CONTRA COSTA
HEALTH SERVICES

Contra Costa Fetal Infant Mortality Review Program

Findings and Accomplishments 1998-2004

Contra Costa Health Services - November 2005

Family, Maternal and
Child Health Programs

FAMILY, MATERNAL AND CHILD HEALTH PROGRAMS

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ACKNOWLEDGEMENTS

The aim of the Fetal Infant Mortality Review Program could not be accomplished without the help, commitment and support of numerous health care providers, community agencies, and public and private institutions that provide ongoing support of our goal to improve and promote the health of women, infants and families in our communities.

We would like to extend a special thank you to the parents who have shared their most personal experiences in the hopes that other families will not have to suffer what they have endured. They have opened up their hearts and homes to teach us what families need from our health care system. We truly commend these extraordinary parents for their courage and willingness to share their experiences with us.

We Remember Them

In the rising of
the sun and in its going
down, we remember them.

In the blowing of the wind and in the chill of winter, we remember them.

In the opening of buds and in the rebirth of spring, we remember them.

In the blueness of the sky and in the warmth of summer, we remember them.

In the rustling of leaves and in the beauty of autumn, we remember them.

In the beginning of the year and when it ends, we remember them.

When we are weary and in need of strength, we remember them.

When we are lost and sick at heart, we remember them.

When we have joys we yearn to share, we
remember them.

For as long as we live, they too shall live,

For they are now a part of us,

As we remember
them.

- Author Unknown

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FOREWORD

The purpose of this report is to describe the Contra Costa Fetal Infant Mortality Review (FIMR) Program and to share the program findings and contributions in addressing fetal and infant mortality from 1998 through 2004.

Initially conceptualized by the Maternal and Child Health Bureau in 1998, FIMR is a community-based case review process designed to uncover patterns and factors associated with fetal and infant death. FIMR involves a comprehensive review of individual cases of fetal and infant death in order to investigate how a wide array of social, health, economic, environmental and safety issues relate to fetal and infant loss on a local level and to improve how community resources and service delivery systems respond to the needs of families. Through this process, the program works to improve pregnancy outcomes and reduce the incidence of fetal and infant mortality.

The value of the FIMR Program is its ability to examine the interrelationships of health and social service systems that impact perinatal outcomes and make recommendations towards achieving more comprehensive systems of care. The FIMR Program reviews approximately 20% of the fetal and infant deaths that occur in Contra Costa each year. While the cases reviewed may not be considered representative of all fetal and infant deaths in Contra Costa, the recommendations that result from the case review have far-reaching implications. The FIMR Program focuses on fetal and infant deaths as sentinel events. This perspective assumes that if one infant dies there are likely many more who experienced similar situations and morbidities and survived. By implementing case review recommendations, the FIMR Program is working not only to decrease infant mortality but to also improve the health of women, infants and families throughout Contra Costa County.

Since 1998, the FIMR Program has identified and addressed several issues including access to complete medical records, grief and bereavement services, SIDS risk reduction and the educational needs of families and providers regarding folic acid, preterm labor and the danger signs of pregnancy. The FIMR Program continues to work on these issues while identifying and addressing emerging issues.

INTRODUCTION

There are few things more devastating than the loss of a baby during pregnancy or in early infancy. The Contra Costa Fetal Infant Mortality Review (FIMR) Program is a community-based case review process that focuses on fetal and infant mortality. The program works to reduce the incidence of fetal and infant mortality and improve pregnancy outcomes and provides support to parents and families who have experienced a pregnancy loss or the death of a baby.

Infant mortality is widely regarded as a measure of a community's social and economic well-being, as well as its health. It reflects a range of factors such as medical issues, the ability of health care systems to respond to the needs of women and infants, environmental factors, and social issues such as poverty, education and culture. Furthermore, infant mortality tells us something about women's lives – their lifestyle and personal habits, their relationships and the stress they experience. The purpose of FIMR is to investigate how a wide array of social, health, economic, environmental and safety issues relate to fetal and infant loss on a local level and to improve how community resources and service delivery systems respond to the needs of families. By addressing systems of care, FIMR works to improve and promote the health and well being of women, infants and their families.

The purpose of this report is to describe Contra Costa's FIMR Program and to share the findings and contributions of the program in addressing fetal and infant mortality from 1998 through 2004.

FIMR PROGRAM DESCRIPTION

The FIMR Program has been operating in Contra Costa since the inception of FIMR in California in 1991. The Perinatal Network of Alameda/Contra Costa first implemented a regional FIMR in 1991 that included West Contra Costa County. In 1997, the program was expanded to include East Contra Costa County. The following year, the California Department of Health Services decided that FIMR Programs should be a part of the core programs under local public health departments. Based on this decision, the responsibility for conducting a local FIMR in Contra Costa County was transitioned to Family, Maternal and Child Health Programs of Contra Costa Health Services.

The FIMR Program focuses on fetal deaths occurring at 20 weeks gestation or greater and infant death up to one year of age. The objectives of the FIMR Program are to:

- Provide grief and bereavement support to parents and their families;
- Provide information and referrals for services to parents and their families;
- Examine the significant social, economic, cultural, safety and health system factors associated with fetal and infant death through a review of individual cases;
- Plan interventions and policies to address these factors to improve service systems and community resources;
- Participate in the implementation of community-based interventions and polices;
- Assess the progress of interventions; and
- Disseminate FIMR findings to local community groups and agencies.

The Contra Costa FIMR Program consists of five key components: family support, maternal interview, records review, case review, and community action. Each component is described below. The FIMR process is illustrated in Figure 1.

Family Support

Contra Costa's FIMR Program is unique in that the first priority of the program is the provision of emotional support to parents and families who have experienced a fetal or infant death. The FIMR Program is notified of recent fetal and infant deaths through a system of referrals with hospitals, prenatal clinics, case management programs and other perinatal providers, and the Office of Vital Registry. FIMR staff contact parents through phone calls and home or hospital visits soon after the pregnancy loss or death of an infant. Through the FIMR referral system, the program is notified of approximately 40% of the fetal and infant deaths that occur in the county. FIMR staff are generally able to make contact with mothers in seven out of 10 referrals.

KEY COMPONENTS of the Contra Costa FIMR Program

- Family Support
- Maternal Interview
- Records Review
- Case Review
- Community Action

During phone calls and visits, FIMR staff provide emotional support, assistance with funeral preparations, information, and referrals to other services that can assist the parents and their families. In addition, staff provide health education on topics such as nutrition, family planning, postpartum care and health insurance.

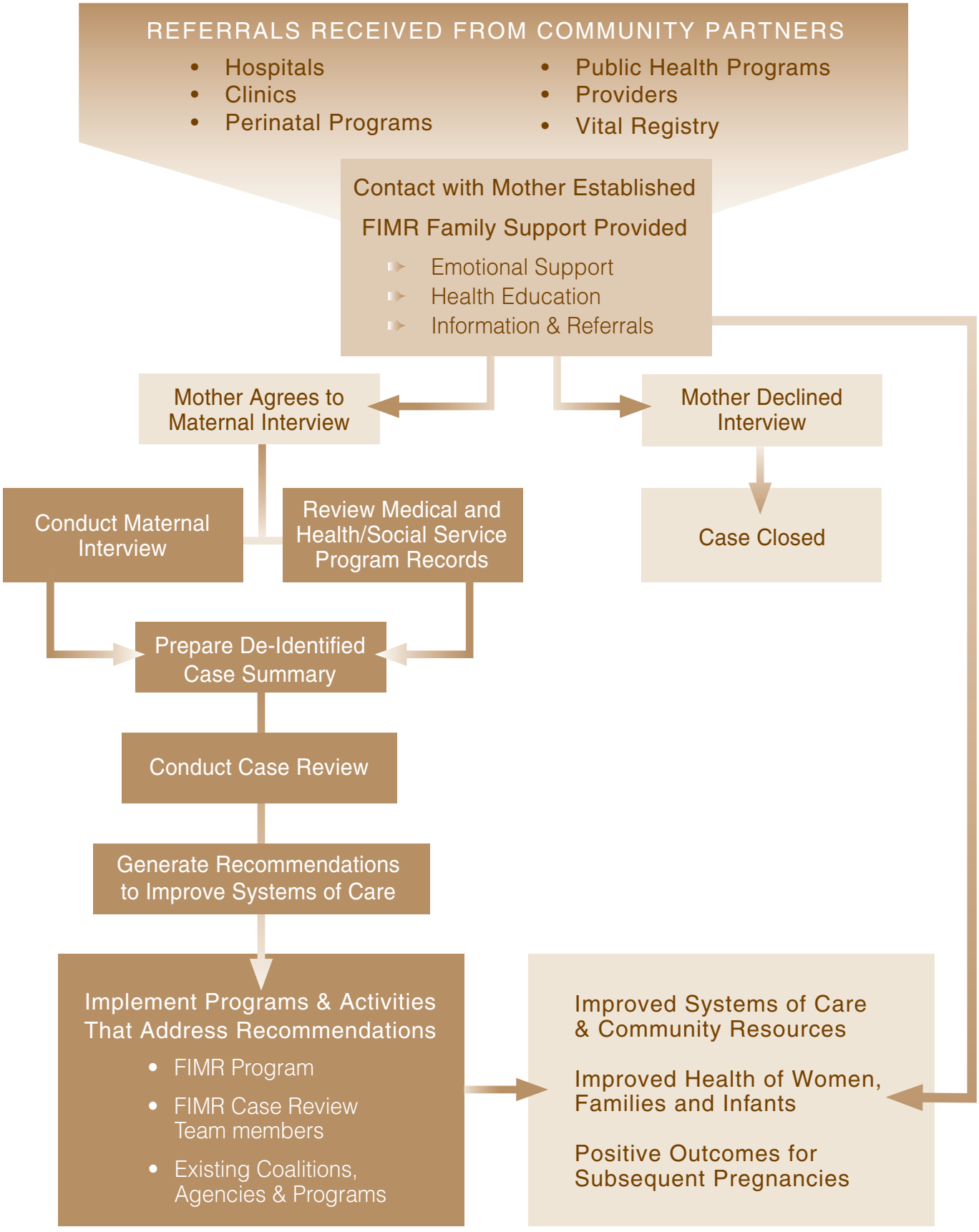
Maternal Interview

After family support has been initiated, mothers may choose to share their experience in the form of an interview, which is subsequently used during the case review process. The maternal interview is the heart of the FIMR Program and is what makes FIMR unique among other case review processes. The maternal interview allows the mother's voice to be heard and provides her with the opportunity to share her experiences while pregnant. This component is crucial to the case review process as the parents' experiences and point of view cannot be understood from medical records alone. As such, when the maternal interview is not obtained, either because the mother could not be located or she declined the interview, the case may not be reviewed. In general, approximately nine out of 10 women contacted by the FIMR Program consent to an interview.

