among all Delaware births in 2002, VLBW infants comprised 2% of the total, and 90% of infants had normal birthweight.

Birthweight (grams)	Infant Deaths in Pilot Sample (%)	Infant Deaths not in Pilot (%)	All Infant Deaths (%)	DE Births (%)
<500	27 (56)	9 (20)	36 (38)	39 (0.4)
500-1,499	15 (31)	9 (20)	24 (26)	183 (2)
<1,500 VLBW	42 (88)	18 (39)	60 (64)	222 (2)
1,500-2,499	3 (6)	5 (11)	8 (9)	881 (7)
<2,500 LBW*	45 (94)	23 (50)	68 (72)	1,103 (10)
2,500+	3 (6)	23 (50)	26 (28)	9,978 (90)
<b>Total</b>	<b>48</b>	<b>46</b>	<b>94</b>	<b>11,083</b>

\*LBW Low birthweight

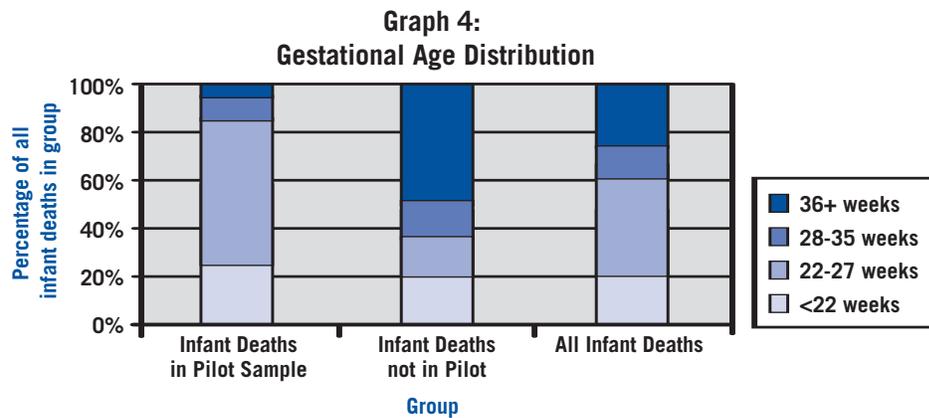


The distribution of gestational ages among infants included in the pilot sample also reveals a disproportionately large number of extremely young infants. While the proportion of pre-viable infants, less than 22 weeks gestation, is similar in both pilot and non-pilot groups, it should be noted that the non-pilot group includes 5 cases of elective abor-

tions. There are many more infants between 22 and 27 weeks in the pilot sample (60%) compared to those not in the pilot sample (17%). (See Table 8 and Graph 4.) Infants close to or at term (36 weeks and older) comprised only 6% of the pilot sample while making up almost half of those infant deaths not included in the pilot and over 90% of all Delaware births in 2002.

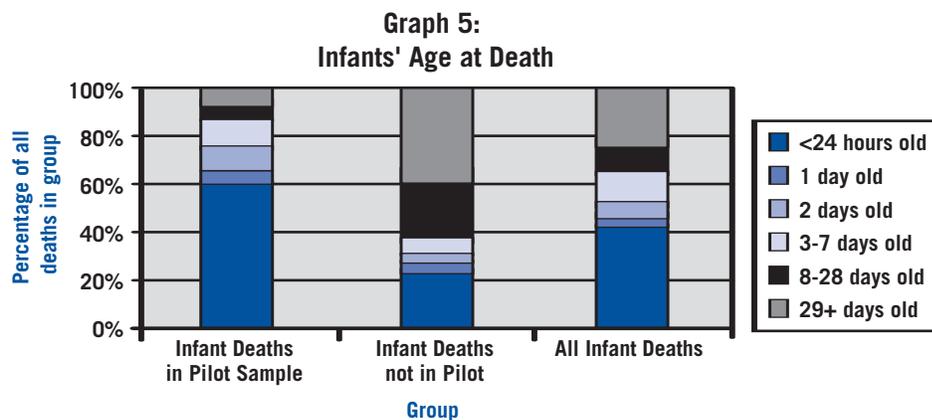
Gestational Age (weeks)	Infant Deaths in Pilot Sample (%)	Infant Deaths not in Pilot (%)	All Infant Deaths (%)	DE Births (%)
<22	11 (23)	9 (20)	20 (21)	*
22-27	29 (60)	8 (17)	37 (39)	*
28-35	5 (10)	7 (15)	12 (13)	834 (8)
36+	3 (6)	22 (48)	25 (27)	10,128 (91)
<b>Total</b>	<b>48</b>	<b>46</b>	<b>94</b>	<b>11,083</b>

\* Different gestational age cut-offs so numbers not comparable



Eighteen infants (38%) in the pilot sample were one of twins, and one infant who died was one of quadruplets. This is ten times the proportion of multiples compared to all live births in Delaware, of which only 3.9% were multiple births in 2002. None of the infants excluded from the FIMR sample were multiples. Four mothers used assisted reproductive technology (ART) to become pregnant in the pilot sample: one had a singleton pregnancy, two had twins and the fourth had quadruplets. Five of these nine infants conceived by ART died and were included in this pilot study. The use of ART is not known among those mothers excluded from the pilot study. Among all women delivering in Delaware in 2002 there were 414 ART procedures that resulted in 154 infants born or 1.4% of all live births.<sup>7</sup>

The age of death of infants in the pilot sample was also skewed to the younger ages compared to those infant deaths not in the pilot most likely as a result of the preponderance of infants with extremely low gestational ages in the pilot sample. Twenty-nine infants (60%) in the pilot sample died on their first day of life (less than 24 hours old): almost 38% of these infants were less than 22 weeks gestation, and 55% were between 22 and 27 weeks gestation. Among those infants excluded from the pilot and who died less than 24 hours old, 70% were less than 22 weeks gestation and 30% were 30 weeks gestation or older. Ninety-two percent of the infants in the pilot sample died in their first 28 days of life and hence are neonatal deaths as compared to about 60% of the infants excluded from the pilot. Graph 5 presents the distribution of the ages at death of infants in and out of the FIMR pilot sample as well as for these two groups combined.



<sup>7</sup> Wright, V.C., Schieve, L.A., Reynolds, M.A., and Jeng, G. Assisted Reproductive Technology Surveillance—United States, 2002. In: Surveillance Summaries, June 3, 2005. MMWR 2005: 54 (No. SS-2): p. 14.

The most common cause of death in the pilot sample was prematurity and its ensuing complications: this accounted for 41 infant deaths or 85% of the pilot sample (Table 9). In contrast, complications of prematurity made up only 20% of the deaths in the non-pilot sample. There were more infants dying of congenital or genetic abnormalities and Sudden Infant Death Syndrome (SIDS) in the non-pilot sample. Of the three term infants included in the pilot, one died from SIDS and two died with the cause of death as Sudden Unexplained Death in Infancy (SUDI). Some of the other causes of death in the non-pilot sample included cardiac complications, renal failure, meconium aspiration, neoplasm, neurological abnormalities, elective abortion, birth asphyxia and complications of pregnancy.

Cause of Death	Infant Deaths in Pilot Sample (%)	Infant Deaths not in Pilot (%)	All Infant Deaths (%)
Complications of prematurity	41 (85)	9 (20)	50 (53)
Congenital or genetic abnormality	3 (6)	10 (22)	13 (14)
SIDS	1 (2)	7 (15)	8 (9)
Sepsis	1 (2)	3 (7)	4 (4)
SUDI	2 (4)	0	2 (2)
Accident	0	2 (4)	2 (2)
Other	0	15 (33)	15 (16)
<b>Total</b>	<b>48</b>	<b>46</b>	<b>94</b>

In summary, the FIMR pilot study sample is not representative of all infant deaths in Delaware. The infant deaths included in the FIMR pilot differ from those deaths not included in the pilot sample in some notable ways:

- There is a significantly higher proportion of cases from suburban New Castle County in the pilot sample ( $p < 0.001$ ) compared to the non-pilot sample. The proportion of cases in both samples from Kent and Sussex Counties was statistically similar.
- There is a significantly higher proportion of cases of mothers who initiated early prenatal care in the pilot sample compared to the non-pilot sample ( $p < 0.001$ ).
- A greater proportion of mothers included in the pilot sample had private health insurance compared to those mothers excluded from the pilot ( $p < 0.05$ ).
- There are about twice as many infants born at very low birthweight (less than 1500 grams) in the pilot

sample compared to the non-pilot sample, and this difference was statistically significant ( $p < 0.001$ ).

- Most infants included in the pilot sample were of very young gestational age and only 6% were close to or at term. In contrast, among those infants not included in the pilot, almost half were close to or at term.
- There is a higher proportion of infants dying from the sequelae of prematurity and in the neonatal period in the FIMR pilot sample as compared to those infants not included in the pilot.

Most of these differences may arise from the fact that only CCHS cases were included in the pilot study. CCHS is the only tertiary NICU collocated with a high-risk obstetric inpatient service in the state and hence is the primary referral center for high-risk obstetric deliveries. This fact may account for the higher proportion of extremely premature infants in the pilot sample and the higher proportion of mothers with better access to healthcare services as measured by the indicators of entry into prenatal care and insurance status. These differences between the pilot sample deaths and those infant deaths not reviewed should be kept in mind when considering the recommendations from the FIMR pilot study.

## CRT Findings: Recommendations Based on the FIMR Pilot Sample

The FIMR pilot study CRTs met regularly over a three-month period to discuss the 48 infant death cases. There were two CRT panels that met on alternating weeks, and each panel reviewed 24 different cases. The CRT panels ranked the amount of information available for review on each case. Table 10 presents the ranking of the completeness of the case summaries reviewed in the pilot study.

Information available for review	Cases in pilot sample (%)
Minimal information (0-25% complete)	5 (10)
Major gaps (25-50% complete)	24 (50)
Minor gaps (50-75% complete)	10 (21)
Substantially complete (75-100% complete)	4 (8)
Undetermined	5 (10)
<b>Total</b>	<b>48</b>

In 50% of the cases there were major gaps in the information available in the case summary. The most common gaps resulted from the lack of a maternal interview, incomplete or unavailable prenatal records and incomplete hospital records. Common components of the hospital records that were not available for case summary included: daily physician progress notes, daily NICU notes, consult notes and detailed bereavement counseling documentation. In 10% of cases the CRT panels did not specify the quality of information available for review.

Given that in many cases complete medical records were not available for summary and review, the ability to determine pertinent risk factors varied from case to case and by the nature of the risk factor itself. In cases without a maternal interview, risk factors such as maternal life stressors, mental health issues or inadequate bereavement support were not easily discernible. Other factors, such as the occurrence of chorioamnionitis or current smoking status, were more readily captured in the hospital records, and so the estimated prevalence of such factors is probably more accurate. This variability in the accuracy of various risk factors' estimated prevalence among pilot cases should be kept in mind.

Despite the limitations in data quality, there is still much that was learned from the information available on the 48 cases reviewed and from the discussion that ensued in the multidisciplinary setting of the CRT panels. In most cases, if a maternal interview was obtained, the social worker who met with the mother was present for the CRT discussion. In this way, the social worker could add more detail and answer some of the questions that arose during the discussion. The CRT panel members had a wealth of experience in public health and clinical care. Many ideas were triggered by the details presented by the pilot sample cases together with the CRT panelists' collective background experience. Below are the top five issues identified through the review of the pilot sample cases:

1. Preterm labor
2. Healthcare system linkages
3. Bereavement counseling
4. Preconception and interconception care
5. Nutrition counseling.