Records Review

The records review process begins shortly after mothers and families are contacted. The FIMR Program reviews information related to the death from a variety of sources, including medical records, birth and death certificates, coroner's reports, and records from health and social service agencies.

Figure 1: The FIMR Process



Represents a core function of the FIMR Model

Case Review

Based on the data collected from the maternal interview and records review, a case summary is prepared and presented to the Case Review Team (CRT) for review. The CRT is a multidisciplinary team of key community members. The team represents a range of professional organizations and public and private agencies that provide services to women, infants and families. A list of current and former CRT members is included as Appendix A.

As the CRT reviews each case, the group examines circumstances related to individual fetal and infant deaths. During this process, the CRT considers several questions, such as:

- What are the issues that have contributed to this death?
- Did the family receive the services or community resources that they needed?
- Are there gaps in the system?
- What does this case reveal about how families use existing resources?

During the case review, the CRT identifies system problems that require change and makes recommendations for how to improve policies and services that affect families. While some factors that contribute to fetal and infant death may not be modifiable with the skills and resources currently available, many factors can be addressed.

Throughout the case review process, confidentiality of all information is strictly maintained. All information that could identify the mother, providers and institutions is removed from cases prior to being submitted to the CRT for review.

The CRT does not review all cases that are referred to the FIMR Program. Typically the CRT reviews between 20 and 30 cases per year. Between 1998 and 2004, the CRT reviewed approximately half (46%) of the cases that were referred to the FIMR Program.

Community Action

The final step in the FIMR process is to translate CRT recommendations into action. Typically, recommendations from the CRT are presented to a community action team that is responsible for turning the recommendations into action. In Contra Costa, the community action process is accomplished through issue-specific task force groups that are assembled to address different recommendations. Task force members may include CRT members as well as representatives of organizations and agencies who are interested in or affected by the issues being addressed.

Community actions designed to address the CRT recommendations may take many forms and can address systems changes on various levels. For example, actions may involve an intervention to educate individuals, providers or the public while others may target changing organizational practices or legislative policies.

Summary of FIMR Process

The FIMR process described above is often referred to as the Cycle of Improvement (Figure 2). The continuous nature of the process provides a feedback mechanism that can help identify the extent to which the recommendations and actions are working. Over time, the review of new cases will reveal how successful interventions, programs and policies have been because the change, or lack thereof, will be evident in future case reviews. As such, FIMR can function as a mechanism for continuous quality improvement.

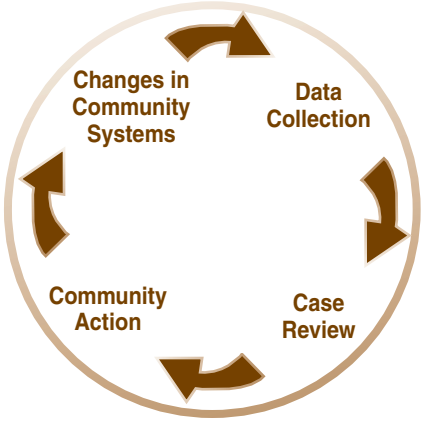


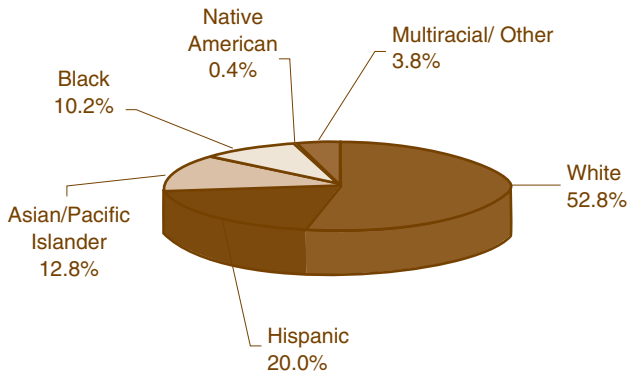
Figure 2: The Cycle of Improvement

OVERVIEW OF FETAL & INFANT MORTALITY IN CONTRA COSTA COUNTY

Description of Contra Costa County

In 2000, Contra Costa County was home to 948,816 people.[1] U.S. Census data show that between 1990 and 2000, Contra Costa's population increased by 18%. In addition, the population has become more racially and ethnically diverse; people of color currently comprise 42% of the population. Adults make up 74% of the population in the county and women of reproductive age (15 to 44 years) comprise 21%. Figure 3 shows the racial/ethnic breakdown of women of reproductive age.

Figure 3: Race/Ethnicity of Women Aged 15 to 44 Years in Contra Costa, 2000[1]



SUMMARY OF FETAL & INFANT MORTALITY IN CONTRA COSTA

Fetal Mortality Ratio[4]

- 2003 Fetal Mortality Ratio = 5.1 deaths per 1,000 live births and fetal deaths.
- Between 1993 – 2003: fluctuated between 4.3 and 7.1 fetal deaths per 1,000 live births and fetal deaths.
- Average of 71 fetal deaths per year from 1993 – 2003.

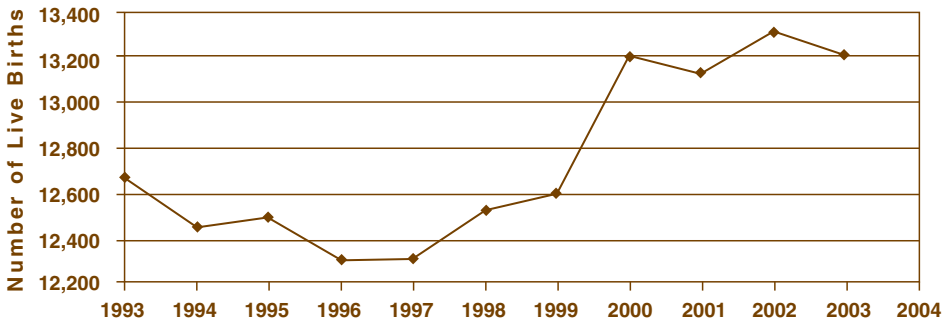
Infant Mortality Rate[2,6]

- 2003 Infant Mortality Rate = 3.6 deaths per 1,000 live births.
- From 1993 to 2003, rates have decreased overall from 5.9 to 3.6 deaths per 1,000 live births.
- Average of 65 infant deaths per year from 1993 – 2003.
- Racial/ethnic disparities exist in infant, neonatal & postneonatal mortality rates.

Live Births

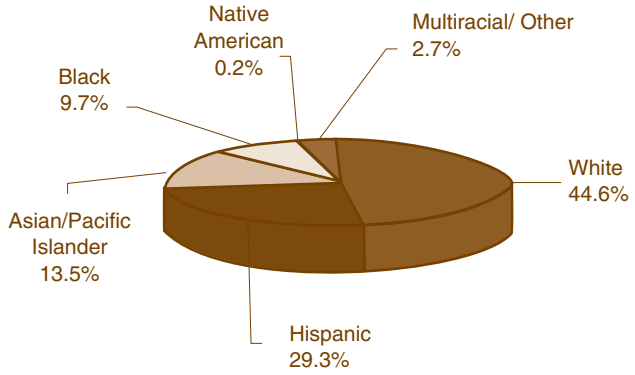
Since 1993, there has been an overall increase in the number of live births to Contra Costa residents (Figure 4). In 2003, the number of live births was 13,210.

Figure 4: Live Births to Contra Costa Residents, 1993 – 2003[2]



Data on live births by race/ethnicity indicates that in 2001, almost half of the births were White infants and just over a quarter were Hispanic infants (Figure 5).

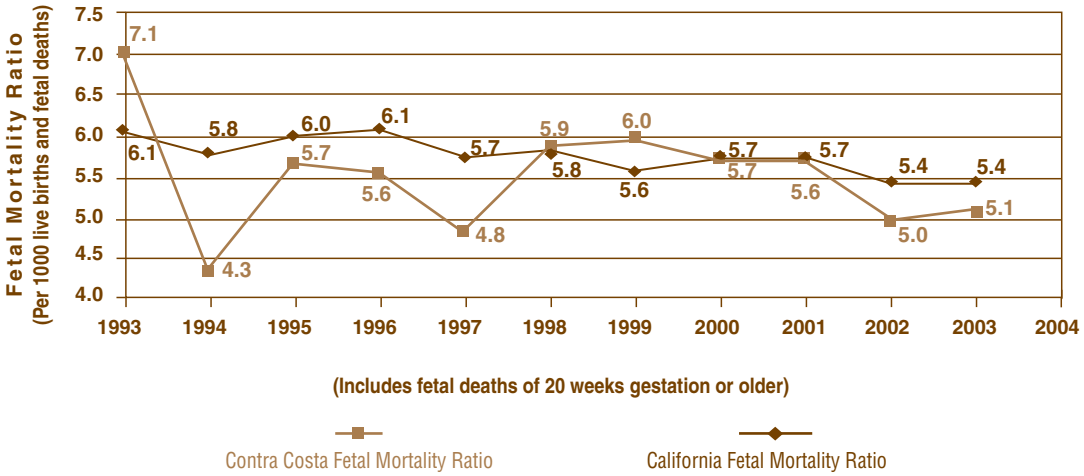
Figure 5: Live Births to Contra Costa Residents by Race/Ethnicity, 2001[3]



Fetal Mortality

The State of California monitors fetal deaths that occur at 20 weeks gestation or greater*. Between 1993 and 2003, the fetal mortality ratio† in Contra Costa fluctuated between 4.3 and 7.1 fetal deaths per 1,000 live births and fetal deaths (Figure 6). In 2003, the fetal mortality ratio for Contra Costa was 5.1 fetal deaths per 1,000 live births and fetal deaths. This is above the Healthy People 2010 objective of 4.1 fetal deaths per 1,000 live births plus fetal deaths.[5] In general, the fetal mortality ratio for Contra Costa has been lower than for California. On average, 71 fetal deaths per year have occurred to Contra Costa residents between 1993 and 2003.[4]

Figure 6: Trends in Fetal Mortality Ratios in Contra Costa and California, 1993 – 2003[4]



* The State of California considers a fetal loss at less than 20 weeks gestation to be a miscarriage. These losses are not monitored by California's vital statistics system.

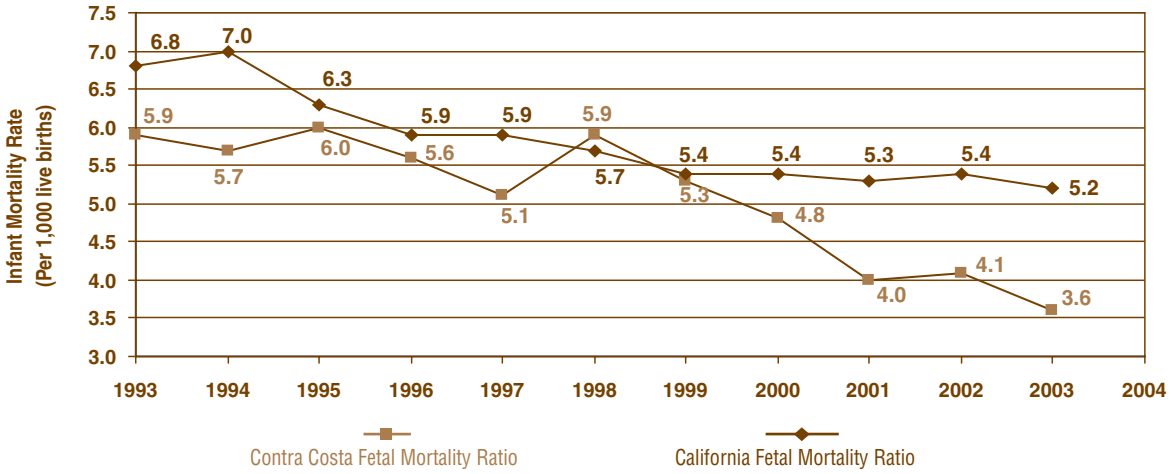
† The fetal mortality ratio is defined as:

$$\frac{\text{the total number of fetal deaths occurring at 20 weeks gestation or greater}}{\text{(the number of live births + the number of fetal deaths at 20 weeks gestation or greater)/1000}}$$

Infant Mortality

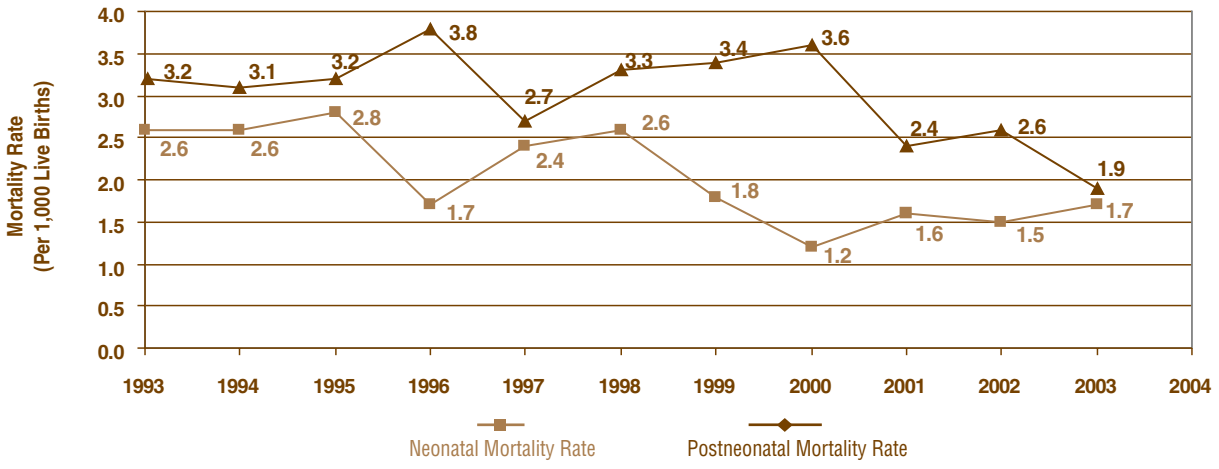
From 1993 through 2003, the infant mortality rate in Contra Costa fluctuated between a high of 6.0 deaths per 1,000 live births in 1995 to a low of 3.6 deaths per 1,000 live births in 2003 (Figure 7). In general, the infant mortality rate for Contra Costa has been lower than the infant mortality rate for California during this period. In 2001, the infant mortality rate in Contra Costa dropped below the Healthy People 2010 objective of 4.5 deaths per 1,000 live births and has remained below this level in 2002 and 2003.[5] Between 1993 and 2003, an average of 65 infants have died each year in Contra Costa.[6]

Figure 7: Trends in Infant Mortality Rates in Contra Costa and California, 1993 – 2003 [2,6]



Between 1993 and 2003, the neonatal and postneonatal mortality rates‡ decreased in Contra Costa (Figure 8). In 2001, the neonatal mortality rate dropped below the Healthy People 2010 objective of 2.9 neonatal deaths per 1,000 live births and remained below this level in 2002 and 2003.[5] The county's postneonatal mortality rates from 1993 through 2003, however, have remained at or above the Healthy People 2010 objective of 1.2 postneonatal deaths per 1,000 live births. The average number of neonatal and postneonatal deaths in Contra Costa during this time period was 39 and 26 deaths per year, respectively.

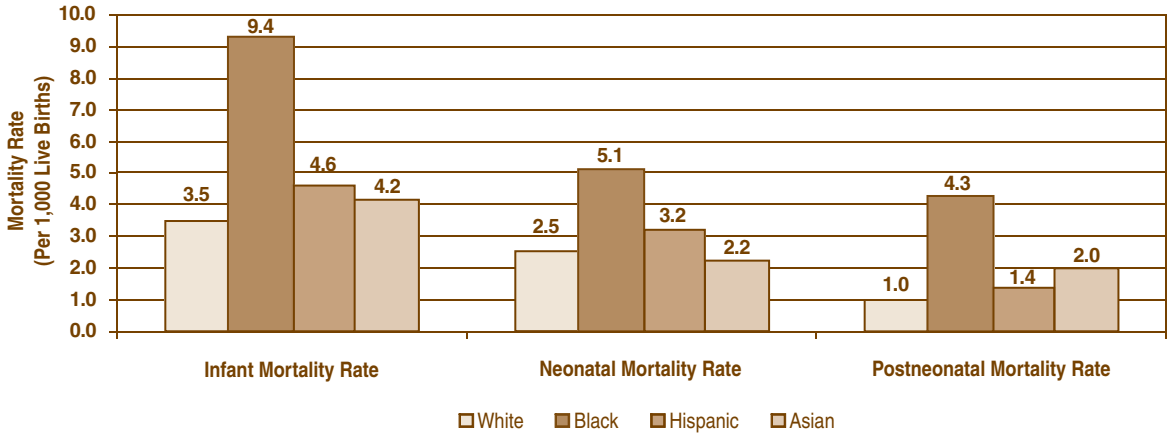
Figure 8: Trends in Neonatal and Postneonatal Mortality Rates for Contra Costa, 1993 – 2003 [2,6]



‡The neonatal mortality rate is the number of deaths of live-born infants that occur before 28 days of age per 1,000 live births. Postneonatal mortality rate is the number deaths of infants that occur from 28 through 364 days of age per 1,000 live births.

A review of infant mortality rates in Contra Costa reveals disparities between racial and ethnic groups, with Blacks experiencing the highest infant, neonatal and postneonatal mortality rates. The three-year averages for infant mortality rates from 1999 through 2001 indicate that the infant mortality rate for Black infants is 2.0 to 2.7 times higher than Whites, Hispanics and Asians (Figure 9). This corresponds to racial and ethnic disparities in state and national data. Similarly, the neonatal mortality rate for Blacks is 1.6 to 2.3 times higher than other racial/ethnic groups and the postneonatal mortality rate ranges from 2.2 to 4.3 times higher. A main objective of Healthy People 2010 is to eliminate health disparities such as those that exist among infant mortality rates.[5]

Figure 9: Three-Year Average Mortality Rate by Race/Ethnicity*, Contra Costa 1999 – 2001[2,6]



* Race/ethnicity definitions are based on California Department of Health Services data. Data for White includes that for "Other" and "Not Stated" races. Data for White, Black and Asian does not include Hispanic. Hispanic data includes any race.

Leading Causes of Infant Death

The California vital statistics data system typically categorizes causes of infant death into groups. In Contra Costa, over 75% of the 172 infant deaths that occurred in 2000 through 2002 fell into three main categories of causes of infant death. These three categories are:

1. Conditions originating in the perinatal period (47.6%),
2. Congenital malformations, deformations and chromosomal abnormalities (22.2%), and
3. Sudden Infant Death Syndrome (SIDS, 8.1%).

This data mirrors data for California for this time period. Table 1 shows the specific causes of infant death that comprise the categories listed above.

Table 1: Breakdown of Leading Causes of Infant Death Categories for Contra Costa, 2000 – 2002[6]

Cause of Death Category	Specific Cause of Death	Percent of Total Cases of Infant Death
Conditions originating in the perinatal period	Disorders related to short gestation and low birth weight	13.4%
	Newborn affected by maternal factors, complications of pregnancy, and labor & delivery, such as: • Maternal hypertension disorders • Maternal complications of pregnancy (e.g., incompetent cervix, premature rupture of membranes, multiple pregnancy) • Complications of placenta, cord and membranes • Maternal conditions unrelated to present pregnancy	8.7%
	Intrauterine hypoxia and birth asphyxia	1.7%
	Respiratory distress of newborn	1.7%
	Infections specific to the perinatal period	1.7%
	Other respiratory conditions originating in the perinatal period	4.7%
	Other & unspecified conditions originating in perinatal period	15.7%
Congenital malformations, deformations and chromosomal abnormalities	Congenital malformations of the heart	9.9%
	Congenital malformations of the respiratory system	4.1%
	Other congenital malformations and deformations	2.3%
	Other congenital malformations of the circulatory system	1.2%
	Other congenital malformations of the nervous system	1.2%
	All other chromosomal abnormalities, not classified elsewhere	3.5%
Sudden Infant Death Syndrome		8.1%

DESCRIPTION OF CASES REVIEWED BY THE FIMR PROGRAM

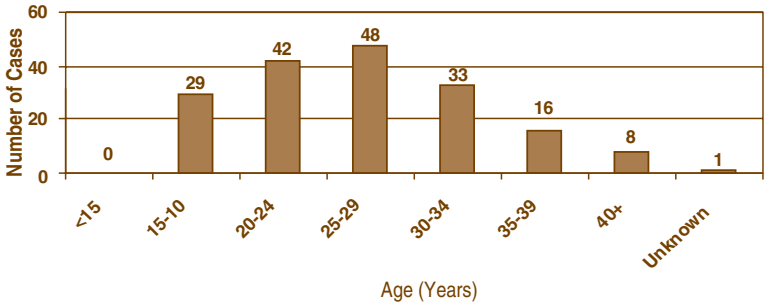
The FIMR Program only reviews a portion of the fetal and infant deaths that occur each year to Contra Costa residents. From 1998 through 2004, the Contra Costa FIMR Program reviewed 177 cases, or an average of 25 cases per year. These cases represent approximately 20% of the fetal and infant deaths that occurred to Contra Costa residents and approximately half (46%) of the cases referred to the FIMR Program during this time period.