For a complete listing of all the CRT recommendations, please see Appendix 3.

### 1. PRETERM LABOR

**The Issue:** In 65% of the pilot sample cases the mother went into preterm labor. Forty-four percent of all cases in the pilot involved women with incompetent cervix and 37% involved women with chorioamnionitis. These percentages are much higher than in the general population of pregnant women as described in the literature: the prevalence of preterm births (before 37 weeks) is about 11% in the U.S. and preterm births before 28 weeks occur in about 1.9% of births to Black women and 0.5% of births to White women.<sup>8</sup> Chorioamnionitis occurs in 1-5% of term pregnancies and up to 25% of preterm deliveries.<sup>9</sup> Also, 40% of the pilot sample cases involved multiple gestation and 30% of the pilot sample mothers had a history of preterm delivery. Both these factors are known risks for preterm labor.

<sup>8</sup> Holzman, C. Preterm Birth: From Prediction to Prevention. Am J Public Health 1998; 88(2): p. 183.

<sup>9</sup> Gabbe, S.G., Niebyl, J.R. and Simpson J.L. Obstetrics: Normal and Problem Pregnancies, 4th ed. Churchill Livingstone, Inc. 2002: Orlando, FL: p. 1301.

The preponderance of preterm labor and the fact that many mothers in the pilot sample presented late to medical attention with advanced preterm labor and/or cervical dilation raised the CRT panels' concern. The CRT panels made specific recommendations to address the issue of preterm labor in 11 of the 48 pilot sample cases.

**Many women did not appear to correctly identify early signs of preterm labor or chorioamnionitis. In the words of one maternal interviewer:**

**“(The mother) did not receive enough information on preterm labor signs and symptoms. She felt that since she was a first-time mother, she did not recognize the difference between contractions and fetal movement.**

**It was not until the mother was having an ultrasound that contractions were pointed out to her. She then realized that she had been having contractions (since) 4 months.”**

**The Recommendation:** There is a need for a more comprehensive approach to preterm labor education.

- Education on the signs and symptoms of preterm labor should begin with the first prenatal visit and be reinforced throughout pregnancy.
- Prenatal classes for mothers with risk factors for preterm labor—such as a history of preterm labor or multiple gestation—should be promoted and offered in more venues. The classes should cover the risks of prematurity to the infant in order to help women become informed decision-makers if an emergency arises.
- Videos that educate on preterm labor and the risks of prematurity could be disseminated for use in clinic waiting areas, thus reaching a wider audience of pregnant women.
- Potential partners in this endeavor include the American College of Obstetricians and Gynecologists, a group which sets the professional standards of care for prenatal education, and the March of Dimes, an organization committed to increasing public awareness on the risks of prematurity.

## 2. HEALTHCARE SYSTEM LINKAGES

**The Issue:** Review of 12 cases in the pilot sample prompted the CRT panels to make a specific recommendation based on the delay in follow-up or inadequate referrals made for high-risk pregnant women. Of particular concern were women on Medicaid followed by private physicians, women with psychosocial issues or women with risks identified in the emergency room or hospital setting. The prevalence of psychosocial issues was high in the pilot sample: 42% of the pilot sample mothers had significant life stressors, and 28% of them had some kind of mental health issue evident on case review. In 9% of FIMR pilot sample cases mothers had care that was described as fragmented between several providers.

**Many of the women who were eligible for help did not receive referrals to public assistance and public health programs.**

**One illustrative case involved a mother who had to switch from private insurance to Medicaid upon becoming pregnant as her private plan did not cover prenatal care. The mother developed pre-eclampsia and was put on bedrest. According to the maternal interviewer: the mother “was stressed about finances. . . . (She) used all her vacation pay to pay rent and food bills . . . (and) was not aware of economic (assistance) services until after she delivered” at 26 weeks gestation.**

**The Recommendation:** Facilitate the screening and referral of high-risk pregnant women to increase access to case management, mental healthcare and public assistance programs as appropriate.

- Develop and distribute a community resource list to obstetric and family practice clinics. This community resource list should be given to all pregnant women regardless of their insurance status and would include information on preterm labor and Medicaid application and eligibility.
- A toll-free phone number and website should be developed to allow women to get help in accessing needed services.

### 3. BEREAVEMENT COUNSELING

- Develop and disseminate a mini psychosocial screening tool for obstetric providers, office staff, emergency room staff and hospitals to screen all pregnant women for mental health and social assistance needs.
- Work towards a single point-of-entry system for pregnant women and providers.
  - Promote a toll-free number and website that women can use to access care. One possibility is to add prenatal referral capabilities to the Delaware Helpline.
  - Develop and promote an easy to use DPH access number for providers to call and refer any woman identified at-risk by the mini psychosocial screen. Providers may also use this number to refer women who have missed prenatal care appointments and may need more help getting to the clinic or women who have had a miscarriage or intrauterine fetal demise and may need bereavement counseling. The referral number should access DPH social workers who can then do a more complete assessment and connect the mother with other referrals or case management services.
- Improve communication and adequacy of follow-up between primary obstetric providers, emergency room staff, obstetric in-patient triage, hospital discharge planners and DPH.
  - Provide in-service education on the different types of home visiting services and case management services available in the community to hospital discharge planners and hospital social workers.
  - Work with professional groups and hospitals to promote the timely and systematic transfer of records between hospitals and primary obstetric clinics.

**The Issue:** Many women with infant losses are not accessing bereavement support services. Some of these women refused support services offered, others may not have felt comfortable with the type of services offered. In most cases, bereavement support is affiliated with hospitals and thus may not be easily attended by some families who are culturally isolated from the medical system. The adequacy of bereavement support services was difficult to assess in cases without a maternal interview but was deemed a factor in 19% of the all the pilot cases. As noted before, in another 28% of cases mental health issues were identified and could accentuate the mother's need for professional help to work through her grief.

#### **Inadequate bereavement support as an issue was raised in 11 cases and prompted the CRT recommendation to address the concern.**

- **In one case, a mother who did receive support from a variety of sources articulates the importance of quality services: “People made assumptions on how I should feel and react. (Bereavement support) professionals did not expect me to be an intelligent, educated woman and take care of my own health care needs.”**
- **Another woman describes the need for “support groups and people like me that I could relate to, that suffered the same thing I had been through.”**
- **Emphasizing the need for continuing support after hospital discharge, one mother states that the counseling “she received at the hospital immediately after the death . . . could have been followed up by a more pro-active follow-up procedure” and “more aggressive outreach to mothers.”**

**The Recommendation:** There is a need for more culturally appropriate and community-based bereavement support services.

- There should be a standardized packet of information distributed to families in the hospital that contains grief counseling resources in the community. Providing a standard packet will assure that all women receive some basic information for their review at a later time when they are more able to process information and access help.
- All mothers with a fetal or infant loss should receive a phone call from a bereavement counselor after discharge from the hospital to provide the mother with another opportunity to ask questions, receive counseling and be referred for services.
- Community resources for bereavement support should be culturally appropriate. There is a particular need for more peer support and community-based services for Black women in Wilmington; potential community partners to meet this need include churches, funeral parlors and the Mental Health Association.
- More home visiting services are needed to provide one-on-one support for women and men who do not feel comfortable in a group setting.

#### 4. PRECONCEPTION AND INTERCONCEPTION CARE

**The Issue:** Concern about the mother's preconception and interconception—between pregnancy--health was raised specifically in 12 cases reviewed. The preconception and interconception periods are very important in the health of the mother and of her infant, and a notable proportion of the FIMR pilot sample included women who had suboptimal health as evinced by significant medical issues, significant past obstetric history or poor lifestyle choices at the time of pregnancy.

**28% of the mothers in the pilot sample had chronic medical issues.**

**26% were current smokers.**

**30% had a history of prior preterm delivery and/or a low birthweight infant.**

**19% had unintended pregnancies.**

**19% had short inter-pregnancy intervals (less than 6 months).**

**These latter two factors were not always discernible in the review of cases lacking a maternal interview, and so it is likely that their prevalence is underestimated in the pilot sample.**

**The Recommendation:** There should be a comprehensive strategy to expand the vision and the provision of preconception and interconception care to encompass all women and not only those who want to become pregnant.

- Develop a public education campaign to promote women's health especially among groups at risk for poor health and pregnancy outcomes. This education should begin in school, for example in Wellness Centers, and promote healthy lifestyle choices.
- A consistent message on healthy lifestyle should be repeated in many venues where women access the healthcare system including OB/GYN care, family practice visits, family planning visits, sexually transmitted disease (STD) clinics and ART visits. All these venues are potential opportunities for identifying risk factors and counseling women on risk modification. Of particular importance would be counseling women with a negative pregnancy test and identified risk factors.
- For women with a history of poor pregnancy outcomes or significant risk factors, provide wrap-around services such as case management to prolong inter-pregnancy intervals and modify risk factors. Such services should include nutrition counseling, family planning, genetic counseling, general health checks, psychosocial screening and bereavement support as appropriate. The level of services should be stratified based on the woman's level of risk for subsequent poor pregnancy outcomes.

## 5. NUTRITION COUNSELING

**The Issue:** Twenty-one percent of pilot mothers were determined by the CRT panels to have inadequate weight gain during pregnancy. Five percent had excessive weight gain, and 9% had some other nutritional issue. Thirty-seven percent of mothers were obese. The concern voiced by the CRT panels was that of inadequate or excessive weight gain during pregnancy among women with such risk factors as multiple gestation, obesity or chronic medical conditions. This resulted in the following recommendation on nutrition during the discussion of 6 pilot cases.

**The Recommendation:** Nutrition counseling services should be more widely available and reimbursable as a standard of care in pregnancy, especially among high-risk women.

- All high-risk women, such as those with multiple gestation, diabetes, obesity or chronic diseases, should be referred for nutrition counseling.
- Expand nutrition counseling services in the private sector.
- Providers should be educated on the importance of regular weight checks, assessment of appropriate weight gain and nutritional histories as standards of prenatal care.
- Work with insurance companies to increase reimbursement for nutrition services and counseling.

### **The CRT panels also made recommendations on the following topics:**

- **Mental health**
- **Access to care**
- **Medicaid**
- **Medical care and quality assurance**
- **Teen pregnancies**
- **Health insurance**
- **Family planning**
- **Smoking**
- **Workplace stress**
- **Unsafe infant sleep practices**
- **Infections during pregnancy**
- **Reporting of live births, infant deaths and fetal deaths**

**For a complete list of the CRT recommendations please see Appendix 3.**

## DISCUSSION

### Limitations of the Pilot Study and Lessons Learned

There are some limitations to the FIMR pilot study that should be put forth along with the lessons learned as these lessons were most informed by the challenges faced in the course of conducting the pilot. First, based on the method of selecting cases and limiting inclusion to births and infant deaths occurring at CCHS, the pilot sample is not representative of all infant deaths in Delaware. As noted before, the pilot sample appears to differ from the infant deaths excluded from the pilot on the maternal characteristics of area of residence, insurance status and entry into prenatal care. The pilot sample also differs from those cases not included on the infant characteristics of gestational age at birth, birthweight and cause of death: the cases included in the pilot tended to be younger infants and had a higher proportion of infants dying from complications of prematurity in the neonatal period. There were few cases of term infants and postneonatal deaths included in the pilot sample. These comparisons suggest that there may be some important differences in those cases not reviewed that would make them different from the cases included in the pilot study, and hence the recommendations derived from the pilot study may not be generalizable to all infant deaths in Delaware.