This section describes the 177 cases that have been reviewed by the FIMR Program. Of these cases, 60% were fetal deaths, 25% were neonatal deaths and 15% were postneonatal deaths. The FIMR Program does not use random sampling to select cases for review, therefore the data presented in this section should not be considered representative of the entire population of fetal and infant deaths in Contra Costa.

Maternal Age

Figure 10 shows the distribution of maternal age for cases reviewed by the FIMR Program. The largest age group is 25 to 29 years, followed by 20 to 24 years. Together these two age groups constitute 51% of reviewed cases. Adolescents and young women age 15 to 19 represent 16% of the cases while women age 35 and older represent 14%.

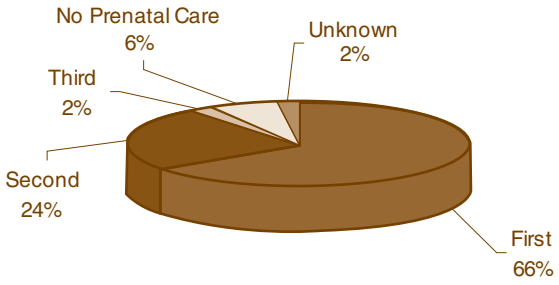
Figure 10: Maternal Age For Reviewed FIMR Cases, 1998 – 2004 (n=177)



Trimester Prenatal Care Started

In the majority of cases reviewed, the mother began her prenatal care within the first trimester (also called early entry into prenatal care, Figure 11). Approximately 25% began prenatal care in their second trimester or third trimester, while 6% of mothers received no prenatal care.

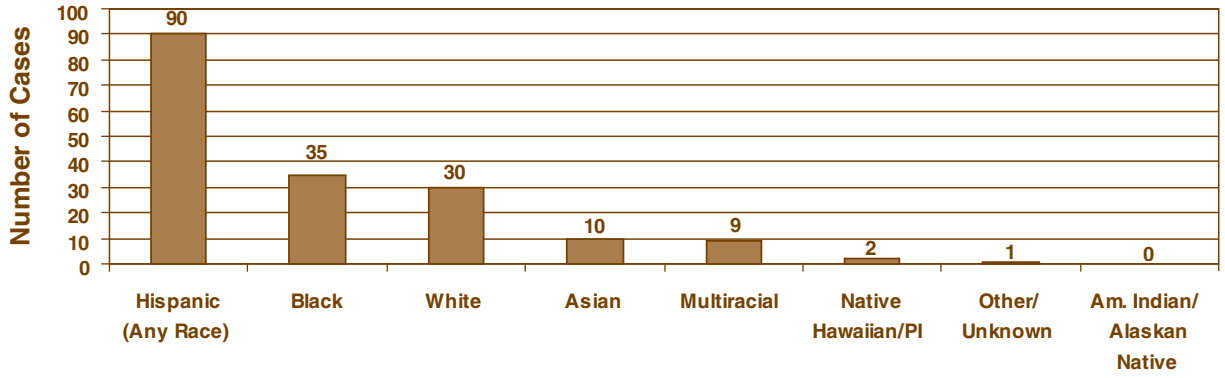
Figure 11: Trimester Prenatal Care Started for Reviewed FIMR Cases, 1998 – 2004 (n=177)



Fetal and Infant Race/Ethnicity

Figure 12 shows the distribution of reviewed FIMR cases by fetal and infant racial and ethnic group. Approximately half (51%) of the cases were Hispanic. Black and White cases constituted 20% and 17% of reviewed cases, respectively. Asian and multiracial cases each constituted less than 10%.

Figure 12: Fetal and Infant Race/Ethnicity Among Reviewed FIMR Cases, 1998 – 2004 (n=177)



A breakdown of cases in each racial and ethnic group by type of death is shown in Table 2. Hispanic, White, and multiracial cases had a similar distribution of death in which 50 to 60% of cases were fetal deaths, approximately 30% were neonatal deaths and the remaining deaths were postneonatal. In comparison, 70% of Black cases were fetal deaths and the remaining cases were split between neonatal and postneonatal deaths. The Asian cases were primarily neonatal (50%) or fetal (40%).

Table 2: Reviewed FIMR Cases by Type of Death and Race/Ethnicity, 1998 – 2004

TYPE OF DEATH	RACE/ETHNICITY OF FETUS OR INFANT						
	Hispanic, any race (n=90)	Black (n=35)	White (n=30)	Asian (n=10)	Multiracial (n=9)	Native Hawaiian/PI (n=2)	Other/ Unknown (n=1)
Fetal	60%	71%	53%	40%	56%	50%	100%
Neonatal	26%	14%	30%	50%	33%	0%	0%
Postneonatal	14%	14%	17%	10%	11%	50%	0%
TOTAL	100%	100%	100%	100%	100%	100%	100%

Gestational Age

Babies born at 37 weeks gestation or older are considered to be mature while those born at less than 37 weeks are premature. Among fetal cases, 26% involved full-term, mature babies that died before delivery (Table 3). Overall, the largest gestational age group among fetal cases was 20 to 23 weeks.

Babies that are born prematurely are at greater risk for complications and death. Nationwide, prematurity is the leading cause of neonatal death.[7] Among the infant death cases reviewed by FIMR, 62% involved infants who were premature at delivery.

Table 3: Gestational Age for Reviewed FIMR Cases, 1998 – 2004

GESTATIONAL AGE	FETAL CASES		INFANT CASES	
	Number of Cases	Percent of Fetal Cases	Number of Cases	Percent of Infant Cases
20 – 23 weeks	31	29%	17	24%
24 – 27 weeks	13	12%	12	17%
28 – 31 weeks	16	15%	6	8%
32 – 36 weeks	13	12%	16	23%
37 + weeks	28	26%	19	27%
Unknown	5	5%	1	1%
TOTAL	106	100%	71	100%

Delivery and Birth Weights

Table 4 shows the delivery and birth weights for fetal and infant cases reviewed by the FIMR Program. The distribution of delivery and birth weights should not be compared by type of death without also looking at gestational age since gestational age is directly related to weight.

As suggested by the distribution of fetal cases by gestational age, the majority of fetal cases (68%) were less than 2,500 grams. Among infant cases, the distribution of infants weighing less than 2,500 grams and those weighing 2,500 grams or more at birth were approximately equal.

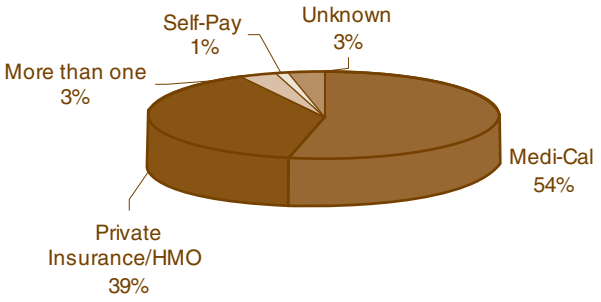
Table 4: Fetal Delivery Weights and Infant Birth Weights for Reviewed FIMR Cases, 1998 – 2004

Weight Class	Fetal Delivery Weight (n=106)	Infant Birth Weight (n=71)
≥2,500 grams	23%	46%
< 2,500 grams	68%	50%
Unknown	9%	4%
TOTAL	100%	100%

Type of Health Insurance

Figure 13 shows that in most of the cases reviewed by the FIMR Program, the mother had Medi-Cal (54%), or a private insurance plan or HMO (39%). A small percentage of women (3%) reported more than one type of insurance during the perinatal period and only 1% of women self-paid.

Figure 13: Type of Health Insurance Among Reviewed FIMR Cases, 1998-2004 (n=177)



Region of the County

During the review process, FIMR cases are classified into three regions of the county based on maternal residence. Most of the reviewed cases occurred to women living in East County (45%) and West County (37%). Sixteen percent occurred to women in Central County, and in the remaining 2% of cases maternal residence was not specified.

FIMR CASE REVIEW FINDINGS AND RECOMMENDATIONS

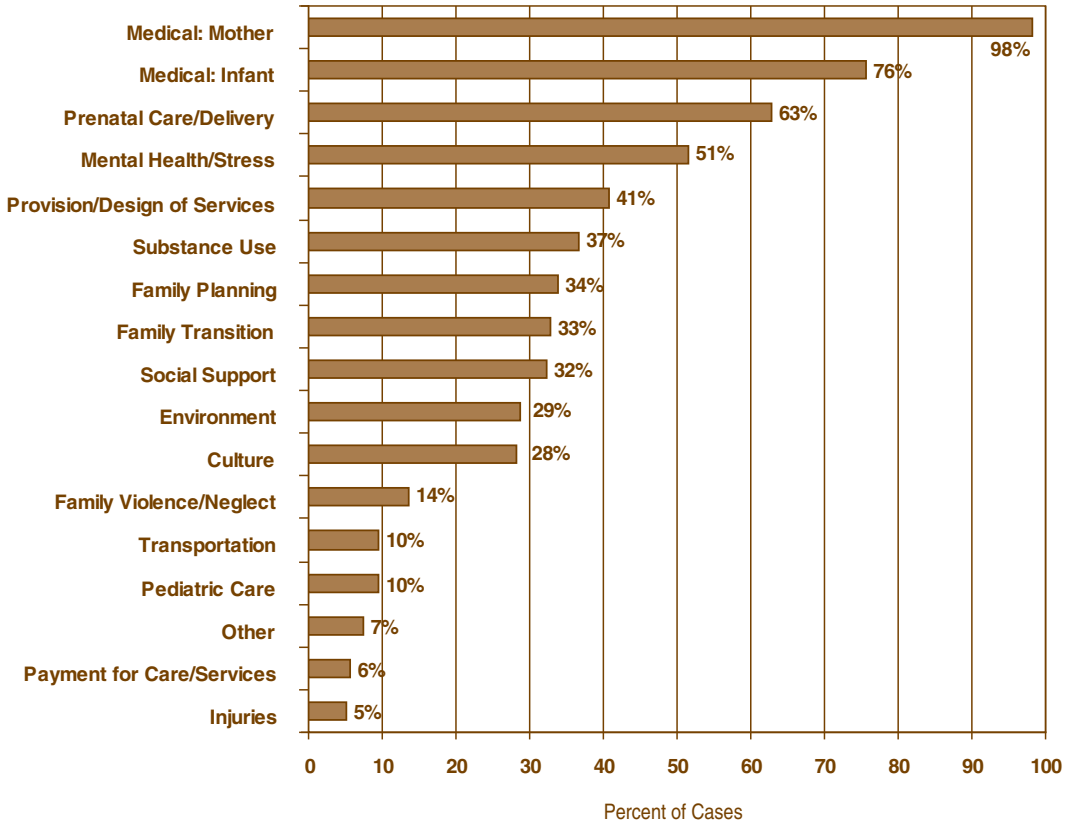
During the case review process, the CRT identifies factors and issues associated with each case and makes recommendations for systems changes to address these factors and issues. This section discusses the results of the case review process.

Issues Related to Fetal and Infant Mortality

The identification of issues related to fetal and infant mortality is an important component of the case review process. To facilitate this process, the National FIMR Program has identified and defined over 100 issues that fall into 17 general categories for use by CRTs. Appendix B provides definitions for each category and issue related to fetal and infant mortality.

Figure 14 shows how frequently each general category of issues was identified during the case review process. Medical issues were the most frequently identified with almost all (98%) of the cases reviewed involving one or more medical issues related to the mother and the majority of cases (76%) involving at least one medical issue related to the fetus or infant. Prenatal care/delivery issues were identified in approximately two-thirds of cases (63%) and mental health and stress-related issues were identified in half of the cases. Other categories of issues that were identified in at least 25% of the cases include provision/design of services, substance use, family planning, family transition, social support, environment and culture.

Figure 14: Categories* Identified During the Case Review Process, 1998 – 2004 (n=177)



* See Appendix B for a description of the categories of issues shown in Figure 14.

Summary of Major Findings and Recommendations

The final component of the case review process is the development of recommendations for change based on the case review findings. Although the findings and recommendations vary each year depending on the cases reviewed, the findings can be summarized and categorized into several groups. While findings and recommendations from individual cases may be targeted to specific components of our systems of care (e.g., prenatal care providers, emergency rooms, perinatal case management programs, etc.), the categories of findings presented below are broadly defined and may be applied to various components of our systems of care:

- **Grief & Bereavement:** Provide adequate grief follow-up after a fetal or infant loss, increase the availability of grief services for parents and families, increase awareness of the importance of grief and bereavement among providers, develop bereavement guidelines for providers, and include grief and bereavement services as a part of the continuum of perinatal care.
- **SIDS Risk Reduction:** Enhance and continue education on risk reduction for providers, parents, and families.
- **Case Closure/Post-loss Follow-up and Interconception Care:** Following a fetal or infant loss, provide comprehensive services to assess grief, health, family planning, genetic counseling and other referral needs before closing a case.
- **Care Coordination:** Strengthen coordination between local agencies and programs and increase knowledge of available resources among providers, agencies and programs.
- **Language-appropriate Services:** Increase availability and use of linguistically appropriate services.
- **Asthma:** Promote effective medical and case management.
- **Nutritional Issues:** Promote comprehensive and consistent nutritional assessment and interventions, specifically around obesity/weight management and gestational diabetes.
- **Adequate Patient Education:** Ensure clients receive adequate health education. Examples of specific topics include folic acid, preterm labor, danger signs of pregnancy, and decreased fetal movement/kick counts.
- **Medical Records:** Improve access to and timely transfer of complete, legible prenatal records.
- **Presumptive Eligibility§:** Increase awareness and utilization among providers and women.
- **Substance Abuse:** Promote identification of substance abuse issues and enhance case management services and resources.

TRANSLATING RECOMMENDATIONS INTO ACTION

The FIMR Program works with various community agencies and programs to translate case review recommendations into action. As shown above, issues and recommendations can vary greatly in content, complexity and level of intervention (e.g., individual, system or policy). In deciding which recommendations to address, the FIMR Program considers available resources, feasibility and uniqueness.

§ Presumptive Eligibility is a Medi-Cal program that provides immediate, temporary health coverage for all low-income pregnant women, regardless of citizenship.

Since 1998, the FIMR Program has initiated several interventions to improve systems of care and community resources based on CRT recommendations. For each intervention, the FIMR Program recruited a variety of health and social service providers to help develop and implement the effort. The interventions are described below.

Prenatal Health Card

The CRT reviewed several cases that had major issues related to the accessibility of prenatal records, including:

- lost prenatal records,
- the inability of hospital staff to gain access to prenatal records,
- frequent emergency room encounters,
- illegible documentation, and
- deliveries that occurred outside of the clients' health plan service systems.

In many of these cases, information contained in the clients' prenatal records was critical to the attending provider. A task force was convened in 1998 to develop a prenatal health card in response to these issues.

The prenatal health card is a pocket card for prenatal clients that enables women to have basic medical information, including lab and diagnostic tests results, available when their prenatal records are inaccessible. The objective of the card is to improve birth outcomes by enhancing communication between pregnant women and their providers. By carrying this card, a pregnant woman can provide any potential provider, either at a regular appointment or in an emergency, with essential information about her prenatal care and medical and obstetric risk factors.

The card is currently distributed to pregnant women by prenatal providers in five clinics in Contra Costa. Women are instructed to bring their cards to routine prenatal appointments as well as any emergency room or hospital visits, and providers are trained to fill out the cards. In addition to medical information, the card also includes resource phone numbers and health education information.

The Contra Costa FIMR Program has shared the prenatal health card with other FIMR Programs in California and other states. To date, several FIMR programs in California – Alameda County, Butte County, Glenn County, San Diego County, Santa Clara County and Sonoma County – as well as perinatal programs and organizations in New Jersey and Maryland have adopted the card for use in their regions. In addition, the California Chapter of the March of Dimes electronically distributed the card to perinatal providers throughout Northern California in 2003 as part of a prematurity resource CD.

The prenatal health card is an ongoing intervention. The card has been periodically revised and the FIMR Program continues to work with providers to promote and expand its use. Most recently, the FIMR Program began working with Alta Bates Summit Medical Center in 2004 to expand the use of the card to the hospital's clinic partners in Alameda County and West Contra Costa.

Folic Acid Community Campaign

Folic acid is a B vitamin that if taken before pregnancy can significantly reduce the risk of having a baby with a birth defect of the brain and spine (called neural tube defects). After reviewing several cases of neural tube defects, the CRT determined that women were not receiving consistent and comprehensive information on folic acid from their providers. In response to this finding, the CRT recommended a community-wide education campaign be conducted.

In 2003, the FIMR Program implemented the Folic Acid Community Campaign with support from the March of Dimes and the United States Department of Agriculture, California Nutrition Network. The purpose of this campaign is to raise awareness of folic acid and its role in preventing birth defects of the brain and spine. The campaign consists of the following key components:

- **Collaborative efforts:** The FIMR Program has collaborated with several programs and agencies on the design and implementation of the campaign.
- **Media activities:** Media activities have included on-screen theater advertising in movie theaters, transit advertising, a project website, a CD of campaign materials, mailings to food stamp recipients, and local cable TV shows and advertising. The CD has been distributed to local health jurisdictions throughout the state.
- **Regional trainings:** Folic acid trainings have been conducted for public health nurses, community health workers, nutrition staff, public health interpreters, health educators and other public health providers.
- **Educational materials and incentives:** Folic acid brochures were developed in six languages as well as a bilingual (English/Spanish) magnet, fact sheet, flyer and mailer.

The media activities concluded in July 2004, but the FIMR Program still conducts trainings as requested.

Grief and Bereavement Guidelines

A major issue identified by the CRT is the lack of available and accessible community grief and bereavement services for families who experience a pregnancy loss or infant death. Of notable concern is the issue that existing perinatal and infant case management services may close cases immediately after families experience a pregnancy loss or infant death. This is often a missed opportunity to provide families with resources and support.

In 1999, the FIMR Grief and Bereavement Task Force was convened to develop a plan to address the issues of inadequate grief support. A key activity of the task force was the development of grief follow-up guidelines for perinatal and infant case management programs. In 2001, the task force published *Guidelines Following a Pregnancy Loss or Infant Death* and began distributing the publication to local perinatal providers. The purpose of the guidelines is to give health care providers information that they can use to assure that families in their care who experience a pregnancy loss or infant death receive sensitive and compassionate case closure. Future activities for the task force include organizing and conducting local trainings on the guidelines to local agencies.

Annual Teleconference on Grief Awareness

Every year since 1999, the FIMR Program has sponsored participation in a national teleconference on grief awareness. The teleconference addresses a different aspect of grief awareness each year. Previous teleconferences have focused on living with grief at work, at home and at worship; children and adolescents; older adults; and coping with public tragedy. This annual activity addresses the need to increase grief awareness among health care providers as identified by the CRT.

Day of Remembrance

The Day of Remembrance is a memorial service that is conducted every year in December. The service was established in 1999 in response to the needs of bereaved families and is produced by families and communities with assistance from FIMR staff. The service provides an opportunity for families to honor and remember their lost babies and children and to receive support from and connect with other bereaved families.

Support Groups

FIMR staff periodically conduct support groups in English and Spanish for bereaved mothers and families. This service was established in response to requests from families. The support groups typically last six weeks and are designed to provide support after a pregnancy or infant loss and prior to subsequent pregnancies. The support groups cover a range of issues such as grief and bereavement, depression, family planning, nutrition, genetic counseling, and preconception health care. To date, eight support groups have been conducted.

Support and Share

The FIMR Program and the Contra Costa Crisis Center collaborated in 1999 to conduct "Caring for Ourselves," an informal brown bag support group for county health care providers who care for families throughout our community. This activity acknowledged the difficulties and challenges providers face and provided a supportive environment where they could share their experiences, thoughts, and feelings. The support group was conducted for one year.

Prematurity & Danger Signs of Pregnancy Awareness Project

Data from the case review process indicates that approximately 6 out of 10 cases reviewed involved preterm labor, a maternal history of preterm labor, or no fetal movement. Additionally, in some cases women delayed seeking care after experiencing decreased fetal movement. In order to address these issues, the CRT recommended improved education of clients about preterm labor and danger signs of pregnancy.