- There is a higher proportion of cases from suburban New Castle County and fewer cases from Kent and Sussex Counties in the pilot sample.
- A greater proportion of mothers included in the pilot sample had early prenatal care compared to those mothers excluded from the pilot.
- A greater proportion of mothers included in the pilot sample had private health insurance compared to those mothers excluded from the pilot.
- There are about twice as many infants born at very low birthweight (less than 1500 grams) in the pilot sample.
- Most infants included in the pilot sample were of very young gestational age and only 6% were close to or at term. In contrast, among those infants not included in the pilot, almost half were close to or at term.
- There is a higher proportion of infants dying from the sequelae of prematurity and in the neonatal period in the FIMR pilot sample as compared to those infants not included in the pilot.

However, the pilot study did cover over half the cases of infant deaths in 2003 that occurred in the State. The fact that some recurring themes became evident during the case reviews does suggest that there were issues of public health importance uncovered in the pilot sample. Also, based on the description of the maternal and infant characteristics, the pilot sample does seem to provide more insight on the population of mothers described in a recent analysis as having the greatest increase in infant mortality rates among very low birthweight infants.<sup>10</sup> This again suggests that the issues raised by the review of the pilot sample cases are of public health importance.

A second limitation of the pilot study was the limited availability of records and maternal interviews for case review. In about 50% of the cases, the CRT

<sup>10</sup>Centers for Disease Control and Prevention. Increasing Infant Mortality Among Very Low Birthweight Infants—Delaware, 1994-2000. MMWR 2003; 52: pp. 862-866.

panels felt that there were major gaps in the information available for review. This does affect the CRT's ability to identify systems issues and risk factors associated with each case. Some information was more readily available from hospital records, but other information—particularly pertaining to the mother's life and psychosocial well being—was hard to discern in the absence of a maternal interview.

The response rate of 38% in the maternal interviews was actually higher than predicted at the outset of the pilot. Based on discussions with staff at the National FIMR Program, it was thought that about 20-30% of mothers would accept the maternal interview. In FIMR programs that are well established, the maternal interview acceptance rate can be as high as 60-70% when contact is initiated in the first three months after an infant death.<sup>11</sup> The major challenge in the pilot study was that the mothers included were up to two years out from the infant death, and so often times just getting an accurate address or phone number for the mother was difficult. Many of the mothers, once contacted, said that they did not want to re-open the memories of the infant loss and they had moved on. However, for those women who did agree to an interview, they often had much to share about their experience. The maternal interviewers heard unresolved feelings of grief and unrecognized opportunities to provide help to the mother. When appropriate, the maternal interviewers referred the mothers, some of whom were pregnant again, to needed services such as Smart Start, WIC or family planning.

The limitations of the pilot study are part of the learning curve and the experience gained in executing the pilot can inform the plan for the long-term implementation of FIMR in Delaware. The first lesson learned is that it is important to include infant deaths from all three counties as there may be different populations at risk in different areas and varied health system issues. Delaware is small enough that to review all cases of infant deaths, about 100 per year, is a feasible number. Alternatively, a random selection of cases from each county could be included for review. It may also be beneficial to convene separate CRT panels by county or city to really look closely at community-level systems issues. A second lesson learned is that data collection for

FIMR needs to be supported by more complete medical records requested by subpoena. This may involve reviewing the initial records provided by the delivering hospital and identifying further clinics or practices to subpoena for records. This step-wise approach would lengthen the case abstraction process but improve the quality of data for CRT review.

Finally, the maternal interview should be done in the initial one or two months after the infant death and be incorporated into the provision of bereavement support services to the mother and family. In this way, the maternal interview acceptance rate may increase, and, more importantly, the mother would feel better supported by the long-term relationship established with a medical social worker who has bereavement counseling expertise. These lessons learned and other proposed details for the implementation of FIMR are presented in Part II of this report.

<sup>11</sup> NFIMR. A Guide for Home Interviewers. p. 18.

## The Infant Mortality Task Force and FIMR

There are some notable areas of overlap and links between the findings of the FIMR pilot study and the Report of the IMTF released May 2005. FIMR itself is the first recommendation of the IMTF report and is an integral part of other recommendations enumerated in the report. For example, FIMR would be part of the continuous quality improvement “for services and programs developed to eliminate infant mortality” as stated in Recommendation 12 of the IMTF report. FIMR provides on-going feedback on programs. By an in-depth review of cases as is done through FIMR, qualitative insights and trends in service delivery can be revealed from the point of view of the women and families who should be or are actually receiving program services. This type of feedback is not provided by any other means apart from the systematic and long-term implementation of FIMR.

The FIMR database as described in Part II of this report could also be part of the “epidemiological surveillance system to evaluate and investigate trends and factors underlying infant mortality and disparity,” as stated in Recommendation 13 of the IMTF report. The FIMR database can be tailored to meet Delaware’s specific needs and the research agenda on infant mortality. The FIMR database can also match the information collected through the Pregnancy Risk Assessment Monitoring System (PRAMS), which is Recommendation 2 of the IMTF report. The re-establishment of PRAMS would benefit FIMR as PRAMS would provide a comparison group for the FIMR data. PRAMS could provide data on the prevalence of some risk factors in the population of all pregnant women in Delaware, and this would be the denominator for FIMR’s estimate of the prevalence of those same risk factors in the subset of women who experience a fetal or infant death. In this way, more qualitative and specific comparisons can be made between all pregnant women and women with a fetal or infant death in Delaware. These comparisons can better inform policy, future research and program planning to reduce infant mortality and improve maternal health.

There are also some common areas of recommendations between the FIMR pilot and the IMTF report. Recommending increased efforts to promote preconception and interconception care is one such commonality. The IMTF report recommends establishing standards of care for services in preconception and interconception health, requiring insurers to cover those services and increasing comprehensive case management services to provide the care (Recommendations 6, 7 and 8 of the Task Force Report.) The CRTs involved in the FIMR pilot also put forth improving women’s preconception and interconception care as a priority. FIMR case review recognizes the need for more private and public sector linkages to support expanded case management services, and FIMR recommendations include some proposed steps to strengthen those linkages. Finally, the IMTF report Recommendation 15, “Conduct a statewide education campaign on infant mortality targeted at high-risk populations” is similar to the FIMR recommendation of increasing the vision of preconception and interconception health to include promoting healthy lifestyle choices for women through a multi-pronged approach.

To move forward on the agenda put forth by the IMTF report and the findings of the FIMR pilot will take coordinated, committed action. The challenges are great, but so are the opportunities backed by political and social will.

## **PART II: PLANNING FOR FIMR IN DELAWARE**

## OBJECTIVE

The next steps for FIMR in Delaware are to continue to build upon the groundwork of the pilot study and expand towards statewide implementation of the FIMR model. The experiences of the FIMR pilot study, the advice from experts at the National FIMR Program and the input of committed Delaware professionals in the field of public health and medicine inform the following FIMR implementation plan. This proposed FIMR plan is intended to be a starting point to open the dialogue on the best practices of FIMR that can be applied to its role in Delaware.

## AN OVERVIEW OF CONSIDERATIONS FOR FIMR IN DELAWARE

### Coordinating with the Child Death, Near Death and Stillbirth Commission

Based on current legislation and a common purpose to prevent all causes of infant and child mortality, FIMR can exist under the authority of the CDNDSC in Delaware. The CDNDSC in Delaware is charged with reviewing all deaths of children up to the age of 18 years. In recent years the mandate of the Commission was expanded to include review of stillbirths down to 27 weeks gestation. With this change to include stillbirths, the scope of the CDNDSC in Delaware is broader than for comparable bodies in other states, and a commonality of goal and mission makes the CDNDSC the appropriate home for FIMR. The CDNDSC review is intended to identify preventable points of intervention to reduce child morbidity and mortality and to improve the systems of care for child health and welfare in the state. The Commission has subpoena power to obtain medical records and to call witnesses with knowledge on the child death. Regional panels in New Castle County and Kent and Sussex Counties review information from medical records and state agencies on each child death to identify recommendations for improving systems of care for children. These recommendations are then presented to the Commission for inclusion in the report to the Governor.

Nationally, there are models for various levels of integration between FIMR and child death review processes.<sup>12,13</sup> These models build upon the similarities between the two mortality review processes: both processes stress identifying points of prevention to reduce future child and infant morbidity and mortality through systems change. However, there are factors that differentiate the two types of reviews that are worth bearing in mind. FIMR tends toward a more public health emphasis with involvement of community groups as well as health providers. FIMR cases often do not involve traditionally preventable causes but, through the maternal interview, may be able to provide feedback on the health and social

service systems of care from the consumer's—the mother's—perspective. Child death reviews include participants from law enforcement and criminal justice and thus tend more to focus on child welfare and protection services and the systems of care that identify and prevent child abuse. In Delaware this role of the CDNDSC has been expanded with the recent legislation to authorize review of child abuse or neglect cases that result in near death.

FIMR and child death review also have some procedural differences in the review processes themselves. While both FIMR and child death reviews involve closed meetings and records that are confidential, in the FIMR case review the case is de-identified by the abstractor who has previously compiled all available records on the case and striped the case summary of identifying information on the family and providers involved. In the child death review, the case identifiers are included at the time of the review, and each agency on the review panel brings forth any information in their records on the case.

Beyond the differences of the two processes, the opportunities also exist to improve both FIMR and child death review by sharing best practices and making them common to both reviews.<sup>14</sup> In Delaware the integration of FIMR and child death review may enhance efficiency of common steps such as subpoena of medical records and database tracking. To begin, there can be one system to identify fetal, infant and child deaths through vital statistics reporting. The Office of Vital Statistics can forward linked birth and death certificates or fetal death certificates to the CDNDSC on a current basis. CDNDSC staff can then generate case numbers and issue subpoenas to procure the medical records for review. In addition to the child or fetus' medical records, the mother's prenatal and delivery records should also be included in the subpoena request. (See Appendix 4 for diagrams of the process flow.) The CDNDSC staff can also send requests to state agencies such as DPH, Department of Services for Children, Youth and their

<sup>12</sup> Hutchins, E., Grason, H. and Handler, A. FIMR and Other Mortality Reviews as Public Health Tools for Strengthening Maternal and Child Health Systems in Communities: Where Do We Need To Go Next? *MCH Journal* 2004; 8(4): 259-268.

<sup>13</sup> NFIMR. FIMR and Child Fatality Review: Opportunities for Local Collaboration. [http://www.acog.org/departments/dept\\_notice.cfm?recno=10&bulletin=1139](http://www.acog.org/departments/dept_notice.cfm?recno=10&bulletin=1139) accessed 2/9/05.

<sup>14</sup> NFIMR. Transferring Components of the Fetal and Infant Mortality Review Methodology to Maternal Mortality Review and Child Fatality Review. [http://www.acog.org/departments/dept\\_notice.cfm?recno=10&bulletin=2353](http://www.acog.org/departments/dept_notice.cfm?recno=10&bulletin=2353) accessed 2/9/05.

Families, and law enforcement for any further information on the child and mother involved in a death. CDNDSC staff can then compile the medical records as well as the state agencies' records.

At this point the CDNDSC Executive Director and FIMR Coordinator can triage the cases for FIMR or child death panel review. Written criteria would need to be developed to systematize the triage process, but primarily the triage decision should be based on the age of the child at death and the cause of death. Cases of infant death, occurring in the first year of life, should go to FIMR. However, cases of suspected abuse or neglect, even if occurring in the first year of life, should be referred for child death panel review. Sudden Infant Death Syndrome (SIDS) and Sudden Unexplained Death in Infancy (SUDI) cases could go either to child death review or FIMR or could go to both review processes for a more thorough consideration.