In 2004, the Prematurity Task Force was established to provide guidance in the development and implementation of the Prematurity & Danger Signs of Pregnancy Awareness Project. The purpose of the project is to:

1. Raise provider awareness around the importance of client education regarding preterm labor and the danger signs of pregnancy, and

2. Distribute educational materials to providers to support their efforts to educate clients on preterm labor and the danger signs of pregnancy.

The project activities include conducting Grand Rounds at local hospitals and site visits to perinatal providers, distributing resource kits and client education materials in English and Spanish to providers, and sponsoring TV shows and public service announcements on the local cable television station. This project is being implemented with support from the March of Dimes and is ongoing through 2005.

SIDS Strategic Planning Event

After reviewing several SIDS deaths, one recommendation prioritized by the CRT was to ensure that California Assembly Bill (AB) 757 was being fully implemented in medical facilities. AB 757 states, in part, that all medical facilities must inform parents or guardians of SIDS risk reduction measures prior to hospital discharge.

To address this issue, the FIMR and SIDS Programs organized a strategic planning event in 2000 to bring private and community providers together to address SIDS risk reduction at a policy level. Twenty-three public and private agencies participated and the event resulted in language being added to policies and procedures of participating agencies to assure the community was receiving a coordinated and consistent risk reduction message. The SIDS Program continues to provide technical assistance and follow-up for agencies as they implement their protocols and activities.

Safe Place to Sleep

In 2000, the FIMR Program supported a collaborative project with the SIDS and Prenatal Care Guidance (PCG) Programs of Contra Costa County. The aim of this project was to promote infant safety by providing low-income families with cribs and education on SIDS risk reduction and safe sleeping. During the project, 18 cribs were distributed to low-income families. This project addressed CRT recommendations regarding knowledge and awareness of SIDS risk reduction. The Safe Place to Sleep project was funded by the California Kid's Plate grant.

Mercury Thermometer Exchange

In 2002, the FIMR Program partnered with the SIDS Program, Public Health Clinic Services, Medically Vulnerable Infant Program, and Hazardous Waste Program on a mercury thermometer exchange project. Packets were created for new parents that contained a digital thermometer, infant nail clippers, and a spoon for administering liquid medicines to infants. All items were printed with the SIDS "Back to Sleep" logo and tag line. SIDS risk reduction education materials were also included in the packets. Parents who owned mercury thermometers were encouraged to hand them in and use the digital thermometer in the future.

The objective of this project was to reinforce the SIDS "Back to Sleep" message with useful incentive items while reducing the number of mercury thermometers in use. Public Health Nurses from Public Health Clinic Services and the Medically Vulnerable Infant Program distributed the packets to new parents. This project addressed CRT recommendations regarding knowledge and awareness of SIDS risk reduction and reinforced safe infant care practices.

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GLOSSARY

Birth weight: The weight of an infant immediately after delivery or as soon thereafter as feasible. Normal birth weight is 2,500 grams (5.5 lbs) or greater.

Early Entry into Prenatal Care: The mother begins prenatal care in the first three months of her pregnancy (i.e., first trimester).

Fetal death: Death prior to birth (i.e., complete expulsion or extraction from the mother of a product of human conception, fetus and placenta), irrespective of the duration of pregnancy; the death is indicated by the fact that, after birth the fetus does not breathe or show any other evidence of life, such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles This definition excludes induced terminations of pregnancy, but includes intrauterine fetal demise.[8]

Fetal mortality ratio: The number of fetal deaths occurring at 20 weeks gestation or older per 1,000 live births and fetal deaths.

Gestational age: The number of completed weeks that have elapsed between the first day of the last menstrual period (not the presumed time of conception) and the date of delivery, regardless of whether the pregnancy results in a live birth or fetal death.

Infant mortality rate: The number of deaths of all live born infants less than 1 year of age (i.e., 364 days old or younger) per 1,000 live births.

Live birth: The birth (i.e., complete expulsion or extraction from the mother of a product of human conception), irrespective of the duration of pregnancy, after which the infant breathes or shows any other evidence of life, such as a beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles whether or not the umbilical cord has been cut or the placenta is attached.[8]

Low birth weight: A birth weight of less than 2,500 grams (5.5 lbs).

Neonatal mortality rate: The number of deaths of live-born infants less than 28 days old per 1,000 live births.

Postneonatal mortality rate: The number of deaths of live-born infants between 28 and 364 days old per 1,000 live births.

Very low birth weight: A birth weight of 1,500 grams (3.3 lbs) or less.

APPENDICES

APPENDIX A - CASE REVIEW TEAM MEMBERS

CURRENT CASE REVIEW TEAM MEMBERS	
Judy Bliss, MD Family Practice Physician Contra Costa Regional Medical Center	**Pam McCoy** Health Start Coordinator Pittsburg Health Center
Barbara Boehler Regional Perinatal Programs Manager Regional Perinatal Programs of California	**Susan Moore** Director of Grief Counseling Contra Costa Counseling Center
Patti Creel Community Health Specialist Prenatal Care Guidance Program	**Leigh Pierson-Brown** Pediatric Nurse Practitioner Public Health Clinic Services
Maureen Crosgrove Medical Social Worker Kaiser Permanante Medical Center	**Gloria Sandoval** Executive Director STAND! Against Domestic Violence
Dawn Dailey FIMR Program Manager Family, Maternal & Child Health Programs	**Bob Schaff, MD** Pediatrician Kaiser Permanente Medical Center
Nazli Ghamarifard Senior Health Promotion Specialist Blue Cross of California	**Yolanda Thompson** FIMR Community Health Specialist Family, Maternal & Child Health Programs
Claudette Garner Director of Contra Costa Programs The Perinatal Council	**Laurel Waters, MD** Perinatal & Pediatric Pathologist PerinatalPath
Itika Greene Perinatal Services Coordinator Family, Maternal & Child Health Programs	**Karin Wonnenberg** Public Health Nurse Public Health Clinic Services
Julie Kelly Director of Social Support Services Contra Costa Regional Medical Center	**Sha'ala Yeates** Lactation Consultant/Health Educator Kaiser Permanente
Kristina Kutter FIMR Project Coordinator Family, Maternal & Child Health Programs	**Patt Young** Black Infant Health Program Supervisor The Perinatal Council
Kiko Malin Director of Program Services March of Dimes	

FORMER CASE REVIEW TEAM MEMBERS	
Marian Bick Perinatal Program Liaison Contra Costa Health Plan	**Susan Lindheim, MD** Pediatrician Kaiser Permanente Medical Center
Sean Casey Acting Executive Director First 5 Contra Costa Children & Families Commission	**Yvonne Lynum** Program Services Manager March of Dimes
Diana Cosio Community Resource Center Blue Cross of California	**Jeffrey Maier, MD** Obstetrician Kaiser Permanente Medical Center
LeNai Dohr Registered Nurse Sutter Delta Hospital	**Patricia Martin** Community Health Specialist Prenatal Care Guidance Program
Tracy Hill Family Advocate The Perinatal Council	**Sgt. Maurice McClain** Investigative Bureau Richmond Police Department
Doris James Public Health Nurse California Children's Services	**Mona Mena** Executive Director Perinatal Network of Alameda/Contra Costa
Gwendolyn Johnson, MD Pediatrician Contra Costa Regional Medical Center	**Lt. Tom Moore** Sheriff-Coroner's Office Contra Costa County
Diana Jorgensen Medically Vulnerable Infant Program Manager Developmental Disabilities Council	**Cheri Pies, MSW, DrPH** Director Family, Maternal & Child Health Programs
Kezia Kakai Program Coordinator Ujima Family Recovery Services	**Debbie Shrem** Director of Program Services March of Dimes
Leslie Kowalewski Associate State Director March of Dimes	

APPENDIX B - DESCRIPTION OF ISSUES RELATED TO FETAL AND INFANT MORTALITY

Issues Related to Fetal-Infant Mortality Checklist

1. Medical: Mother
- ❑ Teen pregnancy
- ❑ Pregnancy > 35
- ❑ Cord problem
- ❑ No fetal movement
- ❑ Placental abruption
- ❑ Diabetes
- ❑ Incompetent cervix
- ❑ Infection during pregnancy
- ❑ Insufficient weight gain
- ❑ Multiple gestation
- ❑ Obesity
- ❑ Poor nutrition
- ❑ Pre-eclampsia/eclampsia
- ❑ Preterm labor
- ❑ Pre-existing hypertension
- ❑ STD
- ❑ Pregnancy < 1 year apart
- ❑ PROM
- ❑ Previous TABs/SABs
- ❑ Previous fetal loss
- ❑ Previous infant loss
- ❑ Previous LBW delivery
- ❑ Previous preterm delivery
- ❑ First pregnancy < 18 yrs old
- ❑ > 4 live births
- ❑ Other_____
- ❑ Unknown * ☐ Not a factor *

2. Medical: Fetal/Infant
- ❑ Intrauterine growth retardation
- ❑ Congenital anomalies
- ❑ Prematurity/extreme prematurity
- ❑ Inadequate fetal monitoring
- ❑ Failure to thrive
- ❑ Substance exposure
- ❑ Feeding problems
- ❑ Respiratory distress syndrome
- ❑ Inappropriate level of care facility
- ❑ Other_____
- ❑ Unknown * ☐ Not a factor *

3. Payment for care/services

a.
- ❑ Self-pay/medically indigent *
- ❑ Medi-Cal *
- ❑ Private insurance/HMO/ prepaid health plan *

b.
- ❑ Barriers related to insurance coverage
- ❑ Eligibility unclear
- ❑ Other_____
- ❑ Unknown * ☐ Not a factor *

4. Prenatal care/delivery
- ❑ Standard of care not met
- ❑ Inadequate assessment
- ❑ No prenatal care
- ❑ Late entry into prenatal care
- ❑ Lack of referrals to additional services
- ❑ Missed appointments
- ❑ Multiple providers/sites
- ❑ Other_____
- ❑ Unknown * ☐ Not a factor *

5. Pediatric care
- ❑ Standard of care not met
- ❑ Inadequate assessment
- ❑ No pediatric care
- ❑ Not breast fed or minimally breastfed
- ❑ Lack of referrals to additional services
- ❑ Missed appointments
- ❑ Multiple providers/sites
- ❑ Breastfed *
- ❑ Other_____
- ❑ Unknown * ☐ Not a factor *

6. Substance Use
- ❑ OTC/prescription drugs
- ❑ Positive drug test
- ❑ Tobacco use
- ❑ Alcohol use
- ❑ Illicit drugs (list type) _____
- ❑ Other_____
- ❑ Unknown * ☐ Not a factor *

7. Social support
- ❑ Lack of supportive friends/family
- ❑ Negative influence of friends/family
- ❑ FOB not involved
- ❑ Other_____
- ❑ Unknown * ☐ Not a factor *

8. Family Transition
- ❑ Frequent/recent moves
- ❑ Job loss
- ❑ Concern regarding citizenship
- ❑ Single parent
- ❑ Married/living together *
- ❑ Divorce/separation
- ❑ Parent in prison/parole or probation
- ❑ Living in shelter/homeless
- ❑ Major illness/death in family
- ❑ Other_____
- ❑ Unknown * ☐ Not a factor *

9. Mental Health/Stress
- ❑ Maternal history of mental illness
- ❑ Depression/mental illness during pregnancy/ postpartum
- ❑ Multiple stresses during pregnancy/infancy
- ❑ Other_____
- ❑ Unknown * ☐ Not a factor *

10. Family Violence/Neglect
- ❑ Abuse/harassment of mother
- ❑ Child abuse
- ❑ Child neglect
- ❑ Other_____
- ❑ Unknown * ☐ Not a factor *

11. Culture
- ❑ Language/cultural differences/inability to communicate with provider
- ❑ Cultural beliefs re: pregnancy/health
- ❑ Other_____
- ❑ Unknown * ☐ Not a factor *

12. Transportation
- ❑ No public transportation
- ❑ Inadequate/unreliable transportation
- ❑ Other_____
- ❑ Unknown * ☐ Not a factor *

13. Provision/design of services
- ❑ Inadequate patient/client education/information (specify)_____
- ❑ Service unavailable in area
- ❑ Mother/child not eligible
- ❑ Lack of communication among providers/services
- ❑ Fear of/dissatisfaction with system(s)
- ❑ Perceived receptivity
- ❑ Other_____
- ❑ Unknown * ☐ Not a factor *

14. Environment
- ❑ Substandard housing
- ❑ Overcrowding
- ❑ Exposure to toxic substances
- ❑ Second-hand smoke
- ❑ Car seat not used/used improperly
- ❑ Infant sleeping with others
- ❑ Sleeping in non-infant bed
- ❑ Soft bedding

Environment, cont.
- ❑ Infant overheating
- ❑ Non-supine positioning
- ❑ Lack of adult visual supervision
- ❑ Other_____
- ❑ Unknown * ☐ Not a factor *

15. Family Planning
- ❑ Lacks knowledge of FP methods/resources
- ❑ No B/C; intended Pregnancy *
- ❑ No B/C; unintended pregnancy
- ❑ Failed contraceptive
- ❑ Other_____
- ❑ Unknown * ☐ Not a factor *

16. Injuries
- ❑ MV occupant
- ❑ Suffocation
- ❑ Choking/strangulation
- ❑ Fire/burn
- ❑ Drowning/near drowning
- ❑ Poisoning/toxicity
- ❑ Shaken baby syndrome
- ❑ Other_____
- ❑ Unknown * ☐ Not a factor *

17. Other
- ❑ Grief counseling received *
- ❑ Psychosocial support prior to discharge *
- ❑ Other_____

Note:
* Data for these items were not included in the analysis used to create Figure 14 of this report.

Definition of Issues Related to Fetal-Infant Mortality

The National FIMR Program has identified and defined a list of factors most commonly identified in FIMR reviews. These factors are listed on the "Issues Related to Fetal-Infant Mortality" form and defined below. The list is not intended to be exhaustive, but serves as an aid to noting particular factors that commonly appear in reviewed cases. During the case review process, the case review team identifies all those factors that were evident in a case within the general categories listed below. The following definitions appear in all categories:

Other	An additional situation/ condition not specifically listed in the category.
Unknown	No information is available regarding this category.
Not a Factor	There were no issues in this category relating to this case, or this category does not apply in this case.
1. Medical Mother	
Teen pregnancy	Mother was less than 18 years old at time of delivery.
Pregnancy > 35	Mother was over age 35 at time of delivery.
Cord problem	Evidence of cord torsion, nuchal cord, insufficient cord vessels, or other problems relating to the umbilical cord, usually noted in prenatal or delivery records or in placental pathology report.
No Fetal Movement	Mother experienced no fetal movement or decreased fetal movement prior to delivery, usually noted during maternal interview or documented in prenatal or delivery records.
Placental abruption	Abruption or partial abruption of the placenta, usually noted in delivery record or placental pathology report.
Diabetes	Gestational or pre-existing diabetes, usually noted in prenatal or delivery records.
Incompetent cervix	Rapid and unexpected premature dilation of the cervix, usually noted in delivery record or strongly suspected by clinicians on the case review team.
Infection during pregnancy	Vaginosis detected prenatally or at delivery, or evidence of chorioamnionitis or other infection at delivery, usually noted in prenatal or delivery records or on placental pathology.
Insufficient weight gain	Little or no gain – or loss – given the mother's stature for any prolonged period during pregnancy or over the entire course of the pregnancy. This is usually noted in prenatal record or strongly suspected by clinicians on the case review team.
Multiple gestation	Gestation of twins or higher order, usually noted prenatally.
Obesity	Morbidly overweight given the mother's height, usually noted in the prenatal record or strongly suspected by clinicians on the review team.
Poor nutrition	Food intake is insufficient for a healthy pregnancy, given the mother's size and stature; usually noted in the prenatal record or strongly suspected by clinicians on the case review team.

Pre-eclampsia/eclampsia	Late-term pregnancy-induced hypertension, usually noted in prenatal or delivery record.
Preterm labor	Onset of labor before 37 weeks gestation.
Pre-existing hypertension	High blood pressure documented before pregnancy; usually noted in prenatal record or by mother's report.
Sexually transmitted diseases (STD)	Infections that are commonly transmitted sexually, e.g., syphilis, gonorrhea, chlamydia, HIV, etc., usually noted in prenatal or delivery record.
Pregnancy < 1 year apart	Less than one year from end of previous pregnancy to conception of this pregnancy, by mother's report or calculated from medical record.
Premature rupture of membranes (PROM)	Rupture of membranes ("water broke") before the onset of labor.
Previous TABs/SABs	Loss of a previous pregnancy before 20 weeks either by elective abortion (TAB) or miscarriage (SAB), usually noted in maternal interview or prenatal record.
Previous fetal loss	Loss of a previous pregnancy at 20 weeks or later, not live-born; usually noted in maternal interview or prenatal record.
Previous infant loss	Previous loss of a live-born infant less than one year of age, usually noted in maternal interview or prenatal record.
Previous low birth weight (LBW) delivery	Previous delivery of a newborn less than 2,500 grams birth weight, usually noted in maternal interview or prenatal record.
Previous preterm delivery	Previous delivery before 37 weeks gestation, either stillborn or live-born; usually noted in maternal interview or prenatal record.
First pregnancy < 18 years old	Mother's first pregnancy was as a teenager (less than 18 years old), usually noted in maternal interview or on prenatal record.
> 4 live births	Mother has had 4 or more live births prior to this pregnancy, usually noted in maternal interview, medical records, birth certificate or fetal death certificate.
2. Medical: Fetal/Infant	
Intrauterine growth retardation (IUGR)	Fetal growth inconsistent with fetal age, usually noted in prenatal records and confirmed by sonogram or strongly suspected by clinicians on the case review team.
Congenital anomalies	Birth defects, malformations, chromosomal syndromes and other conditions noted prenatally, at delivery or on autopsy.
Prematurity/extreme prematurity	Infant experienced conditions associated with prematurity (< 37 weeks) or extreme prematurity (< 34 weeks), usually noted in infant medical records, autopsy, or death certificate.

Inadequate fetal monitoring	Fetal monitoring of high-risk patient and/or patient receiving oxytocics or conduction anesthetics was not adequately conducted. Inadequate fetal monitoring of high-risk fetus prior to labor. Non-stress testing or contraction stress testing was inadequately conducted to assess fetal well being in pregnancy complication.
Failure to thrive	The abnormal retardation of the growth and development of an infant resulting from conditions that interfere with normal metabolism, appetite and activity. Causative factors include chromosomal abnormalities, major organ system defects that lead to deficiency or malfunction, systemic disease or acute illness, physical deprivation (primarily malnutrition) and various psychosocial factors.
Substance exposure	Infant exhibits symptoms of in utero substance exposure or is known to have been exposed to substances during pregnancy.
Feeding problems	Infant exhibits inability or lack of desire to feed from breast or bottle, or regurgitates soon after feeding.
Respiratory distress syndrome	An acute lung disease of the newborn caused by progressive respiratory failure resulting from inadequate surfactant function superimposed on a structurally immature lung. The condition occurs most often in premature babies and in babies of diabetics.
Inappropriate level of care facility	Infant delivered or mother treated in facility without level of care designation appropriate for maternal or infant conditions.
3. Payment for care/services	
Self-pay/medically indigent	Family did not have insurance, Medi-Cal or other means for paying for prenatal care, delivery and/or pediatric care.
Medi-Cal	Family's medical care paid for by non-managed-care Medi-Cal, California Children Services or other government support.
Private insurance/HMO/ prepaid health plan	Family's medical care paid for by non-Medi-Cal insurance, HMO, or other plan.
Barriers related to insurance coverage	Delay, loss or inaccessibility of medical services due to problems with finding appropriate providers, receiving authorization for treatment, etc.
Eligibility unclear	Family eligibility for health coverage was unclear, resulting in delay or loss of medical services.
4. Prenatal Care/Delivery	
Standard of care not met	Prenatal assessment or treatment did not meet commonly accepted obstetric practice standards.
Inadequate assessment	Prenatal providers did not appropriately assess for certain conditions or circumstances.
No prenatal care	Mother received no prenatal care.