The FIMR Coordinator can begin abstracting the medical and state agencies' records of selected cases. Early on, the FIMR Coordinator should notify the maternal interviewer so that contact with the mother can be initiated.

**Based on the pilot study experience, it would be most beneficial for the maternal interviewer to have a close working relationship with DPH medical social workers who do case management and outreach as the maternal interviewer may need to refer mothers to DPH for follow-up. A memorandum of understanding could be developed to define the roles and responsibilities of DPH in this partnership to support and follow-up FIMR cases.**

After interviews have been completed and the record abstractions have been done, the FIMR Coordinator can compose a case summary to be presented to the FIMR CRT. A CRT meeting monthly can review 3-4 cases in two hours. There could be one CRT for New Castle County and one for Kent and Sussex Counties, but the numbers of CRTs may change based upon the number of fetal and infant death cases in a particular area. For example, by tracking FIMR cases, it may become clear that the

issues for women in Wilmington are different enough and the FIMR case load high enough to warrant the establishment of a separate CRT for the City of Wilmington. In a year a single CRT could review about 40 cases, so three to four CRTs could cover all the infant and fetal death cases in Delaware in a year. The FIMR Coordinator can compile the recommendations from the CRT discussions and present them to the child death panels or to the Commission directly.

Once approved by the Commissioners, FIMR and child death review recommendations can be reported jointly to the Governor, the Legislature, the Child Protection Accountability Commission, the Director of DPH and the public. An annual conference to share the recommendations and raise awareness on important issues relating to fetal, infant and child mortality may be helpful to further the agenda for change.

Turning recommendations into action steps, there may be another opportunity for close collaboration with one combined action planning process for FIMR and child death review. (See Appendix 4.) FIMR and CDNDSC staff can compile recommendations and triage them for consideration by one or more of three action teams: a legislative action team, a state agencies' team and a community action team. One or all of the action teams may consider each recommendation. The legislative action team would work on advocacy and policy changes at the level of the Delaware General Assembly to further the recommendations and reduce infant and child mortality. This team would consist of members involved in politics, advocacy, budget appropriations and policy-making. The state agencies' team would interpret recommendations and find avenues for changes within state agencies to implement the recommendations. Members of this planning team should be executive level staff with the ability to make policy

## The Role of the Division of Public Health

For the successful integration and implementation of recommendations coming out of the FIMR and child death review, there is a need to expand the role of DPH as an integral part of the review and action planning steps. First, the CDNDSC legislation could be revised to allow the Director of DPH membership on the commission. Second, as part of the FIMR data gathering, maternal interviewers should work closely with DPH medical social workers to refer and provide follow-up for mothers and families. FIMR maternal interviews could be integrated with the current bereavement support activities of DPH medical social workers in which the interview may serve as a needs assessment and history-taking tool. In the course of the FIMR interview, the maternal interviewer may identify case management, bereavement support or referral needs for the mother with the fetal or infant loss. This same social worker could then continue to follow the family to provide for those needs to the extent possible. If the maternal interviewer's caseload becomes too great, she should work closely with DPH staff to ensure that the mother is followed up in an appropriate manner by one of DPH's medical social workers. This model maximizes continuity of care for the mother and family involved.

In the implementation phase, many of the FIMR and CDNDSC recommendations will involve functions or programs that fall under the authority of DPH, and hence there should be executive level representatives from DPH on both the legislative action team and the state agencies' team. There may also be a role for an Implementation Coordinator who is also a high-level DPH executive and can oversee the coordination of the action teams' efforts, track the implementation steps and work closely with the CDNDSC Executive Director and the FIMR Coordinator. This would enhance the role for DPH in the action implementation steps as well as further the coordination between the CDNDSC and DPH.

- **The legislative action team would work on advocacy and policy changes at the level of the Delaware General Assembly to further the recommendations and reduce infant and child mortality.**
- **The state agencies' team would interpret recommendations and find avenues for changes within state agencies to implement the recommendations. Members of this planning team should be executive level staff with the ability to make policy and program changes within their respective agencies.**
- **The community action team (CAT) is comprised of members from the community who can bring the community's perspective to interpret recommendations into feasible action steps at the local level.**

and program changes within their respective agencies. Some changes may also need to be coordinated between agencies, and the forum of the state agencies' team would allow for more points of integration and coordination.

Finally, the community action team is based on the National FIMR model but may be adapted to implement recommendations coming from both the FIMR and child death review processes. The community action team (CAT) probably benefits from being more geographically defined. For example, a separate CAT may represent each of the counties and the City of Wilmington. The members should be involved in their community and be able to bring the community's perspective to translate recommendations into feasible action steps based on local culture and resources available. Depending on the recommendation at hand, CATs may establish task forces or sub-teams to bring together the appropriate stakeholders to carry out particular projects.

FIMR staff and CDNDSC staff would help coordinate and facilitate communication between the action teams, as well as report back to the Commission on the progress to date on implementing recommendations. The action steps should be included in the annual report to the Governor and other stakeholders.

## Staffing and Budget

Staffing for FIMR may be coordinated with the staffing and capabilities of the CDNDSC. To accommodate the added case load of work—an estimated 120 cases per year of which about 40 are fetal deaths over 27 weeks gestation—three full-time staff could carry out FIMR activities: a FIMR Coordinator, a maternal interviewer and an administrative specialist (Appendix 5). The FIMR Coordinator would need to have some medical background as he or she would be responsible for medical record abstractions as well as other functions such as: coordinating and running trainings, preparing case summaries, facilitating CRT and action team meetings, managing the FIMR database and coordinating with the CDNDSC Executive Director. The CDNDSC Executive Director and the FIMR Coordinator could also work collaboratively to develop a marketing and communications strategy for the FIMR program, build a funding base for FIMR activities and keep community partners engaged in the process.

The maternal interviewer may be one medical social worker or a full-time position split amongst two or more social workers. The maternal interviewers would conduct the interviews and report back to the CRT as needed. The rest of their time would be spent providing bereavement support and case management services to families identified through the FIMR process. In-state travel costs will be greatest for the maternal interviewers and should be factored into the budget.

The administrative specialist would help maintain the database for FIMR, schedule meetings and provide administrative support for the FIMR Coordinator.

Also to be considered in the budget are some contractual services. Depending on the level of medical expertise of the FIMR Coordinator, it would be beneficial to have a physician consultant to help train the FIMR Coordinator to do medical record abstractions and to answer any medical questions that may come up while writing the case summary or presenting to the CRT. The physician consultant should be familiar with the FIMR process and would play a

role in the start-up of FIMR to ensure integrity of the process. Information technology support to create a FIMR database specific to Delaware's needs and to interface with the CDNDSC database will also be needed in the first year. Other budget line items are given in Appendix 5.

## RECOMMENDED STEPS TO IMPLEMENT FIMR IN DELAWARE

### Legislative Issues

Working to implement legislative changes that institutionalize FIMR would mandate its continuation in Delaware. To that end, FIMR should be included as a part of the CDNDSC functions enumerated in the Delaware code (Title 31 “Welfare,” Part I, Chapter 3, Subchapter II). The suggested changes to the legislation include:

- Establish the FIMR CRTs and community action teams in Delaware based on the national FIMR model.
- Expand the Commission membership to include the Director of DPH and the chairpersons of the FIMR CRTs.
- Lower the gestational age of fetal deaths to be included for FIMR review to 20 weeks, but still exclude any fetal deaths resulting from an elective medical procedure. This would make State protocols consistent with those advocated by the National FIMR Program.
- Maintain the confidentiality of all FIMR records, and grant immunity to FIMR participants as long as they are acting in good faith.
- Make the implementation of FIMR contingent on adequate funding.

These changes have been drafted as a bill that was introduced in the Delaware General Assembly on June 9, 2005 (Senate Bill 157). This bill was not passed and may be reintroduced in the next session of the General Assembly.

### Funding

The proposed FIMR budget (Appendix 5) was shared with the Data Committee of the IMTF to help inform their recommendations for implementing FIMR statewide and appears in the May 2005 IMTF report. FIMR is one of the first recommendations listed in the Task Force Report, and as such, it is hopeful that the Governor and the General Assembly will appropriate the funds needed to execute FIMR as part of the CDNDSC fiscal year 2006 budget. State funding is the primary source of support for most FIMR programs: about 60% of FIMR programs are fully or partially funded by their state’s general funds.<sup>15</sup> Some states fund FIMR with Title V Maternal and Child Health Services Block Grant dollars as FIMR can be an integral part of the needs assessment process that is federally mandated for Title V programs.<sup>16</sup> Nationwide, one-third of FIMR programs receive some federal funding, 18% receive some local funds and 5% receive some foundation grants.<sup>17</sup> Federal funds and foundation grants are often one-time only funds that may be used initially as seed money to help establish new FIMR programs.<sup>18</sup>

Community partnerships also help to sustain FIMR programs by monetary and non-monetary means. Local health departments, businesses or non-profit groups may donate staff support, office space, equipment or printing costs. The annual FIMR and child death review conference may be co-sponsored by a nonprofit group or community partner with a shared agenda of raising awareness on topics affecting infant and child health. It often takes creativity and flexibility to put together the package of resources necessary to sustain a FIMR program, and to this end, the importance of sharing FIMR’s successes and the annual report with community partners as part of a marketing and communications strategy cannot be overlooked.<sup>19</sup>

<sup>15</sup> Misra DP, et. al. The Nationwide Evaluation of Fetal and Infant Mortality Review (FIMR) Programs: Development and Implementation of Recommendations and Conduct of essential Maternal and Child Health Services by FIMR Programs. *MCH Journal* 2004; 8(4): p. 221.

<sup>16</sup> FIMR Manual: A Guide for Communities, p. 23.

<sup>17</sup> Misra 2004, p. 221.

<sup>18</sup> FIMR Manual: A Guide for Communities, p. 23.

<sup>19</sup> Kerr, D.B. and Hutchins, E. Sustaining the FIMR Program: A Toolkit. ACOG, pp. 6-7 and 41-42.

## FIMR Planning Group

One of the immediate steps following the passage of legislation and allotment of funds for FIMR will be to establish a FIMR Planning Group to oversee the development of the infrastructure to conduct FIMR. The planning group will need to establish the procedures for FIMR as part of the CDNDSC. These procedures may best be written by representatives from the CDNDSC and DPH and would outline the roles and responsibilities of each agency, the process flow for information transfer between agencies and safeguards for ensuring confidentiality. Appendix 6 presents a proposed timeline for the initial implementation steps of a statewide FIMR.