Late entry into prenatal care	Mother's first prenatal visit was after 14 weeks gestation.
Lack of referrals to additional services	Conditions or circumstances were identified in assessment, but no referral(s) was made to existing, appropriate services.
Missed appointments	Missed prenatal appointments resulted in sporadic care.
Multiple providers/sites	Mother received prenatal care from several providers, resulting in sporadic and fragmented care.
5. Pediatric Care	
Standard of care not met	Infant assessment or treatment did not meet commonly accepted pediatric practice standards.
Inadequate assessment	Pediatric providers did not appropriately assess for certain conditions or circumstances.
No pediatric care	The infant was never seen for routine visits, immunizations or other non-emergent care.
Not breastfed or minimally breastfed	Infant was not breastfed or was minimally breastfed (irregular, occasional or minimal breastfeeds of which the vast majority [more than half] of all feeds are not breastfeeds).
Lack of referrals to additional services	Conditions or circumstances were identified in assessment, but no referral(s) was made to existing, appropriate services.
Missed appointments	Missed pediatric appointments resulted in ineffective pediatric care.
Multiple providers/sites	Infant received pediatric care from several providers resulting in sporadic and fragmented care.
Breastfed	The infant was at least regularly breastfed with half or more of all feeds being breastfeeds.
6. Substance Use	
OTC/prescription drugs	Any use by the mother of any over-the-counter or prescription drug during or after pregnancy up to the time of the infant's death and not under the apparent supervision of a physician, as reported by the mother in the interview or medical record or as a positive toxicology screen result.
Positive drug test	The mother had any positive toxicology screen for substances during pregnancy or at delivery, or the infant had a positive toxicology screen post delivery.
Tobacco use	Any use by the mother of any tobacco product during or after pregnancy up to the time of the infant's death, noted either by mother in the interview or in the medical record. Note: Second-hand smoke from any source in the home is noted in category #14, Environment.

Alcohol use	Any use by the mother of any alcohol during or after pregnancy up to the time of the infant's death, noted either by mother in the interview or in the medical record as reported or as a positive toxicology screen result.
Illicit drugs	Any use by the mother of any illegal substance during or after pregnancy up to the time of the infant's death, noted either by mother in the interview or in the medical record as reported or as a positive toxicology screen result. Specify the type of drug, if known, in the space provided.
7. Social Support	
Lack of supportive friends/ family	The mother had few or no friends or family members providing emotional, financial, or physical support during or after her pregnancy.
Negative influence of friends/family	The mother's friends and/or family members contributed to her acting in a manner detrimental to her health or her baby's health.
FOB not involved	The father of this pregnancy did not contribute in a significant emotional, financial, or physical fashion.
8. Family Transition	
Frequent/recent moves	Living situation is unstable and mother has moved frequently before, during or after the pregnancy.
Job loss	The mother or another household financial supporter lost his or her job immediately before, during or after the pregnancy, or while the infant was alive.
Concern regarding citizenship	The mother or other principal caretakers exhibited concerns that their documentation or citizenship status may compromise their ability to seek or receive services.
Single parent	A one-parent household in which the mother/father is raising the infant and/ or other children while living separately from the father/mother and without a live-in intimate, supportive partner.
Married/living together	A two-parent household. Mother has a live-in, relatively long-term intimate relationship with either the father of her child(ren) or someone who acts as a parental figure to the child(ren). They may be married or not.
Divorce/separation	The mother separated or divorced from her spouse or intimate partner immediately before, during or after the pregnancy, or while the infant was alive.
Parent in prison/parole or probation	Either biological parent or other individual in the role of parent was incarcerated, paroled or on probation immediately before, during or after the pregnancy, or while the infant was alive.
Living in shelter/homeless	The mother and baby were homeless, living on the street, living in a shelter, or making frequent moves among friends and family members immediately before, during or after the pregnancy, or while the infant was alive.

Major illness/death in family	A major illness or death of a family member had an impact on the family's economic status or essential functions immediately before, during or after the pregnancy, or while the infant was alive.
9. Mental Health/Stress	
Maternal history of mental illness	The mother of the baby has a history of suicidal attempts or gestures, hospitalization, supervised medication or other indicators of mental illness.
Depression/mental illness during pregnancy/ postpartum	The mother of the baby displays clinical symptoms of depression, makes suicidal attempts or gestures, is hospitalized or under supervised medication, or otherwise is experiencing mental illness during pregnancy or during the time the infant is alive.
Multiple stresses during pregnancy/infancy	The mother experiences three or more family, economic, environmental, or other stresses during pregnancy or during the time the infant is alive.
10. Family Violence/Neglect	
Abuse/harassment of mother	Evidence of assaultive and coercive behaviors, including physical, sexual, and psychological attacks, as well as economic coercion, used against the woman or adolescent by an intimate partner (e.g., current or former dating, marriage or cohabitating partner of the same or opposite sex). May be indicated by personal report, medical records, law enforcement reports and/ or social services records, etc.
Child abuse	Includes physical, emotional and sexual abuse of the infant who died and/or children in the household. Physical abuse is any act that results in non-accidental physical injury to the child such as assault or shaken baby syndrome. Emotional abuse includes subjecting the child to verbal abuse, unpredictable responses, continual negative moods, constant family discord, and double-message communication. Sexual Abuse is a sexual assault on, or the sexual exploitation of, the child. May be indicated by personal report, suspected or confirmed reports to child protective services; law enforcement records; and/or medical records, etc.
Child neglect	The negligent treatment or maltreatment of any children in the household by the parent or caretaker under circumstances indicating harm or threatened harm to the children's health or welfare; includes severe neglect and general neglect. Severe neglect is the negligent failure to protect the child from severe malnutrition or medically diagnosed nonorganic failure to thrive and willfully causing or permitting the child to be placed in a situation such that his/her person or health is endangered (e.g., intentional failure to provide adequate food, clothing, shelter or medical care). General neglect is the negligent failure to provide adequate food, clothing, shelter, medical care or supervision. May be indicated by personal report, suspected or confirmed reports to child protective services, law enforcement records and/or medical records, etc.

11. Culture	
Language/cultural differences/inability to communicate with provider	The mother and/or other principal caretakers for the child were not able to communicate expediently with providers because of language differences. Includes use of interpreters.
Cultural beliefs re: pregnancy/health	The mother or other principal caretakers for the child exhibited health beliefs inconsistent with standard medical practice.
12. Transportation	
No public transportation	No existent public transportation during pregnancy, time of delivery, postpartum, and infant follow up.
Inadequate/unreliable transportation	Mother or other principal caretaker did not have reliable transportation to needed services, or ineffective transportation caused mother or caretaker to miss appointments or services.
13. Provision/Design of Services	
Inadequate patient/client education/information	The family/client did not receive prevention education and information that would have helped to prevent the fetal/infant death. Specify the education topic area in the space provided (e.g., shaken baby syndrome, motor vehicle occupant safety, suffocation/choking/strangulation, fire/burn, drowning, etc.).
Service unavailable in area	A needed or required service does not exist reasonably nearby the family.
Mother/child not eligible	The mother, principal caretaker, and/or child are not eligible for a particular service.
Lack of communication among providers/services	The service providers in the case were not known to each other or did not share with each other potentially important information about the case.
Fear of/dissatisfaction with system(s)	The family's fear of, or dissatisfaction with, a provider or providers was a factor in their not using a service or provider in a timely or effective manner.
Perceived receptivity	The mother and/or family members felt that they were negatively perceived by a provider or providers due to their race, education, language, socioeconomic status or other reason. The mother and/or family may also have felt that they were treated poorly or disrespectfully.
14. Environment	
Substandard housing	Any housing that does not meet local housing codes.
Overcrowding	More people living in housing space than the space was designed to accommodate.

Exposure to toxic substances	Mother, father, or infant were exposed to carcinogens, teratogens, toxins, etc., in the workplace, home, or industrial setting before or during pregnancy or during the time the infant was alive. For example, pesticides/ herbicides used in agriculture, chemicals used in cosmetology, etc.
Second-hand smoke	Regular/ongoing smoke inhaled by a pregnant woman or infant from burning tobacco (cigarettes, pipes, or cigars) or exhaled by a smoker.
Car seat not used/used improperly	While in a moving vehicle, the infant was not restrained or restrained incorrectly in a child passenger safety seat at the time of injury leading to death.
Infant sleeping with others	Infant was placed in near proximity to one or more persons, on the same sleep surface, when found unresponsive.
Sleeping in non-infant bed	Infant was sleeping on a sleep surface other than those designed and marketed for safe infant sleep, when found unresponsive.
Soft bedding	Infant was found unresponsive on bedding softer than a firm crib mattress and/or near pillows, blankets, comforter, waterbed, sheepskin, etc.
Infant overheating	When found unresponsive, the infant was overheated by: over dressing with too many clothes or blankets; the room or area being overheated from a furnace, space heater, fireplace, oven, woodburning stove; or lack of ventilation, allowing heat build up (e.g., enclosed car).
Non-supine positioning	Infant found unresponsive in other than a supine position.
Lack of adult visual supervision	Infant was found unresponsive after an episode where vigilant adult visual supervision of an infant would have been reasonable and expected under the circumstances (e.g., in or near water, heat source or open flame, risk of falling, choking on items, etc.). Note in #10, Family Violence/Neglect, whether child neglect was a factor.
15. Family Planning	
Lacks knowledge of FP methods/resources	The mother lacks knowledge of family planning methods or how to access family planning resources.
No B/C; intended pregnancy	The mother was intending to get pregnant and neither she nor her partner used a family planning method prior to the pregnancy.
No B/C; unintended pregnancy	The mother was not intending to get pregnant and neither she nor her partner used a family planning method prior to the pregnancy.
Failed contraceptive	The mother and/or her partner used a family planning method but she became pregnant anyway.
16. Injuries	
Motor vehicle occupant	Infant died due to injuries or conditions resulting from a motor vehicle crash. Note in #14, Environment, whether the child was secured in a child passenger restraint system while riding in automobile.

Suffocation	Infant died due to injuries or conditions resulting from suffocation/ smothering.
Choking/strangulation	Infant died due to injuries or conditions that may have resulted from choking, strangulation or hanging.
Fire/burn	Infant died due to injuries or conditions resulting from fire, flames, acid burn and/or scalding with hot food or liquid (includes death due to fire-related causes e.g., smoke inhalation). Note in #6, Substance Use, the use of smoked tobacco or illicit drugs as the source of the fire/burn, if applicable.
Drowning/near drowning	Infant died due to injuries or conditions resulting from drowning/submersion in water or other liquid. Note in #14, Environment, the lack of adult visual supervision, if applicable.
Poisoning/toxicity	Infant died due to injuries or conditions resulting from poisoning by drugs, medicines, or biological substances, including cleansing agents, poisonous plants, gasoline, or carbon monoxide, etc. Note in #6, Substance Use, if poisoning is related to illicit drug use.
Shaken baby syndrome	Infant died due to injuries or conditions resulting from shaking by another.
17. Other	
Grief counseling received	The mother received grief counseling either in the hospital or afterwards.
Psychosocial support prior to discharge	The mother received psychosocial support from hospital staff prior to being discharged.

Source: National Fetal Infant Mortality Review Program.

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