## Community Partnerships

The FIMR Planning Group will also need to develop a communications and marketing strategy to engage an expanded network of community partners early on. While the FIMR pilot study has laid some groundwork in the building of community partnerships, more efforts need to be made to inform potential partners in Kent and Sussex Counties about FIMR. Using the forum of presenting the FIMR pilot study results can further relationships with current and new community partners. Making formal presentations of the key recommendations coming out of the pilot study to current partners will help maintain the trust, commitment and goodwill of all the groups and individuals who put in time and effort to participate in the pilot study. In addition, meetings should be scheduled with new downstate partners including the executives and obstetric and gynecology (OB/GYN) chairs of each of the hospitals, local DPH supervisors, community clinic directors and the Kent and Sussex Prenatal Task Force. Other groups with whom to meet and discuss the FIMR pilot study findings and the role of FIMR statewide may include:

- The newly formed Delaware Healthy Mother and Infant Consortium, or its transition committee
- The Medical Society of Delaware
- Local chapters of professional societies such as the American College of Obstetricians and Gynecologists, the American Academy of Pediatrics and the American Academy of Family Physicians
- The Delaware Health Care Commission
- Insurance companies and the State Medicaid contractor
- The Delaware Public Health Association
- The Delaware Healthcare Association
- The Wilmington Healthy Start Consortium
- The Delaware Safe Kids Coalition

Among the materials from the National FIMR program is the “Community Participation: A FIMR Member Checklist,” a useful tool to review when planning for meetings with potential community partners and recruiting volunteers to the CRT and community action teams.<sup>20</sup>

<sup>20</sup> FIMR Manual: A Guide for Communities, p. 36.

## HIPAA and IRB Considerations

In Delaware, the statute governing the functions of the CDNDSC provide authority for investigating fetal and infant deaths: “The Commission shall have the power to investigate and review the facts and circumstances of all deaths and near deaths of children under the age of 18 and stillbirths which occur in Delaware.”<sup>21</sup> The CDNDSC is also granted with subpoena power to request all records pertaining to the fetal, infant or child death. This state law preempts the Standards for Privacy of Individually Identifiable Health Information (the “Privacy Rule”) issued in 2002 by Health and Human Services to implement the requirement of the Health Insurance Portability and Accountability Act (HIPAA) of 1996. The Privacy Rule does not affect any state law that provides for the “reporting of disease or injury, child abuse, birth, or death, or for public health surveillance, investigation, or intervention.”<sup>22</sup> Hence, the Delaware Code governing the functions of the CDNDSC holds precedence and covered entities such as hospitals, physician offices and health plans must comply with the request for medical records made by the CDNDSC. By the same token, IRB approval is not required to obtain the medical records and engage in this mortality review process.<sup>23</sup> FIMR also falls under the exemptions of the Freedom of Information Act that pertain to “medical files and similar files the disclosure of which would constitute a clearly unwarranted invasion of personal privacy.”<sup>24</sup> CRT and community action team meetings are closed to the public, but the aggregate findings and recommendations made in the FIMR annual report should be available to the public.

<sup>21</sup> Delaware Code Title 31, Part I, chapter 3, subchapter II. <http://www.delcode.state.de.us/title31/c003/sc02/index.htm#TopOfPage> accessed 6/14/05.

<sup>22</sup> HHS. Summary of the HIPAA Privacy Rule. <http://www.hhs.gov/ocr/privacysummary.pdf> accessed 6/14/05.

<sup>23</sup> NFIMR. The Fetal and Infant Mortality Review Process: The HIPAA Privacy Regulations. ACOG 2003.

<sup>24</sup> The Freedom of Information Act, [http://www.usdoj.gov/oip/foia\\_updates/Vol\\_XVII\\_4/page2.htm](http://www.usdoj.gov/oip/foia_updates/Vol_XVII_4/page2.htm) accessed on 6/22/05.

## Staff Training

As stated by the Johns Hopkins University Women's and Children's Health Policy Center evaluation of national FIMR programs, FIMR Coordinators "and other leaders need to be knowledgeable about both perinatal health and community action strategies."<sup>25</sup> Training the FIMR Coordinator and the FIMR staff on how to use case review findings positively impacts the implementation of recommendations developed from the case review process. In addition, when FIMR staff are trained on strategies for implementing recommendations, a similar, significant effect is noted.<sup>26</sup> Specific training for the FIMR Coordinator and staff are vital to the success and trouble-shooting skills needed to sustain a FIMR program. There are many resources for providing formal and informal training.

The National FIMR (NFIMR) Program was established in 1990 as a collaborative effort between the Maternal Child Health Bureau and the American College of Obstetricians and Gynecologists (ACOG) for the purpose of providing technical support to state and local FIMR programs. Staff at NFIMR are ready and eager to answer questions as they arise. There is an NFIMR conference once every three years, as well as much information on the NFIMR website and electronic newsletter. NFIMR staff have supported the Delaware FIMR pilot study with background materials, phone consultations and on-site trainings. Jodi Schaefer, a consultant with Baltimore's HealthCare Answers, was identified through NFIMR as a resource for training the pilot study's maternal interviewers. The Maryland FIMR Coordinators Andy Hannon and Jeanne Brinkley and the Cecil County FIMR Director Carol King were also valuable resources during the execution of the pilot study.

Training will be needed for FIMR maternal interviewers based on their familiarity with the FIMR model, the maternal interview questionnaire and bereavement counseling. On-going meetings between the maternal interviewers, their supervisors and FIMR staff will also help provide a chance for de-briefing and mutual support in what is very emotional and demanding work.

Training will also be needed for CRT and CAT volunteers. There are resources from NFIMR to help plan for such trainings, and these are listed in the bibliography. Training on the FIMR model and the process steps is the basis for participants' understanding their role in the big picture and may be planned in conjunction with an annual child death and FIMR meeting. Mock case reviews as well as examples of CRT recommendations and actions steps from other FIMR programs can help introduce this type of systems review to CRT members. In both CRT and CAT meetings, work on group dynamics will be an ongoing issue, especially as different members may come to the meetings with different agendas. Spending some time articulating a common group objective or mission statement will help bring some of those differences out and form the basis for finding common ground on which to move forward.

<sup>25</sup> Misra 2004, p. 227.

<sup>26</sup> Misra, 2004, p. 225-226.

### THE FIMR SCIENTIFIC ADVISORY GROUP

In order to collect the appropriate and necessary data in the course of record review and maternal interview, it would be helpful to have a FIMR Scientific Advisory Group. The Scientific Advisory Group would be comprised of clinicians, public health professionals and researchers working on analyzing the trends in infant mortality in Delaware. Members of the Scientific Advisory Group may overlap with the Delaware Healthy Mother and Infant Consortium and the Center for Excellence in Maternal Child Health and Epidemiology within DPH. The advisory group would be charged with periodically reviewing Delaware's FIMR data collection forms to ensure that the data collected is relevant and can help inform current hypotheses and research in the field of infant mortality and maternal health. Some examples of data not currently covered in the NFIMR data collection forms that may be considered for inclusion would be data on oral health of the mother, the primary language of the mother, type of assisted reproductive technology procedures used in the past or present pregnancy, symptoms at the onset of labor and time between rupture of membranes, delivery and infant death.

### DATABASE

The FIMR Scientific Advisory Group could also review the set up and maintenance of a FIMR database. Ideally, information on FIMR cases needs to be entered in a database compatible with that used by the CDNDSC staff for the other child death cases. However, there may need to be a separate database with more information specific to FIMR cases that could be maintained by the FIMR Coordinator and the administrative assistant. This database should be developed to correspond with the information collected by PRAMS to maximize comparability of the FIMR cases and the general population of pregnant women in Delaware.

The Scientific Advisory Group would also be able to help inform the design of FIMR and determine case selection criteria. In this regard, there is some guidance from NFIMR and the lessons learned from the FIMR pilot study as well. Cases of suspected infant abuse or neglect, cases in which the mother is undergoing inpatient psychiatric treatment or cases in which the family is pursuing litigation with providers because of the circumstances surrounding the fetal or infant death are not appropriate for inclusion in FIMR.<sup>27</sup> Ideally all other fetal and infant deaths in Delaware should be reviewed, but this may be too large a caseload and beyond the FIMR and CDNDSC staff resource capabilities. Alternatively, a random subset of the deaths may be selected for review. The selection of cases may also differ based on location. In Kent and Sussex Counties, the number of infant deaths is about one-third of the state total, and so in these counties it may be possible to review all infant deaths. In New Castle County, however, a random subset of the infant deaths may need to be reviewed if staff or CRT time is limited.

### MEDICAL RECORD REVIEW

Based on the NFIMR model and recommendations from the pilot study CRT panels, medical records to consider including in the subpoena and data collection steps for FIMR include:

- Labor and delivery records
- Postpartum records
- Infant care after delivery, including NICU records and progress notes
- Pediatric clinic visits
- Obstetric triage records
- Emergency room visits for the mother or for the infant
- Obstetric care providers' clinic visit notes covering prenatal care
- Assisted reproductive technology clinic notes
- Records of any prior infant or fetal death occurring to the same mother in the preceding two years
- Records of the surviving sibling's birth in a multiple gestation in which one fetus or infant dies
- Insurance records for the mother and/or infant in the year before and after the death.

<sup>27</sup> NFIMR. FIMR Manual: A Guide for Communities, p. 51.

Some of these types of records are not currently collected in the child death review process and hence would involve an investment of time and effort to meet with key partners in hospitals and clinics. Specifically, prenatal records from various outpatient sources, OB triage visits and ER visits are very important to construct a full picture of the medical care accessed by the mother during pregnancy. Postpartum records would help provide information on interconception care, an issue of importance as raised by the FIMR pilot study and the IMTF. Private clinicians may at first be reluctant to share their records with the FIMR abstractor. Carefully presenting the purpose, process and legislative authority for FIMR will be necessary to build clinician trust and support.

Even among hospital records it was noted that some key documents were not included in the medical record forwarded to the CDNDSC. Based on CRT input during the FIMR pilot study, hospital records should include:

- Emergency room visit notes and discharge instructions
- Obstetric triage notes and discharge instructions
- Perinatal bereavement records
- Disposition consent forms
- The death protocol
- Maternal discharge instructions
- Information for the stillborn certificate
- The death notice
- Physician progress notes

To obtain these documents, it may be necessary to enumerate them in the initial subpoena request.

### OTHER RECORDS TO REVIEW

In addition to medical records, it is important to consider reviewing social service records in order to gain a well-rounded picture of the services accessed by the mother and family in the FIMR case. For the FIMR pilot study, the state service database was utilized to reveal contacts with the mother and infant at public health clinics and WIC. Other programs of key importance to a systems review of maternal child health services would include Smart Start, Resource Mothers and other

community-based prenatal and postpartum home visitation records. Records from the Department of Services for Children, Youth and their Families may be included as this agency is already an important partner in child death reviews and would provide insight into some counseling or behavioral services used by the parents in the FIMR case. In addition, Medicaid claims data may provide a more complete picture of the location and types of services accessed by mothers and infants before and after pregnancy.

In order to begin accessing these other records, the CDNDSC Executive Director and FIMR Coordinator should make on-site visits to different programs and agencies and identify a key contact person for record retrieval. Discussions on maintaining confidentiality while doing the chart review would be important from the outset. The key contacts at outside agencies should sign a FIMR confidentiality statement and return or destroy all identifying information shared in the process of pulling charts for review.

### MATERNAL INTERVIEWS

Based on feedback from the pilot study's maternal interviewers, there are some improvements to be made in the process of contacting mothers for an interview and the provision of bereavement support services after an infant or fetal death. FIMR cases should be identified as soon as possible after the death and contact tracing initiated for the interview immediately. The maternal interviewer could make initial contact with the mother by phone, letter or a visit while the mother is still in the hospital. The purpose of this initial contact is an introduction to the support services offered by the maternal interviewer and DPH. All the maternal interviewers in the pilot study agreed that the first home visit with the mother should be solely for the purpose of bereavement support and should take place within the first few weeks after a death. Then on the second or third subsequent home visit, the maternal interviewer can engage the mother to complete the FIMR interview. The mother should be presented with the FIMR interview as a voluntary, confidential opportunity to tell her story. She should sign an informed consent. (See Appendix 2 for sample forms.) The interview will help to identify further

referral or counseling needs. It is important to consider the FIMR interview as one step in a longer relationship of bereavement support and case management offered to the mother. The maternal interviewer or a DPH medical social worker may need to follow the mother for six to twelve months after the fetal or infant death depending on the mother's needs.

## CONFIDENTIALITY

Maintaining confidentiality is of paramount importance in the FIMR process. Confidentiality not only protects the mothers and families involved in the cases but also preserves the community, physician and hospital trust in the FIMR process and the integrity of the information shared. To that end, there are some specific steps that need to be put into place from the beginning.

- All electronic data such as linked birth and death certificates should be stored on a password-protected computer.
- Personal identifiers such as names and addresses should be deleted from the databases after the case has been reviewed.
- Hard copies of documents should be marked as "Confidential" and stored in a locked file cabinet.
- All data abstraction forms and completed maternal

interview forms should be stripped of personal identifiers such as the date of delivery, the date of death (if it is a small enough community that these may identify a case), and hospital and provider names.

- Medical records, other social service records, data abstraction forms and completed maternal interviews should be destroyed once a CRT has reviewed the case.
- The case summaries are de-identified, collected and shredded after each CRT meeting.
- The FIMR staff and CRT members' discussions of cases are also confidential. All FIMR staff and CRT volunteers should sign a pledge of confidentiality, and all discussions should be closed to the public.
- The outcome of a particular case discussion should not be shared with anyone outside the CRT meeting, even the family involved in the case. The families may be offered a copy of the final FIMR report presenting all the recommendations in aggregate.

If any concerns or questions should arise concerning confidentiality, the NFIMR staff may be consulted for further guidance.

## FIMR Process Evaluation and Monitoring

The FIMR Planning Group should discuss and set up process evaluation and monitoring strategies for FIMR. In the national evaluation of FIMR programs, investigators at Johns Hopkins University developed ten content areas in which they surveyed FIMR programs. These content areas are: prenatal care, substance abuse, SIDS, smoking, infections during pregnancy, domestic violence, monitoring of maternal complications, family planning, very low birth weight and multiple pregnancies.<sup>28</sup> In Delaware, the CDNDSC Executive Director and the FIMR Coordinator should report on the discussion, development and implementation of recommendations in these content areas specifically as well as other content areas deemed by the CRTs to be important in the State. Process indicators for tracking the implementation of recommendations include: the action steps developed, the group or agency responsible for the action steps, the time line for implementation, resources available to aid in implementation and the current status of the proposed action.

Participants in the FIMR process can also offer important insights into the functioning of FIMR. Mothers involved in maternal interviews should receive a thank you card after the interview that includes a form to offer feedback on their experience during the maternal interview. An example of a maternal interview evaluation form is provided by NFIMR.<sup>29</sup> The CRT and community action team members can also provide feedback on the meetings, case summary forms and changes made individually through their participation in FIMR. Finally, any participants of trainings sponsored by the CDNDSC and FIMR should also be given the opportunity to provide feedback on the content and effectiveness of the training programs.

<sup>28</sup> Misra 2004, p. 223.

<sup>29</sup> NFIMR. Fetal and Infant Mortality Review Manual: A Guide for Communities, p. 50.

## CONCLUSION

There is much that was learned during the course of the FIMR pilot study and that is applicable to planning for the continuation of FIMR. The limitations in data collection and maternal interview acceptance have been informative opportunities to propose changes to the FIMR process in Delaware. Limiting cases to CCHS also led to some biases in the sample of infant death cases selected for review in the pilot study, and in the next phase of FIMR, a concerted effort must be made to engage hospitals throughout the State.

Not to be overlooked are the many positive aspects that have been a part of the FIMR pilot study and that can be built upon in the future. Partnerships have been forged with many professional, hospital-based and community-based organizations and individuals, including those who so generously gave of their time to make up the CRT panels. The collaboration and exchange of information with the IMTF has helped to widen the base of support for a common agenda in maternal and child health. In the future, there will be many more opportunities for collaboration to meet IMTF and FIMR recommendations as overseen by the Delaware Healthy Mother and Infant Consortium. It should be kept in mind that the FIMR process is a dynamic one, and changes can and should be made based on future information, experiences and feedback. Thirty-nine states and 200 communities in the U.S. have a FIMR, and varied local needs and available resources mean that there are just as many versions of the national FIMR model. Delaware has a unique opportunity to capitalize on the momentum of the IMTF Report and the FIMR pilot study and move forward to improve services and health outcomes for women, children and their families.

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## APPENDICES

### Appendix 1: Case Review Team Members, FIMR Pilot Study

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Epidemiologist and Community Member

**Bridget Wheatley, RN, MS**

Delaware Early Children's Center

## Appendix 2: FIMR Pilot Study Forms FIMR Home Interview Consent Form

### Purpose of Interview

The Division of Public Health and the Nemours Health and Prevention Services are conducting a Fetal and Infant Mortality Review (FIMR) Program. The purpose is to identify factors associated with fetal and infant deaths and to find ways to help families such as yours in the future. To achieve these goals, we wish to interview mothers (or other family members) who have recently experienced the loss of a fetus or infant. You have been asked to participate in the program because you have recently lost a fetus or infant. If you voluntarily agree to participate, a trained interviewer from the Division of Public Health will ask you a series of questions about the death of your baby and about your pregnancy, health, family, and use of healthcare and social services. The interview will take place in your home at a time that is convenient for you. The interview will take about one hour. Although participation in this program may not benefit you or your family directly, it may help to prevent other families in the future from losing their baby.

### Description of Potential Risk

Talking about the death of your baby may prove difficult for you. The interviewer is not a professional counselor, but, if you wish, will give you the names of professional people who can help you deal with the loss of your baby. If, during the course of the interview, you feel you do not want to continue, you may ask the interviewer to stop the interview at any time. There is no expected risk of injury for participants in this study.

### Description of Potential Benefits

Participation in the interview may be a positive experience for you. You may find that talking about the death of your baby can help ease the pain of your loss. In addition, the information you provide to this program may help prevent the loss of a baby to future families.

### Alternative Procedures

The alternative to participating in this interview is to choose not to participate at all.

### Confidentiality of Records

All information that identifies you, your family, or your health providers will be removed before the interview questionnaire is reviewed. All Fetal and Infant Mortality Review staff and consultants have signed an oath of confidentiality. Therefore, confidentiality will be protected to the full extent permitted by law.

### Compensation

You will not be paid for participating in the interview.

### Voluntary Participation

Your participation in this program is completely voluntary and you may refuse to answer any questions that you do not wish to answer. You are also free to end the interview at any time without any consequences to you or your family.

### Questions

If you have any questions concerning the interview or the Fetal and Infant Mortality Review Program, you may call Terry Dombrowski.

### Consent

I have read this form and understand the purpose and conditions for participation in the Fetal and Infant Mortality Review Program. I hereby consent to participate in the program. I agree to participate in an interview. I understand that all information obtained from the interview will be strictly confidential, and neither my name, my baby's name, nor the name of anyone else in my family will appear in any publications or reports or be given to anyone.

Name: \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

Interviewer's Name: \_\_\_\_\_

Interviewer's Signature: \_\_\_\_\_

Date: \_\_\_\_\_

## Delaware FIMR Pilot Study Case Summary Form

Date of CRT Review: \_\_\_\_\_

Case # \_\_\_\_\_

Reason for Case Review: \_\_\_\_\_

Maternal Interview: \_\_\_\_\_

General Information	Mother	Father
Ethnicity		
Age		
Highest Level of Education		
Marital Status		
Employment		
Residence		
<b>Medical Record Information</b>		
Height		
Pre-Pregnancy Weight		
Weight Gain during Pregnancy		
LMP (Month/Year)		
EDD (Month/Year)		
Delivery (Month/Year)		
Prior Reproductive History	G P (term) (premature) (abortions) (living children).	
Last pregnancy (Month/Year)		
Any ETOH, tobacco or drugs		
Past Medical History		
Medications		
Planned pregnancy?		
Medical Insurance		
<b>DPH Information:</b>		
<b>Maternal Interview: Learning of Pregnancy</b>		

<b>Prenatal Care</b>	
# Prenatal visits =	Week GA began PNC =
#ER visits during pregnancy =	# Prenatal Ed. Sessions =
# Healthy Start home visits =	# Telephone calls =
<b>Maternal Interview: Prenatal Summary</b>	
<b>Labor &amp; Delivery</b>	
Consults:	
<b>Diagnosis</b>	
<b>Placenta Pathology Report</b>	
<b>Maternal Interview: Delivery</b>	
<b>Autopsy:</b>	
<b>Post Partum Care/Family Planning/Birth Control</b>	
<b>Maternal Interview: Other Comments</b>	
<b>Medical History of Infant:</b>	
Birth	
Care	
Death	
Diagnosis	
<b>Maternal Interview: Bereavement</b>	
<b>Events Since Infant Death</b>	

## Delaware Pilot Study FIMR Case Discussion Guide

Case # \_\_\_\_\_

Date \_\_\_\_\_

**Purpose:** To review individual cases of infant death to identify areas of improvement in the systems of care for women, children and their families.

1. Problems or risk factors specific to this case:

- Pre-conception
  
- Prenatal
  
- Labor and Delivery
  
- Postpartum
  
- Infant
  
- General/Other

2. Personal strengths or service delivery structures that supported the success this family had in accessing services

3. Service delivery or community resources issues raised by this case:

4. Resources or services needed but not used:

5. Resources or services needed but not available:

6. Information not available:

- 0-25% Minimal information available
- 25-50% Major gaps in information available
- 50-75% Minor gaps in information available
- 75-100% Substantially complete information available

7. This case illustrates the following barriers/systems issues:

8. Recommendation(s)/ideas to address the issues highlighted by this case:

	<b>Preconception</b>	<b>Prenatal</b>	<b>Labor &amp; Delivery</b>	<b>Newborn</b>	<b>Infant</b>	<b>Grief</b>
<b>Family received all services needed</b>						
<b>Minor gaps in services needed</b>						
<b>Major gaps in services needed</b>						
<b>Services are not available in community</b>						

## Appendix 3: List of Recommendations from Case Review Team Discussions

### PRETERM LABOR

#### Issue Identified (based on 10 cases)

Mothers presented with advanced preterm labor or cervical dilation. They did not correctly identify early symptoms of preterm labor or chorioamnionitis.

#### Recommendations

- Education on signs and symptoms of preterm labor should be done early in pregnancy (prior to 20 weeks gestation) and be reinforced throughout the pregnancy, for example, in regular prenatal check-ups, ER visits, OB triage and in public education efforts.
- Work with ACOG to coordinate preterm labor education earlier in pregnancy as a standard of OB care.
- There should be an early prenatal education class for multiples and other high-risk women that presents information on the signs and symptoms of preterm labor. Parents can self-refer for the class or be referred through OB office managers.

### HEALTHCARE SYSTEM LINKAGES

#### Issue Identified (based on 11 cases)

Women on Medicaid who go to private physicians may not be getting referrals to public services based on their psychosocial needs or medical risk factors.

#### Recommendations

- Improve the linkages between private providers, DPH and other community-based programs that provide nutrition counseling and social services.
- Work towards a single-point of entry system--either with a health navigator or "one-stop shopping"--for all pregnant women regardless of their being in the public or private sector. For example, each clinic could have a navigator, or there could be a toll-free number for intake and referrals or an informational website.
- Better information is needed on the common practices in private OB offices to plan for interventions and coordinate with other programs and services. It may be helpful to undertake a survey of OB office practices to better inform DPH and other programs that interface with private physicians.
- All clinics should have a community resource list that can be given out to pregnant women regardless of insurance status.
- Generate and disseminate a mini psychosocial screening tool for OB providers or office staff to screen all pregnant women for mental health issues and social assistance needs.
- Explore ways of using insurance screening forms or pregnancy notification forms to expedite referrals for psychosocial issues.
- Create an easy access referral process so that OB providers can enroll mothers with DPH and other service programs.

## HEALTHCARE SYSTEM LINKAGES (CONT.)

### Issue Identified (based on 11 cases)

There is a delay in follow up or inadequate referrals upon hospital discharge of high-risk mothers and/or infants.

Women who miss prenatal care appointments need particular attention.

### Recommendations

- Psychosocial screening should be done at the hospital prior to discharge.
- Hospital staff may need education about the different types of home visiting services available and the criteria for eligibility.
- Reinstate CCHS' comprehensive, multidisciplinary case review meetings for planning hospital discharge of pregnant women.
- Link between OB offices, DPH and Resource Mothers to track down women for prenatal care appointments. Make this referral step easy for OB's to access.

## BEREAVEMENT SUPPORT

### Issue Identified (based on 11 cases)

Culturally appropriate, community-based bereavement support is lacking, particularly for young Black mothers.

Information provided as bereavement support may be limited, or the family's ability to process the information may be compromised in the period immediately following the loss in the hospital.

Parents of multiples who lose one or more of their infants may have unique bereavement issues.

Fathers and families also have grief support needs.

Intrauterine fetal demise is also a time for bereavement support.

### Recommendations

- There is a need for culturally appropriate grief counseling and peer support groups at the community level. Working with the churches, funeral parlors, the Mental Health Association and community groups may help engage Blacks.
- There should be a shift from hospital-based care to community-based care that includes home visits and group services such as bereavement counseling. Home visits in particular can engage women based on where they are now in working through their loss.
- There should be a standardized packet of information distributed to families in the hospital that contains grief counseling resources and information.
- There should be a follow up phone call for all mothers with a fetal or infant loss from a bereavement counselor once the mother has been discharged.
- Send out a grief packet to every family with a loss. Include some specific information on when to seek help, a list of counselors and unique issues for parents of multiples.
- More is needed to encourage men to be involved in bereavement support, and indeed fathers may need some unique services, such as one-on-one peer support, tailored to their different needs at different times.
- Social work or bereavement support counselors should be available to OB clinics in person or by phone to support mothers when bad news is given

## PRECONCEPTION CARE

### Issue Identified (based on 10 cases)

Suboptimal health, significant past OB history or poor lifestyle choices at the time of pregnancy were risk factors for many women in the pilot.

Black women's perception of planning for pregnancy is that it is not something in their control.

### Recommendations

- Expand the vision and provision of preconception care. Do not limit it to those women wanting to become pregnant, but rather promote healthy lifestyle choices among all women. A consistent message repeated in many different venues where women access care is important. Some venues to consider are family planning clinics, gynecological care, family practice and STD clinics. Counseling women who have negative pregnancy tests is a particular priority.
- Look into a targeted public education campaign to promote women's health among high-risk groups.
- There needs to be a paradigm shift in the community about planning for a pregnancy. To change cultural perceptions, families need to be educated not just women.

## INTERCONCEPTION CARE

### Issue Identified (based on 3 cases)

Some women had short inter-pregnancy intervals after an infant loss.

### Recommendations

- Put into place interconception care services that target high-risk women and provide wrap-around services such as: nutritional counseling, family planning, genetic counseling, general health checks, bereavement support and psychosocial intake.
- Case management is needed for some women at high-risk for subsequent poor pregnancy outcomes. This case management could be provided through OB offices, DPH or insurance companies. The case management may be tiered for level of risk.

## NUTRITION COUNSELING

### Issue Identified (based on 6 cases)

Some women with multiple gestation and/or obesity had inadequate or inappropriate weight gain.

### Recommendations

- Nutrition counseling services need to be expanded in the private sector
- All women with multiple gestation should be referred for nutrition counseling.
- Insurance companies should reimburse for nutrition counseling.

## ART

### Issue Identified (based on 4 cases)

Women with chronic or significant medical issues are using ART.

### Recommendations

- There needs to be counseling provided around the decision to use ART, the preconception health of the mother, the optimal inter-pregnancy interval, the outcomes of ART and the outcomes if the mother goes into preterm labor.
- Establish a parents' education class for ART recipients to help inform them of the risks and benefits of ART use.

## MEDICAID

Issue Identified (based on 6 cases)	Recommendations
In some cases there was a delay in women's entering Medicaid.	- Create and disseminate an informational brochure on Medicaid application and eligibility.
Some women perceive Medicaid or public clinics as having inferior quality of care.	- Conduct a social marketing campaign to improve the image of Medicaid and public clinics and focus on their provision of culturally competent care.
Mothers on Medicaid with high-risk factors are not always in Smart Start.	- Trace notification processes for pregnant women with Medicaid: are there gaps? Are referrals made? And if so, by whom?
There are limited resources for drug-abusing mothers.	- Explore the possibility of Medicaid's conducting a cost-effectiveness analysis on drug abuse in pregnancy to examine the rationale for expanding prevention efforts and treatment programs available to women.

## MEDICAL CARE AND QUALITY ASSURANCE

Issue Identified (based on 7 cases)	Recommendations
Some high-risk pregnant women receive care fragmented between different providers.	<ul style="list-style-type: none"> <li>- The communication between ER, in-patient OB providers and primary providers needs to be improved.</li> <li>- Transfer of ER records and postpartum records to private providers needs to be systematized and timely.</li> <li>- There should be a smooth transition with the release of records between ART providers and the OB following the pregnancy.</li> </ul>
Some high-risk women experienced a delay in referral to perinatology until after 20 weeks gestation.	- Review some of the referral practices for obtaining a perinatology consult. Are there some women who should be seen early? Are appointments available in a timely fashion?
There may be variability in high-risk OB care.	- Look into variability of clinical practices in high-risk OB management. What are providers' definitions of fetal viability and is it consistent? When are women referred to perinatology?
In one case there was no medical home established for an infant during a hospital stay.	- A medical home needs to be identified prior to hospital discharge for every infant. Communication and record transfer between the hospital and the outpatient provider should occur in a timely fashion.

## MENTAL HEALTH

### Issue Identified (based on 4 cases)

There are missed opportunities for mental health referrals in outpatient and inpatient care.

### Recommendations

- Every first-line provider should be able to do a brief mental health intake and be aware of initiating a referral.
- Generate and disseminate a mini psychosocial screening tool for OB providers or office staff to screen all pregnant women for mental health issues and social assistance needs.
- Mental health services need to be expanded and the system simplified for navigation. Alternatively, a navigator or single entry point may facilitate access.
- Services need to be culturally sensitive and acceptable as stigma is a major barrier to overcome.

## PRENATAL EDUCATION

### Issue Identified (based on 3 cases)

Time-pressured decisions often have to be made by mothers regarding the management of preterm labor.

### Recommendations

- All pregnant women should be educated on the risks of prematurity. Knowing some of the risks and complications of prematurity may help women process information if confronted with such a situation in the future and make better, informed decisions. The March of Dimes may be a potential partner in such an educational program. The education may occur as classes or videos for viewing in clinic waiting rooms.

## TEEN PREGNANCIES

### Issue Identified (based on 3 cases)

There is a need for teen-centered education.

### Recommendations

- Use school Wellness Centers to get education to children and teens about pregnancy prevention and sexual education.
- Referral should be made to DPH upon discharge from the hospital of a teen mother for follow-up support and education on infant care.

## HEALTH INSURANCE

### Issue Identified (based on 1 case)

Private insurance does not always cover prenatal care services, so a mother may be forced to make the transition from private insurance to Medicaid in the middle of her pregnancy.

### Recommendations

- Work towards universal coverage of prenatal services by all health insurance policies.

### (based on 1 case)

One case involved implantation of four embryos in an ART procedure.

- Work with insurance companies and professional societies to establish standards for in vitro fertilization.

## DEFINITION OF LIVE BIRTH, INFANT DEATH AND FETAL DEATH

### Issue Identified (based on 3 cases)

Many of the FIMR cases reviewed as infant deaths were non-viable births.

### Recommendations

- Explore ways to compare states' practices on defining a fetal death versus an infant death. Options include vital statistics comparisons or using FIMR aggregate data

## FAMILY PLANNING

### Issue Identified (based on 2 cases)

Two mothers did not receive the tubal ligation for which they had consented prenatally.

### Recommendations

- Look into the procedures around tubal ligation: the 30-day notification (in the case of Medicaid patients) and how to handle a tubal in the case of a mother with an infant death or an infant in the NICU.

### (based on 1 case)

One case involved possible contraception failure on Depo Provera.

- There needs to be a system for follow-up reminders and more systematic provision of Depo Provera injections.

## INFANT SLEEP PRACTICES

### Issue Identified (based on 2 cases)

Unsafe infant sleeping practices were a factor in cases due to SIDS and SUDI.

### Recommendations

- Safe sleeping—not just back to sleep—is a message that needs to get out to the public. Cosleeping, bedding, infant feeding practices, smoking or other use of drugs and alcohol by caregivers are all factors in infant sleep safety.

## INFECTIONS IN PREGNANCIES

### Issue Identified (based on 2 cases)

Some women are at high-risk for sexually transmitted diseases.

One case involved a neonatal Herpes Simplex Virus (HSV) infection.

### Recommendations

- There should be universal HIV testing for all pregnant women
- Check into standards of care for HSV testing prenatally.

## SMOKING

### Issue Identified (based on 1 case)

Twenty-six percent of mothers were smoking during pregnancy and another 12% had a recent history of smoking.

### Recommendations

- Smoking cessation efforts during pregnancy should include family members as they are an integral part of the environment and support network for the mother and infant.

## OCCUPATIONAL HEALTH

### Issue Identified (based on 1 case)

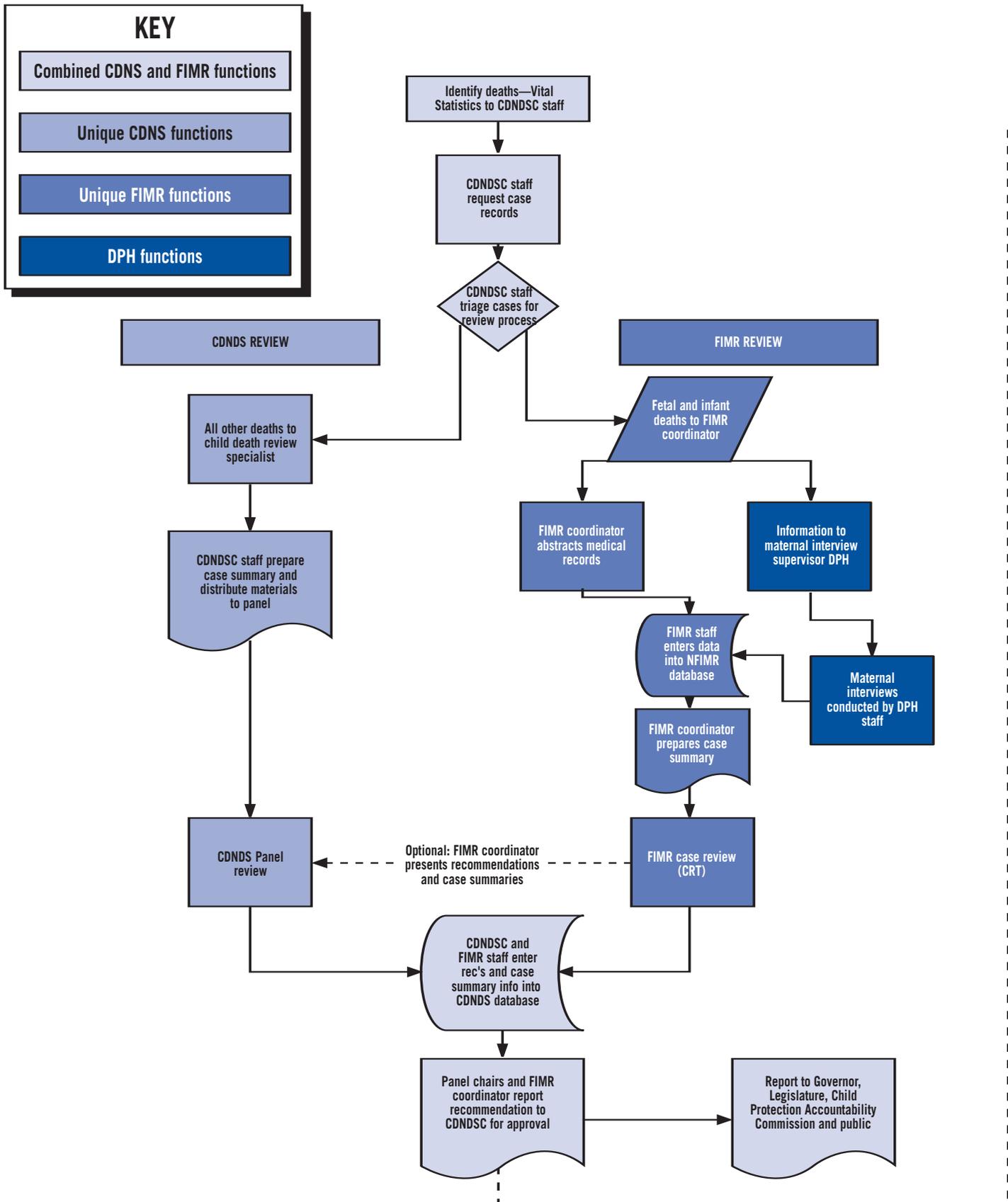
Some women experience stress in the workplace during pregnancy.

### Recommendations

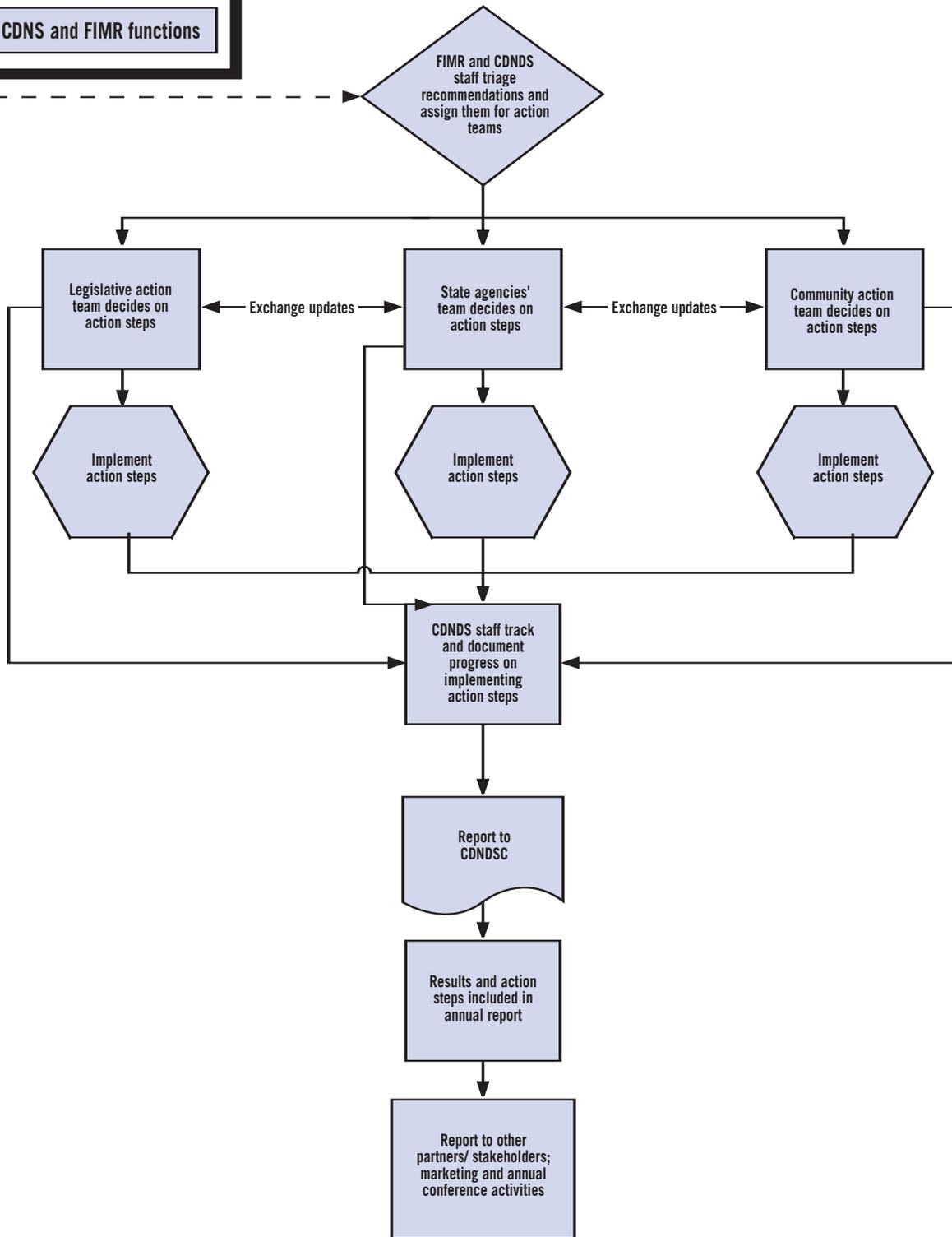
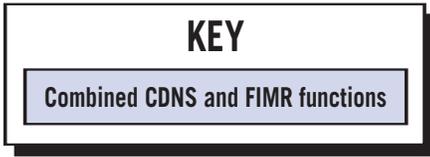
- Employers should help create a pregnancy-friendly workplace with flexible breaks and stress and noise reduction
- There should be short-term disability for medical leave during pregnancy. Specifically, the State of Delaware does not provide disability, maternity or paternity leave.

Appendix 4: Process Flow Diagrams for CDNDSC and FIMR Functions

**CHILD DEATH REVIEW AND FIMR PROCESS FLOW**



# CHILD DEATH REVIEW AND FIMR ACTION PLANNING AND IMPLEMENTATION PROCESS



**Appendix 5: Draft Budget Proposal and Justification for FIMR Implementation,  
Fiscal Year 1(FY 2006)<sup>30</sup>**

**Personnel Costs (FY 04/05 salaries @ 85% midpoint)**

Salaries	
• FIMR Coordinator/RN III - PG 15	\$42,854
• Maternal Interviewer/Sr. Medical Social Work Consultant - PG 14	40,047
• Administrative Specialist I - PG 7	<u>24,940</u>
	107,841
OECs (22%)	<u>23,725</u>
Annualized Personnel Costs FY05	\$131,566
Projected Annualized Personnel Costs FY 06 (add 5%)	\$138,144
<b>Total Personnel Costs year 1 [3.0 FTEs x 9 months (75%)]</b>	<b><u>\$103,608</u></b>

**Travel Costs**

• In-state	\$3,600
• Out of state	<u>2,000</u>
<b>Total Travel Costs</b>	<b><u>\$5,600</u></b>

**Contractual Services**

• Physician Consultant – Year one (start-up) (\$75/hr X 10 hrs/week X 35 weeks)	\$26,250
• IT Consultant – Yr 1 Support	26,000
• Other Contractual Services	<u>8,750</u>
<b>Total Contractual Services</b>	<b><u>\$61,000</u></b>

**Supplies and Material**

<b>Total Supplies and Material</b>	<b><u>\$3,500</u></b>
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**Start Up**

<b>Total Start Up (\$5,000 per FTE X 3 FTEs)</b>	<b><u>\$15,000</u></b>
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<b>TOTAL YEAR ONE FIMR BUDGET</b>	<b><u><u>\$188,708</u></u></b>
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<sup>30</sup> Prepared by Florence Alberque, Executive Director, CDNDSC.

## BUDGET JUSTIFICATION

**FIMR Coordinator/ RN III- PG 15:** The coordinator will be responsible for medical record and agency record abstractions and preparing de-identified summaries of FIMR cases. The coordinator will train CRT and CAT members and facilitate CRT and CAT meetings, work with the Executive Director of CDNDSC to triage cases for review and compile and track recommendations and action steps. The coordinator will also oversee the FIMR database development and management.

**Senior Medical Social Work Consultant – PG 14:** The social work consultant will conduct about 120 maternal interviews per year based on the FIMR interview model. The FIMR interview component will take about 8 hours per case. The remainder of the social worker's time will be devoted to follow up and case management of the mothers identified through FIMR. The social worker will make referrals as appropriate and provide bereavement support services to the mother and her family.

**Administrative Specialist I –PG 7:** The administrative specialist will help maintain the FIMR database, schedule meetings, write meeting minutes, create documents and correspondence and provide administrative support to the FIMR Coordinator.

**Travel:** The social worker conducting maternal interviews will generate most of the in-state travel costs. The cost estimate is based on 120 interviews per year, with one interview per day and a state car costing \$30/day. Out of state costs are calculated based on two staff each attending a conference annually.

**Contractual Services:** The physician consultant will help the FIMR Coordinator abstract medically complex cases and answer any questions the coordinator may have while preparing the case summary. The physician will also attend CRT meetings and provide medical background to the team as needed.

The IT support costs are calculated to help develop a database for the state FIMR that is compatible with the new child death review database.

Other contractual services include copier rental and maintenance and printing costs of forms and reports.

**Supplies and Materials:** This item includes office supplies, copy paper and small equipment.

**Start Up:** The cost is \$5000 per FTE and includes computers, office furniture, phone set-up, fax, shredder and desk accessories.

**Appendix 6: Timeline for Implementation of FIMR Statewide**

Implementation Step	MONTH						
	Pre-start up	1	2	3	4	5	6
Pass legislation to modify Delaware Code regarding CDNDS Commission functions.	●						
Secure funding for FIMR.	●						
Present FIMR pilot findings to CDNDS Commission for approval.		●					
FIMR Planning Group drafts procedures for FIMR.		■					
Hire FIMR staff.				■			
Train FIMR staff.					■		
Convene the FIMR Scientific Advisory Group to edit data collection forms.			■				
Meet with community partners and present FIMR pilot findings.			■				
Recruit CRT and CAT members.			■				
Train CRT and CAT members.					●		
Identify cases for review.					■		
Request medical and social service records for review.						■	
Begin case abstractions.						■	
Conduct maternal interviews.						■	
Begin CRT meetings to review new cases.							●
Begin CAT meetings to review and implement FIMR pilot recommendations.					■		